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A Protocol for Examining the Pharmacological and Psychological Treatment of Child and Adolescent ADHD in Australia: A Retrospective Cohort Study using Linked National Registry Data

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A Protocol for Examining the Pharmacological and Psychological Treatment of Child and Adolescent ADHD in Australia: A Retrospective Cohort Study using Linked National Registry Data

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Abstract

**Introduction:** Attention-Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder which affects 5% of children globally. In Australia, it is estimated 4.1% of children and adolescents have ADHD. While research has been conducted examining the treatment and outcomes of children with ADHD attending public mental health services during their time in the public system in Australia, it is not known what treatment they received before and after these treatment episodes, which will provide a more complete understanding of these children’s treatment journey.

**Methods and analysis:** We will link clinical data from cohorts of children and adolescents treated in the public child and youth mental health and/or child development services in Brisbane, Melbourne, and Sydney to the Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), and the National Death Index (NDI). MBS data will demonstrate the treatment journey with respect to clinicians seen, and treatment episodes from the public health service datasets will be examined to assess if the type and intensity of treatment is related to treatment outcomes. PBS data will reveal all psychotropic medications prescribed, allowing an examination of not just ADHD medications, but also other psychotropics which may indicate co-occurring conditions (e.g., anxiety and mood disorders). In some cases, the NDI may help understand cessation of treatment, and will also facilitate comparison of mortality rates in children with ADHD and the general population of minors.

**Ethics and dissemination:** This study has been approved by the following institutional Human Research Ethics Committees: 1) Children’s Health Queensland Hospital and Health Service, 2) The University of Queensland, and 3) The Australian Institute for Health and Welfare. Findings will be disseminated through peer reviewed journals, conferences, professional associations, and to public mental health services who treat ADHD.
Strengths and limitations of this study

- The ubiquity of federally subsidised medical care in Australia allows provides comprehensive information regarding medical care, medications, and to a lesser degree allied healthcare for mental health conditions.

- By utilising a data linkage approach to the federal registries, we will be able to describe care across a child’s treatment journey, before, during, and after their contact with state public healthcare systems.

- Linked registry data is limited for psychology, occupational therapy, and social work. Whilst certain attendances with these practitioners will appear in a child’s registry data, information regarding the reason for attendance and intervention received are not available.
PAEDIATRIC ADHD TREATMENT IN AUSTRALIA: A PROTOCOL

A Protocol for Examining the Pharmacological and Psychological Treatment of Child and Adolescent ADHD in Australia: A Retrospective Cohort Study using Linked National Registry Data

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by inattention, impulsivity, hyperactivity, and executive function deficits such as difficulties with motivation and planning. Additionally, problems with emotional and behavioural regulation are common. Globally, community prevalence of ADHD is estimated to affect 2 – 7% of the population. In Australia in 2018-2019 ADHD affected 4.1% of children and adolescents, and had an estimated total cost of US$12.76 billion, including financial and productivity costs, and well-being losses.

Despite treatment for ADHD being demonstrated to improve a gamut of health, social, and occupational domains, the disorder is still associated with a chronic course, with symptoms that continue through childhood into adolescence and often persist into adulthood. The chronic course and difficulty treating ADHD is a global, rather than an exclusively Australian problem. In Italy, for example, only around half of the children with ADHD attending tertiary neuropsychiatry clinics improved on the Clinical Global Impression (CGI) Scale after one year. Whilst there are numerous known moderators of treatment outcome in ADHD [e.g., co-occurring conditions, family income level, and ADHD severity], it is necessary, first, to understand what treatment looks like in ‘real-world’ settings, and whether that treatment is consistent with the recommendations in clinical practice guidelines.

In a case audit of Australian paediatricians, the professional group in Australia most likely to be involved in the treatment of ADHD, Efron, et al. found that most children (75%) with ADHD were prescribed stimulant medications (most commonly methylphenidate), and, in the case of new diagnoses, a third were referred to psychologists for further care. The most
recent published study of treatment of ADHD in Australian children found that Australian General Practitioners (GPs) and paediatricians had a generally high adherence to clinical practice guidelines, with timely recognition of medication side-effects noted as an area for improvement for GPs managing ADHD. Ellis’ study did not examine the practice of psychiatrists, and only examined pharmacological therapies. In Germany, adherence to that country’s clinical practice guideline with respect to prescribing pharmacotherapy for ADHD was very high (97.2%) in a study by Mücke, et al. Furthermore, in a sample of prescribers in the US, McElligott, et al., found that all surveyed prescribers offered stimulants as first-line intervention in moderate or severe ADHD cases, but that some prescribers opted for Lisdexamfetamine as the first-line intervention, rather than Methylphenidate.

Recent research by our group has examined the differences in outcomes for children and treated at Brisbane Child and Youth Mental Health Service (CYMHS) community clinics. It was found that compared to those with emotional disorders children with neurodevelopmental disorders (ADHD and/or Autism) had poorer outcomes in relation to behavioural, attention and social problems on the Health of the Nations Outcomes Scales for Children and Adolescents (HoNOSCA), the Strengths and Difficulties Questionnaire (SDQ), and the Children’s Global Assessment Scale (CGAS) (Leanne Payne et al., Comparing treatment outcomes between ADHD and emotional disorders in children and adolescents within an Australian and Dutch Outpatient Cohort, under review). In Payne’s study, children with ADHD and/or Autism showed improvement on the measures of comorbid emotional symptoms to the same extent as those with emotional disorders.

This good response to treatment of co-morbid emotional conditions is in line with the findings of Gould and colleagues who found the presence of comorbid ADHD did not affect treatment outcomes of Cognitive Behaviour Therapy for anxiety disorders. The poorer response to treatment for attention symptoms is in line with previous studies, but seems
in contrast to the good outcomes reported in treatment trials\textsuperscript{16}, including improvements in core ADHD symptoms\textsuperscript{17}, and improvements in health related quality of life\textsuperscript{18}.

There is a gap between clinical trial and real-world outcomes, and the concept of “voltage drop” is well known, whereby over-time, day-to-day practice and organisational demands may result in reduced fidelity to recommended treatment or research study protocols\textsuperscript{19}. Specific to Australia, community-based public mental health services (in contrast to private services) focus on the more complex cases, typically with comorbidities. Children under the care of these services may experience a treatment ceiling, having already received evidence-based treatment from a primary care provider there may be fewer gains to be made in the public system. This is confirmed by Leanne Payne et al. (\textit{Comparing treatment outcomes between ADHD and emotional disorders in children and adolescents within an Australian and Dutch Outpatient Cohort}, under review) who showed that severity of the symptoms in children attending CYMHS in Queensland, Australia, played a role in explaining poorer routine outcome measure improvement. Few studies have explored the treatment provided to children with ADHD.

Whether the treatment is pharmacological or non-pharmacological, it is important that the child receives a sufficient number of appointments to meet criteria of a \textit{Minimally Adequate Treatment} (MAT). For children experiencing mental health problems, MAT is defined as \geq 4 appointments where medication is utilised as an intervention, and \geq 8 appointments for a non-pharmacological intervention\textsuperscript{20}. Of concern, Sawyer, et al.\textsuperscript{21} found that only one-tenth of Australian children with a mental disorder, including children with ADHD, received MAT, half received some care insufficient to meet MAT, and another third received no healthcare for their mental health difficulties at all.

Provision of care in Australia for children with ADHD occurs in the outpatient system (both public and privately funded). General Practitioners (GP)\textsuperscript{22} can refer children to
other private practitioners, such as psychiatrists, paediatricians, and psychologists. The GP or
other specialist can also make a referral to publicly funded specialised services such as Child
and Youth Mental Health Services (CYMHS) or Child Development Services (CDS). Public
CYMHS also accept children for treatment who have severe and complex mental health
problems, which means that they do not see children with only ADHD, unless there are also
complex circumstances. CDS focus on children with neurodevelopmental disorders, as
opposed to other mental disorders and children are mostly seen by developmental
paediatricians.

In this study, we aim to provide a more complete description of the treatment
provided to children with ADHD that have had at least one treatment episode in the
Australian public system, either CYMHS or CDS. To that end, we will examine their
Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Scheme (MBS) data. PBS
data will show psychotropic prescriptions a child received, when the drug was prescribed,
and the specialty of the prescriber. MBS data relates to Australia’s publicly subsidised health
insurance scheme, and will reveal how often a child attended for medical care, the specialty
of those practitioners, as well as some allied health attendance data (mostly psychologists).
We will also extract data from the National Death Index (NDI), which may help explain some
cases where the child has been shown to prematurely cease treatment (both medications and
healthcare provider appointments). Furthermore, the NDI will contribute to understanding if
the mortality rate in paediatric ADHD is similar to that of the general paediatric population.

Study Aims

To review and describe the treatment provided (via MBS and PBS) to a sample of
children and adolescents (5 to 17 years) who were treated within the public mental health
outpatient or child development services between 2013-2020, and either received a diagnosis
of ADHD in the public system or whose history of prescribed medication suggests a previously made ADHD diagnosis, and to specifically:

(1) describe the prevalence of treatment of ADHD by medication type (including treatment received both pre and post the treatment episode/s within the public outpatient system, i.e. 2002 to the date the data are provided). Examining the entire medication history allows for an evaluation of appropriateness of medication over time both within and outside the public service.

(2) describe the prevalence of treatment with medication for comorbid disorders, for example antidepressants or antipsychotics (including any treatment received pre and post the treatment within the public outpatient system or within the private system).

(3) describe the prevalence of treatment with non-medication therapies (such as psychology) for those with ADHD, as far as can be assessed, including utilising Medicare Benefits Schedule (MBS) data to identify non-medication treatments received in the private system.

(4) describe the prevalence of treatment with stimulants to children and adolescents who did not receive a diagnosis of ADHD within the public system (to capture those who received their ADHD diagnosis pre or post the treatment within the public outpatient system or within the private system)

(5) assess as far as possible the extent to which treatment for ADHD adheres to the current National Institute for Health and Care Excellence (NICE) guideline (NG87), i.e., are the steps that are recommended by NICE in the medication treatment followed?

(6) assess whether both medication and non-medication treatments of ADHD meet the criteria for MAT in terms of number of visits with treatment providers.

(7) assess the extent to which socio-demographic variables as collected in the public system (e.g. Indigenous status, ancestry, language, postcode) are associated with treatment type, comorbidities, and MAT.
(8) assess the extent to which MAT and adherence to the NICE guideline is associated with outcomes as measured during the treatment in the public system or in longitudinal follow up.

Methods and Analysis

Study Design

This protocol describes an observational, retrospective cohort study. Retrospective data from children and adolescents managed by the public health system including demographics, diagnoses, scores on routine outcome measures, and service use will be linked via the Australian Institute of Health and Welfare (AIHW) with the Pharmaceutical Benefits Scheme (PBS), Medicare Benefits Schedule (MBS), and National Death Index (NDI) data. The linked dataset will be analysed per the study aims to provide an overview of treatment of ADHD provided to children and adolescents in Australia.

Study Location

This is a multi-site study, utilising data from Children’s Health Queensland Hospital and Health Service (Child and Youth Mental Health Service (CYMHS) and Child Development Service (CDS)), Royal Children’s Hospital Melbourne (Department of Mental Health), Sydney Children’s Hospital Network (SCHN), and the Clinic for Autism and Neurodevelopment (CAN) Research – Brain and Mind Centre, University of Sydney. The study will be administered by the Child Health Research Centre (CHRC) of the University of Queensland (UQ).

Recruitment of Participants

There will be no active participant recruitment, as the research team will be accessing previously collected data and linking to the PBS, MBS, and NDI data via the Australian Institute for Health and Welfare.
Study Population and Eligibility Criteria

Children and adolescents who meet the following criteria will be eligible for linkage:

1. were between the ages of 5 and 17, inclusive, at first treatment episode, who received an episode of care at CYMHS community clinics – CHQ HHS, or Department of Mental Health, Royal Children’s Hospital Melbourne, between 01/01/2013 and 31/12/2018 or
2. were assessed/treated at CDS at either CHQ HHS or the SCHN, or at the Autism Clinic for Translational Research, Brain and Mind Centre, University of Sydney AND are participating in the Improving Outcomes for Mental Health Study (IOMH) in Brisbane or the Child Development Registry study (CDR) in Sydney.

By including young people who had any recorded mental or neurodevelopmental disorder diagnoses (not only ADHD) in their medical records, we can identify if their medication history suggests that they received a diagnosis of ADHD within the private system or within the public system outside of the known treatment dates.

Exclusion Criteria

Children seen at CYMHS were excluded if the treatment episode was < 30 days. A treatment episode of that length suggests the child was referred on to another practitioner or service after the initial screening assessment and that a proper diagnostic assessment was not performed.

For the CDS cohort, it is not uncommon for children to be referred-on to other services or practitioners after assessment and diagnosis. As such, the treatment episode length exclusion criteria used for CYMHS is not appropriate for this cohort. Children from the CDS cohort will be excluded if there was not a diagnosis made because the assessment was not finished.
Ethics, Privacy, and Dissemination

This study has been approved by the following Human Research Ethics Committees (HRECs): 1) Children’s Health Queensland Hospital and Health Service HREC (HREC/21/QCHQ/76260), 2) University of Queensland HREC (2021/HE002143), and 3) The Australian Institute for Health and Welfare HREC (EO2021/4/1300).

The dataset for this study will be stored within the Sax Institute’s Secure Unified Research Environment (SURE). In effect, each research project operates within an operating system virtual machine, isolated from other projects and parts of the network. The system is rated as a Tier 3+ data centre, ensuring the highest levels of information security and integrity, and physical server security. The linked dataset will be securely archived for 10 years and then destroyed.

Results of this study will inform clinical practice in the management of ADHD nationally, and internationally. We will disseminate our findings through peer reviewed journals, conferences, professional associations, and to public mental health services whom treat ADHD.

Patient and Public Involvement

Patients and the public were not involved in the design of this study.

Outcomes

Primary Outcome

The mainstay of pharmacological treatments for those with ADHD are the psychostimulants (e.g., Methylphenidate and Amphetamines) 16. The National Institute for Health and Care Excellence (NICE) developed guidelines for the treatment of ADHD, and recommended Methylphenidate and Lisdexamfetamine/Dexamfetamine in the first instance, and Atomoxetine or Guanfacine for those who did not respond, did not tolerate, or had contraindications to stimulants 23.
As such, the primary outcome of this study is the description of the ADHD medications children were prescribed, and whether the sequence of medications trialled followed that which was recommend by the NICE guideline for ADHD (NG87)\textsuperscript{23}. To describe medication treatment of ADHD, we will examine: 1) frequency and dosage of prescription for each drug across our cohorts (both pre and post service episode in the public mental health system), and 2) establish if the sequence of medications trialled was consistent with the recommendations 1.7.7 through 1.7.10 of NG87.

**Secondary Outcomes**

In addition to medications, there is evidence for psychosocial approaches for ADHD, and NICE recommend that where significant impairments remain following medication, children with ADHD receive a course of Cognitive Behaviour Therapy (CBT). CBT for ADHD assists with teaching the child to manage and compensate for the core symptoms of ADHD, such as executive function difficulties, as well as mitigating the emotional sequelae of those difficulties (e.g., difficulty concentrating $\rightarrow$ poor school results $\rightarrow$ negative self-concept $\rightarrow$ giving up on school work). NICE also recommend parenting programs for children under 5 years, or in older children where Oppositional Defiant or Conduct Disorders are comorbid with ADHD\textsuperscript{23}. Meta-analytic work, however, has found discrepant findings with regards to studies reporting the effectiveness of parenting training\textsuperscript{24}. The following secondary outcomes for ADHD and comorbid conditions will be assessed:

1. Frequency of visits with treatment providers, including medical practitioners, and also private psychology/mental health occupational therapy, and mental health social work (if billed through MBS) to assess the extent to which Minimally Adequate Treatment has been met. The data are limited to the extent that we will not be able to examine reasons for professional attendances, or what treatment was provided except for medications through the PBS.
(10) Treatment of comorbid psychiatric conditions including medication (all other psychotropics in Anatomic Therapeutic Chemical (ATC) Codes N03 - Antiepileptics, N05 - Psycholeptics, and N06 – Psychoanaleptics).

(11) Percentage of children who received an ADHD diagnosis (ICD-10 or DSM-V depending on site), before, or after being treated by the public system.

(12) Routinely collected outcomes (varying by site, see Table 1):

Table 1: List of Routine Outcome Measures across Cohort Sites

<table>
<thead>
<tr>
<th>Study Cohort</th>
<th>Available Routine Outcome Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Queensland – Child and Youth Mental Health Service</td>
<td>CGAS, SDQ, HoNOSCA</td>
</tr>
<tr>
<td>Queensland – Child Development Service</td>
<td>CBCL, SRS</td>
</tr>
<tr>
<td>Melbourne – Royal Children’s Hospital Department of Mental Health</td>
<td>CGAS, SDQ, HoNOSCA</td>
</tr>
<tr>
<td>Sydney – Sydney Children’s Hospital Network &amp; Autism Clinic for Translational Research</td>
<td>CBCL, EQ-5D-Y, CHU9D, PedsQL</td>
</tr>
</tbody>
</table>

Abbreviations: CGAS - Children’s Global Assessment Scale; SDQ - Strengths and Difficulties Questionnaire; HoNOSCA - Health of the Nations Outcomes Scales for Children and Adolescents; CBCL - Child Behaviour Checklist; SRS - Social Responsiveness Scale; EQ-5D-Y Proxy – EuroQoL Five Dimension Youth Proxy; CHU9D - Child Health Utility 9D; PedsQL - Pediatric Quality of Life Inventory

Data Analysis

Table 2 outlines the statistical analyses to be conducted, and maps these onto the study aims described earlier in the paper.
### Table 2. Mapping Statistical Analyses to the Study Aims

<table>
<thead>
<tr>
<th>Study Aim</th>
<th>Analyses to be Performed</th>
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<tbody>
<tr>
<td>Describe the frequency of ADHD treatment by medication type</td>
<td><strong>Frequency and descriptive statistics</strong>: Percentage of children who were prescribed and/or dispensed a stimulant or other ADHD medication (yes/no).</td>
</tr>
<tr>
<td>Describe the frequency of treatment with medication for comorbid disorders</td>
<td><strong>Frequency and descriptive statistics</strong>: Percentage of children of the sample who were prescribed and/or dispensed psychotropic medicine other than ADHD medications, and percentage of the sample who received both a stimulant and other psychotropics.</td>
</tr>
<tr>
<td>Describe the frequency of non-medication treatment in those children with ADHD</td>
<td><strong>Frequency and descriptive statistics</strong>: Percentage of children with ADHD who have seen a psychologist, mental health OT or mental health social worker through the Medicare Benefits Schedule.</td>
</tr>
<tr>
<td>Describe the frequency of treatment with stimulants in those children without a public health system ADHD diagnosis</td>
<td><strong>Frequency and descriptive statistics</strong>: Percentage of children who did not receive an ADHD diagnosis in the public system, but were prescribed and/or dispensed a stimulant or other ADHD medication either before or after contact with the public system.</td>
</tr>
<tr>
<td>Assess the extent to which the NICE guideline for ADHD is being followed for medication and non-medication treatments</td>
<td><strong>Frequency and descriptive statistics</strong>: Percentage of children who were prescribed and/or dispensed medications for ADHD in the order recommended by NICE (e.g., Methylphenidate → Lisdexamfetamine/Dexamphetamine → Atomoxetine/Guanfacine).</td>
</tr>
</tbody>
</table>
| Assess the extent to which sociodemographic variables are associated with treatment type, comorbidities, and MAT | **Logistic regression**: Sociodemographic variables (including age, sex, and postcode socioeconomic status) as predictors of receiving medications only, or medications and allied health support.  
**Logistic regression**: Sociodemographic variables as predictors of receiving minimally adequate treatment  
**Multiple regression**: Sociodemographic variables as predictors of number of comorbidities for those with ADHD |
Assess the extent to which MAT and adherence to the NICE guideline are associated with routine outcomes measures administered in the public system. **t-test, descriptive statistics, and regression:** For children with ADHD or a medication history suggestive of ADHD, Mean routine outcome measure scores for those children who received MAT or inadequate treatment dose, and for those children who received NICE recommended treatment compared to not receiving treatment as recommended by NICE. Percentage of children who received MAT or NICE, and improved to no longer be in the ‘clinical range’ compared to those who didn’t receive MAT or NICE recommended treatment. Multiple regression to assess the effects of MAT and NICE recommended treatment on routine outcome measures, whilst controlling for other variables including treatment site.

**Abbreviations:** MAT – Minimally Adequate Treatment, NICE – National Institute for Health and Care Excellence, OT – Occupational Therapist

**Discussion**

Previous research has demonstrated that children with ADHD in the public child and youth mental health system fare worse on routine outcome measures compared to those with emotional disorders. The current study provides a broader evaluation of the public health system’s treatment of ADHD by studying both Child Development Services and Child and Youth Mental Health Services. The types of children typically seen in CDS and CYMHS, respectively, tend to differ. Both focus on complex cases, but CYMHS often only see children with neurodevelopmental disorders when there is co-morbidity, as these services are intended to treat severe mental and behavioural disturbance. CDS is dedicated to the assessment and treatment of neurodevelopmental disorders, so often see children earlier in life but who are still presenting with complex developmental issues. The high threshold for acceptance of a referral by CYMHS generally means that children within CYMHS have received input prior to this episode of care. Extending the data collection outside the CYMHS and CDS clinical episodes will provide a more comprehensive view of the treatment received by these both before and after this episode of care. In particular capturing the treatment children received after their contact with public health services will allow us to estimate long-term adherence to treatment. Insight into the treatment received prior to entry into the public
system (e.g., did the child see a paediatrician or psychiatrist, were psychotropics prescribed – and if so, were the script repeats filled? did the child see a private psychologist?) will generate important information, describing the patient journey and understanding the outcomes of children, as their improvement in the public system may have a ceiling effect if there have already been substantive interventions trialled previously.

**Limitations and Future Research Directions**

Whilst linkage studies in Australia generally provide a comprehensive overview of the points of clinical service a child has received due to the ubiquity of Medicare, there are key limitations on the information provided by federal registries. With regards to the PBS, the issuing of a prescription does not guarantee the child took the medication. Medication compliance is a known issue in ADHD, with Perwien, et al. finding that in a US setting by the second month of treatment, less than 20% of children were compliant in taking their medication. Similarly, Australian data analysed by Efron, et al. found that children prescribed medication for ADHD only took the medication for approximately 40% of the time-period they were under treatment. Further limitations of this study relate to the MBS data – while the MBS data tells researchers the type of practitioner the child saw, the reason for an attendance with a physician or allied health practitioner is not necessarily known. For example, a child with ADHD seeing a paediatrician may be attending for another unrelated concern. Similarly, a child may attend a session with a psychologist under a Mental Health Care Plan (the mechanism allowing a patient to see an allied health practitioner specialising in mental health under the MBS), resulting in a billed MBS item, however there is no way of knowing if ADHD symptoms or strategies were the focus of that session, or if another problem was the focus of treatment, and what the exact intervention was. A further issue with psychology, is that until the COVID-19 pandemic, MBS benefits were limited to 10 sessions per year, meaning there is a possibility that some children continued seeing their psychologist...
privately after the initial sessions, and that this information would not be recorded in the MBS data. Additionally, other than private psychology, mental health OT, and mental health-social work, other mental health services, such as those provided by state governments and public hospitals is block-funded, and therefore would not appear in the MBS output for a particular patient had they attended these services. These situations would lead to underestimating the level of professional input received (i.e., the ‘dose’ of the non-pharmacological intervention).

Whilst we will use Saloner’s definition of Minimally Adequate Treatment based on the previous literature – 4 sessions for medication, 8 sessions for non-pharmacological treatment, there are limitations in the use of this categorisation. MAT is defined for paediatric psychiatric problems broadly, so it is unclear whether the true threshold for MAT for ADHD is in-line with Saloner’s definition, or whether ADHD requires more or even fewer professional attendances to result in effective treatment. Additionally, Ride, et al. found, in a sample of 600 Australian children, that MAT did not improve clinical outcomes in routine practice, indicating that quality of treatment may be more important than quantity/frequency. Ride’s study however, examined outcomes on the Strength and Difficulties Questionnaire and did not have diagnostic information available, which may limit its applicability to an ADHD cohort.

Furthermore, with the cohorts involved, we will not capture the data of those children whose entire pathway from diagnosis of ADHD to treatment was conducted privately, and subsequently whether there are differences in treatment between those treated solely within the private system, versus those children who were treated in the public system or both public and private, as included in our cohorts. Future research could investigate the treatment of children solely seen in the private system, and whether the findings are comparable to the results in this study.
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Author Contributions

Daniel Sullivan wrote the original draft, reviewed/edited, assisted with project administration and data curation. Leanne Payne assisted with writing review/editing, project administration, and conceptualisation. Kelsie Boulton assisted with writing review/editing, project administration, and data curation. Natalie Silove assisted with writing review/editing. Mark Bellgrove assisted with funding acquisition, conceptualisation, and writing review/editing. Emma Sciberras assisted with writing review/editing, conceptualisation. David Coghill assisted with writing review/editing, conceptualisation, and project administration. Adam Guastella assisted with writing review/editing, conceptualisation, project administration. Christel Middeldorp assisted with funding acquisition, writing review/editing, supervision, project administration, conceptualisation, and methodology.

Competing Interests

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Leanne Payne: None

Kelsie Boulton: None

Natalie Silove: None

Mark Bellgrove: President of AADPA, Lead – Australian ADHD Clinical Practice Guideline, Fellowship Funding – National Health and Medical Research Council (NHMRC) of Australia, Research Support Funding – NHMRC and Australian Medical Research Future
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Adam Guastella: None

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PAEDIATRIC ADHD TREATMENT IN AUSTRALIA: A PROTOCOL

References


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Examining the pharmacological and psychological treatment of child and adolescent ADHD in Australia: protocol for a retrospective cohort study using linked national registry data

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Examining the pharmacological and psychological treatment of child and adolescent ADHD in Australia: protocol for a retrospective cohort study using linked national registry data

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Abstract

Introduction: Attention-Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder which affects 5% of children globally. In Australia, it is estimated 4.1% of children and adolescents have ADHD. Whilst research has examined the treatment and outcomes of children with ADHD attending public mental health services during their time in the public system in Australia, it is not known what treatment they received before and after these treatment episodes, which will provide a more complete understanding of these children’s treatment journey.

Methods and analysis: We will link clinical data from cohorts of children and adolescents treated in the public child and youth mental health and/or child development services in Brisbane, Melbourne, and Sydney to the Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), and the National Death Index (NDI). MBS data will demonstrate the treatment journey with respect to clinicians seen, and treatment episodes from the public health service datasets will be examined to assess if the type and intensity of treatment is related to treatment outcomes. PBS data will reveal all psychotropic medications prescribed, allowing an examination of not just ADHD medications, but also other psychotropics which may indicate co-occurring conditions (e.g., anxiety and mood disorders). Statistical analyses will include descriptive statistics to describe rates of specific medications and clinician specialties seen. Linear and logistic regression will be used to model how treatment and sociodemographic variables relate to routinely collected outcome measures in the public health system whilst controlling for covarying factors.
**Ethics and dissemination:** This study has been approved by the following institutional Ethics Committees: 1) Children’s Health Queensland Hospital and Health Service (HREC/21/QCHQ/76260), 2) The University of Queensland (2021/HE002143), and 3) The Australian Institute for Health and Welfare (EO2021/4/1300). Findings will be disseminated through peer reviewed journals, conferences, professional associations, and to public mental health services who treat ADHD.

**Strengths and limitations of this study**

- The ubiquity of federally subsidised medical care in Australia provides comprehensive information regarding medical care, medications, and to a lesser degree allied healthcare for mental health conditions.

- By utilising a data linkage approach to the federal registries, we will be able to describe care across a child’s treatment journey, before, during, and after their contact with state public healthcare systems.

- Linked registry data is limited to attendance only for psychology, occupational therapy, and social work; information regarding the reason for attendance and intervention received are not available.
Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by inattention, impulsivity, hyperactivity, and executive function deficits such as difficulties with motivation and planning. Additionally, problems with emotional and behavioural regulation are common [1]. Globally, ADHD is estimated to affect 2 – 7% of the population [2]. In Australia in 2018-2019 ADHD affected 4.1% of children and adolescents, and had an estimated total cost of US$12.76 billion, including financial and productivity costs, and well-being losses [3].

Despite treatment for ADHD being demonstrated to improve a range of health, social, and occupational domains [4], the disorder is still associated with a chronic course, with symptoms that continue through childhood into adolescence and often persist into adulthood [5]. The chronic course and difficulty treating ADHD is a global, rather than an exclusively Australian problem. In Italy, for example, only around half of the children with ADHD attending tertiary neuropsychiatry clinics improved on the Clinical Global Impression (CGI) Scale after one year [6]. Whilst there are numerous known moderators of treatment outcome in ADHD (e.g., co-occurring conditions, family income level, and ADHD severity [7]), it is necessary, first, to understand what treatment looks like in ‘real-world’ settings, and whether that treatment is consistent with the recommendations in clinical practice guidelines.

Psychostimulants (e.g., methylphenidate and amphetamines) [8] are the mainstay of pharmacological treatments for those with ADHD. The National Institute for Health and Care Excellence (NICE) developed guidelines for the treatment of ADHD, and recommended methylphenidate and lisdexamfetamine/dexamfetamine in the first instance, and atomoxetine or guanfacine for non-responders and those patients with contraindications or severe adverse effects to stimulants [9]. In a case audit of Australian paediatricians, the professional group in Australia most likely to be involved in the treatment of ADHD, Efron, et al. [10] found that
most children (75%) with ADHD were prescribed stimulant medications (most commonly methylphenidate), and, in the case of new diagnoses, a third were referred to psychologists for further care. The most recent published study of treatment of ADHD in Australian children found that Australian General Practitioners (GPs) and paediatricians had a generally high adherence to clinical practice guidelines, with timely recognition of medication side-effects noted as an area for improvement for GPs managing ADHD\(^\text{[11]}\). Ellis’ study did not examine the practice of psychiatrists, and only examined pharmacological therapies. In Germany, adherence to that country’s clinical practice guideline with respect to prescribing pharmacotherapy for ADHD was very high (97.2%) in a study by Mücke, et al.\(^\text{[12]}\). However, another German study of nearly 20,000 initial paediatric ADHD medication claims found that whilst the majority were commenced on stimulants, 13% of children were commenced on a second-line or combination of medications, rather than trialling the stimulants first\(^\text{[13]}\). In the United States, McElligott, et al.\(^\text{[14]}\), found that all surveyed prescribers offered stimulants as first-line intervention in moderate or severe ADHD cases, but that some prescribers opted for lisdexamfetamine as the first-line intervention, rather than Methylphenidate.

In addition to medications, there is evidence for psychosocial approaches for ADHD, and NICE recommend that where significant impairments remain following medication, children with ADHD receive a course of Cognitive Behaviour Therapy (CBT). CBT for ADHD assists with teaching the child to manage and compensate for the core symptoms of ADHD, such as executive function difficulties, as well as mitigating the emotional sequelae of those difficulties (e.g., difficulty concentrating \(\rightarrow\) poor school results \(\rightarrow\) negative self-concept \(\rightarrow\) giving up on school work). NICE also recommend parenting programs for children under 5 years, or in older children, where Oppositional Defiant or Conduct Disorders are comorbid with ADHD\(^\text{[9]}\).
Recent research by our group has examined the differences in outcomes for children treated at Brisbane Child and Youth Mental Health Service (CYMHS) community clinics. It was found that compared to those with emotional disorders, children with neurodevelopmental disorders (ADHD and/or Autism) had poorer outcomes in relation to behavioural, attention and social problems on the Health of the Nations Outcomes Scales for Children and Adolescents (HoNOSCA) [15], the Strengths and Difficulties Questionnaire [15] (SDQ), and the Children’s Global Assessment Scale (CGAS)[16]. Despite having poorer response in behavioural, attention, and social difficulties, in Payne’s [15] study, children with ADHD and/or Autism improved on comorbid emotional symptoms to the same extent as those with emotional disorders.

This good response to treatment of co-morbid emotional conditions is in line with the findings of Gould and colleagues [17] who found the presence of comorbid ADHD did not affect treatment outcomes of Cognitive Behaviour Therapy for anxiety disorders. The poorer response to treatment for attention symptoms found by our group [15] is in line with previous studies [18-20]. A notable discrepancy is that these findings of sub-optimal improvements in attention symptoms in clinical settings are, in contrast, to the good outcomes reported in medication treatment trials [8]. Those trials demonstrate improvements in core ADHD symptoms [21], and improvements in health related quality of life [22] when medication is taken.

There is a gap between clinical trial and real-world outcomes, and the concept of “voltage drop” is well known, whereby over time, day-to-day practice and organisational demands may result in reduced fidelity to recommended treatment or research study protocols [23]. Specific to Australia, community-based public mental health services (in contrast to private services) focus on the more complex cases, typically with comorbidities. Children under the care of these services may experience a treatment ceiling, having already received
evidence-based treatment from a primary care provider there may be fewer gains to be made in the public system. This was confirmed by Payne et al. [15] who showed that severity of the symptoms in children attending CYMHS in Queensland, Australia, played a role in explaining poorer routine outcome measure improvement. Few studies have explored the treatment provided to children with ADHD.

Regardless of whether the treatment is pharmacological or non-pharmacological, it is important that the child receives a sufficient number of appointments to meet criteria of a Minimally Adequate Treatment (MAT). For children experiencing mental health problems, MAT is defined as $\geq 4$ appointments where medication is utilised as an intervention, and $\geq 8$ appointments for a non-pharmacological intervention [24]. Of concern, Sawyer, et al. [25] found that only one-tenth of Australian children with a mental disorder, including children with ADHD, received MAT, half received some care insufficient to meet MAT, and another third received no healthcare for their mental health difficulties at all.

Provision of care in Australia for children with ADHD occurs in the outpatient health system (both public and privately funded). General Practitioners (GP) [26] can refer children to other private practitioners, including psychiatrists, paediatricians, and psychologists. The GP or other specialist can also make a referral to publicly funded specialist services such as Child and Youth Mental Health Services (CYMHS) or Child Development Services (CDS). Public CYMHS accept children for treatment who have severe and complex mental health problems, meaning they do not only see children with ADHD. A diagnosis of only ADHD with no comorbidities is uncommon in CYMHS, with 86.2% of CYMHS children with ADHD also having at least one additional diagnosis [15]. CDS focus on the assessment and diagnosis of children with neurodevelopmental disorders, as opposed to other mental disorders, and children are mostly seen by developmental paediatricians. Given the severity and acuity required to be seen in the public health system in Australia, those young people who have
lesser symptom severity, or who are not accepted into a public clinic will therefore be seen by private practitioners in the community, with the fees of medical practitioners, and some allied health practitioners partially subsidised by a government Medicare rebate. Despite these government rebates, Australian parents seeking paediatric, psychiatric, or psychological consultation for their child’s ADHD often face high out-of-pocket costs. Depending on the clinician specialty, these out-of-pocket costs can be up to $110USD per appointment on average [27].

In this study, we aim to provide a more complete description of the treatment provided to children with ADHD who have had at least one treatment episode in the Australian public system, either CYMHS or CDS. To that end, we will examine their Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Scheme (MBS) data. Around 85% of all Australian prescriptions are PBS subsidised [28], and the medications routinely used to treat ADHD (stimulants and second-line medications such as atomoxetine and guanfacine) are PBS-eligible. This means that PBS data provide a reliable source for ADHD medication prescribed. PBS data will show psychotropic prescriptions a child received, when the drug was prescribed, and the specialty of the prescriber. MBS data relates to Australia’s publicly subsidised health insurance scheme, and will reveal how often a child attended for medical care, the specialty of those practitioners, as well as some allied health attendance data (mostly psychologists). We will also extract data from the National Death Index (NDI) (date of death and underlying/other causes of death), which may help explain some cases where the child has been shown to prematurely cease treatment (both medications and healthcare provider appointments) before reaching the threshold for a minimally adequate treatment. Furthermore, the NDI will contribute to understanding if the mortality rate in paediatric ADHD is similar to that of the general paediatric population.
Study aims

This exploratory study will describe the treatment provided (via MBS and PBS) to a sample of children and adolescents (5 to 17 years) who were treated within the public mental health outpatient or child development services between 2013-2020, and either received a diagnosis of ADHD in the public system or whose history of prescribed medication suggests a previously made ADHD diagnosis, and to specifically:

(1) Describe the prevalence of treatment of ADHD by medication type (including treatment received both pre and post the treatment episode/s within the public outpatient system, i.e. 2002 to the date the data are provided). Examining the entire medication history allows for an evaluation of the appropriateness of medication prescribed over time both within and outside the public service. ‘Appropriateness’ refers to the order in which different medications were trialled (e.g., were stimulants trialled before atomoxetine/guanfacine?), and if medication dose or agent were changed if significant symptoms remained on the outcome measures available.

(2) Describe the prevalence of treatment with medication for comorbid disorders, for example antidepressants or antipsychotics (including any treatment received pre and post the treatment within the public outpatient system or within the private system).

(3) Describe the prevalence of treatment with non-pharmacological therapies (such as psychotherapies) for those with ADHD, as far as can be assessed, including utilising Medicare Benefits Schedule (MBS) data to identify non-medication treatments received in the private system.

(4) Describe the prevalence of treatment with stimulants to children and adolescents who did not receive a diagnosis of ADHD within the public system (to capture those who received their ADHD diagnosis pre or post the treatment within the public outpatient system or within the private system)
(5) Assess as far as possible the extent to which treatment for ADHD adheres to the current National Institute for Health and Care Excellence (NICE) guideline (NG87), i.e., are the steps that are recommended by NICE in the medication treatment followed?

(6) Assess whether both medication and non-medication treatments of ADHD meet the criteria for MAT in terms of number of visits with treatment providers.

(7) Assess the extent to which socio-demographic variables as collected in the public system (e.g. Indigenous status, ancestry, language, postcode) are associated with treatment type, comorbidities, and MAT.

(8) Assess the extent to which MAT and adherence to the NICE guideline is associated with outcomes as measured during the treatment in the public system or in longitudinal follow up.

Methods and analysis

Study design

This protocol describes an observational, retrospective cohort study. Retrospective data from children and adolescents managed by the public health system including demographics, diagnoses, scores on routine outcome measures, and service use will be linked via the Australian Institute of Health and Welfare (AIHW) with the Pharmaceutical Benefits Scheme (PBS), Medicare Benefits Schedule (MBS), and National Death Index (NDI) data. The linked dataset will be analysed per the study aims to provide an overview of treatment of ADHD provided to children and adolescents in Australia.

Study setting

This is a multi-site study, utilising data from Children’s Health Queensland Hospital and Health Service (Child and Youth Mental Health Service (CYMHS) and Child Development Service (CDS)), Royal Children’s Hospital Melbourne (Department of Mental Health),
Sydney Children’s Hospital Network (SCHN), and the Clinic for Autism and Neurodevelopment (CAN) Research – Brain and Mind Centre, University of Sydney. The study will be administered by the Child Health Research Centre (CHRC) of the University of Queensland (UQ).

Study population and eligibility criteria

There will be no active participant recruitment, as the research team will be accessing previously collected data and linking to the PBS, MBS, and NDI data via the Australian Institute for Health and Welfare.

Children and adolescents who meet the following criteria will be eligible for linkage:

1. Were between the ages of 5 and 17, inclusive, at first treatment episode, who received an episode of care at CYMHS community clinics – CHQ HHS, or Department of Mental Health, Royal Children’s Hospital Melbourne, between 01/01/2013 and 31/12/2018 or
2. Were assessed/treated at CDS at either CHQ HHS or the SCHN, or at the Autism Clinic for Translational Research, Brain and Mind Centre, University of Sydney AND are participating in the Improving Outcomes for Mental Health Study (IOMH) in Brisbane or the Child Development Registry study (CDR) in Sydney.

By including young people who had any recorded mental or neurodevelopmental disorder diagnoses (not only ADHD) in their medical records, we can identify if their medication history suggests that they received a diagnosis of ADHD within the private system or within the public system outside of the known treatment dates.

Exclusion criteria

Children seen at CYMHS were excluded if the treatment episode was < 30 days. A treatment episode of that length suggests the child was referred on to another practitioner or service after the initial screening assessment and that a proper diagnostic assessment was not performed.
For the CDS cohort, it is not uncommon for children to be referred-on to other services or practitioners after assessment and diagnosis. As such, the treatment episode length exclusion criteria used for CYMHS is not appropriate for this cohort. Children from the CDS cohort will be excluded if no diagnosis was reached because the assessment was not finished.

**Linkage procedure**

Figure 1 outlines the process of data linkage from individual site datasets through to federal data integration, secure storage, and provision of results to the research team. Site datasets with identifying information are transmitted to the Australian Institute for Health and Welfare, who use the identifying information to integrate the site datasets with the federal MBS and PBS information. The AIHW remove the identifiers and replace this with a linkage key connecting the site content files with the federal content files, before transmitting the deidentified linked data into the secure environment for the researchers to access. The removal of the original identifiers prevents the researchers from re-identifying children in the final linked dataset which contains federal MBS and PBS data. It is a requirement of AIHW ethical approvals that analysis is to be performed in the secure environment, and only results, not the linked datasets can be exported from that secure environment.

**Outcomes**

**Primary outcome**

The primary outcome of this study is the description of the ADHD medications children were prescribed, and whether the sequence of medications trialled followed the NICE guideline for ADHD (NG87)\(^9\). To describe medication treatment of ADHD, we will examine: 1) frequency and dosage of prescription for each drug across our cohorts (both pre and post service episode in the public mental health system), and 2) establish if the sequence of medications trialled was consistent with the recommendations 1.7.7 through 1.7.10 of NG87.

**Secondary outcomes**
The following secondary outcomes for ADHD and comorbid conditions will be assessed:

1) Frequency of visits with treatment providers, including medical practitioners, and also private psychology/mental health occupational therapy, and mental health social work (if billed through MBS) to assess the extent to which Minimally Adequate Treatment has been met. The data are limited to the extent that we will not be able to examine reasons for professional attendances, or what treatment was provided except for medications through the PBS.

2) Treatment of comorbid psychiatric conditions including medication (all other psychotropics in Anatomic Therapeutic Chemical (ATC) Codes N03 - Antiepileptics, N05 - Psycholeptics, and N06 – Psychoanaleptics).

3) Percentage of children who received an ADHD diagnosis (ICD-10 or DSM-V depending on site), before, or after being treated by the public system.

4) How routinely collected outcomes (varying by site, see Table 1) are affected by treatment prior to and during contact with public health, and whether ROMs in state public health services predict future Medicare or PBS medication use:

Table 1: List of routine outcome measures across cohort sites

<table>
<thead>
<tr>
<th>Study cohort</th>
<th>Available routine outcome measures</th>
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<tbody>
<tr>
<td>Queensland – Child and Youth Mental Health Service</td>
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</tr>
<tr>
<td>Queensland – Child Development Service</td>
<td>CBCL, SRS</td>
</tr>
<tr>
<td>Melbourne – Royal Children’s Hospital</td>
<td>CGAS, SDQ, HoNOSCA</td>
</tr>
<tr>
<td>Department of Mental Health</td>
<td></td>
</tr>
<tr>
<td>Sydney – Sydney Children’s Hospital Network &amp; Autism Clinic for Translational Research</td>
<td>CBCL, EQ-5D-Y, CHU9D, PedsQL</td>
</tr>
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</table>
Abbreviations: CGAS - Children’s Global Assessment Scale; SDQ - Strengths and Difficulties Questionnaire; HoNOSCA - Health of the Nations Outcomes Scales for Children and Adolescents; CBCL - Child Behaviour Checklist; SRS - Social Responsiveness Scale; EQ-5D-Y Proxy – EuroQoL Five Dimension Youth Proxy; CHU9D - Child Health Utility 9D; PedsQL - Pediatric Quality of Life Inventory

Data Analysis

Table 2 reports the sociodemographic variables to be described from each of the sites, and for inclusion as covariates in regression analyses.

Table 2: List of sociodemographic variables across cohort sites

<table>
<thead>
<tr>
<th>Study cohort</th>
<th>Available sociodemographic variables</th>
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<tbody>
<tr>
<td>Queensland – Child and Youth Mental Health Service</td>
<td>Month and year of birth, Indigenous status, sex, country of birth, postal code socioeconomic status percentile, language spoken at home</td>
</tr>
<tr>
<td>Queensland – Child Development Service</td>
<td>Month and year of birth, Indigenous status, ancestry (e.g., white/Caucasian, Asian, Pacific Islander), sex, household status (e.g., both parents reside in the home, one parent resides in the home), language spoken at home, parental mental health diagnosis, parental education level, parental income</td>
</tr>
<tr>
<td>Melbourne – Royal Children’s Hospital Department of Mental Health</td>
<td>Month and year of birth, Indigenous status, sex, country of birth, language spoken at home, postal code socioeconomic status percentile</td>
</tr>
</tbody>
</table>
Sydney – Sydney Children’s Hospital Network & Autism Clinic for Translational Research

Month and year of birth, Indigenous status, ancestry, language spoken at home, household status, parental mental health diagnosis, parental education level, parental income level

Table 3 outlines the statistical analyses to be conducted, and maps these onto the study aims described earlier in the paper.
<table>
<thead>
<tr>
<th>Study aim</th>
<th>Analyses to be performed</th>
</tr>
</thead>
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<tr>
<td>Describe the frequency and duration of ADHD treatment by medication type</td>
<td>Frequency and descriptive statistics: Percentage of children who were prescribed and/or dispensed a stimulant or other ADHD medication (yes/no).</td>
</tr>
<tr>
<td>Describe the frequency and duration of treatment with medication for comorbid disorders</td>
<td>Frequency and descriptive statistics: Percentage of children of the sample who were prescribed and/or dispensed psychotropic medicine other than ADHD medications, and percentage of the sample who received both a stimulant and other psychotropics.</td>
</tr>
<tr>
<td>Describe the frequency of non-medication treatment in those children with ADHD</td>
<td>Frequency and descriptive statistics: Percentage of children with ADHD who have seen a psychologist, mental health OT or mental health social worker through the Medicare Benefits Schedule.</td>
</tr>
<tr>
<td>Describe the frequency and duration of treatment with stimulants in those children without a public health system ADHD diagnosis</td>
<td>Frequency and descriptive statistics: Percentage of children who did not receive an ADHD diagnosis in the public system, but were prescribed and/or dispensed a stimulant or other ADHD medication either before or after contact with the public system.</td>
</tr>
<tr>
<td>Assess the extent to which the NICE guideline for ADHD is being followed for medication and non-medication treatments</td>
<td>Frequency and descriptive statistics: Percentage of children who were prescribed and/or dispensed medications for ADHD in the order recommended by NICE (e.g., Methylphenidate $\rightarrow$ Lisdexamfetamine/Dexamphetamine $\rightarrow$ Atomoxetine/Guanfacine).</td>
</tr>
<tr>
<td>Assess the extent to which sociodemographic variables are associated with treatment type, comorbidities, and MAT</td>
<td>Logistic regression: Sociodemographic variables (including age, sex, and postcode socioeconomic status) as predictors of receiving medications only, or medications and allied health support. Logistic regression: Sociodemographic variables as predictors of receiving minimally adequate treatment Multiple regression: Sociodemographic variables as predictors of number of comorbidities for those with ADHD</td>
</tr>
</tbody>
</table>
Assess the extent to which MAT and adherence to the NICE guideline are associated with routine outcomes measures administered in the public system. For children with ADHD or a medication history suggestive of ADHD, Mean routine outcome measure scores will be compared for those children who received MAT, inadequate treatment dose (some intervention, but not MAT), or no treatment. Mean routine outcome measure scores will also be examined in those children who received NICE recommended treatment compared to not receiving treatment as recommended by NICE. Percentage of children who received MAT or NICE, and improved to no longer be in the ‘clinical range’ compared to those who didn’t receive MAT or NICE recommended treatment. Multiple linear regression to assess the effects of MAT and NICE recommended treatment on continuous routine outcome measures in the public system, whilst controlling for personal and sociodemographic factors such as age, sex, socioeconomic status of home address, presence of comorbidity, parental factors, and treatment setting (mental health or child development service).

Logistic regression to quantify the odds ratio of predictors associated with treatment success (outcome measure scores below clinical range).

**Abbreviations:** MAT – Minimally Adequate Treatment, NICE – National Institute for Health and Care Excellence, OT – Occupational Therapist

**Patient and public involvement**

None.

**Ethics and dissemination**

This study has been approved by the following Human Research Ethics Committees (HRECs): 1) Children’s Health Queensland Hospital and Health Service HREC (HREC/21/QCHQ/76260), 2) University of Queensland HREC (2021/HE002143), and 3) The Australian Institute for Health and Welfare HREC (EO2021/4/1300).

The dataset for this study will be stored within the Sax Institute’s Secure Unified Research Environment (SURE). In effect, each research project operates within an operating system virtual machine, isolated from other projects and parts of the network. The system is
rated as a Tier 3+ data centre, ensuring the highest levels of information security and integrity, and physical server security. The linked dataset will be securely archived for 10 years and then destroyed.

Results of this study will inform clinical practice in the management of ADHD nationally, and internationally. We will disseminate our findings through peer reviewed journals, conferences, professional associations, and to public mental health services whom treat ADHD.

At the time of the present publication, the site datasets from Brisbane, Melbourne, and Sydney are being collated by the research team, in preparation for transmission to the Federal registry custodians to perform data linkage. It is anticipated that analyses will be completed within 1 year following provision of the linked dataset back to the research team.

Discussion

Previous research has demonstrated that, compared to those with emotional disorders, children with ADHD in the public child and youth mental health system improve to a lesser extent on routine outcome measures and are more likely to remain in the clinical range at end of treatment [18]. The current study provides a broader evaluation of the public health system’s treatment of ADHD by studying both Child Development Services and Child and Youth Mental Health Services. The types of children typically seen in CDS and CYMHS, respectively, tend to differ. Both focus on complex cases, but CYMHS often only see children with neurodevelopmental disorders when there is co-morbidity, as these services are intended to treat severe mental and behavioural disturbance. CDS is dedicated to the assessment and treatment of neurodevelopmental disorders, so often see children earlier in life but who are still presenting with complex developmental issues. The high threshold for acceptance of a referral by CYMHS generally means that children within CYMHS have
received input prior to this episode of care. Extending the data collection outside the CYMHS and CDS clinical episodes will provide a more comprehensive view of the treatment received by these both before and after this episode of care. In particular, capturing the treatment children received after their contact with public health services will allow us to estimate long-term engagement with treatment. Insight into the treatment received prior to entry into the public system (e.g., Did the child see a paediatrician or psychiatrist? Were psychotropics prescribed – and if so, were the script repeats filled? Did the child see a private psychologist?) will generate important information, describing the patient journey and understanding the outcomes of children, as their improvement in the public system may have a ceiling effect if there have already been substantive interventions trialled previously.

**Limitations and future research directions**

Whilst linkage studies in Australia generally provide a comprehensive overview of the points of clinical service a child has received due to the ubiquity of Medicare, there are key limitations on the information provided by federal registries. With regards to the PBS, the issuing of a prescription does not guarantee the child took the medication. Medication compliance is a known issue in ADHD, with Perwien, et al. finding that in a US setting by the second month of treatment, less than 20% of children were compliant in taking their medication. Similarly, Australian data analysed by Efron, et al. found that children prescribed medication for ADHD only took the medication for approximately 40% of the time-period they were under treatment. Further limitations of this study relate to the MBS data – while the MBS data tells researchers the type of practitioner the child saw, the reason for an attendance with a physician or allied health practitioner is not necessarily known. For example, a child with ADHD seeing a paediatrician may be attending for another unrelated concern. Similarly, a child may attend a session with a psychologist under a Mental Health Care Plan (the mechanism allowing a patient to see an allied health practitioner specialising...
in mental health under the MBS), resulting in a billed MBS item, however there is no way of knowing if ADHD symptoms or strategies were the focus of that session, or if another problem was the focus of treatment, and what the exact intervention was. A further issue with psychology, is that until the COVID-19 pandemic, mental health MBS benefits with allied health practitioners were limited to 10 sessions per year, meaning there is a possibility that some children continued seeing their psychologist privately after the initial sessions, and that this information would not be recorded in the MBS data. Additionally, other than private psychology, mental health OT, and mental health-social work, other mental health services, such as those provided by state governments and public hospitals is block-funded, and therefore would not appear in the MBS output for a particular patient had they attended these services. These situations would lead to underestimating the level of professional input received (i.e., the ‘dose’ of the non-pharmacological intervention).

Whilst we will use Saloner’s definition of Minimally Adequate Treatment based on the previous literature – 4 sessions for medication, 8 sessions for non-pharmacological treatment \[24\], there are limitations in the use of this categorisation. MAT is defined for paediatric psychiatric problems broadly, so it is unclear whether the true threshold for MAT for ADHD is in-line with Saloner’s definition, or whether ADHD requires more or even fewer professional attendances to result in effective treatment. Additionally, Ride, et al. \[31\] found, in a sample of 600 Australian children, that MAT did not improve clinical outcomes in routine practice, indicating that quality of treatment may be more important than quantity/frequency. Ride’s \[31\] study however, examined outcomes on the Strength and Difficulties Questionnaire and did not have diagnostic information available, which may limit its applicability to an ADHD cohort.

Furthermore, with the cohorts involved, we will not capture the data of those children whose entire pathway from diagnosis of ADHD to treatment was conducted privately, and
subsequently whether there are differences in treatment between those treated solely within the private system, versus those children who were treated in the public system or both public and private, as included in our cohorts. Future research could investigate the treatment of children solely seen in the private system, and whether the findings are comparable to the results in this study.

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**Contributors**

Daniel Sullivan wrote the original draft, reviewed/editing, assisted with project administration and data curation. Leanne Payne assisted with writing review/editing, project administration, and conceptualisation. Kelsie Boulton assisted with writing review/editing, project administration, and data curation. Natalie Silove assisted with writing review/editing. Mark Bellgrove assisted with funding acquisition, conceptualisation, and writing review/editing. Emma Sciberras assisted with writing review/editing, conceptualisation. David Coghill assisted with writing review/editing, conceptualisation, and project administration. Adam Guastella assisted with writing review/editing, conceptualisation, project administration. Christel Middeldorp assisted with funding acquisition, writing review/editing, supervision, project administration, conceptualisation, and methodology.

**Competing interests**
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References


**Figure Legends:**

**Figure 1: Linkage flow and procedure for Australian Medicare and Pharmaceutical Benefits Scheme data**

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