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**TITLE PAGE**

## Full title

An audit of enuresis referrals on the waiting list for a tertiary hospital outpatient clinic

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We thank the general practitioners that kindly participated in this study. This project would not have been possible without their participation.

## Conflict of Interest Statement

The authors have declared that they have no conflicts of interest to disclose.

## Abbreviations

BBD – Bowel and Bladder Dysfunction
CCCH – Centre for Child and Community Health
EMR – Electronic Medical Record
HREC – Human Resources Ethics Committee
MSE – Monosymptomatic enuresis
NMSE – Non-monosymptomatic enuresis
RCH – The Royal Children's Hospital, Melbourne, Australia

**MAIN TEXT**

**ABSTRACT**

**Aim**

Enuresis, defined as intermittent incontinence occurring exclusively during sleep, affects 4 - 19% of children, but can be effectively treated using education and alarm-bell therapies. However, delays in treatment are likely to impact upon quality of life of the child, parents and carers. Poor quality and incomplete referrals are thought to be a major driver of inefficiencies. The aim of this study was to explore characteristics of enuresis referrals on the waiting list for a General Medicine clinic at a tertiary paediatric hospital.

**Methods**

An audit was conducted to examine all enuresis referrals on the General Medicine outpatient clinic waiting list in February 2019 at The Royal Children's Hospital, Melbourne. Enuresis

referrals with an organic cause and those for children less than five years of age were excluded.

**Results**

Of the 2613 referrals on the General Medicine waiting list, 486/2613 (19%) were related to enuresis. The median age of patients on the waiting list was 8 years and 65% (315/486) were male. Sufficient detail was provided to determine temporal and disease stratification in 45% (218/486) of referrals; primary versus secondary enuresis, and monosymptomatic versus non-monosymptomatic enuresis. The mean number of days on the waiting list calculated at the time of data extraction (13 February 2019) was 226 (± 179) days.

**Conclusions**

The findings from this study suggest that there are long waiting times for enuresis services and referrals often do not contain complete information.

**Key words**

Bladder Dysfunction, enuresis, quality improvement, wait times, referral, audit

**What is already known on this topic:**

- The quality of referrals for specialist care varies considerably.
- Timely management of enuresis is important to limit the negative impacts upon the child and family.

**What this paper adds:**

- At the time of the audit, patients had been on the General Medicine outpatient clinic waiting list for a mean of 226 days.
- Over half of enuresis referrals on the waiting list lacked detailed information about the temporal and/or disease stratification.
- Patients were referred from a wide geographic area, but there were some areas identified where referral numbers were high.

## INTRODUCTION

Enuresis is defined by the International Children's Continence Society (ICCS) as intermittent incontinence of urine that occurs exclusively during sleep.[1] Enuresis is further subdivided into monosymptomatic (MSE) and non-monosymptomatic enuresis (NMSE). Monosymptomatic enuresis is defined as bedwetting without any other symptoms of the lower urinary tract (LUT) or daytime bladder incontinence, whereas NMSE is bedwetting with accompanying daytime LUT symptoms or bladder incontinence.[1] Both MSE and NMSE are termed primary if the child has never experienced a dry period of at least six months. Otherwise, they are regarded as secondary if symptoms develop subsequent to a period of being dry for at least six months. The ICCS recommends that enuresis may only be diagnosed if a child is at least five years of age, has had at least one episode per month, with a minimum duration of three months.[1]

Enuresis has a reported prevalence of 4 – 19%.[2-5] It is more common in younger children[6, 7] and boys, however this gender difference diminishes with increasing age.[3, 6] Primary enuresis is more common than secondary enuresis (87% and 12%, respectively).[6] The greatest proportion of enuresis is attributed to MSE (60 – 75%), in comparison to NMSE (15 – 40%).[6]

Functional incontinence, which includes urinary incontinence, enuresis and faecal incontinence, is a debilitating condition to the quality of life (QoL) of children and their families.[8] A local study reported self-esteem and mental health were the main domains affected by daytime urinary incontinence and/or enuresis.[9] These outcomes are likely to be further impacted by comorbid conditions, including bowel dysfunction and neuropsychiatric disorders (e.g. attention deficit hyperactivity disorder(ADHD).[10]

For preschool children, active treatment is not recommended as enuresis is considered normal in this age group.[10] Families should be advised about normal bladder function and the pathogenesis of enuresis. Simple methods, such as a calendar of dry and wet nights, reward systems such as star charts, fluid restriction, lifting and wakening are effective simple short-term strategies.[11] For children aged six years and above, enuresis alarms and pharmacological therapy are effective active treatments.[10, 12-14] However, alarms are also reported to have a high dropout rate due to difficulties with compliance, initial disruption to the family and the lack of appropriate guidance.[14]

Referrals to specialist care are often sought for enuresis alarms or pharmacological therapy such as desmopressin. Unfortunately, the time from referral to appointment can be several months. A recent Australian audit revealed children with wetting had waited approximately six months for a specialist appointment.[15] Referral quality has been suggested as a factor contributing to delays in specialist care, which is particularly relevant for children with enuresis – a low-morbidity, chronic condition. In a generalist specialist clinic, referrals are received for a range of high to low-morbidity conditions. Information within a referral is used to determine appropriateness and to triage the patient into the following: scheduling an appointment; redirection to a more appropriate clinic; rejection of the referral; or being placed on a wait list. For enuresis, detailed information could help redirect the patient to a more appropriate clinic and decrease wait time to treatment. The importance of timely care is supported by a Canadian study that revealed increasing waiting times were associated with disease flares, hospitalisations and additional referrals for patients with inflammatory bowel disease.[16] They also highlighted the shortfalls of referrals, where 20% of referrals did not include the diagnosis, 45% did not report the duration, and 29% did not report severity.[16]Thus suggesting a link between wait time, referral quality, and poor patient outcomes.

This project aimed to explore characteristics of enuresis referrals on the General Medicine specialist outpatient clinic waiting list at a tertiary paediatric hospital in Melbourne, Australia. The characteristics included demographic data, wait time, temporal and disease stratification, and geographic distribution of referrals.

**METHODS**

We conducted an audit of enuresis referrals on the General Medicine outpatient clinic waiting list at The Royal Children's Hospital (RCH), Melbourne. The list of patients currently waiting for an appointment was extracted on 13 February 2019 from the Electronic Medical Record (EMR). Using a report in EMR, filters were applied to the diagnosis field to identify enuresis referrals. The filters included: enu, ene, noct, wet, alarm, mono, incont, pad, MSE, NMSE, ref, and records where the free-text field was blank. The filtered list was subsequently screened to identify patients referred for enuresis. Referrals were excluded if the patient was less than five years of age and if an organic cause was responsible for urinary incontinence.

For all eligible records, non-identifiable epidemiological data (sex, age and postcode) were extracted from the patient's medical record. Referral information (inclusion of temporal;

primary versus secondary, and disease differentiation; monosymptomatic versus non-monosymptomatic) were retrieved from data contained in the referral.

A measure of socioeconomic status was calculated from the patient's postcode using Socio-Economic Indexes for Areas (SEIFA) data from the 2016 Australian Bureau of Statistics census. The Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) is a decile score corresponding to postcodes in Australia.[17] These deciles were converted to quintiles for this study. Furthermore, these postcodes were used to generate a heatmap of services using a web-based interactive map design platform, ArcGIS (ESRI, California, USA).

Descriptive statistics were performed using Microsoft Excel (Microsoft Corporation, Washington State, USA).

### Ethics approval

This audit was part of the Bowel and Bladder Dysfunction project, a quality-improvement initiative focusing on timely and streamlined care for children with bowel and/or bladder dysfunction. Ethics approval was granted by The RCH Human Research and Ethics Committee (Reference number 35232).

## RESULTS

### Patient demographics

Of all the patients on the General Medicine waiting list, 486/2613 (19%) were referred for enuresis. The median age was 8.0 years (Interquartile range: 1.47 – 10.80) and 65% were male patients (315/486). The majority (308/486; 63%) of patients resided in the most advantaged socioeconomic areas of Melbourne (IRSAD quintiles 4 – 5). (Table 1)

### Referral characteristics

Most of the referrals were for a first appointment (391/486; 81%) with the remainder of referrals requesting a review appointment. The mean waiting time for all referrals was 226 (± 179) days, calculated according to the date of data extraction (13 February 2019). Referrals for a review appointment were on the waiting list for a mean of 163 days (± 153), whereas a referral for a new appointment had a mean of 241 (± 182) days.

One third of all referrals (163/486; 34%) provided limited information as they did not contain sufficient detail to determine both temporal stratification (primary versus secondary) and disease stratification (MSE versus NMSE). A further 22% did not have sufficient information to determine either temporal or disease stratification (n = 63 and n = 42, respectively). For referrals where temporal stratification could be determined, 84% (237/281) were for symptoms of primary enuresis. For referrals where disease stratification could be determined, 69% (179/260) were for symptoms of MSE. (Table 2)

**Geographical data**

There were 172 unique postcodes extracted from the referral data. Almost all referrals were within Victoria (170/172; 99%), with two from New South Wales. (Figure 1) The median frequency of referrals from a corresponding postcode was 2 (IQR: 2, range 1-25) referrals per postcode. Of these postcodes, 9% (15/172) were outliers; >6 referrals per postcode. These outliers accounted for 33% (158/486) of all referrals. (Supplementary Table S1) The postcode of 3030 (Werribee) had the largest number of referrals for one area (25/486; 5%). A heatmap representing the density of referrals using postcode data shows that there were referral hotspots in the Western and Northern suburbs of Melbourne. (Figure 2)

**DISCUSSION**

This study found that paediatric enuresis referrals came from a large geographical area and patients experienced a significant wait for a new or review appointment to be scheduled. Moreover, enuresis referrals often did not contain sufficient detail to ascertain temporal and/or disease stratification.

Our audit demonstrates that enuresis is common, accounting for nearly one fifth of specialist referrals on the General Medicine waiting list and highlights the significant demand placed upon the service. Patients were referred from far and wide across Victoria, and even New South Wales. The large geographical area of referrals is concerning. It suggests that there may be an issue with enuresis service provision, whereby there may be limited availability or access to paediatric enuresis services. Poor resource allocation poses an issue as particular services may become unduly congested, whilst others are not being accessed with consequent detriment to patient care.

The findings also show referrals had waited an average of eight months with no contact from the service. This is unsatisfactory considering the impact that prolonged time to treatment has

upon the QoL of these patients.[8, 18] Our audit did not explore factors contributing to delays, but did reveal that over half of referrals were inadequate in terms of temporal and disease stratification. The inconsistency of referral quality is substantiated in the literature[16] and may contribute to delays with prioritisation and triage. Strategies aimed at improving the delivery of care and improved patient outcomes have been discussed in the literature such as referral initiatives, resource alignment, operational efficiency, and process improvement.[19, 20] Possible strategies to improve referral quality may involve reassessment of appropriateness and completeness checks leading to rejection or requests for further information. These strategies could help reduce the waiting list, may improve clinical handover with subsequent referrals, and provides an education opportunity for both referrers and families. Rejection of referrals may improve referral practices and quality in the long term. However, this practice is also likely to result in longer delays for the child.

Nurse-led clinics or similar supported models of care may not entirely address excessive referrals. However, they offer a possible entry point to services and may be able to address service gaps and meet some of the demand for enuresis services. This may be particularly helpful for the group with MSE for whom timely access to alarm therapy should be a priority. A large systematic review found that nurse practitioners in primary care had higher levels of reported patient satisfaction and quality of care, with longer consultation times noted.[21] Nurse-led enuresis programs have been successfully delivered across primary care settings in Northland and South Auckland, New Zealand.[22, 23] A Melbourne study also noted supportive alarm programs delivering weekly contact with a paediatric nurse resulted in successful management of enuresis and low dropout rates.[24] The attributes of nurse-led or supported models of care, provide the opportunity for longer and more frequent consultations, provision of education and advice, and demonstrate the capability of new service models to improve compliance and treatment outcomes.

The current study quantifies enuresis referral information from primary care. It also describes the relative proportion of patients that had MSE versus NMSE and primary versus secondary enuresis. This is a useful metric in understanding enuresis and what services are required to address care. The data also provides valuable information on service shortfalls; long wait-times, incomplete referrals and large appointment distances. Despite the value of the findings, generalisability is limited as only one clinic waiting list was quantified at a given point in time. Moreover, we were unable to explore reasons behind the SEIFA distribution, which

was skewed to a higher proportion of those from areas of advantage being on the wait list. This is important to ensure delivery of equitable care across all levels of socioeconomic status. Insights into other internal enuresis services, or external health services were outside the scope of this study, therefore, further studies are required to assess additional enuresis services. A qualitative approach to enuresis service provision assessing primary health care perspectives on enuresis service provision may elucidate why there are these service shortfalls and what may be the contributing elements to the identified quantified inadequacies.

**CONCLUSION**

Enuresis contributes to a significant proportion of referrals to the General Medicine outpatient clinic at the RCH in Melbourne and places a significant burden on paediatric healthcare services. These referrals are often inadequate and there is an extensive waiting time for patients referred for enuresis.

Potential improvements to help deliver timely care may include redesign of existing models of care and strategies for redistribution of enuresis services to support access to alarm-based treatments.

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**Table 1** Characteristics of patients referred to the General Medicine outpatient clinic for enuresis

| Characteristic | Participants (n = 486) |
|---|---|
| Age, years | |
| Median | 8.0 |
| IQR | 1.47 – 10.8 |
| Sex, n (%) | |
| Male | 316 (65) |
| Female | 170 (35) |
| Socio-economic disadvantage quintiles†, n (%) | |
| 1 (most disadvantaged) | 36 (8) |
| 2 | 49 (10) |
| 3 | 93 (19) |
| 4 | 151 (31) |
| 5 (most advantaged) | 157 (32) |
| Appointment type, n (%) | |
| First | 391 (81) |
| Review | 95 (20) |
| Time on waiting list‡, days | |
| Mean | 226 |
| Standard deviation | 179 |

† Socio-economic Index of Relative Advantage and Disadvantage (IRSAD) quintile, based on postcode.[17]

‡ Wait time was calculated for new and review appointments. For new patients, date from referral to 13 February 2019 was calculated. For review appointments, date from previous appointment to 13 February 2019 was calculated.

**Table 2** Enuresis referral information stratified according to temporal and disease stratification

| | Temporal stratification | | | |
|---|---|---|---|---|
| Disease stratification | Primary | Secondary | Unclear | Total |
| MSE | 134 | 21 | 24 | 179 |
| NMSE | 44 | 19 | 18 | 81 |
| Unclear | 59 | 4 | 163 | 226 |
| Total | 237 | 44 | 205 | 486 |

MSE, monosymptomatic enuresis; NMSE, non-monosymptomatic enuresis.

Referrals made to the General Medicine outpatient clinic of The Royal Children's Hospital, Melbourne as of 13 February 2019.

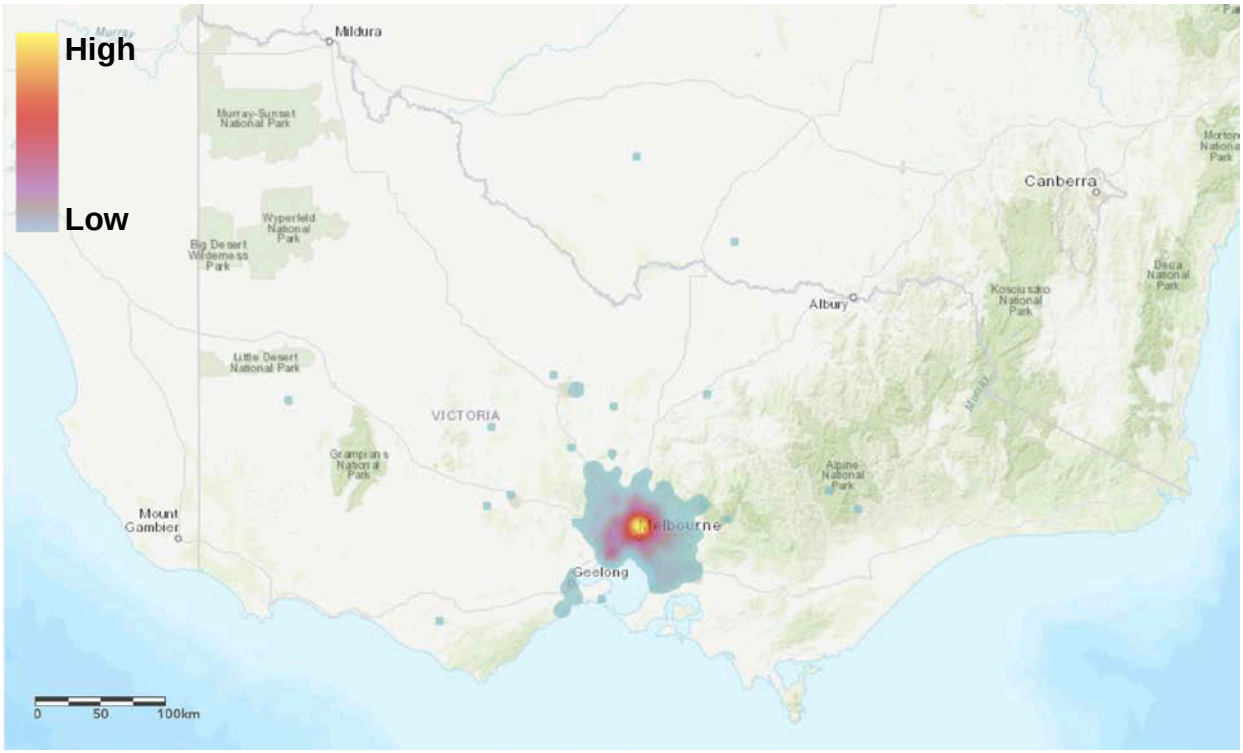


**Figure 1.**

Heatmap of enuresis referrals (n = 486) to The Royal Children's Hospital, Melbourne General Medicine outpatient clinic as of 13 February 2019. A total of 172 unique post codes represented across Victoria and New South Wales, Australia. Generated using ArcGIS ©, a web-based interactive map platform.

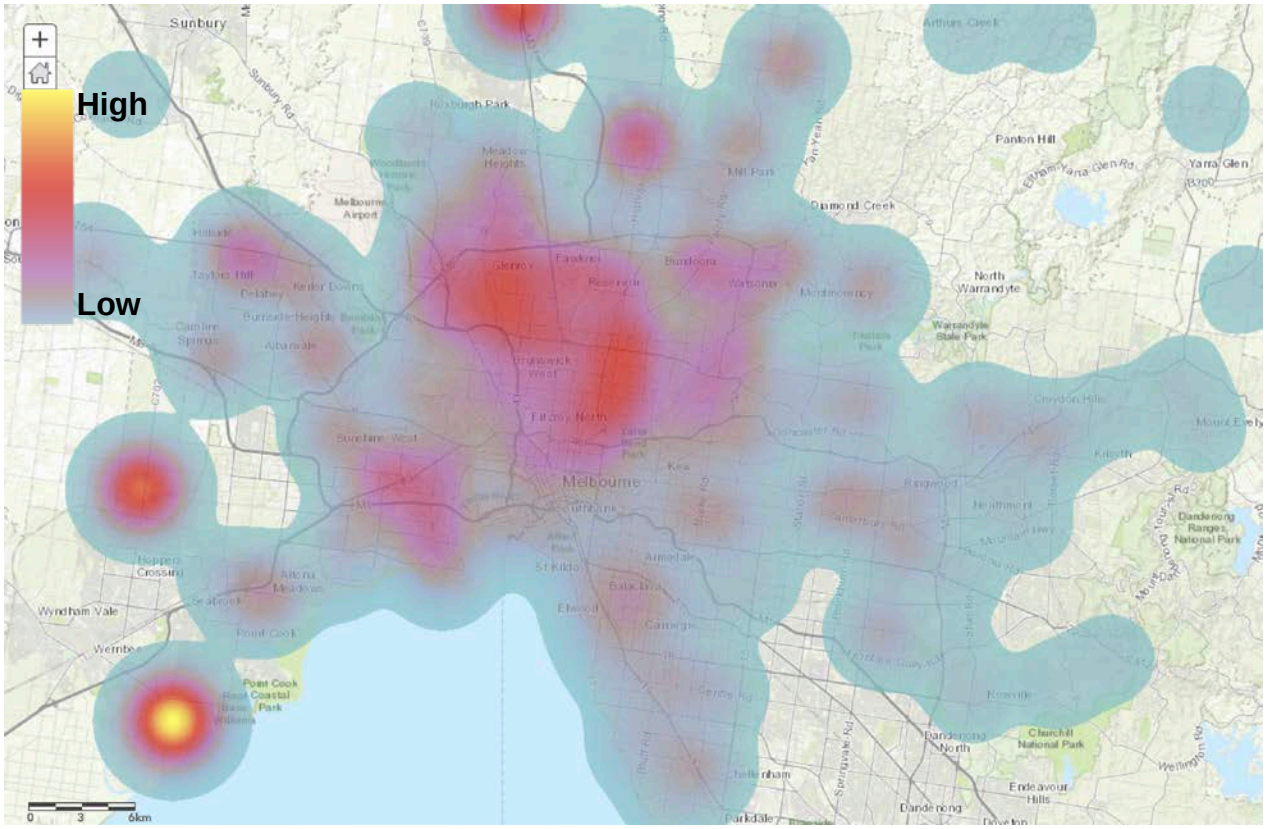


**Figure 2.**

Heatmap of enuresis referrals (n = 486) to The Royal Children's Hospital, Melbourne General Medicine outpatient clinic as of 13 February 2019. A total of 172 unique post codes represented across Victoria and New South Wales, Australia. Generated using ArcGIS ©, a web-based interactive map platform.

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