Young people with urinary incontinence

Data evaluation report
The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this by:

- **service redesign and evaluation** – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services
- **specialist advice on healthcare innovation** – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment
- **initiatives including guidelines and models of care** – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system
- **implementation support** – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW
- **knowledge sharing** – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement
- **continuous capability building** – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care.

Urinary incontinence is a common problem that affects up to 10% of children and young people under the age of 18 and impacts on health, quality of life and health costs. It has emerged as an increasingly significant problem for young adults, and if untreated, can progress to adulthood.

The Childhood Urinary Incontinence Service (CUIS) at the Children’s Hospital at Westmead (CHW) is a multidisciplinary service providing specialist advice for young people aged 3-18 who are intermittent day and/or night time bedwetters. The average CUIS wait time is 399 days.

There are increasing concerns regarding statewide inequity of access to best practice treatment for young people up to age 25 who are no longer able to be treated through the Sydney Children's Hospital Network (SCHN).

The Agency for Clinical Innovation (ACI), in partnership with the Sydney Children’s Hospitals Network (SCHN) and the Continence Foundation of Australia (CFA), took part in a project to improve the management and health outcomes of young people with urinary incontinence in NSW. The project is known as PISCES (paediatric information, schema, continence, education, support).

The Health Economics and Evaluation Team (HEET) analysed data provided by the CHW to answer evaluation questions. This report presents evaluation findings including the description of patient demographics and CUIS patient flow patterns, the description of the service activities and billings, and analysis of the eADVICE program, which is a conservative online self-management program for waiting patients.

Key findings from the data analysis

- Patients attending the CUIS at the CHW are relatively equal in gender distribution, with an average referral age of eight and average first appointment age of nine.
- Transitional patients (15 years and older) tend to have later treatment initiation (age 14), higher comorbidity rates, and require more resources than those of younger ages.
- Patients up to age 20 continue to be seen in the CUIS, which is funded through the Medicare and the Medicare Benefits Schedule.
- Between 2010-2011 and 2014-2015 the Medicare benefits paid for the service was approximately $160,000 per annum, or $844 per patient per year.
- Between 2010-2011 and 2014-2015 an average of 197 individual patients were managed through the service per annum, with each patient attending an average of 5.2 appointments per year.

A simple comparative effectiveness analysis of the eADVICE program indicated that eADVICE is relatively more effective in reducing the demand for clinic visits compared with no eADVICE. eADVICE has the effect of reducing new patients requiring CUIS and reducing appointment volumes for those who do attend.

Recommendations to enhance service efficiency and effectiveness

- Perform further qualitative review to assess referral behaviours against best practice, particularly for transition age patients.
- Perform further qualitative review to understand patient compliance and dropout, particularly for patients not responding to treatment.
- Introduce screening processes to optimise clinic appointment time for patients with ongoing clinical needs.
- Ongoing rollout of the eADVICE program for waiting patients and review of the required administrative support.
- Review of postcode geographic distribution to guide location of telehealth pop up clinics.
- Review and, if required, develop transition pathways for older patients.
- Networking between major CUIS services providing support these recommendations collaboratively across NSW.

---

Contents

Introduction 1
   Background to the PISCES project 1
   Intended outcomes of the PISCES project 1

Evaluation report purpose and scope 2
   Key evaluation questions 3

Method 4
   Data used for analysis and limitations 4
   Patient outcome measurement 6
   Outcome and data matrix 6

Results 7
   CUIS patient demographics 7
   CUIS service description 8
   Complicated urinary incontinence 8
   Wait time 11
   CUIS appointment need 11
   CUIS appointment volume 12
   CUIS outcomes 12
   Impact of eADVICE online program 14
   Comparative effectiveness analysis of eADVICE 20
   Transition age characteristics10 21

Discussion 24
   Referral trends 24
   Waiting list management 24
   eADVICE program implementation 24
   Optimising treatment outcomes 24
   Transition age patients 24
   CUIS and telehealth 24

Conclusion and recommendations 25

Appendix 26
Introduction

Background to the PISCES project

The CUIS at the CHW has been in operation since 2003 and, until recently, was the only multidisciplinary CUIS clinic in NSW. Further services are being established at the Sydney Children’s and John Hunter Hospitals.

There are two CUIS sessions per week with a total of five clinicians seeing children and young people who experience day and/or night time wetting in these sessions. Over time, the CUIS has developed a wait time of up to 20.5 months and there is an increasing concern of clinical management variation of childhood urinary incontinence statewide.

This context has led to the formation of the Paediatric Information, Schema, Continence, Education, Support (PISCES) project. The project steering group incorporates several representatives: clinical experts, ACI Transition Care and Urology/Gynaecology Clinical Network Managers, the ACI Implementation team, Patient Experience and Community Engagement (PEACE) and the Health Economics and Evaluation Team (HEET).

The PISCES project aims to undertake a service and evidence review and develop approaches to guide statewide service improvements.

Intended outcomes of the PISCES project

The aim of the PISCES project is to:

1. improve the management of children with urinary incontinence statewide so that problems that can be effectively treated do not continue into adulthood
2. reduce the variation in management and develop standardised approaches to treatment reinforced by education and information
3. reduce the long waiting times and improving access to specialists.

The PISCES project assessed two service redesign strategies within CUIS:

1. A program called eADVICE (electronic advice and diagnosis via the internet following computerised evaluation) has been developed to support patients and their families/carers.

   eADVICE provides six months unlimited access to an online conservative self-management educational portal. The program incorporates assessment, diagnosis and individualised treatment advice based on an evidenced based algorithm. The advice, which would be relevant to patients’ symptoms, may include:
   - fluid advice
   - timed voiding
   - alarm training
   - medication discussions
   - reducing caffeine
   - bowel programs.

   Five pilot versions of eADVICE have been refined by CUIS clinicians. This evaluation report includes an analysis of the impact of eADVICE.

2. There have been three pop up pilot CUIS supported by telehealth to provide advice, support and training to rural clinicians to improve access and standardise practice. The ACI has been working in collaboration with clinicians to guide ongoing implementation and improvement of this strategy. This component is out of scope of this evaluation.
The purpose of this work is to answer evaluation questions outlined within the CUIS Evaluation Framework\(^2\), by the analysis of data made available by the CUIS at the CHW. Not all of the evaluation questions within this report could be answered by the data provided.

The major foci of this evaluation include:

- the description of patient demographics and CUIS patient flow patterns
- the description of the service activities and billings
- analysing the impact of the eADVICE online self-management program
- undertaking a comparative effectiveness analysis of the eADVICE program
- the description of the differences noted within transition age patients (>15 years).

The patient cohort for the analysis comprises:

- young people from approximately 5-16 years of age at the time of initial consultation, (including some patients aged over 16 years who have an established relationship with the hospital)
- patients with intermittent urinary incontinence (day and night)
- patients on the wait list or attending the CUIS at CHW.

Further information assessing the experiences of the patients, their carers and families will be collected and analysed by the ACI PEACE team and reported separately for this project (see the *Young people with urinary incontinence: Patient experience report*). A guide regarding the pilot telehealth pop up clinics has also been prepared by the implementation team (see the *Young people with urinary incontinence: Telehealth guide*).
### Key evaluation questions

Key evaluation questions and sub-questions have been answered based on data made available (Table 1).

**Table 1: Key evaluation questions and sub-questions**

<table>
<thead>
<tr>
<th>Key evaluation questions</th>
<th>Sub-questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the current impact on resources to the service?*</td>
<td>What is the current impact on resources due to patients receiving treatment?</td>
</tr>
<tr>
<td>What are the impacts on transition from a children’s to adult service?</td>
<td>What are the impacts on chronic illness?</td>
</tr>
<tr>
<td></td>
<td>What are the demands on general practice?</td>
</tr>
<tr>
<td>What impacts has the online eADVICE program had on patient outcomes?</td>
<td>How many patients using eADVICE became dry?</td>
</tr>
<tr>
<td></td>
<td>How many improved?</td>
</tr>
<tr>
<td></td>
<td>How many had no change?</td>
</tr>
<tr>
<td></td>
<td>What is the cost of these patients on the clinic?</td>
</tr>
<tr>
<td>What has been the impact of the use of telehealth to support rural sites?</td>
<td>What value do clinicians (recipients of the pop up service) place on the service?</td>
</tr>
<tr>
<td></td>
<td>How has practice changed as a result of telehealth support?</td>
</tr>
</tbody>
</table>

Note: Cost data are not available and have been analysed instead according to Medicare benefits paid. The questions have been best answered by the data available. The questions/sub-questions regarding telehealth are out of scope for this report.
Method

Data used for analysis and limitations

The following limitations should be considered in assessing the validity and transferability of the results and recommendations in this report:

- The five databases include patients attending the CUIS at the CHW in different timeframes over an extended period of time. The completeness of the data is unknown.
- There is incomplete data due to unknown fields or patients lost to follow-up.
- The data has been sourced from one CUIS clinic (at the CHW), which may not be representative of other clinics.
- The data were collected by medical advanced trainees, research assistants and administration staff, however it is unknown what quality assurance processes for data measurement and recording were undertaken.
- The outcomes reported within the databases are not based on a validated and reliable patient reported outcome measurement tool.
- The timeframes between pre and post treatment outcome data collection across the five databases may be variable. Outcomes were defined by reported response at last visit. This may lead to under-reporting of positive outcomes as patients who improved may not have presented for ongoing appointments.
- Descriptive statistics have been utilised and therefore do not infer statistical significance.
- Unknown external factors may contribute to the results reported, such as treatment received from other sources (e.g. private specialist and primary care).
- The symptoms of childhood urinary incontinence can recur following resolution, therefore outcomes may not indicate long-term resolution.

In addition to these general limitations, there are specific limitations for each database (Table 2).
Table 2: Database descriptions and limitations

<table>
<thead>
<tr>
<th>Database</th>
<th>Description</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Database 1 CUIS wait list 3/7/2014-30/6/2016</td>
<td>Contains 652 records of referrals. Includes current wait list status.</td>
<td>A 14% unable to contact rate for follow up. 22/652 individuals with incomplete or erroneous data (e.g. missing date of birth (DOB) or clinic date prior to referral date); classified as unknown.</td>
</tr>
<tr>
<td>Database 2 CUIS appointments 27/01/2010-7/5/2014</td>
<td>Contains 578 records with appointment dates, demographic, and outcome data, 12-month follow up for patient outcome and status. Two patients in this cohort received the eADVICE program.</td>
<td>Reported methodological data collection inconsistencies for an unknown number of patients. Outcomes measured between appointments rather than between admission and discharge. This cohort has been used as a counterfactual group for eADVICE, therefore outcome comparisons between these two groups may be overestimated.</td>
</tr>
<tr>
<td>Database 3 eADVICE +/- CUIS appointment/s 13/8/2012-5/5/2016</td>
<td>Contains 157 records of patients provided eADVICE. Includes eADVICE version (1-5), eADVICE uptake, outcomes, and CUIS utilisation for 60/157. Exclusion criteria: global developmental delay, not yet toilet trained and neurological basis of condition.</td>
<td>Five eADVICE pilot versions and reported methods of delivery may affect the validity of aggregated results. Pilots 4 &amp; 5 incorporated an avatar to promote treatment adherence and developing a therapeutic alliance with patients. 13-22% missing data in reported areas. Small numbers of patients who went on to attend CUIS appointment from which to draw conclusions on efficiencies.</td>
</tr>
<tr>
<td>Database 4 CUIS transitioning vs younger age 1998-2013</td>
<td>Contains 263 patients. Includes age, comorbidities, outcomes, clinic appointment dates and volumes, and referrals. Data are matched for gender and year of presentation to compare variables amongst age cohorts*.</td>
<td>15 year timeframe of cohort within database may not be representative of current situation.</td>
</tr>
<tr>
<td>Database 5 CUIS MBS revenue 2010/2011-2014/2015</td>
<td>Contains MBS consultation, procedure codes, benefits and service volumes.</td>
<td>MBS benefits volume may not be reflective of costs of service delivery, however since it contributes towards cost of the service, it is used as an approximation for assessing impact on resources. This database may include patients who have received the eADVICE program. The Medicare benefits data do not incorporate activity performed by locum staff working in the clinic during periods of leave of usual specialist staff. This is reported to be for 12, 5 and 6 clinics respectively over the 2013/2014, 2014/2015 and 2015/2016 financial years.</td>
</tr>
</tbody>
</table>

* This matching was reported and conducted by the clinical team from CUIS CHW.
Patient outcome measurement

The outcomes available within the data provided describe a graduated rating of treatment effect assessed from the patient’s first clinic appointment to their final appointment (Table 3).

Table 3: CUIS outcomes

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dry</td>
<td>The optimal outcome to be achieved. This is assessed as 14 consecutive dry nights or dry days.</td>
</tr>
<tr>
<td>Improved</td>
<td>The patient’s symptoms have improved. Less frequency and volume of incontinence.</td>
</tr>
<tr>
<td>Unchanged</td>
<td>There was no change in the patient’s symptoms.</td>
</tr>
<tr>
<td>Worse</td>
<td>The patient’s symptoms have become worse (incidence or volume).</td>
</tr>
<tr>
<td>Unknown</td>
<td>The data are missing or the patient has not been followed up.</td>
</tr>
</tbody>
</table>

Outcome and data matrix

The desired outcomes, related questions, data source and methods of analysis have been linked to demonstrate the analysis methods (Table 4).

Table 4: Outcome, questions data and method matrix

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Evaluation questions</th>
<th>Data source</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improvement in the management of young people with urinary incontinence across NSW so that problems can be effectively treated and do not continue into adulthood.</td>
<td>What is the current level of Medicare benefits paid to the service? What are the current levels of Medicare benefits paid for patients receiving treatment with and without eADVICE? What are the impacts on transition from a children’s to adult service? What are the impacts on chronic illness? What are the demands on general practice?</td>
<td>Databases 1-5 Patient data by sex, age, referral date, date seen, number of appointments, postcode, outcomes, drop-outs and cost data provided 2010/2011 to 2014/2015 financial years Number of patients on waiting list, condition, wait time Number of patients transitioning/referred to adult service Patient outcome data</td>
<td>Data collected by the service Medicare benefits data provided analysed instead of cost Appointment volume, outcome ratios comparisons for eADVICE and no eADVICE. Appointment needed analysis as proportion of appointments/wait list</td>
</tr>
<tr>
<td>Reduction in the long waiting times and improved access to see specialists</td>
<td>What impacts has the online treatment service had on patient outcomes? What were the outcomes of the eADVICE program? What is the cost of these patients on the clinic?</td>
<td>Databases 2-3 Number of patients accessing eADVICE program by age, sex, postcode, number of visits and outcome</td>
<td>Data collected by the service Comparative effectiveness of eADVICE and no eADVICE on patient outcomes</td>
</tr>
</tbody>
</table>
Results

CUIS patient demographics

The gender breakdown of patients on the CUIS waitlist is 56.3% males (366/650) and 43.7% females (284/650) (Figure 1).

Figure 1: Wait-list gender distribution: Database 1 (2014-2016) n=650

![Gender distribution chart]

Note: n=2 patients did not have age data to report.

Patient age at referral date ranges from 2-15, an average and median age of eight; 57.9% patients are represented within the 6-9 age range (Figure 2).

Figure 2: Age at referral date: Database 1 (2014-2016) n=652

![Age distribution chart]

Note: n=2 patients did not have age data to report.

3 Source: Database 1 CUIS waitlist 2014-2016
Of the 652 patients on the wait list, 219 or 34% have attended an appointment with 433 remaining waiting. The average age for those that have attended their first appointment is nine; the age range is 5-15 (Figure 3).

**Figure 3: Age at first appointment: Database 1 (2014-2016) n=219**

![Age at first appointment chart](image)

Wait list patients come from a broad geographic area across 340 suburbs and 210 postcodes.

**CUIS service description**

**CUIS clinic and patient volumes**

Between 2010/2011 and 2014/2015 there have been on average 86 clinics per year, equating to 1.6 clinics per week (Figure 4). Locum staff activity may not be incorporated in this data and may contribute to fluctuations seen.

**Figure 4: CUIS clinics per annum: Database 5 (2010/11-2014/15)**

![CUIS clinics per annum chart](image)

---

4 As at June 2016

5 Source: Database 5 CUIS activity and billing 2010/2011-2014/15
This provides an average of 1023 clinic appointments per annum and 12 patients per clinic, providing a service to 197 new patients per annum. The ratio of new appointments to follow-up appointments over the five years is one new appointment to five follow-up appointments (Figure 5).

Figure 5: CUIS appointment volume per annum new and follow-up: Database 5 (2010/11-2014/15)

CUIS procedure volumes

Uroflow and bladder scan trends show a similar pattern with relative stability in multidisciplinary appointments (Figure 6). Each year 24-33% of all appointments are multidisciplinary in nature, 84-92% involve uroflow and 85-93% involve a bladder scan.

Figure 6: CUIS procedure volumes per annum: Database 5 (2010/11-2014/15)

The CUIS clinic Medicare benefits for the period 2010/11-2014/15 averaged $165,653 per annum (Figure 7) which equates to an average of $844 per patient per annum (Figure 8). This average per annum billing per patient includes new and follow up appointment billings and procedure billings.

Figure 7: Total Medicare Benefits received by CUIS per annum: Database 5 (2010/11-2014/15)

![Bar chart showing total Medicare benefits received by CUIS per annum from 2010/11 to 2014/15.](chart1.png)

Note: New complex patient codes and MBS price increases have been applied from 2013/14.

Figure 8: Total Medicare Benefits per patient per annum: Database 5 (2010/11-2014/15)

![Line and bar chart showing total Medicare benefits per patient per annum from 2010/11 to 2014/15.](chart2.png)

Note: New complex patient codes and price increases occurred from 2013/14 and have been applied.
Wait time

Wait time for the 210 patients who received an initial appointment between 2014 and 2016 ranges from 9-617 days. The first quartile (25%) of patients attended an initial appointment within 392 days and 75% within 440 days. The average wait time was 399 days with the median at 414 days (Figure 9).

Figure 9: Wait time in days: Database 1 (2014-2016) n=210

CUIS appointment need

Phone calls were made to assess appointment need for patients remaining on the wait list. For patients who had not yet received an appointment, it was found that 25% no longer needed the appointment.

Figure 10: Appointment need for patients still on waitlist not yet received appointment: Database 1 (2014-2016) n=420

---

6 Source: Database 1 CUIS waitlist 2014-2016
7 Source: Database 1 CUIS waitlist 2014-2016
**CUIS appointment volume**

The average number of CUIS appointments per patient prior to the introduction of eADVICE is 3.6: a range of 1-20 appointments. 83% of patients receive five appointments or less and 5% receive between 10 and 20 appointments (Figure 12); the median number of appointments is 6.6. When the outliers (highest 5% appointment volumes) are removed the average, the number of appointments attended is three. These results provide a counterfactual for the impact of adding the eADVICE program whilst waiting for a CUIS appointment.

![Figure 11: Number of appointments: Database 2 (2010-2014) n=578](image)

**CUIS outcomes**

At 12-month follow up 23% of patients were assessed as dry, 36% improved, and 41% unchanged at follow up (Figure 13).

![Figure 12: Outcome rates post CUIS: Database 2 (2010-2014) n=578](image)

---

8 Source: Database 2 CUIS appointments 2010-2014
9 Source: Database 2 CUIS appointments 2010-2014
Appointment efficiency per outcome

Lower appointment volumes were noted in patients with an unchanged outcome compared to improved or dry outcomes. The average number of appointments in the unchanged group was 2.1 comparative to 4.5 and 4.7 for dry and improved, respectively (Figure 13).

Figure 13: Average appointment volume/outcome: Database 2 (2010-2014) n=578

There was a 95% dropout rate for patients with an unchanged outcome compared with 63% for improved outcomes (Figure 14).

Figure 14: Dropout rate by outcome: Database 2 (2010-2014) n=578
Impact of eADVICE online program

One hundred fifty-seven patients were offered the eADVICE program whilst on the CUIS wait list. 15% did not utilise or uptake the program, with zero visits to the eADVICE program; the remaining 85% utilised the program to varying degrees. Sixty patients then went on to attend clinic appointments based on usual wait list and appointment processes (Table 5).

Table 5: eADVICE program pathways and outcomes: Database 3 (2012-2015) n=157

<table>
<thead>
<tr>
<th>Patients (%)</th>
<th>Outcome</th>
<th>Total eADVICE program cohort outcomes (n=157)</th>
<th>Cohort eADVICE + CUIS clinic outcomes (n=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Dry</td>
<td>Improved</td>
</tr>
<tr>
<td>n=157 Total Cohort provided eADVICE Program</td>
<td></td>
<td>2%</td>
<td>31%</td>
</tr>
<tr>
<td>eADVICE uptake (n=134)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No eADVICE uptake (n=23)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Uptake of eADVICE program

For patients who did utilise the eADVICE program (85%) there was a range of 1-10 visits, and an average of three. For all patients offered the program the average visits was 2.5 (Figure 15).

Figure 15: Extent of eADVICE uptake: Database 3 (2012-2015) n=157

![Bar chart showing eADVICE visits](image)

eADVICE program outcomes (no CUIS visit)

Following eADVICE, 25% of patients had a dry outcome and 29% improved. This equates to 54% with positive outcomes (dry or improved) (Figure 16).

Figure 16: Outcome rate post eADVICE: Database 3 (2012-2015) n=157

![Bar chart showing patient outcomes](image)
This is 5% less than the proportion of patients achieving positive outcomes after attending CUIS appointments (an average of 3.6 appointments) (Figure 17).

**Figure 17: Outcomes rate comparison: Database 2 and 3 eADVICE V CUIS**

![Bar chart comparing outcomes between eADVICE and CUIS](chart17)

- **eADVICE** (n=157)
- **CUIS** (n=568)

### eADVICE Impact on CUIS Appointment Volumes

Following eADVICE, 60 patients went on to attend clinic appointments and had reduced appointment volumes; 73% (44/60) received three or less appointments with the average number of appointments attended being 2.98 (Figure 18).

**Figure 18: CUIS appointment volume post eADVICE: Database 3 (2012-2015) n=60**

![Bar chart showing appointment volumes](chart18)

There is a 17% reduction in appointment volume for patients provided eADVICE compared with patients not provided eADVICE.
eADVICE treatment efficiency per outcome

Following eADVICE, an average of 2.2 and 3.8 CUIS appointments are attended for patients with dry and improved outcomes respectively, with an average of 5.5 CUIS appointments for patients with an unchanged outcome (Figure 19).

Figure 19: Average appointment volume per outcome following eADVICE: Database 3 (2012-2015) n=60

![Bar chart showing average appointment volume per outcome following eADVICE.](chart19)

Note: n=2 for unchanged category.

This is a different trend in the relative appointment volume per outcome seen prior to the introduction of eADVICE (Figure 20). Positive outcomes consumed lower appointment volumes and higher appointment volumes are provided to patients not responding as quickly to intervention.

Figure 20: Average CUIS appointment volume per outcome- eADVICE V no eADVICE: Databases 2 and 3

![Bar chart showing average appointment volume per outcome before and after eADVICE.](chart20)
eADVICE + CUIS outcomes

Positive outcomes (dry or improved) were seen in 74% of the patients who were offered eADVICE and also attended CUIS appointment/s (Figure 21).

Figure 21: Outcome rate eADVICE + CUIS: database 3 (2012-2015) n=60

![Outcome rate chart](#)

The addition of eADVICE whilst waiting for CUIS appointment had an 8% greater positive outcome (dry or improved) rate than attending the CUIS without eADVICE (Figure 22).

Figure 22: Outcome rate comparison: eADVICE + CUIS V CUIS: database 2 and 3

![Outcome rate comparison chart](#)
eADVICE program version comparison

There are five versions of the eADVICE program (1-5) with the most superior versions considered to be versions 4 and 5. Versions 1-3 (n=65) and versions 4-5 (n=92) were compared.

There was a slight reduction in eADVICE visit rate for versions 4-5 with an average of 2.25 visits, compared with 2.95 for versions 1-3.

Patients who were offered eADVICE pilot versions 4-5 had a reduction in appointments attended compared with patients offered eADVICE pilot versions 1-3 (Figure 23).

Figure 23: Average post eADVICE clinic appointment volume - pilot: Database 3 (2012-2015) n=60

![Average post eADVICE clinic appointment volume](image)

Patients offered eADVICE pilot versions 4-5 had a greater rate of positive outcomes compared with versions 1-3 (Figure 24).

Figure 24: Pilot version comparison outcome rate: Database 3 (2012-2015) n=60

![Pilot version comparison outcome rate](image)
Comparative effectiveness analysis of eADVICE

The Health Economics team analysed the effectiveness of the eADVICE program in terms of patient outcomes. It is not possible to undertake a cost effectiveness analysis due to the limitations of the costing information available. The analysis below complements the information already provided and responds to the evaluation questions within the data limitations.

Methodology of comparative effectiveness analysis

MBS benefits are not an appropriate proxy for the cost of the service. In addition, information on the costs of implementing the eADVICE program was not available, which did not allow for cost estimates to be calculated.

This comparative effectiveness analysis compared the number of face to face CUIS clinic visits required to achieve a positive outcome for two groups of patients. Those patients who had dry or improved outcomes were considered to have achieved a positive outcome.

• Group 1: Patients offered eADVICE whilst waiting for a clinic appointment
• Group 2: Patients not offered eADVICE whilst waiting for a clinic appointment

Results of comparative effectiveness analysis

The results in Table 6 indicate that patients with a positive outcome who were offered the eADVICE service had an average of 2.8 clinic visits. Patients with a positive outcome (success) who were not offered eADVICE had an average of 4.7 clinic visits. Therefore it is considered that eADVICE is relatively more effective in reducing the demand for clinic visits compared with no eADVICE. A breakdown of the data for each group can be seen in the Appendix.

Table 6: Comparative effectiveness of eADVICE and no eADVICE\textsuperscript{10, 11}

<table>
<thead>
<tr>
<th>Visit to incontinence clinic: Success</th>
<th>Clinic visit following eADVICE</th>
<th>Clinic visit in absence of eADVICE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>45</td>
<td>345</td>
</tr>
<tr>
<td>Number of physical visits to the clinic</td>
<td>124</td>
<td>1,605</td>
</tr>
<tr>
<td>Success factor (average clinic visit per patient)</td>
<td>2.8</td>
<td>4.7</td>
</tr>
</tbody>
</table>

\textsuperscript{10} Success is considered as “Dry” or “Improved” Outcome
\textsuperscript{11} E-Advice data available from 2012 onwards and Non E-Advice data available from 2010 onwards
Transition age characteristics

Transition age first appointment

Transitional age is defined as 15 years and older. Comparisons have been made between patients of transition age and those not of transitioning age to identify factors for the condition continuing into older ages. Patients of transitioning age have a later first CUIS appointment; which may indicate a later initiation of treatment (Figure 25).

Figure 25: Age at first CUIS appointment: Database 4 (1998-2013) n=263

The transitioning age patients continue to attend the CUIS after the age of 15 (Figure 26). Referral pathways to transition into appropriate age services may be a factor for this pattern.

Figure 26: Age at final clinic appointment: Database 4 (1998-2013) n=263
Transition age patient comorbidities
The transition age patients have a slightly higher rate of developmental delay and attention deficit hyperactivity disorder (ADHD) than younger patients (Figure 27).

Figure 27: Transition age comorbidity rate comparison: Database 4 (1998-2013) n=263

Transition age CUIS appointment volume
Transition age patients have a higher average number of clinic appointments than younger patients at 5.73 and 4.01 respectively; with a small proportion of transition age patients attending more than 20 appointments (Figure 28).

Figure 28: Appointment volume for transition and non-transition patients: Database 4 (1998-2013) n=263

The transition age patients also attend the CUIS for treatment over a longer period of time than the non-transition age patients (Figure 29).
Transition and non-transition age outcomes

Forty-four percent of the transition age patients had a dry outcome compared with 33% in non-transition age patients however require more resources to achieve this outcome (Figure 30).

Figure 30: Dry outcome rate comparison: Database 4 (1998-2013) n=263

Ten of the 137 transition age patients have had their care transferred and 42 discharged: 85 patients continue to have ongoing symptoms.
Discussion

Referral trends
Patients are currently on average eight years of age at time of referral and nine at first appointment. This can be contrasted with condition onset age and optimal treatment initiation time to determine if improvement opportunities are available to ensure patients are provided timely access to best practice advice for their condition.

Waiting list management
In light of the long wait time, prioritised appointment allocation to patients with higher priority clinical needs could improve the cost effectiveness of the service. It was found that 25% of patients remaining on the waiting list no longer require the appointment. A screening process to identify these patients may improve access for patients with ongoing clinical needs.

eADVICE program implementation
The results of a simple comparative effectiveness analysis indicate that eADVICE is relatively more effective in reducing the demand for clinic visits compared with no eADVICE. eADVICE is a conservative self-management program for waiting patients, with an additive effect of reducing new patients requiring the CUIS and reducing appointment volumes for those who do attend. Although the mechanism of this is unclear, clinicians anecdotally report that earlier initiation of education and treatment reduces appointment time and accelerates recovery. This may be demonstrated by the trend towards greater appointment volumes in patients not responding to treatment in the eADVICE program patient cohort.

It may be feasible that the 25% of eADVICE patients who achieve a dry outcome may not require further treatment within a CUIS appointment. The screening process previously mentioned may help capture patients that have had a positive response to eADVICE (dry outcome) in order to offer available appointments to young people who require ongoing treatment.

It appears that pilot versions 4-5 are superior to pilot versions 1-3 in terms of outcomes, however visit rates were slightly lower. An assessment of required dosage for the intended outcomes of the program will assist in determining if an average of three visits to the eADVICE program is efficacious. Further investigation to understand the modifiable facilitators and barriers to uptake for the 15% of patients that did not utilise the eADVICE program may guide strategies. Provision of the eADVICE to general practitioners/primary care may also facilitate access and early education for patients and families. Based on these outcomes, further implementation of the eADVICE program is recommended.

Optimising treatment outcomes
Dropout rates and poor uptake of treatment interventions appear to be higher in patients who do not achieve positive outcomes (defined as unchanged or worse). Further qualitative analysis for these factors may be important to understand reversible barriers that may improve outcomes.

Transition age patients
Patients of transition age appear to have characteristics that differ to the younger age patients. The age of referral appears to be later with treatment starting at 14. Treatment patterns demonstrate higher appointment volumes over a longer period of time. This may in part be explained by the higher comorbidity rates which may impact on management. Optimal referral and treatment models to prevent the condition advancing into older ages is paramount, however there also appears to be a need for transition pathways into adult services.

CUIS and telehealth
Given the wide geographical area that the CUIS at the CHW supports, the use of telehealth could potentially facilitate access and can be provided to a general practice or a patient’s home. Recently established NSW CUIS in John Hunter and Sydney Children’s Hospitals may impact these geographical patterns and demands, and networking between the three sites may facilitate the identification of boundaries and telehealth relationships if they do not already exist.

Two versions of telehealth funding and criteria are available via the Medicare benefits schedule (MBS) or via NSW Activity Based Funding (ABF). As of 2014-2015 financial year the CUIS at the CHW had no MBS telehealth revenue. This option could be further explored by the service.
Conclusion and recommendations

The CUIS at the CHW is under high demand and achieves positive outcomes for the vast majority of patients. Some innovative initiatives have recently been introduced to try to reduce the significant wait time and improve patient outcomes. The eADVICE program has been a successful example of this.

Recommendations have been made to enhance the efficiency of the service by targeting priority patients and to optimise program outcomes for children with childhood urinary incontinence.

A summary of the recommendations to enhance CUIS efficiency and effectiveness include:

- Perform further qualitative review to assess referral behaviours against best practice, particularly for transition age patients.
- Perform further qualitative review to understand patient compliance and dropout, particularly for patients not responding to treatment.
- Introduce screening processes to optimise clinic appointment time for patients with ongoing clinical needs.
- Ongoing rollout of the eADVICE program for waiting patients and review of the required administrative support.
- Review of postcode geographic distribution to guide location of telehealth pop up clinics
- Review and, if required, develop transition pathways for older patients.
- Networking between major CUIS services providing support these recommendations collaboratively across NSW.
Appendix

Number of clinic visits for group offered eADVICE program (from database 3)

A total of 157 patients participated in the eADVICE program and a number of these patients visited the clinic (face to face). There were 45 patients who had positive outcomes (dry or improved) after visiting the clinic 124 times or an average of 2.8 visits per patient (Table 1).

Patient outcome following eADVICE

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Number of patients</th>
<th>Visits to the clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dry outcome</td>
<td>17</td>
<td>37</td>
</tr>
<tr>
<td>Improved outcome</td>
<td>28</td>
<td>87</td>
</tr>
<tr>
<td>Lost to follow up</td>
<td>13</td>
<td>39</td>
</tr>
<tr>
<td>Not available</td>
<td>92</td>
<td>0</td>
</tr>
<tr>
<td>No follow up yet</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Unchanged outcome</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Grand total</td>
<td>157</td>
<td>179</td>
</tr>
</tbody>
</table>

Number of clinic visits for group not offered eADVICE program (from database 2)

There were 578 patients who visited the CUIS 2087 times or on average every patient attended the CUIS 3.6 times. Data for this group of patients is available for a longer period. Some 345 patients had positive outcomes (dry or improved) after a combined 1605 visits to the clinic or an average of 4.7 visits per person (Table 2).

Patient outcome in absence of eADVICE

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Number of patients</th>
<th>Visits to the clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dry outcome</td>
<td>134</td>
<td>611</td>
</tr>
<tr>
<td>Improved outcome</td>
<td>211</td>
<td>994</td>
</tr>
<tr>
<td>Unchanged outcome</td>
<td>233</td>
<td>482</td>
</tr>
<tr>
<td>Grand total</td>
<td>578</td>
<td>2087</td>
</tr>
</tbody>
</table>