

Young people with urinary incontinence

Project overview



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.

aci.health.nsw.gov.au

AGENCY FOR CLINICAL INNOVATION

Level 4, 67 Albert Avenue
Chatswood NSW 2067

PO Box 699 Chatswood NSW 2057

T +61 2 9464 4666 | F +61 2 9464 4728

E aci-info@health.nsw.gov.au | aci.health.nsw.gov.au

(ACI) 180143, ISBN 978-1-76000-828-4

Produced by: Transition Care and Urology Networks

Further copies of this publication can be obtained from the Agency for Clinical Innovation website at www.aci.health.nsw.gov.au

Disclaimer: Content within this publication was accurate at the time of publication. This work is copyright. It may be reproduced in whole or part for study or training purposes subject to the inclusion of an acknowledgment of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above, requires written permission from the Agency for Clinical Innovation.

Version: V0.11

Date Amended: April 2018

ACI_0024D [04/18]

TRIM: ACI/D17/6920

© Agency for Clinical Innovation 2018

Front Cover Image: Sydney Children's Hospitals Network Operation Art Project

Acknowledgements

Members of the Urinary Incontinence Steering Group

The Urinary Incontinence Steering Group was established to provide leadership and direction in delivering the outcomes outlined in the Urinary Incontinence Project Proposal (Appendix 1). The project involved formation of a time-limited (one year) steering group, with subgroups focusing on specific aspects such as patient experience and resources, telehealth initiatives, clinics, data and development of an overall framework.

The overall aim was to improve the management of young people with urinary incontinence across NSW so that difficulties that can be effectively treated and do not continue into adulthood. The steering group included services providers, clinical experts, consumers, peak bodies and representatives of the ACI Transition Care and Urology Networks, Patient Experience and Consumer Engagement team (PEACE), Health Economics and Evaluation Team (HEET), Clinical re-design and Telehealth.

Steering group

Name	Role	Organisation
Aniruddh Deshpande	Paediatric Urologist	John Hunter Children's Hospital
Bernadette Grattan	Clinical Nurse Consultant Continence	Armidale CHC/Hunter New England Local Health District
Choon Chew	Clinical Nurse Consultant Continence	Western Sydney Local Health District
Dalia Pisk	Social Worker	Trapeze, The Sydney Children's Hospital, Westmead
Gail Nankivell	Physiotherapist	The Children's Hospital at Westmead
Julia Martinovich	Telehealth Manager, Clinical Program Design and Implementation	Agency for Clinical Innovation
Julie Dicker	Continence Nurse Specialist	Wellspect HealthCare
Karen Height	Service Manager	Kaleidoscope Paediatric Rehabilitation Service
Louise Linke	Nurse Practitioner Continence	Bathurst Health Service
Lynne Brodie	Transition Care Network Manager	Agency for Clinical Innovation
Melissa Lim	Clinical Psychology Registrar	The Children's Hospital at Westmead
Michelle Paul	Nurse Practitioner Continence	John Hunter Hospital
Neil Rickwood	Implementation Project Officer, Clinical Program Design and Implementation	Agency for Clinical Innovation
Patrina Caldwell	Senior Staff Specialist	The Children's Hospital at Westmead
Rowen Cockerell	Chief Executive Officer	Continence Foundation Australia
Sarah Barter	Patient Experience and Consumer Engagement, Clinical Program Design and Implementation	Agency for Clinical Innovation
Tanya Pisk	Consumer	
Violeta Sutherland	Urology and Gynaecological Oncology Network Manager	Agency for Clinical Innovation
Vishal Malhotra	Staff Specialist Paediatrician	Dubbo Base Hospital

Members of working groups

Four subgroups were formed:

- a. schema
- b. patient experience
- c. telehealth
- d. data.

Members of these working groups are listed in the separate subgroup reports.

Thanks to the ACI Communications team for its assistance. Thanks also to Catherine Hennessy, PEACE Project Officer, for her work on the Patient Experience Report and input into the overall project.

Working with Aboriginal people

The ACI is committed to improving the health of all patients across NSW, particularly those who have significantly higher rates of health problems and less access to appropriate health services. Children and young people with chronic illnesses and disabilities often fit into this category, as do young Aboriginal people.

Although data are limited, it appears that Aboriginal children and young people are as likely to experience urinary incontinence problems as the general population. However, there may be cultural sensitivities that make the problem of urinary incontinence less likely to be recognised and discussed openly.

An Aboriginal Health Impact Statement was undertaken prior to commencement of this project and consultation has occurred with senior Aboriginal health workers, focus groups and representative organisations. We would like to thank the key stakeholders whose contributions have informed the recommendations arising from this project. These stakeholders, including those who work closely with young Aboriginal people, will continue to be involved in the implementation of the recommendations.

It is important that the appropriate steps are taken to ensure that services are delivered in culturally safe and competent ways across the project lifespan. To achieve optimal health outcomes for Aboriginal children and young people with urinary incontinence, we will need to undertake a cultural audit to identify and address the barriers to access to care and ongoing management. The audit, along with the development of culturally competent and safe services, is described in detail in *Chronic care for Aboriginal people model of care*.

Glossary

Some of the following terminology is based on the International Children's Continence Society Update Report, 2014.¹ Key terminology and acronyms used in this document:

Bladder bowel dysfunction	Concomitant bladder and bowel disturbances of clinical significance and relevance. It can be subcategorised into lower urinary tract dysfunction and bowel dysfunction.
CHW	The Children's Hospital at Westmead (part of Sydney Children's Hospitals Network)
CUIS	The Childhood Urinary Incontinence Service at the Children's Hospital at Westmead
Decreased daytime voiding frequency	Voiding ≤ 3 times per day.
eADVICE	Electronic advice and diagnosis via the internet following computerised evaluation
Enuresis	Intermittent urinary incontinence exclusively during sleep. This can be monosymptomatic (urinary incontinence during sleep with no daytime lower urinary tract dysfunction) or nonmonosymptomatic (urinary incontinence during sleep as well as lower urinary tract symptoms). Primary onset enuresis is when the child has never been dry at night (bedwetting since being a baby); secondary onset enuresis is when the child has had a previous dry period of at least six months.
HEET	Health Economics and Evaluation Team
Increased daytime voiding frequency	Voiding ≥ 8 times per day.
Pop up –	A training clinic that can be established anywhere throughout NSW at the invitation of the local team.
SCHN	Sydney Children's Hospital Network
Urgency	The sudden, unexpected compelling urge to immediately void.
Urinary incontinence	Involuntary leakage of urine. This can be subdivided into continuous (constant day and night urinary leakage) or intermittent (urinary leakage in discrete amounts).
Void	Emptying the bladder or urinating.

Contents

Executive summary	1
Methodology	1
Results	1
Introduction	2
Purpose	3
Method	4
Results	5
Health professional guide	5
Patient experience report	5
Telehealth guide	6
Data evaluation report	6
Pop up clinics	6
Recommendations	7
Discussion	8
Conclusion	9
References	10

Executive summary

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.²⁻⁷ It has emerged as an increasingly significant problem for young adults, and if untreated, can progress to adulthood.

Urinary incontinence is rarely openly acknowledged, due to the perception that it is shameful or embarrassing. It often remains a hidden condition, particularly for young people whose main focus is on establishing independence, finding employment and fitting in with their peers.

Incontinence that begins in childhood is different from incontinence that develops in adulthood, with different aetiology, physiology and treatments required.²⁻⁷

A case for change proposal outlined the current management of urinary incontinence. It outlined the fact that urinary incontinence can be successfully treated by community-based healthcare professionals with adequate training, with tertiary support for complicated cases. This would relieve pressure on specialist services, decrease wait times (which can be up to two years), improve outcomes and allow young people to be treated closer to where they live.

The PISCES project involved establishment of a time-limited (one year) steering committee working with subgroups focusing on specific aspects, such as patient experience and resources, telehealth initiatives, clinic data and development of an overall framework.

The overall aim was to improve the management of young people with urinary incontinence across NSW so that problems that can be effectively treated do not continue into adulthood. Outcomes focused on:

- reducing the current variation in management, which is due to lack of knowledge and lack of standard approaches to treatment
- reducing long waiting times to see a specialist and improving access to specialists (currently the wait time is up to 24 months)
- involving young people and/or their families in the management of urinary continence
- improving awareness of patients and clinicians about appropriate services.

Young adults up to 25 years were included in the project to capture transition of care issues.

Methodology

Working subgroups were formed to:

- develop a NSW guideline/schema to improve the management of urinary incontinence in children and young people
- better understand the experience of children and young people with urinary incontinence, their parents/carers, and healthcare workers using a co-design methodology
- to provide guidance on implementing a telehealth service to provide specialist support to rural health services
- provide education through forums or pop up clinics, which are clinics that can be established anywhere in NSW at the invitation of the local healthcare team.

Results

Apart from this report, the following resources were produced:

- *Young people with urinary incontinence: Health professional guide* – developed to assist clinicians managing children and young people with urinary incontinence in primary health settings.
- *Young people with urinary incontinence: Patient experience report* – documents key themes from interviews with participants, including clinicians (e.g. medical specialists, nurses and allied health professionals), parents and young people.
- *Young people with urinary incontinence: Telehealth guide* – a guide to facilitate training/support for health professionals working outside the metropolitan area who are involved in (or interested in being involved in) the management of children and young people with incontinence using telehealth services.
- *Young people with urinary incontinence: Data evaluation report* – The Health Economics and Evaluation Team (HEET) analysed data provided by Children’s Hospital at Westmead (CHW). The report presents findings related to patient demographics, service delivery trends and outcomes, impact of the eADVICE online self-management program, and implications on service costs and efficiency.

The *Young people with urinary incontinence: Health professional guide* has been sent to several Primary Health Networks for potential inclusion in their pathway program.

Introduction

Urinary incontinence can be caused by a complex group of underlying disorders which are primarily related to dysfunction of the bladder, the bowel, the sleep/arousal mechanism or a combination of these factors. Other less common causes of urinary incontinence include pelvic floor abnormalities and psychological disorders.

It is therefore recommended that initial treatment in primary care is focused on the identification and treatment of bladder and bowel problems. A significant proportion of patients will respond favourably to an approach focused on correcting the bladder and bowel dysfunction. For those who are unresponsive to these interventions, a multidisciplinary approach by experienced and trained clinicians is recommended to improve outcomes.

The Childhood Urinary Incontinence Service (CUIS) at the Children's Hospital at Westmead is a multidisciplinary service providing specialist advice for young people aged 3-18 who are intermittent day and/or nighttime 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).

In response, CUIS Director Dr Patrina Caldwell submitted a case for change proposal to the ACI. The case for change outlined the fact that urinary incontinence can be successfully treated by community-based healthcare professionals with adequate training, with tertiary support for complicated cases. This would relieve pressure on specialist services, decrease wait times (which can be up to two years), improve outcomes and allow young people to be treated closer to where they live.

The case for change was ratified by the transition care executive in early 2016.

The ACI, in partnership with the SCHN and the Continence Foundation of Australia (CFA), is taking 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).

Purpose

The overall aim of the PISCES project is to improve the management of young people with urinary incontinence across NSW so that problems that can be effectively treated do not continue into adulthood. The desired outcomes are:

- a reduction in current variation in management, which is due to lack of knowledge and lack of standard approaches to treatment
- a reduction in waiting times to see a specialist and improved access to specialists (currently the wait time is up to 24 months)
- involvement of young people and/or their families in the management of urinary continence
- improved awareness of patients and clinicians about appropriate services.

Method

A time-limited (one year) steering committee was established to work with subgroups focusing on specific aspects of the PISCES project. Working subgroups were formed to:

- develop a NSW guideline to improve the management of urinary incontinence in children and young people
- better understand the experience of children and young people with urinary incontinence, their parents/carers, and healthcare workers using a co-design methodology
- develop a telehealth service model to provide specialist support to rural health services
- provide education through forums or pop up clinics, which are clinics that can be established anywhere in NSW at the invitation of the local healthcare team.

The HEET analysed data provided by CHW to answer evaluation questions. The Young people with urinary incontinence: Data evaluation report presents findings related to patient demographics, service delivery trends and outcomes, and the impact of the eADVICE online self-management program on service costs and efficiency. This information will guide the PISCES project team in future design and delivery of CUIS.

Deliverables

The four key outcomes included in the overall proposal are listed in Purpose. These were delivered through three components:

- health professional guidance, developed to assist clinicians managing children and young people with urinary incontinence in primary health settings
- interviews with participants, including clinicians (e.g. medical specialists, nurses and allied health professionals), parents and young people, documenting key themes
- a guide to facilitate telehealth training/support for health professionals working outside the metropolitan area who are involved in (or interested in being involved in) the management of children and young people with incontinence using telehealth services.

Deliverables for the telehealth component of the PISCES project will focus on training/support for health professionals working outside the metropolitan area who are involved in (or interested in being involved in) the management of children and young people with incontinence using telehealth services.

Table 1. PISCES project scope

In scope	Out of scope
<ul style="list-style-type: none"> • Children or young adults aged between five (considered toilet conscious) and 25 (early adulthood). Young adults up to 25 years were included to capture transition of care issues. • Metropolitan, rural or remote healthcare sites in the community or hospital with access to eHealth and telehealth. • The patient has intermittent incontinence (e.g. bedwetting (enuresis) or daytime urinary incontinence). Young people with related conditions, such as recurrent urinary tract infections, dysfunctional voiding, constipation and faecal incontinence, will be included if the condition impacts on bladder function. • The target health professionals group included GPs, specialists, subspecialists, continence nurses, continence physiotherapists and psychologists. 	<ul style="list-style-type: none"> • Babies; children not intellectually capable of understanding toilet training; people aged over 25; incontinence related to adult-onset conditions such as post childbirth, cancers and prostate problems. • Services outside NSW. • Continuous incontinence that incorporates neurogenic bladder and uro-surgical conditions. • Faecal incontinence, slow transit constipation without urinary incontinence and recurrent urinary tract infections related to immunological conditions. • Complementary and alternative medicines, unless there was an evidence base to support their inclusion.

Results

The following documents are available as separate reports on the ACI Transition Care Network and Urology Network webpages on the ACI website. They will be also made available to relevant organisations such as the Continence Foundation of Australia (CFA) and the SCHN.

Health professional guide

A document was developed to assist clinicians managing children and young people with urinary incontinence in primary health settings. It aims to:

- assist community health practitioners in initiating effective evidence based care
- minimise delayed or ineffective care
- ensure targeted and appropriate referrals to specialised centres.

The overall goal is to improve clinical outcomes for children and young people with urinary incontinence through timely streamlined care.

The document has been sent to several Primary Health Networks for potential inclusion in their pathway program.

Patient experience report

The patient experience phase of the PISCES project utilised a co-design methodology to capture and understand the experiences of young people with urinary incontinence, their parents and the clinicians who provided healthcare.

Steering group members received co-design methodology coaching from Dr Lynne Maher, Director of Innovation and Improvement, Ko Awatea.

Participants were recruited through CUIS and by advertising in the CFA and the Continence Nurses Society of Australia NSW branch newsletter. The participants were asked to share their experiences and perspectives of what's working well and areas for improvement in regards to the provision of healthcare in NSW for young people with urinary incontinence. Overall, 26 people shared their experiences from September 2016 to November 2016:

- 12 clinicians, including medical specialists, nurses and allied health professionals
- nine parents
- five young people with urinary incontinence.

The project also collected and analysed data from CUIS, including:

- patient demographics
- average waiting time
- patient outcomes
- use of the electronic advice and diagnosis via the internet following computerised evaluation (eADVISE) app, developed and piloted by the clinic
- outcomes for patients transitioning to adult services.

The project team reviewed this data and identified five key themes:

1. difficulties obtaining a timely diagnosis (long waiting period to see a specialist) and support to manage urinary incontinence
2. limited information, stigma, lack of understanding and awareness of wetting, and school problems
3. the impact on the young person and their family of managing the condition
4. confidence in support provided by the specialist interdisciplinary team
5. opportunities for improvement.

Telehealth guide

The *Young people with urinary incontinence: Telehealth guide* aims to outline the models of address the following issues:

- clinical and implementation considerations
- financial considerations
- technical considerations involved in planning and implementation telehealth interventions
- steps to set up and deliver a telehealth consultation.

Data evaluation report

The HEET analysed data provided by CHW to answer evaluation questions. The Young people with urinary incontinence: Data evaluation report presents findings related to patient demographics, service delivery trends and outcomes, and the impact of the eADVICE online self-management program on service costs and efficiency. This information will guide the PISCES project team in future design and delivery of CUIS.

- Data show that patients attending CUIS at CHW are relatively equal in gender distribution.
- The average referral age is eight years old.
- The average first appointment age is nine years old.
- Older patients (aged >15 years) tend to have had later referral and treatment initiation at the age of 14 years. Compared to younger patients, this group has higher comorbidity rates and more resources are required to support these patients.
- The CUIS continues to see patients up to the age of 18, and occasionally older patients.

The eADVICE conservative self-management program for waiting patients reduces new CUIS patients and, for patients who do attend, reduces appointment volumes. The eADVICE program also appears to achieve a higher rate of positive patient outcomes. This enables an increase in the number of patients through the CUIS at the cost of delivering the eADVICE program.

Pop up clinics

There have been three pop up pilot CUIS clinics 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.

Recommendations

Recommendations for each phase of the project are detailed in the separate reports. The table below provides an overview of recommendations.

Table 2. Overview of PISCES subgroup recommendations

Document	Recommendations/next steps
Health professional guide (schema subgroup)	<ul style="list-style-type: none"> Disseminate/promote the PISCES guidelines to primary and community care through the Primary Health Networks, key organisations such as the Continence Foundation of Australia, and ACI Networks. Evaluate the effectiveness of the guidelines to achieve desired outcomes such as assisting community health practitioners in initiating effective evidence based care, minimising delayed or ineffective care, and ensuring targeted and appropriate referrals to specialised centres.
Patient experience report	<ul style="list-style-type: none"> Provide feedback on the final report to all who participated in the surveys. Hold a co-design workshop to identify and prioritise areas for improvement.
Telehealth guide	<ul style="list-style-type: none"> Develop and promote the telehealth proof of concept model and trial it at appropriate sites.
Data evaluation report	<ul style="list-style-type: none"> Perform further qualitative review to assess referral behaviours against best practice, particularly for older patients. Perform further qualitative review to understand patient compliance and drop out, 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 eADVISE program for waiting patients and review of the required administrative support. Review geographic distribution by postcode to guide location of telehealth pop up clinics. Review and, if required, develop transition pathways for older patients. Network between major CUIS services to support these recommendations collaboratively across NSW.

Discussion

The process of forming separate working groups to focus on the main aims of this project brought expertise and different perspectives to specific areas such as clinical guideline development, telehealth, patient experience and health economics. It allowed those with an interest and expertise in one aspect of the project to contribute without having to attend every meeting.

The Urinary Incontinence Steering Group was able to oversee, with a representative expert responsible to lead their subgroup.

Dr Lynne Maher's coaching in co-design methodology provided an opportunity for members to understand a systematic way of involving and capturing the experiences of patients, their families and clinicians. It allowed those working on similar projects at the ACI to share their successes and challenges and learn from each other. This will provide the platform for the patient experience workshop to be held later this year.

In August 2017 the priorities for improvement were explored and collectively agreed upon in a co-design workshop which included representation from staff, patients and families.

During this workshop, an experience map was developed to show the key themes, touchpoints and emotions shared by staff, patients and families. This was presented to all participants as a way to promote deep and meaningful understanding of people's experiences and feelings.

Conclusion

The CUIS at the CHW is under high demand and achieves positive outcomes for the vast majority of patients who visit the service. Some innovative initiatives have recently been introduced to try to reduce the significant wait time and improve patient outcomes. The eADVISE 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. These recommendations will also inform establishment of other clinics at the Randwick campus of SCHN and John Hunter Children's Hospital in Newcastle.

Strategies such as the development of telehealth services and pop up clinics will improve the experience for patients and clinicians in rural and regional areas. Digital initiatives such as the eADVISE app and better online resources will also improve the patient experience.

Outcomes from the patient experience forum held in August 2017 will inform the next steps for implementation of the recommendations.

References

1. Austin PF, Bauer SB, Bower W, Chase J, Franco I, Hoebeke P, et al. *The standardization of terminology of lower urinary tract function in children and adolescents: update report from the Standardization Committee of the International Children's Continence Society*. J Urol. 2014; 191(6):1863-5.
2. Australian Institute of Health and Welfare 2012. *Incontinence in Australia: prevalence, experience and cost 2009, Bulletin no. 112*. Cat. no. AUS 167. Canberra: AIHW.
3. Baker S, Richards D, Caldwell P. *Relational agents to promote eHealth advice adherence*. PRICAI 2014: The 13th Pacific Rim International Conference on Artificial Intelligence, Cham, Switzerland: Springer.
4. Bower WF, Moore KH, Shepherd RB, Adams RD. *The epidemiology of childhood enuresis in Australia*. Br J Urol 1996; 78:602-606.
5. Caldwell P, Sureshkumar P, Kerr M, Hamilton S, Craig J. *Urinary incontinence in adolescents. Moving Beyond Pediatric Incontinence: The Challenges of Transitional Care*, Toronto, Canada: University of Toronto; 2013.
6. Caldwell P, Sureshkumar P, Kerr M, Hamilton S, Teixeira-Pinto A, Macaskill P, Craig J. *A randomised controlled trial of a code-word enuresis alarm*. Archives of Disease in Childhood, 2016; 101(4): 326-331.
7. McGrath K, Caldwell P. *Diagnostic Approach to Constipation in Children*. In Anthony G. Catto-Smith (Eds.), *Constipation - Causes, Diagnosis and Treatment*, (pp. 1-18). 2012; Rijeka, Croatia: InTech Publishers.