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.

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<th>Acronym</th>
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<tr>
<td>ACI</td>
<td>Agency for Clinical Innovation</td>
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<tr>
<td>ADHD</td>
<td>Attention deficit hyperactivity disorder</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>CFA</td>
<td>Continence Foundation of Australia</td>
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<td>CHW</td>
<td>The Children's Hospital at Westmead</td>
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<td>CUIS</td>
<td>Childhood Urinary Incontinence Service</td>
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<td>eADVICE</td>
<td>Electronic advice and diagnosis via the internet following computerised evaluation</td>
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<td>HEET</td>
<td>Health Economics and Evaluation Team</td>
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<td>MBS</td>
<td>Medicare Benefits Schedule</td>
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<td>PEACE</td>
<td>Patient Experience and Community Engagement</td>
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<td>PISCES</td>
<td>Paediatric Information, Schema, Continence, Education, Support</td>
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<td>SCHN</td>
<td>Sydney Children's Hospitals Network</td>
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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.
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Introduction

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).

PISCES utilised a co-design methodology to capture and understand the experiences of young people with urinary incontinence, their parents and the clinicians who provide healthcare. Dr Lynne Maher, Director of Innovation and Improvement, Ko Awatea, provided coaching in co-design methodology, which moves the phases: engage, capture, understand, improve and measure.

This report has been developed as one component of the PISCES project.
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.

As part of this project, clinicians, parents and young people were invited to provide feedback on their experiences, including use of the interactive eADVICE program, which provides online treatment advice to patients, supervised by their general practitioner (GP), while they are awaiting a specialist appointment.
Method

Participants were recruited through the Childhood Urinary Incontinence Service (CUIS) at the Children’s Hospital at Westmead, the Continence Foundation of Australia and the Continence Nurses Society of Australia. Advertisements were placed in the Continence Foundation of Australia and the Continence Nurses Society of Australia (NSW Branch) newsletters.

The project team contacted each potential participant to provide further information about the project and invite them to consent to a face-to-face or telephone interview. Some participants also shared their experiences in writing.

Project team members interviewed 26 participants using an interview prompt sheet with standard open-ended questions. Participants were asked what is working well, what is not working well and how healthcare can be improved for young people with urinary incontinence. Between September 2016 to November 2016, the following people shared their experiences:

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

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 (eADVICE) app, developed and piloted by the clinic
- outcomes for patients transitioning to adult services.
Results

The project team reviewed the 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

Children often presented with a varied and complex history of urinary incontinence, including family history and a range of comorbidities.

Parents were routinely told that the child will grow out of it, and no further support or advice was provided. The routine recommended treatment interventions were unsuccessful.

’I had problems for many years with pain and wetting and went to lots of doctors but nothing was ever found.’

‘Many times we sought help and advice through the only channels we knew of. Once again the same advice as before was still being provided. We tried and tried without any success.’

There was a convoluted, unclear pathway to obtain diagnosis and appropriate, effective treatment for the child’s condition. Patients frequently encountered delays. Parents reported feeling dismissed and frustrated by the lack of support and information available to them while waiting for specialist care. They often found their way to the specialist multidisciplinary clinic by accident or as a result of their own research/advocacy.

’I feel like we were only taken seriously when he turned 7. He’s now 10 and we are still trying to fix it. Why do we have to wait so long?’

2. Limited information, stigma, lack of understanding and awareness of wetting, and school problems

Parents found it difficult to know where to find relevant trusted information about urinary incontinence, particularly online.

’I had nowhere to go, no directions. I didn’t know who, didn’t know how, what or where to start.’

’The internet gave her basically nothing … didn’t know the name of the condition and that it was called enuresis, so when looking on the internet, you don’t know what to look for.’

’It’s just so frustrating.’

Parents reported a lack of empathy and support in schools.

’It wasn’t once or twice and it didn’t matter that I was crying in the principal’s office. I had letters from [the doctor] saying that [the child] had a problem and needed to be able to go to the toilet when he needed to but it didn’t matter.’

’She’s been bullied. She’s also got learning difficulties.’

’The teachers weren’t very helpful … they just weren’t prepared.’

General practitioners and primary health care professionals had a limited understanding and awareness about how to manage urinary incontinence in children.

’[Many] clinicians including general practitioners… don’t feel confident or comfortable in managing children with wetting problems or don’t know what to do once basic treatments they’ve tried have failed.’
Opportunities were identified for more accessible information to reduce stigma, raise awareness and lead to earlier diagnosis and treatment. This would significantly reduce the stress, distress and impact on the child and family.

Those who used the eADVICE program reported that it provided helpful information and strategies to understand and manage the condition while waiting for specialist care.

‘[The eADVICE program] would be invaluable for other families to be able to find information to be able to beat bedwetting. It should be available to people.’

3. The impact on the young person and their family of managing the condition

Participants reported severe stress caused by managing the urinary incontinence. There was an impact on the child, parents and families. Some examples included sleep deprivation, the financial burden of treatment costs, difficulty managing several appointments with health professionals and the expectations or concerns of schools.

‘I think one of the hardest things has been the lack of sleep and what this does to my alertness during the day. This does lead to me being disciplined at times when I cannot fully explain to the teacher why I am falling asleep.’

‘This has impacted his school life, his social life, his sleep, his confidence; so many social aspects ... We’ve spent a fortune going to GPs and paediatricians.’

4. Confidence in support provided by the specialist interdisciplinary team

Parents and young people reported feeling relieved once they attended the specialist interdisciplinary clinic and felt confident about the treatment and management approach provided to them.

Parents and young people also valued a good relationship with a trusted GP to help them navigate the health system.

‘Without the Westmead enuresis clinic we would never have been able to diagnose the problem, would never have been able to successfully treat the problem and we would have had two very unhappy, socially isolated boys and a very tired family. Their work is invaluable yet their services appear to be the only one of their kind operating in the Sydney area.’

‘The doctors at the hospital have helped a lot. I take some medications to help my bladder and it is making it easier for me now during the day and night time.’

‘The focus was on the incontinence/bladder problems rather than the whole impact it was having on her. No-one asked how it was for her and how it made her feel.’

‘Adult incontinence services are built around things like prostate problems or post childbirth with stress incontinence and there’s very little training for adult continence advisors about how to treat continence problems that begin in childhood.’
5. **Opportunities for improvement**

Participants also emphasised the need for:

- increased access to and reach of specialist interdisciplinary care (such as the SCHN model) to ensure early intervention
- more education and training options to support clinicians to develop skills and expertise in the area of paediatric urinary incontinence
- an improved evidence base and understanding of clinical guidelines and outcomes (including long term) for management of paediatric urinary incontinence
- more patient and family-centred service and clinic environments that are responsive to the needs of young people and families.

‘I have been on medication for over four years to try and expand my bladder. Now I am in my final year of school and I am close to being dry at night. I have participated in a 12 month study at [the hospital] to try and help them work out what interventions may help children like myself.’

‘It would be good for other young people to know they aren’t alone...just that this can happen to adolescents and not just in children so raising awareness would be good. Also knowing where to look online.’

‘Being able to share experiences – also for people to know you can’t help it. It shouldn’t define you but the stigma still sticks. Talking about the problem more, even in classrooms, would help make it less of a taboo.’
Next steps

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.

![Experience map](image)

**Picture 1: Experience map**

Workshop participants were asked to reflect on the experience map and identify opportunities for improvement by answering the following question: How might we make things better for young people and their families?

This ‘How Might We’ question prompted the group to brainstorm ideas in an open and collaborative way. This generated a number of opportunities for improvement which fell broadly into three categories:

1. education
2. governance
3. awareness.

Some opportunities included:

- increasing knowledge and empathy in schools
- targeting education for GPs and practice nurses
- establishing a network to drive priorities and advocacy
- rolling out the eADVICE program
- generating conversation using different formats and mediums.
Participants evaluated these opportunities by considering the following:

1. Does it address the ‘How Might We’ question in a meaningful way?
2. Are there resources available to progress the opportunity?
3. Is the opportunity different enough to initiatives already in place?

Following this process, there was consensus that it was not necessary to focus on targeting GPs and practice nurses or rolling out the eADVICE program, as this is already being addressed. The group agreed to explore the remaining three opportunities. A number of ideation sessions were held between September 2017 and December 2017 to progress these priorities, and they will be reported on in 2018.