# The ACT Draft Child and Adolescent Clinical Services Plan 2023-2030

## Asthma Australia Submission, June 2023

## ABOUT ASTHMA AUSTRALIA

Asthma Australia is a for-purpose, consumer organisation that has been improving the lives of people with asthma since 1962. Asthma affects one in nine Australians or 2.7 million people. Asthma is an inflammatory condition of the airways, restricting airflow and can be fatal. There is no cure, but most people with asthma can experience good control.

Our purpose is to help people breathe better so they can live freely. We deliver evidence-based prevention and health strategies to more than half a million people each year. Asthma Australia has an ambitious goal to **halve avoidable hospital presentations for asthma by 2030**, with an initial focus on **reducing preventable hospitalisations in children aged 5-9**.

## ASTHMA IN THE ACT

One in eight (12.1%) people have asthma in the Australian Capital Territory (ACT), above the national average of one in nine people (11%).[1] In 2022, asthma was the 8th leading contributor to the overall burden of disease in Australia, having risen from 10th place in 2003.[2] In 2020, asthma caused 8 deaths in the ACT.[3] The ACT As a chronic condition, asthma places a significant burden on the daily lives of people with asthma and their families, as well as ACT's health care system and resources.

## CHILDREN AND YOUNG PEOPLE AND ASTHMA

**Asthma is the leading cause of burden of disease for people aged 5–14 years,** 460,000 children have asthma, representing 14.2% of the total disease burden for boys, and 11.7% for girls.[4] It is one of the most common conditions for preventable hospitalisations in the ACT.[5] **Children are much more likely than adults to be hospitalised for asthma,** with over 17,000 children with asthma hospitalised in 2022. [6]

**Asthma is a key reason for missing school** due to chronic illness,[7] and some 42% of children aged 0-14 had to take time off school in 2014/15 due to their asthma.[8]

# RESPONSE TO THE DRAFT ACTION PLAN CLINICAL SERVICES PLAN

Asthma Australia welcomes the opportunity to provide feedback on the Draft Child and Adolescent Clinical Services Plan 2023-2030 (the Draft Plan). As asthma is the leading cause of burden of disease for people aged 5–14 years,[9] it is critical that the needs and experiences of children and young people with asthma and their carers are considered in the Draft Plan's development. In our submission, we provide details of a range of initiatives and approaches that can help reduce paediatric asthma re/hospitalisations and improve asthma care and management in the community under each objective of the Draft Clinical Services Plan.

# OBJECTIVE 1: IMPROVE CARE AND PROCESSES FOR CHILDREN USING ACT PUBLIC HOSPITALS, INCLUDING SERIOUSLY UNWELL CHILDREN

Children are much more likely than adults to be hospitalised for asthma, with over 17,000 children with asthma hospitalised across the nation in 2022 for their condition.[10] In particular, children under 15 are more likely to be hospitalised for their asthma (442 per 100,000 population) than those aged 15 and over (98 per 100,000).[11] In addition, research suggests that Australian hospitals are not following best practice and guidelines to meet the needs of children and young people with asthma. For example, the results from a recent study with children aged 3-18 years admitted to Victorian hospitals in 2017/2018 found that almost 75% were discharged without a preventer and more than 80% did not have a follow-up appointment at the hospital.[12]

Asthma Australia welcomes Objective 1 and its supporting actions. However, the actions must accommodate the needs of the many children and young people with asthma who too frequently find themselves in need of hospital and emergency care. To this end, ACT Health should consider how to ensure that the acute care network, enhanced paediatric ED and upskilled staff are aware of and apply the best practice guidelines for asthma management as set out in the Australian Asthma Handbook.[13] In addition, acute services and staff need to be equipped to meet increased flare-ups that commonly align with seasons (e.g. due to bushfires or the use of wood heaters in winter) and the complications and complexities that common comorbidities with asthma can cause (e.g. such as obesity or allergic rhinitis).

As ACT Health is aware, Asthma Australia provides education to consumers and healthcare professionals in the community in ACT to help increase the understanding and application of best practice asthma management. We would welcome discussion with ACT Health about how we could support the implementation of best practice asthma care approaches for children and young people within ACT hospitals.

### PAEDIATRIC LIAISON AND NAVIGATION SERVICE

We note and welcome Action 1.5 and its aim to 'continue to roll out the new coordination and priority access options for children with chronic and complex conditions'. We ask that the Paediatric Liaison and Navigation Service (PLaNS) is rolled out to include children and young people with asthma.

Asthma care is provided by a number of different healthcare professionals, including staff working in primary health care (e.g. GPs, primary health care nurses, nurse practitioners, asthma and respiratory educators, Aboriginal health workers, pharmacists, and physiotherapists), secondary care (e.g. hospital staff including emergency department staff, generalist physicians and nurses, and specialists such as respiratory physicians and allergists),[14] and tertiary care. The role of respiratory specialists is vital particularly for patients with poorly controlled and severe asthma. In addition, professionals working outside the healthcare system are also involved in asthma care, such as early childhood educators and teachers, sports coaches and community care workers.

With so many different support services and staff in their care journey, children and young people with asthma and their carers would greatly benefit from access to PLaNS staff, who could help them coordinate their care and navigate the system to ensure they are connecting with the right services and staff at the right time. PlaNS would be especially helpful for patients with severe or complex asthma that is hard to control and who have more touchpoints with the healthcare system.

**Recommendation**

**Recommendation 1:** That ACT Health include children and young people with asthma in the continued roll-out of the Paediatric Liaison and Navigation Service.

# OBJECTIVE 2: IMPROVE CARE AND SERVICES FOR CHILDREN AND FAMILIES WITH CHRONIC AND COMPLEX CONDITIONS, WHERE CARE IS SHARED WITH SYDNEY CHILDREN'S HOSPITALS NETWORK

## CARE COORDINATION FOR CHILDREN WITH ASTHMA

Many of the 17,000 childhood asthma hospitalisations in Australia could be prevented through improved care and self-management.[15] To this end, we have funded the Community Based Care-Coordination Study based in New South Wales. [16] This study focuses on a personalised and holistic model of care that connects all key stakeholders involved in a child's asthma management, including parents/carers, primary and acute care services, asthma nurses and schools/childcare services. The project currently involves children aged 5-16 years old who present to the emergency department (ED) for asthma and have been to ED at least twice or have been hospitalised at least once in the last 12 months.

Children involved in the study receive an individualised standardised Asthma Action Plan, written instructions for leaving hospital, automated text messages, linkages to relevant community services and a virtual home visit within three months of leaving hospital. The research will measure hospital presentations, general practitioner attendances, missed days from school and asthma-specific indicators of quality of life to evaluate the effectiveness of the model of care.

The project is a continuation of work started in 2016 by the research lead, which to date has evidenced that integrated models of acute and primary asthma care significantly reduce paediatric

asthma emergency presentations and hospitalisations.[17] Further iterations of the project include home visits to detect and manage triggers and the greater use of virtual models of care for decentralised populations.

Asthma Australia would welcome further discussion with ACT Health on this project and whether a community-led project tailored to the ACT would be viable with the aim of identifying the optimum model of care coordination to improve asthma paediatric care within the territory and with NSW services that ACT patients access.

## HOSPITAL DISCHARGE PROTOCOLS

As the Community Based Care-Coordination Study discussed above has shown,[18] effective patient pathways between acute and primary care are essential to providing coordinated asthma care.[19] This is particularly pertinent for ACT patients as they access both ACT and NSW hospitals. In addition, research shows that hospital readmissions among Australian children with asthma are increasing, with around one third of children being readmitted to hospital for asthma a year following their initial admission.[20] Effective hospital discharge protocols have an important part to play in reducing readmission rates by helping to connect patients to appropriate support and care in the community.

Asthma Australia plays a key role in providing community support to people with asthma once they have been discharged from hospital in the ACT. A visit to ED or a stay in hospital is a teachable moment whereby children, young people and their carers will be more open to becoming better educated about their or their child's asthma management and we therefore ideally make contact with patients as soon as possible after leaving hospital. In the past, our role post-discharge was formalised in relation to ED discharge by automatic referrals. However, as ACT Health will be aware automatic referrals have ceased due to the integration of the digital health record and the absence of effective controls in the new system to ensure healthcare professionals obtain informed consent from patients before making referral to our services. Noting that implementing the digital health record was a priority for ACT health services in the previous year, it may be timely to consider how to provide patients with automatic referral to Asthma Australia from hospital in a way that works for ACT Health, healthcare professionals and patients. Solutions to consider include referral to Asthma Australia being:

- embedded into the digital health record with appropriate checks in place to ensure informed consent is obtained,
- promoted in various ways in the hospital including by specific staff, on patient forms, on hospital in-house media displays and/or
- made by a Respiratory Nurse from PLaNs (should this service be rolled out to include asthma) or by the Children's Asthma Education Service if, on making contact with a patient post discharge, they find that they patient would prefer virtual or ongoing support.

Asthma Australia can help identify the most effective solution from a consumer perspective or tailor a specific solution to their needs through engaging with our consumer network.

In addition to developing specific referral processes to community services that are funded by but not provided directly by government, it is important that discharge protocols are developed in collaboration with stakeholders across all levels of governments. ACT Health should develop and adopt national hospital and emergency department discharge and outpatient follow-up protocols/guidelines for people with asthma, with a focus on priority population groups such as

Aboriginal and Torres Strait Islander children.[21] This could also include the use of technology to identify patients who are frequent users of emergency departments and therefore require additional support.[22]

**Recommendations**

**Recommendation 2:** That ACT Health work with key stakeholders including healthcare professionals, consumers and Asthma Australia to develop an appropriate patient referral mechanism to Asthma Australia services upon discharge from hospital.

**Recommendation 3:** That the ACT Government work with other state and territory governments to develop and implement nationally consistent hospital discharge protocols for asthma.

# OBJECTIVE 3: IMPROVE CARE AND SERVICES FOR CHILDREN REQUIRING LOCAL OUTPATIENT AND COMMUNITY BASED SERVICES

## EDUCATION FOR PEOPLE WITH ASTHMA

Respondents to the Capital Health Network's Needs Assessment Survey 2021-2024 found that asthma education is a service gap in the ACT.[23] Asthma is a complex condition and its management and the many medicines that support its control mean that consumers require significant education and support to ensure medication adherence, correct inhaler technique, appropriate risk reduction, understanding of asthma triggers and management of asthma alongside other conditions.[24] For children and young people, education needs to be designed to meet their needs, and/or those of their carers at home, at school and in the community.

Asthma Australia delivers education programs nationally online targeting schools and teachers. Our programs are designed to increase knowledge, confidence and health behaviours that optimise asthma control and effective self-management. In addition, we provide an asthma education telephone service (1800 ASTHMA), which can help support people with their asthma control as well as care coordination.[25] These services help to support the ACT Children Asthma Education Service for 0-18 year olds, about which many consumers and healthcare professionals have little knowledge.

**Recommendation**

**Recommendation 4:** That ACT Health increase support for effective self-management asthma practices through increasing knowledge, confidence and skills of children and young people with asthma, and their carers at home, at school and in the community.

## EDUCATION FOR HEALTHCARE PROFESSIONALS

There is evidence of health professional non-adherence to Australia's best practice guidelines.[26] For example, Australian data shows that less than 20% of patients are being dispensed enough of inhaled corticosteroids alone or via combination preventer inhalers to be taking their treatment in accordance with guidelines.[27] This means a significant proportion of people with asthma will not be getting therapeutic benefit from their medicine and instead risk symptom escalation and/or may inappropriately rely on reliever medicine,[28] the use of oral corticosteroids and emergency healthcare services to manage their asthma all to the detriment of their quality of life. [29,30,31] Further, too few people with asthma have written Asthma Action Plans, one of the most effective interventions for achieving good asthma control.[32] Nationally, 54.7% of children with asthma aged 0-14 years old have an Asthma Action Plan,[33] while 44% of the 17,000 children hospitalised for asthma in 2017/8 did not have a written Asthma Action Plan.[34]

Supporting health professionals to deliver consistent, best practice asthma care based on the asthma treatment guidelines will close the gap between evidence and practice, improve patient health outcomes and quality of life, and ultimately reduce the burden of asthma on the healthcare system.[35] Greater investment and sustained effort is required to support professionals, especially those working with priority population groups that are disproportionally impacted by asthma, such as Aboriginal health professionals and non-health professionals in Aboriginal community controlled organisations.

Asthma Australia has partnered with Reed Medical Education to **create a free accredited learning module (ALM) for GPs** and other health professionals on asthma management available via Think GP.[36] Based on the Australian Asthma Guidelines, the ALM is divided into six modules covering asthma basics, partnering with patients, adjusting treatment and encouraging adherence, preventative care to stop asthma flares, **paediatric asthma** and severe asthma. Real world tips, patient case studies and downloadable resources are included throughout the ALM, as well as information on ways to tailor treatment for Aboriginal and Torres Strait Islander people and for culturally and linguistically diverse populations. To date, over 8,000 healthcare professionals across Australia have enrolled in these modules and their feedback demonstrates high satisfaction with content, increased knowledge, confidence and planned behaviour change.

ACT Health should deliver education, training and support for healthcare professionals to develop the workforce and its capacity to provide consistent, best practice asthma care in the community. Education, training and support should include:[37]

- Detecting and diagnosing asthma and other acute and chronic respiratory conditions in a timely and appropriate manner
- Supporting patient and carer self-management practices (particularly for newly diagnosed) and assisting patient behaviour change, with a focus on addressing incorrect inhaler technique, poor adherence, patient preferences and practical issues
- Managing asthma alongside comorbid conditions
- Enhancing asthma health literacy and evidence-based shared decision making
- Appropriate prescribing of preventer medicine
- Delivering asthma action plans combined with patient education in self-monitoring, review of medicines and assessment of severity
- Annually reviewing asthma patients, and
- Developing management strategies in school and childcare services.

**Recommendations**

**Recommendation 5:** That ACT Health deliver education, training and support for healthcare professionals that support best practice in asthma self-management practices, quality use of asthma medicines, a stepped approach to asthma treatment as set out in the Australian Asthma Handbook, and greater awareness of the asthma services available.

**Recommendations 6:** That ACT Health promote Asthma Australia's free, accredited learning module for asthma management amongst GPs and other healthcare professionals within the community.

# OBJECTIVE 4: ENABLING THE HEALTH SYSTEM TO BETTER RESPOND TO THE NEEDS OF CHILDREN AND THEIR FAMILIES

## IMPROVING CHILDHOOD ASTHMA MANAGEMENT

Asthma Australia has recently completed a project with the Victorian Government to improve the utility and uptake of asthma action plans for children in Melbourne's inner west.[38] The project was part of an umbrella project 'Improving Childhood Asthma Management' with six different streams each led by a relevant stakeholder and all with the shared aim of improving the management of asthma amongst children to thereby increase their quality of life and health outcomes.

Asthma Action Plans have been an important recognised tool for patients with asthma to prevent and control asthma symptoms, providing directions on what to do when asthma worsens and when to seek medical assistance. [39] According to Australia guidelines, GPs should provide an action plan for every person with asthma and they should be reviewed by a GP every six months for children whenever asthma symptoms or medication treatment changes. However, as noted previously in Objective 3, too few people with asthma have written Asthma Action Plans. Nationally, 54.7% of children with asthma aged 0-14 years old have an Asthma Action Plan,[40] while 44% of the 17,000 children hospitalised for asthma in 2017/8 did not have a written Asthma Action Plan.[41]

Our project identified the key stakeholders involved in action plan use and co-designed system changes with them to elevate their usefulness for a child and their support network. This primarily involved working with parents, schools, GPs, primary health networks, hospitals and the Victorian Departments of Education and Training (DET) and Health. Key outcomes from the project included:

- reducing barriers for parents and schools by eliminating confusion about what is an acceptable Asthma Action Plan,
- understanding action plan portability/accessibility options and working towards local solutions to support their uptake,
- enhancing GP understanding of the use of action plans as an education opportunity for management by a child and their support network, and
- improving sustainable relationships between key stakeholders and service providers.

Given its success, a project like ICAM would undoubtedly benefit children with asthma and all stakeholders involved in supporting them in the ACT. The implementation of the Clinical Services Plan provides an opportune context to deliver and embed key structural and behavioural changes that arise from an ACT ICAM to help improve care and outcomes for children with asthma and their families.

**Recommendation**

**Recommendation 7:** Fund an ACT Improving Childhood Asthma Management project that brings together key stakeholders to overcome the local barriers to effective management of childhood asthma and thereby improve the health outcomes and quality of life of children with asthma.

## SOCIAL DETERMINANTS OF HEALTH

Asthma Australia welcomes the Draft Plan's recognition that the social determinants of health can influence children's health. The social determinants of health significantly affect the risk of developing asthma and of its exacerbation. For example, people living in the lowest socioeconomic areas have the highest prevalence of asthma at 13% compared to 10% for those living in the highest socioeconomic area.[42] For First Australians, the prevalence of asthma is around 1.6 times as high as the prevalence for non-Indigenous Australians.[43] In the ACT, asthma is one of the most common self-reported chronic health problems among Indigenous populations,[44] and the 2021–24 ACT PHN Needs Assessment notes that: '[t]he gaps between Indigenous and non-Indigenous populations in the ACT in terms of asthma, mental and behavioural conditions were most significant.'[45]

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