



ACT
Government

**Canberra Health
Services**

Model of Care

Paediatric Liaison and Navigation Service



Consultation draft – October 2022

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Approvals

Position	Name	Signature	Date

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***Once this document has been approved, please remove the DRAFT watermark.**

Acknowledgement

This Model of Care has been developed through a co-design process with ACT Health Care Consumer's Association and the support and advice of the Paediatric Navigation Consumer Reference Group. The Consumer Reference Group's members include parents of children who receive specialist medical care interstate, and representatives of Arthritis ACT, the Stella Bella Little Stars Foundation, ACT Down Syndrome Association, Cystic Fibrosis ACT and Diabetes NSW and ACT. The Health Care Consumers' Association provides secretariat support to the Group. The Consumer Reference Group members have shared their time, knowledge and lived experience to contribute to the development of PLANS, so that the new service is best placed to meet families' needs and expectations.

The Model of Care includes comments and perspectives from parents of children with complex health needs who receive, or previously received, specialist medical care interstate. Many of these were shared in conversations in 2019-20 as part of the Kids Interstate Shared Care Project ⁽¹⁾, which was undertaken by the Health Care Consumers' Association with support from the ACT Health Directorate. The aim of the project was to identify opportunities to improve the experiences of children and families who receive interstate paediatric shared care.

Glossary

In this document some words have specific meanings:

Child / Children: This includes newborns, babies, children, and young people up to 18 years of age.

Case management: Case Management is a collaborative process of assessment, planning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost-effective outcomes. ⁽²⁾

Capacity building: Capacity building (or capacity development) is a process of managed change in which people and organisations strengthen their skills, processes, and resources so they can: set and achieve goals and sustain their work and impact. Capacity building involves fostering a shared vision and ways of working; building partnerships to use resources effectively; ongoing learning and skills development (which may include mentoring, training, education, and reflective practice), monitoring and evaluation, and working collaboratively with a range of partners.

Chronic conditions: Long-term and persistent conditions, that often lead to gradual deterioration of health and loss of independence, not often immediately life threatening, though they may have acute stages. ⁽²⁾

Complex Health care needs: A combination of health care needs across medical and psychosocial issues, that require access and support from multiple health services within the health and community sectors.

Community of Practice: A group of people who share the same interests, set of problems or professional work who come together to share learnings, best practice, and knowledge. The aim is to focus on sharing experiences and learnings, creating new knowledge and advancing the area of professional practice.

Family: There is wide variation in the composition of Australian families which can include combinations of mother, father, same-sex parents, stepparents, infants, children, youths, other family members, kin and non-related carers. It should be interpreted broadly to include those who are closest to the child in knowledge, care, and affection.

Holistic approach: To provide support and care that looks at the person in the context of their physical, emotional, social, psychological, and cultural wellbeing.

Integrated care: Creating relationships, structures, and infrastructure to drive seamless provision of the right care, at the right time, at the right place by the most appropriate provider in partnership with the child and their family. It is characterised by a high degree of communication, coordination, and collaboration in partnership with the child and family and across health and other care providers such as education, early childhood, and family services. It involves the sharing of information and development and management of a comprehensive care plan to address the physical, emotional, social, psychological, and spiritual needs of a child and family.

Shared Care Planning: The process of developing a care plan with the child and family that reflects the individual patient goals, develops strategies and tasks to achieve the goals. The process facilitates communication between the child their family and clinicians to support short and long-term healthcare outcomes and experiences.

Strengths based approach: This care approach focuses on the child and the families' strengths (including personal strengths and social and community networks) and not on their deficits. Consideration is also given to the child's environment and life experiences outside of the presenting symptoms and behaviours. Strengths-based practice is holistic and multidisciplinary and works with the child and family to promote their wellbeing.

Trauma informed care: Care that is based on knowledge and understanding of how trauma affects children and families lives and the services they need. Consideration is given to the child and families environment outside of the presenting symptoms and how traumatic events shape a person's emotions, thoughts, and behaviours.

Patient navigation / Patient Navigator: While there are many definitions of a patient navigator, they share a common goal to anticipate and identify barriers to good patient care and help patients to remove them. In doing so they improve patient outcomes and the overall quality of health care delivery.⁽⁴⁾

Shared Care: A child and family-oriented cooperation of hospitals, general practitioners, specialists, and other Healthcare Professionals to achieve high quality healthcare of a child.

Warm transfer: Involves actively communicating with the other service to which the child is connected, to provide essential information about their needs before transferring their care. Support is maintained for the child and family until they are received by the other service.

1. Introduction

This Model of Care (MoC) for the ACT Paediatric Liaison and Navigation Service (PLaNS) sets out the evidence-based framework for providing the right care, at the right time, by the right person / team and in the right location.

PLaNS puts children with complex health needs, and their families, at the centre of their own care. PLaNS involve families and children in care planning, anticipates and removes barriers to care, and assists families to make durable connections to the services and supports they need. It will help families solve problems, coordinate clinical care, and improve the flow of information between the care team and families. PLaNS will listen to children and families and acknowledge that they are experts in their own health.

The aim of this MoC is to define and clearly articulate the aims, principles, and approach of the new service, to ensure that all health professionals are 'viewing the same picture', working towards common goals and most importantly evaluating performance on an agreed approach to care.

This MoC:

- outlines the principles, benefits, and elements of care,
- provides the basis for how we deliver evidence-based care to every patient, every day, through integrated clinical practice, education, and research; and
- contains information about patient flow (how patients enter, move through, and exit the service) and service co-ordination, that provide the linkages required for seamless patient treatment.

A MoC is a dynamic document and will be updated over time to support new evidence and improved ways of working. Any updates will include relevant change management principles and processes to ensure clear engagement and communication.

This MoC will be stored on the Canberra Health Services (CHS) 'Models of Care' intranet site. It will be reviewed and updated regularly through consultation, evaluation, and the relevant communication.

"When our son is in hospital he is often in pain and distressed. As parents, we want to focus on providing him with support and comfort. However, we are often distracted from this role by having to navigate the hospital system. We welcome the introduction of the PLaNS team, and with the support of this team, to continually improving our son's care experience."

Consumer Participant

2. Principles

Our vision and role reflect what we want our health service to stand for, to be known for and to deliver every day. The vision and role are more than just words - they are our promise to each other, to our patients and their families and to the community. We all have a role to play in delivering on this promise:

- Vision: Creating exceptional health care together
- Role: To be a health service that is trusted by our community

Our values, together with our vision and role, tell the world what we stand for as an organisation. They reflect who we are now, and what we want to be known for. They capture our commitment to delivering exceptional health care to our community.

Our values:

- We are reliable - we always do what we say
- We are progressive - we embrace innovation
- We are respectful - we value everyone
- We are kind - we make everyone feel welcome and safe.

In addition to the organisational values, this service model is founded on the following **service principles**. They will guide our work and how we deliver services for children and families accessing PLaNS.

Our services principles:

- **Child and family centred care** – focuses on the individual needs of the child in the context of their family. Child and family centred care is an active partnership between the child, their family and healthcare providers in the decision making, planning and provision of care. It is respectful and provides flexible, tailored, and holistic care.
- **Capacity building** – through learning, skills development and fostering connections between people and organisations, PLaNS support families and children, health professionals, and health and community services to increase their capacity to provide care and support to children with complex health needs.

“So when you’ve got to fight that system [*interstate hospital*], fight in this system, try to keep your job, try to keep your husband’s job... Try to keep your relationship... Try not to lose your house... Make sure your other kids are okay, with really not a heck of a lot of

- **Strengths-based** - focuses on the strengths of each individual child and their family. This includes their personal strengths and their social and community networks. Strengths-based practice is holistic, multidisciplinary and works with the individual and family to promote their wellbeing. It is outcomes-led and not service-led.
- **Integrated and collaborative** – PLaNS supports children and families to connect to pathways of care through integration with accessible and appropriate services. This will include hospital and community-based child and family health and wellbeing services, and educational and social services support. Families that participate in PLaNS can expect to receive services as part of a single individually tailored care pathway that meets their needs, with smooth transitions including between health, education, and social care components.
- **Trauma responsive** – an approach to delivery of care, which acknowledges that trauma can have pervasive impacts on children and families lives and will shape the way consumers partner in

their own care and interact with the health service. A trauma informed response supports safety, trustworthiness, choice, collaboration, and empowerment.

- **Evidence informed best practice and continuous quality evaluation** – PLaNS will use data, evidence, research and child and family experiences of care, and feedback indicators, to create a continuous feedback loop between research, clinical practice and the outcomes for children and families.
- **Trustworthy** – PLaNS will seek to be trustworthy in all they do with families and children. This includes giving realistic information about what they can help with and where the families will need to seek assistance elsewhere, and the expected times for receiving service, including returning calls.

3. Benefits to be realised

The Patient Liaison and Navigation Service will provide child and family-centred, navigation, support the coordination of care for children with complex health care needs. The service aims to:

1. Improve the coordination of care for children and their families,
2. Provide clear pathways for families to escalate concerns about the health, wellbeing, or care of their child, and
3. Support families to navigate the complexities of shared care with interstate hospital and health services.

These benefits apply to all children who access care in the ACT through CHS inpatient, outpatient, or community-based services, private paediatric care and who are receiving specialist care interstate. These benefits also apply to family members of these children.

The key elements to improve outcomes within the PLaNS model are:

- **Advocacy** - *PLaNS will advocate with and for families and children, to better coordinate care and help remove barriers to care.*

PLaNS will:

- Listen to what families and children say about their goals, priorities and needs,
- Be creative and persistent in helping families anticipate and overcome barriers to coordinated care,
- Be a single point of contact in the health system for families and children,
- Be a single point of contact for colleagues providing care to the child and family,
- Promote child and family-centred care (within PLaNS and beyond), and
- Provide personalised holistic, child and family-centred assessment and planning recognising children and families as experts in their own health.

“...if there are other things out there that are wonderful that are going to really help but nobody knows about them then what’s the point of them?” – Consumer Participant

- **Linkage** - *PLaNS will facilitate partnerships with everyone involved in the care of the child and family.*
PLaNS will:
 - Connect families and children to the services and resources they need,
 - Seek and identify opportunities to improve information sharing within the care team,
 - Provide coordinated care,
 - Recognise and support the role of all family members caring for the child, and
 - Build professional relationships (within and beyond PLaNS) to coordinate care.
- **Empowerment** - *PLaNS values families' and children's knowledge about their health and their care needs and will support them to build skills and confidence to manage the health conditions that affect them.*
PLaNS will:
 - Provide the information that each child and family needs, at the right time, and in the way that suits each family and child best,
 - Involve family members and children in decisions, setting goals and developing care plans, and
 - Support families to manage their child's health at home, and to access care in the community, where this is safe and appropriate.
- **Health system improvement** – *PLaNS will actively contribute to service and system improvement.*
PLaNS will:
 - Assess and monitor systems for improvement,
 - Enhance existing services,
 - Ensure succession planning, and
 - Promote research.

These key elements are adapted from HCCA's 2018 Patient Navigation Model for the ACT and developed with advice from members of the Paediatric Navigation Service Consumer Reference Group.

"Dealing with the health system is like playing a game of Tetris – every time you move there's another block" – Consumer Participant

4. Description of service

The PLaNS is a service that provides information, coordination, and navigation for children aged 0-18 years old with complex health care needs with a focus on opportunities to improve a child's experience and health outcomes through information sharing and integration of primary, secondary and tertiary services. This will include children who have a shared care arrangement between CHS and interstate health services, and those who have multiple health service providers involved in their care.

The service will have dedicated staff who will work with existing CHS and external services to improve the interdisciplinary approach to coordination of care and outcomes for these children.

The service will support the integration of health, community and other support services that are involved in the care and support of these children and their families, recognising the impact social determinants of health have on the individual child's health outcomes and their family's wellbeing. The MOC is informed by research, best practice and the lived experience of children and their families.

The service will be multidisciplinary with the initial team members located in the Central Health Intake service and Paediatrics at Centenary Hospital for Women and Children. As the service evolves, further positions will be located within other services that support and provide care to this cohort of children and their families.

The scope of PLaNS includes:

- A centralised point of contact for children and families seeking information, support, and navigation in the coordination of care.
- A liaison function, to proactively facilitate the sharing of information between all organisations, units and clinicians involved in the child's care.
- A patient navigator function to:
 - provide a single point of contact for children and families,
 - clarify the role of specialists and units involved in care, and
 - provide information and referral to appropriate clinical, wellbeing and psychosocial support services.
- Advocacy and support for the individual needs of the child within the context of their family and community.
- Care planning to support seamless transfer of care and transition between services.
- Outpatient/ outreach nursing care, to prevent avoidable hospital admission for minor/non acute health issues.
- Promote and enable opportunities for interdisciplinary learning and upskilling of health care professionals in family-centred Paediatric care.

5. Patient/client journey

Entry

The client/parent or service provider working with the child or family can access PLaNS through the Central Health Intake service. This may be via phone, electronic referral, or email. All contacts will be reviewed by the Paediatric Liaison officer or Care Navigator and, if eligible, the child will be registered as a client of PLaNS. If the referral does not meet the service criteria the officer will assist with information, warm transfer, or redirection to an appropriate service.

A direct phone line for PLaNS has been established for health professionals and service providers for enquiries, referrals and case management and will be provided to parents once their child has been registered with the service.

“One voice does not represent another and particularly in the disability space, each person is to be approached and treated with a clean slate and free from bias in perception and stigmas of ‘they know someone with x who didn’t have that experience’ or that ‘most parents with a child with x, handle it this way’ etc.” Consumer participant

Assessment of need

Following registration an interview will be held with the child and parent/s with a full needs assessment undertaken by the Paediatric Liaison officer or Care Navigator. This assessment will include the medical and psychosocial aspects of the child within the family context and identification of services already involved in the care of the child. Consent will be sought from the parent/guardian for the PLaNS worker to engage with providers outside CHS in line with agreed care plan. The service will triage and prioritise involvement of the PLaNS team based on this assessment

Care planning

Care Planning will be undertaken in partnership with the child and parent/s or guardian/s. The process will be based on the individuals’ goals and develop strategies and identify tasks to achieve these goals. All care plans will include:

- Goals set in partnership with the child, family, treating teams and those involved in the care and support.
- Management plans for specific conditions, devices, emergency response or predictable health events.
- Key people involved in the care of the child and family including their roles such as direct service provider, case management or coordination.

Care plans will be uploaded to the child’s medical record on the summary page of the clinical patient folder (CPF).

Due to the complexity and changing nature of children’s medical, educational, and psychosocial needs the care plan will need to have flexibility for review timeframes.

Care co-ordination

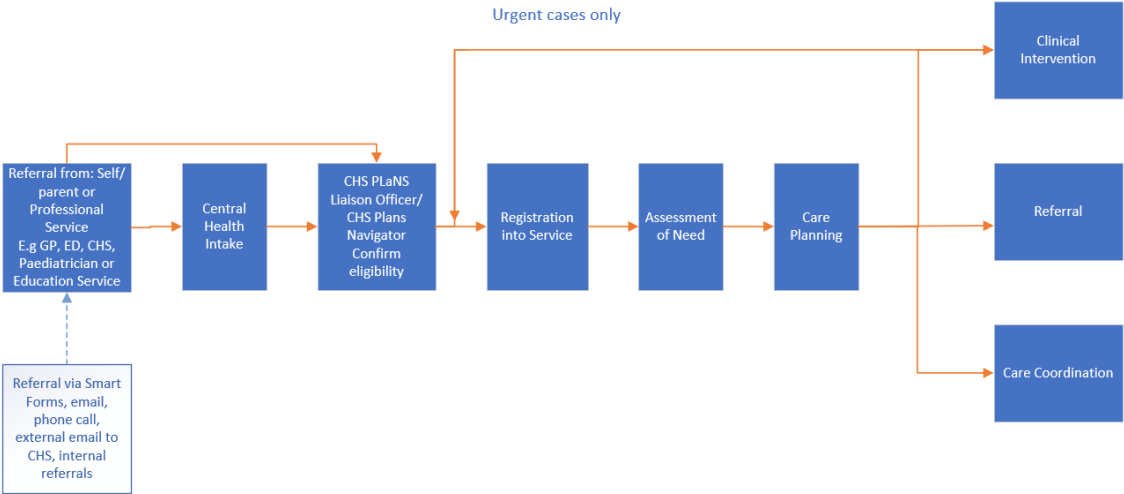
The level of care coordination, support and/or clinical interventions by PLaNS will vary based on the needs of the child, care coordination providers already involved and the family context. Levels of involvement will likely vary across the period the child is involved with the service dependant on their health and psychosocial needs.

If a child has an established care coordinator working with them and their family, PLaNS will work with the provider to assist in the sharing of information and navigation of services to improve the child’s care and experience.

Where there is no care coordinator identified, PLaNS will provide a care coordination role working with the family to identify if there is a preferred care provider to work with them on providing care coordination.

“During our 36hrs in [the hospital] there were lots of conversations with [interstate hospital] between registrars ‘about’ her condition, but never ‘with’ or ‘including’ the person who understood her the most – me. If just one of those conversations had included me, my child would have been transferred immediately to SCH.” Consumer participant

CHS Paediatric Liaison and Navigation Service (PLaNS)



Exiting and transitioning from PLaNS

A child is eligible to remain a client of the service until the age of 18 and requiring access to health services in the ACT. Transition planning will occur for adolescents approaching 18 ensuring there is a smooth, supported, and informed process to transition to adult services, where they are needed. PLaNS will support the adolescent and family whilst they are establishing relationships and successfully transitioning to adult services.

If active involvement is not required by the PLaNS team, the child may remain a client of the service or choose to exit with the ability to re-enter when required.

Discharge from the service will occur if a child moves permanently interstate and is not accessing services in the ACT. The service will ensure that when a discharge occurs the child and/or parent/s (guardian/s) are well supported with appropriate referral to services.

6. Interdependencies

Consistent with an integrated care model, there are a wide range of interdependent functional relationships to enable the MOC. These include all areas of CHS that provide care to children, private specialists, interstate health services, primary health care providers, education services, government, and non-government community services. Each of these services have a critical role to play in the provision of coordinated, collaborative and integrated care for children. PLaNS will work with all services to ensure each child receives integrated and coordinated care.

7. Workforce

The PLaNS is an interdisciplinary service funded to provide nursing, allied health and administrative/navigation support roles. The service will commence with a Paediatric Liaison Officer and a Care Navigator position with development of Allied health and navigation support roles underway.

8. Governance

The PLaNS will comprise of a team of professionals working under the auspice of the Patient Navigation Service with the Director of Integrated Care providing leadership to ensure service delivery is in line with the strategic direction, model of care, organisational accountability targets and corporate and clinical governance.

The individual positions will be based within a range of work areas across CHS with the direct line management and professional supervision provided from the work areas to ensure appropriate clinical and administrative supervision for the specific role.

9. Accreditation and Training

All staff working in the PLaNS will be appropriately qualified and will maintain their professional accreditation and competency standards as required by their relevant professional body under legislative and organisational requirements.

Through the Director of Integrated Care, a Community of Practice will be established to facilitate continued and shared learning to improve practice and the experience and outcomes for children and their families.

10. Monitoring and Evaluation

Monitoring and evaluation of the PLaNS will occur through a range of qualitative and quantitative mechanisms. Key indicators will be identified to measure consumer experience, service and system level performance and monitored through:

- CHS’s Clinical Governance Structure and Committees
- CHS’s Risk Management Processes
- CHS’s Partnering for Exceptional Care Framework
- Operational and management performance monitoring processes
- National Safety and Quality Health Service (NSQHS) Standards set by the Australian Commission on Safety and Quality in Health Care.

To ensure that a consumer focus is taken in the monitoring and evaluation, the HCCA Consumer Reference Group will participate in the development of the performance measures and be engaged in the data review process, using a co-design method.

“Most of us just want to make the system better so the next kid and the next family don’t have to go through it...” - Consumer Participant

11. Records management

Following the relevant consultation, this finalised document and any further updates will be electronically stored on the CHS intranet site – ‘Models of Care’, to ensure accessibility for all staff.

12. Abbreviations

MOC	Model of Care
PLaNS	Paediatric Liaison and Navigation Service
CHS	Canberra Health Service
HCCA	Health Care Consumer’s Association
CHI	Central Health Intake
CPF	Clinical Patient Folder
ACT	Australian Capital Territory
NSQHSS	National Safety and Quality Health Service Standards
ACSQHC	Australian Commission on Safety and Quality in Health Care

13. References

1. [Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care - HCCA](#)
2. <https://cmsa.org/who-we-are/what-is-a-case-manager/>
3. Australian Health Ministers' Advisory Council, 2017, *National Strategic Framework for Chronic Conditions*, Australian Government Canberra
4. National Complex Needs Alliance in Health Consumers' Association 2018 *A Model for Patient Navigation for the ACT*, HCCA Canberra: at: [A model for patient navigation in the ACT for people with chronic and complex conditions - HCCA](#)
5. Harold Freeman "A model patient navigator program". *Oncology Issues*. Volume 19, Pages 44-47, 2004. 11 Allison Pedersen and Thomas F Hack, "Pilots of Oncology Health Care: A Concept Analysis of the Patient Navigator Role" *Oncology Nursing Forum*, Volume 37, Issue 1. January 2010.

14. Model of Care Development Participants

Position	Name
CHS, COO and project sponsor	Cathie O'Neill
CHS, Executive Director, Women, Youth & Children (WYC)	Susan Frieberg
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CHS, Cancer and Ambulatory Support (CAS), Palliative Care	Toni Ashmore
CHS, GP Liaison Unit Medical Director	Ann-Marie Svoboda
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CHS, WYC, Director Allied Health	Pip Golley
CHS, WYC, CNM Paed. Outpatients and Day stay	Fiona Matthews
CHS, Director, Paediatrics at Canberra Hospital	Blessy Charles
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CHS, Executive Director, CAS	Kath Wakefield
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CHS, Service Co-Ordinator, Paediatric Endocrinology Service	Rosemary Young
CHS, Chief Information Officer	Nasa Walton
CHS, Allied Health	Allied Health Directors Meeting
CHS, CAS	Paediatric Haemophilia Team
CHS, Speech Pathology	Tim Tooke
CHS, NDIS project team	Barbara Bolton, Kelsey Cook
Parents	Sarah Pratt and Jeremy Johnson
CHS, Hip Dysplasia Clinic, Neonatology	Amanda Dyson, Olivia Laslett
ACT Health Directorate	Health Service Planning team
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CHS, Occupational Therapy Services	Domenico Tripodi

CHS, WYC, ADON, Community Health Programs	Carolyn Thomas
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ACT Health Directorate	Digital Health Record Team
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CHS, Paediatrician	Anne Mitchell
Kids GPS, Sydney Children Hospital Network (SCHN)	Nadine Shaw and Natalie Hooke
Executive Director, Rehabilitation and Community Services	Jo Morris
Nurse Navigator, General Paediatrics, Rural and Remote, Children's Health, Queensland Hospitals and Health Service	Catherine Bracken
ACT Muscular Dystrophy Association	Rob Oakley
A Village for Every Child, Community Development Officer	Sarah Brittle
Carer's ACT, Manager, Policy and Advocacy	Kamla Brisbane
ADACAS (Aged, Disability and Carer Advocacy Service) Systemic Advocacy Team Leader	Lauren O'Brien
Diabetes NSW and ACT, ACT Community Engagement Coordinator	Kat King
Companion House, Community Development & Training Team Leader and Lead Practice Nurse	Glenn Flanagan and Allison McGurgan
ACT Council of Social Service, CASP Development Officer	Emma Hawke
Playgroups ACT Executive Officer	Carley Jones
Community Assistance and Support Program Network Members / ACTCOSS CASP Network Secretariat	Network Members
Asthma ACT Health Projects & Partnerships Coordinator	Janine Lourenz
Epilepsy ACT CEO	Fiona Allardyce

ACKNOWLEDGMENT OF COUNTRY

Canberra Health Services acknowledges the Traditional Custodians of the land, the Ngunnawal people. Canberra Health Services respects their continuing culture and connections to the land and the unique contributions they make to the life of this area. Canberra Health Services also acknowledges and welcomes Aboriginal and Torres Strait Islander peoples who are part of the community we serve.

ACCESSIBILITY

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