

2023 Sarcoma Summit

Recommendations and Progress Update

Background

- In 2023, Sydney Local Health District hosted a Sarcoma Summit at RPA Hospital
- The first event of its kind in Australia, the Summit focused on building a stronger understanding between patients, families, researchers and clinicians and enhancing partnerships to improve patient care
- Key themes from the Summit included:
 - Service enhancement – including access to services outside of normal hours & time with patients
 - Access to information / education
 - Support for patients, families and friends
- The key themes informed recommendations to improve the care and experiences of patients, their families and carers at RPA Hospital – outlined in the 2023 Sarcoma Summit Action Plan

2023 Sarcoma Summit Action Plan

– Achievements

Theme	Action	Update
Service enhancement – access to services outside of normal hours	RPA Virtual Model of Care, advice on: <ul style="list-style-type: none"> ○ Symptom management ○ Pain Management ○ Chemotherapy ○ Radiotherapy ○ Any concerns before or after surgery 	<ul style="list-style-type: none"> ○ Launched February 2024 ○ Nursing and medical clinicians available 24/7 for advice ○ Available to patients of RPA and Chris O'Brien Lifehouse sarcoma services, their families, carers and clinicians
Service enhancement – time with patients	Appointment of 2 x additional Clinical Nurse Consultants (CNCs)	<ul style="list-style-type: none"> ○ 2 x CNC positions established within RPA sarcoma service – 3 CNCs total ○ New CNCs commenced May / June 2024 ○ Every patient allocated a CNC to coordinate care both pre- and post-operatively, and provide ongoing clinical care and support ○ CNCs involved in weekly outpatient clinics and multidisciplinary team meetings ○ Future addition of social work and clinical psychology
Service enhancement	Relocation of the outpatient clinic to specialised clinic space	<ul style="list-style-type: none"> ○ Transitioned 12 April 2024 to newly refurbished Scott Skirving multidisciplinary clinic space at RPA – includes 17 consult rooms, waiting rooms, breakout rooms, quiet rooms and meeting rooms ○ 1 x Program Coordinator and 2 x Administration Officer positions established and recruited to – to support service delivery and streamline processes for the statewide RPA sarcoma service

2023 Sarcoma Summit Action Plan

– Achievements

Theme	Action	Update
Access to information / education	HealthPathway Development	<ul style="list-style-type: none"> 2 x pathways relevant to sarcoma now available on Sydney Community HealthPathways website to provide GPs and other clinicians guidance on assessment and referral Communication issued August 2024 in Central Eastern Sydney Primary Health Network(PHN) newsletter to increase GP awareness of RPA service, key changes and referral pathways Future plan to inform additional PHNs about statewide RPA sarcoma service
	Clinical trial information, including CALD involvement	<ul style="list-style-type: none"> Bone & Soft Tissue Sarcoma Research program now governed by Surgical Outcomes Research Centre (SOuRCe) and Institute of Academic Surgery (IAS) Development of new 'ROBUST' database and the inaugural Sarcoma Annual Report Ongoing expansion of research program for opportunities in publication, collaboration, research and clinical trials to improve evidence-based patient care
	Education – GPs, physiotherapy, occupational therapy, psychology, social work, administration	<ul style="list-style-type: none"> Education on sarcoma delivered to all new team members of RPA sarcoma service – including CNCs and administrative staff Inaugural GP webinar in planning Future plan to formalise and expand education sessions for clinicians
Support for patients, families and friends	2024 Event	<ul style="list-style-type: none"> 2024 Sarcoma Symposium in planning – Friday 8 November 2024, 1pm to 5:30pm <ul style="list-style-type: none"> Presentations on service developments, key issues, clinical research and work of not-for-profit organisations Panel discussion involving patients, carers, families, clinicians and researchers on relevant topics

2023 Sarcoma Summit Action Plan

– In Progress

Theme	Action	Update
Access to information / education	Education – patients, families, friends	<ul style="list-style-type: none"> ○ Patient information booklet in development by CNCs – general information on sarcoma, treatment, and what to expect as both an inpatient and outpatient at RPA
	Update the prospectus	<ul style="list-style-type: none"> ○ Set of communication materials in development to meet the needs of a range of different stakeholders and streamline information (e.g., patients, clinicians, referrers, etc.) – patient information booklet, Sarcoma Annual Report, website redevelopment
	Hip Disarticulation / Hemipelvectomy patient handbook	<ul style="list-style-type: none"> ○ To complement general patient information booklet, future addition of social work and psychology to RPA service will enable peer support and connection of patients undergoing this procedure for information on what to expect
Support for patients, families and friends	Peer, sibling, parental and financial support	<ul style="list-style-type: none"> ○ RPA Virtual advice and support line available to patients' families ○ Future addition of social work and clinical psychology to greatly improve provision of information and organisation of available supports for patients and their families ○ Information on available supports to be included in patient information booklet
Service enhancement	Access to genetics and the involvement of geneticists in the MDT	<ul style="list-style-type: none"> ○ Currently being investigated with key stakeholders