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Sarcoma at the Margins: Why Rare Cancer Research Needs a Policy Reset

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As Asia-Pacific accelerates investments in precision medicine, genomics and AI-driven oncology, rare cancers risk being left behind. Sarcoma, despite its complexity and significant impact on children and young adults, remains underfunded and understudied. Addressing this gap will require stronger regional collaboration, targeted funding and policies that prioritise unmet clinical need alongside disease prevalence.

The Asia-Pacific (APAC) region is entering a transformative era in cancer research. Governments are investing heavily in genomics, immunotherapy, precision medicine, artificial intelligence (AI) and advanced therapeutics, recognising that cancer will remain one of the region's biggest health and economic challenges. Governments across the region are investing billions of dollars in biomedical innovation, recognising that cancer will remain one of the greatest health and economic challenges of the coming decades.

Yet amid this wave of innovation, one group of cancers remains consistently underrepresented in research priorities: sarcoma. Sarcoma accounts for only around 1 per cent of adult cancers, but it represents more than 20 per cent of childhood cancers and encompasses over 100 distinct subtypes affecting bone and soft tissue. Each subtype has unique biological characteristics, clinical behaviours and treatment requirements. In reality, sarcoma is not one disease but many. Its rarity,

however, has become its greatest disadvantage.

Across the Asia-Pacific region, research funding is naturally directed towards common cancers such as breast, lung, colorectal and prostate cancer. These diseases affect larger populations and attract greater public awareness, philanthropic support and commercial investment. This focus has contributed to major advances in diagnosis, treatment and survival outcomes. However, it has also created a significant evidence gap for rare cancers.

In many countries, sarcoma receives only a small fraction of overall cancer research funding despite imposing a disproportionate burden on patients, families and healthcare systems. Limited investment leads to fewer clinical trials, fewer discoveries and fewer treatment options. The result is a cycle that continues to disadvantage patients living with rare cancers. The challenge is compounded by the nature of the disease itself.

Unlike common cancers, sarcoma is highly heterogeneous. With more than 100 recognised subtypes, individual sarcomas may affect only a handful of patients each year within a single country. This makes conventional clinical trial design difficult. Recruiting enough participants to generate meaningful evidence often requires multiple institutions and countries working together over extended periods.

For researchers, this presents significant logistical and funding challenges. For patients, it can mean delayed access to innovative therapies and fewer opportunities to participate in clinical trials.

These challenges are particularly relevant in the Asia-Pacific region, where patient populations are geographically dispersed and healthcare systems differ widely in infrastructure, research capacity and regulatory frameworks. Yet these barriers should not be viewed as reasons to reduce investment. Rather, they underscore the need for greater regional collaboration. Recent international studies demonstrate what can be achieved when institutions and countries work together.

The CASPS trial investigating cediranib in alveolar soft-part sarcoma showed that even one of the rarest sarcoma subtypes could be studied through a rigorous randomised clinical trial when specialist centres across Australia, the United Kingdom and Europe collaborated.

More recently, the SU2C-SARC032 study demonstrated that adding to standard treatment significantly improved disease-free survival for patients with high-risk soft tissue sarcoma.

Importantly, these studies did more than advance scientific knowledge. They generated evidence capable of informing reimbursement and policy decisions, helping to ensure that research discoveries translate into real-world patient benefit.

This highlights an important lesson for the Asia-Pacific region. The future of sarcoma research will depend less on individual institutions and more on interconnected research networks. Advances in genomic sequencing, digital pathology, artificial intelligence and precision oncology are creating new opportunities to study rare cancers at scale. Shared genomic databases, multinational biobanks and adaptive clinical trial designs can help overcome the limitations posed by small patient populations. Harmonised ethics and regulatory processes can further accelerate cross-border research while reducing duplication and cost.

The Asia-Pacific region is uniquely positioned to lead this effort. Australia and New Zealand have established strong international reputations in sarcoma care and clinical research. Singapore, Japan, South Korea and China continue to make substantial investments in precision medicine and translational science. Across Southeast Asia, research infrastructure is rapidly expanding as governments recognise the strategic importance of biomedical innovation. Together, these strengths provide the foundation for a coordinated regional approach to sarcoma research.

Such an approach would not only accelerate scientific discovery but also generate evidence that reflects the genetic and demographic diversity of Asia-Pacific populations. This is increasingly important as oncology moves towards more personalised treatment approaches. Therapies developed and validated in one population may not always perform the same way across diverse patient groups. Regional collaboration therefore contributes both to scientific excellence and to better patient outcomes. However, scientific capability alone will not solve the problem.

Funding remains one of the greatest barriers to progress. Rare cancers often struggle within traditional research funding models because grant assessment processes frequently prioritise diseases with larger patient populations. Commercial incentives may also be limited, as pharmaceutical companies face smaller market opportunities compared with common cancers.

This creates a paradox within oncology. The cancers with some of the greatest unmet clinical needs are often those least likely to receive sustained research investment.

Addressing this imbalance requires a broader policy perspective. Funding decisions should be guided not only by disease prevalence but also by factors such as unmet need, disease complexity, quality-of-life impact and the potential for scientific innovation.

The value of rare cancer research extends far beyond the patients directly affected. Historically, research into rare cancers has contributed significantly to advances in targeted therapies, molecular diagnostics and precision medicine. Insights gained from understanding uncommon tumour biology have often informed treatment approaches across multiple cancer types. Investment in sarcoma research should therefore not be viewed as support for a niche area of medicine. Rather, it should be recognised as part of a broader strategy to strengthen cancer innovation.

The economic case is equally compelling. Delayed diagnosis and advanced disease frequently result in repeated surgeries, prolonged hospitalisation, rehabilitation needs and lifelong disability. For children, adolescents and young adults, the personal and societal consequences can extend across decades. Improving diagnosis, treatment and trial access has the potential to reduce these long-term burdens while improving survival and quality of life.

Most importantly, there is a fundamental issue of equity. Patients with rare cancers should not face poorer outcomes simply because their disease is uncommon. The promise of modern oncology is that treatment becomes increasingly tailored to individual patients and tumour biology. Achieving that vision requires ensuring that research investment extends beyond the most common cancers.

The Asia-Pacific region now has an opportunity to redefine how rare cancer research is supported. By investing in regional research networks, encouraging multinational clinical trials, sharing infrastructure and adopting policies that reward collaboration, governments can accelerate progress not only for sarcoma but for rare cancers more broadly. If precision medicine is the future of cancer care, then precision funding must become part of the conversation. Research investment should reflect unmet need as well as incidence, and scientific opportunity as well as market size.

The future of sarcoma care will be shaped not only by scientific discovery but also by the policy choices made today. Investing in sarcoma research is more than a commitment to a rare cancer community. It is an investment in innovation, collaboration and a more equitable future for cancer care across the Asia-Pacific region.

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