## The Medical Journal of Australia • MJA MEDIA RELEASE

## **CALL FOR NATIONAL STRATEGY FOR RARE CANCERS IN TEENS**

## EMBARGOED UNTIL 12:01 am Monday, 15 October 2018

ADOLESCENTS and young adults (AYAs) are disproportionately diagnosed with rarer cancers with poor diagnoses, but are disadvantaged by a complex research environment in Australia which results in poorer clinical trial access and participation, according to the authors of a Perspective published today by the *Medical Journal of Australia*.

Dr Adam Walczak, Youth Cancer Services and Clinical Trials Manager of CanTeen, and colleagues, wrote that the Australian Government currently lacked a national strategy to guide research investment and related policy development to address the rare cancers in the AYA sector.

"The US example, the *Recalcitrant Cancer Research Act*, requires the National Cancer Institute to develop and action scientific frameworks coordinating prevention, early detection and treatment-focused research in cancers with survival rates below 50%," Walczak and colleagues wrote.

"While the recent Senate inquiry is a critical step towards a nationally consistent approach to rare and low survival cancers, an overarching Australian strategy to address these cancers is urgently needed."

Five-year (all cancers) survival is high for AYAs (88%), but that number masks their poorer outcomes for certain central nervous system (41%) and soft tissue cancers (49%).

"Despite recent treatment advances, survival gains have been smaller for AYAs than other age groups, in part, due to AYAs being disproportionately diagnosed with rarer cancers, which tend to have poorer prognoses and are responsible for the majority of AYA cancer deaths," wrote Walczak and colleagues.

"Establishing treatment efficacy in this population is particularly important, as mounting evidence suggests that cancers diagnosed in the AYA age range may have distinct biology, prognosis and clinical behaviour (eg, likelihood of metastasising or recurrence in distant organs), and different responses to otherwise successful paediatric or adult treatments."

Funding for research into treatments for rare cancers in AYA is hard to come by, as the pharmaceutical industry finds them least attractive because of their narrower applications, particularly without "foundational government support".

"Australian research and infrastructure-funding approaches have historically favoured areas with substantial evidence base and researchers with established, field-specific track records. This funding approach has disadvantaged rare and low survival cancer research," wrote Walczak and colleagues, calling for a "government-supported rare and low survival cancer taskforce uniting consumer, government, academic, industry, not-for-profit and service delivery stakeholders".

"Building on the momentum of the recent Senate inquiry into the impact of funding models on rare and low survival cancer research presents a real opportunity to improve outcomes for AYA patients with cancer and the broader Australian population affected by rare and low survival cancers by taking a coordinated, affirmative action approach leveraging cross-sectoral coordination and investment," the authors concluded.

## Please remember to credit The MJA.

The Medical Journal of Australia is a publication of the Australian Medical Association.

The statements or opinions that are expressed in the MJA reflect the views of the authors and do not represent the official policy of the AMA or the MJA unless that is so stated.

CONTACTS: Dr Adam Walczak

Youth Cancer Services and Clinical Trials Manager

CanTeen

Email: adam.walczak.canteen.org.au