

## IMPROVING IPTAAS EQUITY POSITION STATEMENT July 2018

### BACKGROUND

The Guidelines for Assessment for the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS), state it is “a NSW Government initiative designed to financially assist people, particularly in isolated or rural areas, who have to travel significant distances to access specialist medical and/or oral health surgical treatment which is not available locally.” The IPTAAS guidelines lists clinical trials and unproven medical treatments as “Ineligible for Assistance”. The Guidelines define a clinical trial as “testing a drug, surgical or other therapeutic or preventative procedure, or a diagnostic device or service”.

This is a discriminatory provision for those who live in regional, rural and remote (RRR) locations, and who cannot afford the cost of participating in a clinical trial, and reduces the pool of participants for medical research.

Clinical trials in Australia have been predominantly commercial trials, but there is a growing trend for investigator-initiated or industry-independent clinical trials. For RRR patients, telehealth clinical trials are an exciting opportunity to improve their standard of healthcare, and IPTAAS should be available to such patients.

Further, there are restrictions on the distance travelled by a patient for claiming IPTAAS, with a current threshold of 100km from the nearest treating specialist or combined trips to and from the specialist needing to exceed 200kms/week.

In February 2016, the NSW Government improved IPTAAS equity in broadening eligibility to include rural and isolated patients travelling to highly specialised allied health clinics, with the purpose of assisting ‘patients for whom continuation with a treatment or therapy plan is difficult due to the need to access highly specialised allied health services which are only available in very limited locations’.

The restriction of those on clinical trials from using the NSW Government’s IPTAAS is at odds with the goals of the Australian Government to increase the number and location of clinical trials, and participation in them, across Australia. To deny the IPTAAS subsidy to RRR patients for trials is to deny them access to the best medical treatment available and is contributing to their lower survival rates.

Cancer Voices NSW therefore believes the NSW Government should:

- remove the provisions in IPTAAS that discriminate against rural and isolated patients in restricting their access to clinical trials, and
- introduce a ‘sliding scale’ of reimbursements for those travelling less than the current threshold distances.

*See also ‘Further Background’ at the end of this position statement*

### AIM

To improve equity for patients with cancer when utilizing the Isolated Patients Travel and Accommodation Scheme (IPTAAS)

### OBJECTIVES/STRATEGIES

- I. Influence government decision-making to remove the restrictions on IPTAAS eligibility for cancer patients participating in clinical trials
- II. influence government decision making to introduce a ‘sliding scale’ for reimbursements for those claiming IPTAAS who travel less than the current threshold distances

## **ACTIONS**

- develop an updated policy and position statement on the need to improve equity for rural and isolated patients who are currently discriminated against under IPTAAS
- identify key decision-makers and influencers who can help achieve reform to current discriminatory IPTAAS provisions
- meet with key decision-makers and influencers on IPTAAS as the focus of Cancer Voices NSW advocacy in the lead-up to the 2019 NSW election
- use CVN's online, social media and printed publications presence, and participation in meetings and at conferences, to present and advocate on the need for increased equity in IPTAAS
- evaluate the initial responses from key decision-makers and influencers as the basis for further advocacy, including letter writing and publicity, to reinforce the need for a government decision to improve IPTAAS equity

## **KEY RELATIONSHIPS**

- Minister for Health; Parliamentary Secretary for Rural and Regional Health
- Shadow Minister for Health
- The Greens NSW health spokesperson
- Regional MPs
- Ministry of Health
- Clinical Oncology Society of Australia (COSA) Australasian Tele-trial Model Consortium
- Cancer Council NSW, including its CanAct Community and local Cancer Action Networks
- other cancer advocacy groups
- Health Consumers NSW
- NSW Country Women's Association

*Version as at:* Number 1, Final, 17 July 2018

## FURTHER BACKGROUND

### Equitable access for Rural, Regional and Remote patients to Clinical Trials

Deloitte Access Economics' "Access to cancer treatment in non-metropolitan areas of Australia" 2011 reports that "people living in non-metropolitan regions fare worse than their metropolitan counterparts across a wide spectrum of cancers" and that "One-year and five-year relative survival rates for all cancers decreased as remoteness of residence increased, with significant differences between major cities, inner regional and outer regional".

Optimal Care Pathways (OCP) have been developed and implemented nationally for 15 types of cancers and have been endorsed by the National Cancer Expert Review Group (NCERG), Cancer Australia, Cancer Council Australia, and the Australian Health Ministers Advisory Council (AHMAC). The OCP quick reference guide for patients with acute myeloid leukaemia (AML) states "*participation in clinical trials...is considered a standard of care for patients with AML*". By excluding clinical trials from IPTAAS, the NSW Government is potentially denying RRR patients access to optimal care.

Many cancer trials utilise a drug that has been approved for a particular cancer, in an unlisted cancer type. Under the current arrangements, a regional patient with the unlisted cancer type must pay for all their travel and accommodation, whereas the other patient will be eligible for the IPTAAS subsidy.

The Australian Government currently funds 13 National Cancer Cooperative Trials Groups through Cancer Australia to develop industry-independent cancer clinical trials protocols. According to the Cancer Australia website, the aim of this funding is to "increase the:

- participation in clinical trials by people affected by cancer
- number of cancer clinical trials conducted in Australia
- number of clinical sites actively participating in clinical trials
- involvement of clinicians and researchers in clinical trials within Australia"