



Government of **Western Australia**
Department of **Health**
WA Cancer and Palliative Care Network

Facsimile

WA Cancer and Palliative Care Network

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DATE: 16/05/2014

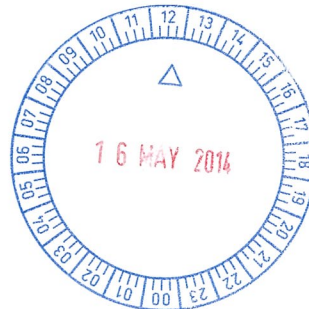
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MESSAGE:

Good afternoon Lauren,
Please find attached the WACPCN submission for the PATS inquiry.

Kind regards,

Rachel Jenkin
Coordinator of Nursing
WA Cancer & Palliative Care Network



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Date: 12th May 2014

The Standing Committee on Public Administration has commenced an inquiry into the Patient Assisted Travel Scheme (PATS) in Western Australia.

The WA Cancer & Palliative Care Network (WACPCN) understands that the Western Australian Government is currently conducting a review of the Patient Assisted Travel Scheme (PATS). The WACPCN would like to contribute to this review and asks that this submission representing oncology patients is accepted as part of the enquiry. The following summary acknowledges that there have been previous improvements to the scheme and supports this current initiative to build and improve on the current system.

In 2012 the WA Cancer registry reported over 11,939 incidences of newly diagnosed cancer, over 24% residing in rural/regional WA¹. This figure is predicted to rise by 50% before 2030².

The WA Cancer & Palliative Care Network is the Department of Health's lead state-wide organisation committed to improving the experience and outcomes of patients diagnosed with cancer and accessing palliative care services. Through the implementation of The WA Cancer Plan 2012-2017 equitable, safe and quality services are being made available to all cancer patients. Accessibility has been significantly improved by the development of new and expanded services across the State as well as the introduction of the WA Rural and Metropolitan Cancer Nurse Coordination service³. The addition of a travel assistance scheme that can adapt to the increasing incidence of cancer, as well as the changing context of Western Australia's health care system would greatly impact on improved outcomes for cancer patients.

Background

- Cancer patients experience very complex treatment pathways that consist of a combination of Surgery, Chemotherapy and Radiation. They experience side effects before, during and after treatments, have high levels of anxiety and distress and are often dependent on ongoing specialist support services as a result of the treatments that they have received.
- Western Australia provides the majority of its oncology services in the metropolitan area although some new and expanded oncology services are available in larger regional centres.
- The demand for accommodation and travel assistance through the PATs Scheme has risen significantly for Oncology patients over the past three years due largely to a recorded increase in cancer incidence. The increased cost of accommodation, limitations to the availability of accommodation in the metropolitan area due to fly in/ fly out workers and changes to how oncology services are being provided across Western Australia is, however impacting on accessibility and affordability.
- Changes to eligibility criteria, subsidy rates and overall administration of the PAT scheme in recent years have not taken these issues into account leading to delays in patients accessing oncology treatments, related supportive care and follow up (such as specialist oral dental appointments post radiotherapy).
- Patients in Western Australia are expected to access treatment and care across multiple sites and have to navigate between public and private institutions due to the partnerships that now exist between service providers.



- The increase in private oncology service providers has reduced the ability to refer patients to services closer to home and this has impacted significantly on patient's ability to access PATS support.
- Patients are initially seen by a Multidisciplinary team who make evidence-based treatment decisions. Patients are then required to have appointments with up to 6 treating specialists on this initial visit depending on the treatment decision (this cannot be predicted by the patients GP and adds additional administrative workloads). Accessing all these appointments at this time prevents the patient from multiple return trips, ensures patients have access to fully informed treatment decision making and allows timely planning of treatment delivery.
- The Rural and Metropolitan Cancer Nurse Coordination (CNC) service is now an established service that provides patients with information and support throughout their cancer experience. The CNC team have expert knowledge of the patients treatment pathway and assist patients in navigating through the continuum of referral pathways.

Specific Issues

How adequately PATS delivers assistance to regional people accessing specialist medical care, including:

a) the level of funding applied to the transport and accommodation subsidies provided;

There is increasing disparity between the financial assistance patients receive through PATS. This is dependent on variables that include the distance the patient lives from the treatment centre; the type and length of treatment required; the available provision of services on one hospital site; eligibility for reimbursement of expenses through PATS; inconsistency in administration of financial support and whether the patient has private health insurance. Some of the issues relate to;

- Metropolitan Perth accommodation costs have increased significantly according to the 2012 Australian Bureau of Statistics but PATS funding has not increased³.
- Reduced availability of budget accommodation due to increased population of fly in/fly out workers.
- With the opening of Fiona Stanley Hospital – there is NO commercial accommodation close to this hospital for rural patients to access.
- Patients are often required to receive their treatments across multiple health care institutions in order to receive the evidence based care they have been recommended but have to self-fund travel between sites. This can amount to a considerable amount when treatments are daily for a 6-8 week period. For example, a patient referred to Fremantle hospital for treatment of a rectal cancer will be required to have surgery, chemotherapy and radiation treatment over a 6 month period. Their surgery and chemotherapy will be completed at Fremantle but radiotherapy is not provided at Fremantle so patients are required to attend either RPH or Perth Radiation Clinic –Wembly (if they have private health care cover) at their own expense.
- Another example of the burden of travel includes patients having to travel to multiple sites for treatment due to existing service restrictions, financial assistance does not take this into account for patients. For example a patient diagnosed with a Gynaecological cancer will have surgery at King Edward Memorial Hospital, receive chemotherapy at SCGH at



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the same time as radiotherapy at RPH. These patients are expected to self-manage and self-fund their travel between sites.

- Patients referred to Fremantle hospital have limited access to local accommodation and are often required to stay at Crawford Lodge (over 20kms away) and are expected to self-fund their travel between accommodation and the treating centre. Patients often have no choice in where they are referred and in this case a referral to Fremantle means additional expense for the patient.
- Patients receiving hyperbaric treatment as a result of their radiotherapy (a known complication of treatment) have a daily journey for 6 to 10 weeks from their accommodation to Fremantle hospital. They are expected to self-fund this travel.
- Increases in the cost of fuel mean that \$20 p/day for a patient living 70km radius from Perth does not adequately support their travel.

b) eligibility for PATS funding

There are inconsistencies in which patients are considered eligible for flights/accommodation/fuel allowance/taxi vouchers and these disparities can be dependent on the ethnicity of the patient and differ between administrators within regional areas.

- Some patients are not considered eligible for flights for follow up appointments/supportive treatment i.e. Specialist Speech Pathology, lymphoedema therapist or Specialist Oral health appointments, even when these specialist services are not accessible in regional WA and are required as a direct result of ongoing treatment.
- Patients who have been encouraged to utilise their private health care insurance are often refused financial assistance for travel to receive treatment and supportive care in the metropolitan area where the private clinician is based.
- Patients often travel to Perth for diagnostic work-up (this includes pathological staging and dictates the treatment they will receive) at the request of a multidisciplinary team of specialists. A GP does not have detailed information about who has made the request or which specialists will treat the patient, - a patient may be under as many as 6 specialists at this stage. PATS administrators often refuse to provide support for these patients. This is a vital aspect of treatment planning.
- Patients who become unwell after receiving treatment and have to remain in Perth for extended periods are not being supported with accommodation, and are refused return flights when they become well.
- Private clinicians in the metropolitan area will not always refer patients for care closer to home and patients from the South West are being refused support to return to Perth to see their treating private clinician. These patients have no choice but to continue to receive treatment and care in Perth and should be eligible for financial support. In some cases they have been encouraged to use their private health care insurance in the public institution and are then disadvantaged through PATS.
- South West Oncology services are not always appropriate for all cancer patients, for example some thoracic, colorectal, head & neck cancers and most UGI cancers require



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referral to a comprehensive metropolitan service due to the complex nature of their treatment requirements. PATS refuse to support these patients with accommodation and fuel assistance because they believe the service is provided in the South West. This does not align with The Models of Care for Cancer which indicates where patients should be referred in order that they receive the right care, in the right place by the right team.

- Not all Patients are eligible for appointments with some Allied Health Care Professionals despite these appointments being directly related to treatment. For example, a Head & Neck Cancer patient is required to undergo specialist oral/dental health assessment as well as speech and dietetic assessment at key periods before, during and after their treatment in order to prevent them from admission to hospital. This is routine for this patient group, requires additional presentations to Perth and ongoing post treatment follow up, PATS does not cover this despite it being a requirement before commencing treatment.
- There are disparities in eligibility for patients living on or around the 100km radius; for example patients living in Northam or York may receive assistance but those from Toodyay will not. This also relates to patients living in a 70km radius of Perth.
- PATS administrators calculate distances differently i.e. some calculate from a post office address to the GPO in Perth and others from the patient's home address to treating hospital. This changes the eligibility of patients who live on the 100km radius.
- Many cancer patients require an escort as they are not well enough to travel alone due to their diagnosis or the side effects of treatments. These patients require an escort who should be eligible for flights and accommodation.
- Some regional PATS have refused to allow carers to stay in Perth whilst a patient is admitted to hospital meaning that additional flights are required to bring the carer back to Perth to escort the patient home on discharge, this increases the overall cost of a patients PATS assistance, other PATS administrators refuse to assist/pay for the carer to fly home even though the patient will be hospitalised for longer than 2 weeks and the carer is required to work to support the family.
- Patients have been refused flights from some regions and made to take a bus journey of up to 16 hours. This is inappropriate for cancer patients and can mean patients are not fit enough to receive treatment on arrival and can impact on recovery post treatment.
- There is a 6 month limitation to PATS entitlement away from home, however some cancer treatments are routinely longer than 6 months and sometimes a patient can be required to stay in Perth for up to 12 months.

c) the administration process

- Patients from regional WA who have a confirmed cancer diagnosis but require pathological work up to establish evidence based treatment pathways are often refused access to PATS assistance. Patients are initially seen in Perth by a Multidisciplinary team of individuals who make evidence-based treatment decisions. Patients are then



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required to have appointments with up to 6 treating specialists, on this initial visit depending on the treatment decision (this cannot be predicted by the patients GP). This prevents the patient from multiple return trips, ensures patients have access to fully informed treatment decision making and allows timely planning of treatment delivery. Regional GP's do not have access to the names of the individual clinicians the patients will see when first diagnosed and therefore cannot provide this information on the initial PATS request. Patients have been refused flights and accommodation because they have not had this information supplied on the initial request form. This information is known by the Cancer Nurse Coordination service.

- Currently the Specialist is the only individual who can sign the PATS Specialist Certification Form and is required to identify future appointment dates. This creates significant issues for patients; new patients are seen by a multidisciplinary team of specialists who make decisions on the treatment plan and then the patient has appointments in up to 6 specialist areas; new patients are mostly seen by registrars not consultants and each individual specialist team does not know the appointment plan of the other treating areas. The Cancer Nurse Coordination Team do have access to this information. Inconsistency in assistance with booking accommodation; patients are advised, as per the PATS policy to book accommodation through the local PATS clerks but this is not consistent across the State and Great Southern and South West refuse to assist patients with this aspect.
- Long delays in reimbursing patients for personal costs, this is often up to 8 weeks. Most of these patients are on reduced income or health care cards.
- Inconsistency in provision of taxi vouchers and flights, some patients have had flights refused despite living over 350 kms from treating centres. This has delayed access to treatment and has the potential to impact on patient outcomes. There is inconsistency with the provision of taxi vouchers even for patients from the same regional area.
- Inconsistency in calculation of distances to treating centres (see above)
- Inconsistency in the length of time between appointments before a patient is required to pay for their own return flight. Some allow 7 days while others allow 10 days.

d) whether there is consideration of exceptional circumstances;

- The current administration of PATS varies considerably and therefore it is challenging to determine if exceptional circumstances are treated equitably; the evidence above would suggest that the disparities are wide spread and dependent on many variables.

2) any incidental matter

- Patients agreeing to use their private health care funds are penalised and do not have equitable access to PATS.
- For most oncology patients, payment of travel and accommodation expenses is an up-front cost. This can have significant impact on low income earners, singles,



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unemployed and those who have been forced to leave work to undergo treatment. There is no consideration for loss on income within the current PATS.

- In addition, a patient's escort may also be required to leave work on a temporary or permanent basis. As a result, a two income family may become a single-income or no income household.
- Patients required to remain in the metropolitan area for lengthy periods of treatment (i.e. Chemo/Radiation) often require support from an escort due to treatment related side effects. PATS administrators often refuse to support the escort and the patient becomes too unwell to complete treatment, and is either sent home (they will need to return for treatment when well enough) or admitted to hospital at additional expense to the Department of Health.
- Patients are not generally given a choice as to where they are referred and therefore are disadvantaged if referred to Fremantle as there is limited accommodation. This will be escalated once Fiona Stanley Hospital (FSH) opens as there is no accommodation provision on or near the site. The train line runs between the CBD and this will not help patients staying at Crawford or Milroy Lodge as they will still need to take a taxi to the train station.

The WACPCN acknowledge that the Standing Committee have not requested recommendations within this submission but request that the committee consider the following;

- Authorisation of PATS forms by other multidisciplinary team members such as the Rural/Metropolitan Cancer Nurse Coordinators who have expert knowledge across the continuum of treatment and care. This would ensure patients have access to the appropriate financial support relevant to the complexity of their treatment pathways. In addition the administrative burden will be eased on GP's and Specialists who are required to sign increasing numbers of PATS forms.
- All new and suspected cancer patients are provided with equitable access to flights/accommodation/taxi vouchers, relevant to their treatment plan and the treating centre that they are referred to.
- The Standing Committee is also asked to investigate the current level of funding and review the financial subsidy for accommodation costs in line with current and increasing prices.

References

1. Threlfall TJ, Thompson JR (2014). **Cancer incidence and mortality in Western Australia, 2012**. Department of Health, Western Australia, Perth. Statistical Series Number 99.
2. Australian Bureau of Statistics. **Western Australia at a glance 2010. Cat. no. 1306.5**
3. Australian Bureau of Statistics. **Tourist Accommodation, Small Area Data, Western Australia, Dec 2012**
4. WA Cancer & Palliative Care Network, Department of Health, Western Australia 2011. Department of Health, Western Australia.