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Mr Elton Humphrey
Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
CANBERRA ACT 2600

Please find attached a submission to the Committee in relation to its inquiry into patient assisted travel schemes in Australia.

As background, the Northern Territory Breast Cancer Voice Inc was established in 1998 to provide advocacy for women facing a breast cancer diagnosis and awareness of breast cancer services. Members have had breast cancer or in some instances are close to those who have. Women who are prominent in the organisation are also active on the national scene, including involvement with the Breast Cancer Network of Australia, the National Breast Cancer Foundation and Dragons Abreast Australia.

I would be happy to provide further information if this is required. My contact details are shown below.

Yours sincerely

Pat Hancock
Chair
NT Breast Cancer Voice

SUBMISSION TO THE INQUIRY INTO THE OPERATION AND EFFECTIVENESS OF PATIENT ASSISTED TRAVEL SCHEMES – NORTHERN TERRITORY BREAST CANCER VOICE (NTBCV)

The small population size and geographic remoteness of the Northern Territory makes it atypical to other states/territories with regard to the demand placed upon the NT's PATS. Difficulties with recruitment and retention of specialist staff to the Royal Darwin Hospital and Darwin Private Hospital means that PATS is required to be utilised for inter- as well as intrastate travel.

The three issues in relation to PATS which are of particular concern to NTBCV are:

1. equitable access to treatment services in the major centres for women in regional and remote areas, especially Indigenous women;
2. means of ensuring that women in regional and remote centres have access to preventative services, such as Breastscreen; and
3. quality of services and care provided to women required to travel interstate for radiation oncology.

The Northern Territory's PATS is, on the whole, well administered and fair. However problems do arise at times through miscommunication and a lack of understanding of administrative staff of the trauma that patients who already stressed from a life-threatening illness face through separation from family and home. This is especially so when it is for an extended period of treatment such as when needing to have radiotherapy. This could be overcome by staff being trained to realise that their major task is not to defend PATS from the possibly roting by clients but to ensure the best possible care and concern for people forced to travel interstate to access services residents of larger cities take for granted.

NTBCV would support the establishment of special guidelines for the administration of PATS which required training for staff and the process of interacting with clients, by requiring that this is undertaken in a supportive and empathetic environment and not an office environment. NTBCV considers that there is a role for not for profit organisations such as advocacy and assistance groups, especially consumer groups, who, having been through the system understand the issues and how clients feel, to take part. This is consistent with the protocols of other areas of medical research and treatment which require consumer input to processes and procedures.

It is considered that miscommunication between administrative staff and the specialists, administrative staff and clients/carers, NT and interstate hospitals, as well as interstate hospitals and clients/carers, would be greatly reduced if there was greater consistency between the PATS administered by each state/territory. It is the very differences which lead to confusion with regard to the criteria of the scheme governing an individual client's travel for treatment and consequent miscommunication between the various parties.

While acknowledging that including eligibility to travel for preventative treatment such as Breastscreen would place undue pressure on PATS for other services (hearing testing, etc. which also requires specialist equipment not available in all remote

health centres), it is considered that other means of ensuring access to preventative treatment could be explored.

One option would be to provide a biennial eligibility PATS to allow residents in remote localities to travel to their nearest relevant town or city for a range of preventative and treatment services. Another is to educate staff of health centres and the clients themselves to utilise opportunities when travelling to a major centre, either under PATS or not, to schedule these services for the same time. (While bookings for Breastscreen usually need to be scheduled some time in advance, appointments are made available for out of town women to access a mammogram at short notice.)