INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

Name: Name suppressed

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CANBERRA ACT 2600 AUSTRALIA

Re - Inquiry into health outcomes and access to health and hospital services in regional rural and remote New South Wales

Thank you for the opportunity to put forward a submission toward the inquiry into health outcomes in regional, remote, and rural New South Wales.

I write this submission to government as a community member and employee living and working in rural, regional, and remote communities in NSW. My role working in Western and the Far West of NSW has provided insight into the challenges people living in regional and rural communities face.

Firstly, I want to share a few lines of my own family's personal cancer experience. My 4-year-old son was diagnosed with Retinoblastoma in 2008. Before we knew it, we were off to Westmead Children's Hospital 2 weeks after his diagnosis to have his left eye removed. Living in regional NSW can certainly have its challenges with access to services and medical treatment, fortunately, for our family from Bathurst I had a grandmother who lived 15 minutes from Westmead Children's Hospital.

We were the lucky ones; we had a supportive homely environment, free accommodation, a short distance to travel each day and a familiar area to travel to. There was a fantastic multidisciplinary health care team based in the one health precinct. The multidisciplinary team consisted of:

- a paediatric oncologist
- a paediatric ophthalmologist
- an oculurist (eye maker)
- a genetics counsellor

My son is now 17 and driving! We certainly had a challenging time which is thankfully behind us now.

I would also like to share the cancer journey of Mr Terry Betts who has a lived cancer experience:

"My name is Terry Betts; I am a 65-year-old male living in Orange.

In 2006 I was diagnosed with a Squamous Cell Carcinoma (SCC) in the tongue and neck. I was sent to St Vincent's Hospital in Sydney for surgery twice, the difficulty and isolation of having to travel from regional NSW has both been a financial and emotional impact for my family and me. This impact on the individual and their family and/or carer is often not considered.

The second surgery came early after I began bleeding from the throat, I had to be flown to Sydney, again isolating me from my family and support network. Again, I had to travel to Sydney after a recuperation period when I required Radiation and Chemo therapies. I was required to stay in Sydney for approximately eight weeks. I was fortunate that at the time the Jean Colvin Hostel for Region Cancer patients was available at a subsidised rate. But this still necessitated me being removed from my family and friends for an extended period. This

is a significant emotional/psychological burden not just for a person undergoing this type of treatment but also for the family of the patient.

Another impact, largely forgotten is the ongoing issues associated with this type of treatment and cancer, Radiation therapy, though effective, damages many functions of the throat and mouth and continues for many years. Some time back, there was government support for sufferers of chronic illness. I am not sure what the current support is at this point in time. I still suffer from dental issues due to the damage to my salivary glands at the time of treatment requiring frequent trips to the dentist. These have eased and now require only three-monthly visits, though sometimes more often. Whilst the government support was available, via a referral from my GP, the financial burden from repeated and frequent dental visits was significant, the financial assistance was certainly a necessity for me.

There are many long-term effects of various treatments that adversely impact the health of survivors and therefore strain the finances of said survivor. Patients do not need the additional burden of always having to find out how to afford to continue treatment.

Any initiative that supports a patient staying at or near home, with their support network, will improve the efficacy of any treatment received. As would any initiative that is designed to assist the patient mitigate the ongoing and long-term effects of treatment. These initiatives could include but not be limited to things like; increased IPTAAS financial support, reintroduction of the chronic illness/disease support. If there is a means to support patients/survivors to continue to be effective, functioning members of our communities we should embrace it.

Currently I am a diagnosed Stage 4 Metastatic SCC patient and am undergoing regular scans and consults with my Oncologist, I am still a functioning member of my community and with appropriate support hope to continue to be so for some time."

Working and living in regional communities has provided insight into the health challenges people living in rural, regional, and remote NSW are experiencing. For cancer patients and their families and/or carers these challenges are around healthcare access, in particular to:

- Transport,
- Cost of treatment.
- Costs for accommodation; and
- Distances travelled to and from cancer treatment.

Sometimes Community Transport is an option for people. However, there are a number of barriers that cancer patients face including:

- It's often not an individualised service and
- Not flexible enough to meet the needs of patients on cancer treatment regimes.
- Often a patient needs to be eligible for a "My Aged Care" package or an NDIS package to access Community Transport services.

The Isolated Patient Travel Accommodation and Assistance Scheme (IPTAAS) is also available to community members. The problem being the amount of work involved to complete an application. For those who are not literate they face a huge barrier and dismiss the thought of even trying to get help to complete an application for assistance.

The concern here is health outcomes. These barriers and challenges are stopping our communities from accessing life saving cancer treatment. The more remotely people live the more likely they are to die from cancer. That is not good enough!

Here, I want to highlight the success of the Remote Video Assisted Chemotherapy service that commenced in October 2017 in Coonabarabran NSW.

Remote Video Assisted Chemotherapy is a supported chemotherapy outreach service between Alan Coates Cancer Treatment Centre in Dubbo and Coonabarabran Health Service.

Patients meet with their oncologist based in Dubbo via a video link before their treatment and then a trained chemotherapy nurse based in Coonabarabran oversees a local nurse to administer their treatment.

It's a great initiative to allow flexibility for some local people to receive cancer treatment closer to their family and community whilst preventing issues such as travel and accommodation costs.

Fortunately, we have people who make our health system work., They are dedicated and compassionate – working incredibly hard to meet rising demand for health services with the scarce resources they have.

How can we address this?

- Government needs to enable and support services like the Remote Video Assisted Chemotherapy Outreach Service to ensure the best health outcomes for people living in rural, regional, and remote NSW.
- 2. We need access to resources and services for our community members and health professionals that adequately match the current and future health needs of our communities.
- 3. There are gaps in allied health services that must be addressed before additional population places further strain on the health system.
- 4. Non-urgent transport, to access health services and treatment, needs to also be an integral part of our health system.

We are expected to see some significant population growth across NSW over the next few years. How can we expect our health services to cope with this growth when it is unable to support the people that are already here.

Unfortunately, it's not only the increasing population that will place a strain on health services. Census information and statistics from the Cancer Institute show rural, regional, and remote communities face additional social, economic and health challenges including, higher smoking rates, lower screening rates, higher obesity levels, and lower household incomes than the NSW average.

The provision of health services should not be a one-dimensional treatment of an isolated and specific disease – we need to take a more holistic and innovative approach to health and invest in the future health outcomes of our people.

Health funding is an investment. It's an investment because every dollar spent today means less cost in illness, and hospitalisations tomorrow.

Again, thank you for the opportunity to make this submission.