Addendum - Victorian Rare Cancer Trials Alliance - Australian Government Senate Inquiry Submission

Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer, by increasing participation in clinical trials.

Victorian Rare Cancer Trials Alliance

The Victorian Rare Cancer Trials Alliance (VRCTA) was formed in early 2023 to provide collaborative strategic direction and leadership to enhance access to and participation in clinical trials in Rare Cancers (RC) across Victoria, particularly for those living in regional, rural and remote areas. The VRCTA also provides an interface with Government to promote support of this initiative. Through its diverse stakeholder representation and expert knowledge, the VRCTA is uniquely positioned to identify and address barriers facing RC clinical trials, leveraging existing investment in Victoria to lead a national agenda for the RC population (refer to Appendix 1 for working group membership).

Addendum

Further to the TrialHub written submission to Senate Estimates dated 31st August 2023 and the follow up verbal presentation to the Community Affairs Reference committee on the 1st February 2024, TrialHub wishes to expand on the impact of our fellowship program in attracting and retaining a skilled clinical trial workforce to support the selection and conduct of clinical trials in regional Victoria.

In Australia, approximately seven million people (28% of the population) live in rural and remote areas, and health workforce shortages have been strongly attributed to unaddressed healthcare needs. In an attempt to address this inequity, the TrialHub program has invested in a fellowship program in which medical oncology and hematology trainees undertake additional placements in a regional health service to support clinical trial programs. The fellowship program offers mentoring and professional development opportunities to ensure there is ongoing training, education and support for these isolated roles. Whilst in its early stages, three early career researchers have extended their appointments in the regional health services in which they were placed, thereby offering long term opportunities to build and extend the clinical trial program within these regional and remote communities. These clinicians have obtained additional research and trials skills not available through routine existing medical oncology training which are becoming increasingly relevant for clinical practice in metropolitan and regional settings.

In addition, upskilling a workforce remaining in regional centres increases the capacity of sites available to conduct clinical trials across the state. This is relevant when considering a feasibility process employed by health services when evaluating whether to start-up a trial at their hospital, with many factors included and more trials than capacity meaning low recruiting trials (the majority of rare cancer trials) may be less competitive. More sites available with the skills and expertise to host trials, as well as an equitable process for start-up site selection, is a particular focus of the VRCTA.

The TrialHub fellowship program has already made a significant impact on increasing clinical trials uptake in general in regional and remote areas and making clinical trials more accessible for local patients, and we are committed to carry on this mission and focus on rare cancer trials by providing ongoing guidance and support to our partner regional health services through various TrialHub programs.

Signatories

Chloe Georgiou **Anne Woollett**

VRCTA Members

Christie Allen, Cancer Council Victoria; Malaka Ameratunga, Alfred Health; Jayesh Desai, Peter MacCallum Cancer Centre, VCCC; Hui Gan, Austin Health; Chloe Georgiou, Australian Rare Cancer Portal; Mahesh Iddawela, Gippsland Cancer Care; Lama Karroum, MPCCC; Damien Kee, Australian Rare Cancer Portal; Kurt Lackovic, Cancer Trials Australia; Belinda Lee, Northern Health; Donna Long, Regional Trials Network; Krishna Rachakonda, Mildura Health; Gary Richardson, Cabrini Health; Clare Scott, Australian Rare Cancer Portal, Walter and Eliza Hall Institute; Kylie Shackleton, TrialHub; Mark Shackleton, Alfred Health, MPCCC; Dayna Swiatek ex officio; Quan Tran, LaTrobe

Regional Health; Maureen Turner, BioGrid Australia; Craig Underhill, Border Medical Oncology, Regional Trials Network; Richard Vines, Rare Cancers Australia; Mark Voskoboynik, Alfred Health; Anne Woollett, TrialHub

Organisations

TrialHub, based at Alfred Health, has the remit to improve access and participation in clinical trials across geographical regions in Victoria so those with cancer and rare diseases have access to clinical trials no matter where they live. Partner sites have been established at six clinical sites across outer metro, regional and rural Victoria, as an important mechanism for building and sustaining clinical trial capacity in new and emerging clinical trial sites. This is particularly relevant in trials of rare diseases where potentially low recruitment numbers at any one site makes the conduct of these types of trials a real challenge financially. Through our program, and in consultation with other leading programs, the identification, selection and conduct of clinical trials for rare cancers, particularly for regional trial centres, has identified a significant challenge.

The Australian Rare Cancer (ARC) Portal, hosted by BioGrid Australia and funded by Omico, is an online referral service for clinicians to access a network of rare cancer expertise, guidelines and information about molecular testing and clinical trials, as well as access to research for their patients diagnosed with a rare cancer (RC). The ARC Portal as an additional source of support for cancer specialists who are caring for a RC patient, for whom they require additional specialist advice.

Cancer Trials Australia (CTA) supports more oncology clinical trials conducted in Australia than any other individual organisation. Established as a not-for-profit company in 2003, initially through a collaboration between multiple Melbourne based hospitals, CTA has grown to include 36 hospital and medical research institute Members across six Australian states and New Zealand. We have supported the administration of over 2,100 cancer clinical trials since 2003, which have recruited in excess of 13,000 Australian patients. In 2023 alone, we will administer over 230 clinical trials opening across the country, the vast majority of which are sponsored by international pharma and biotech, driving significant investment into Australia and bringing novel therapies to Australian patients sooner. CTA has a long history of advancing our national clinical trials sector. In 2006, CTA was instrumental in the development of the Clinical Trial Notification scheme, in partnership with the TGA. This scheme along with the R&D tax incentive, confer significant advantage to Australia in streamlining approval for novel therapies, and are key drivers of international biotech choosing to conduct their clinical activities in Australia. CTA was also heavily involved in the deployment of the Human Research Ethics Committee National Mutual Acceptance scheme across our members, and development of the Medicines Australia Clinical Trial Research Agreement templates.

The Regional Trial Network Victoria (RTN-Vic) was created to improve access and recruitment to high quality cancer clinical trials for rural and regional areas of Victoria. RTN-Vic developed a partnership with six clinical trial sites in regional Victoria and Cancer Trials Australia. It was originally funded by the Cancer Council Victoria and the Victorian Cancer Agency (VCA). The RTN-Vic has these regional sites; Barwon Health, Bendigo Health, Border Medical Oncology Research Unit, Goulburn Valley Health, Grampians Health, South West Healthcare, Mildura Base Public Hospital, and Latrobe Regional Hospital.

Rare Cancers Australia Ltd (RCA) is a charity whose purpose is to improve the lives and health outcomes of Australians living with rare and less common cancers. Key focus areas include creating a patient community, advocacy, patient support programs, fundraising, treatment & research, along with early diagnosis. They are particularly knowledgeable in how to support individual patient fund-raising for high-cost cancer therapies.

The Victorian Comprehensive Cancer Centre (VCCC) includes the Early Drug Development team at Peter MacCallum Cancer Centre (PMCC), comprising a large number of clinical trials which are relevant for RC patients, including those with defined molecular aberrations, as well as those without, for example those seeing combination immunotherapy trials; as well as Clinical Trials Australia (CTA) which has the potential to provide streamlined information for those seeking information about clinical trials which are relevant for RC patients, both with and without defined molecular aberrations.

Monash Partners Comprehensive Cancer Consortium (MPCCC) Precision Oncology Program brings together expert cancer researchers and clinicians from across partner organisations to enable comprehensive genomic profiling to tailor specialised treatment and management plans for individual patients, which include RC clinical trials.