



Queensland Clinical Networks

Queensland Cancer Clinical Network

File No.

## Senate Standing Community Affairs References Committee Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

### Background

The Australian Senate referred the 'Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer' to the Senate Community Affairs References Committee for inquiry and report by the first sitting Thursday in March 2024.

The Community Affairs References Committee Secretary corresponded with Mr Shaun Drummond, previous Director-General, Queensland Health on 28 June 2023 advising of the Inquiry and inviting Queensland Health to make a submission addressing some or all of the Inquiry's Terms of Reference. The Committee is also interested in receiving information about the Queensland Patient Travel Subsidy Scheme.

The Queensland Cancer Clinical Network (QCaCN) has been invited to provide a submission to this Inquiry.

### Consultation

The Queensland Cancer Clinical Network (QCaCN) within the Healthcare Improvement Unit, Clinical Excellence Queensland, has reviewed the Inquiry's Terms of Reference and provides feedback via this submission. To ensure a holistic review of this topic, the QCaCN consulted with the following groups of clinicians and incorporated feedback accordingly.

- Queensland Aboriginal and Torres Strait Islander Clinical Network
- Queensland Cancer Clinical Network Steering Committee
- Queensland Child and Youth Clinical Network
- Queensland Dementia Ageing and Frailty Clinical Network
- Queensland Gastroenterology Clinical Network
- Queensland Maternity and Neonatal Clinical Network
- Queensland Paediatric Palliative Care, Haematology and Oncology Network
- Queensland Palliative Care Clinical Network
- Queensland Renal Clinical Network
- Queensland Respiratory and Sleep Clinical Network
- Queensland Rural and Remote Clinical Network
- Queensland Sexual Health Clinical Network
- Queensland Surgical Advisory Committee
- Queensland Health Patient Travel Subsidy Scheme, Corporate Services Division

In addition, the Queensland Cancer Clinical Network Co-Chairs have cleared the submission for approval.

**Queensland  
Government**

## Terms of Reference

Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer with particular reference to:

- a) barriers to screening and diagnosis, including the impact of factors such as:
  - i. geographic location,
  - ii. cost,
  - iii. cultural and language barriers,
  - iv. type of cancer, and
  - v. availability of treating practitioners;
- b) barriers to accessing appropriate treatment;
- c) the adequacy of support services after diagnosis;
- d) the adequacy of Commonwealth funding for research into rare, less common and neuroendocrine cancer; and
- e) any other related matters.

## Rare and less common cancers

Cancer is a major cause of illness in Australia and has a substantial social and economic impact on individuals, families, and the community. Rare cancers remain largely unknown and understudied. This submission identifies some of the reasons why this is the case, in the context of the Inquiry's Terms of Reference.

Cancer Australia describes that a rare cancer is a term that encompasses both rare and less common cancers. *A rare cancer is defined as a type of cancer that has less than six incidences per year per 100,000 population. A less common cancer is defined as one that has between six and 12 incidences per year per 100,000 population*<sup>1</sup>. For the purposes of this submission where the term 'rare cancer' is used, it includes less-common cancers.

Every year, it is estimated that 42,000 people are diagnosed with a form of rare or less common cancer in Australia<sup>2</sup>. Rare cancer symptoms can be problematic to identify and are more likely to be diagnosed at a later stage making them often difficult to treat. Approximately 130,000 Australians will be diagnosed with cancer this year<sup>3</sup> with rare cancers contributing to one-third of the cases, however they account for half of all cancer deaths in Australia<sup>4</sup>.

The Rare Cancers Australia<sup>5</sup> website displays over 200 different types of rare or less common cancers which are many and varied from haematological cancers, sarcomas, gastrointestinal and reproductive organ cancers, brain tumours, nervous system tumours, germ cell tumours, pancreatic cancer, head and neck cancers and neuroendocrine tumours.

Rare cancers:

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<sup>1</sup><https://www.canceraustralia.gov.au/about-us/news/rare-and-less-common-cancers>

<sup>2</sup><https://www.canceraustralia.gov.au/about-us/news/rare-and-less-common-cancers>

<sup>3</sup><https://www.canceraustralia.gov.au/awareness>

<sup>4</sup><https://www.cancervic.org.au/cancer-information/rare-and-less-common-cancers/overview.html>

<sup>5</sup><https://knowledge.rarecancers.org.au/knowledgebase/cancer-types>

- do not have screening programs to detect cancer early and are complicated by a late diagnosis making the cancer more complex to treat<sup>6</sup>.
- are found in people much younger or older than those who are typically diagnosed with it, this includes children<sup>7</sup>.
- can be a common cancer found in an unexpected location e.g., a melanoma that started in the eye<sup>8</sup>.
- can often go undiagnosed as the symptoms may present like a common condition or common cancer which doctors may investigate first, leading to a diagnosis delay.
- have limited information and data for patients and clinicians which adds to the complexity of symptoms going unnoticed<sup>9</sup>.
- may have specific but very rarely seen changes (e.g., under the microscope) and additional expertise may be required to reach the correct diagnosis<sup>10</sup>.
- treatments have not advanced at the same pace as treatments for more common cancers such as breast cancer<sup>11</sup>.
- patients do not have the same level of support, treatment options and resources available that is specific to their rare cancer compared with more common cancers.
- there are very few experts who specialise in rare cancers.
- patients have fewer opportunities to participate in clinical trials due to the small numbers which in turn disadvantages these groups of patients and heavily affects regional, rural, and remote patients' access to these trials.

Any cancer found in children is, by population, rare. Cancers in children are very different to those occurring in adults, are not detected by screening and involve a large multidisciplinary team for optimising treatment outcomes. Outcomes have improved over time because of the focus upon skilled multidisciplinary care, management on collaborative clinical trials (non-pharmaceutical) and directed / led from a specialist paediatric cancer centre. Optimising care closer to home is one of the remits of the Queensland Health's Queensland Paediatric Palliative Care, Haematology and Oncology Network (QPPHON), as well as advocacy for skilled workforce especially allied health and nursing which is crucial to enable follow up of patients and after cancer treatment care.

Rare cancers are more difficult to treat<sup>12</sup>:

- Due to lower incidence rates, less funding is available to research rare cancers compared to more common cancers.
- There are limited clinical tissue samples of rare cancers which restricts the scientists' abilities to discover how these cancers respond to existing or new treatment.
- There are fewer patients with the same type of cancer which makes it difficult to have new therapies and treatments designed, approved, and tested.

The number of patients diagnosed with rare cancers are much lower in numbers compared with more common cancers. As a result, the broad geographical span of healthcare services across Queensland means that some smaller hospitals may occasionally see a patient with rare cancer compared with the larger metropolitan hospitals. Treatment for rare cancers is often complex and requires expensive specialised equipment, which is available only in the

<sup>6</sup> <https://www.rarecancers.org.au/page/158/why-rare-cancer-patients-need-our-support>

<sup>7</sup> <https://www.rarecancers.org.au/page/159/what-is-a-rare-cancer>

<sup>8</sup> <https://www.rarecancers.org.au/page/159/what-is-a-rare-cancer>

<sup>9</sup> <https://www.cancervic.org.au/cancer-information/rare-and-less-common-cancers/overview.html>

<sup>10</sup> <https://www.wehi.edu.au/research/diseases/rare-cancers/>

<sup>11</sup> <https://www.wehi.edu.au/research/diseases/rare-cancers/>

<sup>12</sup> <https://www.wehi.edu.au/research/diseases/rare-cancers/>

larger metropolitan hospitals. From a patient safety and fiscal perspective training, maintenance and cost of the equipment can only be justified at the larger centres.

Overall Australians living in rural and remote areas have shorter lives, higher levels of disease and poorer access to health services, compared with people living in metropolitan areas. Health inequalities in rural and remote areas may be due to factors including<sup>13</sup>:

- Challenges in accessing healthcare or specialists.
- Social determinants of health such as education and employment opportunities.
- Higher rates of risky behaviours such as smoking, obesity, and alcohol use.
- Higher rates of occupational risk such as from farming or mining work related accidents.

To achieve equity in health outcomes for all Queenslanders, health and wellbeing must be viewed through the social determinants of health lens as per the World Health Organisation<sup>14</sup> which includes socio-economic position, education, employment and job security, food security, housing, basic amenities and the environment, access to affordable health service of decent quality. Being able to address these social determinants of health is fundamental for improving health and reducing inequities in health especially for regional, rural and remote populations.

## Screening

Cancer screening is an intervention that can diagnose a cancer early and for which early intervention will change the outcome of that cancer. As such it is limited to cancers with a longer natural history and usually has a surgical intervention.

Screening is one of the most effective ways to detect early signs of cancer and at an early stage when treatment is likely to be more effective<sup>15</sup>. Tests have been developed that can detect these cancers well before any symptoms are present. Screening is different to diagnostic testing which is used to confirm cancer when a person already has symptoms<sup>16</sup>.

Currently no screening programs exist in Australia to detect rare cancers early. Australia has only three National Screening Programs for cervical cancer, bowel cancer and breast cancer with all offered free of charge to the public.

Rare cancers can be slow growing however they can also be explosive in growth, which is difficult to fit into a screening model. The distribution of location and behaviours of rare cancers means that no current single test could be undertaken. The frequency of these cancers, by definition, means that the screening test which is usually radiologic is then applied to a population. Far greater population numbers are then exposed to the risk (physically and cost) of the screening versus benefit it can provide. More research is needed to identify and/or develop better screening tools.

## Treatment Options

Cancer treatment is dependent upon the type of cancer, what will give the patient the best outcome, where the cancer is located (solid tumour or blood cancer), whether the cancer has spread, the patient's health and their preferences.

Typically, there are three main treatment options for cancer diagnoses with curative intent – surgery, radiation therapy and chemotherapy. There are also other drug therapies available including targeted therapy, hormone therapy and immunotherapy.

<sup>13</sup> <https://www.pancare.org.au/cancer-outcomes-in-regional-australia/>

<sup>14</sup> [https://www.who.int/health-topics/social-determinants-of-health#tab=tab\\_1](https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1)

<sup>15</sup> <https://www.cancer.org.au/cancer-information/causes-and-prevention/early-detection-and-screening>

<sup>16</sup> <https://www.health.gov.au/topics/cancer/screening-for-cancer>

Surgery is a procedure to remove a tumour (cancer) from the body or repair part of the body that has been affected by cancer. For many patients' surgery may be the only treatment needed if the cancer is found early enough. Surgery may be part of a treatment plan in combination with other treatment options.

Radiation therapy, or radiotherapy, uses a controlled dose of radiation to kill cancer cells or damage them so they cannot grow, multiply or spread. The radiation is usually in the form of focused high energy x-ray beams. Radiation therapy is a localised treatment, meaning that it should only affect the area being targeted. Treatment is carefully planned to do as little harm as possible to the normal body tissue near the cancer<sup>17</sup>. Radiation therapy may be given in conjunction with other treatment options.

Chemotherapy uses cytotoxic drugs to kill or slow the growth of the cancer. It damages cells that are dividing rapidly. Chemotherapy drugs enter the bloodstream and travel through the body to target rapidly dividing cancer cells in the organs and tissues, which is known as systemic treatment. As chemotherapy damages cells that divide rapidly, serious side effects can arise as a result of impact upon non-cancer cells. Chemotherapy can be given in conjunction with (before and/or after) other treatment options and requires trained clinical staff to provide safe delivery and monitoring.

Targeted therapy is a drug treatment that targets specific features of cancer cells to stop the cancer growing and spreading. The drugs circulate through the body but work in a more focused way than chemotherapy and can often have fewer/different side effects<sup>18</sup>. Targeted therapy may not work for everyone who has been diagnosed with cancer. However, targeted future therapies for rare cancers are being developed. Research into genome sequencing and genetic testing offer a chance of earlier intervention, and individualised therapies hold the potential to improve the quality of life for people with rare cancer.

Treatment for rare cancer types requires specialist care found in metropolitan tertiary/quaternary hospitals which leaves logistical challenges for more effective diagnosis and treatment for people living in rural and disadvantaged areas<sup>19</sup>.

Cancer clinical trials investigate the safety and efficacy of new cancer treatments and new drug combinations. They aim to identify if new treatment options are viable and efficacious to replace or complement existing treatments. Queensland is the program lead and a collaborator in the Australian Teletrial Program<sup>20</sup> (ATP) along with Victoria, Tasmania, South Australia, Northern Territory and Western Australia. The Australian Teletrial Program is funded by the Medical Research Future Fund Regional Rural and Remote Clinical Trials Enabling Infrastructure fund and was established in 2019. The program has a vision of creating a network of clinical trials in Australia that enables the geographically dispersed regional, rural, and remote, and Aboriginal and Torres Strait Islander communities to access clinical trials as close to home as possible. The Australian Teletrial Program is not limited to cancer clinical trials, however within Queensland, cancer clinical trials are more common than non-cancer trials. Teletrials is a model that uses telehealth to connect regional and rural clinical trial site clusters<sup>21</sup> for some cancers.

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<sup>17</sup> <https://cancerqld.org.au/cancer-information/cancer-treatments/treatment-choices/radiation-therapy/>

<sup>18</sup> <https://cancerqld.org.au/content/resources/library/Understanding%20Targeted%20therapy.pdf>

<sup>19</sup> <https://cancerqld.org.au/research-snapshot-spatial-patterns-in-rare-cancer-types-dasgupta-2022/>

<sup>20</sup> <https://australianteletrialprogram.com.au/>

<sup>21</sup> <https://australianteletrialprogram.com.au/about/>

## Neuroendocrine Tumours (NETs)

Neuroendocrine tumours (NETs) are cancers found in the pancreas, lungs, abdomen, reproductive organs, and bowel. They are less common and complicated because they can disguise themselves behind common symptoms such as inflammatory bowel syndrome (IBS), asthma, and anxiety<sup>22</sup>. The gastrointestinal tract accounts for 54.1% of Neuroendocrine Tumours<sup>23</sup>.

The Neuroendocrine Tumour Optimal Care Pathway (OCP)<sup>24</sup> allows patients to receive the right care, at the right time, in the right place. The Optimal Care Pathway is a framework for the delivery of consistent, safe, high-quality, and evidence-based care for people with Neuroendocrine Tumour cancer. Optimal Care Pathways cover care from prevention, early detection through to recovery, living with a chronic disease or end of life care. It aims to improve patient outcomes through promoting quality cancer care and ensuring that all people diagnosed with a Neuroendocrine Tumour cancer receive the best care, irrespective of where they live or whether they receive cancer treatment<sup>25</sup>.

## Terms of Reference Feedback

a) Barriers to screening and diagnosis, including the impact of factors such as:

**i. geographic location**

- One of the main barriers for cancer screening and diagnosis is the geographical size of Queensland and distances travelled from regional or remote areas to metropolitan hospitals for specialist treatment for rare cancers.
- Approximately 38% of Queenslanders live in regional and remote parts of the state<sup>26</sup>.
- People living in rural and remote areas face barriers to accessing health care due to challenges of geographic spread as mentioned, lower population numbers, limited health infrastructure, and the higher costs of delivering rural and remote health care<sup>27</sup>.
- Patients in rural and remote communities may not have consistent access to a General Practitioner (GP) or primary healthcare provider. Specialist services are even more limited. This can be:
  - due to workforce shortages (attraction / retention of medical staff in rural and remote areas).
  - funding through the lack of bulk billing options where General Practitioners do not or are unable to bulk bill consultations.
  - due to distance from the patient's property to the primary healthcare provider.
- Attending appointments in more regional areas takes the person away from the land / farm which affects their livelihood and could exacerbate a delayed or late cancer diagnosis.
- Patients who are unable to access timely consultations with a General Practitioner risk a delayed rare cancer diagnosis as symptoms may be ignored making treatment more complex, if treatable at all.

<sup>22</sup> <https://neuroendocrine.org.au/about-us/>

<sup>23</sup> <https://neuroendocrine.org.au/what-are-nets/>

<sup>24</sup> <https://www.cancer.org.au/assets/pdf/neuroendocrine-tumours-1st-edition>

<sup>25</sup> <https://neuroendocrine.org.au/optimal-care-pathway/>

<sup>26</sup> [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0019/1011286/cho-report-2020-full.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0019/1011286/cho-report-2020-full.pdf), page 3

<sup>27</sup> <https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health>

- Despite healthcare being more accessible by using technology (such as telehealth), those that live rurally or remotely may not have easy access to a computer or the skills to use one, along with the challenges of speed, cost, and access to reliable internet as well as the availability of reliable infrastructure at the health facility.
- When patients do not have easy access to online information, media or unable to navigate the complex health system due to living in more rural and remote areas, it can contribute to lower levels of health awareness
- Low health literacy may be associated with some of the social determinants of health including lower socioeconomic status, older age, lower levels of education and being from a culturally and linguistically diverse background. Patients with low health literacy are more likely to have worse health outcomes overall due to<sup>28</sup>:
  - a lower engagement with health services and preventative services such as cancer screening.
  - higher hospital readmission rates.
  - poorer understanding of medication instructions.
  - lower ability to recognise potential cancer symptoms and/or self-manage their care.

Subsequently the geographical location may lead to a delayed or later rare cancer diagnosis.

- Whilst most Aboriginal and Torres Strait Islander peoples live in non-remote areas (79% in 2011), the proportion of Aboriginal and Torres Strait Islander peoples living in remote areas is higher (21%) compared to the non-Indigenous population (2%).<sup>29</sup>
- **Queensland Health activities to reduce geographic location barriers**
  - Education at the primary healthcare and regional, rural, and remote hospital level on the low incidence cancer and the requirement to escalate care to the more experienced cancer hospitals or facilities.
  - Options to reduce the impact on the patient are explored by the Multidisciplinary Team and where possible specialist guidance for local care closer to the patient's home is provided.
  - Ongoing roll-out of updated and accessible technology between metropolitan hospitals and regional, rural, and remote health facilities using telehealth involving videoconferencing and phone calls for patient consultations, referrals, prescriptions, and test results.
  - Program lead and partner in the Australian Teletrial Program (ATP) which aims to reduce the barriers in Queensland by:
    - Closing the gap in health outcomes for all Queenslanders.
    - Expanding the reach of clinical trials.
    - Setting up streamlined regulatory processes that are responsive to the needs of Queensland communities.
    - Developing the clinical trials workforce capacity and capability.
    - Building an interconnected clinical trials system.
  - In response to the Australian Teletrial Program, the Queensland Regional Clinical Trial Coordinating Centre was established and brings specialised healthcare to patients in remote and rural areas using

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<sup>28</sup> <https://www.aihw.gov.au/reports/aus/234/determinants-of-health/health-literacy>

<sup>29</sup> <https://www.acn.edu.au/wp-content/uploads/position-statement-discussion-paper-improving-health-outcomes-rural-remote-australia.pdf>

communication technologies such as videoconferencing. The centre has a vision of creating a network of clinical trials in Queensland that enables the geographically dispersed regional, remote, and rural communities to access clinical trials as close to home as possible.

## ii. cost

- Barriers related to cancer diagnosis and costs:
  - When a patient attends a public hospital facility for a diagnosis, there is no cost to attend the appointment, however there may be indirect costs such as transport / parking costs and time required to attend the appointment (no work, no pay).
  - Costs to the patient, healthcare provider and community depends upon the type of rare cancer, the diagnostic tools and equipment required, along with the cost of evidence-based treatments.
- **Queensland Health activities to reduce barriers related to costs**
  - Implementation of the *Cancer Screening Strategic Framework 2019 to 2026*<sup>30</sup>.
    - Population based cancer screening programs (such as BreastScreen) help protect the health of Queenslanders through prevention and early detection.
    - The Framework provides a prevention and early detection pathway for improved cancer outcomes for Queenslanders.
    - The Framework focuses on increasing participation in the National Cancer Screening Programs (bowel and cervical cancer screening) and ensuring timely, safe, and high-quality health service provision across the entire participant screening pathway.
    - Highlights the commitment to using cancer screening to reduce overall health system costs.
  - Costs are minimised by experienced clinicians using evidence-based care and streamlining the diagnostic and treatment pathway.
- The Senate's Standing Committee of Community Affairs is interested in receiving information about the Queensland Patient Travel Subsidy Scheme.
  - The Patient Travel Subsidy Scheme (PTSS) provides financial assistance to eligible patients who are required to travel for specialist health services not available locally (within 50 kilometres of the patient's closest public hospital or public health facility).
  - The PTSS assists with travel and accommodation costs only. It is not intended to cover all costs associated with accessing specialist health services. The cost of meals, parking, telephone calls and transfers e.g. taxis and airport transfers are not covered.
  - Patients must meet the following criteria:
    - eligible for Medicare
    - permanent Queensland resident or person of no fixed address
    - referred to travel more than 50km one way, from the public hospital or public health facility closest to their permanent address to attend the nearest eligible specialist health service
    - have an eligible referral for an approved speciality.

<sup>30</sup> [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0033/944718/cancerscreening-2019-26.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0033/944718/cancerscreening-2019-26.pdf)



- There are no limits to PTSS subsidy payments. Eligible patients will receive PTSS subsidies as per PTSS policy for as long as medically needed.
- Eligible patients may qualify for financial assistance for an escort to travel with them. An escort is defined as a person who accompanies a patient when they travel to access a specialist health service.
- Patients are not eligible for PTSS if they are taking part in clinical trials and experimental procedures. Clinical trials are defined in the PTSS Guideline as research investigations in which people volunteer to test new treatments, interventions or tests that have not been proven. Eligibility for PTSS is for recognised specialist medical treatment.
- Commencing in 2023-24, accommodation rates for eligible PTSS patients increased from \$60 per person, per night to \$70 per person, per night and mileage concession rates increased from 30 cents to 34 cents per kilometre. Also commencing from 2023-24 is funding to support full cost of repatriation of deceased patients under the PTSS scheme to their Queensland place of residence, Queensland traditional homeland, or Queensland First Nations County.
- The patient's local Hospital and Health Service are able to manage the approval, booking and payment processes.

### iii. cultural and language barriers

- Cancer is the leading cause of death for Aboriginal and Torres Strait Islander Queenslanders. To achieve health equity for Aboriginal and Torres Strait Islander people, the social determinants of health must be addressed. These determinants include structural racism and discrimination, intergenerational trauma stemming from the effects of colonisation, and socioeconomic inequalities<sup>31</sup>.
- In Queensland, 79% of the Aboriginal and Torres Strait Islander population live in remote areas<sup>32</sup> and they have poorer access to health services than non-Aboriginal and Torres Strait Islander Australians due to barriers such as availability of healthcare, cost, and a lack of culturally appropriate health services.
- Limited availability of Aboriginal and Torres Strait Islander Health Workers in rural and remote locations can adversely affect Aboriginal and Torres Strait Islander populations in seeking healthcare, including cancer screening and diagnosis. Aboriginal and Torres Strait Islander Health Workers have been recognised as contributing to improving outcomes and facilitating access to the health system for Aboriginal and Torres Strait Islander people<sup>33</sup>.
- Aboriginal and Torres Strait Islander people have lower participation rates in cancer screening programs than non-Aboriginal and Torres Strait Islander Australians. An example of this is the National Bowel Cancer Screening Program where in 2018-19, 27% of Aboriginal and Torres Strait Islander Australians participated compared with 43% of non-Aboriginal and Torres

<sup>31</sup> Queensland Cancer Strategy for Aboriginal and Torres Strait Islander Peoples Implementation Plan 2023-2028, page 5

<sup>32</sup> <https://www.acn.edu.au/wp-content/uploads/position-statement-discussion-paper-improving-health-outcomes-rural-remote-australia.pdf>

<sup>33</sup> <https://www.rrh.org.au/journal/article/2897>

Strait Islander Australians<sup>34</sup>. This shows that our Aboriginal and Torres Strait Islander populations are more at risk of having later stage cancer by the time they are diagnosed, which makes it more difficult to successfully treat.

- Other cultural and language barriers:
  - People from culturally and linguistically diverse (CALD) backgrounds have poorer cancer outcomes and lower screening rates due to insufficient knowledge, perceptions that screening tests are unpleasant, language and literacy barriers, fatalistic cancer views and spiritual beliefs<sup>35</sup>.
  - For older people, cognitive impairment, frailty and multimorbidity are more prevalent than in younger people. Cognitive impairment is considered a barrier for all older people with cancer however it is more significant for older people from culturally and linguistically diverse backgrounds. Cognitive impairment affects a person's symptom recognition and reporting, taking actions in seeking diagnosis and ability to understand and consent to, and tolerate treatment. This is magnified when a patient has challenges with written and spoken English.
  - Patients with language barriers may be less aware of the availability of healthcare and cancer screening programs, lack the ability to navigate the complex health system, lack the confidence to seek the required information in their language, which in turn could lead to a delayed cancer diagnosis.
  - Cultural barriers include embarrassment about the procedure and barriers related to the patient's circumstances, beliefs, background and inequities in society, or the belief that cancer equals death.<sup>36</sup>
  - Language barriers can lead to a lack of knowledge about the purpose of screening tests, the role of screening in prevention and early detection and the risks of the cancer the test is screening for.
- **Queensland Health is reducing cultural and language barriers by:**
  - Employing senior nurses who are highly experienced and have an in-depth understanding of the health system. Nurse Navigators<sup>37</sup>:
    - Use a multidisciplinary approach to monitor high needs patients, identify actions required to manage their health care and direct patients to the right service at the right time and in the right place.
    - Provide a central point of communication and engagement to ensure optimal care and coordination of services along a patient's entire health care journey.
    - Educate and help patients to better understand their health conditions and enable them to self-manage, participate in decisions about their health care and improve their own health outcomes.
    - There are 400 Nurse Navigators across Queensland covering every Hospital and Health Service.
  - Queensland Health has translated information available on its website<sup>38</sup> and includes fact sheets covering topics such as seeing a doctor,

<sup>34</sup> <https://www.health.gov.au/our-work/national-bowel-cancer-screening-program/indigenous/alternative-access>

<sup>35</sup> Phillipson L, Pitts L, Hall J, Tubaro T. Factors contributing to low readiness and capacity of culturally diverse participants to use the Australian national bowel screening kit. Public Health Res Pract. 2018;29(1):e28231810. First published: 30 August 2018.

<sup>36</sup> <https://www.health.gov.au/our-work/ncsp-healthcare-provider-toolkit/barriers-to-screening/patient-related-barriers>

<sup>37</sup> <https://www.health.qld.gov.au/ocnmo/nursing/nurse-navigators>

<sup>38</sup> <https://www.health.qld.gov.au/multicultural>

medicines, allied health, and support services in many different languages.

- Every Hospital and Health Service across Queensland offers interpreter services 24 hours a day, at no charge to the patient. Interpreters help by relaying spoken information between the patient and the medical practitioner either physically present on site, through videoconference or over the phone.
- Queensland has identified key priorities to address social determinants of health for Aboriginal and Torres Strait Islander peoples:
  - Priority 2: Prevention and early detection
    - Conduct a cancer screening gap analysis for Aboriginal and Torres Strait Islander communities in Queensland and work with Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ATSI CCHOs) to codesign a strategy to increase access to screening for those communities currently underserved.
  - Priority 3: Cancer awareness and understanding
    - Conduct a systematic review of existing cancer education resources and services for Aboriginal and Torres Strait Islander peoples to identify gaps.
    - Partner with community-controlled organisations to codesign localised approaches to increasing awareness of cancer risk and protective factors, promote screening and early diagnosis, dispel myths, and reduce fear and stigma around cancer.
    - Partner with Institute for Urban Indigenous Health (IUIH) and Education Queensland to introduce cancer education and health promotion into public schools from Prep to Year 12 – prioritising schools with a high proportion of Aboriginal and Torres Strait Islander students.
  - Priority 4: Optimal cancer care
    - Embed a statewide Aboriginal and Torres Strait Islander cancer coordination/ wraparound care model into the new Queensland Cancer Centre, ensuring that it has outreach into both urban and regional areas.
    - Enable dying on Country with support from community health services and social wellbeing teams.
    - Partner with community-controlled organisations to promote and embed the Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer across all health care services.
    - Establish a statewide consumer advocacy group.

#### iv. type of cancer

- Currently, there are three population-based cancer screening programs offered in Australia for bowel, breast, and cervical cancers. The Australian Government will be implementing a Lung Cancer Screening Program by mid-2025.
- Haematological cancers are usually harder to treat even in some metropolitan centres due to the lack of specialists. This includes paediatric haematological

malignancies and non-malignant conditions which require haematopoietic stem cell transplantation.

- Rare cancers often require more specialised treatment, medicines, and equipment. This includes paediatric cancers where specialist paediatric clinicians are required from medical, nursing, and allied health professions.
- National<sup>39</sup> and international literature has highlighted that the presenting age of the patient, in concert with more vague symptoms, has led to diagnostic delay, particularly for children, adolescents and young adults who face additional barriers to accessing healthcare including:
  - A lack of age-specific healthcare that meets a young person's needs
  - Confidentiality concerns
  - Proactive engagement with health professionals
  - Cost and transport
  - Ability to access healthcare outside of vocation and employment commitments
- Breast cancer related to pregnancy is relatively rare however it poses significant challenges due to the physiological changes and hormone fluctuations that occur during pregnancy and breastfeeding. These changes may lead to delays in the diagnosis and treatment of breast cancer. Treatment decisions need to balance the potential risks to the mother and baby while aiming to provide effective cancer care.
- Human papillomavirus (HPV) related Anal Cancer in People Living with human immunodeficiency virus (HIV), with highest impact on men who have sex with men, age, women living with HIV.
- **Queensland Health is reducing barriers to screening and diagnosis including the impact of factors such as the type of cancer by:**
  - Screening in patients with anal cancer to look for precursor interepithelial neoplasia changes which is similar to Cervical Screening, but more technical and less developed although from a recent Anchor study<sup>40</sup>, now evidence in treatment of Anal intraepithelial neoplasia (AIN), awaiting Australian Guidelines.
  - Implementation of the Optimal Care Pathway for Adolescents and Young Adults with Cancer<sup>41</sup>.
  - Undertaking a full medical history and physical examination at the first pregnancy antenatal appointment. The initial physical examination includes a breast examination and discussion on normal breast changes. If anytime during the pregnancy or post-partum a woman raises a breast concern, persistent lump, or persistent pain a breast examination would be conducted and where required, referred for further investigation.

#### v. availability of treating practitioners

- There is a small and finite number of practitioners skilled in the high resolution anoscopy for direct visualisation (similar concept as colposcopy) in Queensland and Australia.

<sup>39</sup> <https://www.bmj.com/content/347/bmj.f6493.full>

<sup>40</sup> [Treatment of Anal High-Grade Squamous Intraepithelial Lesions to Prevent Anal Cancer | NEJM](https://www.bmj.com/content/347/bmj.f6493.full)

<sup>41</sup> <https://www.cancer.org.au/assets/pdf/optimal-care-pathway-for-adolescents-and-young-adults-with-cancer>

- **Queensland Health is reducing barriers to screening and diagnosis including the impact of factors such as the availability of treating practitioners by:**
  - Most Sexual Health clinicians in Queensland, including primary care can test for anal cancer screening and routine digital anal/rectal examination, which can also be a self-examination.

**b) barriers to accessing appropriate treatment**

- Distance and greater travel time would be two of the barriers for over one-third of Queenslanders who live in regional, rural, and remote locations. These patients must travel further for appropriate care and in the case of rare cancers, this is usually to a larger metropolitan hospital.
- A study<sup>42</sup> undertaken in the USA examined the relationship between distance to facilities and treatment, and it found that living further from radiation treatment facilities decreased the likelihood of receiving the therapy. Greater distance may alter treatment choice and as a result have a negative effect on outcomes. Patients living in rural areas may see fewer specialists and more generalists. The study found that cancer patients from non-metropolitan areas have substantially longer travel times which may contribute to the reduced access to cancer treatment and poorer outcomes. They found patients with rarer cancers had longer travel times due to the fewer available care providers.
- If a patient becomes unwell during their active treatment and must travel long distances to see a specialist or facility, they may be more likely to cancel the appointment or delay their treatment which adds to the complexity of their rare cancer treatment.
- Treatment planning for rare cancer is very difficult. Compared with more common cancers, there are fewer clinical trials and limited information and data to support new medications leading to fewer proven treatment options and fewer subsidised medicines<sup>43</sup>. It can take at least a year for a new drug to be approved and subsidised and for patients with advanced disease due to a delayed diagnosis, this is concerning as they may only have a short time to live.
- Multimorbidity and frailty may impact a person's ability to undertake treatment. Patients with cognitive impairment (more prevalent in older people) may have a reduced ability to understand and consent to and tolerate treatment.
- Lack of clinician education for rare cancers and identifying when and what treatment is required. Inappropriately treated rare cancers increases the costs and adverse outcomes for the patient and the health system.
- The lack of local specialist services across public and private jurisdictions does not provide for a cohesive wide approach for enhanced access and support.
- **Queensland Health is reducing barriers to accessing appropriate treatment by:**
  - Implementing the Optimal Care Pathways (OCPs) which are an integrated model of care and provides a national standard for the high-quality cancer care that patients should expect.

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<sup>42</sup> Segel JE, Lengerich EJ. Rural-urban differences in the association between individual, facility, and clinical characteristics and travel time for cancer treatment. *BMC Public Health*. 2020 Feb 6;20(1):196. doi: 10.1186/s12889-020-8282-z. PMID: 32028942; PMCID: PMC7006189.

<sup>43</sup> <https://www.rarecancers.org.au/page/158/why-rare-cancer-patients-need-our-support>

- OCPs set out key principles for optimal cancer care at each step of the patient journey from prevention through to survivorship and end of life care, and optimal timeframes for tests or procedures<sup>44</sup>.
- There are OCPs for 26 cancers, with many being considered rare cancers (e.g., Pancreatic, Neuroendocrine Tumours, Sarcoma, Acute Leukaemia in children, Adolescents and Young Adults).
- An OCP is also available for Aboriginal and Torres Strait Islander People with Cancer<sup>45</sup>.
- OCPs are endorsed by Cancer Australia, all states and territories and Cancer Council Australia.
- A recent Queensland Government announcement of increased travel subsidy to boost the PTSS, to ensure oncology patients travelling to access appropriate treatment are financially supported. In the 2023–24 State Budget, the Queensland Government has invested \$70.3 million over four years towards the PTSS, which is the first increase in many years.
- Providing health access and health literacy to all including:
  - Aboriginal and Torres Strait Islander People
  - Correctional Services
  - Women’s Services
  - Lesbian, gay, bisexual, transgender (and gender diverse), intersex, queer/questioning and asexual (LGBTIQA+) communities
  - People Living with Human Immunodeficiency Virus (PLHIV)
  - Men who have sex with men
  - Youth, Drug and Alcohol communities
  - Culturally and Linguistically Diverse communities

**c) the adequacy of support services after diagnosis**

- For all cancers access to support such as mental health, rehabilitation, and residential care can be difficult across Queensland regardless of whether metropolitan, regional, rural, or remote locations due to workforce shortages and attraction / retention of staff.
- For regional, rural, and remote areas, there may be additional infrastructure, funding, and equipment issues.
- Patients can access Non-Government Organisations (NGO) and charity organisations which can provide much-needed support such as counselling, practical support, emotional support, referrals to schemes or programs to continue living independently etc. However, the lack of funding to these organisations hinders the ability to provide this fundamental community and patient service.
- Often patients do not know that these organisations exist and part of the treatment pathway and information for the patient should be raising awareness on how to access additional support.
- There is a lack of specialist allied health support in many locations outside of metropolitan areas for patients with rare cancers, specifically those occurring in paediatric and adolescent populations. Services are required to ensure optimal cancer treatment, anticipation, and management of potential side effects of

<sup>44</sup> <https://www.canceraustralia.gov.au/optimal-cancer-care-pathways>

<sup>45</sup> <https://www.canceraustralia.gov.au/about-us/news/optimal-cancer-care-aboriginal-and-torres-strait-islander-people>

treatment including psychosocial impacts and longer-term care of the patient and family in community.

- Lack of availability of support services after cancer treatment in a regional, rural, or remote location can be problematic.
- There is a need for longer term support and follow up of patients after cancer treatment to identify treatable recurrent disease early, monitor and manage side effects of treatment and enable optimisation of quality of life for the person.
- Psychosocial support, rehabilitation services and mental health services are required, and support for reintegration into the workforce/education and aged care as appropriate.
- While cancer remains one of the leading causes of death across all ages, availability, timely and equitable access to palliative care is essential.
- Patients who are older and frail, and patients with cognitive impairment may not have access to adequate support services after diagnosis especially if the person has not been able to undertake or complete treatment because of their multimorbidity's.
- Access to Palliative Care services should ideally occur at the time of cancer diagnosis and/or treatment planning. Palliative care is 'person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life'<sup>46</sup>. Palliative care treats physical, emotional, spiritual, or social symptoms because of a condition or disease.
- There are many reasons why palliative care clinicians may not be a part of the conversation at diagnosis. These could include - clinicians and patients being unaware that palliative care is more than just making a patient comfortable at end-of-life; lack of knowledge of palliative care supports and services; lack of recognition or knowledge of what palliative care can offer; lack of regional, rural, and remote palliative care services.
- Palliative care clinicians help patients with managing their symptoms and improve quality of life. Patients may enter and exit palliative care throughout their cancer journey particularly if their prognosis is potentially years from diagnosis.
- **Queensland Health is reducing barriers to accessing support services after diagnosis by:**
  - Maintaining a comprehensive list of and links to Cancer Support Organisations on the Queensland Government website<sup>47</sup> including Cancer Council Australia; Cancer Council Queensland; Cancer Australia; CanTeen; Leukaemia Foundation Queensland; Ovarian Cancer Australia; Lung Foundation Australia; and Pseudomyxoma Survivor (appendix and rare peritoneal malignancies).
  - Maintaining information and links on the Queensland Government website for Community and Home Care Services allowing consumers and patients to tap into programs and schemes to regain their independence or continue living safely in their homes and actively participate in their communities after cancer diagnosis and treatment (not limited to only cancer patients)<sup>48</sup>.

<sup>46</sup> <https://palliativecare.org.au/resource/what-is-palliative-care/>

<sup>47</sup> <https://www.qld.gov.au/health/support/cancer/support-groups>

<sup>48</sup> <https://www.qld.gov.au/community/getting-support-health-social-issue/community-home-care-services>

- Information on the Queensland Government website for care and support including care at end of life<sup>49</sup> and palliative care via the Centre for Palliative Care Research and Education (CPCRE)<sup>50</sup>.
- The establishment of ARCHWAYS (**AfteR Cancer Health and Wellness Adolescent and Young adult Service**) which is a small virtual statewide service hosted within the Gold Coast Hospital and Health Service for young people diagnosed with cancer between 15-25 years of age. It is Australia's only dedicated statewide Adolescent and Young Adult (AYA) survivorship service supporting young people after cancer treatment, empowering young people to manage their ongoing health and wellness, and connecting with primary and community supports.
- The Queensland Youth Cancer Service (QYCS) is a joint Commonwealth and State funded initiative. Their achievements include:
  - Connecting >80% of Adolescent and Young Adults (AYAs) diagnosed with cancer in Queensland hospitals with AYA specific supports including psychosocial care, vocational/ education support and OncoFertility pathways specific to the needs of AYAs.
  - Establishing a statewide AYA OncoFertility pathway, allowing all young people regardless of treatment location, to access world-class fertility consultations +/- preservation at minimal-to-no out of pocket expense for five years.
  - Building clinician AYA cancer capability and capacity throughout cancer centres in Queensland Hospitals, including metropolitan, regional, and rural locations, through Statewide Virtual Grand Rounds and Annual Workshops.
- The The Sony Foundation Australia's 'You Can Centre' located at the Royal Brisbane and Women's Hospital<sup>51</sup>:
  - Purposefully designed to support Adolescent and Young Adults (AYAs) from across Queensland aged 15 to 25 years undergoing cancer treatment.
  - A social haven away from hospital wards, the centre provides a contemporary space for young people to be together and provide peer support.
  - The Centre hosts many programs and workshops on art, music, and beauty to support post-cancer wellness or during treatment wellness for young people.
- Access to Specialist and Generalist Palliative care varies across Queensland, however the Palliative Care reform roll out of funding for expansion of specialist and generalist palliative care local services from 2023 to 2026 will improve access for assessments and supports for patients across Queensland. Models of care will still vary due to different staffing and environments (e.g., distance). Early referrals for assessments are encouraged.
- Focusing on inclusion of Aboriginal and Torres Strait Islander Health Workers into palliative care services across Queensland.
- Queensland Paediatric Palliative Care, Haematology and Oncology Network (QPPHON) supported paediatric regional outreach clinics to

<sup>49</sup> <https://www.qld.gov.au/health/support/end-of-life>

<sup>50</sup> <https://www.health.qld.gov.au/cpcre>

<sup>51</sup> <https://metronorth.health.qld.gov.au/rbwh/healthcare-services/you-can-centre>



provide clinical follow up to patients as close to home as possible where applicable.

- The Specialist Palliative Care in Aged Care (SPACE) Project aims to enhance equitable access to specialist palliative care for older Queenslanders living in residential aged care facilities. This is particularly relevant for patients at end of life with complex needs and care because of a rare cancer. It increases opportunities for people to die in their place of choice, supported by improved capacity in aged care, care coordination and clinical governance.
- The Specialist Palliative Rural Telehealth service (SPaRTa) focuses on palliative care patients and their local health care providers in rural and remote regions of Queensland where tertiary level specialist palliative care services are not readily accessible due to local workforce availability and/or geographical isolation<sup>52</sup>. SPaRTa uses Multi-Purpose Health Service or General Practitioner (GP) videoconferencing equipment in areas where there are infrastructure issues or where patients do not have access to video-enabled communication devices. SPaRTa helps reduce hospital admissions; improves access to specialist palliative care services in rural and remote Queensland; end of life care is achieved in the patient's chosen location (and improves quality of life by reducing travel away from home and country).

**d) the adequacy of Commonwealth funding for research into rare, less common and neuroendocrine cancer**

- The Queensland Clinical Networks are unable to comment on Commonwealth funding.

**e) any other related matters**

- Strategies in improving rare cancer care in the older population should consider partnering with geriatricians for cognitive diagnosis and optimisation of geriatric syndromes, which may impact on cancer treatment, as well as ensuring the persons have adequate support practically and in communication and decision making during the diagnosis and treatment processes.
- People Living with Human Immunodeficiency Virus (PLHIV) and Human Papillomavirus (HPV) related cancer screening programs are needed in Sexual Health Clinics, Public Health, High Caseload General Practitioners, Non-Government Organisations.
- Statewide education and coordination of care as per Queensland Paediatric Palliative Care, Haematology and Oncology Network with the identification of regional centre nursing and medical champions.

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<sup>52</sup> <https://clinicalexcellence.qld.gov.au/improvement-exchange/specialist-palliative-care-rural-telehealth>