

**COMMUNITY AFFAIRS REFERENCES COMMITTEE: *Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer***

**Contact:**

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**RESPONSES TO QUESTIONS TAKEN ON NOTICE**

**1. Why do you think My health record is important, but is currently not being used enough and so not reaching its potential?**

MyHealth Record (MyHR) has the potential to improve the care of people with rare and less common cancers. This system can provide access to information that can make healthcare management easier, safer, and more effective, ultimately improving the accuracy and efficiency of diagnosis, treatment delivery and care. It could also help address the fragmentation of care delivery, particularly when people move between public and private settings, across primary and tertiary care and jurisdictional borders, which is often the case with rare and less common cancers. Although 99% of GPs and pharmacies are connected and regularly input MBS and PBS data, only 48% of specialists are registered and only 26% have used the system.<sup>1</sup> Until greater levels of participation are reached across the whole healthcare system and all patient-level healthcare data input, MyHR will not reach its full potential.

Cancer Council Australia (CCA) has long advocated for a national, de-identified linked health dataset that brings together all cancer datasets and links to datasets, including data from electronic medical records. The ability to link this data will provide a complete picture of the factors that influence cancer care and outcomes. CCA has published a discussion paper on this vision,<sup>2</sup> and under the Australian Cancer Plan we have partnered with Cancer Australia and the Australian Institute of Health and Welfare to develop a National Cancer Data Framework, due for completion in the middle of this year.

MyHR has the potential to be a valuable source of population, individual, and service and system-level information about healthcare utilisation and outcomes in Australia. This could provide access to population-wide cancer data which could be used by researchers and service providers to identify where improvements to care and service provision can be made and enable greater insights into the factors that contribute to the development of cancer. This could lead to improved use of health data informing the delivery of programs and services to reduce the impact of cancer in Australia and deliver more equitable cancer outcomes.

1. Australian Digital Health Agency. MyHealth Record Statistics. December 2023. Available at: <https://www.digitalhealth.gov.au/sites/default/files/documents/my-health-record-statistics-december-2023.pdf>.
2. Cancer Council Australia. National Data Strategy for Cancer. Available at: <https://www.cancer.org.au/assets/pdf/developing-national-data-strategy-for-cancer>.

## 2. Cancer Council's summary of State and Territory Patient Travel and Accommodation programs

What is not covered by the scheme?	Patient contribution	Private vehicle	Public transport	Air travel	Taxi travel	Accommodation
<b>New South Wales</b> Scheme last updated August 2022 <b>Eligibility:</b> NSW or Lord Howe residents enrolled with Medicare not receiving, or eligible for financial assistance for travel and accommodation from third-party insurance or other Australian government services. They must be referred for treatment at the nearest health service, receive treatment at an approved health service, and need to travel ≥ 100km one way, or at ≥ 200km per week by making multiple trips to and from treatment. Includes participation in non-commercial clinical trials						
<ul style="list-style-type: none"> <li>Commercial clinical trials</li> <li>Health screening programs</li> <li>General dentistry</li> </ul>	N/A	40 cents per km, no restrictions on km travelled or maximum claim. Includes EVs. No ability to claim tolls or parking.	Full economy-class fare (including booking fees) reimbursement less the GST.	Prior approval by referring doctor or treating practitioner to get an air approval code by contacting the local IPTAAS office and providing the medical reason for not being able to travel by other modes. If there is no air approval code, IPTAAS will either reimburse at the same rate as private car travel (distance between home and treatment address) or the cost of the flight (excluding GST), whichever is the lesser amount.	1-day appointment: \$20 max. 2-7 day appointment: \$40 max. 8-14 day appointment: \$80 max. 15+ days appointment: \$160 max.	<u>Not-for-profit or Commercial</u> \$75 per night first 7 nights, \$120 per night from day 8. NFP accommodation is provided by organisations that are registered as a charity or government entity in the Australian Business Register, which can be searched using either the accommodation provider's name or ABN. <u>Private</u> \$40 Per night, includes Airbnb bookings and staying with family/friends
<b>Queensland</b> Scheme last updated July 2023 <b>Eligibility:</b> Qld resident, or person of no fixed address or a study living at a Qld boarding school or university campus eligible for Medicare that is required due to clinical/medical reasons** to travel ≥ 50km to attend the nearest eligible specialist health service. Patients also need to have an eligible referral for an approved specialty, and are unable to use Telehealth. Full cost of the repatriation of a deceased patient to their place of residence is included in the Scheme.						
<ul style="list-style-type: none"> <li>People travelling on holidays or business and live in another state, including fly-in fly-out (FIFO) or temporary workers who are not permanent Queensland residents.</li> </ul>	Patients who do not have a recognised concession card must pay for the first four nights of accommodation each financial year. A recognised concession card holder includes Pensioner Concession Card, Centrelink Healthcare Card, Commonwealth Seniors	34 cents per km, from the street address of the patient's closest public hospital or public health facility (not from home address) to the closest public treating facility. No restrictions on km	Full reimbursement at economy/government rate, including GST. If the approved mode of transport is more expensive than the economy/ government rate, the patient is responsible for the additional costs.	Full reimbursement at economy/government rate. If the approved mode of transport is more expensive than the economy/government rate, the patient is responsible for the additional costs.	Potentially, limited circumstance	<u>Commercial</u> \$70 per night each for commercial accommodation for patient and approved escort (≥ 18 years). For example, hotel, motel, caravan park, apartment, bed and breakfast, rental arrangement, Airbnb or similar, flat or accommodation facility

<ul style="list-style-type: none"> <li>• People eligible to claim assistance from a third party.</li> <li>• People transported, using urgent or non-urgent transport, arranged by Qld Health.</li> <li>• People seeking a second opinion without a medical referral to an eligible specialist service.</li> <li>• Allied health services</li> <li>• Clinical trials</li> <li>• General dentistry</li> <li>• General practitioner</li> </ul>	Health Card, or Department of Veteran Affairs Health Card. These are government issued.	travelled or maximum claim. Only one mileage subsidy is paid per private motor vehicle per return trip. No ability to claim tolls or parking.				<p>associated with non-government organisations.</p> <p><u>Private</u></p> <p>\$10 per night each</p> <p>For example, staying with friends or relatives.</p> <p>Accommodation will only be subsidised for the period the patient is clinically required to be away from home for medical reasons, or where a return journey cannot reasonably be completed in one day.</p>
<p><b>Victoria</b></p> <p>Scheme last updated October 2020</p> <p><b>Eligibility:</b> Vic resident receiving medical treatment under designated Medicare codes. Need to travel ≥ 100km one way, or ≥ 500km per week for a minimum of 5 consecutive weeks.</p>						
<ul style="list-style-type: none"> <li>• People living in states and/or territories other than Victoria.</li> <li>• People away from their permanent place of residence when the treatment episode begins.</li> <li>• People undertaking a journey to or from outside Australia for medical treatment.</li> <li>• Services such as: <ul style="list-style-type: none"> <li>• Allied health services</li> <li>• Clinical trials</li> <li>• General practitioner</li> </ul> </li> </ul>	\$100 every 12 months, excludes Pensioners and Health Care Card Holders.	21 cents per km, irrespective of engine capacity or the number of people in the vehicle. No restrictions on km travelled or maximum claim. Community transport services*** are reimbursed at the rate charged or 20 cents per km, whichever is the lesser amount. No ability to claim tolls or parking.	Full economy-class, or relevant concession fare reimbursement. If you choose to travel first class, the equivalent economy class fare will be reimbursed.	≥ 350km one-way, economy fare, commercial flight only to the most appropriate approved medical specialist.	To nearest public transport when there are no other transport options available to travel from permanent place of residence to the nearest public transport, or from the public transport to the nearest most appropriate approved medical specialist.	<p><u>Commercial</u></p> <p>\$45 per night (ex GST) each for commercial accommodation for patient and approved escort (≥ 18 years). Authorised officer**** must state on the VPTAS claim form that it is necessary for you and your escort(s) to be accommodation close to or at the location where you are receiving approved medical specialist services.</p> <p>For example, hotels, motels, caravan parks, apartments, flats and accommodation facilities associated with a health service.</p> <p><u>Private</u></p> <p>No subsidy</p>

## Western Australia

Scheme last updated June 2023

**Eligibility:** Permanent resident of WA Country Health Service region who needs to travel  $\geq 100\text{km}$  one way to nearest eligible medical specialist service, including Telehealth. People who need to travel between 70 – 100km for cancer or dialysis treatment are eligible for \$20 subsidy.

<ul style="list-style-type: none"> <li>People travelling to the treatment centre for another reason, such as for a holiday or to visit friends, and then need specialist treatment.</li> <li>People who are FIFO worker.</li> <li>People on a bridging visa.</li> <li>People who are students at boarding for school or university and need medical treatment while living in the treatment centre, such as Perth. However, a parent may be eligible for escort assistance to visit their child in the treatment centre.</li> <li>People eligible for alternate forms of assistance, such as through the Department of Veterans Affairs, workers compensation or other insurance such as travel insurance.</li> <li>Extraction of third molars</li> <li>Orthodontic treatment</li> </ul>	None.	<p>16 cents per km. No restrictions on km travelled or maximum claim.</p> <p>25 cents per km when travelling in a minibus or similar group transport vehicle owned by a community or organisation (payment to relevant organisation).</p> <p>No ability to claim tolls or parking.</p> <p>\$20 per return trip for surface travel including private vehicle, train or bus for renal and cancer treatment where the patient is required to travel between 70-100km one way</p>	Full economy-class or discounted fare reimbursement (coach or rail).	<p>People living in Pilbara, Kimberley and some remote areas if travel to nearest specialist involves travel by road or <math>\geq 16</math> hours one way, or subject to excessive connection delays and prolonged stops.</p> <p>Patients who are travelling for cancer treatment and must travel by road <math>\geq 350\text{km}</math> from place of residence or hometown to treatment centre.</p> <p>Subsidised at economy fare rate.</p>	Limited and exceptional circumstances. Considered on a case-by-case basis	<p>Patient are eligible if they live <math>\geq 100\text{km}</math> from the treatment centre, and:</p> <ul style="list-style-type: none"> <li>the medical specialist certifies that you need to stay overnight for follow-up; and</li> <li>the forward and return journeys cannot reasonably be completed in one day because of factors, such as time required travelling, type of travel, transport schedules and availability, or medical condition.</li> </ul> <p><u>Commercial</u> \$106.10 per night for patient. \$121.10 per night for patient and approved escort (<math>\geq 18</math> years).</p> <p><u>Private</u> \$20 per night for patient. \$40 per night for patient and approved escort (<math>\geq 18</math> years).</p>
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<ul style="list-style-type: none"> <li>• Non-surgical temporo-mandibular joint treatment</li> <li>• Implant surgery or crown and bridge treatment</li> <li>• Endodontics</li> <li>• Periodontal surgery or treatment</li> <li>• MBS items in the Allied Health and Dental Services book</li> <li>• Cosmetic surgery</li> <li>• Complementary health treatments</li> <li>• Physiotherapy, speech therapy, podiatry, occupational therapy and other allied health treatments</li> </ul>						
<p><b>South Australia</b>  Scheme last updated Jan 2023  <b>Eligibility:</b> SA residents who need to travel ≥ 100km one way from the nearest treating specialist for Medicare claimable treatment on doctor's referral.  PATS claims will be accepted from patients who have claimed benefits from their private health fund towards travel and/or accommodation costs provided the:</p> <ul style="list-style-type: none"> <li>• Benefit paid by the fund is less than the applicable PATS rate. In such instances patients will be paid the difference between the benefit paid and the PATS rates, or</li> <li>• Patient has already claimed the maximum benefit available from fund.</li> </ul> <p>Those with a life limiting illness (12 month or less) will be supported to see a specialist of their choice, and will not be required to attend the nearest specialist.</p>						
<ul style="list-style-type: none"> <li>• South Australian resident is on holidays or visiting families or friends both intra and interstate.</li> <li>• Resident of another state or territory is on holidays or visiting family or friends in SA.</li> <li>• Undertaking a journey to or from outside Australia.</li> </ul>	Non-concession card holders are required to pay for their first night of accommodation.	32 cents per km. No restrictions on km travelled or maximum claim. Multiple patients traveling in one vehicle, only one application for travel reimbursement is eligible for subsidy. The cost of a rental car is not eligible for a PATS subsidy. Normal vehicle	Essential by medical specialist or authorised officer.	Full economy-class fare reimbursement if: <ul style="list-style-type: none"> <li>• Medical specialist or authorised officer confirms that the patient is unable to travel by surface modes of travel for medical reasons;</li> <li>• When the combined costs of surface travel subsidy and two nights of accommodation subsidy is more than return air travel, air travel may be chosen as</li> </ul>	No	<u>Commercial</u> \$44 per night per person for patient and approved escort (≥ 18 years). For example, commercial accommodation may be a hotel, motel, caravan park, apartment, flat or an accommodation associated with health organisations. Accommodation booked through third parties such as Airbnb will be subsidised as long as a tax invoice is provided alongside the claim

<ul style="list-style-type: none"> <li>• Those eligible to apply for assistance under another State, Territory or Commonwealth Scheme, personal or other insurance scheme, or a registered benefits organisation, including DVA.</li> <li>• For injuries which occurred at work and are covered by WorkCover.</li> <li>• Injuries due to a motor vehicle accident and covered by the Motor Accident Commission of SA.</li> <li>• Injuries are eligible for compensation, damages or other payment in respect to the illness or injury being treated or when you are able to claim through your employer.</li> <li>• A person chooses to bypass their nearest medical specialist service.</li> <li>• Family member or carer of the client who travels separately to the client is not eligible for a travel subsidy.</li> <li>• Clinical trials or experimental treatments, excluding phase IV trials</li> </ul>		<p>subsidy will be paid for fuel costs.</p> <p>No ability to claim tolls or parking.</p>		<p>the most economical form of travel.</p> <ul style="list-style-type: none"> <li>• Air travel may be authorised when the most economical public transport option does not provide an appropriate travel option to the nearest specialist. This authorisation must be provided by a regional LHN local authorising clinician. If the cost of flights is more, a subsidy calculated as above will be paid in lieu</li> <li>• Clients who are medically required to travel by air to their treatment location and who reside more than 100km from their nearest airport are entitled to claim an additional fuel subsidy for return travel to that airport.</li> </ul>		<p>Facilities providing rehabilitation (e.g. slow-stream rehabilitation involving physiotherapy or other therapies), primary care services (e.g. step-down units) and supported residential facilities are not considered commercial accommodation.</p>
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<ul style="list-style-type: none"> <li>Allied health services</li> <li>GP services</li> <li>Appointments with a medical specialist for a second opinion</li> <li>General dental</li> <li>Monitoring programs</li> <li>Surgery provided for cosmetic reasons</li> </ul>						
<b>Australian Capital Territory</b> Scheme last updated July 2023 <b>Eligibility:</b> ACT and Jervis Bay residents referred interstate for 'nearest treating specialist' for treatment not available in the ACT.						
<ul style="list-style-type: none"> <li>General practitioners</li> <li>General dentistry</li> <li>Appointments with a medical specialist for a second opinion</li> <li>Specialist medical and/or oral health surgical treatment for injury or illness incurred during business or recreational travel</li> <li>Allied health services</li> <li>Prosthetic or orthotic services</li> <li>Repatriation of a deceased person will not be subsidised.</li> </ul>	None.	Private Fuel Vehicle Sydney: up to \$165 per trip Melbourne: up to \$330 per trip Adelaide: up to \$660 per trip Brisbane: up to \$660 per trip Private Electric Vehicle Sydney: up to \$40 per trip Melbourne: up to \$60 per trip If no accommodation is claimed up to \$25 per day can be claimed for parking.	Full economy-class fare reimbursement up to the following maximums: Coach Sydney: \$130 Melbourne: \$160 Adelaide: \$290 Brisbane: \$390 Rail Sydney: \$125 Melbourne: \$230 Adelaide: \$260 Brisbane: \$260	Full economy-class fare Prior approval required on certification by referring medical practitioner or treating specialist that the patient has a specific medical condition that requires them to travel by air. Approval must be obtained from the ACT IPTAS Office.	No	Not for Profit Accommodation \$50 per night for patient and one approved escort each If patient is a child, \$50 will also be paid for the second escort for a total subsidy of \$150. Commercial Accommodation \$70 per night for patient and one approved escort each If patient is a child, \$70 will also be paid for the second escort for a total subsidy of \$210. Commercial accommodation includes: <ul style="list-style-type: none"> <li>Hotels and motels</li> <li>Hostels</li> <li>BnBs</li> <li>AirBnBs</li> </ul>
<b>Northern Territory</b> Scheme last updated June 2017 <b>Eligibility:</b> Australian citizen or permanent resident living in NT live ≥ 200km away from nearest approved specialist or need to travel ≥ 400km in one week for renal or oncology treatment.						
<ul style="list-style-type: none"> <li>People who are on a holiday or on business and live in another jurisdiction.</li> </ul>	None.	20 cents per km. No restrictions on km travelled or maximum claim.	Full reimbursement of lowest available fare. \$50 reimbursement for ground travel at	Full reimbursement of lowest available fare (and escort if approved).	\$50 reimbursement for ground travel at destination. Escorts are not eligible.	Accommodation assistance is provided in the following circumstances: <ul style="list-style-type: none"> <li>The forward and return journeys cannot</li> </ul>

<ul style="list-style-type: none"> <li>People undertaking a journey to or from Australia.</li> <li>People who are FIFO contractor whose permanent residence is not in the NT.</li> <li>People who have an accepted claim from a third party. For example, workers compensation, travel insurance or the Territory Insurance Office.</li> <li>People who have coverage from a third party. For example, Commonwealth Department of Veterans Affairs or NT Department of Corrections.</li> <li>People who are a medical reciprocal rights card holders.</li> <li>Clinical trials</li> </ul>		<p>≥3 patients travelling together, 60 cents per km (20cents per patient). No ability to claim tolls or parking.</p>	destination. Approved escorts are not eligible.			<p>reasonably be completed in one day;</p> <ul style="list-style-type: none"> <li>The specialist certifies that the patient needs to stay for pre- or post-treatment; or</li> <li>Transport schedules are limited and the patient needs to stay overnight</li> </ul> <p><u>Commercial</u> \$60 per night per person. Private eg; friends or family \$20 per night per person.</p>
<p><b>Tasmania</b> Scheme last updated Jan 2023</p> <p><b>Eligibility:</b> Tasmanian resident who needs to travel ≥50km one way to the nearest oncology or dialysis treatment centre, and ≥75 km one way to the nearest appropriate specialist medical service or to access lymphoedema treatment. Participation in a clinical trial subject to approval on a clinical basis.</p>						
	<p>Non-concession cardholders contribute \$82.50 to each return journey. Maximum contribution for the financial year is \$330.</p>	<p>24 cents per km, no restrictions on km travelled or maximum claim. No ability to claim tolls or parking.</p>	<p>Full coach economy-class fare reimbursement. King and Furneaux Island residents can claim most economical, appropriate transport from airport to and from medical facility.</p>	<p>King and Furneaux Island residents can claim return economy airfare (Island Resident rates), plus most economical, appropriate transport from airport to and from medical facility.</p>	<p>King and Furneaux Island residents can claim most economical, appropriate transport from airport to and from medical facility.</p>	<p><u>Commercial</u> \$76 per night for patient and approved escort (≥ 18 years) staying in Tasmania. \$98 per night for patient and approved escort (≥ 18 years) travelling interstate. Private accommodation not eligible for the subsidy. Non-cardholders and escorts must pay first 2</p>



						nights accommodation for each stay.
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