National Rural Health Alliance

National Pancreatic Cancer Roadmap Consultation Submission

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… healthy and sustainable rural, regional and remote communities

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Introduction

The National Rural Health Alliance (the Alliance) welcomes the opportunity to provide a perspective on the impact and experience of pancreatic cancer in rural, regional and remote (hereafter rural) Australia to inform the development of the National Pancreatic Cancer Roadmap. The Alliance comprises 44 national member organisations and is focused on improving the health and wellbeing of the 7 million people residing outside our major cities. Our members include health consumers, health care professionals, service providers, health educators, students, and the Indigenous health sector. Well-rounded representation of the rural health sector enables us to work toward our vision of 'healthy and sustainable rural, regional and remote communities'.

We acknowledge the challenges of providing best-practice pancreatic cancer care. Timeframes from presentation to investigation, diagnosis, referral and treatment are tight, and care needs are high – with a focus on multidisciplinary, coordinated care and palliative care for many patients.[1] This submission will highlight differences in epidemiology and outcomes of pancreatic cancer in people living in rural Australia, compared with major cities. It will also emphasise the inequities experienced by Aboriginal and Torres Strait Islander peoples, who make up a larger proportion of the population with increasing remoteness.[2] We will discuss the reasons for these disparities, with a focus on access to services and health workforce issues. Other issues faced by pancreatic cancer patients who are unable to access services close to their home will also be explored. We conclude with recommendations to improve the experience of pancreatic cancer patients and their families in the future.

Differences in epidemiology and outcomes by remoteness and Indigenous status

While the incidence of and mortality due to pancreatic cancer is similar across geographical regions (if slightly lower in very remote areas)[3], the five-year observed survival reduces with remoteness – from 9.4 per cent in major cities, to 7.3 per cent in inner regional areas, and 6.8 per cent in outer regional areas.[4] Data for remote and very remote areas is not published due to concerns about low numbers, confidentiality or quality.

The incidence of pancreatic cancer as an age-standardised rate per 100,000 population is, however, higher in Indigenous people (17.1 compared with 10.8 in non-Indigenous people).[5] Mortality due to pancreatic cancer is also higher in Indigenous people (12.3 per cent compared with 9.6 per cent in non-Indigenous people).[6] Though poor data quality precludes reporting of pancreatic cancer survival in Aboriginal and Torres Strait Islander peoples, five-year observed survival for all cancers combined is 44.9 per cent in Indigenous people, compared with 58.2 per cent in non-Indigenous people.[7]

People living outside major cities in Australia carry a higher burden due to pancreatic cancer, and the higher incidence and poorer outcomes in Indigenous people contribute significantly to this. This disparity in outcomes has not been narrowing over time.[8]

Why are outcomes worse in rural Australia?

A number of factors are proposed as driving the difference in pancreatic cancer outcomes in rural Australia, including:

- the higher proportion of Aboriginal and Torres Strait Islander peoples
- higher levels of socioeconomic disadvantage[9]

- higher prevalence of risk factors – particularly smoking, overweight and obesity, type 2 diabetes and chronic alcohol consumption
- delays in diagnosis[10] or treatment[8]
- treatment disparities.

Smoking is recognised as the most established risk factor for pancreatic cancer[1]; it occurs at elevated rates outside major cities – 12.8 per cent of people were daily smokers in 2017–18 in major cities, compared with 16.5 per cent in inner regional areas and 19.5 per cent in outer regional or remote areas[11] – and at a higher level in the Indigenous population.[12] Overweight and obesity and type 2 diabetes are also recognised risk factors for pancreatic cancer[13], along with chronic alcohol consumption.[1] Overweight and obesity is more prevalent outside major cities[14]; type 2 diabetes is more prevalent in outer regional and remote areas[15]; and a higher proportion of people exceed lifetime risk guidelines for alcohol consumption with increasing remoteness.[16]

Delays in diagnosis or treatment can have dire consequences in pancreatic cancer due to the tight timeframes required to enable successful treatment. Alteration to diagnostic and treatment pathways is, at least in part, related to timely and affordable access to services. Treatment disparities include lower rates of chemotherapy administration[17], lower likelihood of having surgical treatment at a high-volume specialist centre[18] (which has been shown to improve outcomes in pancreatic cancer)[19] and reduced access to clinical trials.([19])

Service access

Mapping of rural oncology services performed in 2006 provides evidence of a reduction in cancer services with increasing remoteness.[18] This survey of regional hospitals administering chemotherapy (RHAC) highlighted reduced access to specialist oncology services – both medical and surgical – in rural areas, resulting in an increased load on general physicians, general practitioners, other doctors and non-chemotherapy trained nurses. Although allied health care was available in many locations, accessibility was compromised by long wait times, high cost and restrictions to service eligibility. Psychosocial support services were lacking, as was access to multidisciplinary clinics.

While we acknowledge investment in the infrastructure of regional cancer centres (RCCs) as a significant initiative to improve access to cancer care in rural Australia, it is important to note that 52 per cent of these centres are located in inner regional areas[19] and at a significant distance from many patients living rurally. A report from the Clinical Oncological Society of Australia in 2012 suggested that, despite the roll out of RCCs, limited access to diagnostic imaging – particularly MRI – and radiotherapy outside inner regional areas persisted.[19] Another cross-sectional survey completed in 2016, after the commencement of the RCC project, found respondents from remote regions were significantly more likely to report a lack of specialist medical practitioners.[20] Interestingly, gaps in survivorship and supportive care were reported by the highest number of respondents in all geographic areas, including major cities.

A focus on palliative care

Due to the poor prognosis of pancreatic cancer and the palliative rather than curative nature of treatment in many patients, early referral to specialist palliative care is advocated.[1] It has been estimated that Australia has half the palliative medicine specialists it needs to adequately care for the population at large[19], with this discrepancy amplified in rural areas. Only 24 per cent of RHAC reported having a palliative care specialist.[18] General practitioners were found to provide most palliative care in 34 per cent of these hospitals – their access to specialist support via outreach

reducing with remoteness.[18] A workforce of palliative care trained nurses supported by doctors and professional development contribute significantly to the provision of palliative care in rural areas.[19]

The *Optimal care pathway for people with pancreatic cancer* highlights the importance, for many patients, of: quick transitions from presentation to specialist care; access to multidisciplinary team-based care; supportive care that takes account of physical, psychological, social, informational and spiritual needs; and palliative care.[1] The state of services in rural Australia make the provision of best-practice care close to home difficult.

Workforce challenges

The provision of cancer services is intimately linked with the presence of an appropriately trained workforce. However, we know attracting and retaining a well-distributed health workforce in rural Australia is difficult. The prevalence of medical specialists (not oncology-specific) reduces with remoteness[22], as does the prevalence of many allied health professionals.[23] Though general practitioners[22] and nurses[24] are more prevalent, they need support and training to be able to provide quality cancer care close to patients' homes. Although there is no agreed staffing mix for RCCs to date[10], the Clinical Oncological Society of Australia reported that there were inadequate staffing levels within RCCs across many professional disciplines.[19] This reinforces the workforce-related challenges of providing access to services, despite investment in infrastructure. If we are to improve the outcomes and experience of people from rural Australia who have pancreatic cancer, work must be done to improve the recruitment and retention of health professionals in areas of need. Where this is not possible, innovative models of care might bring the care to the patient via various forms of outreach.

Issues for patients due to lack of services close to home

When people cannot access the care they need close to home, they need to travel – sometimes to major cities – for treatment. This is particularly true for pancreatic cancer patients. Outer regional and remote residents were found to have the greatest travel burden to receive treatment – 61 per cent travelled at least two hours one way and 49 per cent lived away from home.[25] Those who travelled more than two hours, or lived away from home, faced significantly greater financial difficulties. Travelling and living away from home presents increased costs; might require a patient or their family to take time off work or present challenges to caring responsibilities, including for children; and removes people from their families, communities and broader support networks – with an associated financial and personal burden. Hence, travel and accommodation assistance schemes are an important component of holistic cancer care for rural people.

How might we do better?

Prevention

The burden of pancreatic cancer risk factors is greater in rural Australia, particularly in Indigenous populations. The two most effective prevention strategies are reducing smoking and normalising body weight.[1] Action on these (and other) risk factors that differentially effect rural people has the potential to narrow the gap in incidence of this cancer in Indigenous Australians and improve pancreatic cancer rates more generally in rural people. The importance of a focus on prevention in rural Australia cannot be overstated.

Access and workforce

Travel and accommodation support is required for those who must travel to receive appropriate care – to reduce the inequity of the financial burden this presents for rural people. Schemes must be funded adequately, on an ongoing basis, and be easy for patients and their families to access and navigate.

We acknowledge that it would be very difficult to provide face-to-face diagnostic services and specialist oncology services in all areas of Australia and that there may always be indications for travel to a major city. Given the nature of diagnosis and treatment for pancreatic cancer, this is likely to be the case for initial care. However, outreach services are an important mechanism to take high-quality care to pancreatic cancer patients in rural areas after the initial phase. These services might be provided via digital means, shared care arrangements, fly-in fly-out or other visiting services, or include virtual multidisciplinary teams.[8] Access to high-quality digital health care requires investment in the infrastructure to support it, as well as training for health professionals and an adequate ongoing funding mechanism. Continuity of relationship with visiting services is also an important consideration.

Development of a staffing profile for rural oncology units has been proposed, to guide delivery of equitable care in rural areas[10], alongside a specific staffing matrix for RCCs.[19] The Clinical Oncological Society of Australia has proposed a number of recommendations to develop the oncology workforce in rural Australia including: the presence of trainee oncology positions in rural areas (for doctors); enhancing the regional oncology experience of medical trainees from all disciplines; increasing options for oncology training in the existing rural workforce (for nursing, allied health and non-clinical staff); accreditation of oncology nurses; and increasing access to Indigenous liaison officers at RCCs.[19]

The presence of a care coordinator is advocated as part of the multidisciplinary team in pancreatic cancer care.[1] There is some evidence of the effectiveness of similar roles but little data on their specific nature in rural areas.[26] Disease specific models of case management and cancer support exist for other cancers but are not feasible in pancreatic cancer. Thus, further work is required to determine the optimal model for providing this care locally to pancreatic cancer patients.

Quality care

A focus on multidisciplinary, supportive care is imperative in the management of pancreatic cancer and requires development, given the current state of services in rural Australia – where access to allied health, psychosocial support, specialist palliative care and multidisciplinary teams is poor. Strong but flexible referral pathways([19],[27]) and cancer care networks([19],[26],[27]) are proposed by several authors as a way of facilitating delivery of best-practice care between major cities and rural areas, including engagement of multidisciplinary team members. A specific focus on Indigenous service provision is key to changing outcomes and the experience of pancreatic cancer for patients in rural Australia. This includes prioritising the provision of care to Aboriginal and Torres Strait Islander peoples by Aboriginal and Torres Strait Islander peoples[19], working in partnership with communities to enhance understanding of cancer, and ensuring care is culturally safe and respectful.[26]

Research

Support for clinical trials in regional centres has the potential to increase access to novel treatments for rural people, with flow-on effects for outcomes. Further funding for health systems and policy research is required to evaluate the success of measures aimed at reducing the city–country divide in pancreatic cancer outcomes.[8]

Conclusion

Pancreatic cancer survival rates are lower in rural areas when compared with major cities and the burden of pancreatic cancer in Aboriginal and Torres Strait Islander populations is high. Poor pancreatic cancer outcomes in rural areas are thought to be related to reduced access to diagnostic services and specialist oncology services. In response to these issues, we highlight:

- the importance of prevention in reducing inequality in pancreatic cancer incidence and outcomes for Aboriginal and Torres Strait Islander peoples and improving incidence in rural people more generally
- the need for patient travel and accommodation schemes aimed at reducing financial and personal costs
- the case for providing specialist oncology services via outreach
- strategies for addressing workforce supply issues in rural areas.

It is considered key to ensure the provision of quality care by focusing on multidisciplinary, supportive care services, developing referral pathways and cancer care networks, and tailoring services to the specific needs of Indigenous people. There is also an important role for rural-focused research in this area.

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National Rural Health Alliance – member organisations

Allied Health Professions Australia Rural and Remote
Australasian College for Emergency Medicine
Australasian College of Health Service Management (Regional, Rural and Remote Special Interest Group)
Australasian College of Paramedicine
Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine
Australian Chiropractors Association (Aboriginal and Torres Strait Islander Rural and Remote Practitioner Network)
Australian College of Midwives (Rural and Remote Advisory Committee)
Australian College of Nursing (Rural Nursing and Midwifery Community of Interest)
Australian College of Rural and Remote Medicine
Australian Dental Association (Rural Dentists' Network)
Australian General Practice Accreditation Limited
Australian Healthcare and Hospitals Association
Australian Indigenous Doctors' Association
Australian Nursing and Midwifery Federation (rural members)
Australian Paediatric Society
Australian Physiotherapy Association (Rural Advisory Council)
Australian Psychological Society (Rural and Remote Psychology Interest Group)
Australian Rural Health Education Network
Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
Council of Ambulance Authorities
Country Women's Association of Australia
CRANAplus
Exercise and Sports Science Australia
Federation of Rural Australian Medical Educators
Isolated Children's Parents' Association
National Aboriginal Community Controlled Health Organisation
National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners
National Rural Health Student Network
Optometry Australia (Rural Optometry Group)
Pharmaceutical Society of Australia (Rural Special Interest Group)
Regional Medical Specialists Association
Royal Australasian College of Medical Administrators
Royal Australasian College of Surgeons (Rural Surgery Section)
Royal Australian and New Zealand College of Obstetricians and Gynaecologists
Royal Australian and New Zealand College of Psychiatrists
Royal Australian College of General Practitioners Rural Faculty
Royal Far West
Royal Flying Doctor Service
Rural Doctors Association of Australia
Rural Health Workforce Australia
Rural Pharmacists Australia
Services for Australian Rural and Remote Allied Health
Society of Hospital Pharmacists of Australia
Speech Pathology Australia