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Are General Practitioners getting the information they need from hospitals and specialists to provide quality cancer care for Indigenous Australians?

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ontributors

FCV, RB, GG and AdW contributed to the conception and design of the study. PCV performed the data analysis and trikes responsibility for the integrity and the accuracy of the data. PCV drafted the report. All authors contributed the interpretation of data, revising draft critically for important intellectual content, and approved the final version.

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conflict of interest

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Patient consent

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Chics approvals

Human Research Ethics Committees of the Darling Downs Hospital and Health Service, Menzies School of Research, and MR Berghofer Medical Research Institute.

Abstract

Background

Cancer care involves many different healthcare providers. Delayed or inaccurate communication between specialists and general practitioners (GPs) may negatively affect care.

Aim

To describe the pattern and variation of communication between primary health care (PHC) services and hospitals and specialists in relation to the patient's cancer care.

Methods

A retrospective audit of clinical records of Indigenous Australians diagnosed with cancer during 2010-2016 identified via ten PHC services in Queensland is described. Poisson regression was used to model the dichotomous outcome availability of hospital discharge summary vs not.

Results

A total of 138 patient records were audited. 115 of those patients visited the PHC service for cancer-related care after cancer diagnosis; 40.0% visited the service before a discharge summary was available, and 36.5% of the patients had no discharge summary in their medical notes. While most discharge summaries noted important information about the patient's cancer, 42.4% lacked details regarding the discharge medications regimen.

onclusions

Deficits in communication and information transfer between specialists and GPs may adversely affect patient care. I digenous Australians are a relatively disadvantaged group that experience poor health outcomes and relatively poor access to care. The low proportion of discharge summaries noting discharge medication regimen is of concern among Indigenous Australians with cancer who have high comorbidity burden and low health literacy. Our findings provide an insight into some of the factors associated with quality of cancer care, and may provide guidance for focus areas for further research and improvement efforts.

Introduction

Concer care is complex and involves many different healthcare providers. Delayed communication and inaccurate information transfer between health care professionals may have serious implications for continuity of care and patient affety.¹⁻⁶ Primary health care (PHC) services have an important role in post-discharge cancer care, and accurate communication between hospital-based specialists and PHC services is imperative.^{7,8}

Ir high-income countries with universal health-care systems, there is increasing acceptance of the role of GPs in cancer care.⁸⁻¹³ High quality PHC is particularly important for groups who experience disproportionate barriers to access to care; such as ethnic minorities,¹⁴ patients who live in rural¹⁵ and more deprived areas,^{14,16} and Indigenous populations.¹⁷⁻¹⁹

Aboriginal and Torres Strait Islander people in Australia (respectfully referred to here as Indigenous Australians) comprise 3% of the total Australian population,²⁰ and experience socioeconomic and health disparities.²¹ Cancer is the second leading cause of death for Indigenous Australians.²² Compared to mainstream Australia, they experience marked disparities in cancer mortality²³ and survival^{18,19,24} which are largely attributed to being diagnosed later,^{18,19,25} receiving less treatment,^{18,19} and experiencing higher rates of comorbidities.^{18,19,26 20,23,27} In Australia, the availability of health services generally decreases with increase in remoteness.²⁸⁻³⁰ As a higher proportion of Indigenous Australians live in rural areas,²⁰ together with other Australians they have worse cancer outcomes than those living in major cities.³¹⁻³³

In Australia, community-based PHC services play an important role in prevention and management of disease in general. However, GP involvement in cancer care is varied, with GPs based in rural areas having a greater role in cancer care than their major city counterparts.³⁴ In an effort to close the health disparities gap between Indigenous and non-Indigenous Australians, community controlled PHC services (referred to as Aboriginal Community Controlled Health Organizations (ACCHOs)) exist in many parts of Australia (e.g. there are 25 ACCHOs in Queensland). The quality of care delivered by ACCHOs is generally at least on par with mainstream services.³⁵⁻³⁷ ACCHOs offer welcoming social spaces, culturally safe care that is responsive to holistic needs,³⁸ and many Indigenous Australians value their accessibility.³⁶

From an international perspective, the services provided to Indigenous Australians with cancer form a useful case study. ith a view to exploring the coordination and continuity of care of Indigenous Australians with cancer, we describe the pattern and variation of communication between PHC services and hospitals and specialists in relation to the patient's ncer care after cancer diagnosis. We also examine factors associated with availability of a hospital discharge summary (nDS) in the patient's medical notes at the PHC service as a proxy measure for communication between hospitals and PHC services.

Methods

We conducted a retrospective audit of PHC service records of Indigenous cancer patients. The details about the collection of PHC services in Queensland, Australia have been described previously.³⁹ In brief, a purposive convenience ample of Queensland Health-operated and ACCOSs with at least ten Indigenous cancer patients who attended the r actice at least once within the last 12 months (referred to as "active patients") were invited to participate in the study. Ten PHC services agreed to participate; except for one service, all were ACCHOs.³⁹ The audit took place between February 2015 and December 2016. Data were collected from the date of cancer diagnosis to the date of audit (referred to as the "audit period"). Indigenous Australian adults diagnosed after 2010 with any cancer, except non-melanoma skin cancers, and who were active patients were eligible.

P tients' demographic and clinical data were abstracted from their medical records at the PHC services by trained r viewers using a structured form. A registered nurse and a clinician independently categorized cancer type and stage;⁴⁰ when disagreement occurred, a discussion was held to facilitate consensus. A modified Charlson comorbidity index was calculated; patients were grouped as 0 (no comorbidity) with higher scores indicating higher comorbidity burden.^{41,42}

Information on communications to and from the PHC service about the patient that were related to their cancer (e.g. referrals, HDS), letters from specialists (e.g. oncologists) were collected. In particular, we collected information about the reason for communication, if related to patient's cancer treatment then date and type of treatment was recorded. Regarding discharge summaries and letters from specialists, the audit sought records of information relating to patient's medical history, physical findings, results of procedures and tests, treatment and consultant recommendations (items were checked whether present or absent).

Data analysis

Analysis was completed using Stata/SE (Version 15; College Station, TX). The rate of communications were calculated using person years at risk (PYAR) as a denominator (e.g. a patient who supplied six months of data to the study [e.g. from cancer diagnosis to the date of medical chart audit] would contribute 0.5 years to the denominator). Poisson regression was undertaken to compare rate of communication by PHC service, health service and patient characteristics, and to model the dichotomous outcome availability of HDS vs not. The vce(robust)⁴³ option was used to obtain robust standard errors for the parameter estimates to control for mild violation of underlying assumptions. The significance of variables in the Poisson regression modeling was assessed using Wald tests. The multivariable models included variables that had the strongest impact on outcome or statistical significance as determined by bivariate analysis ($p \le 0.200$), but also taking into account our understanding of the relationships and dependencies among variables. The final model is cluded gender, cancer type and receipt of radiotherapy. Incidence rate ratios (IRR) and 95% confidence interval (CI) were reported. Statistical significance was set at alpha=0.05, and all p values were 2-sided.

Results

A total of 475 patients were identified. After medical chart review, 304 were excluded (e.g. ineligible, not enough information to assess eligibility; see details in **Figure 1**). The characteristics of the 138 patients included hereafter are chown in **Table 1**.

A date of diagnosis was available for 89.9% of the patients, and the source of information on date of diagnosis were Listology (67.4%), followed by clinical diagnosis (11.6%), date of surgery (8.0%), and date of commencement of radiotherapy/chemotherapy (2.8%). For 14 (10.1%) only the year of diagnosis was available. Most medical charts (74.6%) had cancer stage recorded (or stage was not applicable); 43% of patients had localized cancers, and for 25.4% cancer stage was missing. Most patients (89.9%) received cancer treatment; 67.4% had surgery, 40.6% chemotherapy, and 3.1% radiotherapy. Ten patients (7.2%) did not receive any of these treatments. The date of surgery was available for 9.7% of those who had surgery. Approximate date of commencement of chemotherapy and radiotherapy were a allable for 48.2% and 66.7%, respectively.

Most patients (93.5%) had at least one comorbidity reported in their medical notes (range 0 to 14 comorbidities (mean 4.4, SD=2.7). The most commonly recorded comorbidities included hypertension (59.0%), type 2 diabetes (39.6%), hyperlipidemia (34.5%), gastroesophageal reflux (27.3%), asthma (19.4%), osteoarthritis (18.0%), and depression (17.3%). Using the Charlson comorbidity index, 65.2% of the patients had at least one comorbidity and 34.8% had none.

Patient visits to the PHC service

All patients audited had at least one visit to the PHC service that was related to their cancer during the audit period. Most (n=115, 83.3%) had at least one visit for patient care (e.g. presented with symptoms, wound care, scheduled

appointment, request of medical prescription). For 16.7% of the patients the only reason for visiting the service was to check results or to request pathology/imaging tests, or for administrative reasons (e.g. to organize referrals, arrange transport). During the visits for patient care most patients had a consultation with a GP (81.3%) and/or a health worker (37.9%), and/or a nurse (11.1%)

Communications to and from PHC services

A total of 2957 communications to and from the PHC services that were related to the patient's cancer were identified; 62% occurred within 12 months following the patient's cancer diagnosis. One-third of all communications (32.6%) were for administrative reasons (e.g. 12.9% to organize referrals); 27.3% related to patient care (e.g. 21.1% to organize eatment plan and care coordination); 27.1% related to patient follow-up, 16.7% checking or requesting tests and 12.5% to organize appointments (**Table 2**).

During the 12-month period following cancer diagnosis, the rate of communications to and from PHC services was 16.5 per PYAR, and it varied significantly by service and patient characteristics (**Figure 2**). Larger PHC services and larger treating hospitals, PHC services located in inner/outer regional areas, and PHC services with a permanent GP had significantly greater rate of communications compared to their respective counterparts. Patients who did not undergo surgery, had fewer comorbidities, received chemotherapy and/or radiotherapy, male gender, were most disadvantaged, and patients who lived in regional areas or major cities had significantly greater rate of communications compared to their respective counterparts.

Scharge summaries

A total of 165 HDSs were identified among the 138 patients included in this audit. Eighty-two patients had at least one NDS in the patient's notes (49.3% had one, 23.3% had two, 12.3% had three, and 15.1% had 4 to 8 HDSs). Reasons for multiple HDSs were multiple admissions or HDSs from different health professionals that related to the same hospital amission. Fifty-six patients (40.6%) had no HDS in the patient's notes.

Most HDSs noted the patient's medical history (80.6%), physical findings (86.7%), dates of hospitalization (80.0%), details of treatment provided while in hospital (89.7%), hospital course (52.7%), results of procedures (69.7%) and tests (50.9%), consultant recommendations (55.2%), follow-up plan (70.9%), and physician's contact details (83.6%). Discharge medication regimen was noted in less than half of the HDSs (42.4%).

Focusing on the 115 patients who visited the PHC service for cancer-related care after their cancer diagnosis, 42 patients (36.5%) had no HDS in their medical notes during the audit period (the date of HDS was ineligible for 1 patient). For 26 patients (22.6%) the HDS was available in the patient's notes at the time of their first visit after cancer diagnosis, and for 46 patients (40.0%) their first visit occurred before a HDS was available.

Of the factors examined, gender and rurality of residence were the only factors independently associated with availability of HDS at the PHC service. Female patients were less likely to have a HDS at the service (IRR=0.61, 95%CI 0.41-0.89), and compared to their major cities counterparts patients residing in outer/inner region or remote/very remote were more likely to have a HDS at the service (IRR=1.84, 95%CI 1.14-2.96 and IRR=1.45, 95%CI 0.84-2.53, respectively p=0.039) (**Table 3**).

Communication between PHC services and specialists

The collection of data about communication between PHC services and specialists that did not occur via the HDSs was not straightforward, particularly when the method of communication was not via letter (e.g. telephone, email, fax). For ome, it was not clear if the communication was from a specialist (e.g. only a department or doctor's name was noted and not his/her specialty), while for others the information was fragmented. We have therefore described here immunications initiated by a specialist (clearly identified as such e.g. oncologists, surgeon) and via letter (referred to as retters from a specialist'). Of 467 'letters from a specialist' identified, 46 were excluded because not enough information was available to examine its content fairly, and 421 were described here. Most letters were very comprehensive and provided a detailed description of the patient's medical history (79.1%), physical findings (91.2%), treatment provided while in hospital (77.4%), result of procedures (68.6%), consultant recommendations (78.9%), follow-up plan (85.4%), and physician's contact details (96.7 %). Results of tests were noted in 25.7% of the 'letters from a specialist'. We could not ascertain whether result of tests were not noted because patients did not have tests or they did have tests but esults were not noted in the letter.

Discussion

While there is evidence of the increasing role of the GP in cancer care,⁸ barriers exist for the delivery of quality care. The primary form of communication between hospital-based specialists and GPs is the HDS, and receipt of the HDS by services and the assessment of its content have been previously used to assess the coordination and continuity of ure.⁴⁴⁻⁴⁷ For over two-thirds of patients who visited the PHC service for cancer-related care after their diagnosis, the v it occurred before a HDS was available in the patient's notes. Absence of timely communication between hospital-bised specialists and GPs via the HDSs for many patients seeking care related to their cancer highlights difficulties that many PHC services endure in providing quality care. While most HDSs contained important information (e.g. medical history, treatment details), they often lacked details regarding the discharge medications regimen. Patients in general, and in particular those with low health literacy, have poor understanding and recall of their prescribed medications.⁴⁸ Particularly for patients who are hospitalized for their treatment and who have multiple comorbidities, the timeliness and accuracy of hospital discharge communication is important as they may require early post-discharge follow-up in primary care. Incomplete or delayed access to information by GPs has been linked to preventable medical errors.⁵

Indigenous Australians with cancer have higher rates of comorbidities than other Australians.^{18,19} Patients with comorbidities may be more likely to develop long-term relationships with their PHC services or GPs. Compared to a

previous study which recruited 248 Indigenous cancer patients from hospitals in Queensland,⁴⁹ a higher proportion of patients included here had localized cancers (42.8% vs. 24.6% in the hospital based study) and missing cancer stage (25.4% vs. 5.6%). While lack of cancer stage in up to 10% of hospital-based medical charts of Indigenous Australians with cancer have been previously reported,^{18,19,49} the higher proportion of medical charts at PHC services with missing cancer stage is of concern and it may be attributed to poor communication between hospitals and PHC services.

Comparable data about the quality of HDSs in cancer population, and data on tracking HDSs from the hospital to the PHC setting, is scarce. In other disease groups, both the quality and the availability of HDSs in the PHC setting varied. In a review of 55 studies including mixed disease populations and countries, HDSs often lacked important information (e.g. %-22% lacked treatment or hospital course, 2%-40% lacked discharge medications), and the availability of a HDS at the tirst post-discharge visit at PHC physicians was low (12%-34%) and remained poor at 4 weeks (51%-77%). Their findings out noting discharge medication and availability of HDSs in the PHC setting after cancer treatment were comparable to our study. In Canada, the transmission of HDS in cardiovascular disease population to the PHC setting was low (42%-51%), the quality of information varied, and in many cases, diverged from the information deemed useful and pertinent.^{50,51} In a cross-sectional study of the general hospital-admitted population in Italy, while kidney dysfunction frequently occurred during hospitalization, information about it was noted in the patient's HDS in only one out of four alfected patients.⁵²

The challenges faced by study staff when collecting data about communication between PHC services and specialists of at did not occur via the HDS may reflect the suboptimal level of communication and information transfer between GPs and oncology specialists. Other groups have shown that coordination of care between GPs and cancer specialists has proven to be a considerable challenge.⁵³⁻⁵⁵ In a qualitative content analysis of the letters from specialists to GPs from 50 patients with lung, breast or colorectal cancer in the Netherlands, while information about cancer treatment was always present, only limited detail was noted about the intent of the treatment (curative vs. palliative), treatment alternatives, about how the patient had reacted to the information received.⁵⁵ A Canadian study reported substantial munication challenges between health professionals involved in cancer care (e.g. delays in medical transcription, ⁴¹ficulties accessing patient information, lack of rapport between GPs and cancer specialists.⁵³

Although having more localized cancers,^{18,19} patients audited appeared to be similar to the Indigenous cancer patients recruited in previous studies in Queensland.^{18,19,49} Limiting the study to patients currently attending the participating service may have excluded those who had more advanced cancers and who had died from their cancer. Despite the inclusion of PHC services from a mixture of remote, rural, and urban areas, the voluntary nature of participation may limit the generalizability of our findings. Our study focused on written communication included in patient records. Non-recorded phone calls between healthcare providers were, therefore, not included. Lastly, while detailed information about the reasons for communications to and from PHC services were collected, a limitation of the data is the lack of in depth examination of the content of the letters from specialists. For example, presence or absence about the details of

treatment were recorded, but details about the exact type of surgery, chemotherapy or radiotherapy, or whether an explicit statement about whether the treatment was given with curative or palliative intent were not collected.

Transitions of care between the hospital and PHC setting are periods of vulnerability for patients. Deficits in communication and information transfer between hospital-based specialists and GPs may adversely affect patient care. The low proportion of HDS noting discharge medication regimen is of particular concern among Indigenous Australians with cancer who have high comorbidity burden and low health literacy. Ensuring that transfer of relevant patient information from hospital-based specialists to GPs occurs in a timely matter is essential to improve the coordination and continuity of care.^{24,56,57}

The use of electronic records,^{54,58} GPs participating in multidisciplinary team meetings,⁵⁹ the use of patient journey r apping tools,⁶⁰ and of Patient Navigators and/or Cancer Care Coordinators^{54,61} have been put forward as practical surategies to improve communication between GPs and hospital-based services and assist patients to better transition from hospital to community health services. Guidelines for HDSs could improve quality and consistency of content for the purpose of promoting quality of cancer care in PHC. Our findings provide insight into some of the factors associated with quality of cancer care, and may provide guidance for focus areas for further research and improvement efforts.

Peferences

Poon EG, Gandhi TK, Sequist TD, Murff HJ, Karson AS, Bates DW. "I wish I had seen this test result earlier!":
 Dissatisfaction with test result management systems in primary care. *Arch Intern Med* 2004; **164**(20): 2223-8.
 Coleman EA, Berenson RA. Lost in transition: challenges and opportunities for improving the quality of transitional care. *Ann Intern Med* 2004; **141**(7): 533-6.

Coleman EA, Min SJ, Chomiak A, Kramer AM. Posthospital care transitions: patterns, complications, and risk identification. *Health Serv Res* 2004; **39**(5): 1449-65.

van Walraven C, Mamdani M, Fang J, Austin PC. Continuity of care and patient outcomes after hospital scharge. *J Gen Intern Med* 2004; **19**(6): 624-31.

Moore C, Wisnivesky J, Williams S, McGinn T. Medical errors related to discontinuity of care from an inpatient to a outpatient setting. *J Gen Intern Med* 2003; **18**(8): 646-51.

6 Kripalani S, LeFevre F, Phillips CO, Williams MV, Basaviah P, Baker DW. Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity care. JAMA 2007; **297**(8): 831-41.

7. Easley J, Miedema B, O'Brien MA, et al. The role of family physicians in cancer care: perspectives of primary and specialty care providers. *Curr Oncol* 2017; **24**(2): 75-80.

8. Meiklejohn JA, Mimery A, Martin JH, et al. The role of the GP in follow-up cancer care: a systematic literature review. *J Cancer Surviv* 2016; **10**(6): 990-1011.

9. Rubin G, Berendsen A, Crawford SM, et al. The expanding role of primary care in cancer control. *Lancet Oncol* 2015; **16**(12): 1231-72.

10. Holtedahl K, Scheel BI, Johansen ML. General practitioners' participation in cancer treatment in Norway. *Rural Remote Health* 2018; **18**(2): 4276.

11. Coory M, Thompson A, Ganguly I. Cancer among people living in rural and remote Indigenous communities in Queensland. *MJA* 2000; **173**: 301-4.

12. DeMario MD, Ratain MJ. Oral chemotherapy: rationale and future directions. *J Clin Oncol* 1998; **16**(7): 2557-67.

13. Riechelmann RP, Tannock IF, Wang L, Saad ED, Taback NA, Krzyzanowska MK. Potential drug interactions and duplicate prescriptions among cancer patients. *J Natl Cancer Inst* 2007; **99**(8): 592-600.

14. Kish JK, Yu M, Percy-Laurry A, Altekruse SF. Racial and ethnic disparities in cancer survival by neighborhood socioeconomic status in Surveillance, Epidemiology, and End Results (SEER) Registries. *J Natl Cancer Inst Monogr* 2014; **2014**(49): 236-43.

15. Cramb SM, Moraga P, Mengersen KL, Baade PD. Spatial variation in cancer incidence and survival over time across Queensland, Australia. *Spat Spatiotemporal Epidemiol* 2017; **23**: 59-67.

16. Cancer Research UK. Cancer survival statistics 2011. <u>http://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/all-cancerscombined</u>.

17. McGahan CE, Linn K, Guno P, et al. Cancer in First Nations people living in British Columbia, Canada: an analysis of incidence and survival from 1993 to 2010. *Cancer Causes Control* 2017; **28**(10): 1105-16.

18. Moore SP, Green AC, Bray F, et al. Survival disparities in Australia: an analysis of patterns of care and comorbidities among indigenous and non-indigenous cancer patients. *BMC Cancer* 2014; **14**: 517.

19. Valery PC, Coory M, Stirling J, Green AC. Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study. *Lancet* 2006; **367**(9525): 1842-8.

2. Australian Bureau of Statistics (ABS). Estimates and projections, Aboriginal and Torres Strait Islander Australians. 2014.

Gracey M. Why closing the Aboriginal health gap is so elusive. Intern Med J 2014; 44(11): 1141-3.

2). Australian Institute of Health and Welfare (AIHW), Cancer Australia. Cancer in Aboriginal & Torres Strait Islander people of Australia. Canberra: AIHW 2018.

23. Australian Institute of Health and Welfare (AIHW). The health and welfare of Australia's Aboriginal and Torres Crait Islander peoples 2015. Canberra: AIHW, 2015.

24. Chong A, Roder D. Exploring differences in survival from cancer among Indigenous and non-Indigenous Australians: implications for health service delivery and research. *Asian Pac J Cancer Prev* 2010; **11**(4): 953-61.

23. Condon JR, Barnes T, Cunningham J, Armstrong BK. Long-term trends in cancer mortality for Indigenous Australians in the Northern Territory. *Med J Aust* 2004; **180**(10): 504-7.

26. Weir K, Supramaniam R, Gibberd A, Dillon A, Armstrong BK, O'Connell DL. Comparing colorectal cancer treatment and survival for Aboriginal and non-Aboriginal people in New South Wales. *Med J Aust* 2016; **204**(4): 156.

27. Cunningham J. Diagnostic and therapeutic procedures among Australian hospital patients identified as indigenous. *Med J Aust* 2002; **176**: 58-62.

23. Whop LJ, Garvey G, Lokuge K, Mallitt KA, Valery PC. Cancer support services--are they appropriate and accessible or Indigenous cancer patients in Queensland, Australia? *Rural Remote Health* 2012; **12**: 2018.

National Rural Health Alliance. The health of people living in remote Australia. 2016.

http://www.ruralhealth.org.au/factsheets/thumbs (accessed 25 Jun 2018.

21.

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Adams D, Marx G. Daily life as an Australian medical oncologist. J Oncol Pract 2010; 6(3): 146-8.

31. Baade PD, Dasgupta P, Aitken JF, Turrell G. Geographic remoteness, area-level socioeconomic disadvantage and i equalities in colorectal cancer survival in Queensland: a multilevel analysis. *BMC Cancer* 2013; **13**: 493.

32. McGrath P. Accommodation for patients and carers during relocation for treatment for leukaemia: a descriptive ofile. *Support Care Cancer* 1999; **7**(1): 6-10.

33. Zucca A, Boyes A, Newling G, Hall A, Girgis A. Travelling all over the countryside: travel-related burden and inancial difficulties reported by cancer patients in New South Wales and Victoria. *Aust J Rural Health* 2011; **19**(6): 298-215.

34. Johnson CE, Lizama N, Garg N, Ghosh M, Emery J, Saunders C. Australian general practitioners' preferences for managing the care of people diagnosed with cancer. *Asia Pac J Clin Oncol* 2014; **10**(2): e90-8.

35. Campbell MA, Hunt J, Scrimgeour DJ, Davey M, Jones V. Contribution of Aboriginal Community-Controlled Health Services to improving Aboriginal health: an evidence review. *Aust Health Rev* 2017.

36. Panaretto KS, Gardner KL, Button S, et al. Prevention and management of chronic disease in Aboriginal and Islander Community Controlled Health Services in Queensland: a quality improvement study assessing change in selected clinical performance indicators over time in a cohort of services. *BMJ Open* 2013; **3**(4).

37. Panaretto KS, Wenitong M, Button S, Ring IT. Aboriginal community controlled health services: leading the way in primary care. *Med J Aust* 2014; **200**(11): 649-52.

38. Gomersall JS, Gibson O, Dwyer J, et al. What Indigenous Australian clients value about primary health care: a systematic review of qualitative evidence. *Aust N Z J Public Health* 2017; **41**(4): 417-23.

39. de Witt A, Cunningham FC, Bailie R, et al. Identification of Australian Aboriginal and Torres Strait Islander Cancer Patients in the Primary Health Care Setting. *Front Public Health* 2017; **5**: 199.

40. Young JL, Roffers S, Ries L, Fritz A, Hurlbut AE. Summary Staging Manual 2000: Codes and Coding Instructions. Bethesda, MD National Cancer Institute, 2001.

41. Diaz A, Bernardes CM, Garvey G, Valery PC. Supportive care needs among Indigenous cancer patients in Queensland, Australia: less comorbidity is associated with greater practical and cultural unmet need. *Eur J Cancer Care (Engl)* 2016; **25**(2): 242-53.

42. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *J Chronic Dis* 1987; **40**(5): 373-83.

43. Cameron AC, Trivedi PK. Microeconometrics Using Stata. College Station, Texas: Stata Press, 2009.

44. Robelia PM, Kashiwagi DT, Jenkins SM, Newman JS, Sorita A. Information Transfer and the Hospital Discharge Summary: National Primary Care Provider Perspectives of Challenges and Opportunities. *J Am Board Fam Med* 2017; **30**(6): 758-65.

45. Hesselink G, Schoonhoven L, Barach P, et al. Improving patient handovers from hospital to primary care: a systematic review. *Ann Intern Med* 2012; **157**(6): 417-28.

Tang N. A primary care physician's ideal transitions of care--where's the evidence? *J Hosp Med* 2013; 8(8): 472-7.
 Yemm R, Bhattacharya D, Wright D, Poland F. What constitutes a high quality discharge summary? A comparison between the views of secondary and primary care doctors. *Int J Med Educ* 2014; 5: 125-31.

4). Kim N, Talwalkar J, Holmboe E. Challenges in ambulatory resident education: medication knowledge in disadvantaged patients. *Conn Med* 2006; **70**(9): 549-57.

49. Garvey G, Beesley VL, Janda M, et al. Psychometric properties of an Australian supportive care needs sessment tool for Indigenous patients with cancer. *Cancer* 2015; **121**(17): 3018-26.

50. Polyzotis PA, Suskin N, Unsworth K, et al. Primary care provider receipt of cardiac rehabilitation discharge summaries: are they getting what they want to promote long-term risk reduction? *Circ Cardiovasc Qual Outcomes* 2013; o(1): 83-9.

51. Riley DL, Krepostman S, Stewart DE, Suskin N, Arthur HM, Grace SL. A mixed methods study of continuity of care from cardiac rehabilitation to primary care physicians. *Can J Cardiol* 2009; **25**(6): e187-92.

52. Sautenet B, Caille A, Giraudeau B, et al. Deficits in information transfer between hospital-based and primarycare physicians, the case of kidney disease: a cross-sectional study. *J Nephrol* 2015; **28**(5): 563-70.

Easley J, Miedema B, Carroll JC, et al. Coordination of cancer care between family physicians and cancer s ecialists: Importance of communication. *Can Fam Physician* 2016; **62**(10): e608-e15.

Brouwers MC, Vukmirovic M, Tomasone JR, et al. Documenting coordination of cancer care between primary re providers and oncology specialists in Canada. *Can Fam Physician* 2016; **62**(10): e616-e25.

55. Stegmann ME, Meijer JM, Nuver J, et al. Correspondence between primary and secondary care about patients with cancer: A qualitative mixed-methods analysis. *Eur J Cancer Care (Engl)* 2018: e12903.

56. Shahid S, Finn L, Bessarab D, Thompson SC. 'Nowhere to room ... nobody told them': logistical and cultural inpediments to Aboriginal peoples' participation in cancer treatment. *Aust Health Rev* 2011; **35**(2): 235-41.

57. Jiwa M, Saunders CM, Thompson SC, et al. Timely cancer diagnosis and management as a chronic condition: portunities for primary care. *Med J Aust* 2008; **189**(2): 78-82.

53. British Columbia eHealth Steering Committee. eHealth Strategic Framework. Vancouver British Columbia Unistry of Health, 2005.

Mitchell GK. The role of general practice in cancer care. *Aust Fam Physician* 2008; **37**(9): 698-702.

60. Kelly J, Dwyer J, Mackean T, O'Donnell K, Willis E. Coproducing Aboriginal patient journey mapping tools for improved quality and coordination of care. *Aust J Prim Health* 2016.

61. Bernardes CM, Martin J, Cole P, et al. Lessons learned from a pilot study of an Indigenous patient navigator intervention in Queensland, Australia. *Eur J Cancer Care (Engl)* 2018; **27**(1).

Figure 1. Flow chart of case ascertainment

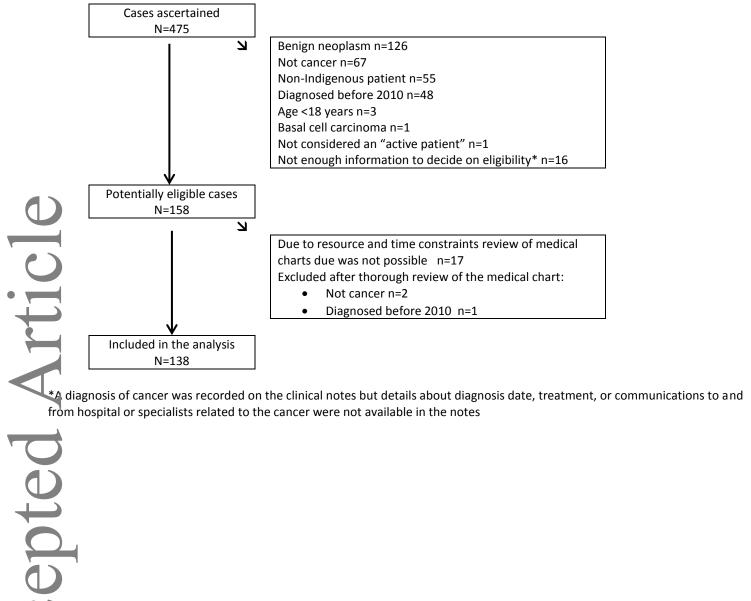


Table 1. Sociodemographic and clinical characteristics of 138 Indigenous cancer patients

	N=138	%
Age at diagnosis*	100	,.
20-39	13	9.4
40-59	69	50.
	56	50. 40.
≥60 S err	00	40.
Sex	50	27
Male	52	37.
Female	86	62.
Indigenous status		
Aboriginal	126	91.
Torres Strait Islander	6	4.3
Aboriginal & Torres Strait Islander	6	4.3
Socioeconomic advantage/disadvantage (SEIFA) §		
Most affluent	27	19.
Low to intermediate advantage	47	34.
Most disadvantaged	63	46.
Rurality of residence (ARIA) §		
Major city	35	25.
Outer/inner regional	66	48.
Remote/very remote	36	26.
Cancer type [¶]		
Breast	40	29.
Female genital organs	22	15.
Digestive organs	16	11.
Respiratory and intrathoracic organs	15	10.
	13	10.
Male genital organs Other cancers**		
	31	22.
Cancer stage	50	12
Local	59	42.
Regional	20	14.
Distant	16	11.
Not applicable (e.g. leukaemias, lymphomas)	8	5.8
Missing	35	25.
Cancer treatment		
Yes	124	89.
No	10	7.2
Not clear in the medical notes	4	2.9
Cancer treatment by type [¥]		
Surgery	93	67.
Radiotherapy	54	39.
Chemotherapy	56	40.
Charlson comorbidity index (CCI)		
CCI=0 (no comorbidity)	48	34.
CCI=1	43	31.
CCI>2	43	34.
Comorbidities	77	54.
Cardiovascular disease	96	69.
Disorders of the endocrine system	80	58.
Disorders of the respiratory system	51	37.
Disorders of the digestive tract	50	36.
Disorders of the musculoskeletal system	42	30.
Mental disorders	39	28.
Disorders of the nervous system	26	18.
Disorders of the genitourinary system	22	15.
Cancers other than the current cancer	5	3.6

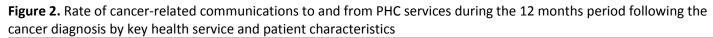
* Approximate age for 14 patients for whom we had year of diagnosis; ** Other cancers include 8 lymphoid, haematopoietic and related tissue, 7 lip, oral cavity and pharynx, 4 thyroid and other endocrine glands, 3 eye, brain and other parts of central nervous system, 3 urinary tract, 3 skin (excluding squamous cell and basal cell carcinoma), 1 bone and articular cartilage, and for 2 cases it was recorded in the notes that patient had cancer but cancer type was not clear); ^{*} Totals do not add up to 100% as patients could have received more than one treatment, and it was not clear in the notes whether patients had surgery (n=4), chemotherapy (n=10) or radiotherapy (n=17); [§] Post code for place of residence was missing for 1 case;

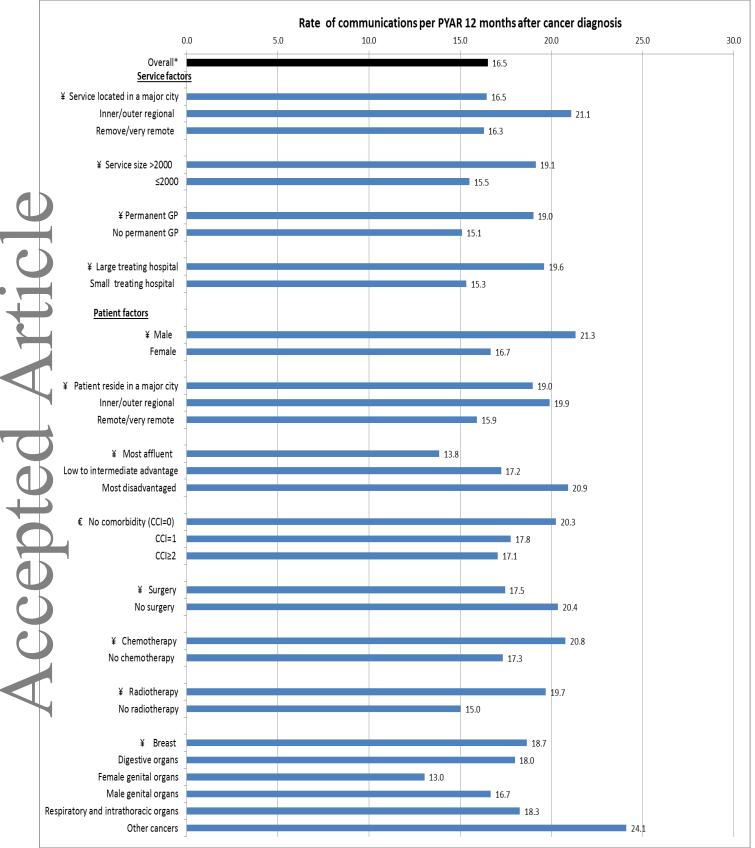
Table 2. Total number of communications by reasons

		Within 12 months N=1842 (%)	Audit period N=2957 (%)
Admi	inistrative	623 (33.8)	965 (32.6)
	Referral (e.g. specialists, allied health, support services) Discharge summary Arrangement of transport or accommodation Medical record transfer (e.g. patient's medical chart) Centrelink and other administrative forms (e.g. carer allowance, sickness benefit allowance, disability form, insurance forms, superannuation)	199 (10.8) 125 (6.8) 128 (6.9) 80 (4.3) 120 (6.5)	382 (12.9) 165 (5.6) 154 (5.2) 139 (4.7) 177 (11.4)
Relat	ed to patient care	554 (30.1)	807 (27.3)
\mathbf{O}	Treatment plan, cancer care coordination (e.g. multidisciplinary team meeting reports, treatment care plan, patient's symptoms, case conference, co-ordinating specialist appointments) Medical prescription (e.g. query about medication, order materials	432 (23.4) 65 (3.5)	624 (21.1)
	such as drainage bags)	05 (5.5)	92 (3.1)
$\mathbf{\Sigma}$	Medical certificate or report (e.g. request for or provision of) Medical review (e.g. home medicine review report)	36 (2.0) 33 (1.8)	61 (2.1) 50 (1.7)
	Patient education or counselling (e.g. counselling to quit smoking, pre admission information)	16 (0.9)	16 (0.5)
Follo	w-up	497 (27.0)	800 (27.1)
	Hospital follow-up (e.g. treatment update, progress notes) Patient follow-up in general or post-operative follow-up Allied health (e.g. reports from and communications to allied health professionals)	408 (25.4) 77 (4.2) 19 (1.0)	676 (22.9) 99 (3.4) 32 (1.1)
Test	results (requests for or results from)	282 (15.3)	495 (16.7)
0	Pathology tests (e.g. blood tests, swab, urine test) Radiology / imaging tests (e.g. x-ray, CT scan) Other tests (e.g. electrocardiogram, spirometry, endoscopy, colonoscopy)	157 (8.5) 126 (6.8) 16 (0.9)	268 (9.1) 225 (7.6) 25 (0.8)
	intments	191 (10.4)	371 (12.5)
6	Offer, change or cancelation of appointments Appointment reminder notices Fail to attend appointment notices	131 (7.2) 34 (1.8) 27 (1.5)	268 (9.0) 63 (2.1) 42 (1.4)

 Fail to attend appointment notices
 27 (1.5)
 42 (1.4)

 Precentages are calculated out of the total number of communications and they do not add up to 100% because more than one could be present for communication; reason missing for 4 communications.





Rate per person years at risk (PYAR) as a denominator; * p-value <0.001 for the difference between cancer types; * p-value=0.006;

Table 3. Availability of hospital discharge summary by key health service and patient characteristics

	Discharge summary			
	Available (N=82)	Not available (N=56)	Unadjusted IRR (95% CI)	Adjusted ^a IRR (95% CI)
Health service characteristics				
Size of PHC service				
>2000	62 (57.4)	46 (42.6)	1.00	1.00
≤2000	20 (66.7)	10 (33.3)	1.09 (0.70-1.70)	1.14 (0.74-1.77)
Location of PHC service				
Major city	32 (51.6)	30 (48.4)	1.00	1.00
Outer/inner regional	34 (65.4)	18 (34.6)	0.97 (0.65-1.46)	0.91 (0.59-1.38)
Remote/very remote	16 (66.7)	8 (33.3)	1.01 (0.57-1.77)	0.97 (0.56-1.69)
P IC service had a permanent GP				
Yes	65 (57.5)	48 (42.5)	1.00	1.00
No	17 (68.0)	8 (32.0)	1.22 (0.76-1.96)	1.31 (0.82-2.10)
s' le of treating hospital *				
Large	62 (63.9)	35 (36.1)	1.00	1.00
Small	20 (58.8)	14 (41.2)	0.86 (0.56-1.33)	0.87 (0.57-1.32)
Patient characteristics				
Male	34 (65.4)	18 (34.6)	1.00	1.00
Female	48 (55.8)	38 (44.2)	0.64 (0.44-0.93)	0.61 (0.41-0.89)
Socioeconomic advantage/disadvantage (SEIFA) [§]				
Most affluent	13 (15.9)	14 (25.5)	1.00	1.00
Low to intermediate advantage	29 (35.4)	18 (32.7)	0.88 (0.47- 1.65)	0.82 (0.43-1.58)
Most disadvantaged	40 (48.8)	23 (41.8)	0.95 (0.51- 1.76)	0.94 (0.50-1.77)
R rality of residence (ARIA) [§]				
Major city	17 (20.7)	18 (32.7)	1.00	1.00 ^b
Outer/inner regional	42 (51.2)	24 (43.6)	1.78 (1.10- 2.87)	1.84 (1.14-2.96)
Remote/very remote	23 (28.1)	13 (23.6)	1.53 (0.88-2.67)	1.45 (0.84-2.53)
currer type [¶]				
Breast	22 (55.0)	18 (45.0)	1.00	1.00
Female genital organs	11 (50.0)	11 (50.0)	0.92 (0.49-1.72)	0.94 (0.49-1.76)
Digestive organs	12 (75.0)	4 (25.0)	1.35 (0.72-2.51)	1.11 (0.60-2.06)
Respiratory and intrathoracic organs	10 (66.7)	5 (33.3)	1.36 (0.76-2.42)	1.19 (0.58-2.45)
Male genital organs	7 (50.0)	7 (50.0)	1.07 (0.51-2.21)	0.78 (0.31-1.99)
Other	20 (64.5)	11 (35.5)	1.85 (1.15-2.97)	1.54 (0.84-2.83)
Surgery (reference category no surgery)*	62 (66.7)	31 (33.3)	1.12 (0.68-1.82)	1.26 (0.76-2.07)
Radiotherapy (reference category no radiotherapy)*	39 (72.2)	15 (27.8)	1.43 (0.97-2.11)	1.47 (0.99-2.17)
Chemotherapy (reference category no chemotherapy)*	40 (71.4)	16 (28.6)	1.23 (0.84-1.79)	1.25 (0.85-1.83)
Charlson comorbidity index (CCI)				
CCI=0 (no comorbidity)	29 (60.4)	19 (39.6)	1.00	1.00
CCI=1	28 (65.1)	15 (34.9)	0.94 (0.61-1.46)	1.04 (0.67-1.61)
CCI≥2	25 (53.2)	22 (40.6)	1.05 (0.66-1.69)	1.12 (0.70-1.78)

Row percentages are displayed. * Information about treating hospital or hospital where patient was admitted for diagnosis was not available for 7 patients, and it was not clear in the notes whether patients had surgery (n=4), chemotherapy (n=10) or radiotherapy (n=17) - these were included as a category in the model but IRR not presented here; [¶] Cancer types with less than 10 cases and 2 cases for whom cancer type was not clear were grouped as 'other'; ^ª IRR adjusted for sex and surgery; p-value=0.039.