Changing roles of population-based cancer registries in Australia

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Abstract.   Registries have key roles in cancer incidence, mortality and survival monitoring and in showing disparities across the population. Incidence monitoring began in New South Wales in 1972 and other jurisdictions soon followed. Registry data are used to evaluate outcomes of preventive, screening, treatment and support services. They have shown decreases in cancer incidence following interventions and have been used for workforce and other infrastructure planning. Crude markers of optimal radiotherapy and chemotherapy exist and registry data are used to show shortfalls against these markers. The data are also used to investigate cancer clusters and environmental concerns. Survival data are used to assess service performance and interval cancer data are used in screening accreditation. Registries enable determination of risk of multiple primary cancers. Clinical quality registries are used for clinical quality improvement. Population-based cancer registries and linked administrative data complement clinical registries by providing high-level system-wide data. The USA Commission on Cancer has long used registries for quality assurance and service accreditation. Increasingly population-based registry data in Australia are linked with administrative data on service delivery to assess system performance. Addition of tumour stage and other prognostic indicators is important for these analyses and is facilitated by the roll-out of structured pathology reporting. Data linkage with administrative data, following checks on the quality of these data, enables assessment of patterns of care and other performance indicators for health-system monitoring. Australian cancer registries have evolved and increasingly are contributing to broader information networks for health system management.

Traditional roles

Cancer registries perform a fundamentally important role in monitoring incidence, mortality and survival by cancer type across the population and show sociodemographic disparities.[1] Registries are indispensible for demonstrating the changing burden of cancers and how they affect different segments of the population. Incidence monitoring first began in NSW in 1972 but other jurisdictions soon followed.[1] The Australian Institute of Health and Welfare first compiled and reported national data in 1982, followed shortly after by survival data.[1,2]

Registry data help to direct initiatives to improve preventive, screening, treatment and support services.[3–5] Examples of this include the targeting of antismoking and cervical screening initiatives at lower socioeconomic and remote sectors of the population in response to elevated incidence rates of lung and cervical cancers in those groups.[6,7] Registry data demonstrated the decreases in cancer incidence following these initiatives.[6,7]

Cancer registry data are also used for workforce and other infrastructure planning.[8–10] Crude markers of optimal radiotherapy and chemotherapy use have been developed;[11,12] registry data have been used to show shortfalls in service delivery against these markers,[11,12] leading to improvements in service configuration.[8–10]

Registry data are used to investigate cancer clusters.[13–15] Cancer concerns arising from exposures to occupational and ambient environmental hazards are also investigated with registry data.[16–21] Examples have included exposures to radon gas in mining and household settings,[16] asbestos dust in mining,

building and domestic environments,[17] combustion products of fossil fuels,[18] agricultural pesticides,[19] industrial solvents,[20] and by-products of water disinfection.[21]
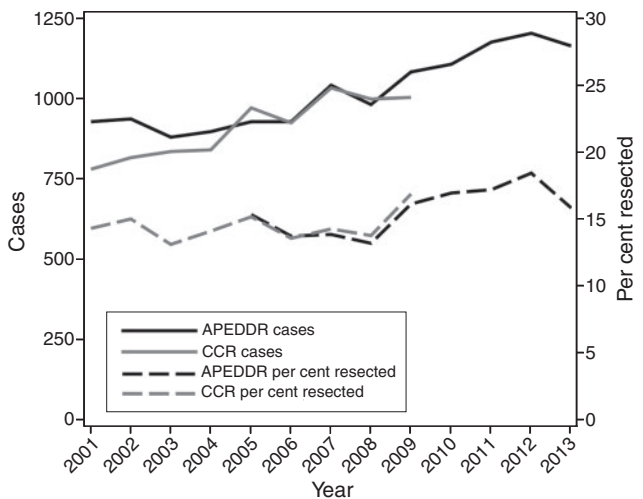

Fig. 1. Annual numbers of pancreatic, ampullary and periampullary cancers diagnosed in New South Wales and the per cent of people resected: a comparison of data from the Central Cancer Registry (CCR) and the Admitted Patient, Emergency Department and Deaths Register (APEDDR) by year, NSW, 2001–2013.

More recent roles

Health service evaluations use survival data from registries to assess service performance.[22] Favourable trends have included improved survival from childhood cancers, cancers of the breast, large bowel, testis, lymphomas and chronic myeloid leukaemia.[23,24] Conversely emerging cancers of concern are highlighted, with current examples including mesothelioma and hepatocellular carcinoma.

Registry data enable interval cancer rates to be determined and are used as part of the accreditation of screening services.[25] Registries are used to evaluate effects of screening and treatment services on cancer mortality and to investigate downsides, including potential for 'over-diagnosis'.[26–31]

The risk of multiple primary cancers following index cancer diagnoses has been investigated with registry data, along with implications for medical surveillance protocols.[32] Clinical quality registries are used for clinical quality surveillance and improvement.[33] They commonly rely on population-based registry data for assessing cancer coverage and the extent to which their recorded cases are representative of all cases.[34] Population-based cancer registries complement the role of local clinical registries when, for example, the local registry no longer has a person in their geographical catchment area, thus allowing for more complete survival analyses.[34]

The US Commission on Cancer has long used clinical registries (hospital-based) for quality assurance and service
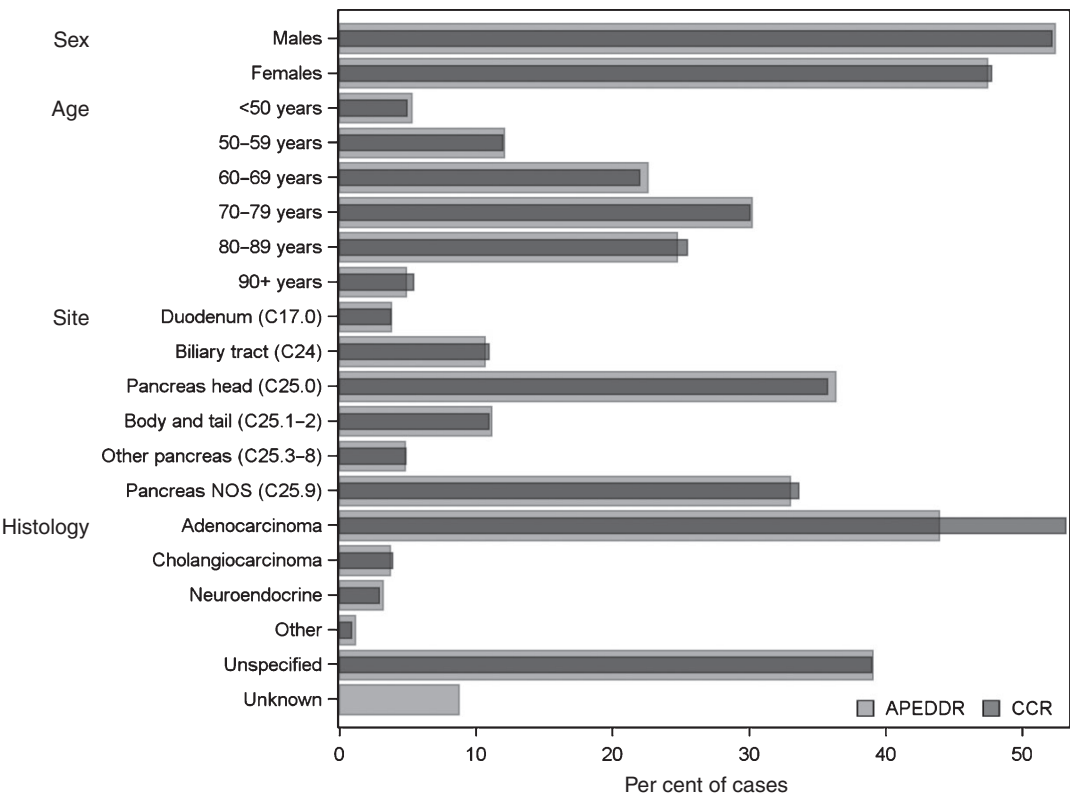

Fig. 2. Numbers of pancreatic, ampullary and periampullary cancers diagnosed in New South Wales by demographic (sex and age) and tumour characteristics (primary site and histology): a comparison of data from the Central Cancer Registry (CCR) and the Admitted Patient, Emergency Department and Deaths Register (APEDDR), NSW, 2005–2009. NOS, not otherwise specified.

accreditation.[35] Clinical registry data on case survival, patterns of care and other clinical indicators have been used to assess service quality.[34]

Emerging roles

Increasingly, population registry data are linked with administrative data on service delivery to assess system-wide performance.[36–40] Addition of tumour/node/metastases (TNM) cancer stage and other prognostic indicators to registry databases is important for these analyses and is facilitated by the increased use of structured pathology reporting advocated by the Royal College of Pathologists of Australasia.[41]

Registry data linkage with administrative data enables assessment of patterns of care and other performance indicators for health-system monitoring.[36–40] Administrative data may lack the quality of customised registry data, but they complement the registry data and are adequate for showing broad population-wide patterns of care.[34,36–38] Clinical registries may be used to validate linked administrative data in instances where these data cover common patient groups.[34,40]

Increasing timeliness of service monitoring

Population-based cancer registry data generally are not available until a year (at best) after reporting periods of interest in order to gain maximum accuracy and complete case ascertainment.[1] To achieve greater currency for quality assurance, administrative data are sometimes substituted but are of more variable quality. Examples include linked hospital and death record data. The accuracy of such alternatives needs to be checked and cancer registry data are used for this purpose. NSW cancer registry data are used to validate the accuracy of more timely linked hospital and death record data by direct comparison of data from these sources for earlier periods of data overlap. Linked NSW hospital and death data are commonly used to monitor surgical resection rates and associated mortality rates.[36–38] The validity of these data needs to be checked when service agencies use them to monitor service performance. This validation process is illustrated with pancreatic cancer data.

Figure 1 shows good agreement between numbers of pancreatic cases and resection rates derived from the cancer registry and linked databases compared with data from the admitted patient dataset and the death index for 2005–2008. (The larger difference in case numbers for 2009 reflects partial completion of cancer coding for that year at the time of data extraction.).

Figure 2 shows good agreement for patient demographics and tumour primary site for 2005–2009, although for histology type, recording is less complete in hospital administrative data. Linked registry, hospital and death data and linked hospital and death data gave similar 90-day mortality rates of 5.3% and 5.5% respectively for all causes of death for 2001 to 2006. One-year survivals were also similar at 75.7% and 73.5%.

For these applications, the contemporary linked administrative data for pancreatic cancer appear to be accurate enough for broad population-based monitoring.

Conclusion

Roles of Australian cancer registries have evolved since their introduction in the 1970s. Increasingly they are contributing to broader information networks for health systems management. In addition to traditional incidence and mortality monitoring, data on stage and stage-specific survivals and linked patterns of care are being used. Structured reporting (pathology, surgery and radiology) is increasing opportunities for automated collection by registries of data on stage, grade, biomarkers and other prognostic indicators.

Competing interests

None declared.

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