CHAPTER 10

CANCER REPORT

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Recording of Cancers in People with End Stage Kidney Disease: Agreement of ANZDATA and the New South Wales Cancer Registry

ANZDATA has prospectively collected data from all renal units in Australia and New Zealand from the first use of renal-replacement therapy in Australia and New Zealand in 1963. The clinical data collected has included records for all new cancers in all patients, except for squamous and basal cell cancers of the skin, when only the first diagnosis of these cancer types during dialysis therapy and the first diagnosis after transplantation is recorded for each patient.

Cancers are coded for site and cell type using codes adapted from the International Classification of Diseases for Oncology (ICD-O), first edition. Cancer records include stage, treatment and dates of recurrence and may or may not be supported by pathology reports. Additional information or clarification may be sought by the registry from the reporting renal unit. Quality control methods for data entry and consistency are routine for all data held in ANZDATA, and corrections are also made when inaccuracies are identified when the data are used. Verification and audit of ANZDATA cancer records for accuracy and completeness has not previously taken place. Direct audit would involve a retrospective review of case notes and patient records at each renal unit across Australia and New Zealand, requiring personnel, time and resources that the registry does not have. An alternative method is to compare ANZDATA cancer records with those of other agencies holding individual patient records containing details of cancer diagnoses.

We have thus compared the records of incident cancer diagnoses in patients with end stage kidney disease held in ANZDATA (voluntary reporting system) with those reported to the New South Wales (NSW) State Cancer Registry (mandated by State law).

The NSW Cancer Registry

Across Australia, each State and Territory has a population-based cancer registry, reporting to the National cancer statistics clearing house, which collates cancer data for the Australian Institute of Health and Welfare (http://www.aihw.gov.au/cancer/index.cfm). In NSW the NSW Central Cancer Registry (CCR) is the population-based registry of all cancers in residents of NSW, and has been operating since 1972. At the time of this study CCR was managed by the Cancer Council of NSW (http://www.nswcc.org.au), although subsequently management was transferred to the Cancer Institute of NSW (http://www.cancerinstitute.org.au/cancer_inst). CCR is owned and funded by the NSW Department of Health and operates under the authority of the Public Health Act 1991.

Notification of malignant cancers is a statutory requirement for public and private hospitals, departments of radiation oncology, nursing homes, pathology laboratories, outpatient departments and day-procedure centres. When any of these institutions diagnose or treat someone with cancer, they are required by law to notify the NSW CCR. Data are supplemented by pathology reports and death certificates and data for NSW residents are also received from cancer registries in other States and Territories.

Data collected includes identifying and demographic information, brief medical details describing the cancer and a record of at least one episode of care from each notifier. Records are then coded for site (topography) and cell type (morphology) according to the ICD-O, third edition. Notification of basal and squamous cell carcinoma of the skin are not required. Quality control measures implemented routinely include monitoring of rates for each notifier, data entry validation and checks of consistency, periodic checks of the accuracy and reliability of coding and data entry, reconciliation of information from multiple sources, computerized scrutiny for multiple registrations of the same person, correction of inaccuracies found when data are used, coding audit in collaboration with medical experts and other cancer registries.

Data linkage

Comparison of cancer records held by ANZDATA and those held by CCR was achieved through data linkage of the two datasets. Data linkage of individuals present in both datasets (i.e. those with both treated end stage kidney disease and with at least one cancer) was automated using specialised software.

We undertook data linkage using probabilistic methods with demographic data fields to identify individuals. The technique of probabilistic linkage was devel-

oped to facilitate matching of health records when unique identifiers are not available and there are a limited number of variables that are common to the two data sets (Wagner G, Newcombe HB. Methods of Information in Medicine.1970; 9(2):121-38). Data fields used to identify individuals were first name, family name, any other name (alias, pseudonym, name before marriage), sex, postcode, date of birth, date of diagnosis and specific cancer site. Other address details beyond postcode could not be used as these are not recorded by ANZDATA.

The linkage process was automated and was repeated three times, with the relative importance of each matching field altered for each pass by differential weighting. The probability of each field matching within an individual record were aggregated into a score and checked against a pre-determined threshold to decide whether a match had been made, with three outcomes possible: true non-matches (the majority), true matches and potential matches. Manual review of the records for potential matches was undertaken, using standardised and pre-determined criteria (including additional data fields such as date of death) for accepting or rejecting a match. This detects typographical errors and transpositions and increases the accuracy of record classification. This linkage methodology typically identifies 85-99% of true matches, while 1-5% of matches will be false positives.

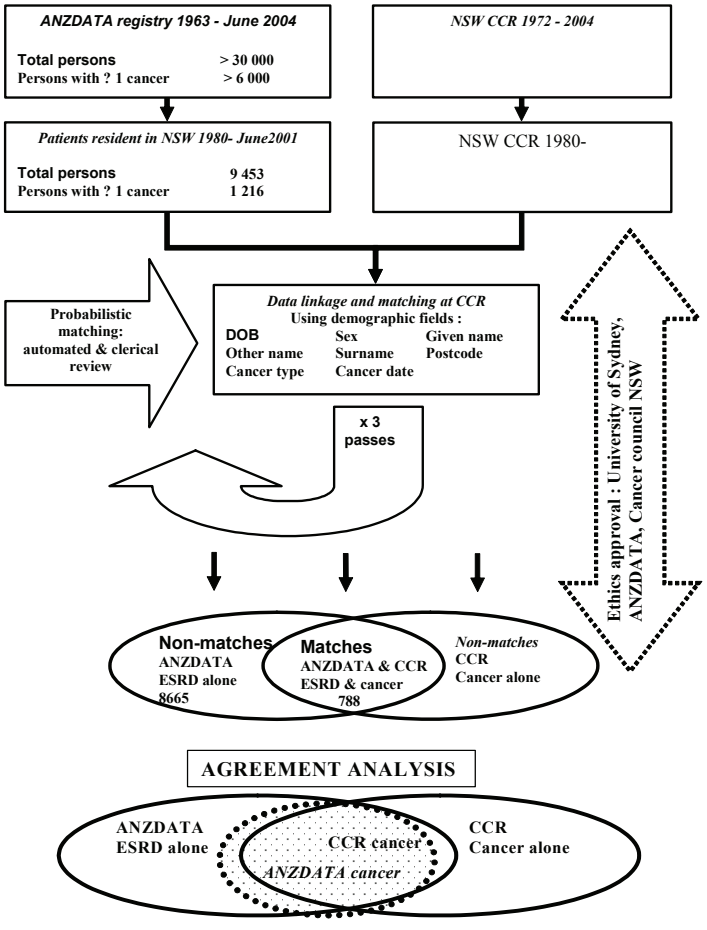
All ANZDATA records of patients resident in NSW, and all CCR records of people with cancer registrations between 1980 – June 30th 2001 were included. The lower and upper year constraints were determined by availability of complete information in CCR, as prior to 1980 some data fields were not collected, and record fields had not yet been completely updated after June 2001.

STATISTICAL ANALYSIS

Two datasets of ANZDATA patients with ESRF alone (non-matches) and those with both ESRF and at least one cancer notified to CCR (matches) were identified as above (fig 10.1).

Figure 10.1

Algorithm to show data flow in establishing linked and matched datasets between ANZDATA and NSW CCR, which were then used for analysis. Cancer records did not include non-melanocytic skin cancers in either registry.



We calculated agreement between the registries for patients with >=1 cancer and for all reported cancers using kappa-statistics of agreement beyond chance. To investigate whether agreement varied by cancer site, coding of cancers in ANZDATA and in CCR were standardised to ICD-O site-specific codes, and site-specific agreement was calculated. To investigate whether agreement varied depending on the modality of renal replacement a patient was under-going when cancer was diagnosed, agreement was then assessed for cancers diagnosed whilst patients were receiving dialysis, and for those diagnosed at any time after first kidney transplantation.

Given that the CCR provides data to national agencies from which public health policy is derived, and is generally regarded as the principal source of summary cancer statistics in NSW, we calculated the sensitivity (the probability that ANZDATA recorded a cancer when CCR had recorded a cancer), specificity (the probability of ANZDATA not recording a cancer when CCR had no cancer recorded) and positive predictive value (PPV - the probability that a patient has the disease, i.e. cancer as recorded by CCR, when restricted to those patients who test positive, i.e. have a cancer as reported by ANZDATA) and negative predictive values (NPV - the probability that a patient will not have the disease, i.e. cancer as recorded by CCR, when restricted to all patients who test negative, i.e. do not have a cancer as defined by ANZDATA) for an ANZDATA recording of cancer compared to CCR, using a CCR cancer record as the reference standard.

To investigate the robustness of our analyses we repeated the above after excluding diagnoses of cancer in patients that were made within 30 days of commencing renal replacement therapy. The thirty day exclusion was chosen as CCR date of diagnosis was supplied as month and year only, and we imputed the day of diagnosis from other data, and also because the chronology of cancer, confirmed cancer diagnosis and the commencement of renal replacement therapy is uncertain in this 'grey area' time-period. We expected errors to be introduced by both these factors, and hypothesised that agreement would be improved after the exclusion of these cases.

To investigate whether disagreement between ANZDATA and CCR cancer records had any important consequences for the interpretation of previous analyses of ANZDATA cancer data, we compared cancer risk in the ANZDATA population first using a CCR record to define a cancer case, and then repeated the analysis using an ANZDATA record to define a cancer case. We calculated standardised incidence ratios (with 95% confidence intervals) for patients on dialysis and after first kidney transplantation, compared to the normal population of NSW. Risk was calculated for all cancers, and then by cancer site, using indirect standardisation, by age, sex and calendar year (in practical terms this means the risk calculation reflected risk for patients with ESRD compared to a NSW population of the same age and sex distribution, with cancers diagnosed in the same years).

We investigated non-concordant cases where cancers were reported in CCR but not in ANZDATA by returning to the master ANZDATA data-set and scrutinising patient records. Where no explanation for disagreement was evident, the potential error was referred back to the reporting renal unit and re-investigated to seek possible explanation. Non-concordant cases in CCR (where ANZDATA reported a cancer but CCR did not) could not be investigated beyond informing CCR, due to the restrictions imposed under ethics conditions relating to privacy laws.

AGREEMENT

A total of 9453 patients from the ANZDATA registry were resident in NSW between 1980 - June 2001, and ANZDATA recorded 881 cancers in 788 patients during this time. Characteristics of the ANZDATA population that underwent linkage with CCR are summarised in Figure 10.2.

Data linkage resulted in a matched dataset of 788 patients who had 867 cancers recorded on CCR and who were also present in the ANZDATA registry. Of these 788 patients with a cancer record on CCR, 610 had a

Figure 10.2

Characteristics of ANZDATA Population Linked to NSW Cancer Council Registry

		Cancer Recorded on ANZDATA	Total
Total Persons		788	**9,453**
Gender	Female	397	**4,335**
	Male	391	**5,118**
Age at ESRF	<20	27	**495**
	20-39	157	**1,893**
	40-54	222	**2,444**
	55-69	312	**3,248**
	>=70	70	**1,373**
Status	Living	201	**4,311**
	Deceased	587	**5,142**
RRT 1980-2001	Dialysis alone	498	**6,933**
	Dialysis then transplanted	201	**2,073**
	Transplanted before 1980	89	**447**

corresponding cancer record on ANZDATA, with an overall agreement of 75.4%. ANZDATA recorded 178 patients with 212 cancers that CCR did not, and CCR recorded 178 patients with 197 cancers that ANZDATA did not. As expected, excluding those cancer records with reported dates of diagnosis within 30 days of commencing renal replacement therapy from analysis improved agreement, with 742 patients with cancer recorded on CCR, and 747 on ANZDATA, 585 patients with cancer records on both registries, with agreement of 77.7%. There was little difference in the agreement of cancer records between the two registries depending on the modality of renal replacement a patient was receiving at the time of reported cancer diagnosis, with agreement of 75.5% for cancers during dialysis therapy, and 75.1% for cancers after transplantation. Full details of calculated agreement at patient and at cancer level, and sensitivity, specificity, PPV and NPV of an ANZDATA record of cancer (when compared to a CCR record), are reported in Figure 10.3. Agreement of cancer records varied by site of cancer (fig 10.4) but was generally good (60-80%) or very good (>80%). On initial analysis ANZDATA recorded lip cancers very poorly, with only one record compared to 53 on CCR. We hypothesised that lip cancers may have been misclassified by ANZDATA and recorded as basal or squamous cell skin cancers, and so the records would not have been included in the linked dataset, but would be present in the master data-set, coded as skin cancers of the face or lip. Interrogation of the ANZDATA master data-set revealed 15 patients with a lip cancer record on CCR who had a skin cancer record on ANZDATA on or around the lip with a similar diagnosis date, which improved overall agreement to 46.2%. Additionally a further nine patients had a skin cancer record at a different body site in the ANZDATA master data-set with a diagnosis date prior to that of the CCR lip diagnosis. Given the ANZDATA policy of recording only the first skin cancer of each morphological type during dialysis and after transplantation, should these nine patients subsequently have developed a basal or squamous cancer of the lip, these would not have been recorded. A further 10 patients had a skin cancer recorded with lip as the topographic site on ANZDATA, that did not have a corresponding lip cancer record on CCR.

Overall and site-specific cancer risk for patients undergoing dialysis therapy are shown in Figure 10.5, comparing the standardised incidence ratios calculated using CCR recorded cancers and using ANZDATA recorded cancers. Overall the estimates

Figure 10.3

Numbers and overall agreement of cancers recorded by ANZDATA and by CCR. Sensitivity, specificity, positive and negative predictive values of ANZDATA cancer records are calculated using CCR as the reference standard. Data are reported for all records, and after excluding those cancer records with diagnosis dates within 30 days of starting dialysis or of transplantation.

Numerator	ANZDATA	CCR	Overall agreement %	Sensitivity % [95% CI]	Specificity % [95% CI]	PPV * %	NPV * %
All persons with cancer	788	788	75.4	77.4 [74.3, 80.3]	97.9 [97.6, 98.2]	77.5	97.9
30 day exclusion	758	742	77.7	80.3 [77.3, 83.1]	98.1 [97.8, 98.4]	78.6	98.3
All cancers	881	867	72.6	75.7 [72.7, 78.5]	97.4 [97.1, 97.7]	74.8	97.5
30 day exclusion	851	816	75.2	79.0 [76.1, 81.8]	97.7 [97.3, 98.0]	76.1	98.0
All persons with cancer on dialysis	517	521	75.5	76.6 [72.7, 80.2]	98.6 [98.3, 98.8]	77.2	98.6
30 day exclusion	487	475	78.9	81.8 [77.2, 84.5]	98.8 [98.6, 99.0]	79.1	98.9
All cancers of dialysis	572	572	73.7	75.3 [71.6, 78.8]	98.4 [98.1, 98.6]	75.6	98.3
30 day exclusion	540	521	77.5	80.2 [76.5, 83.6]	98.6 [98.3, 98.8]	77.7	98.8
All persons with cancer after transplantation	273	267	75.1	78.7 [73.2, 83.4]	97.2 [96.4, 97.8]	76.9	97.5
30 day exclusion	271	265	75.0	78.5 [73.0, 83.3]	97.2 [96.4, 97.8]	76.8	97.5
All cancers after transplantation	309	295	72.5	78.5 [73.0, 83.3]	97.2 [96.4, 97.8]	76.8	97.5
30 day exclusion	306	281	72.5	79.0 [73.8, 83.6]	96.3 [95.5, 97.1]	72.9	97.3

* **PPV** = positive predictive value; the probability that a patient has the disease (i.e. cancer, as recorded by CCR) when restricted to those patients who test positive (i.e. have a cancer as reported by ANZDATA).
* **NPV** = negative predictive value; the probability that a patient will not have the disease (i.e. cancer, as recorded by CCR) when restricted to all patients who test negative (i.e. not having a cancer as defined by ANZDATA).

for each cancer site are very similar, and are also similar to those previously reported by ANZDATA for the whole of Australia and New Zealand's population undergoing dialysis (although when confining the analysis to NSW alone, the population considered is smaller, and so the estimates are less precise, hence the wider confidence intervals). Of note, ANZDATA underestimates the risk of lip cancer and of myeloma when compared to CCR records (SIR 5.75 versus SIR 10.06, respectively). The reason for the underestimation of lip cancers is discussed above. For myeloma it is likely that the discrepancy arises due to the recorded timing of myeloma diagnosis relative to commencing renal replacement therapy; our analysis compared only cancers recorded in ANZDATA after the start of dialysis or after transplantation. Overall agreement of myeloma diagnoses was moderate (46.5% table 3), with CCR recording 32 cases, where ANZDATA had 22. When investigating the possible explanation for the 197 CCR cancer records that were not recorded in ANZDATA (i.e. did not agree), 20 (10.2%) were found to be CCR records of myeloma that ANZDATA did have recorded, but as a pre-ESRD diagnosis (fig 10.5). Given that myeloma often precipitates ESRD, and hence dialysis, and that in clinical circumstances confirmed diagnosis may follow these events, it is possible that the ANZDATA SIR more accurately reflects true risk of new cases of myeloma arising after ESRD. In contrast, ANZDATA overestimates the risk of bladder (SIR 6.97 versus

Figure 10.4

Numbers of cancers by site recorded by ANZDATA and by CCR, overall agreement and sensitivity and specificity of ANZDATA recorded compared to CCR records

Cancer Site	ANZDATA	CCR	Overall agreement %	Sensitivity % [95% CI]	Specificity % [95% CI]	PPV * %	NPV * %
Lip *	16	53	46.2	30.2 [18.3, 44.3]	100 [99.9, 100]	100.0	99.6
Head and neck	26	27	75.4	74.1 [53.7, 88.9]	99.9 [99.9, 100]	76.9	99.9
Oesophagus	13	9	66.6	77.8 [40.0, 97.2]	99.9 [99.9, 100]	58.3	100
Stomach	7	11	66.6	54.5 [23.4, 83.3]	100 [99.9, 100]	85.7	99.9
Small intestine	5	4	66.6	75.0 [19.4, 99.4]	100 [99.9, 100]	60.0	100
Colorectal	94	97	83.6	82.5 [73.4, 89.4]	99.9 [99.7, 99.9]	85.1	99.8
Liver	13	7	59.9	85.7 [42.1, 99.6]	99.9 [99.8, 100]	46.1	100
Pancreas	14	11	66.6	72.7 [39.0, 94,0]	99.9 [99.9, 100]	57.1	100
Nasal cavity or larynx	5	3	75.0	100 [29.2, 100]	99.9 [99.9, 100]	59.4	100
Trachea, bronchus, lung	70	68	78.1	79.4 [67.9, 88.3]	99.8 [99.7, 99.9]	77.1	99.9
Melanoma	61	57	64.1	64.9 [51.1, 77.1]	99.7 [99.6, 99.8]	60.7	99.8
Kaposi's sarcoma	14	10	75.0	90.0 [55.5, 99.7]	99.9 [99.9, 100]	64.3	100
Breast	50	45	86.2	91.1 [78.8, 97.5]	99.9 [99.8, 100]	82.0	100
Cervix	11	12	78.2	75.0 [42.8, 94.5]	100 [99.9, 100]	37.5	100
Uterus, ovary, other female genital	28	21	61.1	71.4 [47.8, 88.7]	99.9 [99.8, 99.9]	53.6	99.9
Prostate	36	39	75.6	71.8 [55.1, 85.0]	99.9 [99.8, 100]	77.8	99.9
Penis, testis, other male genital	5	3	28.5	33.3 [0.84, 90.6]	100 [99.9, 100]	20.1	100
Bladder	74	45	60.9	77.8 [62.9, 88.8]	99.6 [99.4, 99.7]	47.3	99.9
Kidney, ureter, urethra *	86	78	77.9	82.1 [71.7, 89.8]	99.8 [99.6, 99.9]	74.4	99.9
Brain and CNS	7	5	66.7	80.0 [28.4, 99.5]	100 [99.9, 100]	57.2	100
Thyroid	22	20	80.9	77.3 [54.6, 92.2]	100 [99.9, 100]	85.5	99.9
All lymphoma	70	60	83.0	90.0 [79.5, 96.2]	99.8 [99.7, 99.9]	77.2	99.9
Multiple myeloma *	22	32	46.5	36.8 [21.8, 54.0]	99.9 [99.8, 100]	63.6	99.7
All leukaemia	25	24	85.7	87.5 [67.6, 97.3]	100 [99.9, 100]	84.0	100

* Numbers and data reported are for cancer records after the exclusion of those cancers with dates of diagnosis within 30 days of commencement of renal replacement therapy. For these cancer sites there was a large improvement in agreement with this condition imposed. For lip cancers data reported are after correction for ANZDATA lip cancer records misclassified as skin cancers (see text for further details).

4.32) cancers compared to CCR. The reason for this difference is less evident, but may reflect differential classification of recurrent and new multiple tumours between the two registries.

Overall and site-specific cancer risk for patients after first transplant are shown in Figure 10.6. Again, overall the estimates for each cancer site are very similar for CCR and ANZDATA recorded cancers, and are also similar to those previously reported by ANZDATA for the whole of Australia and New Zealand's population, but with a smaller transplant population than dialysis in NSW estimates are less precise. ANZDATA overestimated risk of oesophageal cancer (SIR 8.01 versus 4.00) and underestimated stomach cancer (SIR 0.48 versus 1.91) compared to CCR. However, when the risk of either oesophageal or stomach cancer was calculated, the estimates were similar (SIR 2.91 versus 2.59), suggesting the difference arose through differences in precise classification of cancers in this part of the gastrointestinal tract.

The possible reasons for CCR recording a cancer that ANZDATA did not were further investigated in the ANZDATA master data-set, and the results are shown in Figure 10.7. For the 197 cancers that CCR recorded, a likely explanation was found for 72 (38%). ANZDATA is unlikely to be informed of and so record cancers diagnosed post-mortem than CCR, which collates data from death certificates; 18 (9%) of CCR records had a diagnosis date within a week of date of death. Lip cancers accounted for 33 (17%)

Figure 10.5

Comparison of SIR for **dialysis patients** in NSW 1980 - 30 June 2001, comparing risk calculated from cancers defined by CCR with risk calculated from cancers defined by ANZDATA. Indirectly standardised by age, sex and calendar year, 9006 patients total.

Cancer Site	CCR defined cancers 33,095 person years			ANZDATA defined cancers 32,997 person years		
	Observed	Expected	SIR (95% CI)	Observed	Expected	SIR (95% CI)
All Cancers	572	267.91	2.14 [1.9, -2.32]	572	267.10	2.14 [1.97, 2.32]
Lip	22	2.57	8.56 [5.64, 13.00]	13	2.58	5.05 [2.93, 8.69]
Head and neck	15	6.74	2.23 [1.34, 3.69]	15	6.73	2.23 [1.34, 3.70]
Oesophagus	5	3.43	1.46 [0.61, 3.50]	5	3.43	1.46 [0.61, 3.5]
Stomach	7	7.08	0.99 [0.47, 2.07]	6	7.08	0.85 [0.38, 1.89]
Small intestine	3	0.72	4.17 [1.35, 12.94]	4	0.72	5.56 [2.09, 14.82]
Colorectal	65	42.26	1.54 [1.21, 1.96]	61	42.28	1.44 [1.12, 1.85]
Liver	5	2.11	2.37 [0.99, 5.69]	9	2.11	4.26 [2.22, 8.19]
Pancreas	8	6.02	1.33 [0.66, 2.66]	8	6.02	1.33 [0.66, 2.66]
Nasal cavity or larynx	3	3.33	0.90 [0.29, 2.79]	4	3.33	1.20 [0.45, 3.20]
Lung	50	32.89	1.52 [1.15, 2.01]	53	32.88	1.61 [1.23, 2.11]
Melanoma	39	23.97	1.63 [1.19, 2.23]	41	23.95	1.71 [1.26, 2.33]
Kaposi's sarcoma	3	0.44	6.82 [2.20, 21.15]	3	0.44	6.82 [2.20, 21.15]
Breast	34	30.48	1.12 [0.80, 1.56]	35	30.46	1.15 [0.82, 1.60]
Cervix	6	2.85	2.11 [0.95, 4.69]	4	2.85	1.40 [0.53, 3.74]
Uterus, ovary, other female genital	10	9.21	1.09 [0.58, 2.02]	14	9.21	1.52 [0.90, 2.57]
Prostate	31	40.23	0.77 [0.54, 1.10]	28	40.23	0.70 [0.48, 1.01]
Penis, testis, other male genital	3	1.22	2.45 [0.79, 7.60]	2	1.22	1.63 [0.41, 6.54]
Kidney, ureter, urethra	78	7.91	9.86 [7.90, 12.30]	88	7.89	11.15 [9.05, 13.74]
Bladder	39	9.03	4.32 [3.15, 5.91]	62	9.03	6.87 [5.36, 8.81]
Brain and CNS	3	4.21	0.71 [0.23, 2.21]	4	4.21	0.95 [0.36, 2.53]
Thyroid	17	2.16	7.89 [4.90, 12.69]	14	2.16	6.49 [3.85, 10.96]
All lymphoma	30	11.12	2.7 [1.89, 3.86]	33	11.12	2.97 [2.11, 4.18]
Multiple myeloma	35	3.48	10.06 [7.22, 14.01]	20	3.48	5.75 [3.71, 8.91]
All leukaemia	16	6.97	2.30 [1.41, 3.75]	13	6.97	1.87 [1.08, 3.21]

of CCR records without a corresponding record in ANZDATA, and this is likely to be for reasons discussed above: ANZDATA has misclassified lip cancers as skin cancers. There was no obvious explanation for 100 (51%) cancers with a record in CCR but not in ANZDATA. The site-specific distribution of these cancers is shown in Figure 10.7. Eighteen (9%) were melanomas, and it may be that increasing outpatient treatment of skin lesions at dedicated clinics means that renal units are less aware of malignant melanomas than of other diagnosed cancers, which would require their more active participation in management.

The investigation of potential reasons for the 212 cancers that ANZDATA recorded that CCR did not was not possible, because of privacy legislation.

Figure 10.6

Comparison of SIR for patients after **first transplant** in NSW 1980 - 30th June, comparing risk calculated from cancers defined by CCR with risk calculated from cancers defined by ANZDATA. Indirectly standardised by age, sex and calendar year, 2520 patients total

Cancer	CCR defined cancers 20,127 person years			ANZDATA defined cancers 20,089 person years		
	Observed	Expected	SIR [95% CI]	Observed	Expected	SIR [95% CI]
All cancers	295	89.30	3.30 [2.95, 370]	309	89.42	3.46 [3.09, 3.86]
Lip	31	1.02	30.52 [21.46, 43.40]	3	1.02	2.93 [094, 9.08]
Head and neck	13	2.68	4.86 [2.82, 8.36]	13	2.68	4.86 [2.82, 8.36]
Oesophagus	4	1.00	4.00 [1.50, 10.66]	8	1.00	8.01 [4.01, 16.02]
Stomach	4	2.09	1.91 [0.72, 5.10]	1	2.09	0.48 [0.07, 3.39]
Colorectal	36	13.58	2.65 [1.91, 3.68]	34	13.56	2.51 [1.79, 3.51]
Liver	2	0.67	2.99 [0.75, 11.94]	4	0.67	5.97 [2.24, 15.91]
Pancreas	3	1.75	1.71 [0.55, 5.31]	6	1.75	3.42 [1.54, 7.62]
Lung	18	9.54	1.89 [1.19, 3.00]	17	9.54	1.78 [1.11, 2.87]
Melanoma	22	10.29	2.14 [1.41, 3.25]	26	10.27	2.53 [1.72, 3.72]
Kaposi's sarcoma	7	0.33	21.34 [10.17, 44.75]	13	0.33	39.64 [23.02, 68.27]
Breast	14	14.31	0.98 [0.58, 1.65]	20	14.30	1.40 [0.90, 2.17]
Cervix	6	1.56	3.85 [1.73, 8.56]	7	1.56	4.49 [2.13, 9.41]
Uterus, ovary and other female genital	11	4.21	2.61 [1.45, 4.72]	15	4.21	3.56 [2.15, 5.91]
Prostate	8	8.44	0.95 [0.47, 1.89]	8	8.44	0.95 [0.47, 1.89]
Kidney, ureter, urethra	28	2.69	10.39 [7.18, 15.05]	28	2.70	10.39 [7.17, 15.05]
Bladder	12	2.39	5.03 [2.86, 8.86]	18	2.38	7.56 [4.76, 11.99]
Brain and CNS	2	1.78	1.12 [0.28, 4.49]	3	1.78	1.68 [0.54, 5.22]
Thyroid	5	1.21	4.14 [1.73, 9.96]	6	1.21	4.97 [2.23, 11.07]
All lymphoma	31	4.19	7.40 [5.20, 10.52]	38	4.19	9.07 [6.60, 12.46]
Multiple myeloma	3	1.08	2.78 [0.90, 8.62]	2	1.08	1.85 [046, 7.41]
All leukaemia	8	2.25	3.56 [1.78, 7.11]	12	2.25	5.34 [3.03, 9.40]

Figure 10.7

Investigation of cancers recorded by CCR but not recorded by ANZDATA (total 197 cancers)

Explanation for ANZDATA not recording CCR cancer	Number (% of total 197 cancers)
Likely explanation identified	97 (49)
Explanation:	
Record in ANZDATA pre ESRD	35 (18)
Record in ANZDATA after 30th June 2001	5 (3)
Record in ANZDATA as metastases from earlier cancer	7 (4)
Record in ANZDATA as in-situ premalignant lesion	3 (2)
CCR date of diagnosis within 7 days of death	18 (9)
Recorded (data processing/analysis error)	6 (3)
Lip cancers	33 (17)
No obvious explanation	100 (51)
Site:	
Unknown primary	6 (3)
Melanoma	18 (9)
Bladder	4 (2)
Kidney	5 (3)
Prostate	10 (5)
Colorectal	10 (5)
Head and neck	5 (3)
Trachea, bronchus, lung	4 (2)
Thyroid	5 (3)
Other sites	23 (12)

Conclusions

This analysis shows that ANZDATA cancer reporting has identified and classified the vast majority of cancers correctly when judged against the mandatory reporting system of the NSW CCR, and the voluntary contribution and dedication of all reporting renal units must be commended. There are however some notable cancer types where the ANZDATA registry has under-reported cancers, especially lip cancer through misclassification, and some where ANZDATA appears to have over-reported, such as bladder. It is still unclear whether some missed records arose from lack of recognition, lack of reporting, or differences in the reporting of prevalent versus incident cases between the two registries. There is also unmeasured error which will have arisen in the data linkage process, which can be expected to produce false positive matches in 1-5 % of cases.

Our analysis focused on CCR as the reference standard, and unfortunately we were unable to explore cancer records from the reverse perspective using ANZDATA as the standard, against which we could additionally have better explored the strengths and weakness of CCR.

A project to link all Australian State cancer registries with the full ANZDATA registry file is underway at the present time and will allow refinement of the information we have generated here.

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