JOURNAL OF ADOLESCENT AND YOUNG ADULT ONCOLOGY
Volume 00, Number 00, 2020

DOI: 10.1089/jayao.2020.0151

Cancer Incidence, Mortality, and Survival for Children, Adolescents, and Young Adults in Queensland Between 1987 and 2016

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Purpose: Cancer remains the most common cause of disease-related death among young people and carries a significant burden. In the absence of prior state-based Australian epidemiological studies, this retrospective cohort study reviewed all cases of invasive cancer diagnosed in Queensland children, adolescents, and young adults (AYAs) (0–39 years) from 1987 to 2016 using the Queensland Oncology Repository (QOR).
Methods: Cancers were classified according to Surveillance, Epidemiology and End Results (SEER) AYA site recode. Age-standardized rates (ASRs) were calculated. JoinPoint regression examined trends in ASRs across three age cohorts, for three decades (1987–1996, 1997–2006, and 2007–2016).
Results: In total, 3,576 children aged 0–14 years (ASR = 15.2/100,000), 6,441 aged 15–24 years (ASR = 39.3/100,000), and 29,923 (ASR = 122.6/100,000) aged 25–39 years were diagnosed. Incidence increased for female children, and leukemia was the most common diagnosis. For those 15–24 years, incidence increased initially before decreasing and was higher than other nationally reported rates. For those 25–39 years, incidence increased. For the older cohorts, the most common diagnosis was melanoma. All cohorts demonstrated a decline in mortality and improvement in 5-year relative survival, with those 0–14 years demonstrating the greatest gains. The lowest survival for all cohorts was associated with central nervous system tumors.
Conclusion: These results highlight areas in need of further investigation to improve survival, reduce the burden of cancer for young people, and aid service delivery. Future studies should focus on cancer biology, early detection, barriers in access to clinical trials, innovative models of care, improved data collection, and patient-reported outcomes.

Keywords: cancer epidemiology, childhood cancer, adolescent and young adult oncology, cancer survivorship

Introduction

Compared with other nations, Australia reports a higher incidence of cancer among children 0–14 years old and adolescents and young adults (AYAs) 15–39 years old.[1–3] While mortality is low in high-income countries, cancer remains the most common cause of disease-related death among children and AYAs.[4,5] Research also highlights the lack of gain in survival for certain cancers in those aged 15–24 years, compared with children or older adults.[5] This is due to several factors that include the following: distinct clinical and pathological features; distinct tumor distribution; delayed diagnosis or presentation; barriers in access to clinical trials, appropriately trained health care professionals and access to age-specific services; and a predominant focus to date on childhood cancer research.[4,6–12] For cancer

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survivors, the number of life-years affected is also greatest in young people, leading to this cohort to have the greatest burden of disease.[4]

Clear understanding of the epidemiology of childhood and AYA cancer incidence and mortality is hindered by variation in age definitions.[13] In addition, there are few state-based epidemiological studies described for Australian AYAs, which limit the planning and delivery of age-appropriate services. Queensland is the third largest Australian state or territory by population, with an ethnic composition of English (37.6%), Australian (36.7%), Irish (11.2%), and Aboriginal or Torres Strait Islander (3.6%) people.[14] Queensland is geographically large with a total land area of 1,729,742 km^2.[15] This has specific implications for the delivery of health care with health services spread diversely across public and private sectors, throughout metropolitan, regional, and rural areas. To aid the development of services, reporting of incidence and mortality within and between different age groups is important. This study therefore aimed to describe the incidence, mortality, and survival of invasive cancer in Queensland in three age cohorts (0–14 years, 15–24 years, and 25–39 years) over a 30-year period between 1987 and 2016.

Methods

Study population

This retrospective cohort study included all cases of invasive cancer diagnosed in individuals aged 0–39 years from 1987 to 2016 in Queensland. Data were extracted from the Queensland Oncology Repository (QOR). QOR collates and matches patient-level administrative and clinical data from the Queensland Cancer Register (QCR), together with public and private hospital admissions, pathology, radiology, treatment and mortality data. The QCR is population based, and maintains a register of all cases of cancer (excluding basal and squamous cell carcinoma of the skin) and tumors of uncertain behavior that have been diagnosed in Queensland since the beginning of 1982. Death data were obtained from the Register of Births, Deaths and Marriages with cause of death coded by the Australian Bureau of Statistics. As data were deidentified ethical approval for this study was not required. Cancers were categorized according to the Surveillance, Epidemiology and End Results (SEER) AYA site recode.[7] While cancer in children is generally reported using the International Classification of Childhood Cancers, we elected to use the SEER site AYA recode system to allow for comparison across groups and with other studies.[16–18] The recode includes relevant morphology information from the International Classification of Childhood Cancers, including specific childhood cancers, as well as relevant topographical information for AYAs.[7]

Variables included and age group definition

Variables included age at diagnosis, date of diagnosis, date of death, age at death, primary site, morphology, area-level socioeconomic status at diagnosis, and remoteness of residence at diagnosis. Age groups included 0–14 years, 15–24 years, and 25–39 years. To allow for comparisons with published international data, we also combined the 15–24 and 25–39 year cohorts into one group aged 15–39 years.[4]

Analysis

Age-standardized rates (ASRs) per 100,000 population were directly standardized to the 2001 Australian population.[19] JoinPoint regression package version 4.7.0.0[20] was used to examine trends in ASRs from 1987 to 2016 for all invasive cancers across the three cohorts. A maximum of three joinpoints were specified with a minimum of 6 years between joinpoints. The model that provided the best fit was selected. Monte Carlo Permutation method was used to test for significant trends. Results were expressed as annual percentage change (APC) with 95% confidence intervals (CIs). We also calculated ASRs for each of the three 10-year time periods (1987–1996, 1997–2006, and 2007–2016) for the five most common cancers in each age cohort with differences across time or between sexes expressed as relative change. Five-year relative survival (RS) was calculated for four time periods (1997–2001, 2002–2006, 2007–2011, and 2012–2016) from the date of diagnosis and censored at December 31, 2018. RS estimates were produced using the period method.

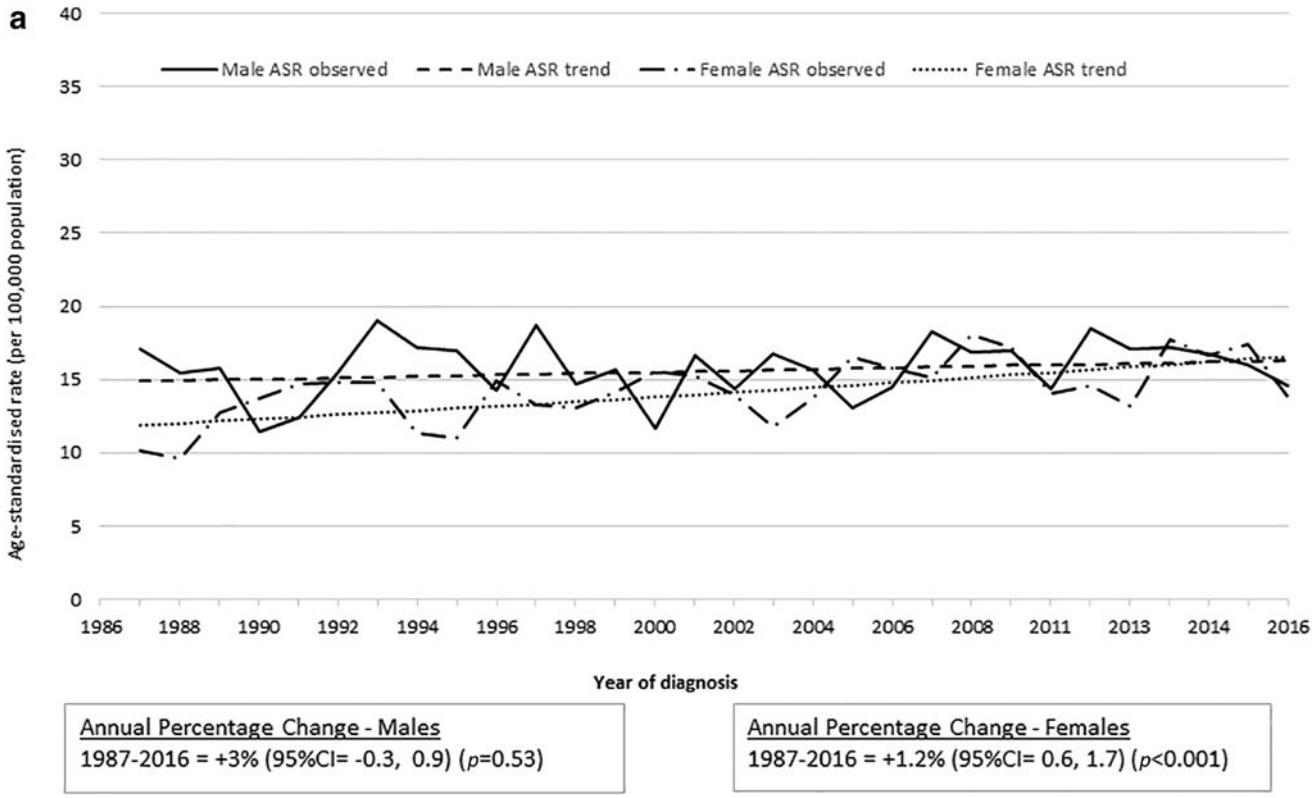
Results

Incidence

Zero to 14 years. From 1987 to 2016 a total of 3576 children were diagnosed with an invasive cancer in Queensland (53.7% male, ASR 15.2/100,000). In males, the ASR for incidence remained stable with no significant change (APC; +0.3%, $p = 0.53$). For females, ASR increased by 1.2% annually ($p = 0.001$) (Fig. 1a). Table 1 presents the most common cancers in children over three 10-year time periods (1987–1996, 1997–2006, and 2007–2016). Leukemia was the most common cancer, with rates $\sim$10% higher in males than in females (5.1/100,000 and 4.8/100,000, respectively, in the most recent period). ASRs for lymphoma were more than doubled in males compared with females (2.3/100,000 and 1.0/100,000 from 2007 to 2016, respectively, Table 1).

Fifteen to 24 years. Over the same time period, 6441 individuals aged 15–24 years were diagnosed with an invasive cancer (49.7% male) (ASR = 39.3/100,000). Incidence increased by 4.2% from 1987 to 1996 for males ($p = 0.07$) before decreasing by 1.3% annually from 1996 to 2016 ($p = 0.002$) (Fig. 1c). A similar pattern was observed for females. The most common cancer in this cohort was melanoma (Table 2). For males, the ASRs in 1987–1996 and 2007–2016 were 15.9/100,000 and 7.6/100,000, respectively (52% decrease). A similar magnitude of change was observed in females with ASR from 1987 to 1996 being 19.2/100,000 and 10.6/100,000 from 2007 to 2016 (45% decrease). In females, thyroid cancer rates more than doubled from 2.2/100,000 in 1987–1996 to 5.1/100,000 from 2006 to 2016 (132% increase) (Table 2). Rates of germ cell tumors were significantly higher in males compared with females for each three time periods, driven mostly by gonadal tumors. There was a 140% increase in ASRs for appendiceal tumors in females from 1987–1996 to 2007–2016 (1.5/100,000 and 3.6/100,000, respectively) (Table 2).

Twenty-five to 39 years. From 1987 to 2016, 29,923 young adults aged 25–39 were diagnosed with an invasive



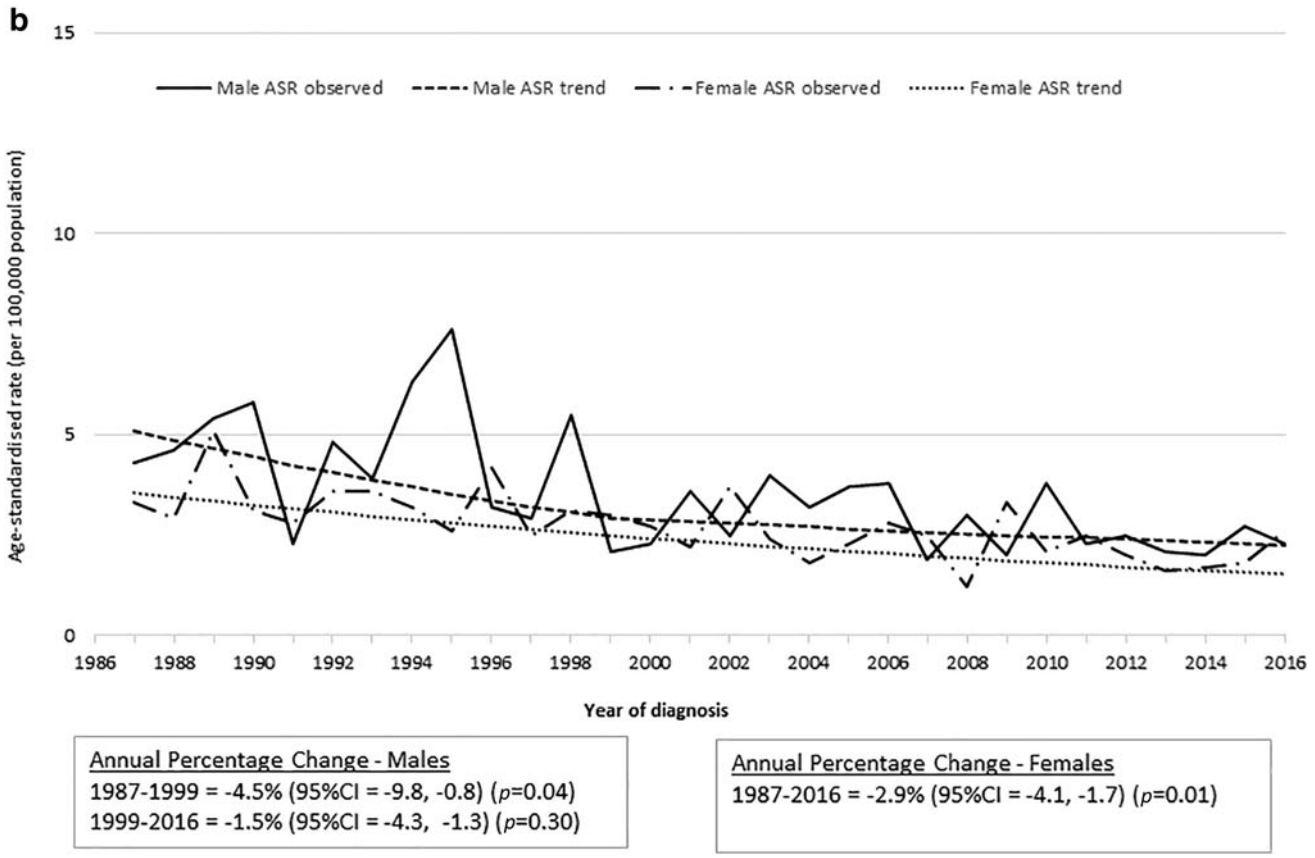
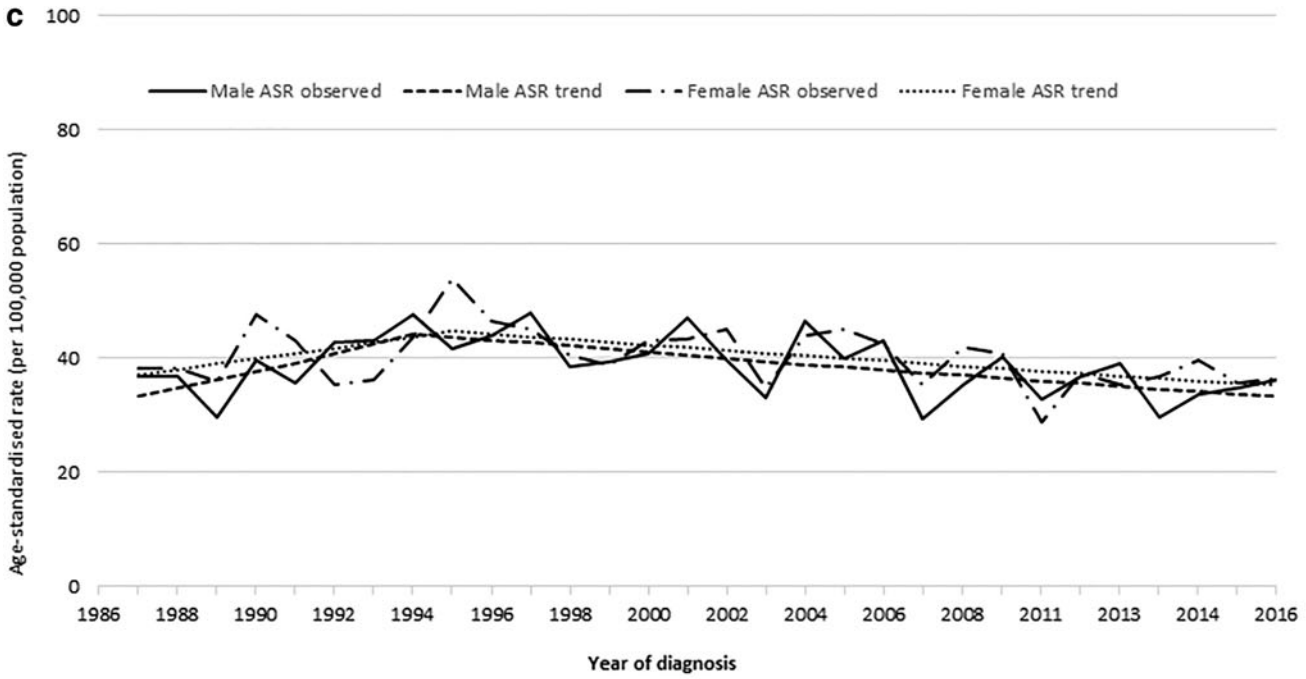


FIG. 1. **(a)** Age-standardized incidence rates for males and females aged 0–14 years, Queensland 1987–2016. **(b)** Age-standardized mortality rates for males and females aged 10–14 years, Queensland 1987–2016. **(c)** Age-standardized incidence rates for males and females aged 15–19 years, Queensland 1987–2016. **(d)** Age-standardized mortality rates for males and females aged 15–19 years, Queensland 1987–2016. **(e)** Age-standardized incidence rates for males and females aged 25–39 years, Queensland 1987–2016. **(f)** Age-standardized mortality rates for males and females aged 25–39 years, Queensland 1987–2016.



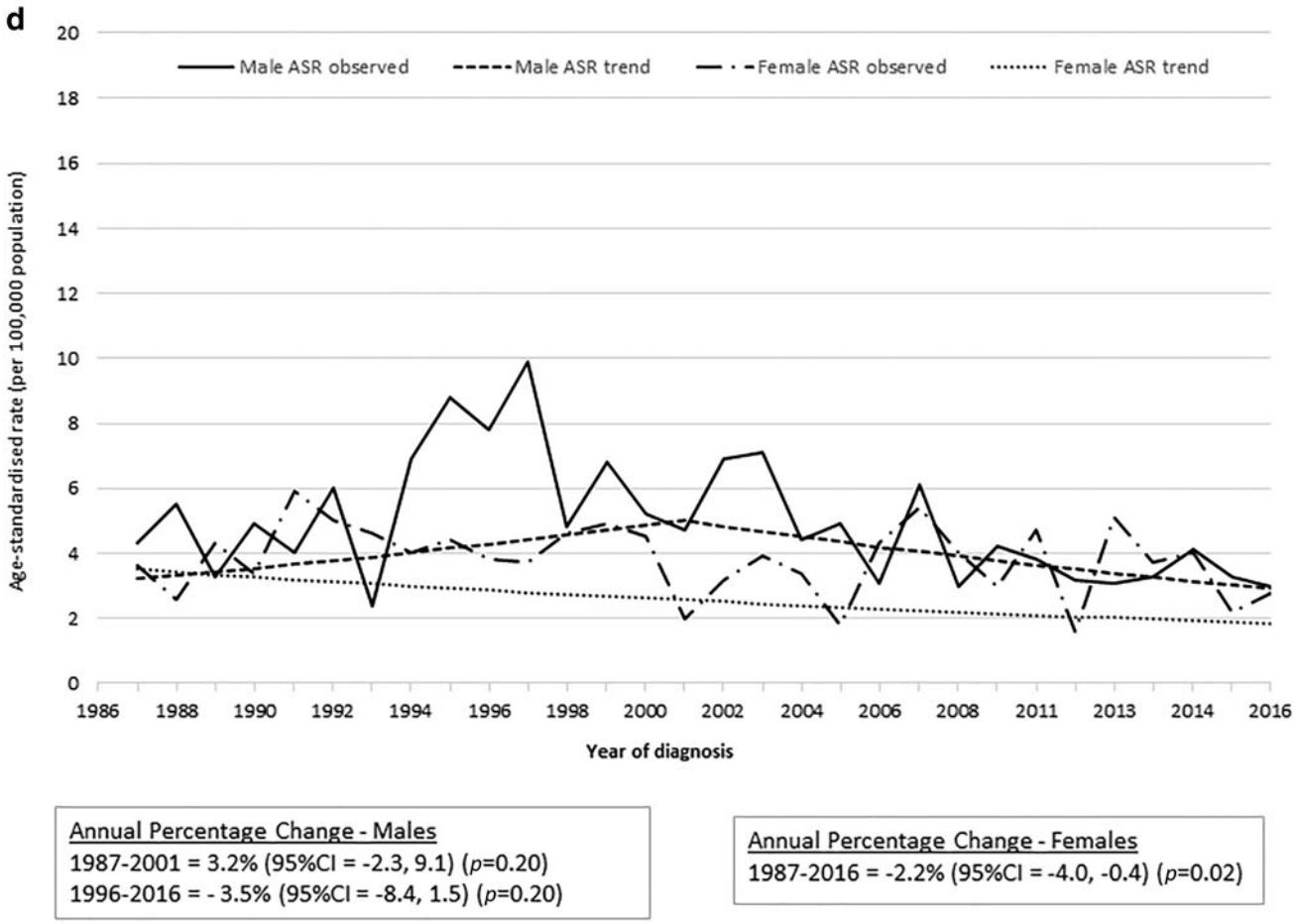


FIG. 1. (Continued).

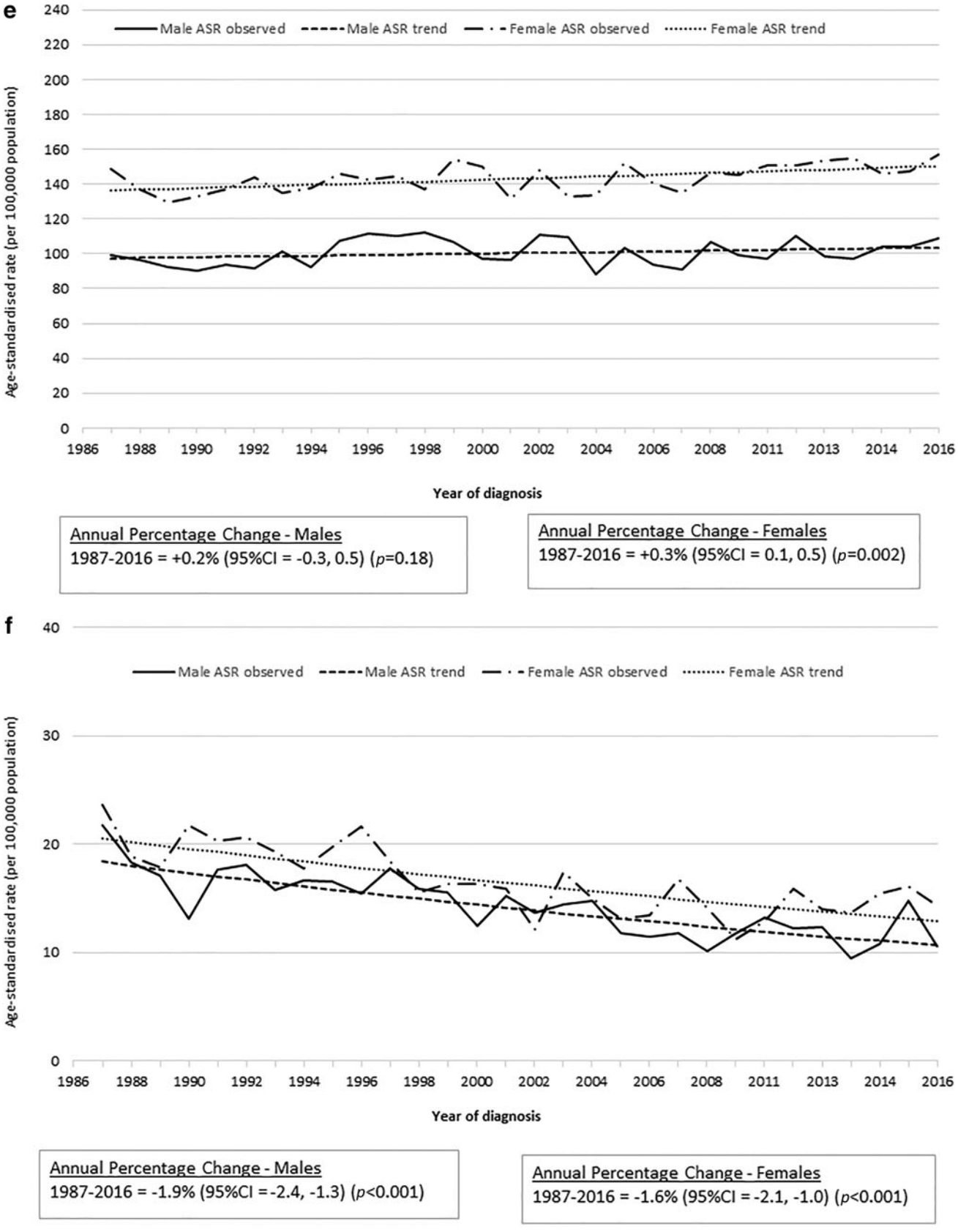


FIG. 1. (Continued).

Table 1. Annual Age-Standardized Site-Specific Incidence Rates (95% Confidence Limits) Per 100,000 for the Most Common Cancers in 0–14 Year Cohort by Sex and Period of Diagnosis, Queensland, Australia

	Incidence					*Mortality*				
	Males		*Females*		*Persons*	*Males*		*Females*		*Persons*
Cancer and time period	*Cases*	*ASR*	*Cases*	*ASR*	*ASR*	*Deaths*	*ASR*	*Deaths*	*ASR*	*ASR*
Leukemias	614		543		1157					
1987–1996	177	5.1 (4.3–5.8)	151	4.6 (3.9–5.3)	4.8 (4.3–5.3)	66	1.9 (1.5–2.4)	44	1.3 (1.0–1.8)	1.6 (1.3–1.9)
1997–2006	196	5.0 (4.3–5.7)	178	4.8 (4.1–5.5)	4.9 (4.4–5.4)	45	1.1 (0.8–1.5)	29	0.8 (0.5–1.1)	1.0 (0.8–1.2)
2007–2016	241	5.1 (4.5–5.8)	214	4.8 (4.2–5.5)	5.0 (4.5–5.4)	24	0.5 (0.3–0.7)	22	0.5 (0.3–0.7)	0.5 (0.4–0.7)
Pediatric and embryonal	280		208		488					
1987–1996	79	2.2 (1.8–2.8)	67	2.0 (1.6–2.5)	2.1 (1.8–2.5)	19	0.5 (0.3–0.8)	21	0.6 (0.4–0.9)	0.6 (0.4–0.8)
1997–2006	89	2.3 (1.8–2.7)	85	2.3 (1.8–2.8)	2.3 (1.9–2.6)	29	0.7 (0.5–1.0)	17	0.5 (0.3–0.7)	0.6 (0.4–0.8)
2007–2016	112	2.3 (1.9–2.8)	117	2.6 (2.1–3.1)	2.4 (2.1–2.8)	18	0.4 (0.2–0.6)	23	0.5 (0.3–0.7)	0.4 (0.3–0.6)
CNS[a]	268		197		465					
1987–1996	76	2.2 (1.7–2.7)	53	1.6 (1.2–2.1)	1.9 (1.6–2.2)	39	1.1 (0.8–1.5)	31	0.9 (0.6–1.3)	1.0 (0.8–1.3)
1997–2006	83	2.1 (1.7–2.6)	63	1.7 (1.3–2.1)	1.9 (1.6–2.2)	33	0.8 (0.6–1.1)	33	0.9 (0.6–1.2)	0.9 (0.7–1.1)
2007–2016	109	2.3 (1.9–2.8)	81	1.8 (1.5–2.3)	2.1 (1.8–2.4)	45	1.0 (07–1.3)	24	0.5 (0.4–0.8)	0.8 (0.6–1.0)
Lymphomas	259		97		356					
1987–1996	70	2.0 (1.6–2.5)	19	0.6 (0.4–0.9)	1.3 (1.1–1.6)	19	0.5 (0.3–0.8)	0	—	0.3 (0.2–0.4)
1997–2006	86	2.2 (1.7–2.7)	36	1.0 (0.7–1.3)	1.6 (1.3–1.9)	5	0.1 (0.1–0.3)	7	0.2 (0.1–0.3)	0.2 (0.1–0.3)
2007–2016	103	2.3 (1.8–2.7)	42	1.0 (0.7–1.3)	1.6 (1.4–1.9)	6	0.1 (0.1–0.3)	5	0.1 (0.1–0.2)	0.1 (0.1–0.2)
Bone[b]	97		98		195					
1987–1996	28	0.8 (0.5–1.1)	22	0.7 (0.4–1.0)	0.7 (0.6–1.0)	7	0.2 (0.1–0.4)	3	—	0.1 (0.1–0.3)
1997–2006	35	0.9 (0.6–1.2)	37	1.0 (0.7–1.3)	0.9 (0.7–1.2)	9	0.2 (0.1–0.4)	5	0.1 (0.1–0.3)	0.2 (0.1–0.3)
2007–2016	34	0.8 (0.5–1.0)	39	0.9 (0.6–1.2)	0.8 (0.7–1.0)	4	—	5	0.1 (0.1–0.2)	0.1 (0.1–0.2)
Soft tissue sarcomas	99		97		196					
1987–1996	34	1.0 (0.7–1.3)	33	1.0 (0.7–1.4)	1.0 (0.8–1.2)	11	0.3 (0.2–0.5)	4	—	0.2 (0.1–0.3)
1997–2006	25	0.6 (0.4–0.9)	23	0.6 (0.4–0.9)	0.6 (0.5–0.8)	3	—	3	—	0.1 (0.1–0.2)
2007–2016	40	0.9 (0.6–1.2)	41	0.9 (0.7–1.2)	0.9 (0.7–1.1)	6	0.1 (0.1–0.3)	8	0.2 (0.1–0.3)	0.2 (0.1–0.2)
Melanoma	76		82		158					
1987–1996	33	0.9 (0.7–1.3)	37	1.1 (0.8–1.6)	1.0 (0.8–1.3)	<5	—	<5	—	—
1997–2006	23	0.6 (0.4–0.9)	30	0.8 (0.5–1.1)	0.7 (0.5–0.9)	<5	—	<5	—	—
2007–2016	20	0.4 (0.3–0.7)	15	0.4 (0.2–0.6)	0.4 (0.3–0.6)	<5	—	<5	—	—
Appendix	32		65		97					
1987–1996	5	0.1 (0.1–0.3)	5	0.2 (0.1–0.3)	0.1 (0.1–0.3)	<5	—	<5	—	—
1997–2006	13	0.3 (0.2–0.5)	22	0.6 (0.4–0.9)	0.5 (0.3–0.6)	<5	—	<5	—	—
2007–2016	14	0.3 (0.2–0.5)	38	0.9 (0.6–1.2)	0.6 (0.4–0.8)	<5	—	<5	—	—

[a]CNS.
[b]Ewings tumor, osteosarcoma, and other tumors of the bone.
Dashes indicate mortality rates not calculated as number of deaths <5.
ASR, age-standardized rate; CNS, central nervous system.

Table 2. Annual Age-Standardized Site-Specific Incidence Rates (95% Confidence Limits) Per 100,000 for the Most Common Cancers in 15–24 Years Cohort by Sex and Period of Diagnosis, Queensland, Australia

	Incidence					*Mortality*				
	Males		*Females*		*Persons*	*Males*		*Females*		*Persons*
Cancer and time period	*Cases*	*ASR*	*Cases*	*ASR*	*ASR*	*Deaths*	*ASR*	*Deaths*	*ASR*	*ASR*
Melanoma	983		1227		2210					
1987–1996	395	15.9 (14.4–17.5)	461	19.2 (17.5–20.9)	17.5 (16.4–18.7)	14	0.6 (0.3–0.9)	9	0.4 (0.2–0.7)	0.5 (0.3–0.7)
1997–2006	340	12.9 (11.6–14.3)	431	16.8 (15.3–18.5)	14.8 (13.8–15.9)	12	0.5 (0.2–0.7)	13	0.5 (0.3–0.8)	0.5 (0.3–0.7)
2007–2016	248	7.6 (6.7–8.6)	335	10.6 (9.5–11.8)	9.1 (8.4–9.9)	7	0.2 (0.1–0.4)	5	0.2 (0.1–0.3)	0.2 (0.1–0.3)
Lymphoma	438		395		833					
1987–1996	105	4.3 (3.5–5.1)	104	4.3 (3.5–5.2)	4.3 (3.7–4.9)	12	0.5 (0.3–0.8)	5	0.2 (0.1–0.4)	0.3 (0.2–0.5)
1997–2006	163	6.2 (5.3–7.2)	127	5.0 (4.2–5.9)	5.6 (5.0–6.3)	23	0.9 (0.6–1.3)	10	0.4 (0.2–0.7)	0.6 (0.4–0.9)
2007–2016	170	5.3 (4.5–6.1)	164	5.3 (4.5–6.1)	5.3 (4.8–5.9)	7	0.2 (0.1–0.4)	8	0.3 (0.1–0.5)	0.2 (0.1–0.4)
Leukemia	253		171		424					
1987–1996	70	2.8 (2.2–3.6)	58	2.4 (1.8–3.1)	2.6 (2.2–3.1)	44	1.8 (1.3–2.3)	28	1.2 (0.8–1.7)	1.5 (1.2–1.8)
1997–2006	89	3.4 (2.7–4.1)	65	2.6 (2.0–3.2)	3.0 (2.5–3.5)	41	1.6 (1.1–2.1)	13	0.5 (0.3–0.8)	1.0 (0.8–1.3)
2007–2016	94	3.0 (2.4–3.6)	48	1.6 (1.1–2.0)	2.3 (1.9–2.7)	22	0.7 (0.4–1.0)	21	0.7 (0.4–1.0)	0.7 (0.5–0.9)
Germ cell[a]	604		94		698					
1987–1996	155	6.2 (5.3–7.2)	37	1.6 (1.1–2.1)	3.9 (3.4–4.5)	11	0.4 (0.2–0.7)	6	0.3 (0.1–0.5)	0.3 (0.2–0.5)
1997–2006	206	7.8 (6.8–8.9)	23	0.9 (0.6–1.3)	4.4 (3.9–5.0)	5	0.2 (0.1–0.4)	<5	—	0.1 (0.1–0.2)
2007–2016	243	7.5 (6.6–8.5)	34	1.1 (0.8–1.5)	4.3 (3.8–4.9)	5	0.1 (0.1–0.3)	<5	—	0.1 (0.1–0.2)
CNS[b]	150		119		269					
1987–1996	49	2.0 (1.5–2.6)	40	1.7 (1.2–2.2)	1.8 (1.5–2.2)	20	0.8 (0.5–1.2)	11	0.5 (0.2–0.8)	0.6 (0.4–0.9)
1997–2006	44	1.7 (1.2–2.2)	41	1.6 (1.1–2.1)	1.6 (1.3–2.0)	21	0.8 (0.5–1.2)	14	0.6 (0.3–0.9)	0.7 (0.5–0.9)
2007–2016	57	1.8 (1.4–2.3)	38	1.2 (0.9–1.6)	1.5 (1.2–1.8)	23	0.7 (0.5–1.1)	18	0.6 (0.4–0.9)	0.7 (0.5–0.9)
Thyroid	73		318		91					
1987–1996	14	0.6 (0.3–0.9)	52	2.2 (1.6–2.8)	1.4 (1.0–1.7)	<5	—	<5	—	—
1997–2006	17	0.6 (0.4–1.0)	107	4.2 (3.4–5.0)	2.4 (2.0–2.8)	<5	—	<5	—	—
2007–2016	42	1.3 (1.0–1.8)	159	5.1 (4.3–5.9)	3.2 (2.7–3.6)	<5	—	<5	—	—
Bone[c]	151		73		224					
1987–1996	44	1.8 (1.3–2.4)	19	0.8 (0.5–1.2)	1.3 (1.0–1.6)	15	0.6 (0.4–1.0)	10	0.4 (0.2–0.7)	0.5 (0.3–0.7)
1997–2006	45	1.7 (1.3–2.3)	35	1.4 (1.0–1.9)	1.5 (1.2–1.9)	22	0.8 (0.5–1.2)	13	0.5 (0.3–0.8)	0.7 (0.5–0.9)
2007–2016	62	2.0 (1.5–2.5)	19	0.6 (0.4–0.9)	1.3 (1.0–1.6)	34	1.1 (0.7–1.5)	15	0.5 (0.3–0.8)	0.8 (0.6–1.0)
Appendix	104		198		302					
1987–1996	19	0.8 (0.5–1.2)	36	1.5 (1.1–2.0)	1.1 (0.9–1.5)	<5	—	<5	—	—
1997–2006	27	1.0 (0.7–1.5)	52	2.0 (1.5–2.6)	1.5 (1.2–1.9)	<5	—	<5	—	—
2007–2016	58	1.8 (1.4–2.3)	110	3.6 (2.9–4.3)	2.7 (2.3–3.1)	<5	—	<5	—	—

[a]Includes gonadal and nongonadal.
[b]CNS.
[c]Ewings tumor, osteosarcoma, and other tumors of the bone; dashes indicate number of deaths <5.

Table 3. Annual Age-Standardized Site-Specific Incidence Rates (95% Confidence Limits) Per 100,000 for Selected Cancers in 25–39 Years Cohort by Sex and Period of Diagnosis, Queensland, Australia

	Incidence					*Mortality*				
	Males		*Females*		*Persons*	*Males*		*Females*		*Persons*
Cancer and time period	*Cases*	*ASR*	*Cases*	*ASR*	*ASR*	*Deaths*	*ASR*	*Deaths*	*ASR*	*ASR*
Melanoma	4336		5224		9560					
1987–1996	1309	37.4 (35.4–39.5)	1538	44.1 (41.9–46.3)	40.7 (39.2–42.2)	108	3.1 (2.5–3.7)	63	1.8 (1.4–2.3)	2.5 (2.1–2.8)
1997–2006	1518	38.0 (36.1–39.9)	1751	43.1 (41.1–45.2)	40.6 (39.2–42.0)	91	2.3 (1.8–2.8)	65	1.6 (1.2–2.0)	1.9 (1.6–2.3)
2007–2016	1509	32.3 (30.6–33.9)	1935	41.0 (39.2–42.8)	36.6 (35.4–37.9)	91	2.0 (1.6–2.4)	69	1.5 (1.1–1.8)	1.7 (1.4–2.0)
Female breast	0		3921		3921					
1987–1996			1086	31.6 (29.8–33.6)				189	5.5 (4.8–6.3)	
1997–2006		N/A	1336	32.9 (31.1–34.7)	N/A		N/A	161	4.0 (3.4–4.6)	N/A
2007–2016			1499	32.1 (30.5–33.7)				146	3.1 (2.6–3.7)	
Lymphoma	996		738		1734					
1987–1996	271	7.7 (6.8–8.6)	184	5.3 (4.5–6.0)	6.5 (5.9–7.1)	72	2.1 (1.6–2.6)	45	1.3 (0.9–1.7)	1.7 (1.4–2.0)
1997–2006	310	7.7 (6.9–8.6)	244	6.0 (5.3–6.8)	6.9 (6.3–7.5)	48	1.2 (0.9–1.6)	24	0.6 (0.4–0.8)	0.9 (0.7–1.1)
2007–2016	415	8.8 (8.0–9.7)	310	6.5 (5.8–7.3)	7.7 (7.1–8.2)	26	0.6 (0.4–0.8)	16	0.3 (0.2–0.5)	0.4 (0.3–0.6)
Leukemia	461		341		802					
1987–1996	144	4.1 (3.4–4.8)	88	2.5 (2.0–3.1)	3.3 (2.9–3.7)	76	2.2 (1.7–2.7)	45	1.3 (0.9–1.7)	1.7 (1.4–2.0)
1997–2006	151	3.8 (3.2–4.4)	109	2.7 (2.2–3.2)	3.2 (2.8–3.6)	53	1.3 (1.0–1.7)	38	0.9 (0.7–1.3)	1.1 (0.9–1.4)
2007–2016	166	3.5 (3.0–4.1)	144	3.0 (2.6–3.6)	3.3 (2.9–3.7)	35	0.7 (0.5–1.0)	41	0.9 (0.6–1.1)	0.8 (0.6–1.0)
Germ cell[a]	1804		112		1816					
1987–1996	390	11.0 (9.9–12.1)	22	0.6 (0.4–0.9)	5.8 (5.3–6.4)	27	0.8 (0.5–1.1)	6	0.2 (0.1–0.3)	0.5 (0.3–0.6)
1997–2006	611	15.3 (14.1–16.5)	37	0.9 (0.6–1.2)	8.0 (7.4–8.7)	25	0.6 (0.4–0.9)	<5	—	0.3 (0.2–0.5)
2007–2016	803	17.0 (15.8–18.1)	53	1.1 (0.8–1.4)	9.0 (8.4–9.6)	16	0.3 (0.2–0.5)	<5	—	0.2 (0.1–0.3)
Cervix			1779		1779					
1987–1996			613	17.6 (16.2–19.0)				76	2.2 (1.7–2.7)	
1997–2006		N/A	523	12.9 (11.8–14.0)	N/A		N/A	59	1.5 (1.1–1.8)	N/A
2007–2016			643	13.6 (12.6–14.7)				70	1.5 (1.2–1.9)	
Thyroid	379		1641		2020					
1987–1996	47	1.3 (1.0–1.7)	259	7.4 (6.5–8.3)	4.4 (3.9–4.9)	<5	—	<5	—	—
1997–2006	144	3.6 (3.0–4.2)	535	13.2 (12.1–14.3)	8.4 (7.8–9.1)	<5	—	<5	—	—
2007–2016	194	4.1 (3.6–4.8)	847	18.0 (16.8–19.2)	11.1 (10.4–11.8)	<5	—	<5	—	—
CNS[b]	493		362		855					
1987–1996	133	3.8 (3.2–4.4)	106	3.0 (2.5–3.6)	3.4 (3.0–3.9)	67	1.9 (1.5–2.4)	62	1.8 (1.4–2.3)	1.9 (1.5–2.0)
1997–2006	164	4.1 (3.5–4.8)	114	2.8 (2.3–3.3)	3.4 (3.1–3.9)	86	2.2 (1.7–2.6)	65	1.6 (1.2–2.0)	1.9 (1.6–2.2)
2007–2016	196	4.2 (3.6–4.8)	142	3.0 (2.5–3.5)	3.6 (3.2–4.0)	77	1.7 (1.3–2.0)	71	1.5 (1.2–1.9)	1.6 (1.3–1.8)

[a]Includes gonadal and nongonadal; dashes indicate number of deaths <5.
[b]CNS.

cancer (41.1% male) (ASR = 122.6/100,000). For females, incidence increased by 0.3% per year ($p = 0.002$) from 1987 to 2016 (Fig. 1e). The most common cancer in those aged 25–39 years was melanoma, with rates decreasing by ~14% in males and 7% in females over time (Table 3). In females, breast was the second most common cancer, with little difference in ASRs over time. Rates of cervical cancer decreased by ~23% from 17.6/100,000 for 1987–2006 to 13.6/100,000 from 2007 to 2016. Thyroid cancer rates were ~340% higher in females compared with males for 2007–2016. ASRs for thyroid cancer in females more than doubled over time (1987–1996 ASR = 7.4/100,000 and ASR 18.0 from 2007 to 2016).

Fifteen to 39 years. From 1987 to 2016, 36,365 cancers (ASR = 91.1/100,000) were diagnosed in this cohort. For females, incidence increased by 0.2% annually from 1987 to 2016 ($p = 0.03$) (Fig. 2).

Mortality

Zero to 14 years. In total, 714 children died in the period 1987–2016, and the mortality rate was 3.0/100,000. As the number of deaths per year was relatively few, 3-year moving ASRs were used in the JoinPoint models. Mortality decreased by 4.5% per year ($p = 0.04$) for males from 1987 to 1999, before stabilizing from 1999 onward. For females, mortality decreased by 2.8% per year ($p < 0.001$) from 1987 to 2016 (Fig. 1b). In males, mortality from leukemia decreased from 1.9/100,000 in 1987–1996 to 0.5/100,000 from 2006 to 2016 (74% decrease) with a similar magnitude of decrease observed for females. Mortality rates decreased by 44% for central nervous system (CNS) tumors in females over time (0.9/100,000 from 1987 to 1996 and 0.5/100,000 from 2007 to 2016).

Fifteen to 24 years. From 1987 to 2016, 707 deaths occurred in those aged 15–24 years (57.1% male, ASR = 4.3/100,000). We found no statistically significant changes in rates over time for males. For females, mortality decreased by 2.2% per year ($p = 0.01$) from 1987 to 2016 (Fig. 1d). The highest mortality was observed for leukemia in males and females, with a reduction of ~50% for both sexes combined over time (Table 2). Mortality decreased over time for melanoma, lymphoma, and germ cell tumors. However, it remained relatively stable for CNS and bone cancers.

Twenty-five to 39 years. Overall, 3701 deaths occurred (46.0% male), and the mortality rate was 15.2/100,000. There was a 1.9% ($p < 0.001$) and 1.6% ($p < 0.001$) annual decrease in mortality for males and females, respectively, over the 30 years of data (Fig. 1f). Mortality rates decreased across several cancers, including melanoma, lymphoma, female breast carcinoma, and germ cell tumors (Table 3). For 2007–2016, the highest mortality was observed for melanoma (1.7/100,000) and CNS cancers (1.6/100,000). The greatest reduction in mortality over time was found for lymphoma with a 76% reduction (1.7/100,000 from 1987 to 1996 and 0.4/100,000 from 2007 to 2016).

Fifteen to 39 years. Mortality in males decreased by 1.8% annually from 1987 to 2016 ($p < 0.001$). A similar magnitude of decrease was observed for females (APC = −1.5%) ($p < 0.001$) (Fig. 5).

Five-year RS

Zero to 14 years. For both sexes combined, 5-year RS was 77.5% (95% CI = 73.9–81.1) for 1997–2001 and 86.1% (95% CI = 83.6–88.6) for 2012–2016 ($p = 0.01$) (Fig. 3). For all cancers combined, RS increased over time by ~6.5% in females and 15.0% in males. Across selected cancers, improvements in 5-year RS were observed for leukemia in males and females. Children with CNS tumors had the lowest survival; however, a 22% and 18% absolute improvement in survival was observed over time for males and females, respectively.

Fifteen to 24 years. The 5-year RS for those diagnosed in the most recent period (2012–2016) was 90.3% for males and 91.6% for females. Survival in males increased by ~3% from the earlier period (1997–2001) to the most recent period (2012–2016). From 1997 to 2001, 5-year RS for leukemia was 54.4% for males and 52.9% for females, and was 81.9% and 74.0% in the period 2012–2016 for males and females, respectively. Survival was lowest for CNS cancers (Fig. 4).

Twenty-five to 39 years. Overall 5-year RS increased from 85.4% to 88.8% for males and from 87.9% to 90.4% for females for the time periods 1997–2001 and 2012–2016, respectively. Survival was highest for melanoma (95.7% and 98.3% for males and females, respectively) in the period 2012–2016. RS for leukemia was 64.3% (males) and 66.9% (females) during 1997–2001, and 85.5% (males) and 71.8% (females) for 2012–2016 (Fig. 5).

Discussion

This study provides a novel examination incidence, mortality, and 5-year RS for Queensland children and AYAs.

Incidence

In children (0–14 years), the overall incidence of cancer we observed is similar to that reported in other developed nations.[21] Trends in incidence varied by gender. While we observed increasing incidence for females, incidence for males was relatively stable. This aligns with an earlier Australian wide study that noted an increase in incidence for females but incidence plateauing among males from 1983 to 2006.[22] However, these differences may also reflect different tumor distribution, as outlined below. The higher incidence rates in the 15–24 year age group in this study compared with others are mainly driven by the higher rates of melanoma.[2] However, the reduction in rates from 1994 to 2016 observed aligns with a recent Australian study that identified decreasing incidence rates from 2009 onward.[17] For the 25–39 year age group, incidence remained relatively stable, with only a small annual percentage increase for females over time. This increase appears to be mainly driven by increasing rates of thyroid cancers. ASRs for 15–39 year age group reflect global data reporting increases in cancer incidence over time, particularly in young adult females.[4,13]

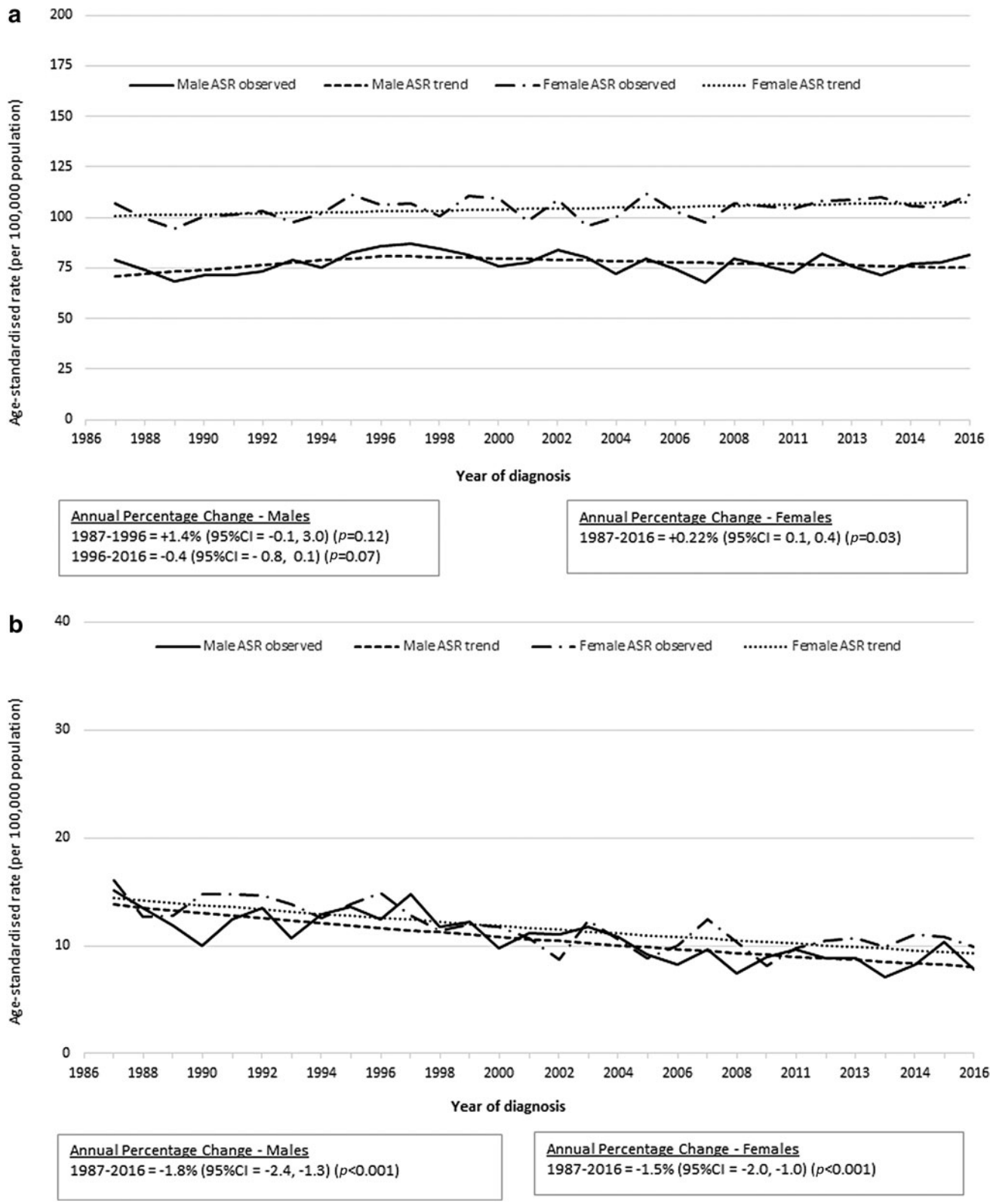


FIG. 2. Age-standardized incidence and mortality rates for males and females aged 15–39 years, Queensland 1987–2016.

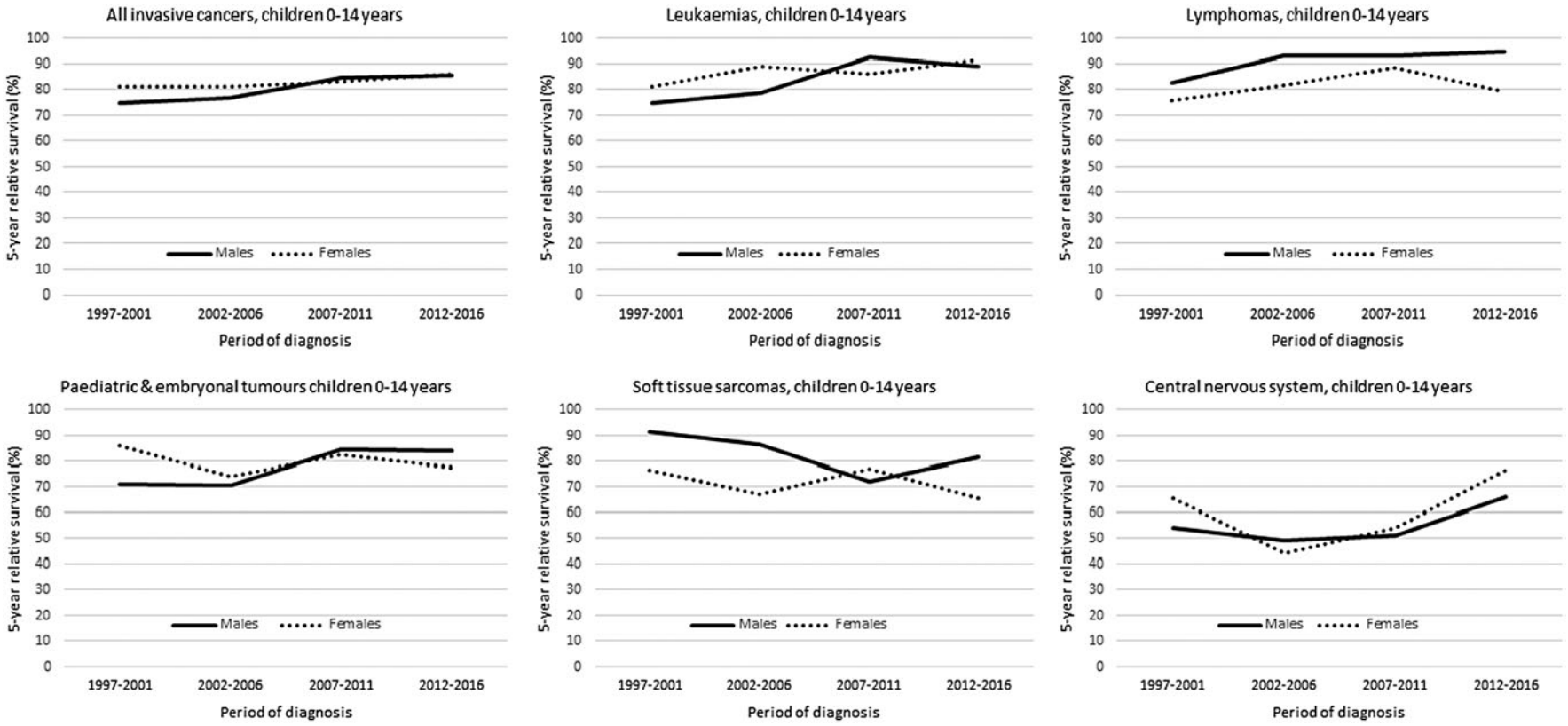


FIG. 3. Five-year RS for all cancers combined and selected cancers, children 0–14 years. RS, relative survival.

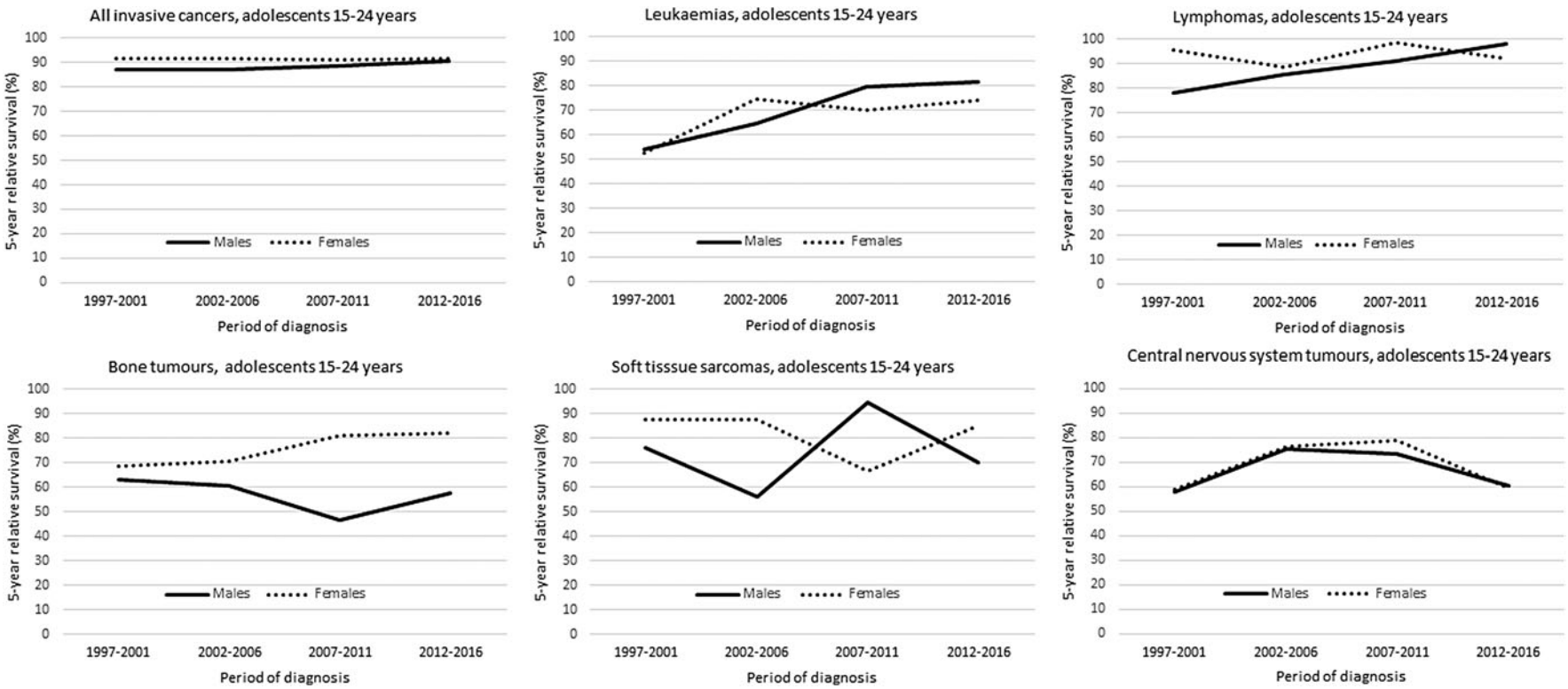


FIG. 4. Five-year RS for all cancers combined and selected cancers, adolescents 15–24 years.

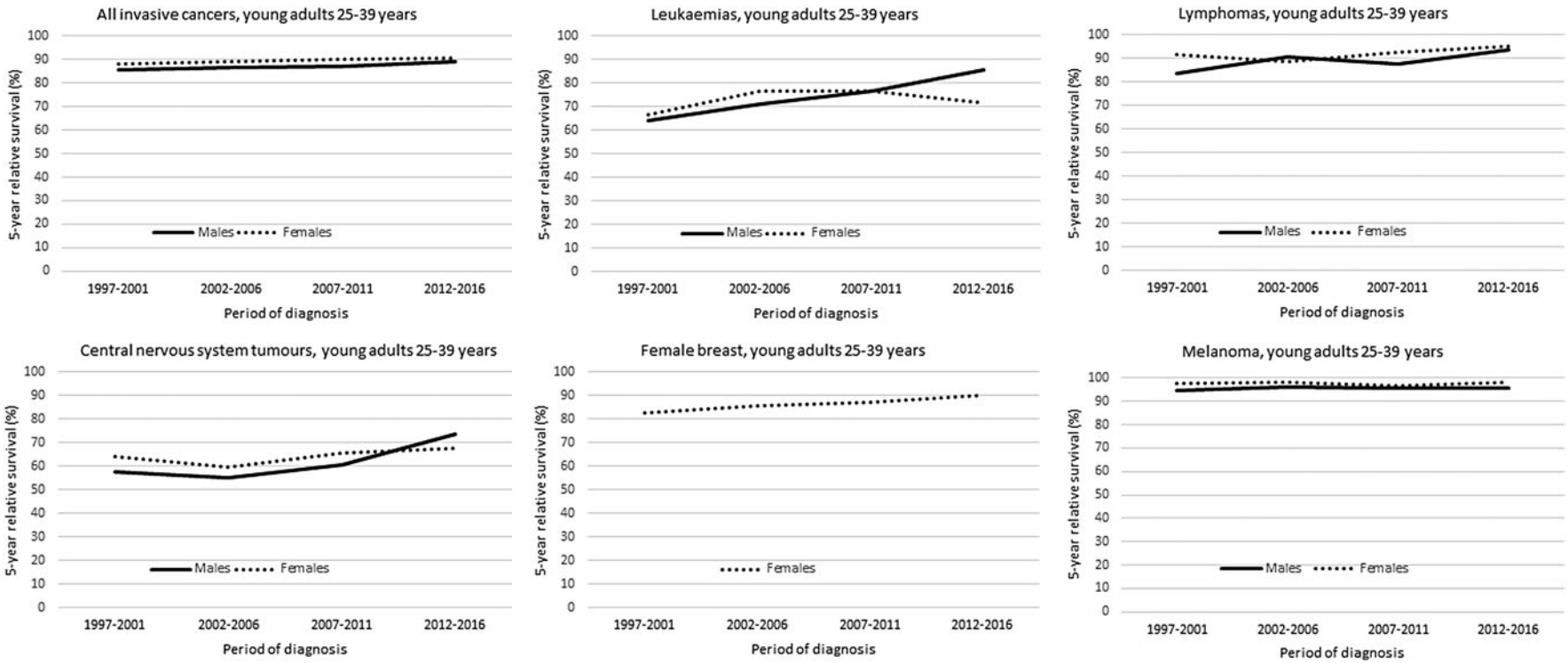


FIG. 5. Five-year RS for all cancers combined and selected cancers, young adults 25–39 years.

Mortality

A significant decline in mortality was observed for children over time. These reductions are similar to those reported elsewhere and likely reflect improvements in the treatment of leukemia as the most common childhood malignancy.[17] Significant mortality reductions were also evident in males and females 15–24 years and 25–39 years. These reductions are similar to those observed in other developed countries and again likely reflect improvements in treatment and management, as well as clinical trial access and multidisciplinary care.[4,13,17,23–25]

Survival

Significant improvements in 5-year RS were observed over time, with the greatest gains found for children, although they demonstrated lower overall RS. For the AYA groups, RS also increased over the same period. In comparison with survival data recently published from New Zealand (80.6% for the period 2000–2009), the EUROCARE consortium (87% for the period 2000–2002), and Canada (85% for the period 2001–2005),[24,26,27] RS for AYAs in this study was superior (89.1%). This likely reflects the high proportion of treatable melanoma in the Queensland cohort.

Disease-specific sites

The distribution of cancers in children is similar to that previously reported, with leukemias, neuroblastoma, rhabdomyosarcoma, and CNS tumors most common.[1,10,22,25,28,29] While numbers were relatively small, a reduction in incidence of melanoma in children was observed over time. A doubling in the incidence of appendiceal tumors in females was found. With changes in pathology practices, these tumors are now more likely to be reviewed.[1,30] In addition, a halving in mortality from leukemia was observed over time, which would be the main driver of reduction in mortality for the whole group. Smaller reductions were observed for lymphomas, pediatric and embryonal tumors. Cancers with the highest mortality among children were CNS cancers, leukemias, and pediatric tumors.

For 15–24 years, while melanoma was the most common cancer observed, a reduction in incidence and mortality over time was found. The timeline suggests that these results may be an encouraging reflection of well-established public health campaigns such as SunSmart in Australia, aimed at reducing sun exposure, as well as improved early detection.[17,31–33] Rates of thyroid cancers more than doubled over the study period and were 300% higher in young adult females than in males. This is consistent with other national and international data.[17] While the exact reasons for increasing incidence are unknown, increased incidental detection from ultrasound and imaging,[34] leading to over diagnosis, is possible. While increasing incidence of colorectal cancers has been reported in national data,[2] when we examined colorectal cancers by subsite, we found that the vast majority were from the appendix and are also likely reflective of incidental findings.[1,30] Unsurprisingly, rates of germ cell tumors were significantly higher in males, driven mostly by gonadal tumors. For 15–24 years, cancers of the bone, CNS, and leukemias were associated with the greatest mortality. However, a reduction in mortality for both males and females over time was found for leukemias.

The data showed an increase in incidence of lymphomas in the 15–24 and 25–39 years cohorts. This may be attributable to changing diagnostic practices or changes in known risk factors associated with viral infection and immunosuppression.[17] The incidence of cervical cancers decreased dramatically over time for young adult females, aligning with other Australian and U.S. data.[35] This is likely the result of improved public sexual health campaigns and improved screening programs. It is hoped that, with the introduction of Australia's Human Papilloma Virus (HPV) Vaccination Program in 2007, the incidence of cervical adenocarcinoma will decrease but further investigation is needed.[17,25] Germ cell tumors increased in males over time although a reduction in mortality was observed for 25–39 years, similar to findings from other recent Australian and U.S. data.[16,17] For females, breast cancer was relatively prevalent in this cohort, with survival improving over time, as consistent with other recent Australian data.[36] For 25–39 years, the highest mortality was found for melanoma and CNS tumors. Higher mortality for melanoma is due to the extremely high incidence in the Queensland population; with a mortality to incidence ratio (MIR) of 0.05, compared with a MIR for CNS cancers of 0.44. The most fatal diseases for all age groups remain those where there have been little advances in treatment and where there remain significant barriers in access to clinical trials.[13,16,17,25,28]

Future directions

Further effort is needed to understand the causes of cancer in children and young people with its unique biological and genetic features. Efforts targeted at early detection and prevention through public health campaigns and appropriate treatment measures have been demonstrated to be effective in the past, and are paramount to further improve outcomes and reduce cancer burden in this population.[4,17,24] Improvements in the treatment of leukemia across all age groups have also led to overall reduction in mortality; however, it also masks the lack of improvement in CNS and sarcomas across the age groups, which should be the focus of future trials. Improving availability of, and access to clinical trials and treatments for rare cancers, remains a priority if survival outcomes are to be improved over time, particularly for AYAs.[13,17] Within Australia, AYA care is complicated by treatment distribution across several health care settings.[37,38] Further research investigating the use of telehealth and technology to connect patients, specialists, and primary care teams is therefore required, which build upon national and international work to date focused on the development of specialist AYA services.[24,27,37,39–41] Improved consistency in data collection and capture is also required along with improved recording of patient-reported outcome measures, to deepen our understanding of the experience, outcomes, and burden of cancer for children, young people, and their families.[42]

Strengths and limitations

As this was a state-based study, the number of cancers in some groups was relatively small. Caution should therefore be exercised when examining trends over time. The use of Australian standard population figures may also limit comparison with international studies. For rare cancers with low incidence and mortality, trends are particularly subject to

fluctuation. In addition, the authors acknowledge that the application of the AYA SEER recode to pediatric data may not fully represent the presentation of some tumor types, which only occur in childhood. The use of population-based verified, cancer registry data is a strength of this study. These results will aid cancer service planning and the delivery of pediatric and AYA cancer care. They also highlight important areas requiring further investigation to continue to improve services and outcomes for young people living with cancer.

Acknowledgments

The authors acknowledge the staff of the Queensland Cancer Register and the Queensland Cancer Control Analysis Team (QCCAT) who contribute to and participate in the maintenance of the Queensland Oncology Repository. Data for this publication have been developed under the auspices of the Queensland Cancer Control Safety and Quality Partnership.

Author Disclosure Statement

The authors declare no current or potential conflicts of interest.

Funding Information

No funding was received for this study.

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