

Measuring & Reporting Cancer & Cancer Management Disparities in Australia

Cancer Survivorship Conference
February 2nd, 2017
Adelaide Convention Centre



University of
South Australia

David Roder
Professor, Cancer Epidemiology and Population Health
Centre for Population Health Research

Main Topics

A. Existing Data

B. Vision from the National Cancer Data Strategy

- › Linked population cancer registry/administrative treatment data?
- › Clinical quality registries?
- › Patient-reported outcomes/experiences

C. Concluding Comments

Cancer Registry Federation

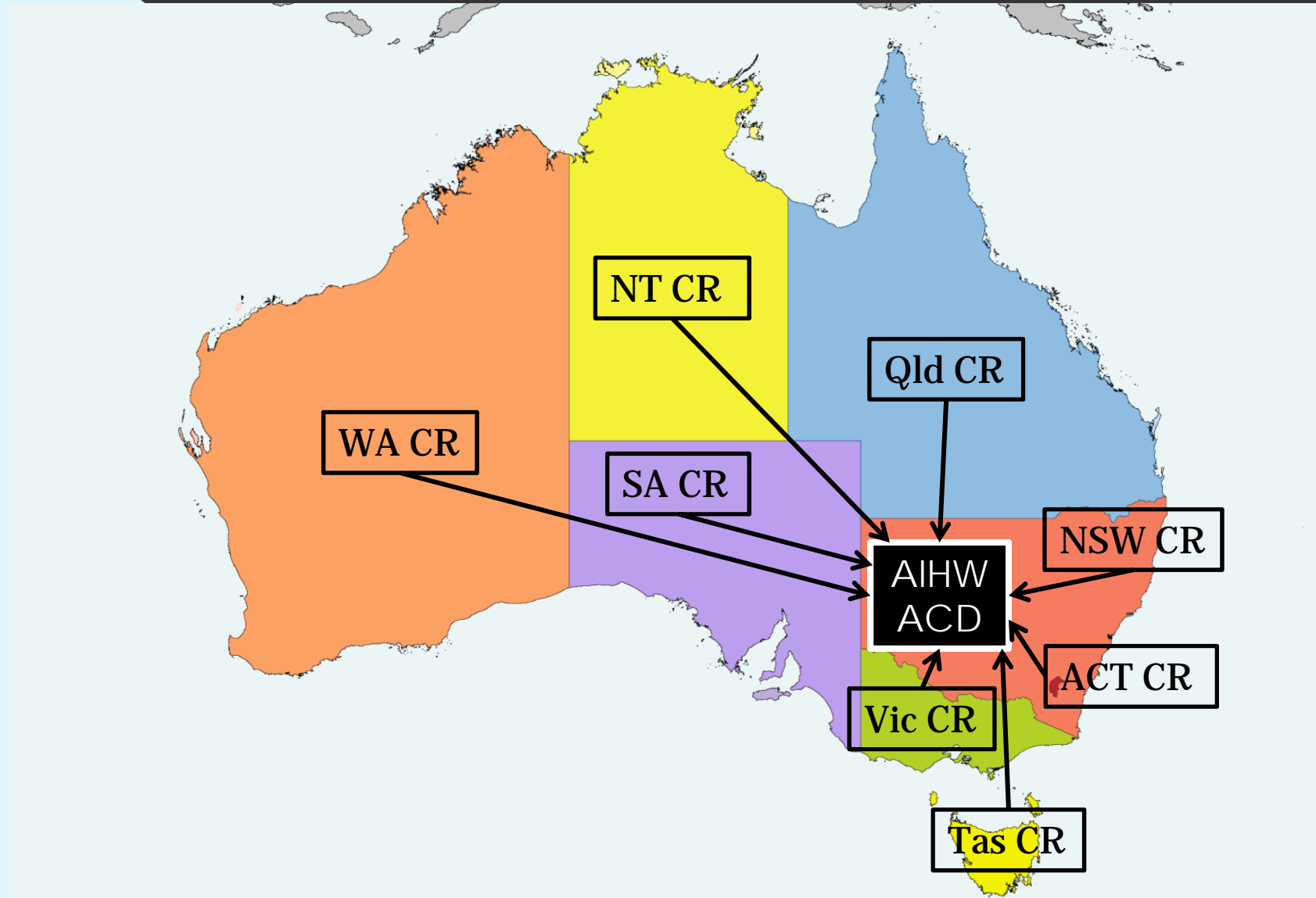


Image source: http://upload.wikimedia.org/wikipedia/commons/1/16/Australia_location_map_recolored.png

National Cancer Registration -Minimum Data Set-

➤ Names

➤ Sex

➤ Residence at diagnosis (postcode)

➤ Birthdate

➤ Country of birth

➤ Aboriginal/Torres Strait Islander status

➤ Diagnosis date

➤ Death date

➤ Cause of death

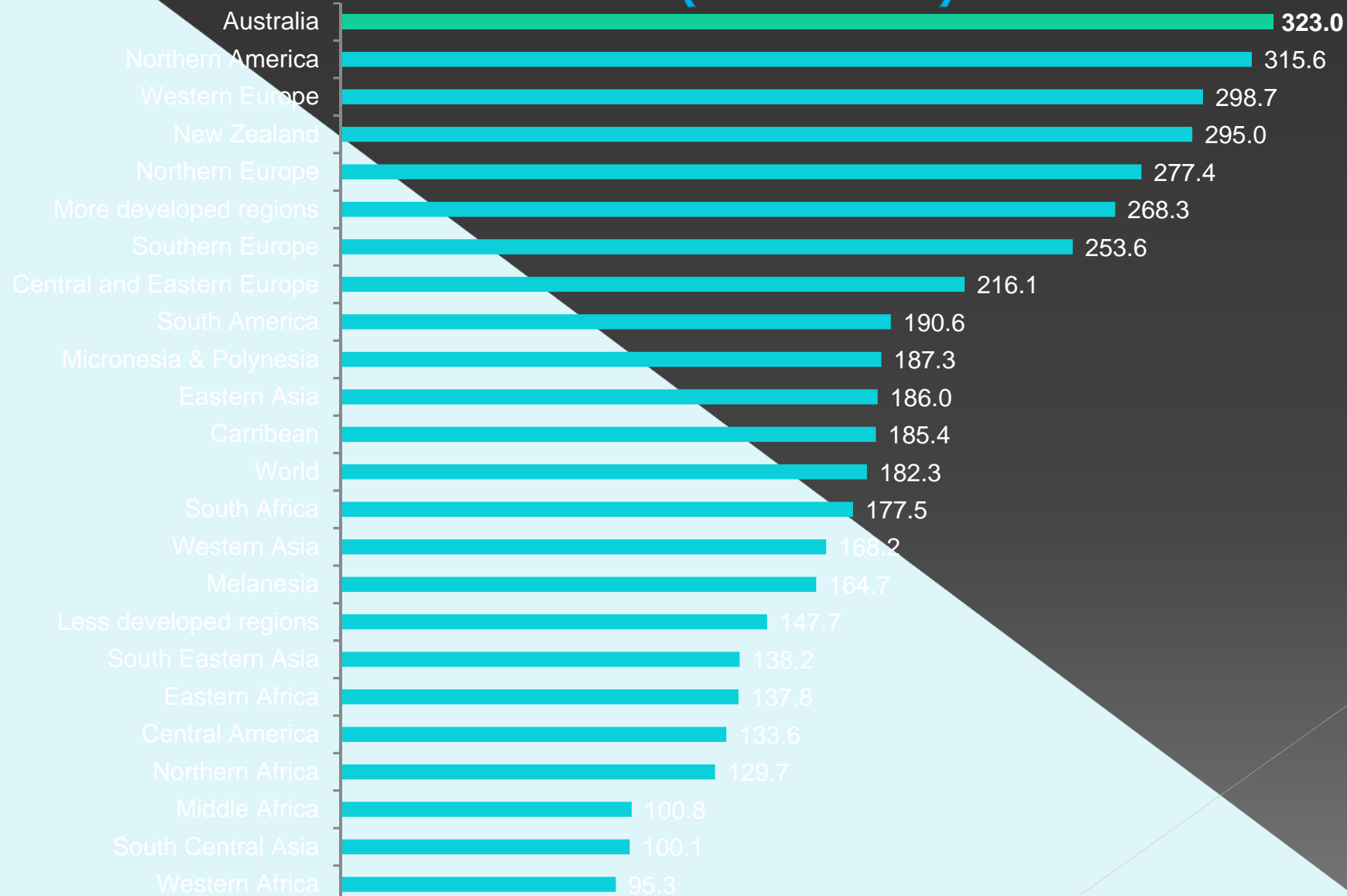
➤ Primary site (topography)

➤ Morphology

National Cancer Registration - Items Missing -

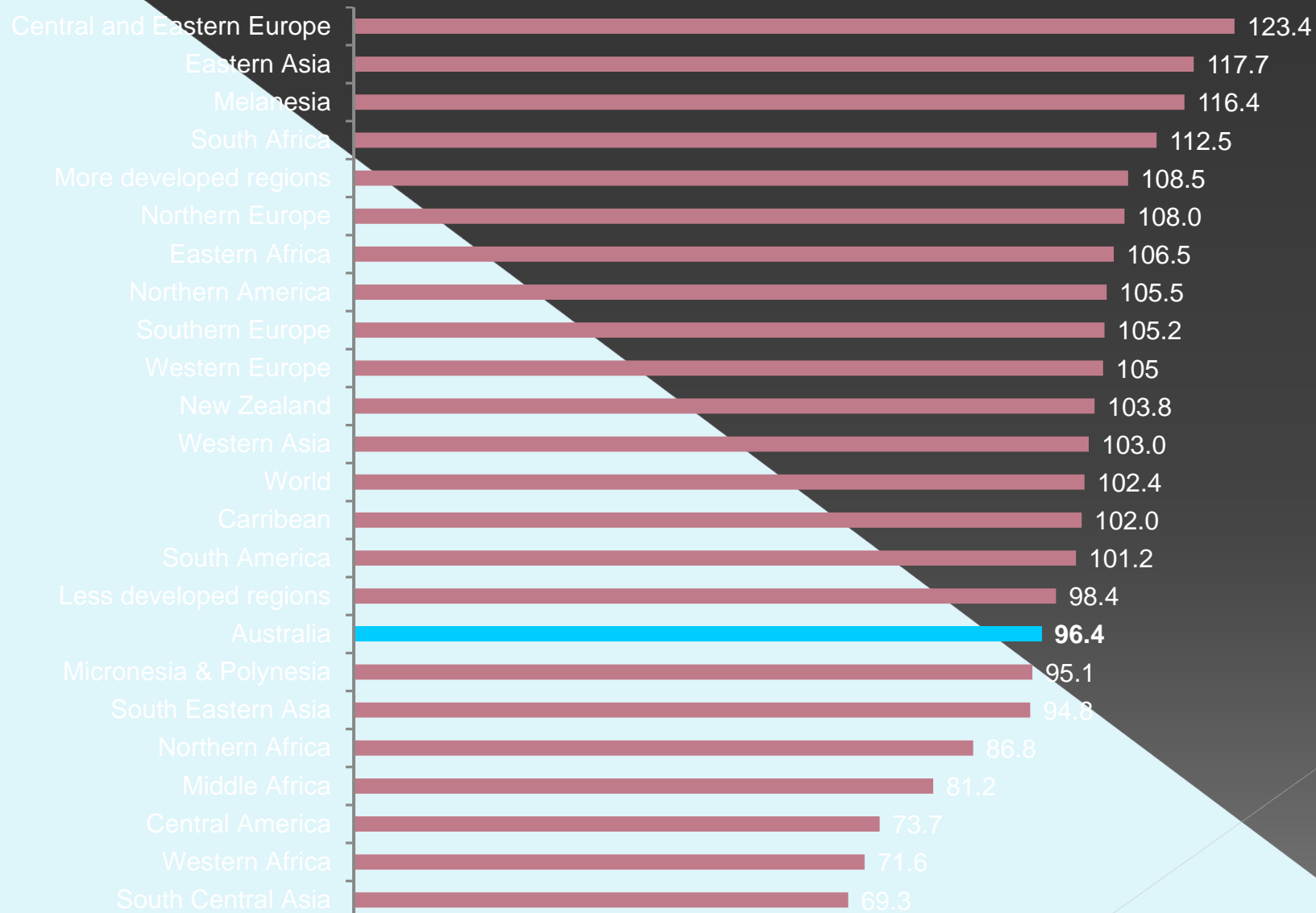
- ◎ **Risk stratification** – cancer stage/other prognostic indicators
- ◎ **Comorbidity indices** – Rx-Risk-V/Charlson/Elixhauser/etc.
- ◎ **Treatment patterns**
- ◎ **Treatment toxicity/late effects**
- ◎ **Recurrence/progression indices**
- ◎ **Patient-reported outcomes** – Physical/Social/Psychological/Spiritual-Existential (e.g., fatigue/pain/sexual dysfunction/fear of recurrence/anxiety/depression/broader quality of life issues)

Age-standardized (WP) cancer incidence per 100,000 population for all cancers combined: GLOBOCAN estimates for 2012 (excl NMSC)*



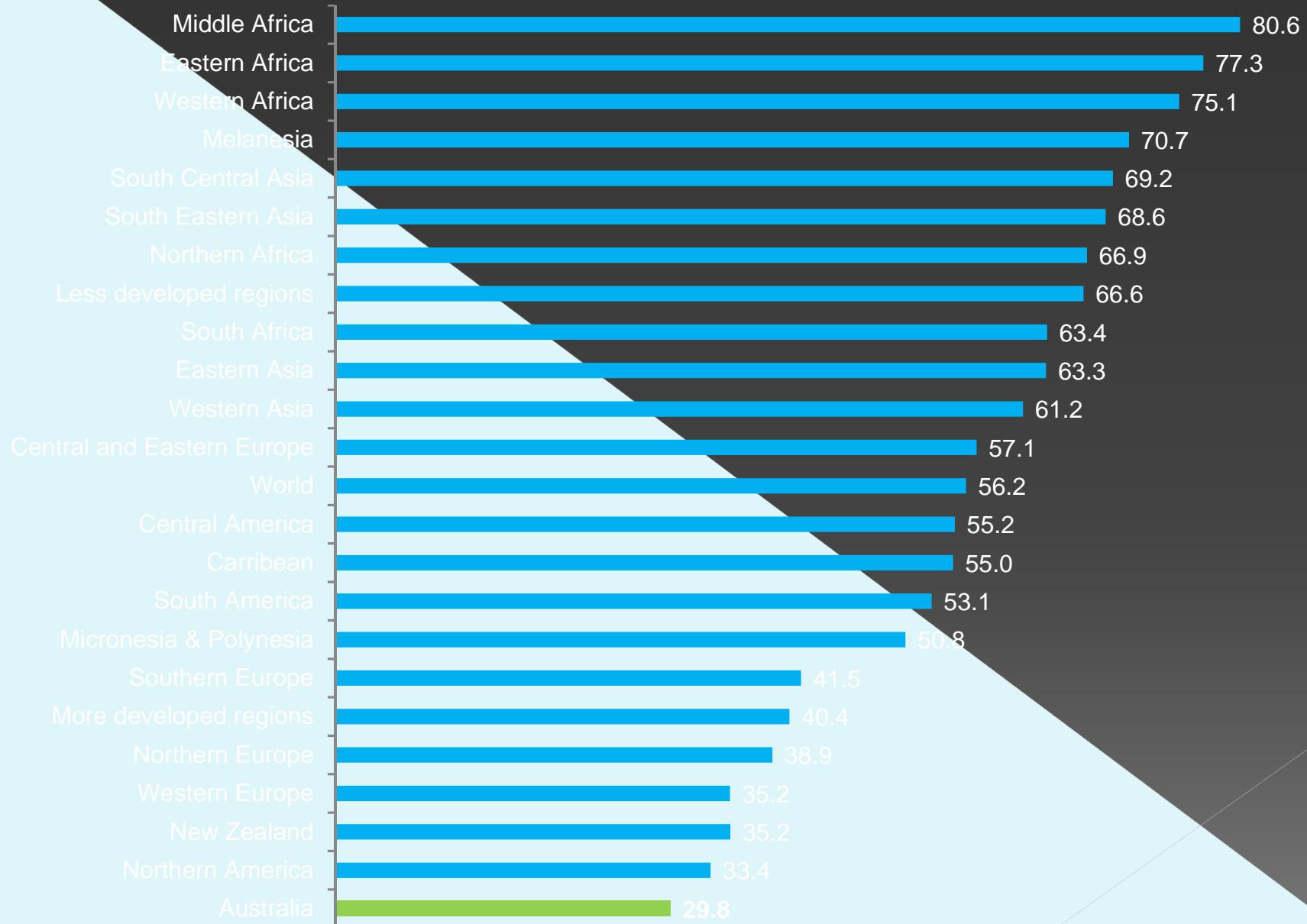
* Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin DM, Forman D, Bray F. GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11 [Internet]. Lyon, France: International Agency for Research on Cancer; 2013. Available from: <http://globocan.iarc.fr>, accessed on 21/10/2014

Age-standardized (WP) cancer mortality per 100,000 population for all cancers combined: GLOBOCAN estimates for 2012*



* Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin DM, Forman D, Bray F. GLOBOCAN 2012 v1.0. Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11 [Internet]. Lyon, France: International Agency for Research on Cancer; 2013. Available from: <http://globocan.iarc.fr>, accessed on 21/10/2014

Numbers of cancer deaths per 100 cases for all cancers combined - GLOBOCAN estimates for 2012 (excl NMSC)*



* Ferlay J, Soerjomataram I, Ervik M, Dikshit R, Eser S, Mathers C, Rebelo M, Parkin DM, Forman D, Bray F. GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11 [Internet]. Lyon, France: International Agency for Research on Cancer; 2013. Available from: <http://globocan.iarc.fr>, accessed on 21/10/2014

**Annual age-standardized (Aust pop, 2001) invasive cancer incidence (95% CL) per 100,000 in Australia for specified diagnostic years*
- All cancers combined (excl NMSC) -**

Males	1982-84	473.9 [470.6, 477.2]
	1985-89	492.7 [490.2, 495.2]
	1990-94	559.2 [556.7, 561.7]
	1995-99	565.7 [563.3, 568.1]
	2000-04	568.9 [566.7, 571.1]
	2005-09	605.2 [603.1, 607.3]
	2010-11	585.5 [582.4, 588.6]
Females	1982-84	331.8 [329.3, 334.3]
	1985-89	348.6 [346.7, 350.5]
	1990-94	374.7 [372.8, 376.6]
	1995-99	394.6 [392.8, 396.4]
	2000-04	403.6 [401.9, 405.3]
	2005-09	406.1 [404.5, 407.7]
	2010-11	406.2 [403.7, 408.7]
Males	1982-2011	551.7 [550.8, 552.6]
Females	1982-2011	381.5 [380.8, 382.2]
SES (SEIFA) 2005-09	Low	498.4 [495.4, 501.7]
	Mid low	504.6 [501.4, 507.8]
	Mid	495.2 [491.9, 498.5]
	Mid high	489.9 [486.5, 493.3]
	High	486.3 [483.0, 489.6]
Remoteness 2005-09 (Residence)	Major city	478.4 [476.8, 480.0]
	Inner regional	540.3 [537.3, 543.4]
	Outer regional	508.2 [504.0, 512.5]
	Remote	578.9 [506.4, 531.5]
Indigenous status** 2005-09	Very remote	393.9 [381.7, 415.3]
	Indigenous	474.5 [457.4, 492.0]
	Non-Indigenous	499.1 [497.3, 500.9]

* Data source: AACR & AIHW

** Estimated from data for NSW, QLD, WA, SA & NT

Annual age-standardized (Aust pop, 2001) cancer mortality rates (95% CL)
per 100,000 in Australia for specified diagnostic years*
- All cancers combined -

Males	1982-84	280.4 [277.8, 283.0]
	1985-89	283.1 [281.2, 285.0]
	1990-94	278.7 [276.9, 280.5]
	1995-99	266.2 [264.5, 267.9]
	2000-04	246.1 [244.6, 247.6]
	2005-09	230.8 [229.5, 232.1]
	2010-11	221.2 [219.2, 223.2]
Females	1982-84	163.9 [162.1, 165.7]
	1985-89	164.9 [163.6, 166.2]
	1990-94	163.7 [162.5, 164.9]
	1995-99	158.6 [157.5, 159.7]
	2000-04	150.2 [149.2, 151.2]
	2005-09	142.7 [141.8, 143.6]
	2010-11	137.2 [135.8, 138.6]
Males	1982-2011	260.3 [259.6, 261.0]
Females	1982-2011	155.6 [155.1, 156.1]
SES (SEIFA): 2009-12	Low	190.1 [188.2, 192.0]
	Mid low	181.6 [179.8, 183.4]
	Mid	173.2 [171.4, 175.0]
	Mid high	164.3 [162.4, 166.2]
	High	149.2 [147.4, 150.9]
Remoteness: 2008-12 (Residence)	Major city	166.7 [165.8, 167.6]
	Inner regional	185.4 [183.8, 187.1]
	Outer regional	190.2 [187.7, 192.8]
	Remote	191.8 [184.3, 199.5]
	Very remote	191.9 [180.2, 204.2]
Indigenous status**: 2008-12	Indigenous	220.9 [210.4, 231.8]
	Non-Indigenous	172.0 [171.2, 172.9]

* Data source: AACR & AIHW

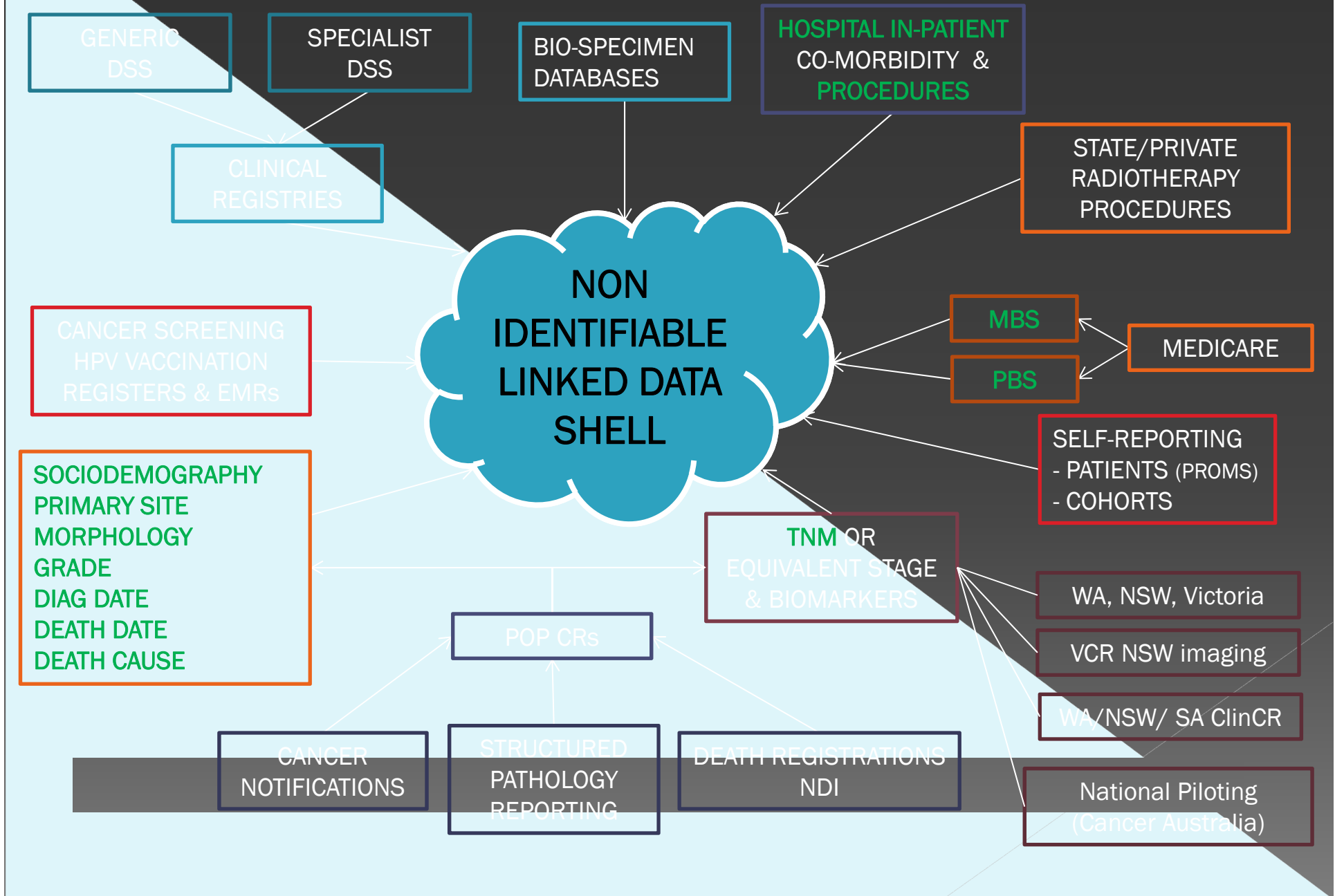
** Estimated from data for NSW, QLD, WA, SA & NT

5-year age-standardized relative survivals for colorectal, female breast and lung cancer for Australia & comparison populations*

		SURVIVAL %					
		Colorectal		Female Breast		Lung	
1995-99	Australia	60.0	[1]	85.0	[3]	13.9	[2]
	Canada	58.1	[3]	85.3	[2]	15.7	[1]
	Denmark	48.2	[5]	76.9	[5]	8.0	[5]
	Norway	56.9	[4]	81.8	[4]	11.0	[4]
	Sweden	58.5	[2]	86.7	[1]	12.7	[3]
	UK	47.8	[6]	74.8	[6]	7.0	[6]
	2000-02	Australia	63.4	[1]	87.0	[2]	15.1
Canada		60.9	[2]	86.4	[3]	15.9	[1]
Denmark		51.7	[5]	81.5	[5]	9.6	[5]
Norway		58.8	[4]	83.8	[4]	11.0	[4]
Sweden		60.6	[3]	89.3	[1]	11.6	[3]
UK		51.3	[6]	78.8	[6]	8.1	[6]
2005-07		Australia	65.9	[1]	88.1	[2]	17.0
	Canada	63.7	[2]	86.3	[3]	18.4	[1]
	Denmark	55.8	[5]	82.4	[5]	10.9	[5]
	Norway	62.0	[4]	85.5	[4]	14.4	[4]
	Sweden	62.6	[3]	88.5	[1]	16.3	[3]
	UK	53.6	[6]	81.6	[6]	8.8	[6]

* Data source: Coleman et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden & the United Kingdom (ICBP) Australian data from NSW/Victoria

Australia: linked cancer data



Data output options from linked database – Australian National Cancer Data Strategy

1. Cancers by primary site & histology

2. Stage/other prognostic indicators

3. Emerging biomarkers

4. Comorbidity indices

5. Patterns of care

6. Early toxicities/complications/late effects

7. Survivorship (generic/disease-specific measures)

8. Appended research data extracts

9. Other

How to add survivorship data?

For whom – all cases, sentinel clinics, representative samples, opportunistic, volunteers via web portal, multiple methods (including periodic focus groups/interview surveys/etc.)?

For what time – at diagnosis, 3-month, 6-month, 12-month, 5 years?

How – face-to-face interview, telephone follow-up, mail questionnaire, mobile phone app, other?

For what outcome domains? What measures?

- Physical – pain, tiredness, sexual function (≥ 10 measurement tools)
- Psychological – anxious, depressed, fear of cancer recurrence (≥ 12 measurement tools)
- Social – Marital/family distress, concern of body image (≥ 15 measurement tools)
- Medical – patient-clinician communication, continuity (≥ 7 measurement tools)
- Spiritual - anger, abandoned, belief system challenged, grief, guilt, despair, isolation, religious issues (≥ 5 measurement tools)

Probability of resection for localized non-small cell lung cancer in NSW; 2003-07*

Age (yrs.)	<60	52.7%	p<0.001
	60-69	48.3%	
	70-79	37.2%	
	80+	16.3%	
Sex	Male	36.9%	p=0.024
	Female	41.0%	
Payment (private/VA)	No	33.5%	p<0.001
	Yes	48.2%	
Remoteness (residence)	Major City	42.7%	p<0.001
	Inner Regional	35.6%	
	Outer regional	26.0%	
	Remote	37.5%	
SES (SEIFA)	Low	37.3%	p<0.001
	Mid-low	35.5%	
	Mid	32.9%	
	Mid-high	44.0%	
Cancer location	High	45.5%	p<0.001
	Main bronchus	8.5%	
	Upper lobe	44.5%	
	Middle lobe	43.0%	
	Lower lobe	49.0%	
Histology	Overlapping	45.2%	p<0.001
	Adenocarcinoma	56.4%	
	Squamous cell	38.7%	
	Large cell	15.1%	
	Other	50.4%	
Co-morbidity	No	45.2%	p<0.001
	Yes	31.2%	

* Source: Currow et al, MJA, 2014

Relative risk (95% CL) of death from lung cancer among localized non-small cell lung cancer in NSW; 2003-07*

Age (yrs.)	<60	1.00		
	60-69	1.52	[1.20, 1.93]	
	70-79	2.24	[1.78, 2.81]	
	80+	3.92	[3.03, 5.08]	
Sex	Male	1.00		
	Female	0.77	[0.66, 0.89]	
Payment (private/VA)	No	1.00		
	Yes	0.60	[0.51, 0.69]	
Remoteness (residence)	Major City	1.00		
	Inner Regional	0.53	[0.46, 0.62]	
	Outer regional	1.27	[1.02, 1.59]	
	Remote	0.74	[0.40, 1.36]	
SES (SEIFA)	High	1.00		
	Mid-high	0.96	[0.74, 1.24]	
	Mid	1.21	[0.95, 1.54]	
	Mid-low	1.31	[1.04, 1.65]	
SES (SEIFA)	Low	1.31	[1.04, 1.67]	
	Cancer location	Main bronchus	1.00	
		Upper lobe	0.39	[0.28, 0.53]
		Middle lobe	0.33	[0.21, 0.51]
Lower lobe		0.35	[0.25, 0.48]	
Overlapping		0.41	[0.18, 0.94]	
Histology	Adenocarcinoma	1.00		
	Squamous cell	1.85	[1.54, 2.24]	
	Large cell	3.63	[2.99, 4.41]	
	Other	0.47	[0.33, 0.66]	
Co-morbidity	No	1.00		
	Yes	1.44	[1.24, 1.68]	
Resection	Lobectomy	1.00		
	Segmental	0.81	[0.53, 1.22]	
	Wedge	1.69	[1.01, 2.82]	
	Pneumonectomy	3.87	[2.14, 7.00]	
	None	11.99	[9.60, 15.00]	

* Source: Currow et al, MJA, 2014

% colorectal patients receiving specified treatments ≤ 12 months of diagnosis and consistency with guidelines; SA 50-79 year olds, 2003-08*

Site/ACPS	Surgery	Radiotherapy	Chemotherapy	Guidelines consistency
Colon:				
A	98%	1%	2%	98%
B	98%	1%	11%	97%
C	98%	3%	61%	60%
D	69%	7%	58%	80%
Rectum:				
A	96%	24%	19%	94%
B	98%	35%	39%	28%
C	97%	45%	71%	37%
D	69%	37%	65%	79%

* Source: Beckmann et al, JECR, 2014

Note: Multivariate analysis (with predictors of cancer site, stage, grade, age, sex, residence (remoteness) SES, co-morbidity and diagnostic year – Stages A-C only show:

- **Surgery:** less for rectum; less for higher grade
- **Radiotherapy:** more for stage C; less for older cases; more for lower SES
- **Chemotherapy:** more for rectum; less for older cases; more for males; less for rural cases; less for multiple co-morbidity
- **Guideline consistency:** less for older cases; less for rectum; less for multiple co-morbidity; less for rural (?) (p=0.062)

Relative risk of death from CRC (95% CI) among 50-79 year old cases in SA; 2003-08*
- Multivariate competing risk regression -

Site	Colon	1.00
	Rectum	0.85 [0.74, 0.98]
ACPS	A	1.00
	B	2.97 [2.21, 3.99]
	C	7.74 [5.75, 10.40]
	D	34.10 [25.0, 46.0]
Grade	Low	1.00
	Intermediate	1.22 [0.72, 2.07]
	High	2.25 [1.32, 3.84]
Age (yrs.): (Diagnosis)	50-59	1.00
	60-69	1.04 [0.89, 1.21]
	70-79	1.12 [0.96, 1.29]
Sex	Females	1.00
	Males	1.07 [0.95, 1.20]
Private insurance	No	1.00
	Yes	0.95 [0.84, 1.06]
Comorbidity	No	1.00
	One (not severe)	0.90 [0.78, 1.05]
	Multiple (or severe)	1.21 [1.02, 1.44]
SES	Low	1.00
	Mid-low	0.94 [0.80, 1.11]
	Mid	0.93 [0.78, 1.10]
	Mid-high	1.06 [0.90, 1.25]
	High	0.75 [0.62, 0.91]
Residence	Urban	1.00
	Outer urban	0.95 [0.79, 1.16]
	Rural	0.98 [0.82, 1.17]
	Remote	1.12 [0.90, 1.39]
Surgery	No	1.00
	Yes	0.51 [0.42, 0.62]
Radiotherapy	No	1.00
	Yes	1.41 [1.18, 1.68]
Chemotherapy	No	1.00
	Yes	0.87 [0.76, 1.00]
Diagnosis year		0.95 [0.92, 0.98]

* Source: Beckmann et al,
 BMC Health Services Res, 2016

Concluding Comments

- Show **incidence, mortality, survival trends** (across population & global differences)

Administrative Clinical Data

- Also show system-wide **stage distributions and other prognostic differences, comparative co-morbidity, broad patterns of care, toxicities/late effects, recurrence** (under development)
- Also provide quality data of high relevance **for clinical research and for validating linked registry-administrative data**
- **Australia should have population-based all-of-system linked databases** (including patient-reported outcomes) for health-system research/service planning/evaluation
- Data uses would include:
 - **Detection of service gaps** (e.g., as relating to the aged/low SES/geographically remote/Aboriginal and Torres Strait Islander, CALD etc.)
 - **Monitoring of roll-out of new clinical protocols**
 - **Detection of longer term toxicities** (pharmaco-vigilance)