# Research into Patterns of Cancer Care in New South Wales Australia

Bruce Armstrong
Professor of Public Health
The University of Sydney



# Acknowledgements



# Chronology

- Jan 2000 to Feb 2001 – *Colorectal cancer*: information on 3,096 patients, 92%
- Oct 2000 to Oct 2002 – *Prostate cancer*: information on 2,031 patients, 64%
- Nov 2001 to Dec 2002 – *Lung cancer*: information on 1,812 patients, 62%
- Oct 2006 to Oct 2007 – *Cutaneous melanoma*: 2,650 patients, ~80%



# Auspice and funding

- Colorectal cancer
  - Cancer Council NSW: NHMRC and MBF
- Prostate cancer
  - Cancer Council NSW: Veterans Affairs and NHMRC
- Lung cancer
  - Cancer Council NSW: NSW Dept of Health
- Melanoma
  - Sydney Melanoma Unit: Cancer Institute NSW



# Rationale

- Justify public support for Cancer Registry
- Justify Cancer Council support for an Epidemiology Research Unit
- Provide a baseline against which improvements in care prompted by guidelines might be measured



# Rationale

- Identify areas of guideline non-compliance
- Identify “health services” delivering poorer care
- Identify population sub-groups receiving poorer care
- Improve the quality and equity of care



# Methods

- Sample all cancers registered by the NSW Central Cancer Registry over a specified period
- Identify primary treating practitioner
- Ask practitioner to complete questionnaire:
  - Basic details of the cancer
  - Primary treatment they gave
  - Referrals to other practitioners for additional treatment
  - Vital status and planned follow-up



# Methods

- Offer fieldwork assistance for practitioners with larger numbers
- Hound practitioners mercilessly for responses
- Collect pathology reports
- Patients not approached and their permission not sought *(colorectal cancer and melanoma)*



# Sample from a questionnaire
# Melanoma - GPs



**1. What is your type of practice?**
- ❑ GP
- ❑ Skin cancer clinic
- ❑ Other *Please specify.* _____

## Patient's presentation with this melanoma

**2. Date of first presentation to you?** __ / __ / __

## Melanoma history

***Did the patient have a:***

**3. Personal history of melanoma?**
- ❑ No
- ❑ Yes
- ❑ Don't know

**4. Family history of melanoma in a blood relative?**
- ❑ No
- ❑ Yes
- ❑ Don't know

## Melanoma risk

**5. Did this patient have lots of moles?**
- ❑ No
- ❑ Yes
- ❑ Don't know

## Details of primary melanoma

**6. How did this melanoma present?** *(Tick one only)*
- ❑ Patient reported this skin lesion
- ❑ Found incidentally when checking another skin lesion
- ❑ Found in a routine skin check
- ❑ Other *Please specify.* _____

**7. Was there a history of:** *(Tick all that apply)*
- ❑ Change in colour, size, elevation or shape of lesion?
- ❑ Bleeding?
- ❑ Itch?
- ❑ Ulceration?

**8. What was the lesion's site?** *(Tick one only)*
- ❑ Head or neck
- ❑ Anterior trunk
- ❑ Posterior trunk
- ❑ Upper limb
- ❑ Lower limb

**9. Did you observe this lesion for a period before biopsy?**
- ❑ No
- ❑ Yes *If yes, how long?* _____

**10. Was the lesion clinically a melanoma?**
- ❑ No
- ❑ Yes
- ❑ Don't know

## Metastases

***Were there:***

**11. Any clinically suspicious lymph nodes?**
- ❑ No
- ❑ Yes *If yes, please specify location(s).* _____
- ❑ Don't know

**12. Any clinical signs of distant spread?**
- ❑ No
- ❑ Yes *If yes, please specify location(s).* _____
- ❑ Don't know

## Investigations

**13. What investigations did you do?**
*(Tick all that apply)*
- ❑ None
- ❑ Chest x-ray
- ❑ Biochemistry or haematology
- ❑ CT scan
- ❑ MRI scan
- ❑ PET scan
- ❑ Bone scan
- ❑ Other *Please specify.* _____

**14. Was there any investigational evidence of metastatic spread?**
- ❑ No
- ❑ Yes *If yes, please specify location(s).* _____

**15. Did you assess the lesion with a dermoscope?**
- ❑ No
- ❑ Yes

## Biopsy of melanoma

**16. Did you refer the patient to another doctor before biopsy?**
- ❑ No
- ❑ Yes *If yes, jump to Q22.*

**17. Did you attempt a complete excision biopsy?**
- ❑ No
- ❑ Yes

*If yes, was it complete?*
- ❑ No
- ❑ Yes





*If yes, please specify.*
Excision margin ____ mm
Did you remove subcutaneous tissue with this lesion?
- ❑ No
- ❑ Yes *Jump to Q19.*

**18. Did you do a partial biopsy?**
- ❑ No
- ❑ Yes *If yes, please specify type.*
  - ❑ Punch biopsy
  - ❑ Shave biopsy
  - ❑ Partial incision biopsy

*If yes, please specify reason for doing partial biopsy.*
- ❑ Lesion site
- ❑ Lesion size
- ❑ Thought to be a non-melanocytic lesion
- ❑ Other *Please specify.* _____

## Your post-biopsy treatment of the primary melanoma

**19. How did you manage the primary lesion next?**
- ❑ Wide excision
  *Please specify:*
  Date of wide excision ___ / ___ / ___
  Time from biopsy to wide excision ____ days
  Excision margin ____ mm
  Depth of excision ____ mm
- ❑ Observation only *Jump to Q22.*
- ❑ Referral to a specialist *Jump to Q22.*

***If you did a wide excision:***

**20. How was surgical repair done?**
- ❑ Primary closure
- ❑ Flap
- ❑ Skin graft

**21. Were there any post-op complications?**
- ❑ No
- ❑ Wound infection
- ❑ Cosmetic deformity
- ❑ Lymphoedema
- ❑ Prolonged pain
- ❑ Other *Please specify.* _____

## Follow-up

**22. Did you recommend follow-up?**
- ❑ No
- ❑ Yes

Who did you recommend do the follow-up?
- ❑ Me
- ❑ GP
- ❑ Dermatologist - *List continues ↗*
- ❑ Surgeon
- ❑ Other *Please specify.* _____

How frequently did you recommend follow-up?
At intervals of ____ months
At other intervals *Please specify* _____

**23. Did you do any of the following?**

*Advise patient on specific changes that suggest melanoma?*
- ❑ Yes
- ❑ No

*Encourage patient to perform skin self-examination?*
- ❑ Yes *If yes, how often?* _____
- ❑ No

*Recommend a skin surveillance program?*
- ❑ Yes
- ❑ No

## Referrals

Please give us the names and addresses of any other doctors to whom you referred this patient for melanoma management.

**Surgeon**

**Dermatologist**

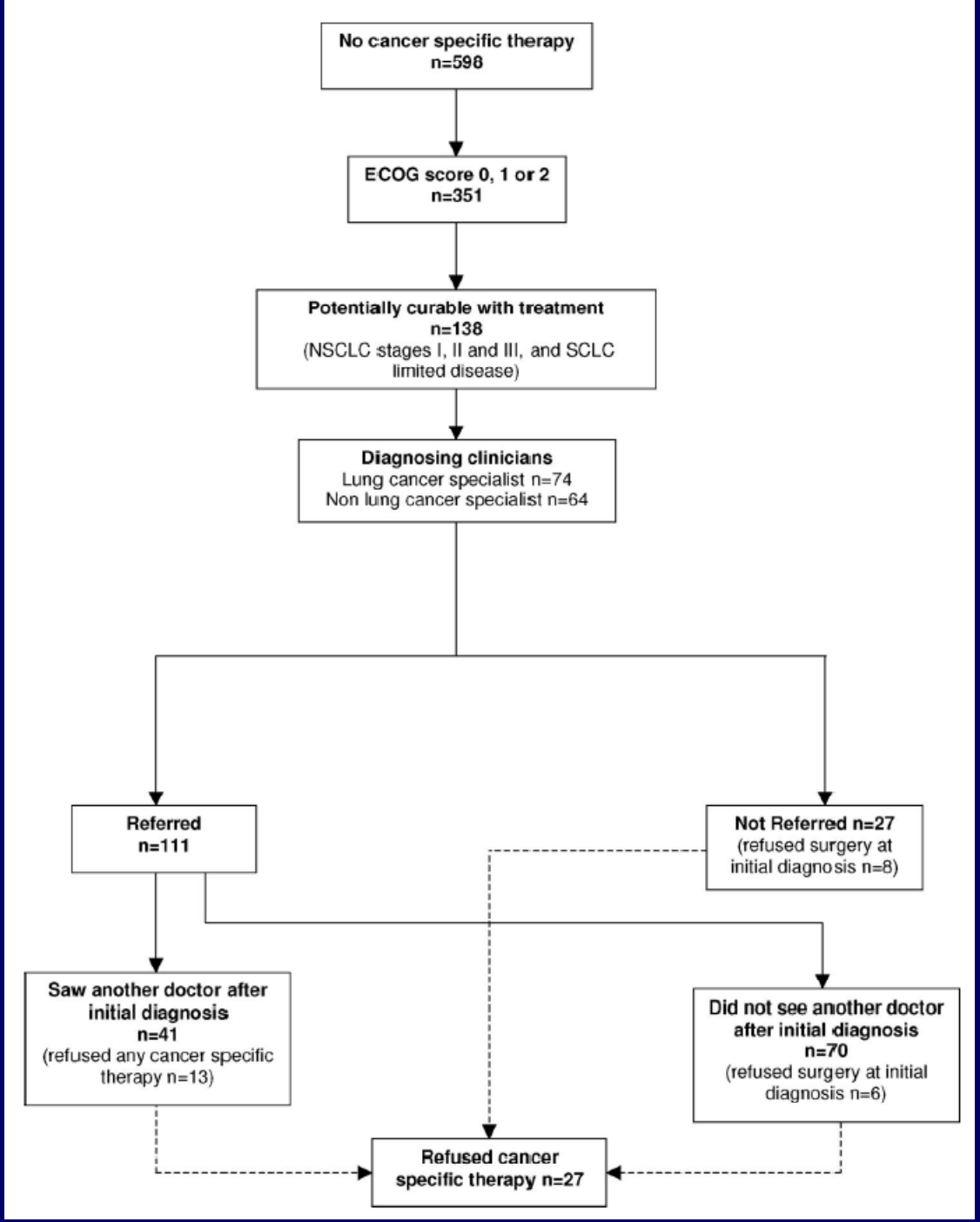
**Medical oncologist**

**Radiation oncologist**

**Other doctor** *Please state specialty if applicable.*

*** Who is this patient's usual family doctor?**
*Please give name and contact details.*

***Please continue to next page.***




# 33% of patients had no specific treatment for lung cancer

Vinod et al Gaps in optimal care for lung cancer J Thoracic Oncol 2008; 3: 871-9

# Independent predictors of no treatment

- Female sex
- Older age
- Resident in an “other urban area”
- Metastatic or unknown stage
- High ECOG score
- Multiple co-morbidities
- Seeing a lung cancer specialist who saw <15 patients or no lung cancer specialist



# Candidate predictors of compliance with colorectal cancer guidelines

- Age
- Sex
- Place of residence
- Elective/emergency
- Colon/rectum
- Dukes stage
- Number of tumours
- Surgical intent
- Colorectal or general surgeon
- Surgeon's caseload
- Hospital location
- Hospital type (tertiary referral, other public, private)
- Hospital caseload



# Predictors of compliance

| Guideline | | Predictors of compliance |
|---|---|---|
| Colonic pouch reconstruction following resection of low rectal cancer | 29% | Curative intent<br>CRC surgeon |
| Adjuvant chemotherapy for people with node positive colon cancer | 76% | Younger age<br>Metro hospital |
| Pre-operative radiotherapy for patients with fixed or tethered rectal cancer | 59% | Younger age<br>Curative intent |



# Predictors of compliance

| | | |
|---|---|---|
| Adjuvant radiotherapy for patients with high-risk rectal cancer | 60% | Younger age<br>Male<br>Just 1 tumour |
| No routine bowel prep for elective surgery | 6% | Larger hospital caseload |
| Antibiotic prophylaxis | 99% | Higher surgeon caseload |
| DVT prophylaxis | 99% | Higher surgeon caseload |

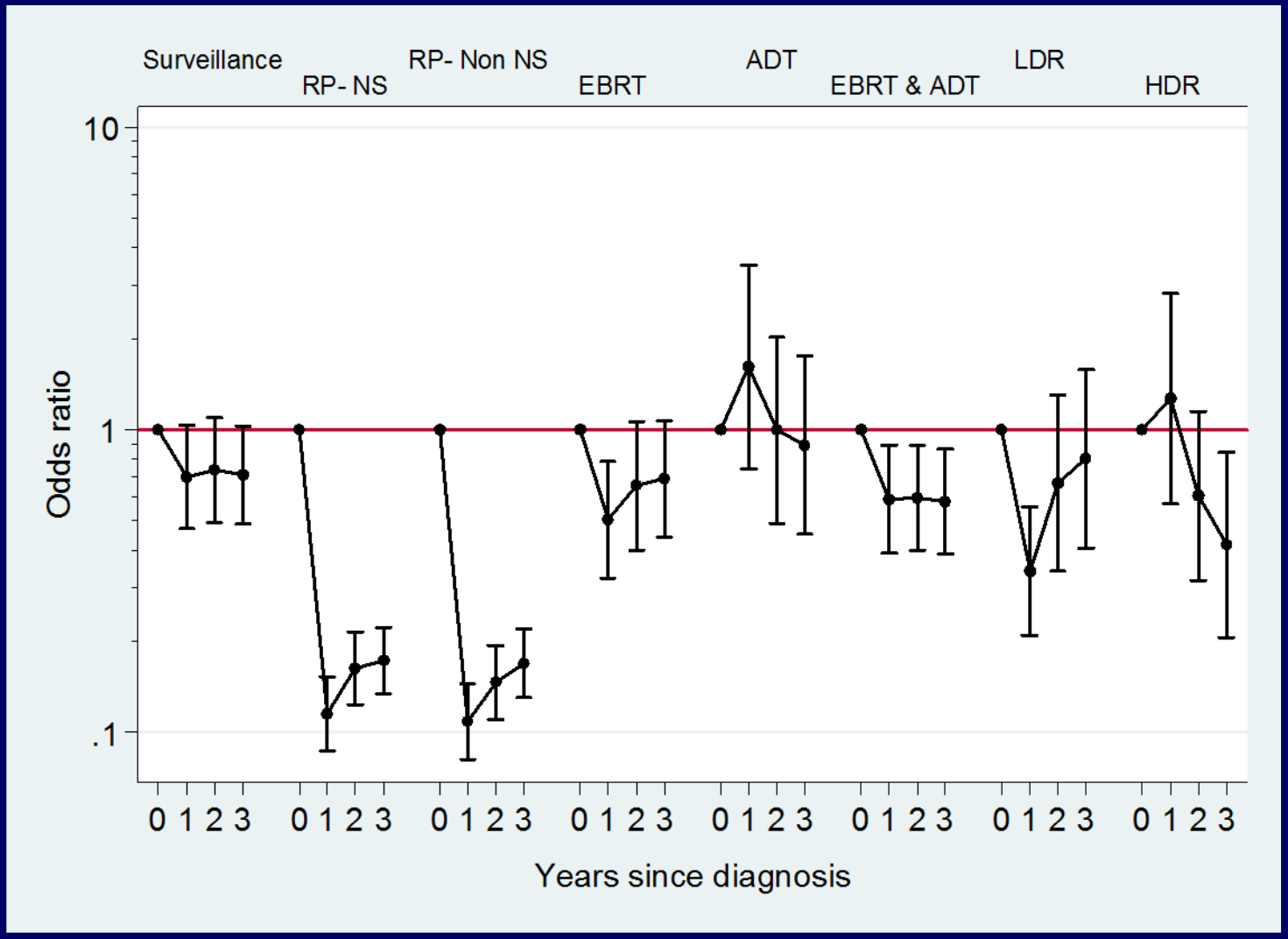


# 0utcomes of localised prostate cancer in men <70

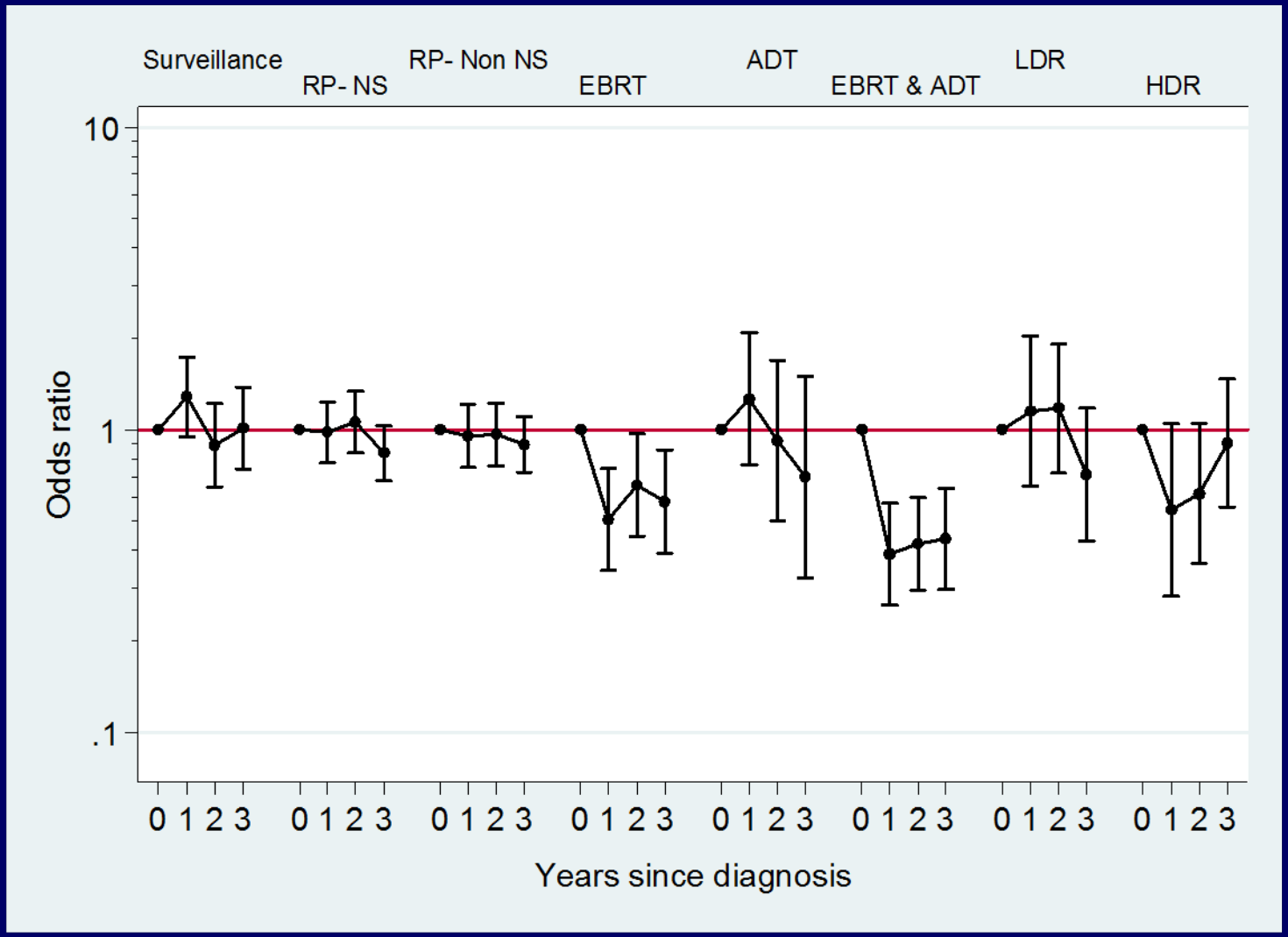
- Included age and residence balanced control sample
- Assessed “disease specific” function using UCLA prostate cancer index
  - Baseline
  - Years 1, 2 and 3
- ORs with reference to control group adjusting for age, baseline function and co-morbidity



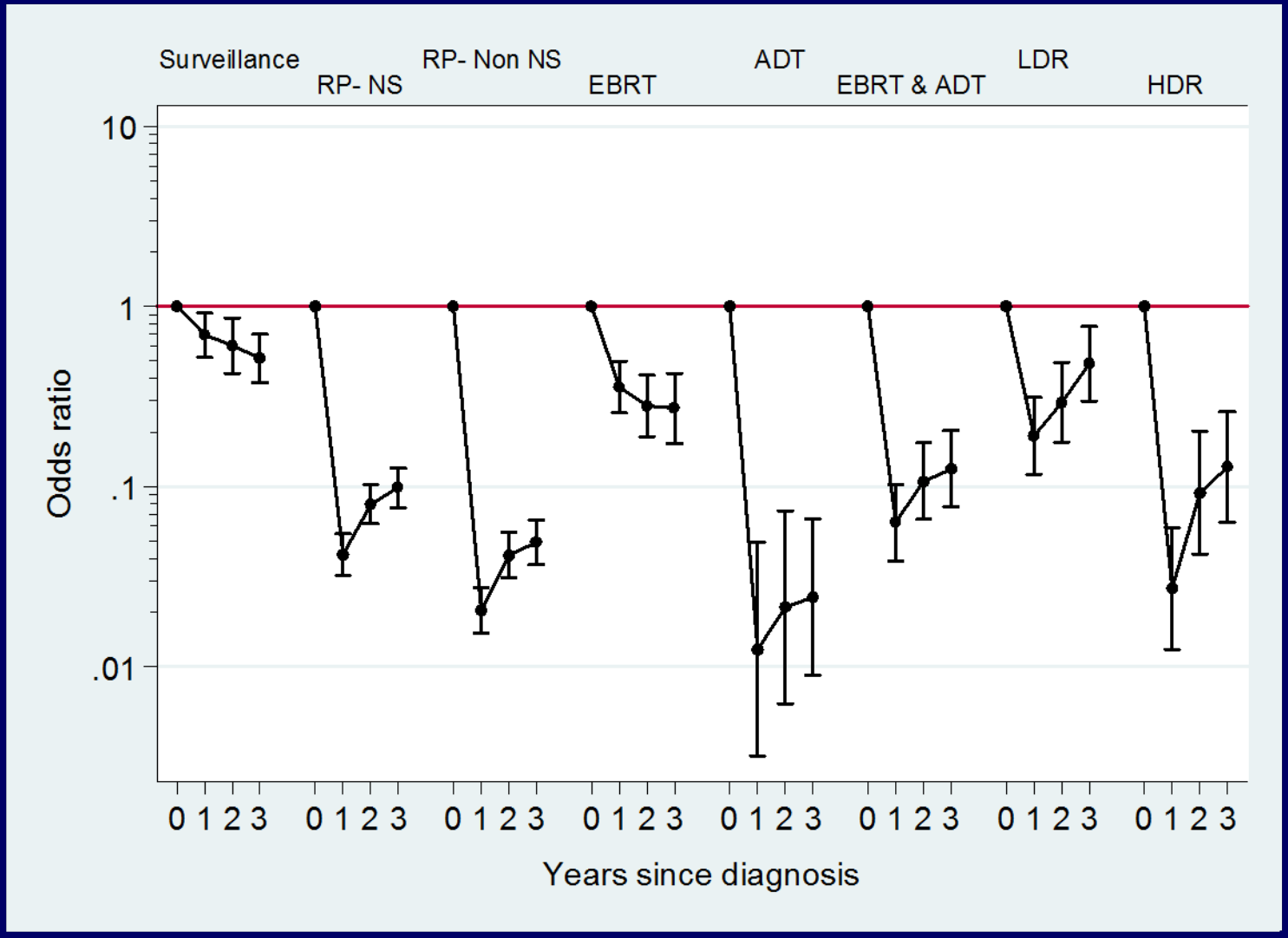
# Urinary function



# Bowel function



# Sexual function



# Completeness of melanoma pathology reports

- Based on a review of pathology reports from cases registered over 6 months
- 2,082 reports of invasive melanoma in 1,787 patients made by 219 pathologists
- 1,397 excision biopsies, wide local excisions or re-excisions; 317 were partial biopsies



# Completeness of melanoma pathology reports

| Essential features | % with each essential feature | | |
|---|---|---|---|
| **Excision Biopsy Reports** | **Synoptic format** (n=410) | **Descriptive format** (n=554) | **Combined format** (n=433) |
| Breslow thickness | 100% | 99.1% | 100% |
| Level of invasion (Clark) | 99.8% | 96.2% | 100% |
| Dermal mitotic rate | 98.8% | 78.9% | 98.8% |
| Ulceration | 98.5% | 75.6% | 99.3% |
| In-situ margin | 72.9% | 38.3% | 83.6% |
| Invasive peripheral margin | 68.0% | 28.9% | 83.4% |
| Deep margin | 94.4% | 45.1% | 95.6% |



# Reflections

- Completion of data collection takes >1 year after end of period of notification
- Costs $500,000+
- Analysis and publication slow with a small team
- Data produced are logically coherent and identify important, remediable failures in care



# Reflections

- Confirm what we know already about specialisation and experience
- Inequalities by place of residence, age and possibly sex are of concern
- Badly need a framework within which intelligence gained is fed back effectively into practice improvement



# Reflections

- Need to learn more about the value of linked consumer experience and outcomes surveys
- Ethics of survey without patients' consent may be controversial, especially if there is a linked consumer survey
- What prospects linked record systems or population-based clinical cancer registries?