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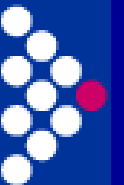
# Cancer Intelligence Requirements for Primary Care

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# Acknowledgements

Grateful thanks to our collaborators:

University Of Oxford : Nada Khan, Alison Ward, Rafael Perera,  
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Oxford Brooks University: Eila Watson

Oxford Cancer Intelligence Unit: Monica Roche

NYCRIS: David Forman





**BANX**

**'Would you mind repeating that?  
I was thinking about my salary'**



# Data needs for the primary care consultation

- Access to the evidence base
  - Screening
  - Diagnosis
  - Curative treatment in hospital
  - Other treatments eg palliative care

# Data needs for the primary care consultation

- Information about individual patients
  - Summary of care
  - GP responsibility
  - Care needs at transfer back
  - Indications for re-referral
- Which are also educational for GPs
- Communication flows!

# GP role in cancer care

Patients identified 5 nodes where GP input was important:

- Diagnosis

- Treatment

- After hospital discharge from follow up

- Relapse

- Palliation

(Kendall 2006)



# Data needs for the primary care researcher

Data needs relate to the same areas.....

Diagnosis

Treatment

After hospital discharge from follow up

Relapse

Palliation

# Diagnosis

- A series of studies using retrospective audit of GP records by Willie Hamilton in Bristol has identified important symptom clusters and pathways of care in:
  - Colorectal
  - Prostate
  - Brain
  - Ovary

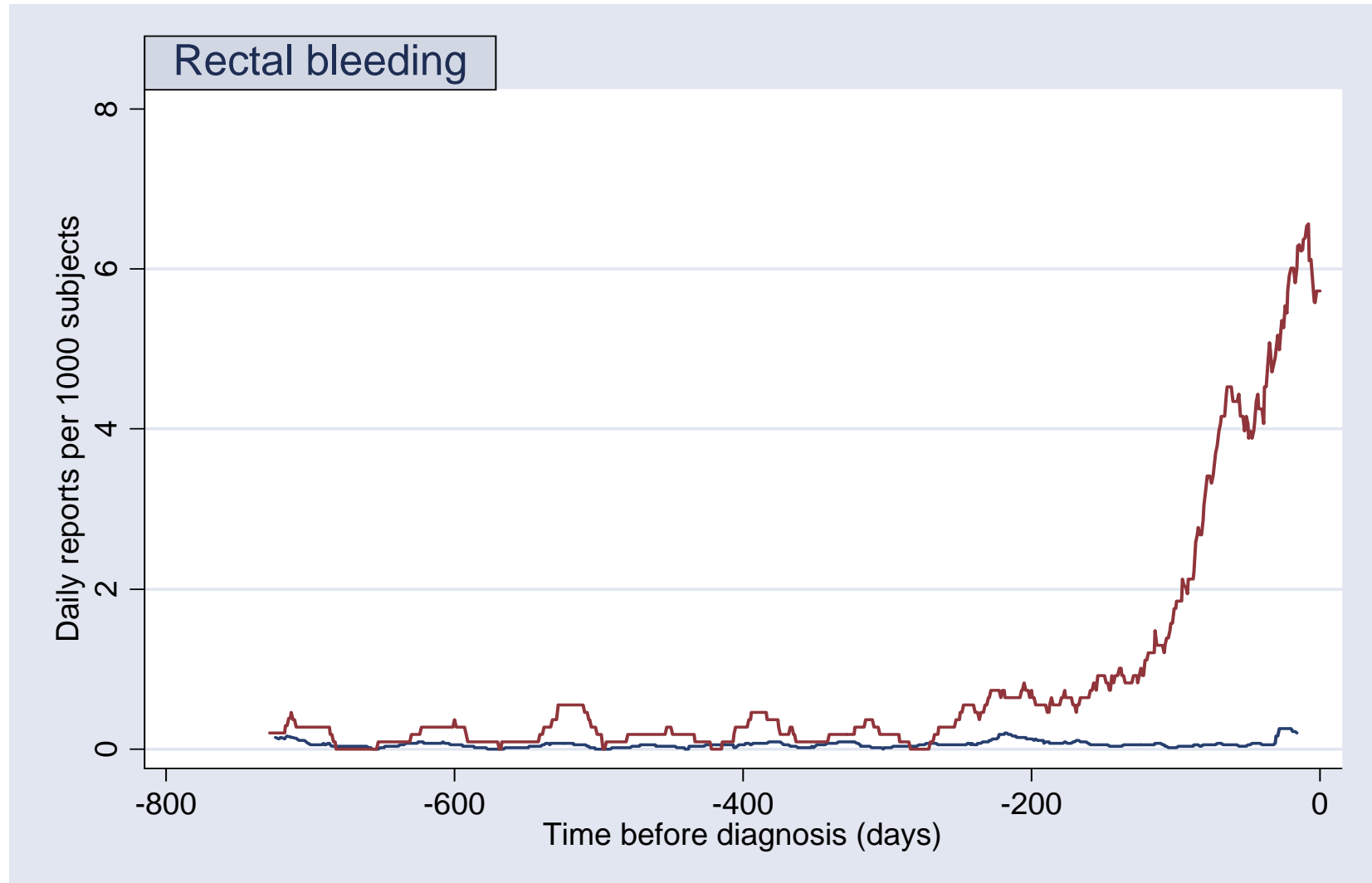
# Univariable analyses

Variable	Number (%) with this variable present		Positive Likelihood ratio (95% CI)
Symptoms			
Rectal bleeding	148 (42.4)	73 (4.2)	10 (7.9, 13)
Loss of weight	94 (26.9)	92 (5.3)	5.1 (3.9, 6.6)
Abdominal pain	148 (42.4)	163 (9.4)	4.5 (3.8, 5.5)
Diarrhoea	132 (37.8)	171 (9.8)	3.9 (3.2, 4.7)
Constipation	91 (26.1)	258 (14.8)	1.8 (1.5, 2.1)
Investigations			
Haemoglobin 12-12.9 g/dl	17 (4.9)	20 (1.2)	4.3 (2.7, 6.8)
Haemoglobin 10-11.9 g/dl	38 (10.9)	49 (2.8)	3.9 (2.8, 5.2)
Haemoglobin <10 g/dl	40 (11.5)	21 (1.2)	9.5 (7.1, 13)

# Positive predictive values II

Constipation	Diarrhoea	Rectal bleeding	Loss of Weight	Abdominal pain	Abdominal tenderness	Abnormal rectal exam	Haemoglobin 10-13g/dl	Haemoglobin < 10 g/dl	
0.42 0.3, 0.5	0.94 0.7, 1.1	2.4 1.9, 3.2	1.2 0.9, 1.6	1.1 0.9, 1.3	1.1 0.8, 1.5	1.5 1.0, 2.2	0.97 0.8, 1.3	2.3 1.6, 3.1	PPV as a single symptom
0.81 0.5, 1.3	1.1 0.6, 1.8	2.4 1.4, 4.4	3.0 1.7, 5.4	1.5 1.0, 2.2	1.7 0.9, 3.4	2.6	1.2 0.6, 2.7	2.6	Constipation
	1.5 1.0, 2.2	3.4 2.1, 6.0	3.1 1.8, 5.5	1.9 1.4, 2.7	2.4 1.3, 4.8	1.1	2.2 1.2, 4.3	2.9	Diarrhoea
		6.8	4.7	3.1 1.9, 5.3	4.5	8.5	3.6	3.2	Rectal bleeding
			1.4 0.8, 2.6	3.4 2.1, 6.0	6.4	7.4	1.3 0.7, 2.6	4.7	Loss of Weight
				3.0 1.8, 5.2	1.4 0.3, 2.2	3.3	2.2 1.1, 4.5	6.9	Abdominal pain
					1.7 0.8, 3.7	5.8	2.7	>10	Abdominal tenderness

# Rectal bleeding results plotted together



# Diagnosis

- Cases identified by registry first
- Labour intensive as symptoms not coded
- Retrospective
- Identifies delay but not significance of delay
- Addition of Registry and HES could investigate delays and how they relate to stage and outcome.

# GP role in cancer care

Patients identified 5 nodes where GP input was important:

Diagnosis

Treatment

After hospital discharge from follow up

Relapse

Palliation

(Kendall 2006)

# Primary care databases

- GPRD
- Q research
- The Health Improvement Network (THIN)
- Practice Team Information (PTI) database from the NHS Scotland Information Services Division
- Health Information Research Unit



# What is the GPRD?

- The General Practice Research Database (GPRD) is the world's largest database of anonymised longitudinal medical records from primary care.
- GPRD has full records for over 3.6 million currently registered patients and over 10 million patients in total
  - 450 practices covering approximately 4.6% of UK population
- What happens in primary care is recorded in the GPRD
  - Clinical events
  - Prescriptions
  - Referrals
  - Tests

# After hospital discharge from follow up

- Study cohort of cancer survivors from the GPRD population
- Inclusion criteria:
  - Diagnosis of breast, colorectal or prostate cancer more than 5 years ago
  - Alive for one or more day between 2001 and 2006
  - Aged 30 or over at time of diagnosis
  - Matched to 4 controls on age, gender and practice
- We have their longitudinal primary care records

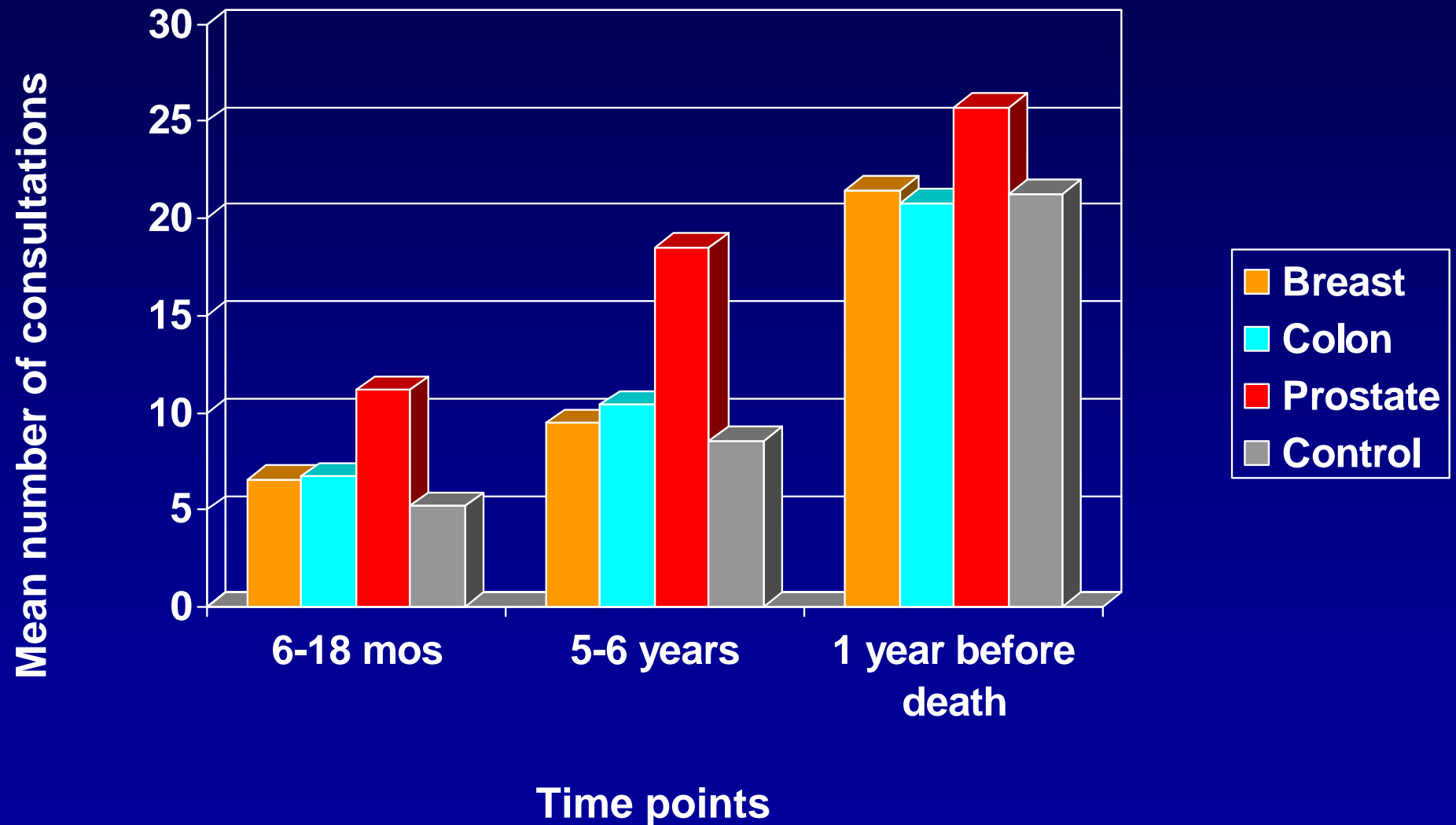
# Cancer survivors in the GPRD

Type of cancer	Gender		Total
	Female	Male	
Breast	18,777	0	18,777
Colorectal	2,880	2,945	5,825
Prostate	0	4,901	4,901
Controls	86,294	30,901	117,195
<b>Total</b>	<b>107,951</b>	<b>38,747</b>	<b>146,686</b>

# Analysis of consultation events

- The comparison is of the number of consultations between survivors of each cancer and their matched controls
- Outcome is the overall count of consultations
- We focussed on the volume of work that patients take to their GPs

# Comparison of consultation rates over time



# Consultations for depression

(Relative risk with 95% CI)	Breast	Colo-rectal	Prostate
6-18 months post diagnosis	1.75 (1.60 - 1.90)	NS	1.87 (1.47- 2.36)
5-6 years post-diagnosis	1.29 (1.17-1.42)	NS	1.64 (1.31-2.06)
Year before death	NS	NS	1.64 (1.08-2.48)

# Pain consultations

(Relative risk with 95% CI)	Breast	Colo-rectal	Prostate
6-18 months post diagnosis	1.47 (1.38 - 1.55)	1.30 (1.17 -1.46 )	1.58 (1.43- 1.76)
5-6 years post-diagnosis	1.21 (1.02-1.44)	NS	1.71 (1.41- 2.09)
Year before death	NS	NS	1.70 (1.39-2.06)

# Deficiencies of GPRD

- Many items not coded especially symptoms
- Incomplete eg smoking data
- Difficult and expensive to obtain hospital data

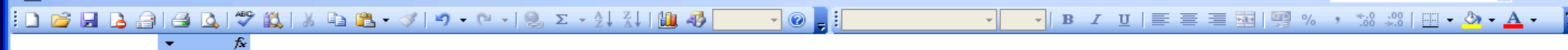


# Added value of registry linkage

- Linkage to registry data will enable individual stage and treatment to be added to the data
- Enabling identification of risk factors for outcomes
- Enabling overall risk stratification

# Added value of linkage to HES

- Better understanding of patient pathway

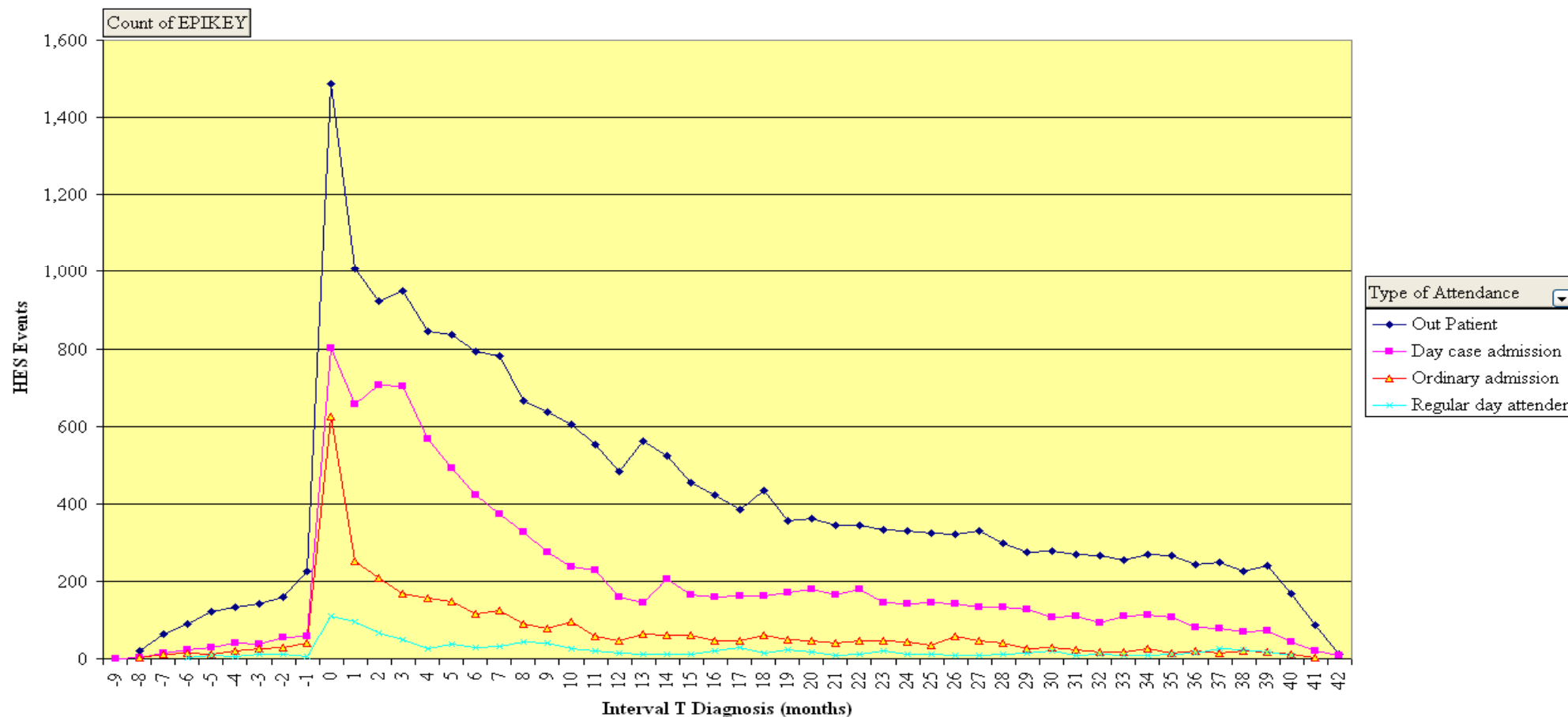


Main Specialty (All)

All Specialties

## HES Activity Before and After Registry Data of Diagnosis (Haem Cohort)

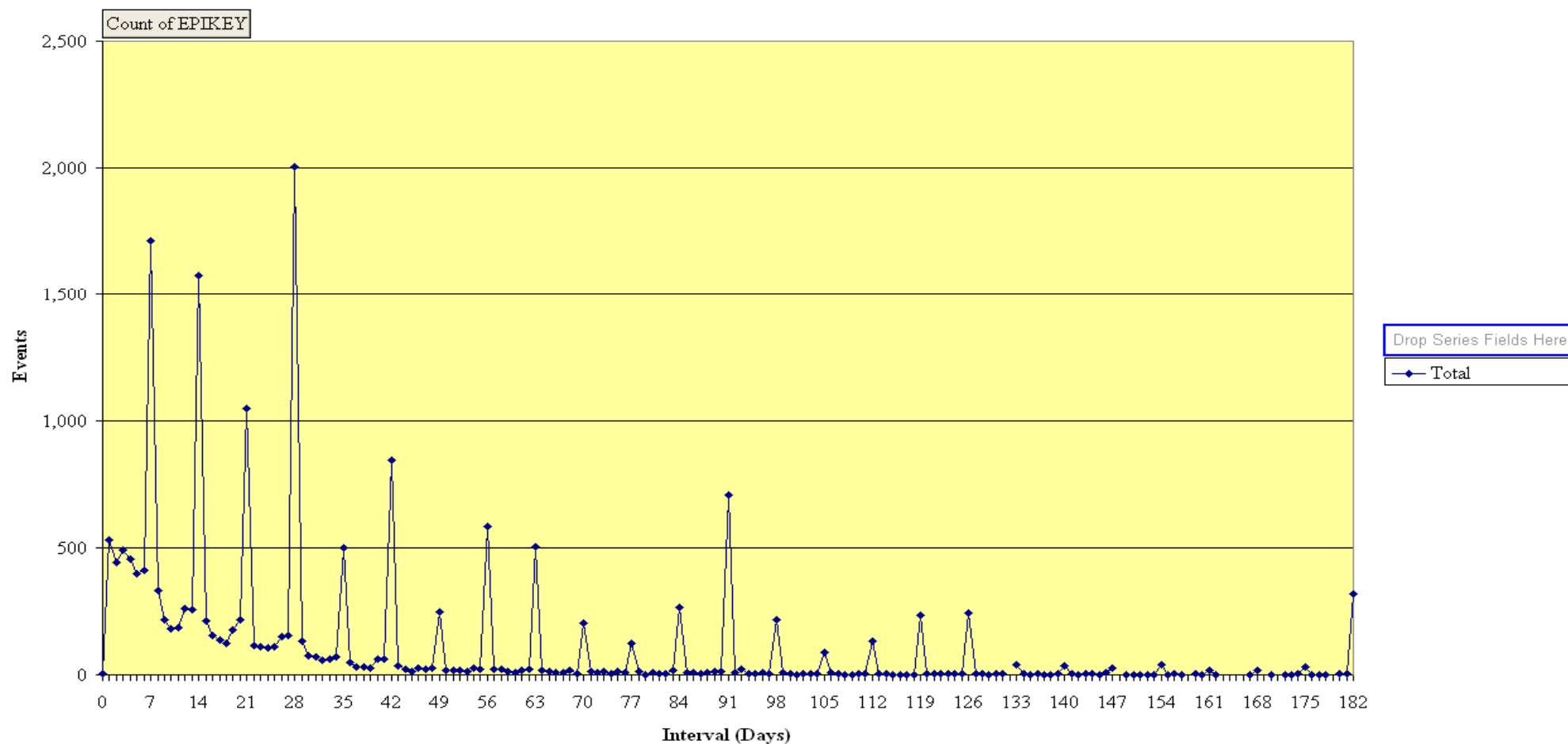

2,270 Patients 78,435 HES Events



DoDiag-TE(m)

Death Status	(All) ▾	Main Specialty	Clinical Haematology ▾	Type of Attendance	Out Patient ▾
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## Interval Between OP Attendance and Previous HES Event (Clinical Haematology)

TE - pFUPE Spec (d) 

# Primary care cancer audit

- Cancer reform strategy led to..
- NCRI/RCGP joint initiative

# Primary care cancer audit

## AIMS

- To better describe the processes, in primary care, leading to a diagnosis of cancer, and their associated timelines
- To better describe patient pathways in the lead-up to a cancer diagnosis
- To identify factors that facilitate quicker diagnosis
- To identify factors that contribute to slower diagnosis
- To identify areas with potential for intervention in order to facilitate quicker diagnosis

# Primary care cancer audit

## ***Secondary aims***

- To address research questions that include:
  - To examine, through modelling of primary care data, the effect on outcomes of reducing time to diagnosis
  - To identify any patterns of missed diagnosis in primary care which might be amenable to educational or other interventions

# Primary care cancer audit

- ***What elements are we interested in?***
  - Patient delay – not feasible
  - Doctor delay - feasible
  - System delay – feasible
- ***How will we identify cases?***
- ***Should we focus on specific cancers?***



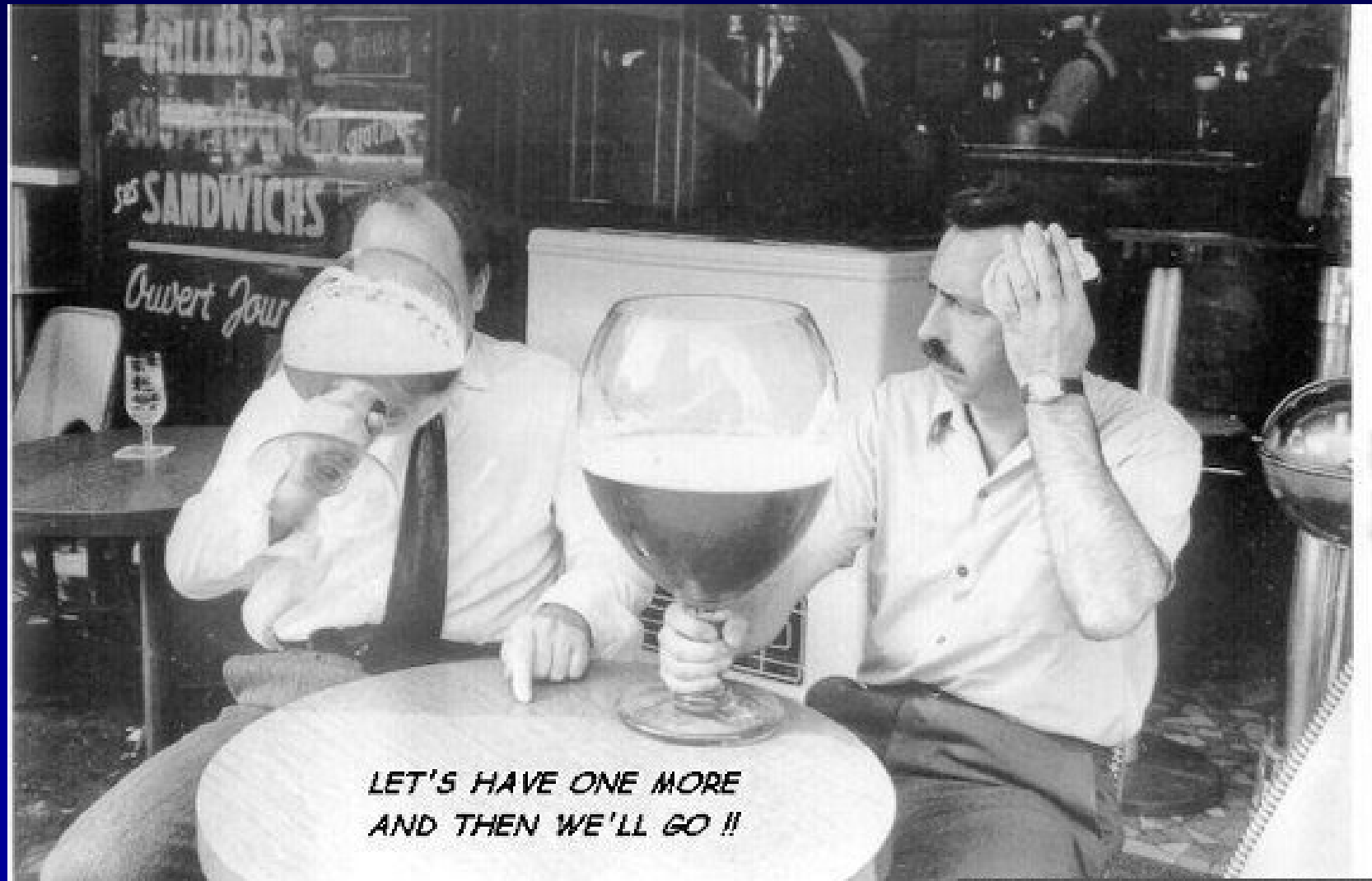
# Primary care cancer audit

- ***What methods should we use?***
  - *Record review*
  - *Practice based review*
- ***Data required***
- ***Doctor comments on process and learning?***
- **Costs**

# Primary care cancer audit

- First steps:
  - Baseline assessment using GPRD of first symptom to diagnosis will identify sites with longest delays
  - Analysis of existing audit data from PCTs with cancer LIS
  - Standardise audit and repeat in other areas
  - Lessons learnt will feed into national audit

It's a big task!



# Consultations 6-18 months post-diagnosis

- Survivors of breast, colorectal and prostate cancer all consulted significantly more than their matched controls in the year following diagnosis

	Crude IRR	95% CI
Breast	1.34	1.32 - 1.36
Colorectal	1.39	1.35 - 1.43
Prostate	1.54	1.46 - 1.58

# Consultations 5-6 years post-diagnosis

- Survivors of breast, colorectal and prostate cancer all consulted significantly more than their matched controls in the 5-6 years post-diagnosis (post-discharge ?)

	Crude IRR	95% CI
Breast	1.39	1.37 – 1.41
Colorectal	1.42	1.38 – 1.45
Prostate	1.58	1.55 – 1.62

# Consultations in the year before death

- Only survivors of prostate cancer consulted more than their matched controls in the year before death.

	Crude IRR	95% CI
Prostate	1.14	1.09 - 1.20