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Descriptive studies and routine sources of data

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Dr Alex Bottle
Senior Lecturer in Medical Statistics
robert.bottle@imperial.ac.uk

Learning outcomes

- To understand the major sources of routine data on health and illness in the UK
- To be able to describe the strengths and weaknesses of routine health data
- To understand standardised mortality ratios and provide examples of their use in comparing health in populations

Hierarchy of studies

- Systematic reviews and meta-analyses
- Randomised Controlled Trials
- Cohort studies
- Case-control studies
- Ecological studies
- Descriptive/cross-sectional studies
- Case report/series

Descriptive v analytical

- Descriptive
  - Distribution of disease: what population or sub-groups are at risk, what geographical locations, frequency over time
- Analytical
  - Determinants of disease: test hypotheses with ultimate goal of judging whether exposure causes or prevents disease

Descriptive studies

- Describe the distribution of factors or disease in relation to:
  - Person (e.g. age, sex, race, marital status, occupation, lifestyle)
  - Place (e.g. variation between and within countries)
  - Time (variation over time and season)

Cross sectional surveys

- Useful for health care providers to allocate resources efficiently and plan effective prevention
- Provide clues leading to hypotheses which can be tested in analytical studies
- Describe status of individuals with respect to absence or presence of both exposure and disease assessed at the same point in time
- …but cannot easily distinguish whether exposure preceded disease

Cross-sectional surveys

- Health Survey for England
- 2001 (2011) Census
- General Lifestyle Survey (old GHS) / Statistics on Income and Living Conditions required by European law (EU-SILC)
- National Survey of NHS Patients; NHS staff survey

Health Survey for England

- Series of annual surveys about England's health
- First proposed in 1990 to improve information of morbidity by the new Central Health Monitoring Unit within the Department of Health
- Core topics each year + special topics
- Access the data from http://www.esds.ac.uk/findingData/hseTitles.asp

Survey aims

- to provide annual data about the nation's health;
- to estimate the proportion of the population with specific health conditions;
- to estimate the prevalence of risk factors associated with those conditions;
- to assess the frequency with which combinations of risk factors occur;
- to examine differences between population sub-groups;
- to monitor targets in the health strategy;
- (from 1995) to measure the height of children at different ages, replacing the national study of health and growth.

‘Core' includes:

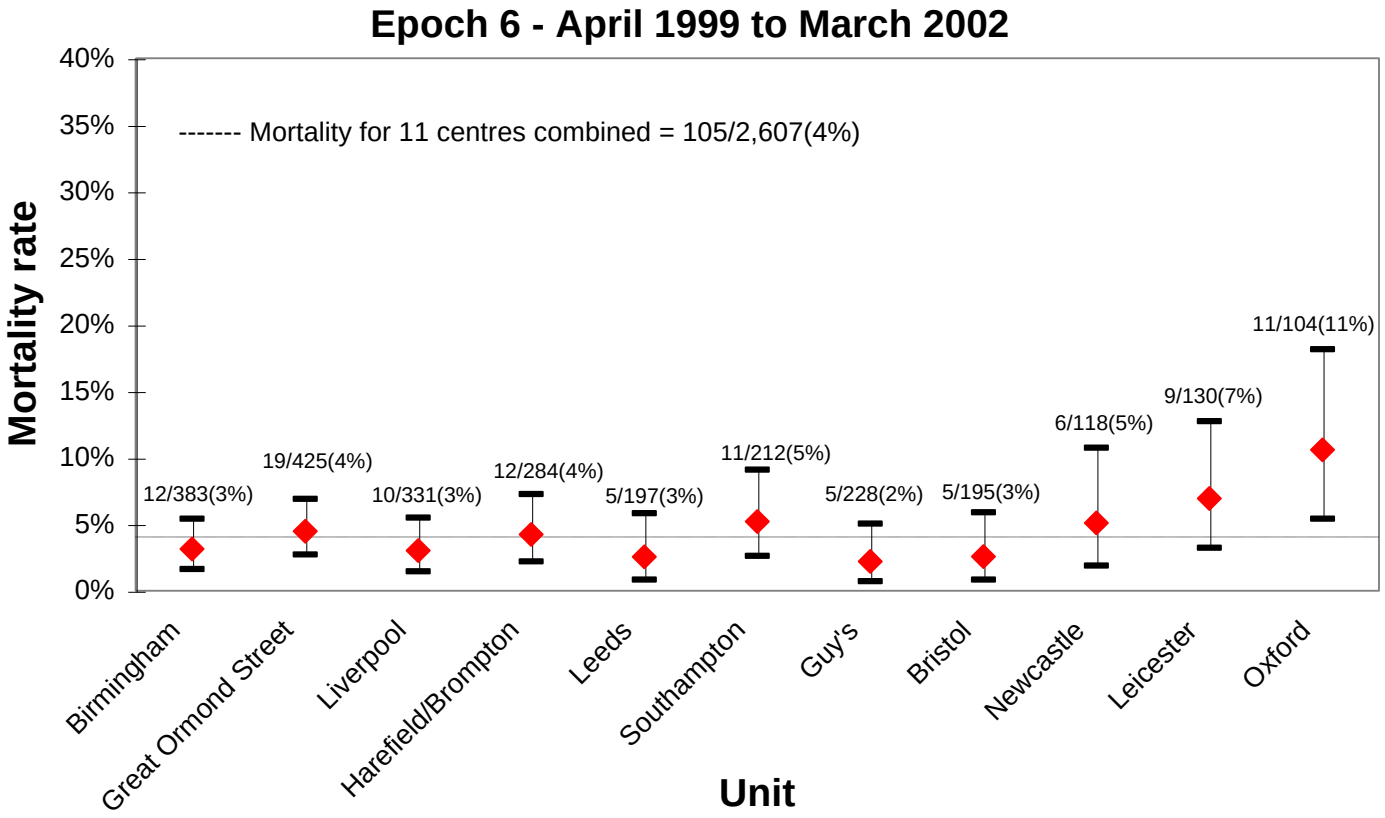
- questions on general health and psycho-social indicators
- smoking
- alcohol
- demographic and socio-economic indicators
- questions about use of health services and prescribed medicines - focus may vary each year to suit the modular content of the survey
- measurements of height, weight and blood pressure

Descriptive studies: variation by place

- Geography
- Hospital
- Unit

Examples…

Mortality from open procedures in children aged under one year for 11 centres; data derived from Hospital Episode Statistics (HES)



Descriptive studies: variation by time

- Death rates
- Infections
- Health service utilisation and/or spending

Examples…

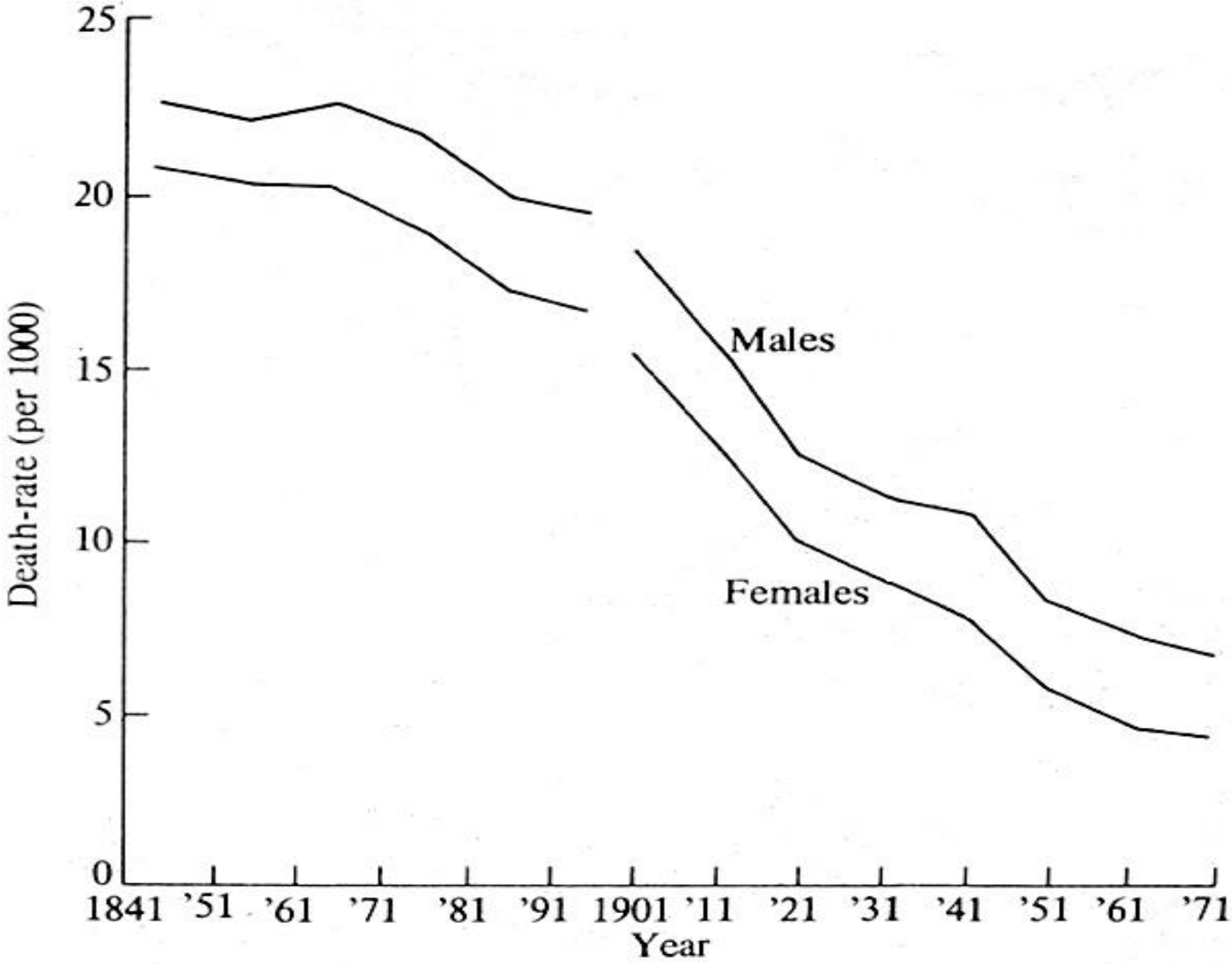
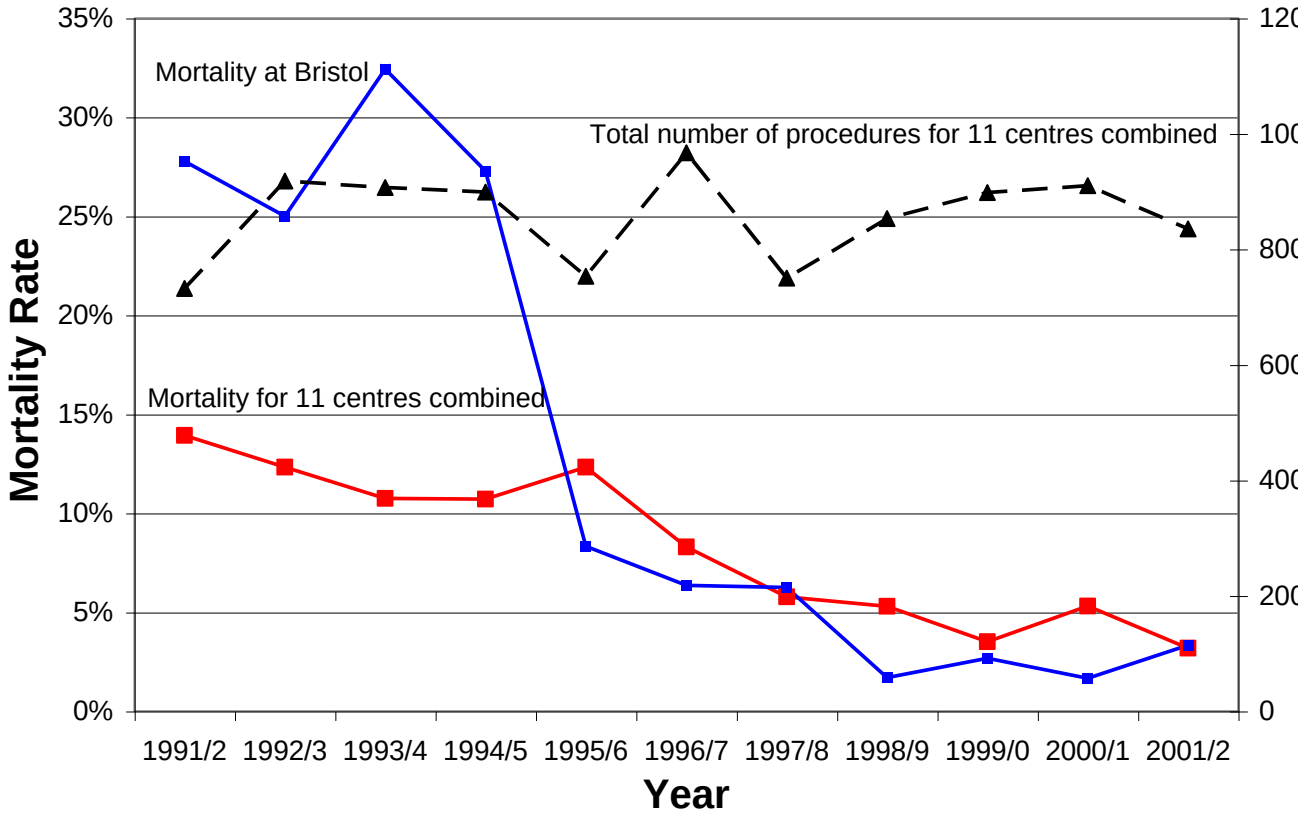


FIGURE 3.1. Death-rates (standardized to 1901 population): England and Wales.

Mortality rate for and number of open operations on children aged under one year from April 1991 to April 2002 in 11 English centres using HES



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Routine data

"Data that are routinely collected and recorded in an ongoing systematic way, often for administrative or statutory purpose and without any specific research question in mind at the time of collection"

Hansell A, Aylin P. *Using routine data in health impact assessment*.

Advantages of routine data

- Relatively cheap
- Already collected and available
- Standardised collection procedures
- Relatively comprehensive – population coverage, large numbers
- Wide range of recorded items
- Available for past years
- Experience in use and interpretation

Disadvantages of routine data

- May not answer the question (no information or not enough detail)
- Incomplete ascertainment (not every case captured)
- Variable quality (e.g. variable diagnosis fields)
- Validity may be variable (i.e. do they measure what you think they measure?)
- Disease labelling may vary over time or by area
- Coding changes may create artefactual increases or decreases in rates, e.g. ICD9 to ICD10
- Need careful interpretation

Types of routine data

- Health outcome data e.g. deaths, hospital admissions, primary care consultations or prescriptions, levels of well-being from surveys
- Exposures and health determinant data e.g. smoking, air pollution, crime statistics
- Disease prevention data e.g. screening and immunisation uptake
- Demographic data e.g. census popn counts
- Geographical data e.g. health authority boundaries, location of GP practices
- Health service provision, e.g. bed/staff counts

Health outcome data

- Mortality
- Cancer
- Notification of infectious diseases
- Terminations of pregnancy
- Congenital anomalies
- Hospital episode statistics
- GP data e.g. QOF
- Road Traffic Accidents

Exposures and health determinants

- Smoking
- Air pollution
- Crime statistics
- Housing conditions

Disease prevention data

- Breast screening
- Cervical screening
- Immunisation uptake

Geographical data

- Primary Care Trust or other boundaries
- Postcodes and their X-Y coordinates
- Location of GP practices
- Distance to nearest hospital, clinic

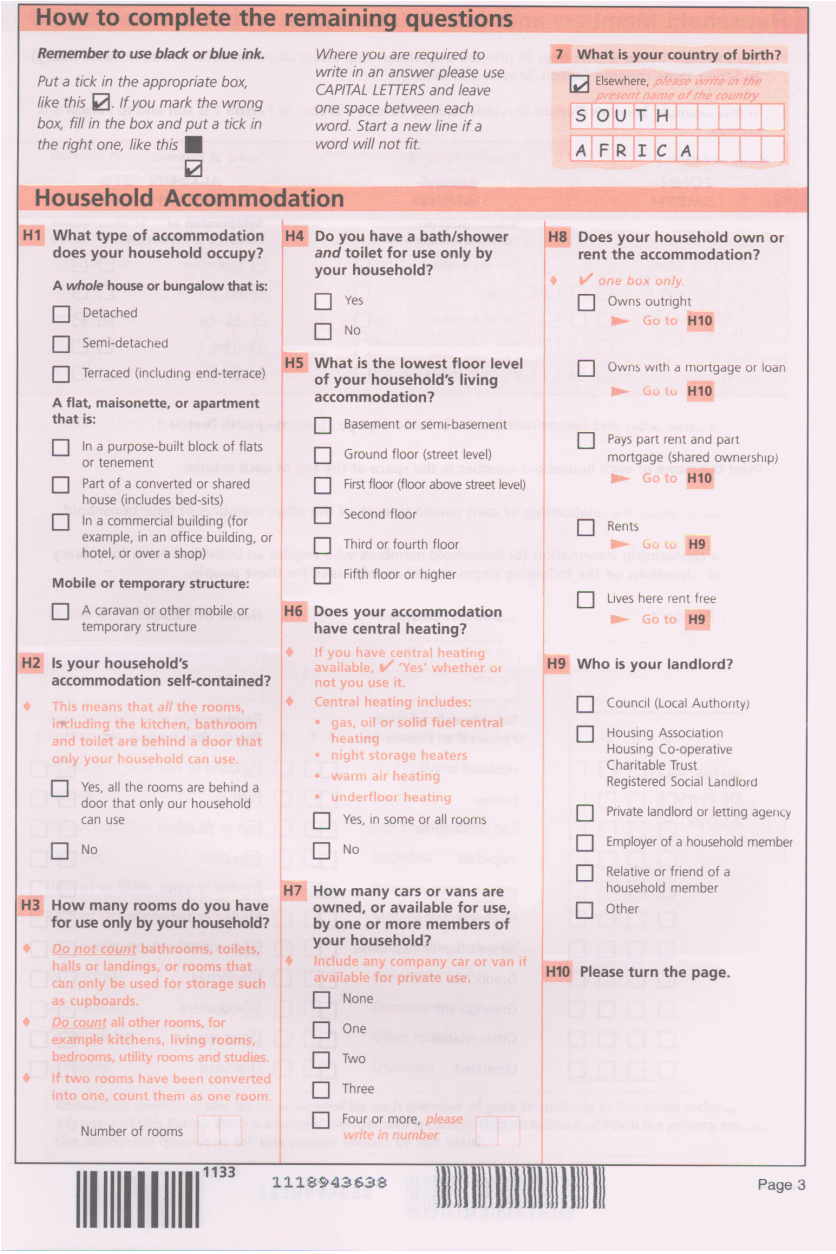
Demographic data

- Census population counts
- Mid-year population estimates inc projections
- Electoral register

Census

- Began in 1801. Every 10 years
- Population estimates
- Health question
- Other health indicators
- Unemployment
- Ethnicity
- Age
- Overcrowding

Population Censuses:
sample page



How to complete the remaining questions

Remember to use black or blue ink.

Put a tick in the appropriate box, like this ☑. If you mark the wrong box, fill in the box and put a tick in the right one, like this ■ ☑

Where you are required to write in an answer please use CAPITAL LETTERS and leave one space between each word. Start a new line if a word will not fit.

7 What is your country of birth?

☑ Elsewhere, *please write in the present name of the country*

SOUTH
AFRICA

Household Accommodation

H1 What type of accommodation does your household occupy?

A *whole* house or bungalow that is:

- ☐ Detached
- ☐ Semi-detached
- ☐ Terraced (including end-terrace)

A flat, maisonette, or apartment that is:

- ☐ In a purpose-built block of flats or tenement
- ☐ Part of a converted or shared house (includes bed-sits)
- ☐ In a commercial building (for example, in an office building, or hotel, or over a shop)

Mobile or temporary structure:

- ☐ A caravan or other mobile or temporary structure

H2 Is your household's accommodation self-contained?

♦ This means that *all* the rooms, including the kitchen, bathroom and toilet are behind a door that only your household can use.

- ☐ Yes, all the rooms are behind a door that only our household can use
- ☐ No

H3 How many rooms do you have for use only by your household?

♦ *Do not count* bathrooms, toilets, halls or landings, or rooms that can only be used for storage such as cupboards.

♦ *Do count* all other rooms, for example kitchens, living rooms, bedrooms, utility rooms and studies.

♦ If two rooms have been converted into one, count them as one room.

Number of rooms ☐☐

H4 Do you have a bath/shower *and* toilet for use only by your household?

- ☐ Yes
- ☐ No

H5 What is the lowest floor level of your household's living accommodation?

- ☐ Basement or semi-basement
- ☐ Ground floor (street level)
- ☐ First floor (floor above street level)
- ☐ Second floor
- ☐ Third or fourth floor
- ☐ Fifth floor or higher

H6 Does your accommodation have central heating?

♦ If you have central heating available, ✔ 'Yes' whether or not you use it.

♦ Central heating includes:

- gas, oil or solid fuel central heating
- night storage heaters
- warm air heating
- underfloor heating

- ☐ Yes, in some or all rooms
- ☐ No

H7 How many cars or vans are owned, or available for use, by one or more members of your household?

♦ Include any company car or van if available for private use.

- ☐ None
- ☐ One
- ☐ Two
- ☐ Three
- ☐ Four or more, *please write in number* ☐☐

H8 Does your household own or rent the accommodation?

♦ ✔ *one box only.*

- ☐ Owns outright → Go to **H10**
- ☐ Owns with a mortgage or loan → Go to **H10**
- ☐ Pays part rent and part mortgage (shared ownership) → Go to **H10**
- ☐ Rents → Go to **H9**
- ☐ Lives here rent free → Go to **H9**

H9 Who is your landlord?

- ☐ Council (Local Authority)
- ☐ Housing Association
  Housing Co-operative
  Charitable Trust
  Registered Social Landlord
- ☐ Private landlord or letting agency
- ☐ Employer of a household member
- ☐ Relative or friend of a household member
- ☐ Other

H10 Please turn the page.

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Page 3

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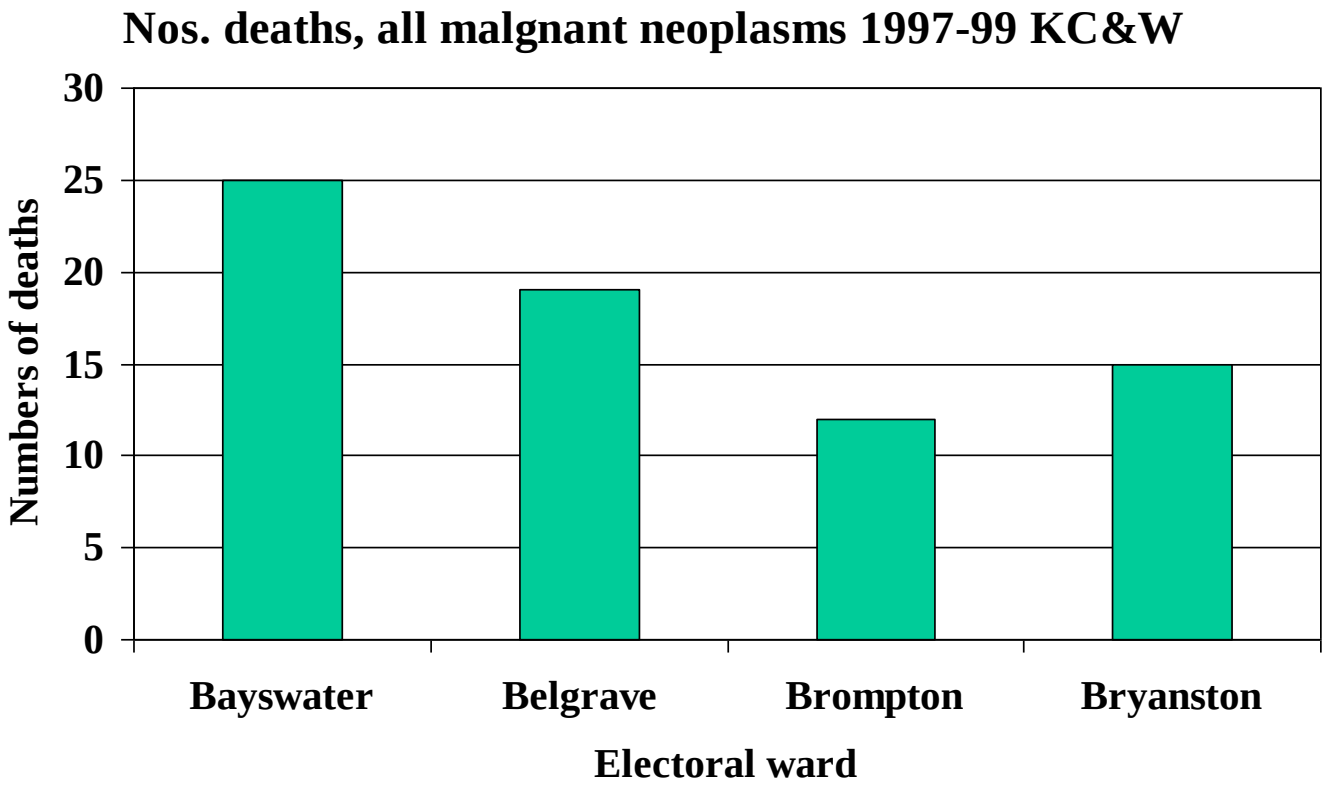
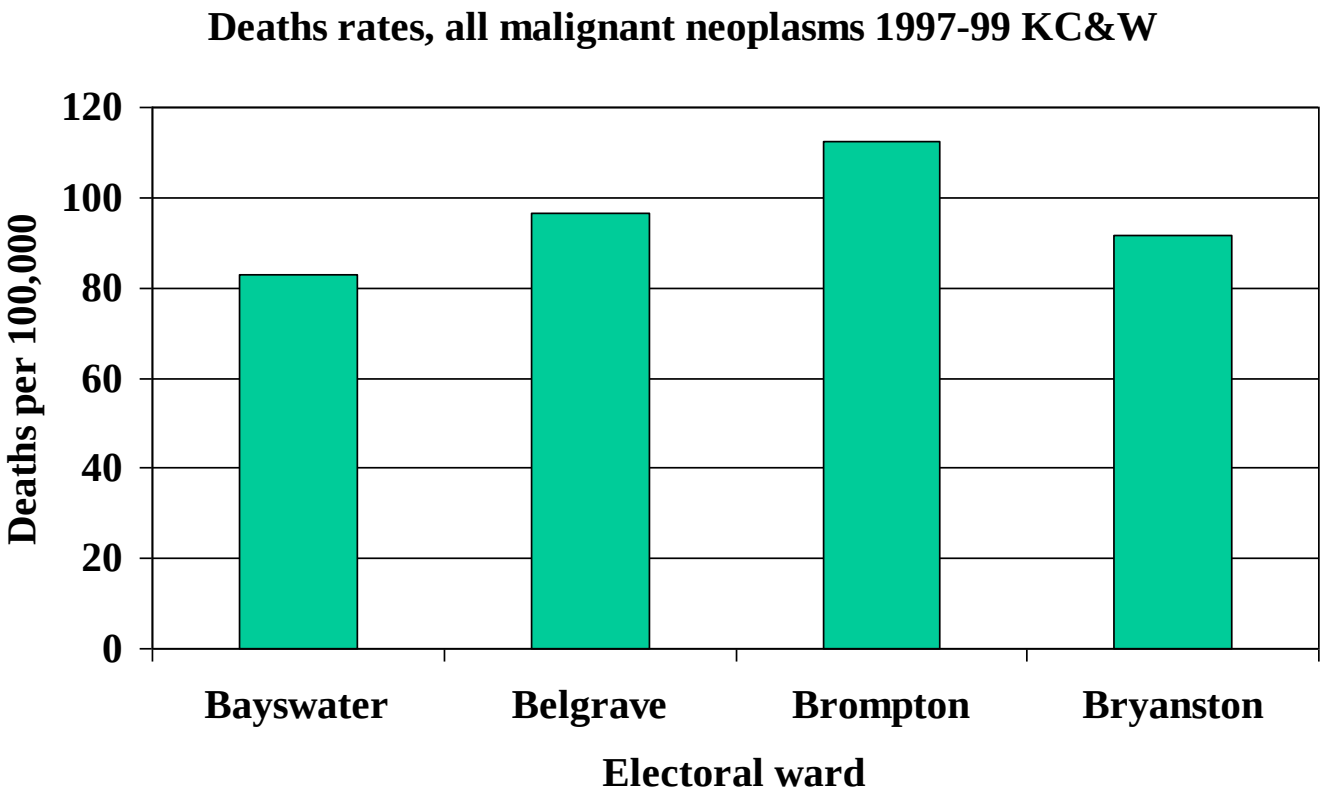
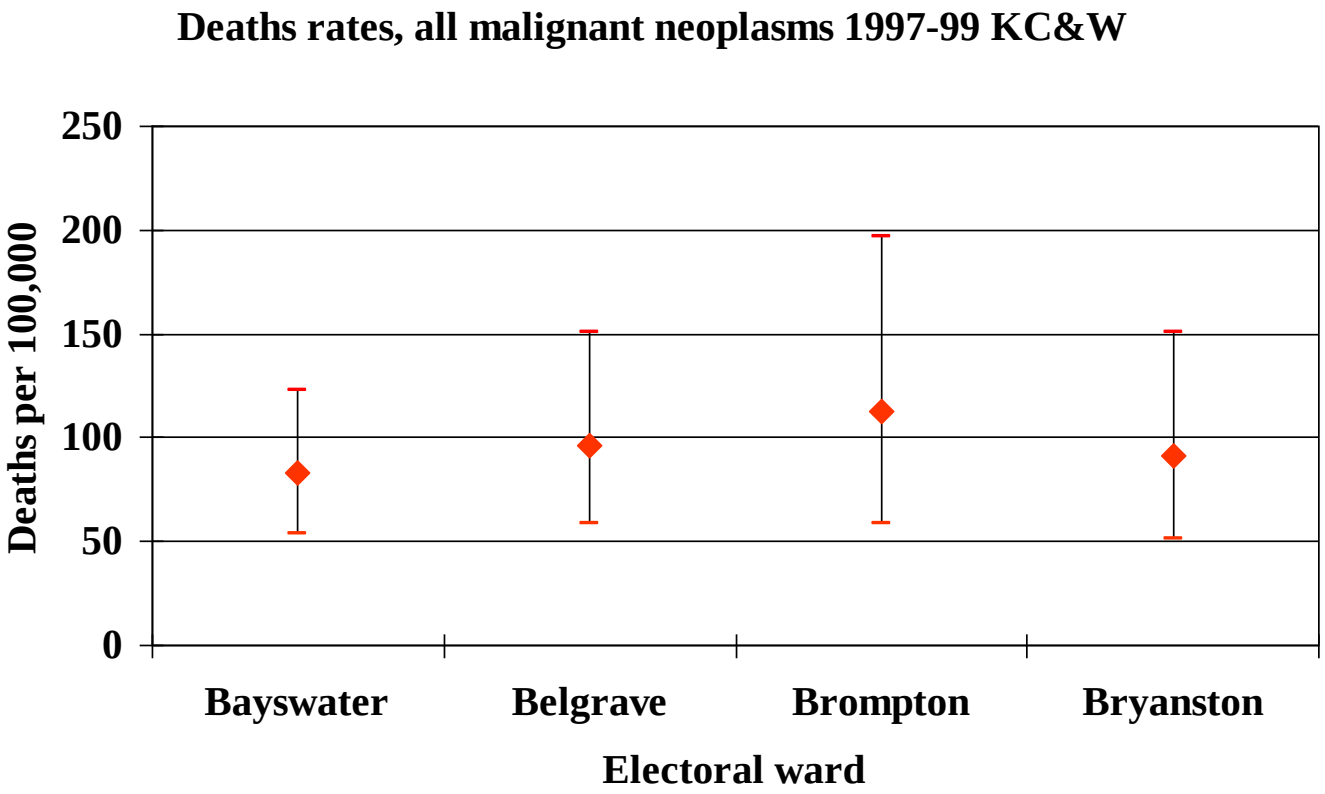
Why population estimates?



Why population estimates?



Why population estimates?

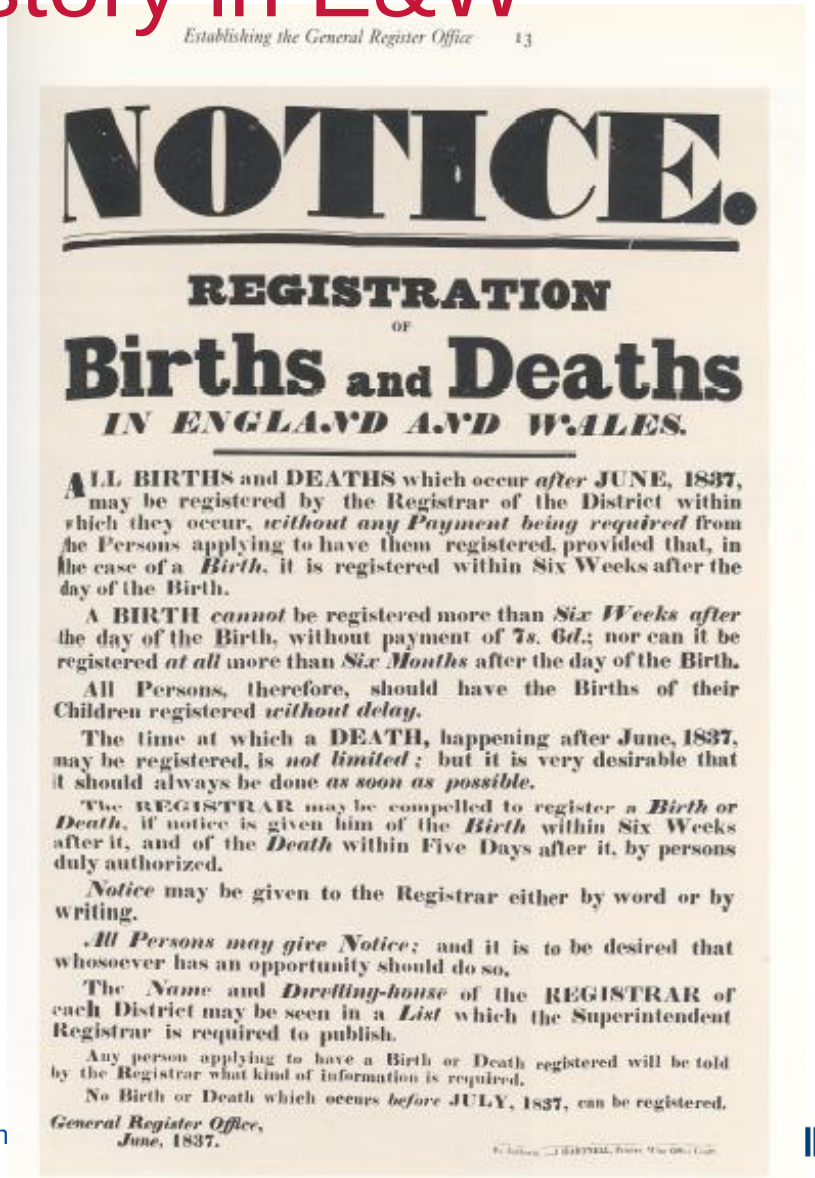


Standardised Mortality Ratio

- Ratio adjusted for age (often also sex)
- Represents the ratio of the number of observed deaths (or cases of disease) (O) in a particular population to the number that would be expected (E), if that population had the same mortality or morbidity experience as a standard population, corrected for differences in age structure.

Vital Registration: History in E&W

1538	Parish registers of baptisms, weddings & funerals (Thomas Cromwell injunction)
1597	Act of Parliament - possibility of extracting national statistics
C17	Rise of non-conformist religions
1754	Lord Hardwicke's Act – state sanctioned marriages
1836	Registration Act & Marriage Act – civil registration begun
1874	Penalties for non-registration



Establishing the General Register Office 13

NOTICE.

REGISTRATION
OF
Births and Deaths
IN ENGLAND AND WALES.

ALL BIRTHS and DEATHS which occur *after* JUNE, 1837, may be registered by the Registrar of the District within which they occur, *without any Payment being required* from the Persons applying to have them registered, provided that, in the case of a *Birth*, it is registered within Six Weeks after the day of the Birth.

A BIRTH *cannot* be registered more than *Six Weeks after* the day of the Birth, without payment of 7*s*. 6*d*.; nor can it be registered *at all* more than *Six Months* after the day of the Birth.

All Persons, therefore, should have the Births of their Children registered *without delay*.

The time at which a DEATH, happening after June, 1837, may be registered, is *not limited*; but it is very desirable that it should always be done *as soon as possible*.

The REGISTRAR may be compelled to register a *Birth* or *Death*, if notice is given him of the *Birth* within Six Weeks after it, and of the *Death* within Five Days after it, by persons duly authorized.

Notice may be given to the Registrar either by word or by writing.

All Persons may give Notice; and it is to be desired that whosoever has an opportunity should do so.

The *Name* and *Dwelling-house* of the REGISTRAR of each District may be seen in a *List* which the Superintendent Registrar is required to publish.

Any person applying to have a Birth or Death registered will be told by the Registrar what kind of information is required.

No Birth or Death which occurs *before* JULY, 1837, can be registered.

General Register Office,
June, 1837.

Vital registration: Information Collected in E&W by Vital Registration

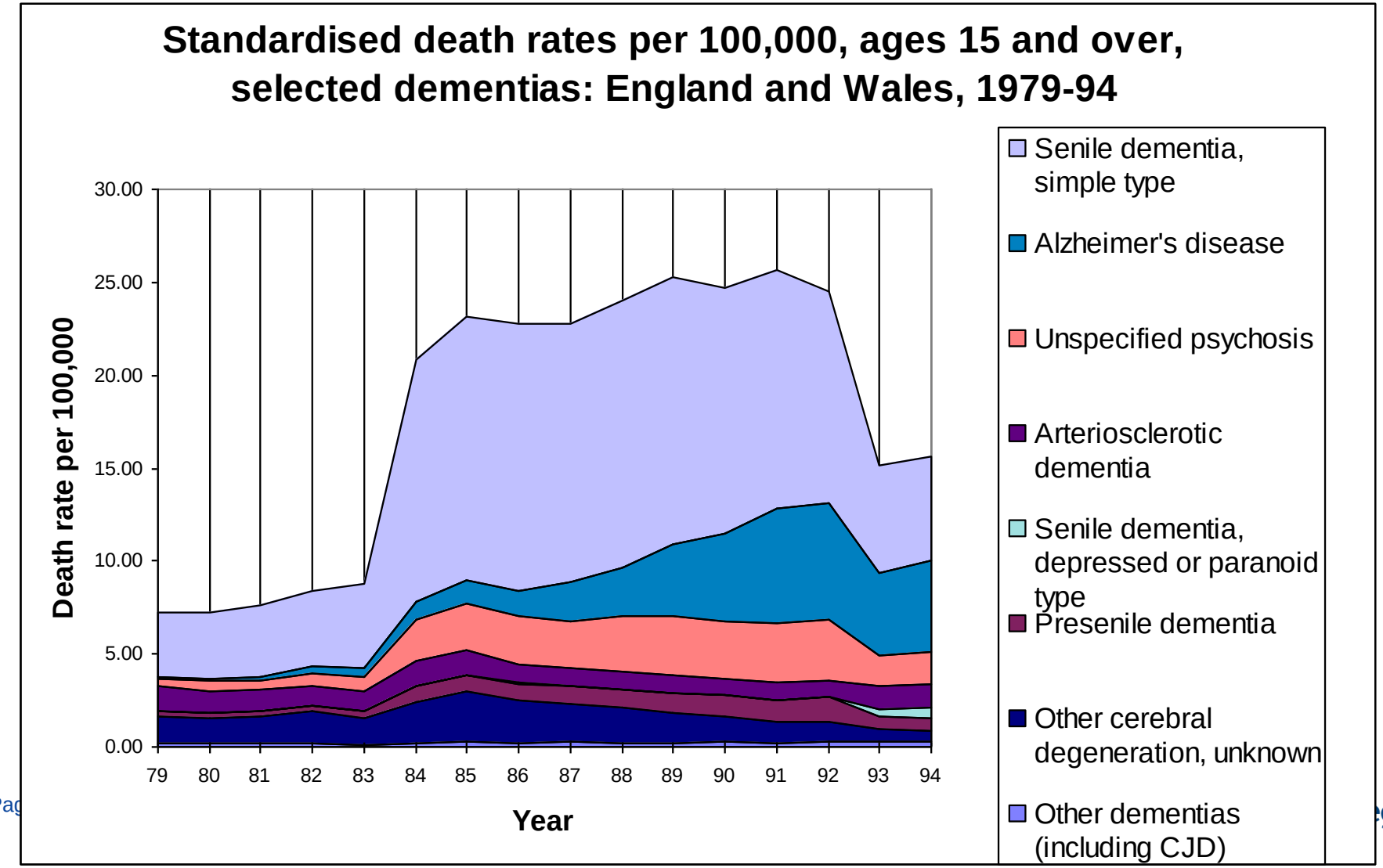
Births	Marriages	Deaths
Date of birth	Date of marriage	Date of death
Place of birth	Place of marriage	Place of death
Name of child	Names if bride & groom	Name of deceased
Sex of child		Sex of deceased
	Occupations of bride & groom	Occupation of deceased
	Previous marital status of bride & groom	
	Ages of bride & groom	Age of deceased at death
		Cause of death
Names of child's parents	Names of parents of bride & groom	(up to three causes)
Occupation of parents	Occupation of fathers of bride & groom	
	Form of ceremony	
Description of informant		Description of informant

Source: A. Hinde, 1998.

Mortality

- Death certificates
- Local registrars of births and deaths
- ONS for coding and processing
- Produced as routinely published tables
  - General DH1
  - By area DH5
  - By cause DH2 etc
- Public Health Mortality Files
- Data extracts

Effect of rule change on death rate: 1984



Births

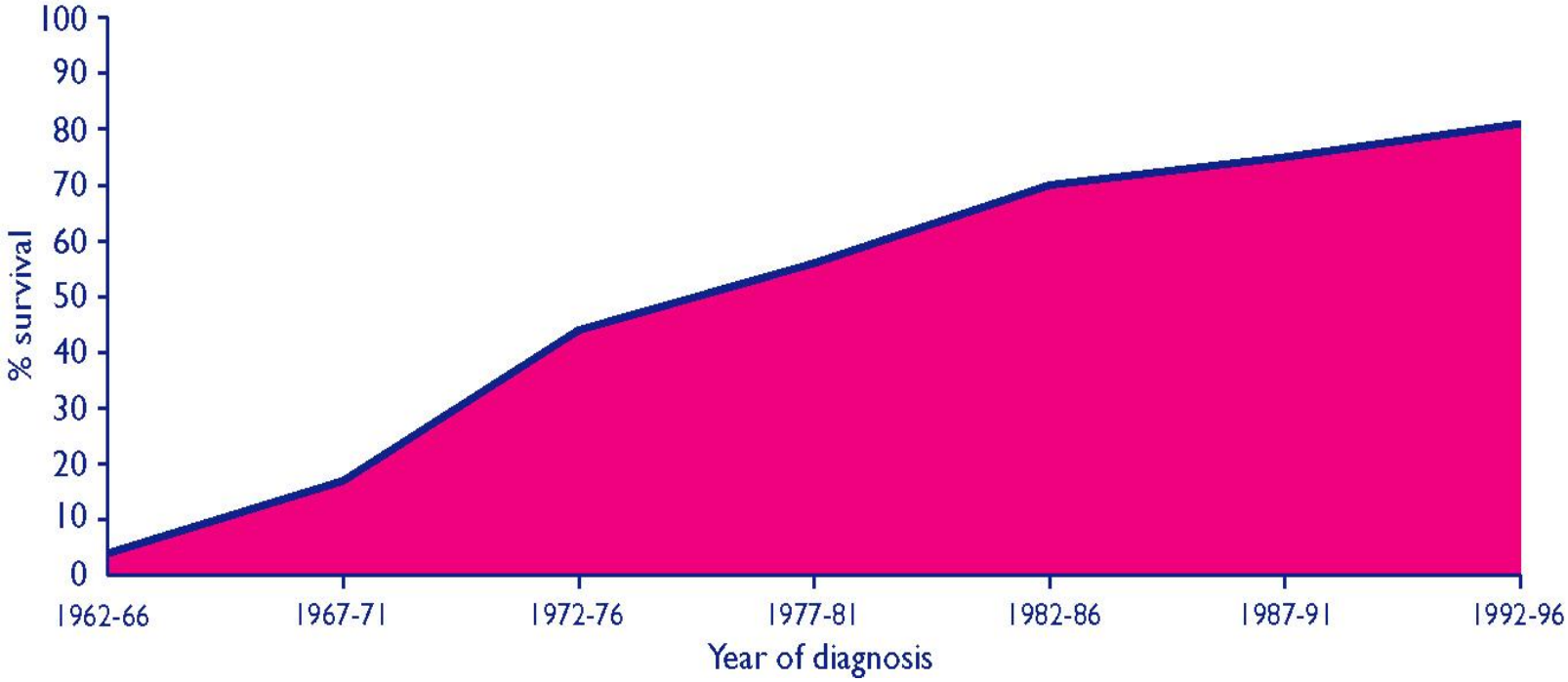
- Birth certificates
- Local registrar of births and deaths
- ONS for coding and processing
- Produced as routinely published tables
  - FM1
- Fertility calculated using populations estimates

Cancer registrations

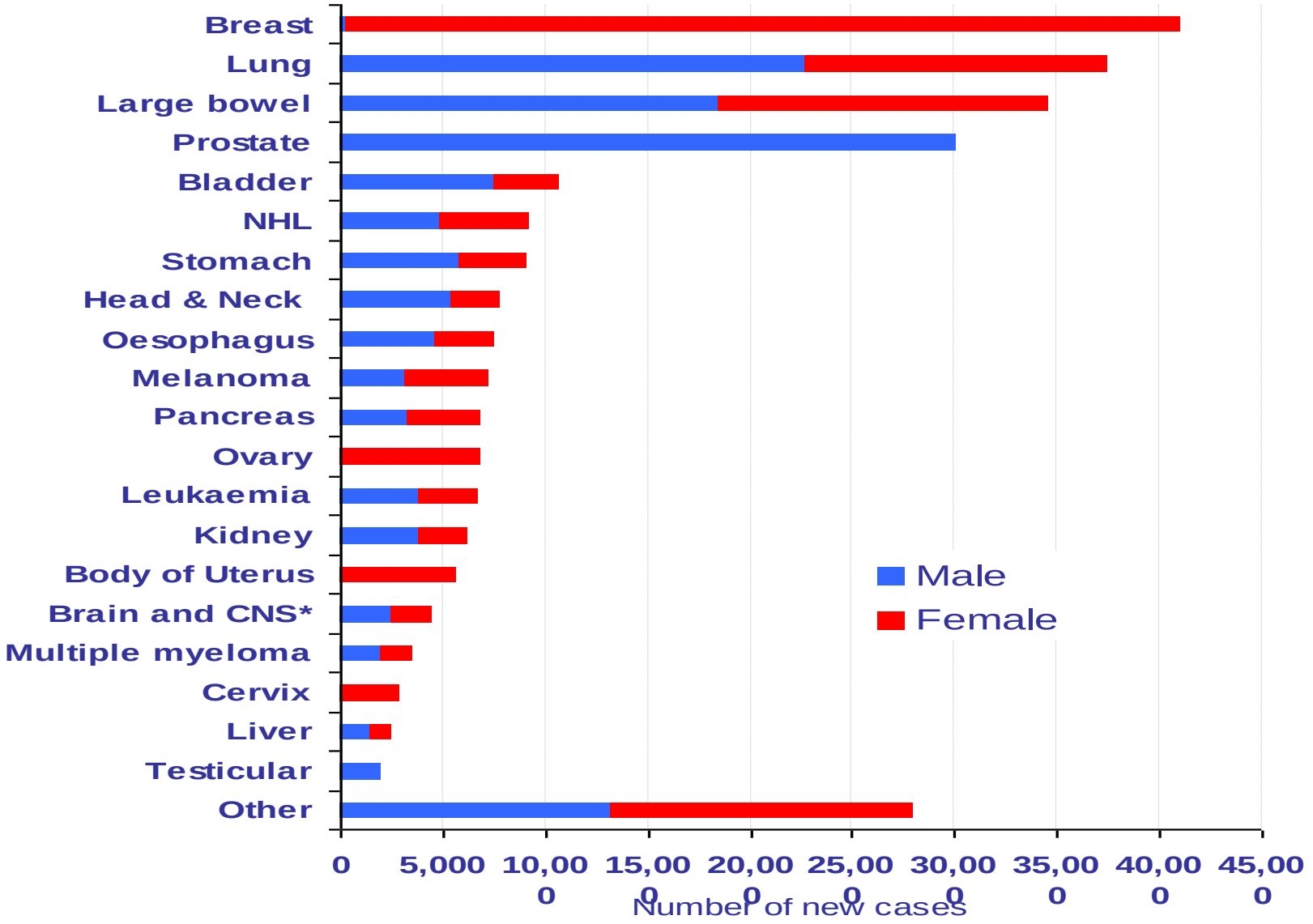
- Voluntary notification to local cancer registry: now national system
- Also from death certificates
- Useful for both incidence and survival information
- Increasingly being linked with hospital adms
- Useful web site

  http://info.cancerresearchuk.org/cancerstats/

Five-year survival from acute lymphoid leukaemia, children aged 0-14, Great Britain, 1962-1996



The twenty most common cancers diagnosed in the UK, 2001



Infectious disease notifications

- Reported by doctors
- Incidence of disease
- Includes food poisoning, meningitis, tuberculosis and plague

http://www.hpa.org.uk/

Notifiable diseases

Acute encephalitis
Acute poliomyelitis
Anthrax
Cholera
Diphtheria
Dysentery
Food poisoning
Leptospirosis
Leprosy
Malaria
Measles
Meningitis
Meningococcal septicaemia
Mumps
Ophthalmia neonatorum
Paratyphoid fever
Plague
Rabies
Relapsing fever
Rubella
Scarlet fever
Smallpox
Tetanus
Tuberculosis
Typhoid fever
Typhus fever
Viral haemorrhagic fever
Viral hepatitis
Whooping cough
Yellow fever

GP data (consultations ± prescribing)

- Individual practice computer systems
- Morbidity surveys in General Practice (most recent MSGP4 in 1991/2)
- Continuous collection of data e.g. CPRD, THIN, Meditel, QRESEARCH
- Weekly Returns Service (spotter practices)
- Quality and Outcomes Framework Information

Quality and Outcomes Framework

- Quality and Outcomes Framework (QOF) is a component of the new General Medical Services contract for GPs from April 2004
- QOF rewards practices for the provision of quality care, and helps to fund further improvements in the delivery of clinical care
- Collected in a national database system: Quality Management Analysis System
- GP Extraction System will give patient-level info – at a cost!

QOF Domains

The clinical domain
MANY indicators in key areas: coronary heart disease, left ventricular disease, stroke or transient ischaemic attack, hypertension, diabetes, chronic obstructive pulmonary disease, epilepsy, hypothyroidism, cancer, mental health, and asthma – more each year

The organisational domain
56 indicators in 5 areas: records and information about patients, patient communication, education and training, practice management and medicine management.

The patient experience domain
Four indicators in two areas: patient surveys and consultation length.

The additional services domain
Ten indicators in four areas: cervical screening, child health surveillance, maternity services, and contraceptive services.

Example of CHD indicators

CHD 1. The practice can produce a register of patients with coronary heart disease

CHD 2. The percentage of patients with newly diagnosed angina (diagnosed after 01/04/03) who are referred for exercise testing and/or specialist assessment

CHD 3. The percentage of patients with coronary heart disease, whose notes record smoking status in the past 15 months, except those who have never smoked where smoking status need be recorded only once

CHD 4. The percentage of patients with coronary heart disease who smoke, whose notes contain a record that smoking cessation advice has been offered within the last 15 months

CHD 5. The percentage of patients with coronary heart disease whose notes have a record of blood pressure in the previous 15 months

CHD 6. The percentage of patients with coronary heart disease, in whom the last blood pressure reading (measured in the last 15 months) is 150/90 or less

Prescribing analysis and cost tabulation (PACT)

- Prescribing Analyses and Costs
- No clinical information
  - diagnosis
  - age
- It counts scripts not patients
- No information on duration of prescription
- 5% of prescriptions are not redeemed

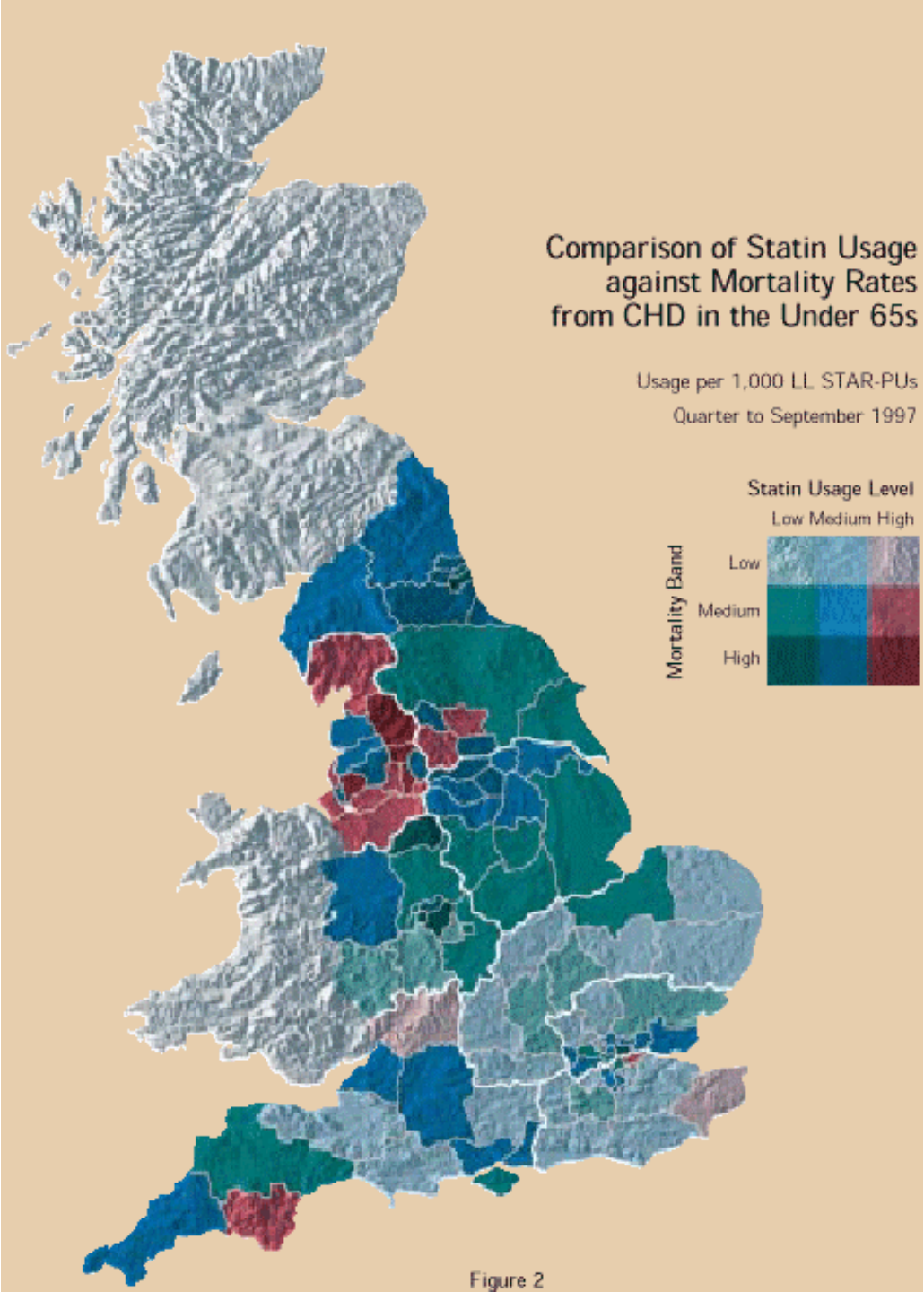

Comparison of Statin Usage against Mortality Rates from CHD in the Under 65s
Usage per 1,000 LL STAR-PUs
Quarter to September 1997
Statin Usage Level
Low Medium High
Mortality Band
Low
Medium
High

Figure 2

Administrative hospital admissions data

- HES (Hospital Episode Statistics) covers all NHS hospitals + ISTCs in England
- 15m records annually (IP, DC) + 60m OPD appts + 17m A&E atts
- Coding uses ICD10 and OPCS
- Data quality still improving
- Many uses

Episodes and Admissions

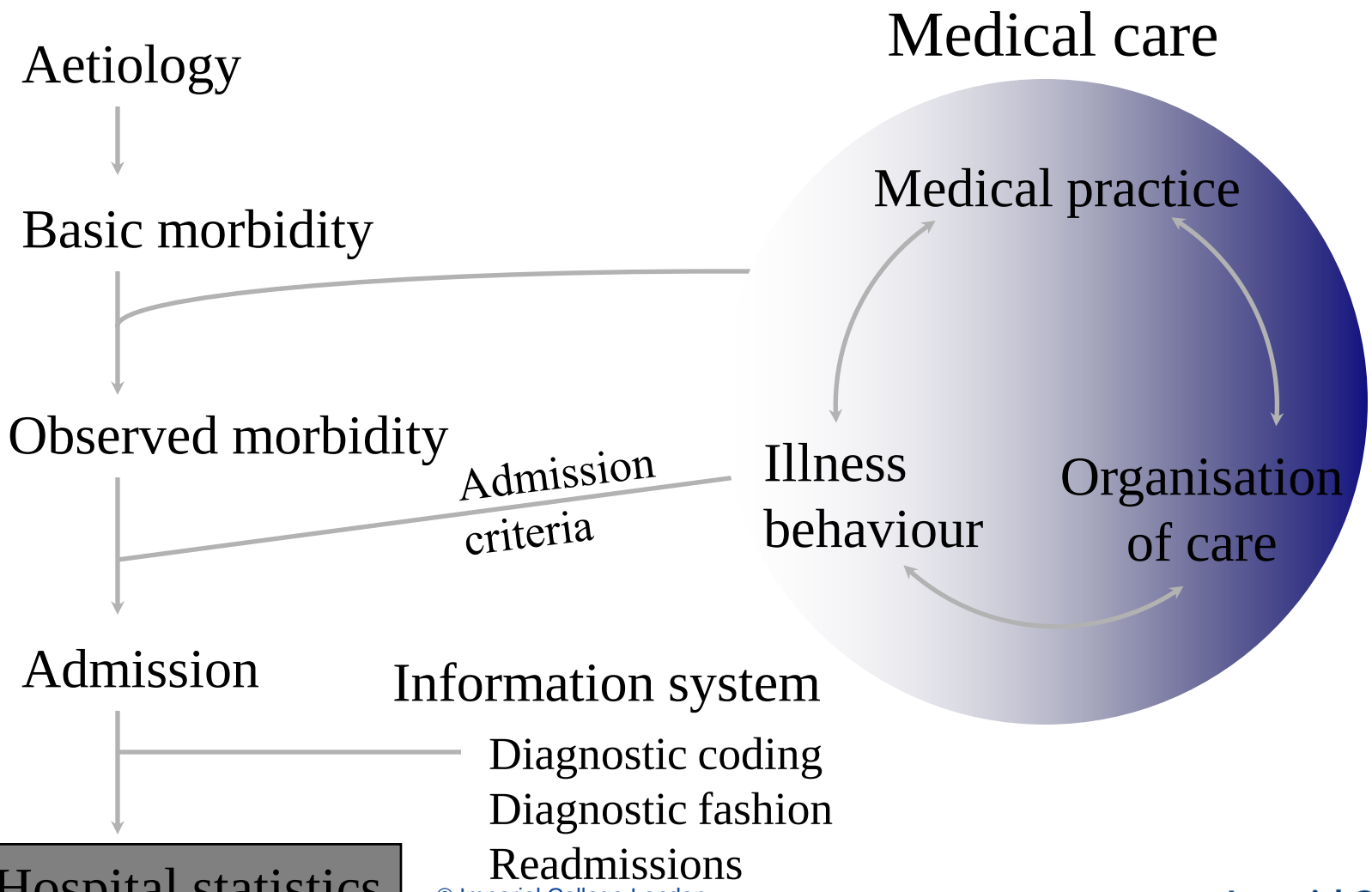
EPISODE

- Finished Consultant Episode - *the time spent under the continuous care of a specific consultant*

ADMISSION

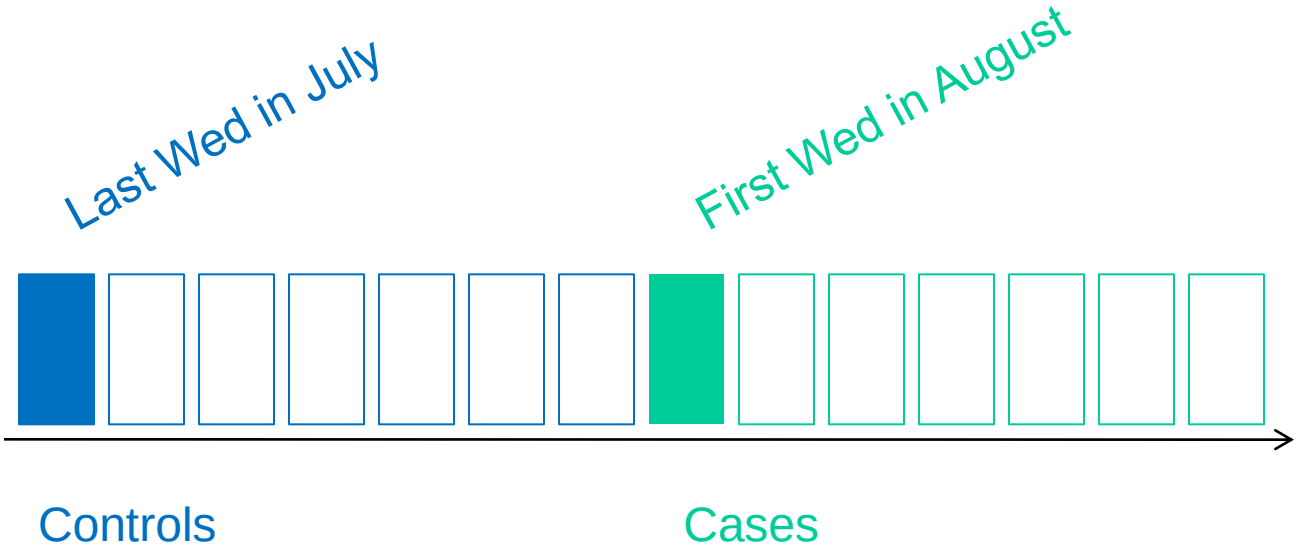
- *a patient's stay in hospital*

Factors affecting hospital statistics



An example of the use of admissions data: the “killing season” (Jen et al 2010)

All non-elective admissions
English NHS Hospitals



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News › Society

The killing season

The European working time directive will cut the number of junior doctors spend on the wards. It ought to make hospita - but does the NHS have enough staff to cope? Mark Goul

Mark Gould
The Guardian, Wednesday 12 May 2004
Article history

August is the cruellest month in the NHS. Cynics call it the It's the month when a fresh intake of junior doctors, their crisp and their palms damp, come out of the lecture roo hands on living patients for the first time.

This year, it was meant to be different: on August 1, th directive (WTD), agreed in 2000, comes into force. It aim of restricting trainee doctors to a 56-hour week the days when hollow-eyed juniors unwittingly killed patients due to a combination of overwork and lack

Unfortunately, it could also bring medical staffing hospitals. Health minister John Hutton has admitt impossible" for the NHS to achieve full complian even though it has had two years to prepare. If directive, they face investigation and possibly Association suggests over 50% of trusts will fo of Physicians estimates a quarter won't meet the

BBC TWO newsnight

Talk about Newsnight

A blog and forum

< JULY 30, 2007 | MAIN | AUGUST 1, 2007 >

Tuesday, 31st July, 2007

Newsnight | 31 Jul 07, 04:36 PM

Presented by **Jeremy Paxman**

JUNIOR DOCTORS

It's long been an open secret in the NHS that you don't want to get sick on August 1st - the day when thousands of junior doctors traditionally start new jobs. This year we've been promised even more chaos than usual, thanks to a controversial reform which has had junior doctors marching on the streets and newspapers predicting mayhem on the wards.

With hours to go before D-day, it looks like the predictions could have been overdone. But that may have been the problem with this story from day one. Our economics editor, Stephanie Flanders, has been finding the truth behind the Great Junior Doctor Fiasco of 2007.

We hope to be bringing together a junior doctors leader and a Government minister live.

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on

Summary of routine data

- They are legion
- They are great
- They have limitations

Learning outcomes

- To understand the major sources of routine data on health and illness in the UK
- To be able to describe the strengths and weaknesses of routine health data
- To understand standardised mortality ratios and provide examples of their use in comparing health in populations