Seminar 4: Unpacking trends and considering reliability

1. In groups of 4 or 5 consider the information given in the appendix on routine data on diseases in the UK. For each of the data sources given (notifiable diseases, hospital episode statistics and cancer registration, answer the following questions:
   a) What sort of things will affect the reliability of the data?
   b) Are there any issues with trying to identify trends in these data?
   c) If you wanted to compare across different countries what issues might there be?

2.
   a) This is a short whole-class exercise looking at the calculation and interpretation of confidence intervals.
   b) The paper by Barrett et al. cited in the reading for this week explores the views of the British public about the use of identifiable data by the National Cancer Registry. These views were obtained via a survey in 2005. What does the following extract from the results section of the abstract show about the British public's views and how precise are these data?

"72% (95% confidence interval 70% to 74%) of all respondents did not consider any of the following to be an invasion of their privacy by the National Cancer Registry: inclusion of postcode, inclusion of name and address, and the receipt of a letter inviting them to a research study on the basis of inclusion in the registry. Only 2% (2% to 3%) of the sample considered all of these to amount to an invasion of privacy".

3. A local doctor has read the article at http://www.bbc.co.uk/news/health-16425519. They know you have been doing an MSc in public health and have asked you to come to a forum and give a brief presentation on trends in whooping cough between 2008 and 2011 to explain the summary given in the BBC article. Using the information in the table above produce a simple figure and a simple table that you might use in the presentation. Do this in small groups of 2 or 3.

4. This is a short whole-class exercise looking at the calculation and interpretation of odds ratios.

Appendix: Routine data in the UK

There are a number of sources of routine data on disease in the UK. These include death certificates, cancer registrations, congenital malformations registrations, infectious disease notifications, hospital episode data, health surveys and Royal College of General Practitioners weekly returns. Here we present brief extracts from websites on hospital episode statistics.

Box 1: Notifiable diseases

Website:
http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/NotificationsOfInfectiousDiseases/ListOfNotifiableDiseases/

Diseases notifiable (to Local Authority Proper Officers) under the Health Protection (Notification) Regulations 2010:

- Acute encephalitis
- Acute infectious hepatitis
- Acute meningitis
- Acute poliomyelitis
- Anthrax
- Botulism
- Brucellosis
- Cholera
- Diphtheria
- Enteric fever (typhoid or paratyphoid fever)
- Food poisoning
- Haemolytic uraemic syndrome (HUS)
- Infectious bloody diarrhoea
- Invasive group A streptococcal disease
- Legionnaires' Disease
- Leprosy
- Malaria
- Measles
- Meningococcal septicaemia
- Mumps
- Plague
- Rabies
- Rubella
- SARS
- Scarlet fever
- Smallpox
- Tetanus
- Tuberculosis
- Typhus
- Viral haemorrhagic fever (VHF)
- Whooping cough
- Yellow fever

Doctors in England and Wales have a statutory duty to notify a 'Proper Officer' of the Local Authority of suspected cases of certain infectious diseases. The attending Registered Medical Practitioner (RMP), should fill out a notification certificate immediately on diagnosis of a suspected notifiable disease and should not wait for laboratory confirmation of the suspected infection or contamination before notification. The certificate should be sent to the Proper Officer

within three days or verbally within 24 hours if the case is considered urgent.

The Proper Officers are required to pass on the entire notification to the HPA within three days of a case being notified, or within 24 hours for cases deemed urgent. Health Protection Units (HPU) are the primary recipient within the HPA of clinical notifications from Proper Officers. To contact your local HPU, use the postcode search or browse by region on the HPA homepage.

The Information Management & Technology Department within the HPA Centre for Infections (CfI) collate the returns at the national level, and publish analyses of local and national trends on a weekly basis.

Box 2: Hospital episode statistics

Website: http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=456

What is HES?

Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions to NHS hospitals in England. It includes private patients treated in NHS hospitals, patients who were resident outside of England and care delivered by treatment centres (including those in the independent sector) funded by the NHS. HES also contains details of all NHS outpatient appointments in England.

HES is the data source for a wide range of healthcare analysis for the NHS, Government and many other organisations and individuals. It contains admitted patient care data from 1989 onwards, with more than 12 million new records added each year, and outpatient attendance data from 2003 onwards, with more than 40 million new records added each year.

HES information is stored as a large collection of separate records - one for each period of care - in a secure data warehouse. Each HES record contains a wide range of information about an individual patient admitted to an NHS hospital. For example:

- clinical information about diagnoses and operations
- information about the patient, such as age group, gender and ethnic category
- administrative information, such as time waited and date of admission
- geographical information on where the patient was treated and the area in which they lived.

Box 3: Cancer registration

http://www.ukacr.org/registration-organisation

The UK is widely acknowledged as having one of the most comprehensive cancer registration systems in the world. There are currently 11 cancer registries in the UK, each covering populations of between approximately 1.65 and 13.8 million people. Cancer registration in England is conducted by eight regional registries, which also submit a standard dataset of information to the Office for National Statistics (ONS), for the collation of national cancer incidence data. Northern Ireland, Scotland and Wales each have one, national, cancer registry.

What is cancer registration?

Cancer registries are unique in being able to provide adequate historical trend and population-based data to monitor changes in cancer incidence or survival over long periods of time.

Historically, the role of the cancer registries has been to collect population-based data on the incidence of, and survival from, all cancers. Regional cancer registries across the UK have been collecting population-based cancer data for over 40 years. The Office for National Statistics (ONS) began collating data from the regional registries in England and Wales during the early 1960s, for the provision of national cancer statistics. The ONS still collates data from all the English registries but Northern Ireland, Scotland and Wales each have just one, national, cancer registry.

All cancer registries share the same main objective: to deliver timely, comparable and high-quality cancer data. Registries achieve this by collecting information on every new diagnosis of cancer (or more specifically condition considered to be registrable) occurring in their populations (a list of mandatory registrable conditions is available to download below).

The information is acquired from a variety of sources including hospitals, cancer centres, treatment centres, hospices, private hospitals, cancer screening programmes, other cancer registers, general practices, nursing homes, death certificates, Hospital Episode Statistics (HES) and Cancer Waiting Time (CWT) data. In many instances, more than one source of information is available to cancer registries from a single organisation, for example hospital patient information systems (PAS), pathology laboratories, medical records departments and radiotherapy databases.

Processing of the data involves checking the validity and completeness of the data and a complex process of clinical data linkage and consolidation. The number of new registrations made each year depends on the population size covered by the individual registry. To give an example, for a registry with a population of 5 million people, around 30,000 new registrations are likely to be added to the database on average each year.

All registries collect a common minimum dataset of information. Cancer registries in England are also working to ensure that they have systems in place to allow them to receive and process the extended list of cancer registration data items for the National Cancer Dataset.

Health protection agency data on laboratory confirmed cases of whooping cough

Website: http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317133571498

The following pages show data from the health protection agency on confirmed cases of whooping cough.

Health Protection Agency

Table 2: Laboratory confirmed cases of Pertussis infection, England and Wales, by region and age group, 2008 to 2012 - Q1 (confirmed by culture, PCR and/or serology)

Region	Age Group	2008	2009	2010	2011	2012 (Q1)	Total
EAST MIDLANDS	<3 months	8	6	2	13	7	36
	3-5 months	1	3	1	2	1	8
	6-11 months	0	0	0	1	0	1
	1-4 years	3	0	1	3	1	8
	5-9 years	0	2	1	5	1	9
	10-14 years	17	4	1	16	12	50
	15+ years	37	41	24	93	50	245
	Total	**66**	**56**	**30**	**133**	**72**	**357**
EAST OF ENGLAND	<3 months	13	3	3	15	7	41
	3-5 months	2	4	0	1	3	10
	6-11 months	1	0	0	0	1	2
	1-4 years	1	5	0	1	0	7
	5-9 years	3	2	2	1	1	9
	10-14 years	14	8	1	11	4	38
	15+ years	39	35	20	76	17	187
	Total	**73**	**57**	**26**	**105**	**33**	**294**
LONDON	<3 months	21	20	10	19	5	75
	3-5 months	4	3	1	4	0	12
	1-4 years	6	3	3	4	0	16
	5-9 years	4	2	1	2	1	10
	10-14 years	15	8	8	5	2	38
	15+ years	56	53	32	58	45	244
	Total	**106**	**89**	**55**	**92**	**53**	**395**

NORTH EAST	<3 months	13	1	3	11	5	33
	3-5 months	4	0	1	2	3	10
	6-11 months	2	0	1	2	1	6
	1-4 years	3	2	1	0	0	6
	5-9 years	1	1	1	2	3	8
	10-14 years	5	5	6	9	7	32
	15+ years	20	14	29	47	38	148
	Total	**48**	**23**	**42**	**73**	**57**	**243**
NORTH WEST	<3 months	27	27	9	25	10	98
	3-5 months	3	4	1	5	0	13
	6-11 months	1	1	1	1	0	4
	1-4 years	2	8	1	2	0	13
	5-9 years	1	5	5	2	1	14
	10-14 years	13	12	4	6	4	39
	15+ years	43	35	44	73	35	230
	Total	**90**	**92**	**65**	**114**	**50**	**411**
SOUTH EAST	<3 months	17	14	8	23	9	71
	3-5 months	8	4	1	6	0	19
	6-11 months	2	0	0	2	0	4
	1-4 years	5	5	2	2	1	15
	5-9 years	5	5	1	2	3	16
	10-14 years	33	17	6	24	25	105
	15+ years	112	108	43	135	116	514
	Total	**182**	**153**	**61**	**194**	**154**	**744**
SOUTH WEST	<3 months	15	5	4	14	4	42
	3-5 months	2	1	3	2	1	9
	6-11 months	1	0	0	1	0	2
	1-4 years	3	1	2	1	0	7
	5-9 years	4	4	2	1	4	15
	10-14 years	26	22	9	27	22	106
	15+ years	112	88	45	133	100	478
	Total	**163**	**121**	**65**	**179**	**131**	**659**

WEST MIDLANDS	<3 months	39	12	5	22	6	84
	3-5 months	6	2	0	3	1	12
	6-11 months	0	2	1	2	0	5
	1-4 years	3	1	1	2	0	7
	5-9 years	2	0	0	2	0	4
	10-14 years	7	3	1	3	1	15
	15+ years	32	30	12	39	17	130
	Total	**89**	**50**	**20**	**73**	**25**	**257**
YORKSHIRE AND THE HUMBER	<3 months	17	12	13	22	9	73
	3-5 months	4	3	0	7	0	14
	6-11 months	1	0	0	0	0	1
	1-4 years	0	3	0	1	4	8
	5-9 years	1	3	2	1	0	7
	10-14 years	4	5	7	11	12	39
	15+ years	32	26	23	50	49	180
	Total	**59**	**52**	**45**	**92**	**74**	**322**
WALES	<3 months	8	8	2	22	3	43
	3-5 months	4	1	0	1	1	7
	6-11 months	0	1	0	0	1	2
	1-4 years	1	0	0	1	0	2
	5-9 years	2	0	0	2	0	4
	10-14 years	1	5	2	1	4	13
	15+ years	10	11	9	40	7	77
	Total	**26**	**26**	**13**	**67**	**16**	**148**
ENGLAND AND WALES	<3 months	178	108	59	186	65	596
	3-5 months	38	25	8	33	10	114
	6-11 months	8	4	3	9	3	27
	1-4 years	27	28	11	17	6	89
	5-9 years	23	24	15	20	14	96
	10-14 years	135	89	45	113	93	475
	15+ years	493	441	281	744	474	2,433
	Total	**902**	**719**	**422**	**1,122**	**665**	**3,830**

*2011 and 2012 data are provisional data