Public Health England

Health Protection Report
weekly report

Volume 9 Numbers 28 Published on: **14 August 2015**

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News

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NHS Lothian investigation report on 2012 Edinburgh legionellosis outbreak

The report of a multi-agency investigation into the outbreak of Legionnaires' Disease that occurred in south-west Edinburgh in the summer of 2012 has been published by NHS Lothian health board [1].

The outbreak was declared on Sunday, 3 June 2012, at which time five confirmed cases suggestive of a developing cluster had been notified. A 'problem assessment group' was converted, the same day, into a full incident management team (IMT), triggering a range of epidemiological, microbiological, environmental and meteorological investigations that are described comprehensively in the outbreak investigation report.

The IMT – chaired by an NHS Lothian consultant in public health medicine and including representatives from Edinburgh City Council, the HSE and Health Protection Scotland – continued functioning for a considerable period after the outbreak was declared over on July 17, so as to codify the lessons learned.

A total of 56 laboratory confirmed cases of *Legionella pneumophila* meeting the outbreak case definition were recorded, including four deaths (a 7.1% case fatality rate). The case fatality rate for all 92 cases that were confirmed, probably or possibly linked to the outbreak was low at 4.3%. The IMT report nevertheless notes the considerable impact on NHS services, with more than 1,000 patients investigated and treated in primary care, 45 confirmed cases being admitted to local acute hospitals, 21 requiring admission to critical care and 19 ITUs. Seven confirmed cases lived outside of the NHS Lothian area.

Although no common source of infection could be definitively identified, the IMT/HSE investigations concluded that that the most likely source was an aerosol release (of *Legionella pneumophila* Sg1 Knoxville ST191), in May, from an industrial complex containing wet cooling towers in the north east of the affected area. At the time of the outbreak, the HSE's Health and Safety Laboratory had been preparing a research report on common contributory factors in legionella outbreaks from which the Lothian investigation benefitted [2].

Among the precautionary measures taken at the outset had been the 'shot dosing' with chemical disinfectant of all registered cooling towers within six kilometres of the centre of the original cluster. Two particular cooling towers in cluster area – identified as potential sources at an early stage of the investigation – had been among the first visited and shot-dosed, and

voluntarily ceased operation on 7 June. HSE improvement notices were served on companies involved in the management of cooling towers and water systems at the two premises [3].

Consequential actions that followed the outbreak, or that benefitted from the lessons learned, included:

- revision of Scottish national legionella outbreak response guidance [4];
- review of the availability of Scottish resources and facilities required for rapid response, and for the duration of outbreaks;
- training and exercising of Scottish joint agency plans;
- publication by the European Centre for Disease Prevention and Control of an outbreak investigation toolbox.

References

1. NHS Lothian (6 August 2015). Legionnaires' disease outbreak in south west Edinburgh June to July 2012: final report of the incident management team;
2. HSL (2012). Legionella outbreaks and HSE investigations: an analysis of contributory factors;
3. HSE (March 2015). Report on legionella intervention programme;
4. Health Protection Scotland/HSE (November 2014). Guideline on the management of legionella cases, incidents, outbreaks an clusters in the community (revised, second edition);
5. ECDC. Legionnaire's disease outbreak investigation toolbox.

New training resources for health professionals on meningococcal vaccination

New training resources explaining changes to the national immunisation schedule – relating to protection against meningococcal disease, for different age groups – have recently been posted on the PHE webpages [1].

These include a dozen videotaped presentations explaining the background to new MenACWY and MenB immunisation programmes in England that involve a number of differently-timed changes to existing routine childhood and adolescent programmes, and a number of different "catch-up" programmes for 'risk' groups.

The changes start to be implemented this month, subject to vaccine availability (see below), with an urgent catch-up MenACWY programme for adolescents – particularly first-time university entrants, whether or not they have previously received a routine meningococcal disease capsular group C (MenC) vaccination.

Two MenACWY vaccines (Menveo® and Nimerix®) are being introduced in response to incidence of invasive meningococcal disease capsular group W (MenW) disease that after a steady increase from a low level since 2009 was deemed, at the start of 2015, to be an outbreak situation requiring an urgent response [2]. This vaccine will provide direct protection to the vaccinated cohort and, by reducing carriage of MenW, will also provide indirect protection to unvaccinated children and adults.

MenACWY vaccine ordering is temporarily suspended in England while delivery of further stocks is awaited. Ordering is expected to reopen later in August and vaccine made available as soon as it is received.

Due to the speed with which the MenACWY programme is being implemented, PHE is holding less vaccine buffer stock than would usually be the case for a national programme. This has increased the likelihood of periods of unavailability such as the current one. PHE is working to ensure that the supply disruption is minimised as quickly as possible and will provide regular updates through the ImmForm news items and Vaccine Update [3].

The new MenB vaccine (Bexsero®), protecting against meningococcal disease capsular group B, will be added to the childhood immunisation programme as part of the routine schedule in England from 1 September 2015.

Full guidance document collections relating to these two strands of the meningococcal immunisation programme are available at:

- Meningococcal ACWY (MenACWY) vaccination programme webpage
- Meningococcal B (MenB) vaccination programme webpage.

References

1. MenB and MenACWY programmes: a training guide for healthcare professionals;
2. Introduction of a meningococcal ACWY immunisation programme for adolescents. Part of the PHE guidance webpage MenACWY programme: information for healthcare professionals;
3. Vaccine Update (newsletter for immunisation practitioners) webpage.

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Infection Reports

Enteric infections

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General outbreaks of foodborne illness in humans, England and Wales: weeks 27-31/2015

Preliminary information has been received about the following outbreaks.

PHE Centre/ Health Protect'n Team	Organism	Location of food prepared or served	Month of outbreak	Number ill	Cases positive	Suspect vehicle	Evidence
South of England	Campylobacter	Rembrandt Hotel	July	3	–	Not known	–
North of England	VTEC O157	Butchers shop	July	12	5	Not known	–
West Midlands	Not known	Residential school	July	53	4	Not known	–

Common gastrointestinal infections, England and Wales, laboratory reports: weeks 27-31/2015

Laboratory reports	Number of reports received					Cumulative totals		
	27/15	28/15	29/15	30/15	31/15	27-31/15	1-31/15	1-31/14
Campylobacter	1615	1571	1470	1399	1532	7587	36270	35636
Escherichia coli O157 *	35	38	29	35	26	163	490	447
Salmonella †	184	181	148	61	17	591	4110	3419
Shigella sonnei	22	37	20	38	11	128	705	602
Rotavirus	131	106	93	82	59	471	4606	3627
Norovirus	65	36	42	76	75	294	5693	3418
Cryptosporidium	41	51	76	52	69	289	1973	1674
Giardia	100	78	66	113	87	444	2447	2022

*Vero cytotoxin–producing isolates: data from PHE's Gastrointestinal Bacteria Reference Unit (GBRU).
† Data from GBRU.

Salmonella infections (faecal specimens) England and Wales, reports to Public Health England (salmonella data set): June 2015

Details of 850 serotypes of salmonella infections recorded in June are given in the table below.

Organism	June 2015
S. Enteritidis PT4	42
S. Enteritidis (other PTs)	260
S. Typhimurium	186
S. Virchow	24
Others (typed)	338
Total salmonella (provisional data)	**850**

Note: Following the introduction of a new laboratory reporting system (SGSS) in December 2014, direct comparisons with data generated by the previous system (LabBase2) may not be valid.

Suspected and laboratory-confirmed reported norovirus outbreaks in hospitals, with regional breakdown: outbreaks occurring in weeks 27-31/15

The hospital norovirus outbreak reporting scheme (HNORS) recorded 12 outbreaks occurring between weeks 27 and 31, 2015, all of which led to ward/bay closures or restriction to admissions. Five outbreaks (42%) were recorded as laboratory confirmed due to norovirus (see table). For the calendar year 2015 – between week 1 (January) and week 31 (week beginning 27 July) – 533 outbreaks were reported. Ninety-five per cent (504) of reported outbreaks resulted in ward/bay closures or restrictions to admissions and 67% (358) were laboratory confirmed as due to norovirus (see table).

Seasonal comparison of laboratory reports of norovirus (England and Wales)

In the 2014/15 season just passed † (from week 27, 2014, to week 26, 2015), there were 8309 laboratory reports of norovirus. This was 6% lower than the average number of laboratory reports for the same period in the seasons between 2009/10 and 2013/2014 (8841). The number of laboratory reports in the most recent weeks will increase as further reports are received.

† The norovirus season runs from July to June (week 27 in year one to week 26 in year two) in order to capture the winter peak in one season.

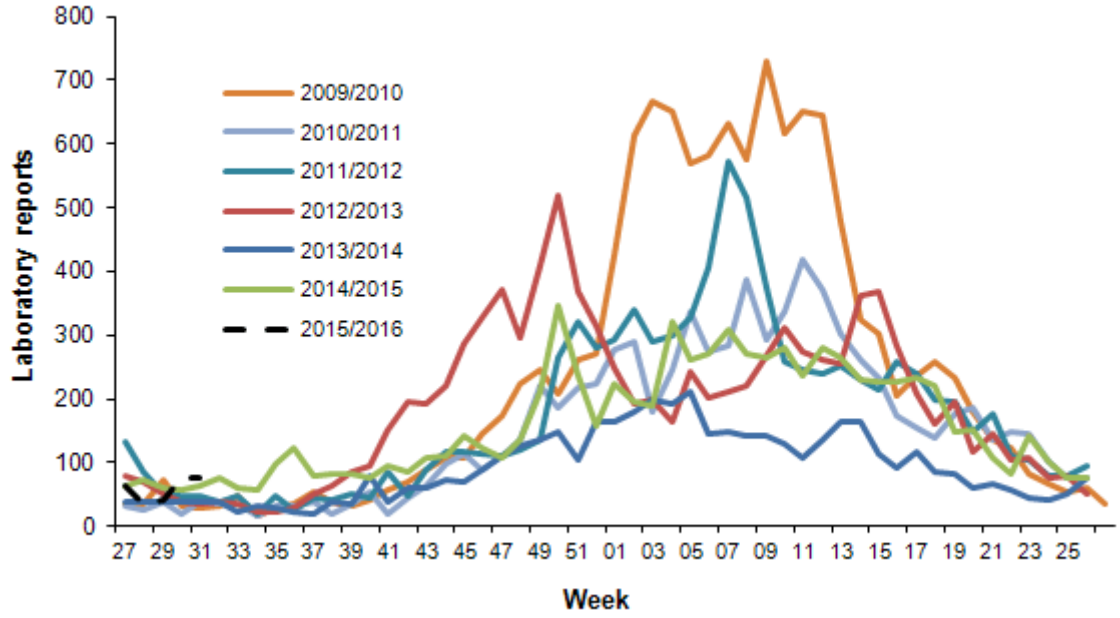
Note: A new laboratory reporting system was commissioned on 1 December 2014; as a result, direct comparisons between the earlier report (based on LabBase2) and the new system (SGSS) may not be valid.

Suspected and laboratory-confirmed reported norovirus outbreaks in hospitals, with regional breakdown: outbreaks occurring in weeks 27-31/2015

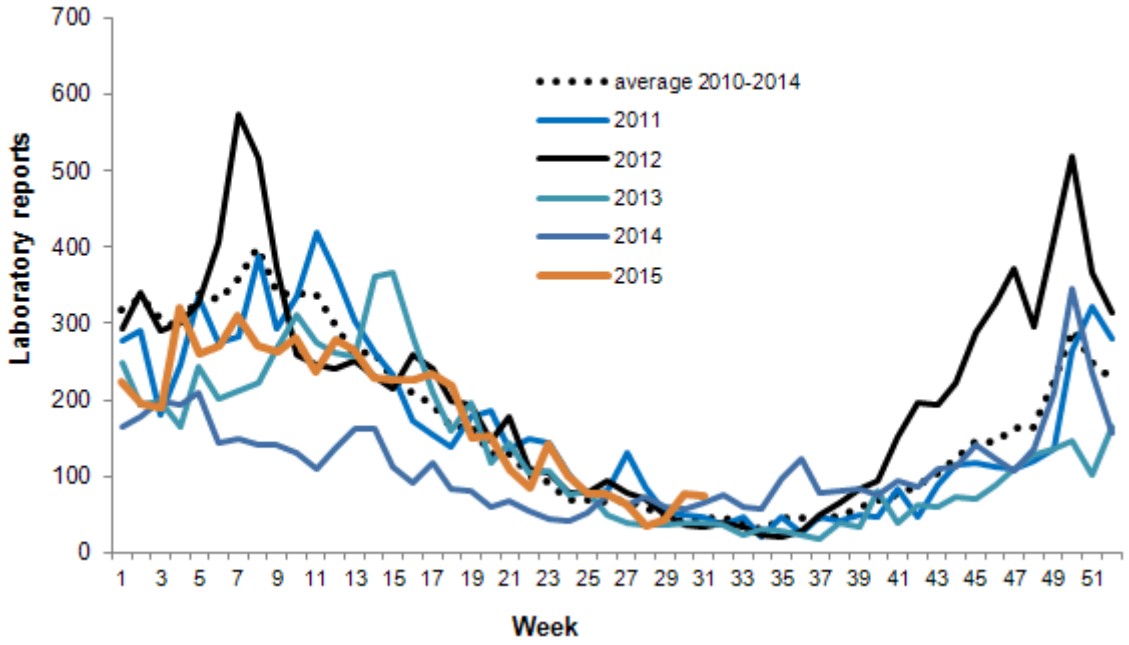
Region/ PHE Centre	Outbreaks between weeks 27-31/2015			Total outbreaks 1-31/2015		
	Outbreaks	Ward/bay closure*	Lab-confirmed	Outbreaks	Ward/bay closure*	Lab-confirmed
Avon, Gloucestershire and Wiltshire	–	–	–	60	59	47
Bedfordshire, Hertfordshire and Northamptonshire	–	–	–	7	7	6
Cheshire and Merseyside	–	–	–	8	6	8
Cumbria and Lancashire	–	–	–	38	37	20
Devon, Cornwall and Somerset	1	1	–	111	111	77
Greater Manchester	–	–	–	17	14	8
Hampshire, Isle of Wight and Dorset	–	–	–	24	23	19
Lincolnshire, Leicestershire, Nottinghamshire and Derbyshire	–	–	–	18	17	14
London	–	–	–	4	4	1
Norfolk, Suffolk, Cambridgeshire and Essex	–	–	–	–	–	–
North East	3	3	2	48	45	30
Sussex, Surrey and Kent	1	1	1	17	17	13
Thames Valley	–	–	–	4	3	1
West Midlands	4	4	–	109	106	56
Yorkshire and the Humber	3	3	2	68	55	58
Total	12	12	5	533	504	358

* Note: not all outbreaks result in whole wards closures, some closures are restricted to bays only.

Current season's laboratory reports (to week 31, 2015) compared to previous seasons' weekly average (England and Wales)



Calendar year 2015 (to week 31) norovirus laboratory reports compared to previous years' weekly mean (2010-2014)



Infection reports / Enteric

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Enteric fever surveillance quarterly report (England, Wales and Northern Ireland): second quarter 2015

This quarterly report summarises the epidemiology of laboratory confirmed cases of typhoid and paratyphoid reported in England, Wales and Northern Ireland between April and June 2015. It includes both reference laboratory and enhanced enteric fever surveillance data. All data for 2015 presented below are provisional; more detailed reports will be produced on an annual basis. More information about enteric fever surveillance, including previous reports, is available on the PHE website [1].

National summary

In the second quarter (Q2) of 2015, 74 laboratory confirmed cases of enteric fever were reported in England and Wales (table 1), 13% lower than the second quarter of 2014 (85) and 34% below the rolling mean (112) for Q2 2008 to 2015 (figure 1). There were no provisional cases reported in Northern Ireland for Q2.

Figure 1. Laboratory confirmed cases of enteric fever by organism, England, Wales and Northern Ireland: second quarter 2008 – 2015

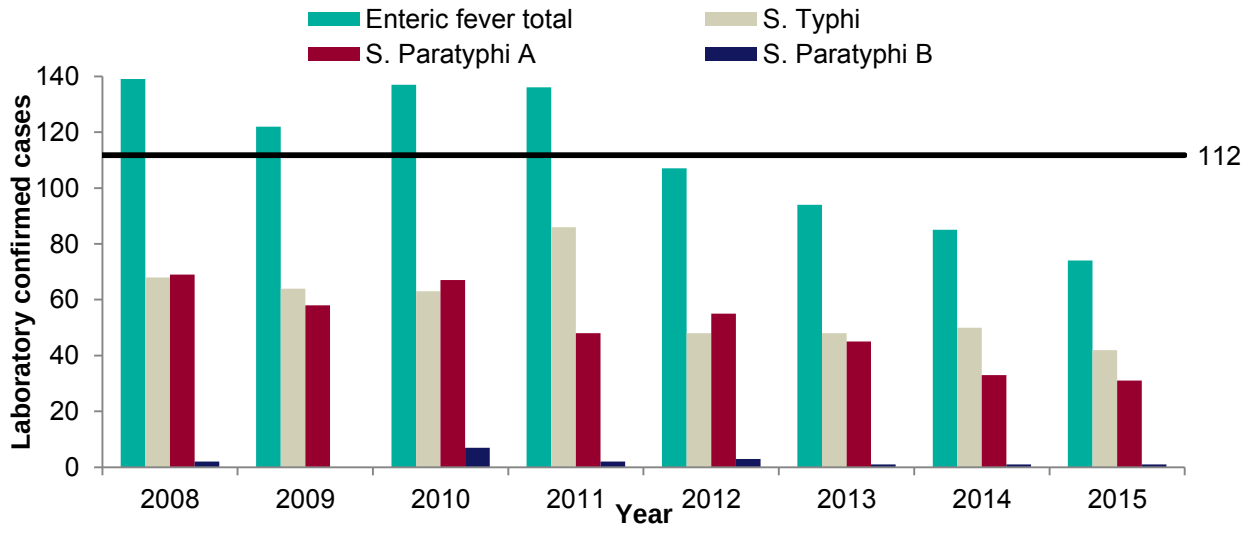


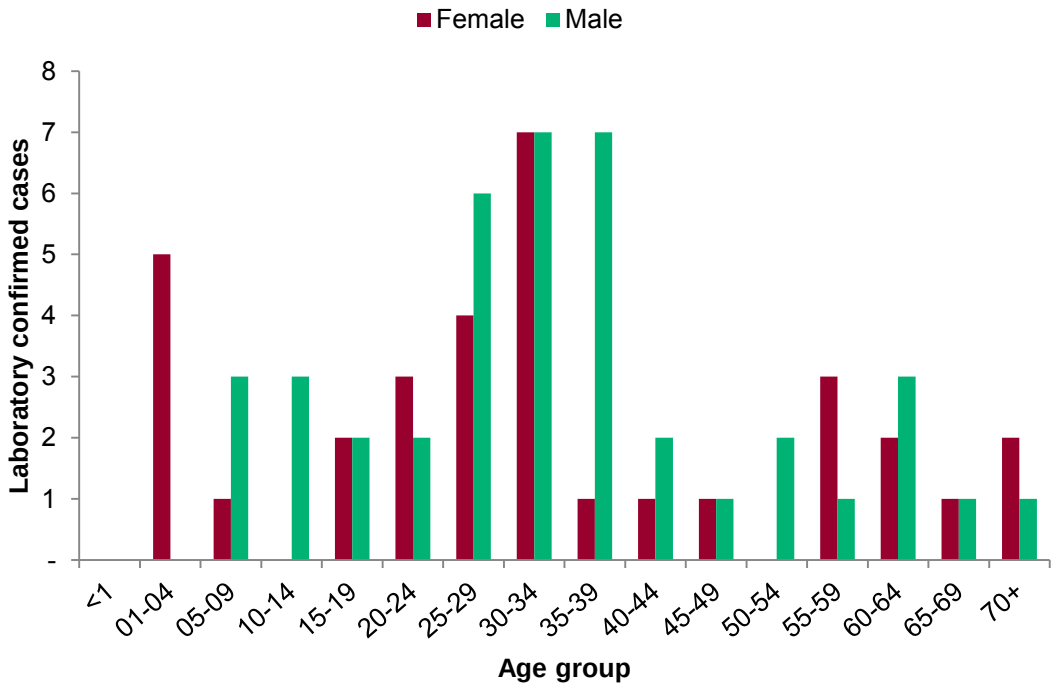
Table 1. Laboratory confirmed cases of enteric fever, England, Wales and Northern Ireland: second quarter 2008 – 2015

Organism	Laboratory confirmed cases							
	Q2 2015	Q2 2014	Q2 2013	Q2 2012	Q2 2011	Q2 2010	Q2 2009	Q2 2008
Salmonella Typhi	42	50	48	48	86	63	64	68
Salmonella Paratyphi A	31	33	45	55	48	67	58	69
Salmonella Paratyphi B	1	1	1	3	2	7	-	2
Salmonella Paratyphi C	-	1	-	-	-	-	-	-
Salmonella Typhi and Paratyphi A	-	-	-	1	-	-	-	-
Enteric fever total	**74**	**85**	**94**	**107**	**136**	**137**	**122**	**139**

Age/sex distribution

In Q2 2015, the median age of cases was 32 years and 15% (for both males and females) were aged 16 years and under (figure 2). Males represented 55% of all cases.

Figure 2. Laboratory confirmed cases of enteric fever by age and sex (N=74): second quarter 2015



Geographical distribution

London PHE Region reported 35% of the total cases during Q2 2015 (table 3). Only regions are shown in this report as the numbers are too small to disaggregate by health protection teams (HPTs); between one and 12 cases were reported by each of HPTs during the second quarter in 2015. HPT data is available on request.

Table 3. Laboratory confirmed cases of enteric fever by region: second quarter 2015

Region	Q2 2015	Q2 2014	% change
London	26	27	-3.7%
Midlands and East of England	17	20	-15.0%
North of England	21	23	-8.7%
South of England	9	15	-40.0%
Wales	1	-	-
Northern Ireland	-	-	-
Grand Total	**74**	**85**	**-12.9%**

Travel history

In the second quarter of 2015, travel history was available for 62/74 cases (84%); of which 57 cases (77%) were presumed to be acquired abroad and five cases had not travelled outside the UK in the 28 days prior to symptoms.

Travel-associated cases

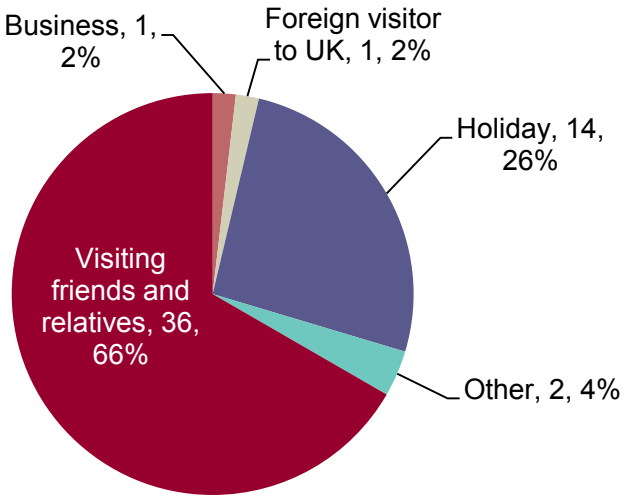
Travel-associated cases were likely to have acquired their infection in: India (29); Pakistan (18); Bangladesh (two); Thailand (two); Bolivia, Philippines, Tanzania, South Africa, Cambodia, Nepal, Malaysia, Mozambique, Senegal (one each).

Some cases travelled to more than one country so totals will not equal the number of total cases that travelled. Where multiple countries of travel have been stated by the case, only risk countries, as identified by the National Travel Health Network and Centre [2], were included for analysis. If a case travelled to multiple risk countries each country was counted individually. India and Pakistan continue to be the most frequently reported countries of travel for the second quarter of 2015.

Reason for travel

Of the 57 cases that had travelled abroad, the reason for travel was known for 54 (95%). Among those, 66% (36/54) of cases travelled to visit friends and relatives (figure 4).

Figure 4. Laboratory-confirmed cases of enteric fever that have travelled abroad (N=54) by reason for travel: second quarter 2015



Non-travel-associated cases

Five cases in the second quarter 2015 had enhanced information available stating they had not travelled abroad within 28 days of developing symptoms.

One of the cases reported falling into a river prior to the onset of illness. Another case had been in close contact with asymptomatic family members who had recently returned from Pakistan. A further case was suspected to have contracted S. Paratyphi infection from a family member who was also identified with the same organism.

The remaining two cases stated that they had not been in recent contact with a probable or confirmed case prior to the onset of illness. Neither of these remaining cases reported links to travellers from endemic countries and no other possible sources have been identified.

Data sources and acknowledgements

Data were collated and analysed by the Travel and Migrant Health Section, National Infection Service, Colindale. Laboratory data were provided by Gastrointestinal Bacterial Reference Unit, National Infections Service, Colindale. Other surveillance data were provided by Environmental Health Officers and local health protection colleagues in PHE through enteric fever enhanced surveillance.

References

1. GOV.UK website. Enhanced surveillance of enteric fever. Available at: https://www.gov.uk/government/collections/typhoid-and-paratyphoid-guidance-data-and-analysis
2. National Travel Health Network and Centre (NaTHNaC) website. Available at: http://www.nathnac.org/

Infection reports / Zoonoses

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Common animal associated infections quarterly report (England and Wales) – second quarter 2015

This quarterly report, produced by the Emerging Infections and Zoonoses Section at Public Health England National Infection Service, and the Health Protection Division of Public Health Wales, summarises confirmed cases of zoonoses reported in England and Wales between April and June 2015 (second quarter; weeks 14-26).

Animal associated infections in England and Wales: laboratory reports to SGSS† (unless otherwise specified) by specimen date, Q2 (weeks 14-26/15)

Disease (Organism)	Reports for weeks 01-13		Reports for weeks 14-26	
	2015*	2014	2015*	2014
Anthrax (*Bacillus anthracis*)	-	-	-	-
Brucellosis** *(Brucella spp.)*	1	2	5	2
Hepatitis E**	202	217	193	250
Hydatid** (*Echinococcus granulosus*)	9	6	8	2
Leptospirosis** *(Leptospira spp.)*	10	7	10	9
Lyme borreliosis** (*Borrelia burgdorferi*)	N/A	N/A	N/A	N/A
Pasteurellosis *(Pasteurella spp.)*	139	126	147	163
Psittacosis (*Chlamydophila psittaci)*	4	6	11	4
Q-fever *(Coxiella burnetii)*	6	10	3	18
Toxoplasmosis**# *(Toxoplasma gondii)*	88	76	86	96

†Second Generation Surveillance System has now replaced LabBase

* Provisional data

** Enhanced surveillance system

Based on date specimen received

N/A=Not Available

Anthrax

There were no cases reported in the second quarter of 2015.

Brucellosis (data from the Brucella Reference Laboratories)
Reports of five *Brucella* cases were received during the second quarter of 2015, compared with two in the second quarter of 2014.

Of the five cases in 2015, all were identified as *Brucella melitensis*. Four were males aged 23 to 61 years, and one was female aged 31 years. Four were known to have come from countries where brucellosis is endemic. Additional epidemiological details and clinical presentations are awaited.

Hepatitis E (data from Public Health Laboratory Birmingham, and Blood Borne Virus Unit Colindale)
There were 193 cases of hepatitis E in the second quarter of 2015 compared to 250* in the same quarter of 2014. One hundred and twenty-eight cases (66%) were male (aged 24-91 years, median 57) and 58 (30%) were female (aged 18-88 years, median 58). The genders of the remaining seven cases were not reported. The persisting observation of the predominance of older men (see table below) remains unexplained. Cases were reported from all regions. The majority of cases (78%, n=151) had no apparent travel history.

The number of cases is consistent with the on-going increase observed since 2010[1].

Laboratory confirmed cases of Hepatitis E infection (week 14-26, 2015)

Age Group	Male	Female	Unknown	Total
0-14	-	-	-	-
15-24	1	2	-	3
25-44	21	12	3	36
45-64	61	23	3	87
>64	45	21	-	66
Unknown	-	-	1	1
Total	**128**	**58**	**7**	**193**

Hydatid disease (data from the Parasitology Reference Laboratory)
Eight cases of hydatid disease were reported during the second quarter of 2015, compared with six during the same quarter of 2014. Five of the cases were female (aged 30 to 74 years) and three were male (aged 34 to 61 years). One patient with long term eosinophilia came from South Africa. Two cases were identified with renal hydatid, two with liver cysts and one with a multilocular cystic lesion.

Leptospirosis (data from the Rare and Imported Pathogens Laboratory, Porton and the Bacteriology Reference Department, Colindale)

The reporting system for leptospirosis changed in the second quarter of 2015. The reference service is now run jointly between BRD and RIPL.

There were ten cases of leptospirosis reported in the second quarter of 2015 compared with 9 in the second quarter of 2014. Seven of the cases were male (aged 18 to 69 years), and three were female (aged 19 to 72 years). The cases were reported by the south of England (n=7) and the north of England (n=3). Four had been travelling (one each to Borneo, France, Malaysia and Borneo/Thailand). One of the cases reported a tick bite and one reported that they had been on a fishing trip in France, that they lived on a river bank and there were rats in the water.

Four of the confirmed cases were diagnosed by PCR alone. These PCR diagnoses have not previously been included in the number of cases of confirmed leptospirosis.

* Figure corrected on 29 September 2015

Lyme disease (data from the Rare and Imported Pathogens Laboratory, Porton)
Data are not yet available for Lyme disease for 2015.

Note: Specimens sent for Lyme borreliosis referral testing should be accompanied by a completed referral form: https://www.gov.uk/lyme-borreliosis-service

Pasteurellosis

A total of 147 confirmed cases of pasteurellosis were reported in the second quarter of 2015. This compares to 163 reported in the same quarter in 2014. The following species were reported: *Pasteurella multocida* (104 cases), *Pasteurella canis* (7 cases), *Pasteurella pneumotropica* (1 case), *Pasteurella* other named (17 cases) and *Pasteurella* sp. (18 cases).

Ninety-six of the cases were female (aged 3 to 95, median 56.5 years) and 51 were male (aged 6 to 84, median 58 years). The north of England and south of England reported the most cases (46 and 45 respectively), and Wales reported the least (2). Eighteen of the cases were associated with cat bites, and six with dog bites.

Laboratory confirmed cases of pasteurellosis (week 14-26, 2015)

Age group	Male	Female
0-14	4	2
15-29	5	7
30-39	3	9
40-49	8	16
50-59	6	17
60-69	12	17
70-79	5	18
80+	8	10
Total	**51**	**96**

Psittacosis

Eleven cases of psittacosis were diagnosed in the second quarter of 2015, compared with four during the second quarter of 2014. Seven were male (aged 25 to 88, median 51 years) and four were female (aged 38 to 61, median 58.5 years). Five of the cases were reported by the Midlands and East of England, five by the south of England and one by the north of England. One case was known to have owned a parrot that recently died of a chlamydial infection.

Note: Serological tests for respiratory chlamydophila infections cannot consistently distinguish psittacosis. The cases reported above have been identified by reporting laboratories as infection with *Chlamydia psittaci*.

Q fever (data from the Rare and Imported Pathogens Laboratory, Porton, and Bristol Reference Laboratory)

There were three cases of Q fever reported in the second quarter of 2015, compared with 18 during the second quarter of 2014. All were male (aged 27, 45 and 66 years) and were reported by the Midlands and East of England (n=2) and the south of England (n=1) regions.

Toxoplasma (Data from the Toxoplasma Reference Unit)
There were 86 cases of toxoplasmosis reported in the second quarter of 2015 compared with 96 in the second quarter of 2014. Five cases reported ocular symptoms. Five cases occurred in pregnant women and there was one confirmed congenital case (which formed a mother-child pair with one of the pregnant cases).

Laboratory confirmed cases of toxoplasma infection (week 14-26, 2015)

Age group	Male	Female	Unknown	Total
0	1	1		2
1-9	1			1
10-14				
15-24	9	11		20
25-44	13	31		44
45-64	6	10		16
>64	2			2
Unknown			1	1
Total	32	53	1	86

Age group	Con-genital	Pregnant	HIV	Organ donor	Organ recipient	Other (Immuno-competent)	Other (Immuno-suppressed)	Total
0	1					1		2
1-9						1		1
10-14								
15-24		1				19		20
25-44		4	3		1	35	1	44
45-64			1			15		16
>64						2		2
Unknown				1				1
Total	1	5	4	1	1	73	1	86

Other zoonotic organisms

Other zoonotic infections of interest diagnosed in the second quarter of 2015 were as follows:

- Five cases of *Capnocytophaga* infection, four of which had bacteraemic infections. Four of the cases were in males aged 20-79 years, and one was in a female aged 26 years. Cases were reported from the Midlands and the East of England (n=3), the north of England (n=1) and the south of England (n=1).
- One case of *Corynebacterium ulcerans* wound infection in a 49 year old man from the south of England who had a pet dog.
- Three cases of *Erysipelothrix* in two females (aged 33 and 89 years) and a male neonate. The two female cases were reported by the north of England, and the neonate was reported from the south of England. Two of the cases were bacteraemic.
- Eight cases of *Mycobacterium marinum* in seven males (aged 36 to 79 years, median 47 years) and one female (aged 70 years). Cases were reported by the Midlands and East of England (n=3), the south of England (n=3) and the north of England (n=2). Seven of the cases were tissue infections, whilst one immunocompromised case suffered from a bacteraemic infection.

Reference

1. https://www.gov.uk/government/publications/hepatitis-e-symptoms-transmission-prevention-treatment/hepatitis-e-symptoms-transmission-treatment-and-prevention

Infection reports / CJD

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Creutzfeldt-Jakob disease (CJD) biannual update (August 2015)

This six-monthly report provides an update on the enhanced surveillance of potential iatrogenic (healthcare-acquired) exposures to Creutzfeldt-Jakob Disease (CJD). The data is correct as of 30 June 2015. For numbers of CJD case reports, readers should consult data provided by the National CJD Research and Surveillance Unit (NCJDRSU, http://www.cjd.ed.ac.uk/data.html).

Monitoring of patients 'at increased risk' of CJD

Individuals who have been identified as ‘at increased risk’ of CJD as a consequence of their medical care are informed of their exposure and asked to follow public health precautions to avoid potentially transmitting the infection to others. They are also followed up to help determine the risks of CJD transmission to patients through different routes and to ascertain whether any people who may have been exposed to increased CJD risks go on to develop CJD.

Public Health follow up activities include clinical monitoring, General Practitioner (GP) updates, and post mortem investigations to determine whether asymptomatic individuals in these groups have been infected with the CJD agent. Some individuals also provide blood or tissue specimens for research purposes. A number of different organisations are involved in these activities: Public Health England (PHE) formerly the Health Protection Agency (HPA), Health Protection Scotland (HPS), UCL Institute of Child Health/Great Ormond Street Hospital (ICH), NHS Blood and Transplant (NHSBT), National CJD Research and Surveillance Unit (NCJDRSU), National Prion Clinic (NPC), and the UK Haemophilia Centre Doctors' Organisation (UKHCDO).

The PHE CJD Section coordinates the collation of data on individuals identified as ‘at increased risk’ of CJD, and who have been informed of this. These individuals are followed up through public health monitoring and research activities by different organisations.

The PHE CJD Section currently holds data on the following groups of patients who have been identified as ‘at increased risk’ of CJD:

- recipients of blood components from donors who subsequently developed vCJD
- blood donors to individuals who later developed vCJD
- other recipients of blood components from these blood donors
- recipients of certain plasma products between 1990 and 2001 (non-bleeding disorder patients)
- certain surgical contacts of patients diagnosed with CJD
- highly transfused recipients.

Data on the following risk groups are not held by PHE, but are held by other organisations:

- bleeding disorder patients who received plasma products between 1990 and 2001 (UKHCDO)
- recipients of human derived growth hormone before 1985 (ICH)
- patients who could have received a dura mater graft before August 1992 (data not currently collected)
- people who have been treated with gonadotrophin sourced from humans before 1973 (data not currently collected)
- family risk of genetic prion disease (NPC).

The data from the UKHCDO are likely to be a slight underestimate of the true number of patients with bleeding disorders who received UK-sourced clotting factors (1990 to 2001), as there was incomplete reporting of identified patients by haemophilia centres to the UKHCDO database. Notified patients are given the option of removing their details from the UKHCDO database, and are then removed from the ‘at increased risk' totals.

The data on patients who received human-derived human growth hormone held by the ICH is also a slight underestimate of the total as a small number of these patients are not included in the ICH follow-up.

Summary of all 'at increased risk' groups on which data are collected (as of 30 June 2015)

'At increased risk' Group	Identified as 'at increased risk'	Number notified		Cases	Asymptomatic infections [a]
		All	Alive		
Recipients of blood from donors who later developed vCJD	67	27	14	3	1
Blood donors to individuals who later developed vCJD	112	108	104	0	0
Other recipients of blood components from these donors	34	32	18	0	0
Plasma product recipients (non-bleeding disorders) who received UK sourced plasma products 1990-2001	2	2	2	0	0
Certain surgical contacts of patients diagnosed with CJD	231	187	162	0	0
Highly transfused recipients	3	3	3	0	0
Total for 'at increased risk' groups where PHE holds data	**449**	**359**	**303**	**3**	**1**
Patients with bleeding disorders who received UK sourced plasma products 1990-2001[b]	4,021	3,540[c]	3,128[c]	0	1
Recipients of human derived growth hormone[b]	1,883	1,883	1,501	77	0
Total for all 'at increased risk' groups	**6,353**	**5,782**	**4,932**	**80**	**2**

a. An asymptomatic infection is when an individual does not exhibit any of the signs and symptoms of CJD in life but abnormal prion protein indicative of CJD infection has been found in tissue obtained at post mortem.

b. These are minimum figures. Central reporting for bleeding disorder patients is incomplete, and a small number of patients have opted out of the central UKHCDO database. A small number of 'at increased risk' growth hormone recipients are not included in the Institute of Child Health study. Not all of the 'at increased risk' growth hormone recipients have been notified. There is no central record of who has been informed.

c. These are the minimum number of people notified based on those patients who were seen for care after the notification exercise. It is likely that many more of the 'at increased risk' patients received their notification letter but as they were not subsequently recorded as being seen for care this cannot be confirmed.