Surveillance of waterborne disease in European member states: a qualitative study
Helen L. Risebro and Paul R. Hunter

ABSTRACT
We sought to explore perceived strengths and weaknesses of surveillance systems for the detection of drinking-water-related illness in Europe based on the experience of individuals utilising such systems. We designed and conducted a qualitative semi-structured interview study with thematic analysis. Interviews took place in six European countries with seven experts in epidemiology, water and public health. Interviewees remarked upon variation between and within countries in laboratory and sampling protocols and reporting practice; these were felt to influence timeliness and sensitivity of laboratory- and clinician-report-based surveillance. Electronic reporting, reminders to report and direct report relay to national level were considered strengths of report-based surveillance. A need was expressed for more detailed case demographic information to facilitate outbreak detection. Existing infrastructure permitting, prescriptions data, anti-diarrhoeal pharmaceutical sales, absenteeism and consultations were cited as useful outbreak indicators. Information regarding consumer water quality complaints was highlighted as a potentially useful data source. Collaboration with water companies (concerning water distribution and incidents), and constructing and maintaining relationships with local and external data providers were cited as requisites of effective surveillance. Inter- and intra-organisational collaboration and information integration are likely to improve surveillance, leading to more astute estimates of the waterborne disease burden.

Key words | disease, drinking water, epidemiology, Europe, outbreak, surveillance

INTRODUCTION
Drinking water has been implicated as the key mode of transmission in various outbreaks of gastrointestinal disease throughout Europe. Causative enteropathogens have included Campylobacter (Hanninen et al. 2003), Cryptosporidium (Guyonnet & Claudet 2002), Escherichia coli O157 (Dev et al. 1991), Giardia (Gornik et al. 2000), norovirus (Kukkula et al. 1999) and Shigella (Samonis et al. 1994). The early detection of outbreaks of infectious intestinal waterborne disease can reduce morbidity and mortality provided that appropriate steps are taken to identify and control the source. Identification of cases and early detection of outbreaks requires effective surveillance systems.

An array of data sources are used for the surveillance of waterborne disease, including vital records registration, passive and active morbidity reporting, epidemic or outbreak reporting, laboratory-, clinic- and hospital-based surveillance systems, sentinel surveillance systems, drug-utilisation data, and media and news broadcasting reports (Chorba 2001). In addition to this, consumer complaints about water quality and poor water quality results can alert authorities to an existing or ensuing waterborne outbreak
Such data may be assembled at a number of administrative or functional levels. \textit{WHO} (1999) discuss surveillance activities in terms of up to four functional levels: peripheral, intermediate, central and regional/international. At the peripheral level, local healthcare providers (such as general practitioners) are involved in case management. Outbreak investigation and district and/or regional collection of data from the peripheral level may take place at the intermediate level. The central level includes support and co-ordination of national surveillance. Examples of national surveillance centres in Europe include: the National Public Health Institute (KTL, in Finland), the Health Protection Agency (HPA, UK), the Robert Koch Institute (RKI, Germany), the National Institute for Public Health and the Environment (RIVM, The Netherlands), the National Institute for Public Health Surveillance (InVS, France) and the Swedish Institute for Infectious Disease Control (SMI). Institutes such as Enter-net, the surveillance network for \textit{Salmonella} and \textit{VTEC O157}, exist at the regional/international level.

Surveillance for waterborne disease may draw upon a mixture of data sources at different functional levels. According to the \textit{Centers for Disease Control} (2001), the credibility of a surveillance system can be assessed on its performance on a number of attributes: simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness and stability. The diverse strategies employed by national systems lead to variation in performance on each of these attributes. There is, therefore, a need to examine these strategies in order to gauge their effectiveness and to inform data on waterborne disease incidence.

In this paper we review existing strategies for waterborne disease surveillance in selected European countries in terms of reported strengths, weaknesses and potential improvements. To inform this paper, information was gathered through direct consultation with experts in epidemiology, water, and public health from Finland, France, Germany, The Netherlands, Sweden and the UK were contacted to request their participation in an interview concerning waterborne disease surveillance. Upon positive response, arrangements were made to conduct the interview at a suitable venue in the respondent’s country.

The interviews aimed to be exploratory in nature and were therefore conducted in a semi-structured format. The following key open requests were posed to interviewees:

- Describe your country’s surveillance systems for waterborne disease.
- What do you consider to be the strengths of your surveillance system?
- What do you consider to be the weaknesses?
- If you could change anything to improve the current surveillance system, what would it be?

If not forthcoming, all interviewees were probed for further information about, and attitude towards,

- statutory reporting practice,
- syndromic and pharmaceutical surveillance,
- water quality.

As the adopted interview style was flexible in nature, throughout the interview a number of sub-questions were also posed to gain clarification and/or to seek additional information on unanticipated responses.

Interviews lasted approximately one hour and were conducted in the English language by one interviewer. All interviews were conducted on a one-to-one basis, with the exception of the interview in France during which two respondents were present.

In order to prevent distraction during the interview, permission was sought from interviewees to record interviews. Interviews were recorded using a digital voice recorder. Following the interview, interviews were downloaded and transcribed verbatim by the interviewer in order to improve accuracy and gain familiarity with the data (\textit{Pole & Lampard} 2002). A transcript was sent to interviewees for comment.

Interview transcripts were analysed using QSR NVivo 2.0, a computer software package. NVivo can be used to

\textbf{METHOD}

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Interview transcripts were analysed using QSR NVivo 2.0, a computer software package. NVivo can be used to
facilitate qualitative data analysis; it enables the analyst to highlight common concepts or nodes (herein referred to as ‘codes’) in transcripts and to ‘look-up’ these codes both within and across transcripts. All data were analysed line by line. The transcripts were segmented according to a priori (strengths, weaknesses, improvements, laboratory reporting, clinician reporting, statutory reporting, pharmaceutical data, syndromic surveillance, water quality) and inductive codes. To increase plausibility, a reflexivity check was carried out whereby interpretation of interview content was verified by interviewees.

**RESULTS AND DISCUSSION**

Approximately seven hours of interview yielded over 33,000 words of transcript. A total of 28 codes emerged from coding the transcripts. In Table 1 the codes have been grouped according to four core themes: laboratory- and clinician-based reporting, syndromic surveillance, water quality and communication. The codes are listed in rank order according to the number of highlighted passages attributed to each code. A highlighted passage is not exclusive to one code; multiple codes may be attributed to a passage. The codes ‘statutory (combined methods)’ and ‘syndromic (combined methods)’ overlap substantially with other codes within their respective themes. The codes grouped under ‘multi-themed’ in Table 2 overlap across themes.

The following results describe the requested strengths, weaknesses and improvements in terms of the themes emerging from the coding exercise. Individual comments and quotes from the consultative exercise are interspersed with narrative in context throughout the section. As a further means of triangulation, information derived from literature sources is interspersed with narrative and quotes to endorse participant observations. Quotes are distinguishable by annotation of the country with which the interviewee is associated.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Results of interview coding exercise</th>
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<td><strong>Themes</strong></td>
<td><strong>Codes</strong></td>
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<td><strong>Laboratory and clinician-based reporting</strong></td>
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**LABORATORY AND CLINICIAN-BASED REPORTING**

To review the burden and incidence of communicable disease, many national institutes will look at disease patterns based upon laboratory-confirmed or clinician-based diagnoses submitted to the institute via a reporting system. This method of surveillance was commented upon by interviewees the most often. Interviewees highlighted and discussed factors bearing influence upon both clinician- and laboratory-based reporting. The following subsections describe these factors in more detail.

**Case detection**

One of the first steps in the reporting pyramid is medical consultation (Wheeler et al. 1999; O’Brien & Halder 2007).
In the majority of cases, waterborne enteropathogens will cause mild self-limiting illness which does not require a consultation. It was suggested that differences in patients’ attitudes towards illness and consultation exist both within and between countries. Healthcare utilisation was also noted to be affected by accessibility and language barriers.

Following a consultation, the protocols for requesting and analysing samples will further influence the sensitivity of a report-based surveillance system. A healthcare professional may be reluctant to request a sample because of the expense of laboratory analysis. It was suggested that the cost of laboratory-confirmed diagnosis should be removed from the clinician’s budget so that investigation remains unrestricted.

“…everyone is trying to cut down costs nowadays, so that they (the clinician) are trying not to take so many samples” Sweden

“The results of the stool culture hardly ever change the treatment; they just will not do it because of the cost to the patient” France (1)

Where results of laboratory analysis are unlikely to affect treatment, prescribing medication was noted to be a cheaper alternative to offering laboratory-confirmed diagnosis.

“…it is definitely more likely that they (the clinician) will prescribe something like that than they would ask for a stool sample.” Germany

Researchers have implied that savings can be made when sample requests are restricted (Morris et al. 1996; Rohner et al. 1997; Crook et al. 2002). Restricting sampling and analysis to selected cases (such as the immunocompromised, newborns or repeat-visit cases), where diagnosis is important and/or where diagnosis can affect the treatment regime, was an approach reported by interviewees. Yet it was also recognised that the sampling protocol should adapt in consideration of community levels of infectious disease.

“At the first visit you will not get a stool culture, they (the clinician) will only use stool culture if the diarrhoea persists, unless if it’s a newborn and then the delay is shorter.” France (1)

“I think I would like the GP to be more aware, to see outbreaks, I mean to see the community and not just the patients.” Sweden

What the laboratories look for and how they look for it will depend, to a great extent, on available equipment, expertise, case-specific characteristics and finance. As a result, not all laboratories will analyse samples for the same pathogens or use the same method, which makes comparing results between laboratories difficult. Laboratories may be more inclined to perform analysis for certain pathogens when they believe them to be more prevalent in the community.

“There is still a wide range of tests which makes it difficult to compare information from one laboratory to another.” Netherlands

“…one of the things that can influence their decision to test for a pathogen or not is also the season.” Netherlands
Interviewees reported that analysis was often restricted to bacteria, followed by viruses and parasites and noted that this may distort the national picture of disease incidence.

“When you submit a stool culture here what you have to look for is Salmonella and Shigella and all the rest is optional unless the doctor specifies on the prescription ….But doctors usually will not do it, they just write ‘stool culture’ and they don’t write anything else.” France (1)

“They need to ask separately for Cryptosporidium which, as I mentioned earlier, I believe is a cause for under-diagnosis. They would have to remember a specific title for Cryptosporidium.” Finland

“For norovirus it’s heavily concentrated on outbreaks, or suspected outbreaks, and not really requested systematically–so it’s not very representative for any kind of trends surveillance…” Finland

“I also think it’s a problem that when they (the clinician) have cases they always start to look for the bacteria and not for the parasites and the viruses.” Sweden

It has been noted in the literature that performing strain typing can help epidemiological investigations by linking cases to a common source with greater accuracy (Beller et al. 1997; Kukkula et al. 1999). Interviewees noted that a lack of typing and sub-typing hindered the detection of small outbreaks from a national perspective.

“…The problem is that we don’t have any subtyping, it’s just a mass of Campylobacter, 2500 a year – so it’s more difficult to find a small waterborne outbreak.” Sweden

In Finland, a large proportion of confirmed cases for 25 pathogens (not all of which are waterborne) have microbial strain data available.

“The typing, subtyping, phage typing, and the epidemiologic susceptibility patterns, are done (at KTL). So this overall system helps us with geographically widely distributed outbreaks which are quite commonly recognised (at KTL).” Finland

However, performing typing for some pathogens was considered costly and not always necessary and, whilst some new molecular methods have improved diagnostic accuracy, they can also prove to be expensive.

“…they are not interested in knowing the serotype (for Salmonella) and it’s costly to send an isolate …” France (1)

“…there are also identification problems in the laboratory with conventional methods failing to identify a large percentage of the infections because the methods aren’t sensitive enough. This is an issue of cost as much as anything else, because it is currently costly to use the full set of molecular methods.” UK

Documentation on diversities in sampling and analysis protocols needs to accompany local and national surveillance statistics in order for them to prove informative.

**Reporting practice**

Following laboratory or clinical confirmation, the diagnosis can be relayed to the relevant authority. The functional level (whether a local, regional or national body) of the “relevant authority” and the disease notified under statutory and voluntary obligation will vary by country. These diverse aspects and methods of reporting practice were discussed by interviewees and are further explained in the following subsections.

**Statutory nature of reporting**

The *Communicable Disease Handbook* by Hawker et al. (2005) contains comprehensive details of the mandatory notification systems for communicable disease surveillance adopted by 27 European countries. Of the 6 countries examined here, Finland holds the most comprehensive inventory incorporating 79 notifiable diseases; over half of these are to be reported by the laboratory and the remainder are laboratory- and clinician-notifiable. By contrast,
in France just 26 diseases are notifiable. It was debated as to whether expanding the list of notifiable pathogens would reduce the administrative burden on clinicians.

“The larger this list becomes, in my opinion, the more likely it becomes that people are not motivated to report the patient. However, ... from the physician’s point of view ... they just don’t want to spend a lot of time thinking about whether it is notifiable or not.”

Netherlands

In Sweden, 60 diseases are statutorily notifiable to SMI and the CMO (County Medical Officer) by both physicians and laboratories in parallel. Since 1 July 2004, Sweden has increased the number of notifiable pathogens to incorporate Cryptosporidium, Leptospira, Vibrio infections other than Vibrio cholera (O1 and O139), all VTEC and Entamoeba histolyca, and also the reporting of foodborne outbreaks. Fourteen diseases are notifiable by the attending clinician to RKI in Germany if suspected or clinically diagnosed in cases or if identified as the cause of death (clinical cases and deaths from tuberculosis are also notifiable). Suspected and clinical cases of foodborne infection or acute infectious gastroenteritis are only notifiable in the event of an outbreak or if the case is involved in food-handling. Outbreaks are also notifiable if they pose a grave danger for the general public (including those caused by pathogens other than the 15 specified). Direct or indirect evidence of a further 47 named pathogens are also notifiable by the laboratory (Infectious Disease Control Act 2001). In the Netherlands, Shigella is only statutorily notifiable by the attending clinician; all remaining statutorily notifiable pathogens listed in Table 3 require notification from the laboratory. As previously mentioned, in some countries complementary notification by the clinician is the convention. In Germany, the Infectious Disease Control Act (IDCA, 2001) states that clinicians are not obligated to report diseases if they have evidence that notification has already been made. Epidemiologists from the CIRE (regional epidemiology units) in France, Consultants in Communicable Disease Control (CCDCs) in England and Wales, and County Medical Officers of Communicable Disease Control (CMOs) in Sweden are examples of appointed regional public health officials or “proper officers”. Direct or complementary reporting to and by proper officers was reported by interviewees to be a component of the national reporting process in some countries.

Reminders to report

In Sweden, following laboratory-confirmed diagnosis the laboratory may send a reminder to the clinician that the case is mandatory to report. A similar scheme was reported to exist in the Netherlands; laboratories can have an agreement with the clinician to report notifiable diseases in their place; subsequently the physician may be contacted
for further information. Where complementary reporting has been adopted, it has been recognised as an effective approach.

“...but the regions that do this, they have good collaboration between the laboratory and the physicians and it works very well.” Netherlands

When a statutorily notifiable pathogen is identified in Finland, the laboratory sends a reminder to the clinician to report this finding as a matter of routine.

“And we considered this a great need because notification...is a rare event in their everyday work so the reminder would be quite a prerequisite to any reasonable level of notification.” Finland

### Coverage, electronic reporting and functional levels

As surveillance of entire populations can be expensive, networks of sentinel healthcare providers may report upon health events in order to make inferences about morbidity at the population level (Chorba 2001). For voluntary reporting systems, interviewees noted that the percentage of the population under surveillance can vary according to the pathogen. For example, there are approximately 4,000 private laboratories in France, of which 1,389 participate in a Salmonella surveillance network and 600 partake in Campylobacter surveillance on a voluntary basis (Gallay et al. 2003). National Reference Centres (CNRs) collect data on Campylobacter, Salmonella and Shigella, and data on E.coli O157, norovirus and gastroenteritis is based on sentinel or partial surveillance. Interviewees commented on the problems associated with detecting outbreaks when surveillance for certain pathogens is limited.

“...a weakness is that our surveillance system is based on so many private laboratories and that we don’t have many public health laboratories. ...For Crypto and Giardia, the few laboratories who will look for it will find it very hard to detect any outbreaks if the GPs don’t notice an increase in cases.” France (1)

The time limit for relaying information can be regimented for pathogens and diseases for which there is a statutory

### Table 3  Disease surveillance and statutory position by country (adapted from Risebro et al. 2006)

<table>
<thead>
<tr>
<th>Pathogen</th>
<th>Finland</th>
<th>France</th>
<th>Germany</th>
<th>Netherlands</th>
<th>Sweden</th>
<th>England</th>
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<tbody>
<tr>
<td>Campylobacter</td>
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<td>Cryptosporidium</td>
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<td>E.coli O157: H7</td>
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<td>Giardia</td>
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<td>Norovirus</td>
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<td>Salmonella</td>
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<td>Shigella</td>
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<td>AGI Food Handler/Poisoning*</td>
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<td>Outbreak</td>
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Information Source: Finland (KTL 2006); France (Vaillant et al. 2004); Germany (Infectious Disease Control Act 2001); Netherlands (Infectious Disease Act 1999; RIVM 2006); Sweden (Lindqvist et al. 2001; Communicable Disease Act 2004; SMI 2006); UK (Hawker et al. 2005; HPA 2006).

* Acute gastroenteritis linked to either a food handler or food poisoning.
• Statutorily notifiable. ○ Data collected on a voluntary reporting basis.— No information on notification procedure to national level was identified.
obligation to report. For example, in the Netherlands, 23 of the 25 clinician-notifiable diseases require notification within 24 h and, owing to severity and infectious nature, two diseases require notification upon suspicion; laboratory-notifiable pathogens are required to be reported within 48 hours (IDA, 1999). A similar notification period can be found in other European countries but it was noted that this is not always adhered to.

“So the lab report as soon as they find a result and the GP should report in 24 hours but that’s not the reality.” Sweden

In voluntary reporting systems, variation between laboratories in the timeliness of reporting was noted thus limiting the capacity for rapid and/or small outbreak detection.

“The extent of their (laboratory) reporting is variable, and the timeliness in particular can vary considerably.” UK

“Although it’s a small percentage that is very slow at reporting, it remains a problem for our national follow-up of disease.” UK

In England, laboratory reports can be submitted to HPA as electronic files transferred to “CoSurv” (a database used for recording isolates and notifications) using the software LabLink+ which is available to all laboratories free of charge. Whilst electronic file transfer is the standard method of reporting, reports can also be submitted via paper forms or computer-generated printed reports. Notifications of Infectious Diseases (NOIDs) received by the CCDC from clinicians are also transferred electronically (Pollock 2003). The electronic transfers are collected regionally and then relayed to the HPA. Variation in the speed of voluntary laboratory reporting was recounted to adversely affect the effectiveness of surveillance from the national perspective.

In Germany, local health departments gather information from healthcare professionals and laboratories, which is relayed to the State Health Department and subsequently to RKI (Hawker et al. 2005). RKI receive the data at county level rather than at the level of the individual; individual case data is requested when necessary. The middle or regional step involved in collating and relaying surveillance data was again noted to slow receipt at the national level.

“It (reporting) would be accelerated if we could have the direct reporting to Berlin but under the existing political system it is not possible to do this.” Germany

Reports from local to state health departments and to RKI were converted from a paper to an electronic system in 2001 yet clinicians and laboratory scientists still report to the local health department in non-electronic format. In a survey of attitudes, practices and needs, it was identified that more than 66% of responding medical microbiology laboratories in Germany would favour electronic reporting of mandatory diseases to the current paper format (Zucs et al. 2005). SmiNet is a computerised reporting system with approximately 16 of the 21 existing Swedish counties connected (Jansson et al. 2005). Paper or electronic notifications from the clinician or laboratory are provided at the county (to the CMO) and national level (to SMI) in parallel. A similar approach is adopted in Finland whereby laboratory notifications are reported directly to the national register level. It was once more noted that reporting directly to the national institute without the middle or regional step reduced delays in receipt of surveillance data. The accuracy of surveillance data obtained through electronic notification was a recognised strength.

“I think that the main strength of our system is now the intense use of electronic notification and feedback….mistakes from human factors and so on are reduced.” Finland

The electronic system automatically extracts all the notifiable findings overnight, which reduces the administrative burden and so facilitates reporting.

“…they don’t have to remember anything; it’s just a matter of ‘enter’ and ‘send’.” Finland

In the Netherlands the Infectious diseases Surveillance Information System (ISIS) is an internet-based system
designed to describe day-to-day changes in the frequency of communicable disease. The speed and accuracy of electronic reporting was yet again noted as a strength of the system.

“I think the main strength of the laboratory system is the speed, we get the data pretty quick and we get the data very complete” Netherlands

ISIS provides an early warning system for public health professionals by collecting mandatory reports of clinician-notifiable diseases and voluntary reports of all laboratory test results (positive and negative) daily in a central database. Notifiable reports are sent by clinicians and laboratories to the Gemeentelijke Geneeskundige Dienst (GGD, the regional health service) by conventional methods (phone, fax and e-mail). Information is then immediately relayed electronically to the Inspectorate of Healthcare (IGZ) and RIVM via OSIRIS (Online System for Internet based Reporting to the Inspectorate and Surveillance centre). In addition, voluntary reports of over 350 pathogens are sent on the same day and directly to RIVM electronically via ISIS. It was reported by the interviewee that information is received voluntarily from 14 participating laboratories; by the end of 2006 it is hoped that an additional 16 laboratories will be recruited, predominantly from the north of the Netherlands with an estimated total population coverage of 10 million. Voluntary reporting coverage is reportedly expected to rise to 35% by the year 2006. Population coverage is higher for some pathogens, for example, surveillance for Salmonella is estimated to cover 64% of the population (Widdowson et al. 2003).

Receipt of reports at the national level at the same time as the regional level was noted to improve the timeliness of surveillance. A further strength was the completeness and content of the available information.

“I think the strength of the notification system is that, since we use an internet-based reporting system, at the national level we identify the report as soon as it enters the regional office. So even if the report is not complete, even if the regional office is finding out new facts about the report, about the notification, we can still view it in the national database which will allow us to identify clusters much sooner. And, in general, the introduction of this internet system increased our detection speed by 8 days.” Netherlands

In the Netherlands, the volume and speed of reporting meningococcal disease, whooping cough and hepatitis A has been demonstrated to improve when the local public health authorities were notified by laboratories as opposed to clinicians (Rietveld et al. 2005). However, although laboratories can rapidly relay confirmed diagnoses, further background information about the patient is often required from the clinician.

Case demographics

Interviewees noted that detecting an outbreak or an association between drinking water and infectious disease can be extremely difficult, especially in the instance of sporadic illness. A common feature of the Nordic countries which offsets them from others is their use of the national identification number. This unique identifier is linked to a number of personal characteristics (including name, nationality, country of birth, and permanent and current place of residence); a record of residences was noted to facilitate the linkage of purportedly sporadic cases of illness. In other countries, personal data in this detail are not easily assembled or accessible but can be requested from different sources if available and necessary. For example, in the Netherlands, RIVM receive a four digit zip code with voluntary laboratory reports; this code represents an area of approximately 50,000 people and mirrors the regional data (with the exception of personally identifiable information, such as name and address).

The importance of collecting detailed demographic patient information was emphasised by some interviewees.

“I think the system would benefit from more detailed information from the laboratory about the background of the patient…I think it is an intrinsic weakness because the laboratory does not get this information from the clinicians at all …” Netherlands

“(If we could) get all the details that we ought to be collecting including the postcode – which I think is
very important in terms of technical analysis afterwards – then I think we’d be much better served and much better able to tackle the issues of outbreak detection.” UK

“The other thing that would be useful would be an ability to access GP data on a national basis in a way which wasn’t breaching confidentiality. Where the data was collected electronically and included the pathogen results …” UK

Receiving the current and permanent address of a patient with the report was said to be more meaningful than receiving the address of the laboratory or the attending clinician. In Germany, it was reported that a patient can visit any clinician which can disperse cases and thus inhibit outbreak detection.

“This means that one GP does not have a picture of the situation around (their) general practice.” Germany

A similar problem was noted in Sweden.

“If it (an outbreak) is in a big city, people will go to different GPs and they (the GPs) won’t realise that it might be a problem…I think this is the real weak point – to really know that something is going on.” Sweden

In England a case will typically visit a clinician which has been assigned to them. Nevertheless, particularly from the national perspective, the address or travel history of the case is still useful for linking sporadic cases of illness and detecting outbreaks.

“The Torbay Cryptosporidium outbreak in 1995 was a local outbreak but there were cases all across the country because it was a holiday resort. So there are things like that that you can see nationally but that you wouldn’t see locally.” UK

“I think we’re quite good at picking up outbreaks but we’re relatively poor at doing endemic or sporadic illness…” UK

“What we can’t see is these sort of sporadic cases that actually are linked but pop up in different parts of Sweden … you will not see it as an outbreak on the spot, but we might see it later in the reporting system.” Sweden

However, specific laws exist to prohibit the linkage of multiple databases at the national level and it was recognised that assembling too much information may infringe upon the privacy of an individual.

“…this law is one part of the package to protect the individual privacy of people in the Netherlands which is a clear obstacle in trying to get most of the data which could be available for public health.” Netherlands

The element of patient contact at consultation provides an opportunity to obtain case demographics and case-specific risk factors such as travel history and animal contact to supplement any laboratory findings. Indeed, in a survey of 17 European countries with surveillance for Campylobacter infections conducted in 2001 (Takkinen et al. 2003), it was identified that demographic information about age and sex was most frequently transmitted to surveillance centres in statutory and sentinel systems (15/16 countries). Travel history was routinely submitted in 9 countries, in 5 countries information about risk factors was gathered, and in just 6 countries information about the suspected source of infection was collected. The purpose of such data collection is to facilitate outbreak detection and underscore environmental issues requiring further investigation by appointed proper officers. It was highlighted that accurate documentation of relevant information from cases is required at the initial consultation from the outset of an outbreak.

“When the GP calls (in an outbreak situation) s/he has seen the patient already and it’s often difficult to get the background information on who s/he has seen…the information is then hard to get.” France (1)

The effectiveness of conventional surveillance can be affected by the speed of information sharing and by the collation of demographic and environmental data but these are issues which also affect syndromic surveillance.
SYNDROMIC SURVEILLANCE

It is apparent that not all of the active communicable disease surveillance institutes monitor enteropathogens associated with drinking water. The World Health Organisation (WHO) Recommended Surveillance Standards (WHO 1999) document suggests that the national surveillance plan compiles a list of priority diseases for surveillance which should be as short as possible. WHO also suggest that specific syndromes are considered for surveillance. Therefore, whilst many waterborne enteropathogens may not be considered a “priority”, the symptoms of these enteropathogens may be encapsulated under adopted syndromic surveillance initiatives. Syndromic surveillance refers to the monitoring of non-traditional data which is often syndrome-related. For the purposes of waterborne enteric disease surveillance, this constitutes individuals displaying symptoms of gastrointestinal illness such as vomiting, diarrhoea, fever and abdominal cramps. It was reported that some countries would like to implement new or enhanced methods of syndromic surveillance.

“Apart from the early outbreak recognition system, we don’t have any systematic clinical surveillance. We will be developing a systematic syndromic surveillance within the next couple of years.” Finland

“Yes, what I would like to change more – I think that we don’t have the slightest idea what’s going on when it comes to sporadic cases and also background figures …” Sweden

“It is hard … to define the burden of disease in a way which would be appropriate for us, or particularly outsiders, to understand the magnitude of the issue now – they just look at the relatively small figures in the statistics. So this type of survey (syndromic) would be quite helpful.” Finland

“I think that we really should try to use other methods … For example, … if more people are calling (the health service) than usual to ask what to do when they have diarrhoea.” Sweden

The possibility of implementing syndromic surveillance during large events was considered; this is an approach which was implemented in France during the 1998 football World Cup (Malfait et al. 1998).

“…I’m certainly not convinced of the added value, but if you have a large event like the World Cup, World Series, or Olympic Games, then clearly syndromic surveillance can be much quicker.” Netherlands

Multiple microbial pathogens can be associated with a single waterborne outbreak (for example, de Jong et al. 1998). Monitoring the volume of faecal samples received at the laboratory may improve the sensitivity of outbreak detection. In the Netherlands, in addition to positive laboratory diagnoses, records are kept of analyses which yield negative results.

“Since we get positive and negative results we could also look at, for example, the number of faecal samples tested or the number of cerebral spinal fluids tested.” Netherlands

Indeed, WHO (1999) recommend that surveillance systems as a whole include zero reporting whereby each site reports for each reporting period even if that means reporting zero cases.

Healthcare consultations

Monitoring the number of consultations with healthcare providers, such as general practitioners and hospital doctors, could address some of the shortcomings of surveillance based upon reports from patient sampling. Mechanisms exist for reporting elevated levels of gastrointestinal illness in the community but interviewees discussed the added value of such an approach.

“In our law, you could report if you have an unusual amount of cases, but it’s seldom reported that way, but the possibility is there.” Sweden

Interviewees reported on studies which have been set up to assess the feasibility of surveillance based upon general practice consultations. In France, approximately 1% of general practitioners report communicable disease via the web as part of a sentinel network called Sentiweb.
Among other diseases, cases of acute diarrhoea are reported to Sentiweb weekly. In Germany, after two days’ absence from work, an individual must retrieve a sick note from the doctor. The reason for absence is reported by the doctor to the health insurer; this data was highlighted as a potentially useful surveillance tool.

“So they have good information, they have good data, and we tried to use it.”  Germany

Data on hospital admissions for gastrointestinal symptoms could be used for retrospective surveillance purposes. However, data collected for use by insurance providers may not always prove informative.

“This (hospital episode data) is not designed for epidemiology at all so the coding is done according to the condition that has required most costs for the patient.”  France (1)

Although not addressed by interviewees, monitoring emergency department (ED) visits has been adopted elsewhere; using ED visits to monitor symptoms (including diarrhoea and vomiting) for rapid outbreak detection has been investigated in New York (Heffernan et al. 2004b) and ambulatory care syndromic surveillance has been set up in Minnesota to monitor influenza-like illness in response to the threat of bioterrorism (Miller et al. 2004). Data collected electronically from emergency services could prove a timely, low-cost surveillance tool in Europe.

**Telephone helplines**

Interviewees discussed the potential for monitoring telephone helplines such as NHS Direct (a UK health advice service) as a method of surveillance.

“So it might give you some feel for the disease burden, but you’ve still got the question of what percentage of people use NHS Direct.”  UK

The use of telephone helpline data has become of increasing significance since the heightened threat of bioterrorism and further research into using NHS Direct as an early warning system has been adopted with this in mind (Baker et al. 2003). In the UK, Cooper et al. (2003) reviewed over 150,000 NHS Direct calls over a period of 6 months; further NHS care was recommended in just over half of all gastrointestinal (GI) illness calls. If only half of all GI callers seek further care, disease burden could be underestimated if solely reliant on the more conventional means of laboratory- and clinician-report-based surveillance.

The feasibility of using telephone helpline data has been examined by researchers elsewhere. Data from nurse hotlines in Milwaukee, Wisconsin, demonstrated over a 17-fold increase in calls for diarrhoea over the period of the infamous 1993 Milwaukee cryptosporidiosis outbreak (Rodman et al. 1998). The authors concluded that this data resource may prove an inexpensive and timely method of surveillance.

**Anti-diarrhoeal drugs surveillance**

Over recent years, monitoring of anti-diarrhoeal drugs data (Sacks et al. 1986; Beaudeau et al. 1999; Edge et al. 2004) has emerged as a means of conducting syndromic surveillance. The number of anti-diarrhoeal drugs either sold over-the-counter from the pharmacy or prescribed by clinicians can be monitored; a rise in sales or prescriptions being indicative of an outbreak. The usefulness and practicalities of using these data were discussed.

“It definitely has an added value… I think to generate hypotheses, which is generally the purpose of surveillance, I think it is excellent.”  Netherlands

“It has potential but like all surveillance systems it needs to be set up and you need to decide what information you are collecting…the diarrhoeal agents are one, but there could be a variety of other conditions where it might be useful to monitor particular drug sales.”  UK

“The drug data, if it was relatively complete, might be quite useful …but again there’s probably some surveillance problems with it as well because not everyone will take drugs for diarrhoea.”  UK
Using pharmaceutical prescriptions data for the purposes of surveillance is already being explored in some countries. In France, a proportion of treatment costs are reimbursed through the social security system and the remainder is paid for either by the patient or through their private health insurance. It was recounts that 11 study sites in France are looking at the feasibility of monitoring data on reimbursed prescriptions as a means of surveillance. Data is also available for water quality incidents including fire brigade exercises which can lead to pressure loss. It is hoped that these data will be integrated and this method of surveillance will be adopted permanently across the whole of France. It was recounts that cases may be more likely to consult for diarrhoeal illness and to obtain a prescription in France than in other countries, which makes pharmaceuticals surveillance a more sensitive tool.

“I think when you go and consult a doctor in France for diarrhoea, I think that the large, large majority will come out with a prescription.” France (1)

“...oral rehydration salts are reimbursed, before they were over the counter and very expensive and so they were not prescribed, but luckily now they are reimbursed so they are also on prescription.” France (1)

The effectiveness of prescriptions surveillance very much depends upon the infrastructure of the existing healthcare system. Differences between countries in the method of reimbursement and data collection mean that pharmaceutical prescription surveillance may not be feasible in some countries.

“In Finland, because of this unique identifier, it would be in principal quite possible but the most inexpensive drugs which go below a certain threshold – which I now think is 10 euro or 15 euro of own expense – are not registered in the electronic reimbursement systems. So it remains local information in such a format that it would be more complicated to try and get it.” Finland

In England, although low income groups have prescription costs reimbursed, the remainder will prefer to purchase over-the-counter anti-diarrhoeal agents as it is often cheaper than the fixed prescription cost. The merits of using over-the-counter sales as a means of surveillance were discussed.

“I think that nobody has such drugs at home waiting for the case, so it is something which you buy in an acute case and this makes the method quite sensitive.” Germany

Experience from previous outbreaks of waterborne disease demonstrates that this method of surveillance could prove informative.

“A waterborne outbreak can be detected in a lot of different ways. I think the most unusual way was in a ski resort in Sweden where the person at the pharmacy... said “there is something wrong in this area because this is the end of February and I have sold more anti-diarrhoeal drugs than I normally sell in the whole year”.” Sweden

One interviewee also noted the potential for using distribution data from pharmaceutical companies.

“...the pharmacologic industry has very good data on what they sell where.” Germany

However, it is worth noting that volume of over-the-counter sales can be affected by a number of factors. Where retail pharmacy sales surveillance has been set up in New York, season, holidays, day of the week, promotional sales, positive influenza tests and temperature are controlled for (Heffernan et al. 2004a).

Absenteeism

In Germany, health insurance data was noted by the interviewee as a possible means of collecting information on individuals who cannot work due to illness. In New York the Department of Health and Mental Hygiene assess worker absenteeism for unusual patterns of illness through analysis of data from a single employer (Heffernan et al. 2004a). Records of school absenteeism were noted to have been used in the investigation of an outbreak.

“...and this was the basis for uncovering the outbreak, it was really a very useful, helpful information source.” Germany
High school and parental absenteeism data has also proved useful in uncovering waterborne disease outbreaks in Sweden (McCarthy et al. 1998).

WATER QUALITY AND CONSUMER COMPLAINTS

Clinical, laboratory and pharmaceutical surveillance can involve significant time delay as they ensue the emergence of cases in the community. In contrast, water quality results, water quality incidents and consumer complaints about the water supply provide timely and somewhat prospective information which is not reliant upon patient attendance and pharmaceutical prescribing and purchasing behaviour.

Water quality incidents

Notification to appropriate public health officials of water quality incidents, such as poor water quality results, pipeline maintenance and treatment deficiencies, can prompt enhanced surveillance for illness in the community. The analysis of routine or periodic final water samples may find water unfit for human consumption leading to the adoption of suitable control measures to limit or prevent cases of illness.

“If there are bad water quality results from a local drinking water producer, those would be informed locally to the local CCDC and the public health team and they would then take action if it was required.” UK

“There was in fact one outbreak … where they had a positive water quality test for Cryptosporidium before the outbreak. In that case, the OCT had to make decisions about what they should do with this before the start of the outbreak.” UK

It is important to understand the dynamic nature of the water supply and therefore collaboration with the local water company is essential.

“It’s often difficult to understand that the water supply movement can change from hour to hour and day to day in addition to changes over a longer period…So it’s that close working between that outbreak or incident control team and the water company that provides that best outcome.” UK

In France, in addition to the public health practitioner, there is also a public health engineer (PHE) who is employed by the Department of Environmental Health. There is often good communication between these two and the PHE is able to quickly retrieve information about the water supply received by cases. In Finland, the Department of Environmental Health is based at KTL which can facilitate collaboration and investigation following suspicions of a waterborne outbreak. However, one interviewee noted that it is rare to be notified of any pipeline repair; such repairs may have led to cases of illness in the community.

“…it may be occasional, but most of the time we will never see this problem when there have been reparation on the pipelines—and you might get sick people.” Sweden

Consumer complaints

Interviewees noted that consumer complaints about the colour, taste or odour of drinking water can help to identify outbreaks and facilitate epidemiological investigations. Interviewees expressed a need for information of this kind to be shared more readily.

“… if we had this information we would have a better idea of where the problems really are.” Germany

“In every outbreak we notice that there are complaints very specific to faecal problems. We get complaints that water smells, peaks of turbidity, but not the same complaints. And we hope that the mayor will report this kind of problem because it’s a more reactive signal. We can prevent the epidemic if we can act very soon.” France (2)

“…in many of these outbreaks in fact there were other complaints which had preceded these cases like bad smells and complaints to the mayor and the mayor often
considers that these complaints are not important.” *France (1)*

“There is a national service number which can be called by anyone in the public, or even a medical professional, with suspicions or complaints about food, food preparation premises, water, contact with water and health effects.” *Netherlands*

An interviewee noted that in Sweden consumer complaints to the environmental health protection board or to the technical department was one of the principal methods of outbreak detection.

“I think people more often call and tell the environmental health protection board or the technical department that there is something wrong.” *Sweden*

**COMMUNICATION**

Across each theme, all interviewees stressed the importance of effective communication between external data providers (such as environmental departments, water companies and schools), local staff, and national surveillance institutes; data from additional external organisations, data integration and information exchange constitute topics further discussed here.

**Collaboration with external data providers**

The Swedish National Food Administration (NFA) is an autonomous government agency whose responsibilities cover drinking water. It was reported that the NFA check newspapers for boiling water advisories and match this data to reports of illness in the community. Along with County Medical Officers and Environmental Health Officers, the NFA was mentioned as a regular contact for surveillance purposes.

“I think that’s a good thing with a small country, we talk a lot with each other.” *Sweden*

One of the main strengths of the Swedish system was reported to be the communication with environmental health officers and the establishment of personal contacts.

“I actually think it’s the personal contacts.” *Sweden*

A desire to collaborate with and integrate data from food safety laboratories and veterinary organisations was noted.

“Another thing I would like to enhance is to integrate human surveillance with, for example, food safety records. There is a widened network of food safety laboratories in the Netherlands and they also test food triggered by complaints from consumers or reports of outbreaks from GPs.” *Netherlands*

“There is already a very extensive veterinary surveillance on several zoonoses, like *Salmonella* and *Brucellosis* and *Campylobacter*, and already at the national level these information streams are compared to each other so probably I would like to try to integrate them a bit more.” *Netherlands*

Interestingly, information about travel destinations from national airline data was highlighted as a data source of potential relevance for establishing malaria risk. In recognition that travel-associated infections are often difficult to detect, major British tour operators have created a surveillance system for travellers’ diarrhoea (*Cartwright 2003*). Some interviewees believed that collaboration with international partners is useful for detecting outbreaks among travellers. Such collaboration has been demonstrated during an outbreak of Vero cytotoxin-producing *Eschericia coli* O157 (VTEC) amongst holidaymakers returning from Fuerteventura, Canary Islands, in March 1997 (*Pebody et al. 1999*). Given our increased population mobility, this stream of travel information and international collaboration may prove ever more significant in the future.

In order to establish a link with the true source of contamination, knowledge about an individual may need to be compiled from multiple data sources. The unique national identification code available in Finland was recognised as a useful tool for assembling data from different sources.

“So the unique personal identifier is the key to be easily able to assemble all the information from different sources.” *Finland*
Geographic Information Systems (GIS) combine relational databases with spatial interpretation allowing users to analyse, manipulate and manage geographic data. Examples of the application of GIS to surveillance have been demonstrated in Europe (Boulos 2004; Rolfhamre et al. 2004). A wish to integrate GIS into the surveillance system was noted by an interviewee.

“And of course as we are working very much with GIS, I would very much appreciate if GIS, a system to make information more transparent, would be integrated into the surveillance as a whole.” Germany

As mentioned previously, when compiling data from different sources and at small geographical or individual case level, it was remarked by interviewees that prevailing laws on data protection should be fully acknowledged and abided by.

**Collaboration with local staff**

Communication between national institutes and local staff was also identified as an essential part of effective surveillance practice.

“And this interaction actually is the basis for our surveillance system, because without their (the laboratories) suggestions and guidance it would be impossible to interpret most of the data.” Netherlands

In terms of outbreak detection, direct communication with the laboratories was noted to be timelier than waiting for collation and analysis of laboratory results at the national institute.

“.. normally we will know about what’s happening with outbreaks long before what we can see from the reporting system.” Sweden

Interviewees also discussed the importance of provision of advice by and feedback from data collators to information providers. In Sweden the County Medical Officer (CMO) is responsible for cases and the Environmental Health Protection Board is responsible for environmental issues, so in an outbreak situation they work together.

The scarcity of outbreaks in local communities can mean that local health practitioners and environmental staff do not have adequate first hand experience to enable them to conduct a thorough investigation.

“The MO (medical officer)… they are not used to this type of outbreak so they normally call directly. And some of the Environmental Health Protection Boards are rather small in Sweden and they might have one waterborne outbreak in the lifetime.” Sweden

“And on the downside, what the health protection teams don’t seem to have is good practical experience of investigating the outbreaks. Because outbreaks occur sporadically across the country, an individual may not necessarily get much experience of investigating an outbreak and processing and analysing the results – so I think that is an area where we could improve.” UK

To address this issue, in an outbreak situation SMI can be called upon by health and environmental practitioners for consultation and advice. Other national institutes or larger, regional offices also offer this service.

“Here, the arrangements are so that the proper authority… is the primary health care centre. Which in a way is a problem because many of them are small units and don’t have enough expertise so need quite a lot of consultation and support.” Finland

“…KTL…are in a consultative position and advise quite a lot in outbreaks…because we get the information very quickly…” Finland

As local experience is variable, it was recognised that standardised guidelines and an appropriate advisory body should be available and transparent to local staff.

“…this is one of the… weaknesses of our system… There is a huge amount of informal contact.” Germany

“The local investigations are really very much down to how well the local public health team operates and that
is variable … We’re trying to produce protocols for doing that, and hopefully, within the next year or two, we should have a degree of better co-ordination...” UK

 Provision of feedback was highlighted by interviewees as a further means of promoting communication, exchanging information and expanding networks. For example, in the Netherlands national data collected from ISIS is updated daily and is available via the internet to the general public in aggregated format; specific surveillance reports are provided on confidential internet pages and alerts are sent via e-mail to specified recipients. Pollock (2003, p 20) suggests that feedback of surveillance data to information providers is necessary for motivational purposes. Interviewees also considered feedback to be an important component of the surveillance system which acted as a reporting incentive to healthcare professionals.

“I think it would be motivation for the doctors to do more for the system, if they would receive information …in filtered form, on what is going on in their area.” Germany

“The communication is very unidirectional and it should be more bidirectional.” Germany

Although interviewees did not address feedback to external information providers, feedback could similarly encourage reporting and facilitate co-operation between organisations.

CONCLUSIONS

In this study interviewees highlighted some of the strengths and weaknesses of national surveillance systems which may impact upon the effectiveness of outbreak detection and the representativeness of national surveillance data. Interviewees also suggested a number of improvements and potential avenues for further research.

Increased use of advancing technological processes has enabled more astute surveillance. Where operational, electronic reporting, reminders from the laboratory to the healthcare professional to report notifiable findings and directrelay of notifications to the national functional level, were highlighted as strengths of report-based surveillance. These methods were noted to improve data quality, timeliness, simplicity and acceptability – some of the desirable attributes of a credible surveillance system (CDC 2001).

Laboratory sampling and analysis were noted to vary both between and within countries with interviewees noting infrequent parasitological analysis in particular. Variation in statutory reporting practice and population coverage for certain enteropathogens was also noted between countries; likely because not all countries list each waterborne enteropathogen as a “priority” disease for surveillance. Such variation was said to adversely affect the timeliness and representativeness of waterborne enteropathogen surveillance. Furthermore, some interviewees felt that supplementing laboratory results with additional information on the background of the patient would be beneficial for the investigation of waterborne disease, especially for linking sporadic cases of illness.

For countries with supporting infrastructure, there is potential for use of data from records of absenteeism, health insurance, telephone helplines, zero reporting and anti-diarrhoeal drug prescriptions and sales for local, cost-effective and timely syndromic surveillance.

Close and frequent communication within the healthcare sector was thought to aid the surveillance of waterborne disease and facilitate outbreak detection. It was suggested that national institutes providing feedback to reporters would encourage bi-directional information flow and reporting. Adequate and accessible advice provided by national institutes in an approachable manner was deemed beneficial in the investigation of outbreaks, particularly where local staff lacked relevant experience. Relaying information about poor water quality results, water quality incidents and complaints from consumers to relevant public health officials was highlighted as an important component of surveillance. Establishing and maintaining links with organisations outside of the water industry and healthcare sector was also noted to be of value. Integrating information from a number of sources is likely to produce the most accurate depiction of waterborne disease incidence and improve outbreak detection.

This exercise sought to explore experience of waterborne disease surveillance across Europe. Practical experiences vary by discipline and functional level; however,
generic principles may be applied to improve surveillance systems. Based on the findings of this exercise, the following recommendations are suggested:

- There is a need to standardise laboratory diagnostic and sampling protocols for the investigation of illnesses of public health importance across Europe.
- Electronic transmission of surveillance data should become the norm across Europe.
- Infectious disease surveillance systems should include the postcode or other geographical locator data which can then be linked to Geographical Information Systems with water zone boundaries.
- For any surveillance system to work it is important that people providing data are given feedback about the results of surveillance.
- Good working relationships and communication are essential between the surveillance managers, local health workers and water utility staff.
- The benefits of syndromic surveillance need to be further researched and evaluated on a country-specific basis.
- Research is needed into ways that consumer complaints and water quality data can be incorporated into infectious disease surveillance systems.

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