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Sensitivity of the Swedish statutory surveillance system for communicable diseases 1998–2002, assessed by the capture–recapture method

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SUMMARY

To assess the sensitivity of the Swedish surveillance system, four notifiable communicable diseases in Sweden were examined during 1998–2002 with the two-sources capture–recapture method, based on parallel clinical and laboratory notifications. The sensitivity (proportion of diagnosed diseases actually being notified) was highest for salmonellosis (99·9%), followed by meningococcal infection (98·7%), and tularaemia (98·5%). For penicillin-resistant pneumococci, introduced as a notifiable disease in 1996, the overall sensitivity was 93·4% – increasing from 86·5% in 1998 to 98·5% in 2002. The system benefited from parallel reporting, with a sensitivity of clinical and laboratory notifications alone (all diseases combined) of 91·6% and 95·9% respectively. The sensitivity of both clinical and laboratory notifications was markedly higher in counties using the national electronic reporting system, SmiNet. Thus, sensitivity was higher for diseases with a long tradition of reporting, and there is a run-in period after a new disease becomes notifiable.

INTRODUCTION

A surveillance system is an ongoing, systematic collection of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health [1, 2]. The core of surveillance is a functional capacity to collect, analyse and disseminate data. The surveillance of communicable diseases is essentially outcome oriented with the main task early detection of outbreaks [3]. Surveillance is increasingly utilized for further immediate health actions such as: (1) measuring the burden of disease and the monitoring of long-term trends (baseline data); (2) defining preventive public health priorities and measures; (3) guiding the planning, implementation, and evaluation of health programmes and interventions; and (4) providing a basis for epidemiological research [2, 4].

Evaluations of surveillance systems should be conducted regularly in order to make sure that the system meets its objectives as effectively as possible, to increase the system's utility and efficiency, and to provide recommendations for the future [1, 5]. A complete evaluation should comprise an assessment of the system's performance and of all its attributes.

Communicable disease surveillance is one of the main responsibilities for the Swedish Institute for Infectious Disease Control (SMI). The surveillance is based upon the statutory reporting of certain communicable diseases according to the Communicable Disease Act. Currently, there are 58 diseases in the Swedish mandatory notification system (54 before 1 July 2004). All diseases, with the exception of HIV

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infection and other sexually transmitted infections (STIs), should be notified with full patient identity within 24 h following diagnosis (no personal identification and reporting within 7 days for HIV/STI). All patients diagnosed with a notifiable disease are simultaneously reported to the SMI and to the county medical officers, both by the clinician and the laboratory.

A computerized reporting system, SmiNet, was introduced in 1997. Prior to that, reporting was entirely based on paper. The main objectives of SmiNet were to simplify, consolidate and enhance the accuracy of the reporting process and the collection of data. At the inception of this study 16 out of 21 counties were connected to the SmiNet system.

On 1 July 2004, an upgraded internet-based version of SmiNet was introduced, and a new communicable disease act came into force. This study, part of the preparations for the transition to the new system, was aimed at evaluating the sensitivity of the Swedish system for statutory surveillance of communicable diseases and to form the basis for future comparisons.

METHODS

Diseases under study

The study was carried out retrospectively with data from 1998 to 2002. All data were collected from EpiArk, an SQL database that since 1997 stores all national data collected from statutory surveillance.

Four diseases with different characteristics were selected to represent different facets of the disease surveillance: (1) demands of urgency *vs*. monitoring of trends; (2) well-known *vs*. newly introduced diseases in the system; and (3) different modes of transmission. Thus, invasive meningococcal infection, salmonellosis, infection due to penicillin-resistant *Streptococcus pneumoniae* (PRP), and tularaemia were selected. Salmonellosis and PRP require laboratory verification for diagnosis, while meningococcal infection and tularaemia may be notified on the basis of clinical and epidemiological features alone. Criteria for notification have been issued by the SMI (available in Swedish from the corresponding author on request).

The capture–recapture method

The capture–recapture method was used for estimating the sensitivity of the surveillance system to detect all diagnosed cases. The sensitivity was defined as the number of notified cases divided by the total number of cases as estimated by the capture–recapture method. This method has its heritage in ecology and wildlife research, as a means of estimating the size of wildlife populations. Within the field of epidemiology, the method has mainly been used for estimation of case populations, by analysing the degree of overlap between incomplete lists of cases from available data sources, and is increasingly used for evaluating the sensitivity of surveillance sources [6, 7].

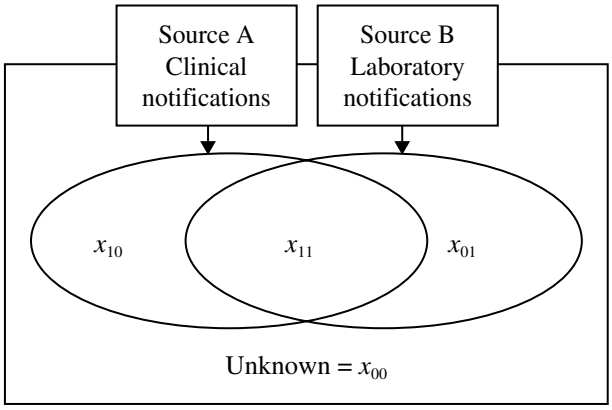

Fig. 1. Schematic description of the distribution of the total number of cases in the capture–recapture model. The cases caught within the circles are notified according to the statutory surveillance, either clinically only, laboratory only, or both, while the cases outside the circles represent the detected cases that never were notified.

In brief, the cases are 'captured' by one data source and are 'recaptured' if they appear in a second data source. Based upon the Swedish statutory surveillance system, the method is schematically illustrated in Figure 1, with clinical notifications defined as source A (the first capture, x_{10}), and laboratory notifications defined as source B (the second capture, x_{01}). The cases captured in the first attempt and then recaptured in the second attempt are the cases reported from both sources (captured twice, x_{11}). The 'uncaptured' cases refer to the unknown number of detected cases that were never reported ($\hat{x}_{00}$). For the calculations we used the formula:

$$\hat{x}_{00} = \frac{x_{10} * x_{01}}{x_{11}}.$$

RESULTS

Of the four diseases salmonellosis was the most common, accounting for more than 80% of the cases (Table 1).

Table 1. *Number of notifications and total number of cases as estimated by the capture–recapture method for each studied disease, 1998–2002*

Disease	Clinical notifications	Laboratory notifications	Overall notified cases	Estimated total cases
Meningococcal infection	287	269	311	315
Salmonellosis	22 236	22 739	23 185	23 202
PRP*	2187	3051	3410	3696
Tularaemia	817	646	855	890
Total	25 527	26 705	27 761	28 103

* Infection due to penicillin-resistant pneumococci.

Table 2. *The estimated sensitivity of each source separately and the overall estimated sensitivity of the surveillance system, combining clinical and laboratory reporting*

Disease	Sensitivity of clinical reporting (%)	Sensitivity of laboratory reporting (%)	Overall sensitivity (%)
Meningococcal infection			
1998	95·0	90·5	99·5
1999	86·0	87·5	98·2
2000	85·1	76·9	96·6
2001	92·4	87·1	99·0
2002	97·4	82·6	99·6
Total	91·1	85·4	98·7
Salmonellosis			
1998	95·2	98·1	99·9
1999	95·8	98·5	99·9
2000	95·5	99·1	100·0
2001	95·9	99·3	100·0
2002	96·8	94·4	99·8
Total	95·8	98·0	99·9
PRP*			
1998	50·4	72·9	86·5
1999	53·2	80·0	90·6
2000	58·1	84·1	93·4
2001	65·9	89·5	96·4
2002	77·4	93·2	98·5
Total	59·9	83·6	93·4
Tularaemia			
1998	75·5	37·0	84·6
1999	80·9	51·4	90·7
2000	97·2	84·3	99·6
2001	89·5	68·0	96·6
2002	97·8	83·4	99·6
Total	94·1	74·4	98·5

* Infection due to penicillin-resistant pneumococci.

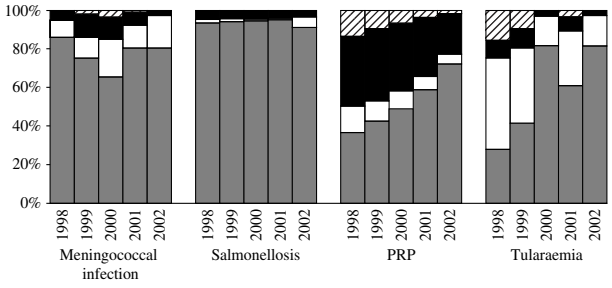

Fig. 2. Estimated sensitivity of the surveillance system for each disease and year, using the capture–recapture method. ▩, Clinical and laboratory notifications; □, clinical notifications only; ■, laboratory notifications only; ▨, not reported.

Salmonellosis had the overall highest level of sensitivity with 99·9% of all diagnosed cases being notified, followed by meningococcal infection (98·7%), tularaemia (98·5%), and PRP (93·4%) (Table 2, Fig. 2). In the estimated proportion of cases that never were reported (1 minus all notified cases), there were some differences, both between diseases and over time, with an apparent improving trend in PRP reporting, from 86·5% in 1998 to 98·5% in 2002 (Fig. 2), and a slightly greater improvement for tularaemia (84·6% in 1998 to 99·6% in 2002). There were only small variations in meningococcal reporting, whilst salmonellosis reporting was consistently high over the entire study period.

An estimation of the sensitivity for each source separately gives an indication of the level of completeness if the reporting was derived from one source only, instead of the present system of parallel reporting (Table 2). The sensitivity of clinical notifications was poorest for PRP, with a total just below 60%, while the other diseases had a total above 90%. For

Table 3. *Number and percent of notifications for each source* (*clinical and laboratory*) *and sensitivity of the surveillance sources in counties connected and not connected the national electronic surveillance system SmiNet* (*data from 1998–2002*)

	SmiNet-connected counties ($n=14672$)*	Not SmiNet-connected counties ($n=13192$)*
Clinical and laboratory notification	13 270 (90·4 %)	11 201 (84·9 %)
Clinical notification only	334 (2·3 %)	722 (5·5 %)
Laboratory notification only	1042 (7·1 %)	1192 (9·0 %)
Neither clinical nor laboratory notification†	26 (0·2 %)	77 (0·6 %)
Sensitivity of clinical notifications	92·7 %	90·4 %
Sensitivity of laboratory notifications	97·5 %	93·9 %

* Counties connected during the study period have contributed to respective groups by year of study.
† Estimated from the capture–recapture method with 95 % confidence intervals.

laboratory notifications, tularaemia reporting was poorest with 74 % in total, and with just 37 % in 1998. Salmonellosis reporting was highest (98 %), with meningococcal infection and PRP around 85 %.

We evaluated differences in sensitivity of the clinical and laboratory notifications between counties both connected and not connected to the national electronic surveillance system, SmiNet (Table 3). Overall, sensitivity of the reporting system was higher in counties connected to SmiNet. This was most pronounced for laboratory reporting, where more than twice as many cases in non-SmiNet counties lacked laboratory notification, compared to counties connected to SmiNet.

DISCUSSION

To ensure that a surveillance system is performing efficiently, evaluation should be made regularly [8]. In this study we focused on the sensitivity of the statutory surveillance in Sweden to identify patients diagnosed with notifiable infections. In another recent study, we analysed the timeliness in the reporting system using the same four diseases as a model [9]. As a new communicable disease act came into force on 1 July 2004, accompanied by an upgraded, internet-based version of SmiNet, these assessments were timely, and will form the basis for future comparisons.

The sensitivity of a surveillance system can be evaluated on two levels, by the proportion of cases with a disease detected, or by its ability to detect outbreaks [5, 7]. The sensitivity is dependent upon several events in the process, and an evaluation may, therefore, comprise both a case detection/diagnosis component, and a case-reporting component. The detection/diagnosis component is related to the proportion of those with a symptomatic infection who actually seek treatment, agree to be sampled, and are correctly diagnosed [10]. This early stage of the surveillance was not addressed in this study. The focus was instead on the later phase – the reporting process, which refers to the proportion of those diagnosed with a notifiable disease that is reported (i.e. completeness of case reporting).

Questions regarding sensitivity in surveillance systems are usually raised when changes in the disease pattern occur [5]. However, if reporting is representative of the target population and consistent over time, it may not need to be complete in order to successfully monitor demographic, spatial and temporal trends [10]. Nevertheless, it has also been shown that under-reporting may adversely affect public health efforts by distorting trends observed in the incidence of disease, preventing accurate assessment of potential benefits or impact of control programmes, and preventing timely identification of disease outbreaks [11]. Furthermore, a high sensitivity is essential for surveillance of uncommonly occurring diseases, for accurately estimating the disease incidence, and for making correct national or international comparisons.

A number of evaluations from various countries have examined the sensitivity of case reporting in surveillance systems. In a review by Doyle et al., 33 assessments of completeness of case reporting were examined, all conducted in the United States between 1970 and 1999. The reporting completeness varied from 9 % to 99 %, and was strongly associated with the disease reported [10]. The sensitivity was significantly higher for HIV/AIDS, tuberculosis and STIs than for other notifiable diseases. The geographical

location seemed to be of less importance and no temporal trends were found [10]. In a study from Hawaii, Effler et al. compared electronic laboratory reporting with the traditional paper-based system, where a 2·3-fold increase in case reporting was found when reporting electronically [12]. A number of evaluations have been carried out in Europe as well, mostly employing the capture–recapture method. Reintjes et al. assessed the sensitivity of STI surveillance in The Netherlands, and found that it varied from 34% to 76% depending on the disease [7]. Another assessment was conducted in England by Devine et al. [13], where the completeness of whooping cough notifications was estimated to be as low as 36%.

Ideally, one would assess the sensitivity by comparing it with a 'gold standard' of disease incidence [7]. Since this is mostly impossible, principally two different methods have been utilized to measure completeness: (1) by dividing the number of cases reported to public health authorities by the total number of cases identified through active case detection and the use of supplementary data sources; or (2) by dividing the number of cases reported to public health authorities by the total number of cases estimated through the use of capture–recapture methods for comparing two or more data sources. The first method, unlike the second, does not account for the number of cases left undetected by all data sources [10].

Because of the Swedish system of parallel reporting with full patient identity, it was possible to use the capture–recapture method in this study. The two-source approach was applied, using clinical notifications as source A and laboratory reports as source B.

There are several key assumptions underlying the capture–recapture method, and to use the method appropriately the following criteria are required: (1) there should be two or more sources (lists) of cases of a given disease; (2) the reports from the two sources should be made independently; (3) individuals identified in one source should be perfectly matched to another source without error; (4) all cases should have equal probability of selection in a source; (5) the same study area and period should be used, and the population under study should be closed [6, 7]. Bias will occur if any of these assumptions are invalid [14].

One of the key assumptions is the independence of sources, i.e. once a case is detected and diagnosed, the clinical and laboratory notifications should be made independently from one another. It has been argued that the issue of independence is often violated in practice [15]. In the Swedish setting, laboratories and clinicians notify independently of each other. The clinical notification is of course entirely, or almost entirely (depending on disease), based on a laboratory diagnosis, but once the laboratory finding is communicated to the clinicians, the decisions and processes leading to notifications from the respective parties are probably entirely independent. Contacts could be frequent between laboratories and clinicians, but such contacts would cover matters of importance to the investigation of the patient – and not issues concerning notification. Failure to notify could be due to systematic errors or negligence, but either way failure of one party to notify would not be recognized by the other party and affect that party's inclination to notify. Therefore, we consider that independence prevailed between the sources. However, in contrast to the multi-sources where it can be done mathematically, the only way to evaluate a true independence between the sources in the two-source model is by conducting a qualitative analysis.

Concerning the remaining assumptions, it is believed that all notifications of salmonellosis and PRP were equally capturable, the data collection took place in the same area during the same period of time, and there was a perfect matching of notifications from the two sources. For tularaemia, where a laboratory diagnosis is not necessary, this is not the case, and the results may have overestimated the sensitivity of the system to capture this disease. Since single cases of meningococcal infection with a rapidly fatal course may also be notified on clinical grounds only (in our experience a rare event), the assumption of equal capturability is not fully met for this disease. This could have resulted in some overestimation of the sensitivity of the system to capture these two diseases.

The multiple approach of the capture–recapture method is more flexible than the two-source method, as it allows consideration of variables that may influence reporting, and can identify reporting patterns for the different sources [6]. Only having access to two data sources, there is an alternative approach to the analysis based on the stratification of capture–recapture data by a third variable, e.g. county or age. For each stratum the estimate of the actual number of cases, and of the degree of completeness for both systems, is derived using the same formulae. A correlation coefficient between the completeness of reporting of both sources, weighted by the number of cases estimated in each stratum, is then calculated [16]. Due to the very high degree of concordance between the

results from two sources, we abstained from this more complex approach.

Although the capture–recapture method can account for false-negatives, there is a possibility of false-positives that are not identified [6]. False-negative matches would underestimate the sensitivity of the reporting system, whereas false-positives would increase the estimates [10]. Consequently, the method relies on standardized case definitions with high sensitivity and specificity.

Since laboratory verification is required for making a clinical diagnosis of salmonellosis and PRP, these two diseases appeared to be best suited for the capture–recapture method. Meningococcal infection could also be regarded as an appropriate disease for the use of this method, given that specimens are almost always obtained and sent to the laboratory, even though a clinical diagnosis can be based on symptoms and signs only.

Diagnoses of tularaemia, on the other hand, may be based on clinical features only, especially in acute outbreaks. This implies that clinical notifications only are sufficient, while a laboratory notification is not always required. However, the sensitivity of tularaemia reporting in this study had its peaks during the two years with the highest incidences (2000 and 2002). This could be due to clinicians and laboratories being more alert and inclined to report during outbreaks. The sensitivity of clinical reporting was overall higher than laboratory reporting for tularaemia. Of particular note was the low reported completeness of 37% for laboratory reporting during 1998. It was later discovered that the laboratory responsible for most of the diagnoses that year was not aware of mandatory reporting. After a reminder, the sensitivity improved, reaching 93·4% (clinical 94·1%, laboratory 74·4%).

The reporting of salmonellosis was consistently high during the entire study period, overall 99·9% (clinical 95·8%, laboratory 98·9%), implying that a 'classic', well-known notifiable disease is better reported. This also applied to invasive meningococcal infection, but the sensitivity for this disease was slightly lower than for salmonellosis, mainly due to poorer laboratory reporting. We cannot rule out that some, or all, of the entire discrepancy was due to clinical diagnoses without laboratory confirmation.

PRP became a notifiable disease in 1996, which could explain the poor sensitivity in 1998, and the subsequent improving trend for each year. This demonstrates that there is a run-in period for a new notifiable disease, especially when it comes to clinical notifications where thousands of clinicians, rather than some 30 laboratories, need to be aware of the new mandatory notification requirement.

Lastly, we investigated if participation in the national electronic surveillance system, SmiNet, improved notification completeness. Both for laboratory notifications and clinical notifications, SmiNet connection was associated with a higher reporting completeness. The differences in laboratory notifications could probably be explained by a better performance in SmiNet counties due to automatic reporting from laboratory computer systems directly to the SmiNet system. The differences in the completeness of clinical notifications may be explained by an informal information exchange between clinicians and county medical officers, in which the formal notification routes were bypassed. Thus, local public health officials knew about these cases, but this information never reached the national level.

Due to small numbers, the capture–recapture method was not applied in the assessment of geographical variations. However, the investigation of reporting sources could provide some information about the completeness of reporting in each county. Reporting of salmonellosis was good throughout the country, while there were more variations in PRP reporting. There were also variations in meningococcal and tularaemia reporting, but the small number of cases made assessment difficult.

It seems clear from this study that the Swedish surveillance system has greatly benefited from parallel reporting, with a markedly lower sensitivity from each of the two reporting sources separately, than from the two combined. Even though the figures reported were at a higher level than most previous studies (above 90% for each of the four diseases), the quality of reporting can still be further improved. This issue has been the focus of Allen & Ferson in New Zealand, who examined barriers to effective notification by general practitioners (GPs) [17]. They suggested that there is a need for ongoing education of GPs, emphasizing diseases to be notified. Further, studies were also recommended in order to explore the best means for GPs to become an integral part of a public health management system. Lack of regular feedback has been identified as one reason for low motivation. Simmons et al. have suggested that feedback of preventative actions resulting from reporting is the most effective way to improve the notification procedure [18].

Four notifiable diseases were investigated, based on their different characteristics. The differences in

reporting completeness between these diseases imply that the selection was relevant, and also suggest that diseases should be evaluated separately. It would also have been of interest to include a STI, especially *Chlamydia* infection, which is by far the most commonly notified disease in Sweden. However, since notification of STI is done without any personal identification it was not possible to perform the two-source capture–recapture method on these diseases.

In conclusion, this study has shown that Sweden has a highly sensitive reporting system, further improved by the double reporting of clinicians and laboratories using electronic reporting systems. The sensitivity in the system is higher for serious diseases with a long tradition of reporting, and there is a run-in period of lower reporting after a new disease has become notifiable. When changes are made in the list of notifiable diseases, specific measures to alert physicians are therefore needed.

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