EUROPEAN CENTRE FOR DISEASE PREVENTION AND CONTROL

Framework for a strategy for infectious disease surveillance in Europe

(2006–2008)

Document for the Management Board

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Introduction

With the new European Centre for Prevention and Disease Control (ECDC), Europe takes another step towards accomplishing a more comprehensive European-level surveillance of communicable disease. Good surveillance data are the cornerstone for public health action and planning, as well as for policy making. Europe is facing new challenges. With increasing globalization and interconnecting in the world and with free movement of people and goods across the borders, diseases move fast around the globe and disease outbreaks are increasingly often multi-national. Disease trends in one country are often mimicked by similar developments in adjacent countries. Cross-national regions are becoming epicentres, not only for trade but also for communicable diseases.

Surveillance is getting a bird's view on events and trends. With these fascinating developments in the world and in Europe it is important that the surveillance systems are constantly upgraded to have the capacity of collecting as much comparable data from many countries, to be analysed in a timely and efficient way, to provide an added value to the European public health community and policy makers. At the same time efficient surveillance systems should have public health action linked to them to ensure that Europe contributes to meet the challenges of global health.

The task to further develop an effective European-level surveillance system together with the Member States (MS) is not an easy one. Each of the 25 MS, has its own system and its own experiences that needs to be taken into account, and with different surveillance systems the data are often not comparable. Other challenges to surveillance that lie ahead include 1) difficulties in recruiting microbiologists in some countries and lack of succession planning; 2) the privatisation agenda in others; and 3) the particular pressures placed on the smaller countries in participating in all the European surveillance activities.

At the same time, it is an enormous strength and advantage to have the experience from so many countries to build on. By using the best practices in the MS, and the knowledge gained in the present Surveillance Networks, Europe has a unique chance to become strongest in the world when it comes to effective disease surveillance – to analyse disease trends, to rapidly identify outbreaks, to spot emerging and re-emerging diseases to detect events of deliberate use of agents to have the best people in Europe working in concert at the ECDC and in the MS when data are to be analysed and interpreted, and by using front-line technologies be superior to anyone when it comes to disseminating the information to all those who need it in their daily struggle to make Europe a safer place to live in. These surveillance systems need to be sustainable, yet flexible enough to address the constantly changing threats.

This paper is the first attempt to present a draft framework for a strategy which will be followed by several additional steps. A further developed and more refined version will go to the next AF, following and taking into consideration the outcome of the discussions in AF 3 and the Management Board on key issues highlighted in the text. In the years to come, this surveillance strategy development will also be a continuous process until we have built up a system that satisfies all the European needs and expectations.

The present situation

Surveillance of communicable diseases in the EU has developed rapidly after the adoption of decision 2119/98/EC by the European Parliament and Council in 1998. With this decision, a Community Network was initiated in order to 1) establish the epidemiological surveillance and 2) to establish an early warning and response system for the prevention and control for communicable diseases in Europe. Currently, surveillance at EU level should cover 46 diseases/health issues specified in Commission Decision 2000/96/EC and its recent amendments 2003/534/EC and 2003/542/EC. There is the Basic Surveillance Network collecting basic data for all diseases listed. Some of the 46 diseases and special health areas defined in Commission Decision 2000/96/EC have a specific surveillance network in place.

Some of the surveillance schemes were set up in the early 1980's. They were funded during their research stage as concerted actions by the Commission and later as actions under the public health area. As a result, the surveillance schemes differ in size, details, structure of organisation, and development phase.

The networks receive data agreed upon by their national members, usually sourced from national surveillance systems and/or national reference laboratories. The overall effectiveness of a European surveillance network depends on the quality of the national surveillance systems and the operational performance of the coordinating partner. Some MS have no national surveillance instituted for a specific disease. National surveillance systems are diverse and quality of data collated varies. Different case definitions and reporting systems (e.g. local physician/laboratory level to national and further to international levels), country specific differences in health care systems and variability in facilities and equipment available for diagnostics contribute to great diversity in national surveillance systems. As stated above, the Commission has adopted in 2002 a Decision (2002/253/EC) on case definitions that should be used for reporting to the Community Network so as to achieve uniformity in reporting.

An overall problem of the networks has been lack of sustainability of the essential surveillance components, due to time-limited contract times, sometimes decreasing community funding and requirements to add novel components in order to get new funding from the Commission. The present surveillance networks are listed in Annex I.

Role of the ECDC

One of the key responsibilities of the ECDC is surveillance: partly to consolidate European surveillance activities of the past years and integrate the relevant parts into the ECDC and partly to take further the European vision of surveillance and to develop a strategy. According to its founding regulation (851/2004/EC), the Centre shall:

- collect, collate, and evaluate relevant scientific and technical data;
- cooperate with the competent bodies recognised by the MS on collection of data;
- coordinate data collection, validation, analysis and dissemination of data at Community level, including on vaccination strategies
- developed the statistical element of this data collection in collaboration with MS using, as necessary, the Community statistical programme, to promote synergy and avoid duplication;
- develop with the competent bodies of the MS and the Commission appropriate procedures to facilitate consultation and data transmission and access;

- carry out technical and scientific evaluation of prevention and control measures at Community level;
- work in close cooperation with the competent bodies of the organisations operating in the field of data collection from the Community, third countries, the WHO, and other international organisations;
- coordinate the European networking of bodies operating in the fields within the Centre's mission, including networks arising from public health activities supported by the Commission;
- operate the dedicated surveillance networks;
- maintain the database(s) for such epidemiological surveillance;
- provide quality assurance by monitoring and evaluating surveillance activities of such dedicated surveillance networks to ensure optimal operation;
- harmonise and rationalise the operating methodologies.

The added value of this coordinated approach to surveillance on the European level will not only include the standardisation of operating procedures of the networks (SOP), the databases and the outputs as much as possible. It would also allow to tackle infectious disease surveillance in a synergistic way and to avoid duplication of work. Having the surveillance coordination in a central place will most likely be economically more efficient. Last but not least diseases could be included both in the surveillance and research agenda according to European priorities.

An ECDC strategy for surveillance

In ECDC's first Work Programme for 2005-2006, adopted by the Management Board, the Centre is required in 2005 to start the preparations to take over responsibility for surveillance activities at the EU level and consult the Advisory Forum to this end, and to submit a planning document on future surveillance strategy to the Management Board by October 2005.

In the first Advisory Forum meeting it was agreed that the process would involve a consultation of stakeholders. Several key points were highlighted in the discussion on the current and future European surveillance at the meeting:

- Duplication of work should be avoided since several institutions request similar data;
- Data should be analysed by experts;
- Optimal procedures for interaction between parties should be further developed;
- Procedures for the networks should be standardized as far as is possible;
- A long term development strategy should be created.

It was also agreed that for the preparation of the strategy document, a small European group of external and internal experts should be involved in 2005. The present document represents the first step in the development of this strategy and is based on an extensive consultation process with various stake holders in all the MS, the European Commission and the WHO Regional Office (see details in Annexes II-III). The draft was discussed at the third meeting of the Advisory Forum and the suggestions from members are incorporated into this current version.

The strategy gives the direction that we wish to take in the transition from surveillance networks funded by the EU Public Health Programme to a coordinated and integrated approach promoted and funded by the ECDC. The document needs to be updated on a regular basis as the Centre gradually grows, but also to meet new demands on European surveillance.

Vision for surveillance in the first phase of ECDC's development

In the early years ECDC must address as a priority the greatest threats to human health from infectious diseases. These include HIV/AIDS, antimicrobial resistance (AMR), influenza, and zoonoses. For these priorities, separate papers outlining the rationale for choosing these diseases as well as the scope of activities are being prepared. ECDC's work on these diseases will not only cover surveillance but tackle them in a comprehensive way including aspects on research and prevention. At the same time work must proceed to put in place the infrastructure for all those infections that the Centre is required to cover as well as providing the means to detect new diseases or syndromes arising in the EU. Particular attention will be paid to surveillance activities that provide a clear EU added value to the national systems. These would provide timely detection of new trends in diseases or risk factors, earlier warning of threats to health from within and without our borders, earlier detection of untoward events and the rapid detection of events that involve more than one MS. This will mean that for example algorithms for the automated detection of unusual clusters within the surveillance data will be developed. The information out of these algorithms will add to the other epidemic intelligence mechanisms being established in the Centre for an early identification and subsequent investigation (by national authorities with or without assistance of ECDC) of health threats. Another added value would be the provision of timely information on international events that require co-ordinated response for effective preventive action.

Much progress has been made over the last decade in developing collaborative surveillance networks. The opportunity must be taken now to address the strengths and weaknesses of the existing arrangements and identify areas for improvement. The starting point has to be an assessment of the objectives of surveillance for each specific infection for the next 5 years and, where necessary, the networks will have to be tailored to fully meet these objectives. It is envisaged that there will be a rolling programme of evaluations since objectives may change with the development of new diagnostic methods, novel surveillance techniques and the availability of new method for prevention and control. The need for enhanced or even new surveillance systems for a particular infection or syndrome may be identified through epidemic intelligence.

ECDC is aware that some DSNs are dynamic and closely linked to alert and response. Care should be taken that coordination by ECDC does not undermine this process, particularly where national reference laboratories are a vital part of surveillance and response.

After the evaluation and prioritisation processes some networks may be modified, some networks may lapse and some new ones will be introduced (objective-orientated), perhaps initially on a pilot/feasibility basis. There has to be a prioritisation process, in partnership with ECDC's stakeholders, including the Advisory Forum which will be involved in the evaluations and also the prioritisation exercise to identify those diseases for which enhanced surveillance is necessary.

Quality assurance will be built into all of the surveillance systems from the outset. It is envisaged that performance indicators (validation, timeliness, frequency of outputs) should be an integral

part of each of the surveillance systems. Such quality assurance has to be built into each step of the surveillance systems so that there is an onus placed on the MS as well as on ECDC.

It is recognised that both ECDC and MS have responsibilities in this area and that it will be necessary to go forward on the basis of partnership. MS have to maintain or set up the structures which are required to provide the relevant data. Some MS have indicated that there is the danger that with ECDC in place MS might become complacent and reduce the level of resources invested in their own systems. Surveillance at EU level can only be of high quality if there is sufficient capacity to generate the data at the national level. In this respect, ECDC will work to assist MS in strengthening the national capacity for surveillance including the application of modern information and communication technology (IT) where requested. This offer for assistance will go especially to the new member states, but of course will be open for each MS who requests support. In the same time ECDC must ensure to put in place the capacity to fulfil its own mission and tasks.

ECDCs stakeholders comprise MS, EU bodies and international agencies, and non-governmental organisations. It is important to establish the modus operandi with each of these in the first year. A close and fruitful working relationship has been already established with the European Commission's DG Sanco and WHO both Head Quarters and the Regional Office for Europe. As a next step memoranda of understanding should be developed with other EC DGs, including DG Research (add in others as appropriate).

European level surveillance should provide information for action that may be useful for those working at local as well as at the national level. The aim should be to influence local good practice through provision of high quality timely information but in no way to undermine the national surveillance function.

Even in the early years it will be prudent to build up collaboration with neighbouring countries, and work closely with WHO in identifying priorities for joint work.

Another generic priority will be the strengthening of collaborations with national reference laboratories in recognition of the vital role that microbiology plays in the surveillance and control of infectious diseases. Some useful ways forward in this respect have been identified through the stakeholder consultation. It is planned that a working group will be convened in 2005 at ECDC to consult and elaborate further on this idea.

More detailed discussion is required with ECDC's stakeholders on the future scope of surveillance activities. It already has a legal responsibility to cover the 46 diseases listed in Dec. 2002/253/EC and Dec. 2003/534/EC but a view must be formed to the extent it should address more generic issues as vaccine coverage and monitoring of antibiotic consumption and behavioural surveillance. It is intended that ECDC will address health care associated as well as community-acquired infections.

A difficult area that requires work in the first year relates to the management of data and the provision of information to take into account issues of data ownership, confidentiality and freedom of information legislation. Operational protocols have to be developed and agreed that will cover all these points of contention. This will be no easy task, but resolution must be achieved in the first year of operation.

The functional relationship between surveillance and response has to be elucidated both within ECDC and between the Centre and the MS. Response needs to be timely and coherent, particularly when co-ordinated investigation is required across several MS.

Obligations are placed on the MS as regards the implementation of the new International Health Regulations, but the stakeholder consultation has indicated that assistance by ECDC would be welcomed, particularly as regards strengthening surveillance and outbreak and response capacity and in providing training for the algorithm.

Definitions

For clarification within this document some of the key terms are defined in the following:

Routine (core) surveillance means the information collected routinely on infectious diseases, like age, gender, date of onset/reporting, diagnosis, symptoms. The laboratory diagnostic criteria and the information within this core set should be gradually refined and enlarged according to agreed upon objectives.

Enhanced surveillance: For priority diseases, routine (core) surveillance is complemented according public health objectives by other surveillance approaches (e.g. behavioural data for HIV, travel information for legionellosis cases, more detailed microbiological information for certain outbreak-prone pathogens).

National Reference Laboratories are laboratories on national level which carry out reference tasks for specific pathogens affecting humans. The term refers to both laboratories that are formally appointed as NRL and to laboratories carrying out these tasks without formal appointment.

European networks comprise the best experts from the MS and ECDC working together to set the standards of the surveillance, to decide on variables to be covered, to interpret the data, to further improve the quality, comparability and timeliness of data, and to link the data to public health action.

Functions and activities within the networks include collection and validation of data, maintenance of data bases, data analysis and interpretation, surveillance output, integration of genetic typing methods, arranging meetings, etc.

Key components of the strategy

This section of this strategy paper sets out the key tasks for the years 2006-2008. There are three critical components that will shape the direction of this work and must commence in early 2006 to further develop the information outputs on infectious diseases in the EU:

- evaluation of the existing networks; an integral part of which will be a review of the objectives for the specific diseases
- to determine the functional specifications of the IT infrastructure
- a prioritisation exercise in collaboration with stakeholders

It is envisaged that this strategy paper should not only provide a clear way forward for the next 3 years, but identify the means and timelines for delivering the key tasks along the way.

Besides, these initial three steps, three main components can be envisaged:

- Routine surveillance, which would correspond to the full development and implementation of the basic surveillance that would be taken over by ECDC as soon as possible

- Enhanced surveillance networks that will address the priority issues in a more intense and coordinated approach. Those networks would include the former DSNs following their evaluation or new network if new identified priority area. For those enhanced networks it will be decided on a case by case basis if they should be located at ECDC or in a MS. However, they will be fully integrated in the ECDC strategy.

- Studies or feasibility project in order to propose new surveillance for emerging infection or new priorities that had not been sufficiently addressed. Those studies could be implemented, based on precise reference terms by MS institutes under ECDC coordination and funding.

1) Strengthening the surveillance networks

Being the backbone of the whole European surveillance system, the overriding aim of the strategy is to further develop the networks which have been built over the past decade. It is important to make the distinction between the networks and the functions and activities within the networks.

Funding: The funding of the networks, their functions and activities, and the staff required to administrate the networks will be taken over by ECDC after the current contracts with the Commission expire – between 1st September 2006 and 1st January 2008, one in 2008 (Annex I) – ECDC ensuring that no gap in funding will arise. An ECDC funding will make it easier to distribute network tasks and activities between ECDC and one or more national institutes/laboratories.

Surveillance activities: After the funding by DG SANCO has ended, the various surveillance activities of the networks will be carried out jointly by ECDC and the networks. A continued strong input from the MS experts will remain essential both for routine surveillance activities and for the further development of surveillance systems. ECDC will have the overall responsibility for co-ordination of the surveillance activities, and as the critical mass of experts at the Centre increases, activities presently carried out by the present network hubs (especially those concerning data handling and surveillance outputs) will be gradually transferred to the Centre while others (especially those concerning diagnostic methods, genetic typing, laboratory QA) will remain in the national institutes. The funding mechanisms for such activities will be calls for tender and/or grant agreements. Analysis and interpretation of data will be a shared responsibility between ECDC and the Member State experts, as they require a detailed knowledge of the specific conditions in each country.

As ECDC has to cover surveillance for all 46 diseases, a prioritisation exercise will be carried out in 2006/2007 to define diseases for which networks should be newly established.

Which network functions and activities to be transferred to ECDC after the present contracts run out will be decided individually for each network depending on the outcome of the network evaluations in 2006–2007. All evaluations should be finished at least 3 months before the end of the current contract of the respective network to allow for taking the appropriate decision about the continuation of funding without a gap. On priority issues, e.g. flu pandemic, ECDC needs to have an option to move very fast without going through a length priority and evaluation process.

A key issue that needs to be continuously addressed is how to retain the closest possible link between expertise in epidemiology and microbiology.

In order to find the optimal solution for Europe on all these issues and to build consensus, a lot of discussion will take in different settings with the involvement of a wide range of stake-holders.

Databases: According to the founding regulation (851/2004/EC), ECDC shall maintain the databases for epidemiological surveillance. To develop databases and systems that could host both basic disease variables, as presently collected by the Basic Surveillance Network, and the more disease-specific data, as collected in the surveillance networks will be a priority in the next couple of years. A unified database that provides all the evidence needed for public health action will have to be developed to provide politicians and public health leaders with the information required. Calls for tenders for ICT framework contracts will be published shortly.

Alert functions: Several of the surveillance networks include alert functions, e.g. relating to outbreaks of food-borne infections and legionellosis. As these are core functions of ECDC, they will be transferred to the Centre as soon as possible after their Commission funding ends (see page 12 and table 3).

Network administration and management: The administration of the various network functions and activities could be done by ECDC or the national institutes, depending on what is most convenient and cost-efficient. For example, arrangement of meetings could be handled by ECDC, while sending out QA panels handled by the national institute in charge of this task. The steering committees of the current networks will be kept to ensure the input of the network members.

Annual meetings: The annual meetings of all network members will be kept to ensure regular direct exchange of information and to stimulate the cooperation between the MS.

Specific projects and feasibility studies: To ensure the continuous development of the surveillance, specific projects and feasibility studies can also be funded through tender procedures or calls for proposals.

2) Interim solutions and agreements

In the interim phase before the present contracts between the Commission and the networks run out, solutions and agreements need to be found, enabling the ECDC to carry out its responsibilities according to Regulation 851/2004/EC. A first step will be to reach agreements with all the networks to give ECDC full access to the present databases. A memorandum of understanding is needed between ECDC, MS and current surveillance networks. In particular, it should be emphasized that ECDC, to be able to fulfil it's mission, should be able to release any European surveillance results any time it is needed for public health reason without asking permission to stakeholders.

The work flow, data flow and information flow of the networks, as well as the case definitions will be part of the Standard Operating Procedures (SOPs) that will be developed in 2005.

A large task in 2006–2007 will be to carry out a thorough evaluation of each of the networks. The results of these evaluations will shape the future activities of the networks and will be decisive for which functions and activities should be transferred to ECDC (and when), and which functions to be carried out in the national institutes.

During this interim situation ECDC shall, however, develop surveillance activities without delay on priority issues, particularly if current tools are identified as not optimal. This may be true for

European Influenza surveillance that has not been implemented to address the pandemic threat. Other similar needs may be identified and should be worked out without delay.

3) Securing laboratory input in the surveillance

As ECDC does not have its own laboratories, the involvement of the national reference laboratories (NRL) will be crucial for the success of a co-ordinated European surveillance system. ECDC therefore needs to develop a strategy on how to work with the NRL, establish contact points and find procedures for communication.

As the European-level surveillance rests on high standard national surveillance, the ECDC will facilitate the development of training programs and exchange of laboratory staff (in particular from new MS) to foster the development of sufficient capacity to detect, identify and characterise infectious agents within the EU (see page 13 and table 9).

The establishment of European Reference Laboratories needs to be further discussed. This may be an option for certain diseases and for special tasks (e.g. reference activities during community-wide outbreaks). However, for frequent diseases, diagnostic capacity (including molecular characterisation) will be needed in each MS (see page 13 and tables 10 and 11). A working group of experts will be set up in 2005 and is expected to deliver a draft plan for securing laboratory input into surveillance by the middle of 2006.

4) Outputs of surveillance data

Since "*surveillance is information for action*", ECDC will need to put heavy emphasis on finding the most effective means of data dissemination. It is important that the output data from the surveillance systems meet the expectations and needs of those engaged in public health in Europe in order to be useful information for decision makers in the public health field. Memoranda of understanding on the respective clearance procedures will be established with the MS (see page 14 and tables 23, 24 and 24a).

EU-level data should then be disseminated through various means, including public and privileged web pages, surveillance reports and articles in scientific journals, and making full use of the media. These will be combined in a way so that the Centre becomes a one-stop-shop for the Member States, the Commission and the European Parliament. All necessary data should be easily available through the ECDC web portal.

Also when constructing the electronic output tools, the best practices in Europe should be utilized, through an inventory of the national output systems, and data should be available in searchable databases, in tables, figures, and using also GIS tools.

Eurosurveillance, as the scientific voice of ECDC, will have an imperative role as the main news messenger. To reach Russian-speaking readers in the eastern neighbouring countries to the EU and some of the new MS, the Centre should seek a strategic partnership with the EpiNorth network and bulletin.

5) Involvement of the learned societies and other specialists in the field of infectious diseases

There are many scientific institutes and other organisations with special expertise and competence that could be used for further enhancing the European surveillance systems, working outside the ECDC and the national institutes, e.g. in academia and in the health care sector. To gain from their experience and knowledge and to maintain close links with front line scientific research

ECDC and the networks need to link to the various learned societies in Europe – as has already been done by some of the present networks. Further involvement should be discussed on a one-to-one basis with the various societies. Interdisciplinary theme-specific workshop should also be organized to foster the cooperation of experts within the Community in order to assist in Community responses to health threats (see page 14 and table 27).

6) Ways to cooperate with WHO, other EU agencies and international institutions and networks in neighbouring countries

WHO: Today there is a parallel reporting on many diseases both to the EU surveillance networks and to the WHO Regional Office for Europe, often in slightly different formats. This double reporting unnecessarily draws valuable resources from more important tasks in the national surveillance institutes. In the recent Memorandum of Understanding between ECDC and WHO/EURO, it was agreed to work towards the development of an integrated European reporting system (see page 14 and tables 18 and 19).

EFSA (European Food Safety Authority): ECDC already established cooperation with EFSA for the zoonoses reporting under the Zoonoses Directive (2003/99/EC).

Other EU agencies: To follow.

Neighbouring countries: The ECDC will therefore make extensive efforts to get good working relations with the neighbouring countries, i.e. Russia, the countries of the Western Newly Independent States (WNIS) and the Southern Mediterranean on all aspects of surveillance. These efforts will build on the contacts already established between the Nordic and Baltic countries and Russia within the EpiNorth network and the Northern Dimension Partnership in Public Health. Through these networks ECDC has been offered access to surveillance data from Russia. Similar collaboration will be sought with the future EpiSouth network (first contacts have been established).

7) Perspectives for future developments

With bioterrorism threats and the emergence of "new" diseases like SARS, effective surveillance system could no longer rest on cases with a microbiological diagnosis being notified through the traditional reporting channels (clinicians and laboratories).

Systems need to be developed that could spot the sudden occurrence of e.g. respiratory tract infections or gastrointestinal complaints before the etiological cause is known. Alternative syndromic surveillance systems built on events rather than microbiological agents should be considered, and possibilities of other inputs in the surveillance systems, such as real-time data on sales of prescription-free drugs, emergency room visits, school or work place absenteeism, etc. should be explored. These alternative surveillance and alert systems must be the responsibility of the Member States. The role of the ECDC should be to be well acquainted with the frontline discussions on all the different new possibilities, and to assist the national surveillance institutes in these matters. Other areas for future developments should be discussed.

8) Conclusion

The current strategy describes the way for European infectious disease surveillance for the transition (next 3 years) from the current decentralised approach to a more coordinated approach.

The opinions and expectations of relevant stakeholders were sought in a wide consultation process and were taken into account when shaping the strategy. The document outlines three components for the future European surveillance: routine surveillance with a basic set of information (that can gradually be enlarged) for all diseases; enhanced surveillance with additional information collected according to public health objectives for priority diseases; specific projects and feasibility studies to test new methods or new approaches to surveillance. The routine surveillance will be located at ECDC. After an evaluation of all networks and a prioritisation exercise for all diseases, the decision will be made which networks or which part of the single networks will be taken to ECDC and for which parts calls for tender will be launched. Collaborations will be developed with WHO, and neighbouring countries and also with the scientific community to join forces and gather the best available expertise in Europe. A long-term strategy for the next decade will be developed based on the current concept until the end of 2006.

References

1. Decision No 2119/98/EC of the European Parliament and of the Council setting up a network fort the epidemiological surveillance and control of communicable diseases in the Community. OJ L268, 3.10.1998, p.1
2. Commission Decision 2000/96/EC on the communicable diseases to be progressively covered by the Community network under Decision No. 2119/98/EC of the European Parliament and of the Council. OJ L28, 3.2.2000, p.50
3. Commission Decision 2002/253/EC laying down case definitions for reporting communicable diseases to the Community network under Decision No. 2119/98/EC of the European Parliament and of the Council. OJ L 86, 3.4.2002, p.44

Annex I. Currently funded surveillance networks and the date their current contracts expire

Project	Contract ends
EISS	2006-08
EuroCJD	2006-08
EARSS	2006-08
EU-IBIS	2006-09
Enternet	2006-09
EWGLINET	2006-12
ESAC	2006-12
BSN	2006-12
EUCAST	2007-04
DIVINE	2007-04
EUVACNET	2007-08
EuroTB	2007-09
ENIVD	2007-11
EuroHIV	2007-12
ESSTI	2007-12
IPSE	2007-12
DIPNET	contract to be negotiated

Annex II. Consultation process

First phase: country visits, selection of countries, semi-structured questionnaire, qualitative text analysis

The objective of a first (smaller) round of consultation was to seek the views on the key strategic issues, seek views on gaps in the key strategic issues and explore potential solutions in order to give the consultation team an overview of options to be used in the subsequent, closed questionnaire to be sent to all 25 MS, Norway, Liechtenstein and Switzerland.

On the basis of a proposed procedure for the consultation, a semi-structured questionnaire on the key strategic issues was developed to obtain information from a subset of stakeholders in selected MS (and the Commission). The selection of the MS was based on the presence of network hubs, balance between small and large countries, and geographical representation, thus Denmark, Portugal, Germany, Greece, Malta, Poland, Portugal, Slovenia, Spain, UK, Commission were selected for interviews.

With the kind assistance of the respective Advisory Forum member, the following stakeholders were approached for interview in each country visited:

- CMO together with State Epidemiologist and ESCON member
- A representative of a reference laboratory
- Network coordinator and project leader if a hub in the country

The results were analysed using qualitative text analysis (ref.) in order to obtain the answer options for the closed questionnaire.

Second phase: closed questionnaires (separate for policy makers, epidemiologists, microbiologists)

For the further approach a questionnaire survey with a closed questionnaire was carried out. The possibility to create a web-based questionnaire facilitated the process of a questionnaire survey and was under the given time constraints the most efficient solution. For different stake holder groups different questionnaires were developed (one for State Epidemiologists and network hubs, one for laboratories and one for policy makers). The following overview shows which questions were asked to the four groups.

Table 1. Overview which questions were asked to the four groups

Section	State Epidemiologists (SE)	Network hubs (NH)	National reference laboratories (NRL)	Policy makers (PM)
Network management	X	X		
Outbreak surveillance	X	X		
Surveillance of zoonoses	X	X		
Laboratory networks	X	X	X	
Collaboration with accession, candidate, neighbouring countries	X	X		X
Collaboration with international organisations (WHO and others)	X	X		X
Functional outputs from surveillance	X	X	X	X
Future issues	X	X	X	X
Strategic issues	X	X	X	X
Capabilities of surveillance system				X

The questionnaires were sent to the AF members in all MS with the request to forward them to the relevant stakeholders in their country: Ministry of Health, Health Committee of national parliament, Chief Medical Officer, Chief Veterinary Officer, State Epidemiologist, ESCON members, Heads of reference laboratories.

In addition the questionnaires were sent to: the Committee on the Environment, Public Health and Food Safety (ENVI) of the European parliament, other EU agencies (EFSA, EMEA, EEA, EMCCDA, Eurostat), European scientific societies (e.g. ESCMID, EUPHA), the EU-funded PH surveillance networks, WHO Regional Office for Europe and WHO Headquarters. The Commission's views were sought during a visit in Luxembourg.

Analysis

Frequency analysis was done according to stakeholder group, small vs. medium vs. larger MS (small – 5 million inhabitants, medium ≥ 5 – 20 million inhabitants, large ≥ 20 million inhabitants, Source: Eurostat (Figures for 2004) at:

http://epp.eurostat.cec.eu.int/portal/page?_pageid=1996,39140985&_dad=portal&_schema=PORTAL&screen=detailref&language=en&product=Yearlies_new_population&root=Yearlies_new_population/C/C1/C11/caa10000), MS with network hubs vs. MS without hubs; (further options: new vs. old MS)

Annex III Preliminary results of the questionnaires

Responses

As of 30th September 2005, we have received responses from 24/28 State Epidemiologists (SE), 13/17 networks, 25/28 national reference laboratories, 44/84-112 policy makers from MS. As of this date, there was one response from the learned societies (1/9) and no response from the ENVI, WHO, and the other European agencies (0/5).

Management of networks

Questions regarding the future management of the surveillance networks have been asked to SE and the network hubs (NH).

There was a good agreement between the opinions of SE and NH regarding the strengths of having surveillance networks in institutes across Europe (table 1). Answers were more divers regarding the strengths of hosting the NH at the ECDC (table 2). For this option MS expect more than NH a better standardization between the networks, reduced costs and shared overheads, sustained funding and long term maintenance of networks, better performance management of surveillance networks, easier access to information on all diseases and also that it would help ECDC to better carry out its mission and link with EU action. Both groups see in this approach a synergy between networks.

Regarding the criteria as to where the network hubs should be hosted, both groups agreed with a high percentage that availability of relevant experience and support infrastructure are important (table 3). The suggested criteria for the order in which the networks should be integrated into ECDC resulted in different views. Most of the SE (22/24, including 6/7 SE from current NH hosting countries) answered that networks related to alert and crisis management should be hosted by ECDC first, only 54% of the NH share this view. According to 63% of SE (57% of SE from current NH hosting countries), but 77% of NH, networks with effective and strong ties to microbiology laboratories on site (of the NH) should not move to ECDC in the short term. Only 54 % of SE and 39% of NH would consider the cost of operation as a criterion for the location of the hubs (slightly more SE from countries not hosting a NH than SE from NH hosting countries, 59% vs. 43%).

We also asked for criteria to determine the success of a network (table 4). All criteria listed were thought to be good assessments of the success of a network by the vast majority in both groups (the least frequently mentioned one was a positive cost-benefit analysis (which should be replaced by cost-effectiveness particularly in relation to the evaluation of the networks). All respondents in both groups agreed that external evaluation of networks should be done.

We specifically asked questions regarding the Basic Surveillance Network, since this is intended to be a model for the basic surveillance information on all diseases (table 5). All respondents agreed to minimize the duplication of data collection between the other networks and the BSN and also between the European networks and WHO and to link the data where feasible. Two thirds (16/24) of the SE are of the opinion that the information collected in BSN should be gradually increased after agreement with MS. The majority of SE agreed to identify priority diseases for MS who can not meet all BSN demands at this time.

Outbreak surveillance

Respondents in both groups agreed that ECDC should collect information on outbreaks in EU MS (table 6). There was also consensus that not all outbreaks should be included, but mainly the ones affecting more than one MS, and national outbreaks if they involved novel sources or novel modes of transmission. The answers on specific diseases for which outbreak data should be collected were inconclusive; this issue requires further clarification and discussion. As objectives for this outbreak surveillance (table 7) most SE indicate to better focus outbreak training needs in MS, to alert MS to new sources so they can respond more efficiently and effectively, and to have performance management of the training and response capacity across Europe. The least frequently mentioned objective was the monitoring of trends. Answers from NH were less clearly distributed.

Surveillance of zoonotic infections

This section referred to the new Zoonoses Directive (2003/99/EC). Since the reporting will be structured in a new way, there is the opportunity to shape it in a way to get the desired and needed information out of it. All the options offered in this section (table 8) were regarded as desirable by at least 60% of the SE. Since the networks are more specialized not all this information seems to be relevant for them. Agreement was among both groups to have more interpreted data.

Laboratory networks

In addition to SE and NH, this section was also asked to the National Reference Laboratories (NRL). All three groups preferred regular communication by email and regular face to face meetings as means for building close working relationships between the NRL and ECDC (table 9). Least favoured by all groups were teleconferences. All groups saw better involvement of microbiologists in EU surveillance as important ways of building the laboratory network of ECDC. In addition the NRL favour also short-term secondments of laboratory staff to ECDC. All groups suggested that ECDC develops a plan for working with reference laboratories. NRL more than SE and NH would like to see a panel of public health microbiologists being established at ECDC.

If in the future, ECDC will need to build networks with the key microbiological laboratories in Europe, all three groups agreed that selection should be based on technical competences and excellence and that the process should be transparent (table 10). There was no clear preference as to how the criteria should be applied, but there was a tendency that how ever the process should be shaped, the final selection should not be done by ECDC alone (table 11). All three groups agreed that ECDC should work in collaboration with surveillance networks and national reference laboratories on the harmonization of laboratory methods for the various pathogens (table 12). A majority in all three groups (although only 54 % of NH) agreed that the laboratory networks should establish molecular databases (table 13), which should have the function of describing the molecular epidemiology of the pathogens and help detecting early trends in molecular epidemiology, events linked within one country, but also detecting community-wide outbreaks (table 14).

Around 50 % of SE, NRL and PM indicated that the safe transportation of laboratory samples is ensured inside their country (only 30% of NH), around 40% of SE, NRL and PM said so for the safe transportation of samples outside of their country (tables 15 and 15a).

Collaboration with national centres in accession, candidate and neighbouring countries (neighbours to the EU)

One third of SE, 85% of NH and 23% of PM have routine surveillance collaboration with neighbouring non-EU countries (table 16). Most of the NH and PM indicated that the data exchange is part of a formal agreement.

As major benefits of such collaboration, SE, NH and PM see the early identification of disease threats, more effective cross-border outbreak investigations (table 16a and 16b). To a lesser extent this collaboration could improve the trust between countries. The major obstacle to collaboration with neighbouring countries was seen by all groups in the lack of resources (table 17 and 17a).

Collaboration with international organizations

Seventy percent of the SE and almost more than 50% of the NH are able to fully meet the requests for routine surveillance information from WHO (table 18). Among the few who cannot fully meet the information requests from WHO, the most frequent reasons are that they don't collect the requested data at all, that the data are requested in a different format to that which the countries supply to other surveillance systems, that there were different case definitions in use and that the data requested didn't fit with the national priorities (table 18). There is wide agreement (SE, NH and PM) for aligning the reporting of surveillance data between ECDC and WHO and the sharing of a data platform between the two organizations (table 19 and 19a). Standardising data collection and exchange of information and reports, to a lesser extent having a single reporting system for both organizations could be ways for a successful coordination (table 20 and 20a). SE, NH and PM see the role of ECDC in supporting the implementation of the International Health Regulations mainly in giving advice to MS and providing training to use the algorithm, but also in strengthening outbreak investigation and surveillance capacity (table 21 and 21a).

Data on infectious diseases are sent to international organisations other than WHO by 60-70% of the respondents. By far most of the respondents send data to EFSA (58% SE, ,23 NH and 50-92 % of PM (table 22 and 22 a). Among the data sent, most of them are trend or incidence data, less frequently outbreak investigation reports (table 23 and 23a).

Functional outputs from surveillance

Most of the SE, NH and PM are content with ECDC's plan to have memoranda of understanding with MS on receipt and use of information by ECDC (table 24 and 24a). As for the authorization process with MS/surveillance networks, 15/24 SE, 10/13 NH, 20/25 NRL and 25/44 PM agreed that there is a necessity for such a process. Most of the SE, NH, NRL and PM (only 60% of the CMOs) consented that any agreement should be EU-wide. NH and NRL indicated that for routine outputs prior agreement should be sought, whereas SE and PM (80% of the CMOs) agreed to this option to a lesser extent (table 25 and 25a).

Future issues

We wanted to have the views of SE, NH and PM on surveillance issues that ECDC should work upon in the future. About 70% of SE and NH wanted ECDC to provide advice and support on mass-gathering surveillance. Ninety percent of the SE, 50% of the NH and most of the PM (only 50% of the CVOs) thought that ECDC should attempt to coordinate surveillance of travel-related infections (table 26 and 26a).

SE, NH, NRL and PM were asked for the best way to liaise with scientists from various disciplines (microbiologists, clinicians and others). All four groups thought that theme-specific workshops should be organized. Publishing in peer-reviewed journals and joint training were also seen as good ways of collaboration between these scientists and ECDC. Organising annual conferences was least frequently mentioned (12/24 SE, 7/13 NH, 15/25 NRL, 30/44 PM) (table 27 and 27a).

Strategic issues

Here we wanted to explore how "learned societies" could best be involved in collaboration (table 28 and 28a). The majority of respondents indicated to ask the societies what kind of collaboration they would expect and also that the societies should feed back the work of ECDC in their meetings. All groups were against the involvement of ECDC staff in the scientific board of the societies (only 2/24 SE, 3/13 NH, 9/25 NRL and 14/44 PM agreed to that).

Special issue for policy-makers: national surveillance systems

Only PM were asked about the national surveillance systems, since the mandate of ECDC also includes to support MS in strengthening their national surveillance systems. The responses from this group are difficult to interpret as a whole, since some countries have sent responses from all four persons who should be targeted for completing the questionnaire. The following results are analysed according to group among the PM (CMO, CVO, MoH, other) to ensure it is only one questionnaire per country.

54% of CMOs and 46% of MoH indicated that their present national surveillance systems are capable of dealing with the current infectious disease situation, but could be improved, 92% of CMOs and 82% of MoH said so for dealing with emerging health threats (both questions were answered with "yes" by 38% of the mixed group). Between 80 and 90 percent of the responding CMOs and MoHs agreed to consider prioritising funding for the development of surveillance infrastructure, around 70% would do so also for developing intervention epidemiology in their countries (table 29).

Issues with consensus

- Strengths of having network hubs in institutes across Europe
- Outbreak surveillance: information should be collected, but not for all outbreaks
- Zoonotic infections: more interpreted data
- Laboratory networks:
    - ECDC to develop plan how to work with NRL,
    - ECDC should work in collaboration with the NH and the NRL (and respective learned societies?) on the harmonisation of laboratory diagnostic criteria for the various pathogens
- Cooperation with WHO:
    - alignment of reporting,
    - sharing of a common data platform

Issues where further discussion is needed

- Strengths of hosting the networks at ECDC:
- SE differ from NH regarding in most of the answers; SE from countries hosting networks tend to answer according to the SE in general not in the line of the networks.
- Criteria for location of network hub: Order of integration into the Centre
- Outbreak surveillance: Diseases for which outbreak information should be collected
- Functional outputs: for routine outputs prior agreement should be sought; answers indicate that the question might have been misunderstood