



## MEETING REPORT

# Moving forward with surveillance in EU and EEA/EFTA countries

Stockholm, 28–29 April 2009

## Executive summary

One year after the European Surveillance System (TESSy) was up and running, several issues needed to be addressed by the national surveillance contact points on their views regarding European surveillance and the use of TESSy as a tool for surveillance. From 28 to 29 April 2009, meeting participants and ECDC staff met in Stockholm to discuss the strategic issues regarding surveillance activities and practices and decide on the operational directions to follow in the near future. The main issues to be addressed were related to the implementation of case definitions, establishment of a process to review proposed changes in TESSy metadata, procedure on access to TESSy data by third parties, and the implementation of geocoding, molecular surveillance and outbreak reporting. Also 'data comparability' was addressed as a crucial issue to be dealt with in surveillance systems across all EU/EEA Member States as well as within ECDC. In particular, projects to be launched on monitoring and the evaluation of data quality, along with a needs assessment of the surveillance systems in EU/EEA Member States were discussed.

The conclusions of the meeting are summed up in the following points:

- Geocoding is feasible but there are some concerns regarding the confidentiality of data.
- The concept paper regarding the implementation of molecular typing at EU level was considered useful.
- There is a need to improve stability of the metadata set. However, this stability can not be reached until all the networks have been transferred. The implementation of case definitions is a stepwise process and will allow a better comparison of data reported at the EU level. In 2010, ECDC, together with the EU/EEA Member States, will monitor the differences in the implementation of the EU case definition at national and European levels.
- The proposals for changes in variable definitions should be sent to the national contact points for surveillance.
- Tools for the evaluation of national surveillance systems should be developed in order to strengthen the surveillance systems in the Member States.
- The information collected on outbreak surveillance can indicate failures of public health practice and/or the surveillance system. The current systems for outbreak surveillance should be evaluated.

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Stockholm, July 2010

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The annual meeting of the ECDC national surveillance contact points took place in a special context as the WHO pandemic alert was announced on 28 April 2009. We would particularly like to thank the participants of the Member States for their active participation in the meeting given the circumstances.

# 1. Background

In January 2008, the first European Surveillance System (TESSy) training session provided an opportunity for the European Centre for Disease Prevention and Control's (ECDC's) national contact points for surveillance to meet in Stockholm. This meeting marked the beginning of a very active year for TESSy. In the first year, 115 users reported 1874 files containing 1.9 million records, of which 1.5 million were counted (the rest were updated and deleted records). Several surveillance reports (zoonoses, HIV, TB, annual epidemiological report) have already been produced and others are in preparation. The TESSy team is well aware that nothing could have been achieved without the patience, great effort and good will of all the colleagues in the Member States (MS).

Although TESSy has been used as a tool for European surveillance since year one, some dedicated surveillance networks (DSNs) (DIPNET, EWGLINET, EARSS, EUVAC.NET, ESAC) had, at the time of the meeting, yet to be transferred to ECDC. The transfer of DSN coordination to ECDC follows the principle that activities are transferred as they were implemented by the DSN. During the annual meetings of the newly nominated national contact points for the respective disease or disease-group, issues regarding data collection and analysis (e.g., proposed changes in variables definition, frequency of reporting, information collected on countries' surveillance system) were discussed as well as any proposals on how to further develop surveillance.

In the meantime, in 2008, the EU case definitions were published [1], the long-term surveillance strategy was approved by the ECDC Management Board (MB) [2], surveillance objectives were discussed in the Advisory Forum (AF) and the procedure for access to and use of TESSy data was discussed by the MB. All these key strategic documents are meant to provide a framework and guide the way surveillance should be developed and performed at the EU level. Now, the major challenge that lies ahead is to implement these strategies.

## 1.1 Objectives of the meeting

Meeting participants and ECDC staff met in Stockholm from 28 to 29 April 2009. The objectives of this meeting were to discuss the main strategic issues regarding surveillance activities and practices and decide on the operational directions to follow in the near future.

In particular, the main issues addressed included the following:

- Implementation of the EU case definitions. Specifically, any difficulties encountered while implementing the revised EU case definitions, the availability of the information necessary to classify cases according to the 2008 EU case definitions, and providing definitions of standard case categories to be reported at the EU level.
- Implementation of the EU surveillance objectives through relating the variable definition/coding as well as the frequency of reporting to the objectives for surveillance.
- Monitoring and evaluating data quality in the Member States and in TESSy, and identifying the needs in the surveillance systems of the MS to improve data comparability at the European level.

The agenda of the meeting can be found in Annex 1.

## 2. Session one: TESSy, a tool for European epidemiological surveillance of communicable diseases

A review of TESSy activities since January 2008 was presented including training, support and communication with the experts from the EU/EEA MS using TESSy helpdesk, changes in metadata, and planning of data collection and management. The planning for 2009 TESSy releases was presented.

### 2.1 Discussions and recommendations

No specific questions or comments were made after the first presentation (review of activities since January 2008). The following points were raised after the second presentation on activities under development in TESSy:

- The test batch functionality should perform a full validation. Currently the test batch functionality for XML and CSV files does not test the reporting period or permissions. The prospective principle should be that a file is guaranteed to be validated successfully if the file has passed validation in test batch, given that the file has not been modified and that identical reporting periods are used.
- A national TESSy module was requested. The European Centre for Disease Prevention and Control replied that TESSy is designed and built for EU reporting and is not suited for modules specific for one country. However, ECDC will respond to requests for best practices and knowledge sharing, if requested, to help a country build (design or tender) a national system. The Centre can also develop functionality through the web service (machine-to-machine communication) to help countries access more TESSy functionality through the national system.

The search functionality of the ECDC portal, being announced in mid-summer, was discussed. The ECDC web portal and the option for extra-net were presented.

## 3. Session two: Planning annual European epidemiological surveillance activities with networks of disease-specific national contact points

The procedure on access to ECDC MS data in TESSy by third parties has been discussed with the ECDC AF and MB since 2008. The annual revision of metadata will be performed at the end of each year. Member States can report data using previous and new metadata in parallel for one year (exceptions are made for DSN transfers and significant errors in the definitions). A review of the change process for the definition and coding of variables was presented and proposals for changes in variable definitions and coding were discussed in this meeting. Proposals were made regarding the frequency of reporting and case categories to be reported at the EU level.

### 3.1 Discussion and recommendations

The procedure on access to ECDC MS data in TESSy by third parties was accepted in the ECDC MB (24–25 June 2009) under the proviso that the procedure be reviewed by the end of 2010.

Although 'place of residence' was considered to be useful for some but not all diseases, this variable should definitely be collected for food- and waterborne diseases in priority. 'Place of notification' was not identified as useful information to be collected unless 'place of residence' was missing. 'Place of residence' and 'place of notification' cannot be collected in some countries for privacy reasons. Data protection issues should be considered as well as coding standards for inclusion of variables in the common set. The variables 'imported' and 'probable country of infection' should be collected for all diseases.

Regarding the variables already defined and that should be extended to other diseases, no specific comment was addressed except that it is not possible to report HIV sero-status in tuberculosis reporting systems in some countries, like the United Kingdom and Italy, for confidentiality reasons.

Frequency of reporting and case categories to be reported at the EU level will require further discussions with the national surveillance coordinators. The following are some of the comments made about continuous reporting:

- It is possible for most of the diseases;
- depending on resources, it can be time consuming to report cases on a continuous basis; and
- continuous reporting can be easy if machine to machine is used.

The following documents will be sent separately:

- Procedure on access to ECDC MS data in TESSy by third parties;
- proposal for a revised TESSy meta-dataset; and
- proposal of a guide for implementation of EU cases definition.

## 4. Session three: Presentation of national surveillance systems

Topics related to surveillance systems were presented for three countries: Romania, Portugal and Ireland.

In Romania, selected diseases that should be investigated rapidly have to be reported within 24 hours. This is part of the early warning system at the national level. For data cleaning and validation, there are specific training and standard procedures to address this operation. Epidemiologists are trained to adapt the new EU case classification. The purpose of this training is to acquire the most accurate information in order to better describe the cases according to new case definitions.

In Portugal, automatic alerts are sent by email or text message. This information has to be combined with regular case reporting. The validation of the data is centralised by epidemiologists. In particular, they have to identify the proper information in order to classify cases. Notifications from the National Institute for Health and laboratory notifications are both under the aegis of the General Director for Health.

In Ireland, the computerised infectious disease reporting (CIDR) system is based on a business object. Two-thirds of reported events are laboratory confirmed. While it is difficult to document the business logic for validation rules, logics are built in where possible. Therefore it is necessary to perform data cleaning and post data-entry checking in order to maintain good quality data. One reason why an open source was chosen in Ireland was because there was no software that could fulfil the requirement for a geographic information system (GIS) project.

## 5. Working groups 1 & 2: Proposal for implementation of geocoding<sup>i</sup>

Geographic information can be used for the detection of cross-border clusters/outbreaks and to monitor the spread of diseases (e.g. influenza). It can also be used to compare data collected in smaller geographical units than a country and to identify cases who have travelled from one point to another between two countries (if individual information is also available on travel).

### 5.1 Discussion and recommendations

The European Centre for Disease Prevention and Control should provide support to MS to collect geographical data. However, it is important to identify how these data will be used at the international level. One of the working groups suggested collecting geographical data using nomenclature for units of territorial statistics (NUTS), but limit the data to the available level and within the legal possibilities of the reporting country.

Concurrently, a working group should be set up—including ECDC and national surveillance contact points—to discuss the following practical issues regarding geocoding:

- How can countries be best supported in providing geographical data?
- How to evaluate the geographical analysis from the data collected?
- How can analysts evaluate the quality/availability of the data provided?
- What information is the country allowed to report (privacy issues should be taken into account)?

A Europe-wide proposal should be drafted by the working group for the implementation of geocoding. This proposal should take into account disease specific objectives and be reviewed and discussed by the MS.

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<sup>i</sup> Geocoding is the process of converting addresses into geographic coordinates, which can be used to place markers or position the map.

## 6. Working group 3: Implementation of molecular surveillance at the EU level

The European Centre for Disease Prevention and Control is proposing a concept paper on how to integrate molecular typing data as part of surveillance at the EU level by taking into account the existing structures in the DSNs and in other networks and being in line with the overall strategy for laboratory collaboration. The molecular typing activities that have been performed by DSNs and transferred to ECDC—i.e., Enter-net (Salmonella, VTEC), EU-IBIS (invasive bacterial diseases), EuroTB (MDR-TB), IPSE (MRSA), EISS (Influenza) and ESSTI (STI)—will be the starting point to develop the coordination and integration of typing data to surveillance.

### 6.1 Discussion and recommendations

The process to achieve consensus on molecular typing methods per disease has been, in principle, agreed upon. During the consensus process, the concept paper was also discussed with the National Microbiologist Focal Points (NMFPS). The members and role of the expert group to be consulted on molecular surveillance have been discussed. These groups should at least include nominated ECDC contact points for surveillance (disease-specific and general), experts nominated by the NMFPS and bioinformatics specialists. A disease-by-disease overview is needed on the capacity to collect molecular data in EU/EEA MS.

As described in the concept paper, the expert groups may be needed to lead the disease/pathogen-specific work to propose the suitable molecular typing techniques per disease for surveillance. The tasks of these expert groups could include defining the typing methods, validation and standardisation of methods, training needs, external quality assurance and ring trial needs, and algorithms (should address routine typing). As stipulated in the concept paper, the objectives for surveillance of molecular typing should be clearly defined before starting any project. Advances in laboratory techniques should be taken into account.

Molecular surveillance should be performed on diseases for which the most added-value for Europe can be derived. A stepwise implementation is specified in the concept paper.

Linkage of molecular typing data and epidemiological data is not always done at the national level, although it might be possible. For some diseases, technical problems may prevent linkage of epidemiological and laboratory typing data. A common identifier should be used to link case-based data from different sources and cases reported in outbreaks from medical doctors and from reference laboratories. Technical problems should be resolved in order to make this linkage possible.



## 7. Working group 4: Implementation of revised EU case definitions

In addition to the legal text endorsed by the Commission under Decision 2008/426/EC [1], a technical note should be published on the ECDC website to specify the case categories that should be reported at the EU level, and the general terms and abbreviations that are repeatedly used in the case definitions.

### 7.1 Discussion and recommendations

Some difficulties have been brought forward regarding the implementation of the case definitions. Guidelines for laboratory confirmation are available from the learned societies and should be distributed. In some countries laboratorial capacity might be low, and this can be aggravated during specific public health events. There are also difficulties adapting national case definitions to European case definitions.

The following actions points were proposed:

- Case categories to be reported should be commented on by the MS.
- Technical specifications attached to the case definitions (technical notes) should be approved by national surveillance contact points and they should add terms that need definition, if necessary (preferably providing a draft definition).
- A system (ECDC forum, like EPIS) should be developed in order to compare the implementation of case definitions in different countries. This can be achieved through systematic comparisons of country case definitions with EU case definitions to see whether there are differences.

## 8. Working group 5: Needs assessment of national surveillance systems

The European Centre for Disease Prevention and Control, together with the Competent Bodies (CBs), should develop and utilise a tool for assessing the needs of national surveillance systems (SS) and then identify the best way of supporting the MS. A method to assess the needs in the MS SS was discussed in the working group.

### 8.1 Discussion and recommendations

Requirements for SS in the MS have been discussed and the following criteria for supporting the MS have been identified:

- Surveillance systems should provide optimal quality data. The same case definition for reporting cases to the EU should be applied. Possible and probable cases should also be reported for some diseases at the EU level. It is also necessary to ensure case verification/validation of SS (sensitivity and specificity). A procedure to assess the exhaustiveness and coverage of SS should be in place. Data plausibility (internal/external) should be assessed through quality checks. Timeliness of reporting should be monitored considering surveillance objectives of the diseases.
- Provide characteristics of data sources (e.g., lab, clinical/sentinel vs. notification etc...).
- Perform evaluations of SS at regular time intervals.
- Estimate cost-effectiveness of surveillance systems.

The recommendations for ECDC include the following:

- Provide/develop standard methodology to MS for evaluation of SS (adaptable to specific disease needs), including, for example, validation study protocol and quality check procedures, depending on agreed upon criteria.
- Development of a tool to allow MS to benchmark performance of their SS and improve quality accordingly.

## 9. Working group 6: Outbreak reporting

Outbreak surveillance at the EU level is currently only mandatory for foodborne outbreaks based on Directive 2003/99/EC [1-3] of the European Parliament and of the Council of 17 November 2003. This Directive requires outbreak reporting of foodborne diseases to the European Food Safety Authority (EFSA). Voluntary outbreak reporting is performed through a European web-based forum maintained by EUVACNET, with limited user access for measles, mumps, rubella, pertussis and varicella. Additionally, the DIVINE network, established in 2004, aimed to 'develop a sustained surveillance and early warning function for outbreaks due to Norovirus and to enhance the European Union's (EU) capability to react to emerging enteric virus threats'.

### 9.1 Discussion and recommendations

The working group explored the following concepts: whether the preparation of outbreak surveillance should be an activity in the coming years; which steps to take in order to pursue this activity; and which diseases to include within the mandate. A first assessment of the usefulness for the different disease groups was presented in a diagram.

The working group identified that the objectives for outbreak reporting should answer the following questions:

- For which disease(s) is it useful?
- In which MS is it available?
- Is there an added value at the European level?

The difference between outbreak detection and outbreak surveillance has been highlighted. A focus should be given on syndromic surveillance rather than laboratory based surveillance. Outbreak surveillance allows producing evidence and effectiveness for action.

The recommendations for ECDC included the following:

- Outbreak surveillance provides a medium European added value.
- As a first step, the current surveillance systems (EFSA, measles outbreak reporting within EUVACNET) that include outbreak surveillance should be evaluated in order to define further objectives.

## 10. Conclusions

Geocoding is feasible but there are some concerns regarding the confidentiality of data.

The concept paper regarding the implementation of molecular typing at EU level was considered useful.

There is a need to improve stability of the metadata set. However, this stability can not be reached until all the networks have been transferred. The implementation of case definitions is a stepwise process and will allow a better comparison of data reported at the EU level. In 2010, ECDC, together with the EU/EEA MS, will monitor the differences in the implementation of the EU case definition at national and European levels.

The proposals for changes in variable definitions should be sent to the national contact points for surveillance.

Tools for the evaluation of national surveillance systems should be developed in order to strengthen the surveillance systems in the MS.

The information collected on outbreak surveillance can indicate failures of public health practice and/or the surveillance system. The current systems for outbreak surveillance should be evaluated.

## References

- [1] 2008/426/EC: Commission Decision of 28 April 2008 amending 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 (notified under document number C(2008) 1589) (Text with EEA relevance). Official Journal L 159 , 18/06/2008 P. 0046 – 0090. <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2008:159:0046:01:EN:HTML>
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- [4] Guidance document from the Task Force on Zoonoses Data Collection on Manual for reporting of food-borne outbreaks in the framework of Directive 2003/99/EC, The EFSA Journal (2009) 257, 1-46
- [5] Gervelmeyer A, Hempen M, Nebel U, Weber C, Bronzwaer S, Ammon A, Makela P. Developing the Community reporting system for foodborne outbreaks. Euro Surveill. 2008;13(45):pii=19029. Available online: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=19029>

# Annex 1: Meeting agenda

## 28 April 2009 — Day 1

- 09:00–09:15**      **Welcome and introduction of participants and objectives of the meeting**  
*Andrea Ammon (ECDC)*
- Session 1**      **TESSy, a tool for European epidemiological surveillance of communicable diseases**  
*Chair: Edward van Straten (ECDC)*
- 09:15–09:40**      Review of activities since January 2008, including trainings held (workshops, online trainings), helpdesk requests, DSN transfers to ECDC, metadata development and lessons learned from data collections, and schedule for annual activities including data calls and nominations.  
*Tina Purnat (ECDC)—Discussion*
- 09:40–10:00**      **Activities under development in TESSy:** new releases, machine-to-machine interface (web service), national TESSy modules.  
*Per Rolfhamre (ECDC)—Discussion*
- 10:00–10:15**      Presentation of the ECDC web portal and the option for extra-net.  
*Catherine Ginisty (ECDC)*
- 10:15–10:45**      **break**
- Session 2**      **Planning annual activities of European epidemiological surveillance with networks of disease-specific national contact points.**  
*Chair: Tina Purnat*
- 10:45–11:15**      Presentation of the Procedure on access to and use of TESSy data by third parties and update from the discussion in the MB.  
*Andrea Ammon*
- 11:15–11:30**      Review of the change process for definition and coding of variables in the European metadataset for surveillance of communicable diseases.  
*Edward van Straten*
- 11:30–12:00**      Proposal and discussion of changes in variables definition and coding.  
*Isabelle Devaux and the disease specific teams (ECDC)*
- 12:00–12:30**      Frequency of reporting and case categories to be reported at EU level in relation to the surveillance objectives.  
*Andrea Ammon*
- 12:30–13:30**      **lunch break**
- Session 3**      **Presentation of national surveillance systems:**  
Impact of TESSy on national surveillance systems, innovative ways of operating surveillance, use of TESSy outputs at national level.  
*Chair: Per Rolfhamre*
- 13:30–14:15**      **Presentations from three countries (15 minutes each):**  
**Romania:** Impact of TESSy on the Romanian National Reporting System (Adriana Pistol).  
**Portugal:** Reform in communicable diseases surveillance system (Mario Carreira).  
**Ireland:** Predefined and ad hoc reporting from a shared national infectious diseases database using business objects software (John Brazil).
- 14:15–14:45**      **Discussion**
- 14:45–15:15**      **break**
- Session 4**      **Working groups**
- 15:15–15:45**      **Short introduction of the topics (plenary):**

Presentation of objectives for strengthening the surveillance of communicable diseases in the European Union.

*Isabelle Devaux*

Implementation of geo-coding in relation to the surveillance objectives

*Edward van Straten (ECDC)*

Implementation of molecular surveillance in EU surveillance

*Johanna Takkinen (ECDC)*

**15:45–17:30**

**Working groups 1 and 2:** Proposal for implementation of geo-coding (due to the signalled interest in the TC, two working groups will be offered for this topic)

**Working group 3:** Implementation of molecular surveillance in EU surveillance

## 29 April 2009 — Day 2

**08:00–09:00**

Technical session for TESSy users (optional): Opportunity to discuss technical topics with the TESSy team (how to prepare a batch, data uploads, data validation).

*(TESSy Operation team member)*

**Session 5**

**Presentations from the working groups**

For working groups 1 to 3, 10 minute presentation and 10 minute discussion; the discussion for working groups 1 and 2 will be done together

*Chair: Edward van Straten*

**09:00–10:00**

Summary reports from WG 1 to 3 followed by a discussion

**10:00–10:30**

**break**

**Session 6**

**Working groups**

**10:30–10:45**

Introduction of the topics (plenary)

**10:45–12:15**

**Working group 4:** Implementation of case definitions: what are the difficulties encountered in the implementation. Case classification to be reported at the EU level.

**Working group 5:** Improving data comparability between countries: How to best identify needs for strengthening national surveillance systems? What information is needed from the national surveillance system?

**Working group 6:** Preparing further development: Surveillance of outbreaks

**12:15–13:30**

**break**

**Session 7**

**Presentations from the working groups;** 10 minute presentation and 10 minute discussion

*Chair: Edward van Straten*

**13:30–14:30**

Summary reports from WG 4 to 6 followed by a discussion

**14:30–15:00**

**Conclusions and next steps**

*Andrea Ammon*

## Annex 2: Participants

Name	Country
Conde Bandera Alejandro	Spain
Bormane Antra	Latvia
Malin Arneborn	Sweden
Mária Avdicová	Slovakia
Nejc Bergant	Slovenia
Sandro Bonfigli	Italy
John Brazil	Ireland
Jitka Castkova	Czech Republic
Norbert Charle	Luxembourg
Andrew Chronias	United Kingdom
Slavica Cvijan	Sweden
Faensen Daniel	Germany
Jevgenia Epshtein	Estonia
Ian Fisher	United Kingdom
Patricia Garvey	Ireland
Anthony Gatt	Malta
Atanas Georgiev	Bulgaria
Marina Golande	Latvia
Peter Grech	Malta
Eva Grilc	Slovenia
Patrick Hau	Luxembourg
Magid Herida	France
Gloria Hernandez Pizzi	Spain
Júlíana Jóna Hédinsdóttir	Iceland
Františka Hrubá	Slovakia
Ionel Iosif	Romania
Natalia Kerbo	Estonia
Rainer Kleyhons	Austria
Anna Kurchatova	Bulgaria
Rasa Liausediene	Lithuania
Mário Fernando Loureiro Carreira	Portugal
Kenn Schultz Nielsen	Denmark
Carlos Manuel Orta Gomes	Portugal
Panagiotis (Takis) Panagiotopoulos	Greece
Stavros Patrinos	Greece
Adriana Pistol	Romania
Bohumir Prochazka	Czech Republic
Barbara Schimmer	Netherlands
Gudrun Sigmundsdottir	Iceland
Aidas Spiccius	Lithuania



## ECDC participants

Name	Title/Unit
Andrea Ammon	Head of unit, SUN
Isabelle Devaux	Expert in general surveillance, SUN
Lennart Nilsson	Data warehouse expert, SUN
Zaibun Nisa	Secretary, SUN
Per Rolfhamre	IT expert
Ines Steffens	Managing editor <i>Eurosurveillance</i> , CCU
Carl Suetens	Senior expert, SUN
Johanna Takkinen	Senior expert surveillance and communications, SUN
Edward van Straten	Head of data management, SUN
Klaus Weist	Seconded national expert, SUN