

REGISTER NUMBER: 519

NOTIFICATION FOR PRIOR CHECKING

Date of submission: 22/7/2009

Case number: 2009-474

Institution: ECDC

Legal basis: article 27-5 of the regulation CE 45/2001⁽¹⁾

(1) OJ L 8, 12.01.2001

Notification no.: 2009-DPO-09

Data received: 15-07-2009

INFORMATION TO BE GIVEN⁽²⁾

(2) Please attach all necessary backup documents

1/ Name and adress of the controller

Andrea Ammon, Head of Surveillance Unit (SUN). Tomtebodavagen 11 A SE 17183 Stockholm, andrea.ammon@ecdc.europa.eu

2/ Organisational parts of the institution or body entrusted with the processing of personal data

Section for Data Management and General Surveillance, Surveillance Unit, ECDC

3/ Name of the processing

The European Surveillance System (TESSy)

4/ Purpose or purposes of the processing

The purpose of TESSy is to perform epidemiological surveillance of communicable diseases, information is collected on cases of communicable diseases covered by the categories as set out in Decision No 2119/98/EC. Processing of data is envisaged for **three different purposes**: **(1)** to collect, validate, analyse and disseminate surveillance data on infectious diseases through TESSy **(2)** to identify the users, nominated by the Member States, with right to access to TESSy and **(3)** to decide on the request of third parties to have access to data contained in TESSy, and to sign contracts with the parts requesting such access.

5/ Description of the category or categories of data subjects

Data subjects of **(1)** are EU citizens who contracted certain infectious diseases (covered by the categories as set out in Decision No 2119/98/EC). Data are collected and uploaded in TESSy database by the MS.

Data subjects of **(2)** are of two different categories: **a)** the "nominators of TESSy users", appointed by the Director of each national competent body for surveillance, have the role to approve new TESSy users nominations from the MS and notify to ECDC changes in user privileges or inactivation of user access to TESSy and data access for others not nominated for access to national data, and **b)** "nominated users" with different profiles assigned by the nominating competent body: "data submitters", "data downloaders" and "data viewers". Each nomination specifies whether the individual has access to data for a specific disease/disease group or to data of all notifiable diseases and can limit the right of the user to process the data (i.e. what can upload and download). Nominated users are experts in surveillance of communicable diseases.

Data subjects of **(3)** are academic institutions, universities, non-EU public health agencies, non-governmental organizations and commercial companies which request access to certain data of TESSy.

6/ Description of the data or categories of data including, if applicable, special categories of data (article 10) and/or origin of data)

(1) With the purpose of epidemiological surveillance of communicable diseases, information is collected on cases of communicable diseases covered by the categories as set out in Decision No 2119/98/EC.

Decision No 2119/98/EC defines epidemiological surveillance as follows: "the ongoing systematic collection, analysis, interpretation and dissemination of health data, including epidemiological studies, concerning the categories of communicable diseases set out in the Annex, in particular relating to the pattern of spread of such diseases over time and space and analysis of the risk factors for contracting such diseases, for the purpose of enabling appropriate preventive measures and counter-measures to be taken"

Collected data includes: age in years (age in month when case younger than 2 years), gender, country of notification, country of birth (data only available for certain diseases) and country of nationality (data only available for certain diseases). Data is uploaded by nominated users chosen by the competent bodies of the MS.

For case based data an identifier (recordId) is provided by the MS that nationally identifies the case. The recordId is only accessible to staff maintaining the system (members of SUN) and the MS that provided the data. All personally identifiable information is removed from the dataset by the submitting MS prior to upload of case-based data into TESSy. Where unique record identifiers are used to report case-based data, they are anonymised and they are not traceable to individuals.

The processing mostly pertains in statistical analysis and descriptive analysis, where in general the data is presented as aggregates. Only when a disease is very rare a description of a single case could be given.

Categories of personal data whose processing is prohibited, with exceptions, by Regulation 45/2001 may include data concerning health.

Data likely to present specific risks may include data relating to health and to suspected offences, offences, criminal convictions or security measures.

Other categories of personal data include data in the form of personal identification numbers (the recordId), and may include data concerning the data subject's private sphere (only information relevant to the epidemiology of specific diseases is collected. For example sexual orientation in relation to sexual transmittable diseases.).

Additional information: a) regarding personal identification numbers, the number stored is not directly linked to personal data. The identifier links to data stored at a national level, that could contain a link to a person. ECDC does not have the right to request this data and can therefore not perform the link; b) information on who from a MS submitted or approved the data is visible to other users within the same MS and to the data controller at ECDC, and is not provided to any third party.

(2) Contact and personal details necessary to identify the user nominators and the nominated users, and define the user profile. Name, Surname, email, phone number, institution/body. No special categories of data or data likely to present specific risks are processed.

(3) Contact details of the institution/company/body interested in the access to the data, and if access is granted and a contract is signed, contact details of the principal researcher assigned to the project.

7/ Information to be given to data subjects

(1) Since data are collected at national level, uploaded from the MS and can't be linked by ECDC to a specific data subject, it is impossible to provide to the data subjects the information contained in art. 12 of Regulation 45/2001.

(2) and **(3)**: privacy statements are included in ECDC and TESSy websites.

8/ Procedures to grant rights of data subjects(*rights of access, to rectify, to block, to erase, to object*)

(1) It is impossible for ECDC to grant rights of access, rectify, block, erase and object to a specific data subjects, because ECDC doesn't know the identity of data subjects.

(2) The Controller may be contacted at any time by email by the data subjects for exercising the right of access, to rectify, to block, to erase the data concerning them. Blocking and erasing data supposes the lost of right to use TESSy.

(3) The Controller may be contacted at any time by email by the data subjects for exercising the right of access, and rectify the data concerning them. If a contract is signed, no erasure will be possible for 10 years after the termination of the contract.

9/ Automated / Manual processing operation

(1) Processing of data is automated; reporting can be both fully automated (on-line reports, aggregates only) or manual.

(2) and **(3)** processing operations are manual.

10/ Storage media of data

(1) Data is stored in electronic format in an anonymous database.

(2) and (3) data are stored in electronic format and in paper in archive binders.

11/ Legal basis and lawfulness of the processing operation

Legal basis (Treaty, Regulation, Decision, etc.) for this processing operation are:

Decision No 2119/98/EC.

Regulation (EC) No 851/2004: article 5.2 describes that ECDC will operate the networks as described in Decision No 2119/98/EC and that ECDC will maintain the database(s) for such epidemiological surveillance.

Moreover the processing operation meets a functional need of the service and, for (2) and (3), the data subject has unambiguously consented to the processing. For (3) data is necessary to perform a contract.

12/ The recipients or categories of recipient to whom the data might be disclosed

(1) All ECDC staff have access to case-based data. Nominated users can have access limited to country data that they received the right to access to. The recordId is only accessible to staff maintaining the system (members of SUN) and the MS that provided the data. Aggregated data can be regularly made accessible on the ECDC web site to the general public in the form of a priori agreed upon/defined aggregated data summary reports. Also, see 15/ below.

(2) Data can be disclosed to SUN staff and ICT to create a user name to grant access.

(3) Data requests for access to TESSy data are directed to ECDC (SUN Unit). ECDC will then forward the request to a Peer-Review Group, consisting of 3 national surveillance coordinators and 2 ECDC experts. Data will also be disclosed to the Head of SUN.

13/ retention policy of (categories of) personal data

(1) For scientific purposes, data is kept for an indefinite period (but no identification of the data subject is possible).

(2) Data are kept for 1 year after contacts are removed from the nominated list by MS.

(3) Data are kept for 10 years after termination of the contract.

**13 a/ time limits for blocking and erasure of the different categories of data
(on justified legitimate request from the data subject)
(Please, specify the time limits for every category, if applicable)**

14/ Historical, statistical or scientific purposes

If you store data for longer periods than mentioned above, please specify, if applicable, why the data must be kept under a form which permits identification,

15/ Proposed transfers of data to third parties or international organisations

(1) Trained staff at the Commission, other EU agencies, competent bodies for surveillance in Member States will have direct access to data. For some diseases (where a joint surveillance is expected), ECDC will grant access, in the form of aggregated and case-based data, to authorized staff at WHO Regional Office for Europe and to staff of non-EU countries participating in the surveillance. Data requests from academic institutions, universities, non-EU public health agencies, non-governmental organisations and commercial companies will be assessed by ECDC through a Peer-Review group consisting of 3 national surveillance coordinators and 2 ECDC experts. In case of positive decision, data will be made available by providing the requested data as an extraction from TESSy. Third parties will have to sign a contract which explains and defines rights and obligations of use of TESSy.

(2) No transfer of data is envisaged.

(3) Data can be disclosed to national surveillance coordinators members of the Peer-review group.

16/ The processing operation presents specific risk which justifies prior checking (*please describe*):

(1) Processing operations likely to present specific risks may include processing of data relating to health.

(2) and **(3)**: processing operations doesn't present specific risks and no prior checking is needed.

AS FORESEEN IN:

☒ Article 27.2.(a) - **limited to (1)**

Processing of data relating to health and to suspected offences, offences, criminal convictions or security measures,

☐ Article 27.2.(b)

Processing operations intended to evaluate personal aspects relating to the data subject,

☐ Article 27.2.(c)

Processing operations allowing linkages not provided for pursuant to national or Community legislation between data processed for different purposes,

☐ Article 27.2.(d)

Processing operations for the purpose of excluding individuals from a right, benefit or contract,

☐ Other (general concept in Article 27.1)

17/ Comments

(1) All data is anonymous and it is impossible for ECDC to link the data to a data subject.

PLACE AND DATE: Stockholm (Sweden), 15/07/2009

DATA PROTECTION OFFICER: Elisabeth Robino

SIGNATURE:

INSTITUTION OR BODY: European Centre for Disease Prevention and Control (ECDC)