ECDC **CORPORATE DOCUMENT**

# Privacy Statement - Processing of personal data for the survey of carbapenem- and/or colistin-resistant Enterobacteriaceae of the European Antimicrobial Resistance Genes Surveillance Network

## 1 Purpose of the processing operation

ECDC processes the personal data collected in accordance with Regulation 2018/1725. Data will be processed for the conduct of the carbapenem- and/or colistin-resistant Enterobacteriaceae (CCRE) survey as part of molecular surveillance of antimicrobial resistant pathogens according to the protocol: https://ecdc.europa.eu/sites/portal/files/documents/Protocol-genomic-surveillance-resistant-Enterobacteriaceae-v2_0.pdf

For the CCRE survey bacterial isolates (carbapenem and/or colistin-resistant Enterobacteriaceae and susceptible control isolates) and related patient data are collected in hospitals in 37 countries with the aim to determine transmission pathways and improve control measures. The patient information related to these bacterial isolates is important to better understand who is at risk for acquiring these resistant bacteria. Further information on the CCRE survey can be found on the homepage of the European Antimicrobial Resistance Genes Surveillance Network (EURGen-Net): https://ecdc.europa.eu/en/about-us/who-we-work/disease-and-laboratory-networks/EURGen-net

## 2 Identity of the data controller

The data controller for this processing operation is European Centre for Disease Prevention and Control (ECDC), Gustav III:S Boulevard 40, 16973 Solna, Sweden. The contact point is data.access@ecdc.europa.eu.

## 3 Legal basis for the processing

The legal basis of the processing operation are:

- Article 5 (a) of Regulation 2018/1725, processing is necessary for the performance of tasks carried out in the public interest attributed by Union or Member State legislation;
- ECDC Founding Regulation (Regulation (EC) No 851/2004), and specifically Article 3 and 11.

# 4 Data subjects and categories of personal data collected

There are two categories of data subjects: 1) Patients whose isolates and data are collected for the CCRE survey 2) Users of the processed patient data.

User groups may include ECDC staff involved in the project, experts nominated by Member States for participation in the project, contractors and sub-contractors working on the project and third parties involved in the project.

The categories of data collected and used for the processing operations are the following:

a) User data:

- Name (first name and surname)
- E-mail
- Phone number
- Address
- Place of employment
- Unit (if ECDC)
- Section (if ECDC).

b) Patient data:

- Age
- Gender
- Type of patient (e.g. in- or outpatient)
- Type of unit/ward (e.g. intensive care unit, surgical, medical)
- Date of hospitalisation
- Isolate unique identifier for the CCRE survey.

Patient data will be collected by national institutions in participating European Union (EU), European Economic Area (EEA), EU candidate and potential candidate countries and will be pseudo-anonymised for the CCRE survey to maintain patient confidentiality before transfer to ECDC. Re-identification of a specific person will not be possible with the patient data available at ECDC. The source from which the patient data originates is medical and laboratory records. The processing of this data will not be used for any automated decision making, including profiling.

# 5 Who has access to this information and to whom is it disclosed?

The recipients of the pseudo-anonymised patient data are the following:

- ECDC staff members
- ECDC's contractors
- Public health experts from participating EU and EEA countries
- Public health experts from participating EU Candidate countries
- Public health experts from other public health collaborating countries
- Experts from other stakeholders (EFSA, EC, WHO)
- Member State and EEA experts nominated by the Coordinating Competent Bodies (for public health experts)
- Experts from non-EEA countries nominated by the national public health authorities

Pseudo-anonymised patient data may be transferred to recipients in third countries or international organisations, for example, Centres for Disease Control and academic institutions for the purpose of improving control of CCRE through surveillance and related research.

Recipients of the user data are the following:

- ECDC staff members
- ECDC's contractors.

User data will not be shared with any institutions or other third parties not involved in access to and maintenance of the CCRE survey databases.

# 6 How long do we keep the patient and user data?

Data will be retained only for as long as necessary until the task is completed.

# 7 How do we protect and safeguard this information?

In order to protect patient and user data, a number of technical and organisational measures have been put in place. Technical measures include appropriate actions to address online security, risk of data loss, alteration of data or unauthorised access, taking into consideration the risk presented by the processing and the nature of the data being processed. Organisational measures include restricting access to the data to authorised persons with a legitimate need to know for the purposes of this processing operation.

The database for the CCRE survey that includes the above mentioned patient data is hosted at the Public Health Agency of Sweden (PHAS) on behalf of ECDC. The web application will be located at the PHAS, on a server protected by a strong firewall and will be under extensive surveillance of incoming traffic. The web application is password-protected and only authorized users as specified above will have access to the data. Backup of the data will occur frequently, incrementally and with redundancy, and technical support will be provided by the PHAS. The Whole Genome Sequencing (WGS) data will be held on a secure platform at the Wellcome Trust Sanger Institute.

Agreements with third parties include the necessary data protection obligations to reflect requirements of Regulation 2018/1725.

# 8 What are the rights of data subjects for the CCRE survey and how can they exercise them?

All data subjects for the CCRE survey have the right to request from the controller access to and rectification or erasure of personal data or restriction of processing it or to object to processing. They have the right to the portability of data. They have the right to withdraw the consent to process their personal data. For this purpose, data.access@ecdc.europa.eu may be contacted at any time.

Exceptions based on Regulation 2018/1725 may apply.

Patient data: Since persons cannot be uniquely identified by ECDC or its contractors from pathogen sequence data and from the linked epidemiological data, requests from these data subjects will be referred to the relevant national authority who provided the isolates or sequences, who may be able to retrieve the information.

User data: Users of WGS databases hosted by ECDC will be managed through the CRM system. If the WGS database is hosted and/or managed by a contractor or collaborator, the contractor or collaborator will provide

secured access to the user's own identification data and assist ECDC with ensuring any necessary remedial action is taken in order to ensure the data subjects' rights are protected.

Should data subjects for the CCRE survey consider that their data is processed by ECDC unlawfully, they can contact the Data Protection Officer at ECDC dpo@ecdc.europa.eu. They also have the right to lodge a complaint with the European Data Protection Supervisor: edps@edps.europa.eu