

## EDPS comments on the European Centre for Disease Prevention and Control (ECDC) draft internal rules concerning restrictions of certain rights of data subjects in the framework of the functioning of the ECDC

### 1. Introduction

- These comments refer to the European Centre for Disease Prevention and Control (ECDC) draft internal rules concerning the restriction of certain rights of data subjects in relation to processing of personal data in the framework of the functioning of the ECDC (hereinafter 'the draft internal rules'). Our comments refer to the document submitted on 7 June 2019.
- We give these comments in accordance with Article 41(2) of Regulation (EU) 2018/1725 (hereinafter 'the Regulation')<sup>1</sup>.

### 2. General comments

- The EDPS welcomes the fact that the ECDC will perform a **necessity and proportionality test** on the need for the restriction of data subjects' rights, according to several provisions of the draft internal rules.
- Concerning the right to information, we also take note that the ECDC is going to publish data protection notices on its website informing all data subjects of the potential restrictions of their rights related to personal data processing.
- These draft internal rules will serve as the ECDC's legal basis to impose restrictions under Article 25 of the Regulation, in the absence of a legal act adopted on the basis of the Treaties. As these restrictions seek to temporarily render unavailable certain rights that lie at the heart of the right to data protection, such as the right to information and the right to erasure, their legal basis should be well defined. Therefore, **the ECDC should assess whether its draft internal rules accurately reflect the specific processing operations it performs or expects to perform**. In doing so, it should consider making a link between the different categories of processing operations in which restrictions may be imposed in Article 1 (2) and the corresponding grounds for restrictions in Article 3(1). Where the ECDC only expects to rely on a certain ground in the light of a specific set processing operations it performs, this could also be further clarified in the draft internal rules.

### 3. EDPS recommendations

- According to the Article 4 (as well as Recital 16) of the draft internal rules, the DPO will be informed without undue delay of each restriction of data subject's rights applied or extended pursuant to the draft internal rules and when the restriction has been lifted. The EDPS recommends the ECDC to **document the involvement of the DPO** along all the procedures, and not only when applying or reviewing a restriction.

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<sup>1</sup> OJ L 295, 21.11.2018, p. 39.

- The ECDC specifically asked the EDPS about the possibility to restrict data subject rights in relation to the European Surveillance System (TESSy) and “other databases containing pseudonymised health data. According to § 5.1 of the ECDC’s policy on data submission, access, and use of data within TESSy – 2015 revision<sup>2</sup> “all personal identifiers will be removed from the data set by the Data Submitter prior to uploading case-based data into TESSy.” As the ECDC states in its email of 11 June 2019, this would leave it, in most cases, unable to identify specific individuals within the database without additional information. However, in scenarios where the data subject could provide sufficient additional information to allow for identification of his/her personal data (see also Article 12 of the Regulation), the ECDC has not presented sufficient reasons why it needs to restrict data subject rights in order to protect the objectives protected by Article 25(1) of the Regulation.

Additionally, the ECDC in its draft internal rules seeks to limit certain rights that do not necessarily require the identification of specific data subjects, such as the right to information and the communication of personal data breaches.

Regarding the right of information to data subjects, the EDPS has previously stated in his Opinion of 3 September 2010<sup>3</sup> that “the ECDC, as the operator of the [TESSy] system is best positioned to play a coordinating role and provide centrally and easily available information on-line, on its website.” The availability of such central information only becomes more important in the case of a significant large-scale event, such as an outbreak, which the ECDC mentioned in the present consultation. As such, it is difficult to see in which scenario the ECDC would want to restrict the information it normally provides to data subjects. In the prior check opinion mentioned, the EDPS implicitly accepted that ECDC could rely on Article 12(2) of the old Regulation (EC) 45/2001 to not individually inform data subjects, but instead publish general information on its website. That approach is still compliant with the new Regulation (see Articles 16(5)(b) and 12(1) of the new Regulation. As this information is a general information notice, it is unlikely that it would require updating in response to a specific outbreak.

In the context of data breach notifications, Article 35 already anticipates a number of scenarios in which the controller could refrain from individual notification to the data subject, such as where this notification would involve disproportionate effort. Therefore, it is unclear why the ECDC would intend to restrict the communication of a data breach involving TESSy or a similar database to data subjects, beyond the limitations already provided in Article 35 of the Regulation.

<sup>2</sup> Available on the ECDC website: <https://ecdc.europa.eu/sites/portal/files/media/en/aboutus/what-we-do/surveillance/Documents/TESSy-policy-data-submission-access-and-use-of-data-2015.pdf>

<sup>3</sup> Prior checking opinion on the European Surveillance System (“TESSy”) notified by the European Centre for Disease Prevention and Control (“ECDC”) on 22 July 2009 (Case 2009-0474), available on the EDPS website: [https://edps.europa.eu/sites/edp/files/publication/10-09-03\\_tessy\\_ecdc\\_en.pdf](https://edps.europa.eu/sites/edp/files/publication/10-09-03_tessy_ecdc_en.pdf).

**In conclusion, the EDPS recommends the ECDCC to remove the “operation of TESSy or similar pseudonymised health databases” as a processing operation for which it may restrict data subject rights.**

Brussels,

**22 JUL 2019**

A handwritten signature in blue ink, consisting of a stylized 'A' followed by a horizontal line and a vertical stroke.