European Parliament
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Committee on Petitions

18.12.2023

NOTICE TO MEMBERS

Subject: Petition No 0225/2019 by Maarit Nermes (Finnish) on stopping the sale of health care and other personal information of Finnish citizens without consent

1. Summary of petition

The petitioner claims that, on 13 March 2019, the Finnish parliament approved legislation permitting the use and even the sale of health care and other personal data, such as social care, unemployment, pension, police and justice system information, without citizens' consent and with the justification that such data will be anonymous (FI laki sosiaali- ja terveystietojen toissijaisesta käytöstä).

She also claims that, when the draft law was discussed in parliament, several constitutional and human rights experts stated that it was in breach of the Finnish Constitution, the European Convention on Human Rights and the EU General Data Protection Regulation.

2. Admissibility

Declared admissible on 14 June 2019. Information requested from Commission under Rule 227(6).

3. **Commission reply**, received on 30 September 2019

The Charter of Fundamental Rights of the European Union guarantees in Article 8 explicitly that everyone has the right to the protection of personal data concerning him or her. On 25 May 2018 Regulation (EU) 2016/679, the General Data Protection Regulation ('GDPR')[1] became applicable. The principles and rules set out by the Regulation apply directly to companies and organisations in the private sector as well as to authorities and public bodies in

[1] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), OJ L 119, 4.5.2016, p. 1–88.

the public sector that process personal data[2] of individuals.

Pursuant to Article 5 GDPR personal data must be processed notably fairly and lawfully, for specific and legitimate purposes, and must not be further processed in a manner incompatible with those purposes. However, further processing of personal data for, amongst other things, scientific research or statistical purposes shall, in accordance with Article 89(1) GDPR not be considered to be incompatible with the initial purposes. Moreover, personal data must be adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.

The processing of personal data is only lawful if at least one of the following six legal grounds is fulfilled, namely: consent of the data subject; necessity for the performance of a contract or for entering into a contract with the data subject; necessity for compliance with a legal obligation incumbent on the data controller; necessity for the protection of the vital interests of the data subject or another natural person; necessity for the performance of a task in the public interest or in the exercise of public authority vested in the controller; necessity for the purposes of the legitimate interests pursued by the data controller or by a third party except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject (Article 6(1) GDPR).

Furthermore, Article 9(1) GDPR prohibits the processing of inter alia genetic data, biometric data for the purpose of uniquely identifying a natural person, and data concerning health unless the processing of these special categories of data is covered by one of the exemptions provided for in Article 9(2) GDPR.

Pursuant to Article 9(2)(j) GDPR, Member State law may provide for the processing of special categories of data for scientific research purposes; such law must be proportionate to the aim pursued, respect the essence of the right to data protection, and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the individuals concerned. Where the law serves as the legal basis for the processing of health data, consent of the concerned individuals may nonetheless be provided for in the law as an ethical standard or an appropriate procedural safeguard[3].

Article 89(1) GDPR requires that the processing for purposes such as scientific research be subject to appropriate safeguards in particular through the implementation of technical and organisational measures to ensure respect for the principle of data minimisation. Those measures may include pseudonymisation. Where the purposes can be fulfilled by further processing which does not permit or no longer permits the identification of the data subjects,

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[2] Personal data is defined in Article 4(1) of Regulation (EU) 2016/679 as 'any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person'.

[3] See Guidelines from the European Data Protection Board on consent under Regulation (EU) 2016/679 of 10 April 2018, page 28, available at: https://edpb.europa.eu/our-work-tools/general-guidance/gdpr-guidelines-recommendations-best-practices_en

those purposes shall be fulfilled in that manner. In this respect it must be recalled that, in the light of Article 4(1) GDPR read together with recital 26, anonymisation should be irreversible by implementing measures ensuring that there is no possibility to re-identify the data subjects.

The recently adopted Finnish law which is the subject of this petition lays down the legal basis and the modalities for the secondary use of social and health information stored in national personal registers. The law deals in some aspects with the processing of personal data for scientific research purposes. Processing for these purposes may therefore fall within the scope of Article 9(2)(j) read in conjunction with Article 89(1) GDPR, provided that the law fulfils all the requirements set out in those provisions.

The Finnish law would also seem to allow secondary use of personal data for purposes other than scientific research, such as for commercial purposes. Pursuant to Article 6(4) GDPR, processing for a purpose other than that for which the personal data have been collected may take place on the basis of Union or Member State law which constitutes a necessary and proportionate measure in a democratic society to safeguard the objectives referred to in Article 23(1) GDPR. This notably requires that the purposes pursued are sufficiently specified in the law and that they relate to important objectives of general public interest of the Union or of a Member State[4].

Considering the high risks incurred by processing health data for secondary purposes, the Commission recalls that a data protection impact assessment should be carried out as part of a general impact assessment in the context of the adoption of the law (Article 35(3) and 35(10) GDPR). Furthermore, the Commission notes that the Finnish Data Protection Ombudsman was consulted on the draft legislation and issued an opinion in which it recommended that the proposed legislation be clarified, in particular in order to clearly identify the purposes of scientific research and those related to development and innovation and to ensure compliance with the GDPR by requiring consent of data subjects for sharing their personal data for purposes other than scientific research[5].

Conclusion

The Commission has received a complaint on the matter raised in this petition and is currently examining it.

4. Commission reply (REV), received on 18 December 2023

The Commission has examined the issue of the Finnish legislation concerning the secondary use of health data following a complaint referred to in its previous reply to this petition. In this context, the Commission has concluded the following:

The GDPR (General Data Protection Regulation) sets horizontal rules for the processing of

[4] Article 23(1)(e) of the GDPR.
[5] See Opinion of the Finnish Data Protection Ombudsman from 20 November 2017 published at: https://www.eduskunta.fi/FI/vaski/JulkaisuMetatieto/Documents/EDK-2017-AK-158197.pdf

personal data that are directly applicable in the Member States. Pursuant to Article 6 GDPR, a processing of personal data is only lawful if one of the six legal grounds for processing is fulfilled, namely: consent of the individual; if necessary for the performance of a contract or for entering into a contract with the person concerned; for the compliance with a legal obligation to which a data controller is subject; for the protection of the vital interests of the data subject or another natural person; for the performance of a task in the public interest or in the exercise of public authority vested in the controller on the basis of an EU or Member State law; or for the purposes of the legitimate interests pursued by the data controller or by a third party except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject (Article 6(1) GDPR). Furthermore, when data relating to health are processed, additional conditions must be fulfilled pursuant to Article 9(2) GDPR.

As a result, consent is one of the legal grounds that may be relied upon to process personal data, but not the only one. Justifications for the processing of health data may also be laid down in EU or national law that meets an objective of public interest and is proportionate to the legitimate aim pursued.

In this respect, the GDPR allows Member States to adopt national laws to provide a legal basis for processing that is necessary for a compliance with a legal obligation or for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller (Article 6(3) GDPR). In such cases, Member States may introduce more specific provisions to adapt the application of the rules of the GDPR by determining more specific requirements for the processing and other measures to ensure lawful and fair processing (Article 6(2) GDPR). Such specifications may notably take place with respect to the processing of health data for reasons of public interest in the area of public health (Article 9(2)(i) GDPR) and for processing necessary for scientific research (Article 9(2)(j) GDPR). Furthermore, pursuant to Article 6(4) GDPR, the processing for a purpose other than that for which the personal data have been collected may be based on a Union or Member State law which constitutes a necessary and proportionate measure in a democratic society to safeguard the objectives referred to in Article 23(1) GDPR. This notably requires that the purposes pursued are sufficiently specified in the law and that they relate to important objectives of general public interest of the Union or of a Member State, including public health and social security[6].

Therefore, under the GDPR, Member States may validly adopt laws that allow for the further processing of health data for purposes of public interest and that may provide further specifications, conditions or limitations to the processing of data concerning health (Article 6(2) GDPR, Article 9(2)(j) GDPR and Article 9(4) GDPR). Such laws must meet important objectives of public interests, be necessary and proportionate to the legitimate aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the individuals concerned.

As regards the secondary use of personal data outside the scope of scientific research, in particular for development and innovation purposes, we have taken note of the changes that were introduced in Section 37 of the Act following the recommendations made by the Finnish Constitutional Committee[7] and the Finnish Data Protection Ombudsman during the legislative

[6] Article 23(1)(e) of the GDPR.

[7] https://www.eduskunta.fi/FI/vaski/Lausunto/Sivut/PeVL_1+2018.aspx

process[8]. Section 37 of the Act allows only the disclosure of aggregated anonymised data where this is necessary for one of the three specific purposes mentioned therein which relate to important objectives of general public interest. The further processing under Section 37 would appear to fulfil the conditions in Article 6(4) of the GDPR.

Conclusion

Based on the information submitted to it, the Commission is not in the position to determine a breach of the European data protection legislation by Finland.

[8] See Opinion of the Finnish Data Protection Ombudsman from 20 November 2017 published at: https://www.eduskunta.fi/FI/vaski/JulkaisuMetatieto/Documents/EDK-2017-AK-158197.pdf