

7.12.2023

A9-0395/550

Amendment 550
Mathilde Androuët
on behalf of the ID Group

Report
Tomislav Sokol
European Health Data Space
(COM(2022)0197 – C9-0167/2022 – 2022/0140(COD))

A9-0395/2023

Proposal for a regulation
Recital 5 a (new)

Text proposed by the Commission

Amendment

(5 a) Although Regulation (EU) 2016/679 does not apply to the personal data of deceased persons, such data, in particular health data, may constitute personal data of the relatives of deceased persons and create certain risks. Member States are encouraged to allow either a person appointed by the data subject during their life or a close relative, if a close relative has a legitimate interest in such protection or for family reasons worthy of protection, to exercise the data subject's rights as a deceased person arising from this Regulation after their death, in particular to fully or partially opt-out of having some or all of their personal electronic health data processed for secondary use. Data holders should ensure that data of deceased individuals are kept in a way that ensures the confidentiality of such data, in particular by applying relevant technical and organisational measures, and is respectful to the deceased individuals and their relatives. Member States are encouraged to allow data subjects to establish instructions for the management of their personal data after death. In cases where a data subject has expressly forbidden it with a written declaration, exercise of data subject rights by an appointed person or a close relative should not be permitted.

Or. en

Justification

The management of post-mortem data is a blind spot in the text. This addition would correct that. It would give all European citizens who have given their consent to share their health data within the EHDS the option of choosing whether their data can be entrusted to a trusted third party upon their death. This choice would be modifiable on request throughout the individual's life.

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Proposal for a regulation
Article 60 a (new)

Text proposed by the Commission

Amendment

Article 60a

***Storage, processing, back-up and transfer
of electronic health data***

***For the purposes of primary and
secondary use of electronic health data,
Member States shall ensure that the
storage, processing and analysis of
electronic health data shall be carried out
exclusively within a secure location or
locations within the territory of the Union,
by a European undertaking or
consortium, governed by Union
legislation, in which the majority of the
shareholdings, whether direct or indirect,
are European, without prejudice to the
possibility of transferring personal
electronic health data in compliance with
Chapter V of Regulation (EU) 2016/679.***

Or. en

Justification

The storage, processing, backup and transfer of electronic health data must be carried out by a out by a European company or consortium, on the European soil and governed by the European law.