Steering Committee on Media and Information Society - CDMSI

COUNCIL OF EUROPE

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CDMSI comments

on the Draft Recommendation on the Protection of Health-Related Data of the Consultative Committee of the Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data

1. The CDMSI examined with interest the Draft Recommendation of the Committee of Ministers to member states on the Protection of Health-Related Data, prepared by the Consultative Committee of the Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data (T-PD).

2. The CDMSI is pleased to note that this draft recommendation contributes to the implementation of the Council of Europe's Internet Governance Strategy 2016-2019. The Internet Governance Strategy also envisages measures aimed at addressing the challenges for the protection of personal data, including health-related data, while ensuring security and safety. Furthermore, the strategy also looks into the governance of mobile health and electronic health in order to improve and preserve patients' access to health care products, information and related services.

3. The CDMSI would like to draw the attention of the T-PD to the following points:

   a. Under paragraph 3, the broad definition of "unidentifiable" may be open to abuse; in this light consider amending the sentence "an individual shall not be regarded as identifiable if identification requires unreasonable time, effort or resources", for example by specifying that the assessment of those criteria should be made on a case-by-case basis.

   b. In relation to paragraph 4.1(c) the CDMSI also proposes to clarify that "the processing of data should be *necessary and* proportionate".

   c. Given the particular sensitivity of health-related data, consider specifying in more detail the scope of legitimate basis provided under paragraph 5.1(a), where the text might benefit from a more specific definition/guidance for interpretation of "administration of care" and "management of health services" and from safeguards preventing broad data sharing arrangements in the health and social sectors. Also consider adding to paragraph 5.1(b) the condition of public interest and/or specific safeguards to mitigate its non-exhaustive nature. Specific

safeguards could also be added to paragraph 5.1(e) to limit potentially wide reasons of public interest.

d. The requirement that genetic data of unborn children should enjoy an appropriate protection contained in paragraph 6 does not appear to be sufficiently specific. Former Recommendation (97)5 was more clear in its requirement that such data should be considered as personal data and enjoy a protection comparable to the protection of the medical data of a minor.

e. Under paragraph 7.3 after "specific criminal offence" consider adding "and subject to appropriate procedural safeguards, such as prior judicial authorisation".

f. The procedural safeguards (i.e. those of access to information and the remedies available) aimed at protecting the rights of the data subject could be more clearly articulated under paragraphs 5.4 and 11.6. As concerns access to information, greater coordination should be ensured between the obligations of the data controller regarding information on processing of health-related data provided in sub paragraph 11.1, and the rights of the data subject regarding communication of his/her health-related data and provision of other information under paragraph 12.1. The type of remedies that should be made available in line with paragraph 12.3 should also be clarified in more detail.

g. Under paragraph 11.1 after "the purpose for which the data are processed" consider deleting "and where appropriate of the relevant legal basis for it". The CDMSI takes the view that the information provided by the data processor should always include the legal basis for the processing of data.

h. The formulation of paragraph 13.1 in the English language version is unclear. The CDMSI proposes an alternative wording: "The processing of health-related data is to be made secure. In this regard, security measures adapted to the risks for human rights and fundamental freedoms must be defined to ensure that all stakeholders observe high standards guaranteeing the lawfulness of the processing and security and confidentiality of such data".

i. The formulation of paragraph 15.2 in the English language version is also unclear. The CDMSI proposes a slightly different wording: "The need to process health-related data for the purposes of scientific research should be evaluated in the light of the aim pursued and the risks to the data subject and, as concerns the processing of genetic data, in light of the risk to his/her biological family".

j. Paragraph 15.11(b), which enables disclosure of the data subject's identity without consent, would benefit, due to the sensitivity of the subject matter, from more detailed guidance on safeguards applicable to interferences with the right to protection of privacy and personal data which follow from the Convention for the Protection of Human Rights and Fundamental Freedoms. In addition to providing that the publication should be in accordance with the law and necessary for the presentation of research findings, the CDMSI proposes to specify that any such publication should also pursue a legitimate aim:

    "b.   where law permits such publication under the condition that it pursues a legitimate aim capable of justifying an interference with the right to protection of privacy and personal data and is indispensable for the presentation of research findings on contemporary events, and only to the

extent that the interest in publishing the data overrides the interests and fundamental rights and freedoms of the data subject".

4. Lastly, the CDMSI invites the T-PD to consider adding to the preamble of the draft recommendation a reference to the Recommendation of the Committee of Ministers CM/Rec(2010)13 on the Protection of individuals with regard to automatic processing of personal data in the context of profiling.