

Open letter to MEPs ahead of the European Parliament's votes on the proposed General Data Protection Regulation and the Initiative report on electronic mass surveillance of European citizens

Brussels, 11 March 2014

Distinguished Member of the European Parliament,

On 12 March 2014, you will be voting on two crucial texts for the privacy of EU citizens: the proposed General Data Protection Regulation (GDPR) – 2012/0011 (COD); and the initiative report on electronic mass surveillance of European citizens – 2013/2188 (INI). These texts will have an impact on the protection of health and medical data.

Ahead of the votes, We - the European physicians, dentists and community pharmacists-, would like to highlight the following points:

General Data Protection Regulation – 2012/0011 (COD)

- **New recital 122a (amendment 84)** foresees that the knowledge of patients' identity shall be left "(...) only to the General Practitioner or to the Specialist who has requested such data processing". Other healthcare professionals will only have the right to access either pseudonymised or anonymised data. **We urge you to refuse this recital** since it may exclude other health professionals, such as pharmacists and dentists, from the possibility of managing patient treatment with the help of patient records.
- An exemption to the **right to be forgotten** should be foreseen for direct treatment purposes. This is currently not the case since article 17.3.b (**amendment 112**), only foresees an exemption for public health purposes. **Article 17.3.b should read "(...) for health purposes in accordance with Article 81"**.
- Data protection law should in no way trump medical law and its ethical approach to **consent**. **We urge you to refuse Article 81.1.b(new) (amendment 191)** which states "(...) the consent may be given for one or more specific and similar researches". This provision puts the basic principle of informed consent in medical research at risk while it is an internationally recognised standard laid down in the WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects, dating from 1964.
- The introduction of requirements for a **Data Protection Officer (DPO) (article 35 - amendment 132) and Impact Assessments** (article 33 - amendment 129) should not create unsustainable burden for healthcare professionals. The proposal to designate a DPO and carry out an impact assessment when the processing of data relates to more than 5000 data subjects during a year would be significantly costly and potentially unsustainable for small medical, community pharmacy and dental practices which often process data of a large group of individuals notwithstanding their relatively small size and limited staff resources. **We urge you to refuse this proposal.**

Initiative report on electronic mass surveillance of European citizens - 2013/2188(INI)

Health professionals are bound by confidentiality obligations. Professional confidentiality is the foundation of trust in the patient – doctor, dentist or pharmacist relationship. Without this trust being guaranteed, the therapeutic relation risks suffering irreversible consequences on the quality of and access to care. The fact that some personal health data – ie. health records – might have been accessed by any unauthorised institutions in

the framework of surveillance programs, constitutes a grave unlawful intrusion in the most intimate sphere of patient's privacy.

We therefore highly support the proposal of the report to launch a *European Digital Habeas Corpus* and its priority action n°6 on the protection of professional confidentiality (paragraph 131). We hence ask you to support the report.

Sincerely,



Dr Wolfgang Doneus
CED President

Dr Katrín Fjeldsted
CPME President

Mr Štefan Krchňák
PGEU President