

A submission concerning the consultation
“A comprehensive approach on personal data protection in the European Union”
COM (2010) 609 final

Introduction

The Commission of the Bishops' Conferences of the European Community (COMECE) brings together Bishop delegates from the Bishops' Conferences of the European Union's Member States. For thirty years now, COMECE has been accompanying the process of European integration, offering its reflections. COMECE is a partner of the EU institutions in the dialogue foreseen by Article 17(3) of the Treaty on the Functioning of the European Union. Its permanent General Secretariat, based in Brussels, analyses EU policies on a day-by-day basis, striving to bring the specific contribution of the Catholic Church into the debate.

In the light of this, the COMECE Secretariat is pleased to submit to the attention of the European Commission the following remarks on the Communication “A comprehensive approach on personal data protection in the European Union” COM (2010) 609 final.

With this regard, we deem it would appropriate, if we explore any future possibility of further contacts with your Services for the discussion of additional elements, on the basis of the specific channel of dialogue foreseen by Article 17(3) of the Treaty on the Functioning of the European Union.

Article 17(1) of the Treaty on the Functioning of the European Union

With the entry into force of the Treaty of Lisbon, Article 17 of the Treaty on the Functioning of the European Union has become primary law of the Union.

Paragraph 1 of Article 17 TFEU provides that *“The Union respects and does not prejudice the status under national law of churches and religious associations or communities in the Member States”*.

In this regard we would suggest as opportune the insertion in the proposal for the revision of Directive 95/46/EC of a provision that makes reference to the one contained in Article 17(1) TFEU¹.

¹ In this context, we would like to recall the precedent of Recital 24 of Directive 2000/78/EC (establishing a general framework for equal treatment in employment and occupation), which included a reference to Declaration No 11 annexed to the Final Act of the Amsterdam Treaty. The text of the said Declaration has now been transposed into Article 17(1) TFEU as for the fact that the Union respects and does not prejudice the status under national law of Churches and religious associations or communities in the Member States.

Genetic data (with reference to paragraph 2.1.6 of the consultation document)

Genetic data, closely related to data concerning health life, for example, is clearly as sensitive as other data already explicitly mentioned in the directive. Therefore, their inclusion as a “sensitive category” is adequate, needed and recommended.

Decoding human genome was an achievement of undeniable importance for fields such as preventive medicine. However, it posed new challenges in the field of data protection.

Clearly linked with personal identity², this issue must be tackled taking into consideration the bold ethical questions it raises in the light of the protection of human dignity.

It is imperative, namely, that genetic data is not used as means for discrimination and/or stigmatization of any individual, family, group or community, for example, for eugenic purposes. In this context, Article 11 (“Non-discrimination”) of the Convention on Human Rights and Biomedicine clearly states that “any form of discrimination against a person on grounds of his or her genetic heritage is prohibited” and Article 3 (“Right to the integrity of the person”) of the Charter of Fundamental Rights of the European Union explicitly prohibits eugenic practices³.

Protection must be granted not only regarding processing, accessing and using but also collecting and storing of genetic data. Deriving from the right to respect for private and family life⁴, the principle of confidentiality is to be applied here. Informed consent, without which any collection of genetic data is abusive, is also paramount⁵.

The conciliation of these rights with other legitimate individual, familial or other collective or public interests shall be pursued by application of the principle of proportionality and taking into consideration the principle of solidarity and also the principle of the primacy of the human being enshrined in Article 2 of the Convention on Human Rights and Biomedicine⁶. In particular, such individual interests should never be submitted to other, strictly commercial ones, which could happen in the case of disclosure of genetic data in the context of insurance or labor relations⁷.

Finally, if it is important to protect individuals against all these threats, it will be of the highest importance to protect the most vulnerable members of the human community – the unborn human beings, *in vivo* or *in vitro* – from similar threats.

² In this sense, see Article 3 (“Person’s identity”) of the International Declaration on Human Genetic Data (UNESCO).

³ See also Article 7 (“Non-discrimination and non-stigmatization”) of the International Declaration on Human Genetic Data (UNESCO).

⁴ See Article 8 of the European Convention on Human Rights. See also Article 10 (“Private life and right to information”) of the Convention on Human Rights and Biomedicine.

⁵ See Article 3 (“Right to the integrity of the person”) of the Charter of Fundamental Rights of the European Union.

⁶ “The interests and welfare of the human being shall prevail over the sole interest of society or science”.

⁷ See Article 12 (“Predictive genetic tests”) of the Convention on Human Rights and Biomedicine. Connected to this matter, the Secretariat of COMECE issued some “Comments on Opinion no. 18 of the European Group of Ethics (EGE) concerning ethical aspects of genetic testing in the workplace”, dated of 10 October 2003, which can be found in <http://www.comece.eu/site/en/publications/otherpublications/article/3338.html>.

Genetic data (with reference to paragraph 2.3 of the consultation document)

Some genetic data can be used for identification of people in what is currently called “identification by genetic prints”. Some of this genetic data can also reveal certain personal genetic characteristics, namely, risks of developing some disease. In order to preserve the values and rights referred to in our answer to 2.1.6, such genetic data should be identified in order not to allow the disclosure of such personal genetic characteristics.

This, alone, is enough reason why it is recommended to introduce specific rules regarding the processing of genetic data for criminal law purposes.

*COMECE Secretariat,
Brussels, 14.01.2011*

Please note: we would like to ask for the present document not to be published on the consultation website, requesting that our entire contribution be treated as confidential, in accordance with point 4 of the Privacy Statement for the present consultation. Thank you.