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**From:** Kaai, Geran  
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**From:** [redacted] [mailto:[redacted]]  
**Sent:** dinsdag 15 april 2014 12:57  
**To:** Kaai, Geran  
**Subject:** EUA position GDPR

Beste Geran,

De European Universities' Association heeft een excellent statement gepubliceerd over de GDPR. Ze ondersteunen de positie van de Wellcome Trust waar de NFU ook de joint statement van de Wellcome Trust ondersteunt en daarnaast geeft de EUA expliciet aandacht aan health research:

The LIBE Committee amendments alter dramatically the ability to be able to conduct medical and health research (Art. 81). The precise legal impact of the proposed amendments for scientific research across Europe is still uncertain, but the unintended consequences may be quite dramatic. It is anticipated that "at worst health research involving personal data would be illegal; at best it would be largely unworkable", as indicated in the Wellcome Trust statement.

Goed om van op de hoogte te zijn lijkt me zo. Ze geven de Raad van Ministers advies om art 81 en 83 te laten staan zoals EC ze initieel heeft voorgesteld en om hun voorgestelde argumenten serieus te nemen in onderhandelingen over deze artikelen in de Raad. Kortom, nog meer lobby naast de brieven die wij al hebben gestuurd, dus zeker iets om mee te nemen in jullie discussies ☺

Hartelijke groet,

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## **EUA statement**

### **On the Proposal for a General Data Protection Regulation: A Potential Threat to the Advancement of Scientific Research Using Personal Data**

#### **Context**

On 25 January 2012, the European Commission proposed a major reform of the EU legal framework on the protection of personal data<sup>1</sup>. The Regulation will establish a single, pan-European law for data protection, replacing the current national laws. The proposal aimed at updating and modernising the principles in the 1995 Data Protection Directive<sup>2</sup> to guarantee privacy rights in the digital age. It included a set of provisions relating to specific data processing in several contexts including a) Processing of personal data and freedom of expression (Art. 80); b) Processing in the employment context (Art. 82); c) Existing data protection rules of churches and religious associations (Art. 85); d) Processing of personal data concerning health (Art. 81); e) Processing for historical, statistical and scientific research purposes (Art. 83). It is worth noting that the provisions for research had been carefully drafted taking account of research performing organisations' needs.

On 21 October 2013, the Civil Liberties, Justice and Home Affairs (LIBE) Committee adopted several amendments to the Commission's proposal. On 12 March 2014 the European Parliament accepted the proposal of the new regulation (first reading) including the amendments proposed by the LIBE Committee (621 votes in favour, 10 against and 22 abstentions).

The Council of Ministers (Justice and Home Affairs, JHA) will meet on 5-6 June 2014 to discuss the proposal and may, in turn, propose amendments to the original proposal by the European Commission.

The EUA statement sets out key messages for the upcoming meeting of the Council of Ministers. Its purpose is to alert those present to the need to balance the protection of individual data and its availability for the purposes of scientific research.

#### **EUA Position**

Scientific research is largely collaborative in nature and Europe's universities are increasingly European and international in their character and activities. The strengthening of international research collaborations between universities is crucial for reaching Horizon 2020 goals and for addressing societal challenges. Universities operate within existing codes of conduct, with their researchers following guidance built on strong and internationally-recognised ethical principles.

EU regulation needs to reflect and support these realities by protecting both individuals' rights to privacy and openness in scientific collaborations, particularly with regard to the international transfer and secondary processing of data.

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<sup>1</sup> COM(2012) 0011, 25 January 2012, [http://ec.europa.eu/justice/data-protection/document/review2012/com\\_2012\\_11\\_en.pdf](http://ec.europa.eu/justice/data-protection/document/review2012/com_2012_11_en.pdf)

<sup>2</sup> Data Protection Directive (95/46/EC), 24 October 1995, <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=OJ:L:1995:281:FULL&from=EN>

Given the importance of the continued pursuit of knowledge and its ultimate application for the benefit of society, and of strengthening research and scientific development in Europe and particularly of Europe's universities, EUA subscribes to the arguments raised in the Wellcome Trust statement<sup>3</sup> and underlines the following:

- The harmonisation of national regulations as proposed by the Commission is seen as a positive development, provided that the necessary exceptions guaranteeing the conduct of scientific research are in place, and that best practice in existing national legislations which regulate the collection and use of personal data in research remain (Art. 81 and Art. 83). Examples include existing data protection laws regulating the activity of ethical committees that can make contextual informed judgements on the justification for access to data to carry out specific research.
- The extent of the use of personal data, including sophisticated arrangements to assure confidentiality (referred to as pseudo-confidentiality), is growing rapidly. The Commission's initial proposal was welcomed because it was drafted to meet the needs of scientific research, and had proportionate mechanisms for protecting individuals' privacy in health and medical research (e.g., personal data should not be used where anonymous data would be sufficient, and, if possible, any identifiable information should be kept separately from other information, as in Art. 83).
- European Universities engaged in research that requires the use of personal data will be affected by the Regulation. Some of the LIBE Committee's amendments in Art. 42, Art. 81 and Art. 83 impose restrictions that may unintentionally threaten scientific advancements in these areas all across Europe. For example, in the field of social sciences, restrictions could affect long-term studies (e.g. The European Social Survey), and in the field of individualised medicine and personalized preventive medicine the effectiveness of essential tools could be severely compromised.
- The LIBE Committee amendments alter dramatically the ability to be able to conduct medical and health research (Art. 81). The precise legal impact of the proposed amendments for scientific research across Europe is still uncertain, but the unintended consequences may be quite dramatic. It is anticipated that "at worst health research involving personal data would be illegal; at best it would be largely unworkable", as indicated in the Wellcome Trust statement.
- Proportionate mechanisms regarding secondary processing of data (Art. 6(4)) and/or international transfer of data (Art. 42), with due safeguard<sup>4</sup> provisions, will be important to support large European investments (e.g., in bio-banks) in research infrastructures and research personnel in reaching their full potential. For instance, the new regulation should avoid restricting unreasonably the secondary processing of personal data to ensure that the secondary use of personal data in scientific research can still be conducted where it is not possible to seek specific consent.
- Europe's universities are increasingly developing research collaborations with research organisations in other areas in the world. The value of and need for international transfers (outside EU) of personal data for research purposes to maintain the competitiveness of European research at a global level should be specifically recognised. Therefore EUA supports the amendment proposed by the ITRE Committee outlined in the Wellcome Trust analysis (new paragraph Art. 83 (4) suggested under amendment 138 of Art. 42(5)).

<sup>3</sup><http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Personal-information/Data-protection-legislation/index.htm>

<sup>4</sup> "safeguard" as indicated in the proposed reform COM (2012) 0011.

Europe's universities must be able to play their full part in realising the ambitious goals of the European Research Area. Moreover, the emergence of complex research issues such as those requiring the use of large personal data sets, require new interdisciplinary approaches and skills. It is therefore important that doctoral education, career development and researchers' exchange and scientific cooperation in areas such as those tackling global society challenges are not negatively impacted by the final adoption of a data protection regulation that fails to take fully into account the needs of Europe's researchers.

Considering the above, EUA calls for the Council of Ministers to:

- Take into consideration in their discussions the arguments here presented to preserve the access to and use of data for scientific research, the purpose of which is to benefit both individuals and society at large.
- Adopt the original EC proposal, and in particular, to keep the content of Articles 81 and 83 as initially drafted.

Brussels, April 2014

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- Rectors' Conference, French Community of Belgium
- Flemish Interuniversity Council
- Bulgarian Rectors' Conference
- Croatian Rectors' Conference
- Cyprus Rectors' Conference
- Czech Rectors' Conference
- Universities Denmark

- Estonian Rectors' Conference
- Universities Finland
- Conference of University Presidents (France)
- German Rectors' Conference
- Greek Rectors' Conference
- Conference of Rectors of Roman Pontifi cal Universities
- Hungarian Rectors' Conference
- Rectors' Conference of Iceland
- Irish Universities Association
- Conference of Italian University Rectors
- Latvian Rectors' Council
- Lithuanian Universities Rectors' Conference
- Rectors' Conference of Luxembourg
- Association of Universities in the Netherlands
- Norwegian Association of Higher Education Institutions
- Conference of Rectors of Academic Schools in Poland
- Council of Rectors of Portuguese Universities
- Romanian Council of Rectors
- Serbian Rectors' Conference
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- Slovenian Rectors' Conference
- Spanish Rectors' Conference
- Association of Swedish Higher Education
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