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*Fifth World Congress for Freedom of Scientific research*

*Speech by*

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Good morning ladies and gentlemen.

It is my real pleasure to contribute to such a prestigious event today. Let me extend my warmest thanks to the organisers, and in particular to Marco Cappato, for the invitation.

An invitation which I am delighted to honour today yet the intricacy of which I would not deny.

The matter that this congress touches upon is all but an easy one and it builds upon a specific thread: that scientific research should be free. And in fact, this goes without saying. Scientific research should be free to operate for the common good.

However, while the curing of diseases and alleviation of pains have always represented top priorities in the 'human agenda', we should not underestimate the role played in this sensitive matter by other attributions of the human being.

Individual's fundamental rights. Freedoms have to enter into dialogue with individual rights, in particular fundamental rights, like privacy and data protection.

The institution I chair is responsible for monitoring compliance by EU institutions with data protection laws. We also advise the regulator on legislation which may have an impact on data protection and privacy.

Personal data is the raw input of research activities. I would say that personal data is critical to ensure quality of and reliability in scientific research.

Genetic, biometric and health data are very sensitive type of data, whose use is able to affect the innermost sphere of intimacy of human beings, for which there is a general prohibition of processing in the GDPR.

There is more: in order for scientific research to be accurate and effective, it needs vast amounts of data. The more data it gets the more precise the response can be. Science

makes use of big data and will continue to do so increasingly. This is the reason why personal data protection needs to play a role in this debate.

The research community is concerned that data protection rules may impede cutting-edge research and innovation and that it may act as a barrier to freedom of research.

The GDPR will be fully applicable in 43 days from now. However, it has recognised the need to facilitate research and innovation. I believe that it will act as the new gold standard on this matter amongst others.

I am not saying that the GDPR provides for the best harmonisation ever. I am rather making the point that it offers unique opportunities for the respect of humans in their entirety.

Today we are addressing challenging topics such as genome editing and regenerative medicine. These processes would imply an important deployment of data-driven technologies. Robotics and AI are only an example to that.

We cannot silence concerns for data protection.

- Science's primary interest is having the greatest amount of data and further reusing it. This challenges some core principles of privacy and data protection according to which the use of data shall be limited to what is necessary, be proportionate and no further-reused for purposes which are not compatible with the original ones;
- Keeping data secure, in particular in cases of long-term projects is another concern;
- Last but not least, the growing tendency towards the use of tracking devices to collect data with applications to research shall be closely looked at.

However, my feeling is that the biggest challenge we have in this debate is defining what genuine scientific research truly is.

While the GDPR does not provide a formal definition, it embraces a wide view of what scientific research is. It covers 'technological development, fundamental research, applied research and privately funded research'.

This means that scientific research carried out by the private sector or by other privately funded research may also benefit from the new provisions. We must be careful about this. The definition of scientific research must not be stretched beyond its intended limits.

As recent controversies around Cambridge Analytica shows, even in cases where research is claimed to be carried out, there are high risks for abuse. These abuses include the misuse of research data for other purposes without the individual's knowledge and consent.

This has to be taken very seriously. Particularly since there is a gap here. Which has to be filled in by resorting to ethics. Genuine scientific research does equal ethical scientific research. I will come back to that later.

Genuine scientific research occupies a privileged position in the new legal system. In detail:

- scientific research purposes legitimise the processing of very sensitive type of data, provided that there is a legal basis for it and that appropriate safeguards are in place;
- researchers can go beyond the purposes for which they first collected (so long as the data will only be used for that purpose);
- derogations exist for transfers to a non-European country. In this assessment, “the legitimate expectations of society for an increase of knowledge should be taken into consideration”. This would have a positive impact on cross-borders collaborative research;
- data subjects’ rights can be derogated by Union or Member State law, however only if the exercise of such rights would likely impair the achievement of research purposes;
- data retention limits can be extended if the processing is performed for research purposes, yet must be subjected to safeguards.

At the same time, scientific research uses of data shall always happen with appropriate safeguards. By limiting data uses to what is necessary, for instance. Other principles of data protection remain equally important and applicable. Transparency and an appropriate level of control for individuals as to what happens to their data also are crucial.

Moreover, the new regulation incentivises data protection standardisation in the field of scientific research. Examples are the elaboration of codes of conduct and certification mechanisms.

Member States can add conditions and limitations with regard to the processing of genetic, biometric or health data. We know that with this the GDPR has not achieved the desirable level of harmonisation. There is risk of fragmentation which must somehow be addressed in order not to impair, for example, the flow of personal data.

The new European Data Protection Board, which will take up their duties as of 25 March, could play a decisive role on this, by ensuring for example that sound guidance is delivered on this matter.

As said, the GDPR will represent the golden, legislative, standard. Legislation however shall be complemented by other elements.

Whenever we interfere with the humans’ innermost sphere and take control over it we are impacting their dignity. And this is about protecting supreme values as enshrined, for example, in the Charter of fundamental rights of the EU.

When dignity is at stake we need to also think and act ethically. The GDPR already contains the seeds of this trend. In fact, it encourages ethical standards for scientific research.

This stems from the truly revolutionary element of GDPR which is the principle of accountability. Accountability prescribes not only compliance with the law, but also requires organisations to achieve it to the highest standards and be able to demonstrate all this. It includes performing data protection assessments and appointing a data protection officer which in the majority of the cases research organisations will be bound to do.

By definition, research aims to preserve or even restore human's dignity by putting itself again in the condition to be, as much as possible, operational in the society. The idea of a human body which is able to heal itself and recover its hampered tissues spurs from there.

However, when highly sensitive information revealing the whole world around a person gets collected, inter-linked with other personal information and re-used, against the same person, sometimes without the person's full awareness, human dignity is impaired.

Self-determination is also key to this debate, and one could by extension see in genome editing precisely this feature. However human dignity, as well self-determination, is a complex phenomenon which entails respect for the basic attributions of the person as a whole. Including personal data.

Personal data tells a story about the individual which, in the best case scenario, would be used for the common good, but in the worst may act as a boomerang against them.

Ethics should be used to pave the way forward. Not as a way to circumvent data protection law but rather a tool to reinforce its effectiveness.

At the end of October I will host the conference of all privacy and data protection commissioners across the globe. They will gather here in Brussels to discuss precisely ethical uses of data. We are confident that the outcome will give a lot of food for thought even for today's purposes.

I am on my conclusive remarks now, ladies and gentlemen.

GDPR is not there to act as a barrier to research, nor to impede it. We are in fact heading to protect the same human being.

However, research itself has lots of applications: we have moved from a publicly-funded formula to a corporate-based settings. In the near future privately-funded firms engaging in scientific research may be asked to report on how they collect and process personal data of people for scientific purposes.

Should this be the case, I hope that they will be able to show that they do better than the practices revealed in the news recently. This is why scientific research has to be ethical, in the first place.

So, I am hopeful but we should operate with caution. Let's not underestimate the need for a level playing field, where science is not only propelled by big players but also small labs.

We need an ethical approach and we need appropriate safeguards in place. I trust that the GDPR will act as a good ally to the entire research community in the path to protect human's vital interests.

Thank you for listening.