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THE CONSULTATIVE COMMITTEE OF THE CONVENTION FOR THE PROTECTION OF INDIVIDUALS WITH REGARD TO AUTOMATIC PROCESSING OF PERSONAL DATA

REPORT BY THE CHAIR OF THE COMMITTEE

20TH ANNIVERSARY OF THE OVIEDO CONVENTION: RELEVANCE AND CHALLENGES

I participated in the Conference organised on the occasion of the 20th Anniversary of the Oviedo Convention which took place in Strasbourg on 24-25 October 2017, in my role of Chair of the Consultative Committee of Convention 108.

My presentation – which was part of Session III, 'New scientific and technological developments' – was about data protection principles in respect of Information technologies/NBIC and Big data with a focus on the action(s) to be undertaken at intergovernmental level to address the identified challenges.

During my presentation I underlined:

- that the Oviedo Convention and Convention 108 "speak the same language" as they
 both aim at ensuring safeguards for protecting fundamental rights in particular
 dignity", "identity", "non-discrimination", "integrity" of the individual. "Transparency"
 and "consent" are also common features of both the tools (although in one case
 informed consent is of course to medical treatment and in the other to the related
 data processing);
- The main novelties of the modernised Convention, in particular in respect of those specific elements (such as genetic and biometric data, health related data, accountability, privacy by design, privacy by default, right not to be subject to automated decisions) which could be particularly relevant in the medical sector and research, and therefore of interest for the audience;
- The major features of the Guidelines on Big Data adopted by the Consultative Committee in January 2017, in particular their main aim, namely to promote an ethical and socially aware use of data by the preliminary consideration of the likely impact of the intended Big Data processing, and its broader ethical and social implications;
- The main features of the draft Recommendation on health related data which will be hopefully finalised at the November Plenary, aiming at updating Recommendation (97)5 to address the manifold difficult challenges raised by the digitalisation of the health sector and the introduction of new technologies.
- The new challenges raised by artificial intelligence in particular in respect of a) the difficulty to define the data controller in a landscape where machines gain increasing autonomy; b) the applicability of the right to know the logic of the processing where such logic due to self-learning may be difficult to be predicted even by designers of the machine.

In respect of the other sessions of the Conference I had the chance to attend, it is worthwhile mentioning the intervention of Bartha Knoppers (Director of the Centre of Genomics and Policy, Faculty of Medicine, McGill University, Montreal) who referred to 'Recommendation (2016)8 on personal health related data for insurance purposes including data resulting from genetic tests', and stressed, amongst others, a) that our healthcare system will no longer be sustainable in the absence of more and more data and links between data to allow a targeted allocation of limited resources; b) the need to de-stigmatise genetic data which should be considered as normal "sensitive medical data" while ensuring adequate and inclusive healthcare coverage to individuals; c) to increase the international collaboration and sharing of health data including genetic data, also to have more supportive systems which recognise diversities.

Alessandra Pierucci Chair of the Committee of Convention 108