

ICDPPC: Meeting paper for July 2015 Executive Committee meeting

**Closed session 2015 (Agenda item 4 for July meeting)**

Note from Secretariat to Executive Committee, 2 July 2015

Please find attached proposed programmes on Genetic and Health issues prepared by France and USA and on Oversight of Security and Intelligence prepared by New Zealand and Netherlands.

**Proposal for a 3 hour Closed Session on Genetic and Health issues**

<b>Genetic and health data: challenges for tomorrow</b>	
<i>20 minutes</i>	<p style="background-color: #d9e1f2;"><b>Medical and business perspective</b></p> <p><b>Laurent Alexandre (FR)</b> , doctor, neurobiologist and neurogeneticist and has a strong interest in transhumanism and biotechnologies. He created the company DNA Vision, the leading European DNA analysis company providing a complete solution for sequencing projects for research and regulatory purposes. <a href="http://www.dnavision.com/">http://www.dnavision.com/</a></p>
<i>20 minutes</i>	<p style="background-color: #d9e1f2;"><b>Computer Science perspective</b></p> <p><b>Yaniv Erlich (USA)</b>. Professor of Computer Science, Columbia University and member of the New York Genome Center: <a href="http://teamerlich.org">http://teamerlich.org</a>. Profile in Nature: “The Genome Hacker”  <a href="http://www.nature.com/polopoly_fs/1.12940!/menu/main/topColumns/topLeftColumn/pdf/497172a.pdf">http://www.nature.com/polopoly_fs/1.12940!/menu/main/topColumns/topLeftColumn/pdf/497172a.pdf</a></p>
<i>20 minutes</i>	<p style="background-color: #d9e1f2;"><b>Legal perspective</b></p> <p><b>Mark Taylor (UK)</b>. Mark Taylor studied law at the University of Hull, graduating with an LLB (Hons) in 1994. He came to Sheffield in 1998 to take the MA in Biotechnological Law and Ethics. He remained in Sheffield to complete a PhD on the morality of regulating genetic discrimination. He has been lecturing at the School of Law since 2002.</p> <p>Qualifications</p> <ul style="list-style-type: none"> <li>• Ph.D., University of Sheffield, 1999-2003 (awarded Oct, 2003)</li> <li>• PCHE, University of Sheffield, 2002</li> <li>• MA in Biotechnological Law and Ethics (with distinction), 1998-99</li> <li>• LLB (Hons), The University of Hull, 1991-1994</li> </ul> <p><b>Recent publication:</b> Genetic Data and the Law - A Critical Perspective on Privacy Protection. Cambridge University Press  <a href="http://www.cambridge.org/ve/academic/subjects/law/medico-legal-bioethics-and-health-law/genetic-data-and-law-critical-perspective-privacy-protection">http://www.cambridge.org/ve/academic/subjects/law/medico-legal-bioethics-and-health-law/genetic-data-and-law-critical-perspective-privacy-protection</a></p>
<i>2 hours</i>	<b>DPA discussion</b>
<i>Alternate Speaker</i>	<p style="background-color: #d9e1f2;"><b>Data subject perspective</b></p> <p><b>Steven Keating (USA)</b>. MIT grad student, survivor of a brain tumor, and advocate for giving patients more access to information collected by providers and researchers. NYT Profile: <a href="http://www.nytimes.com/2015/04/01/technology/the-healing-power-of-your-own-medical-data.html">http://www.nytimes.com/2015/04/01/technology/the-healing-power-of-your-own-medical-data.html</a></p>

**Proposal for a 3 hour Closed Session on oversight of security and intelligence**

Data protection oversight of security and intelligence: The role of Data Protection Authorities in a changing society	
<p><i>30 minute presentation followed by 30 minute discussion</i></p>	<div style="background-color: #cfe2f3; padding: 2px;"><b>Security and intelligence in a changing society: Insights from behind the scenes</b></div> <p>Intelligence agencies derive their legitimacy from a social licence which implies limits to their activities and accountability back to the public through oversight arrangements. The presenter will offer a perspective on the roles, objectives and approaches of intelligence and security agencies in modern society and how these have changed and are evolving. He will touch on how the limits and accountability have changed and offer a view on whether these have kept pace with the new realities of security and intelligence work, particularly in relation to privacy and data protection.</p> <p><b>Sir David Omand, Visiting Professor at the War Studies Department, King’s College, London (UK):</b> Sir David combines an authoritative insider’s experiences tempered with academic reflection and insight.</p> <p>After a distinguished government career in defence, security and intelligence, Omand is now a leading figure in shaping public debate on national security. He was the first appointee, in 2002, to the re-vamped post of UK Security and Intelligence Coordinator, responsible for the UK’s national counter-terrorism strategy and ‘homeland security’. He spent much of his earlier career in the Ministry of Defence, including as Director of GCHQ. He also served for three years in Brussels as Defence Counsellor to NATO and for seven years on the UK’s Joint Intelligence Committee.</p> <p><a href="http://www.kcl.ac.uk/sspp/departments/warstudies/people/visiting/omand.aspx">http://www.kcl.ac.uk/sspp/departments/warstudies/people/visiting/omand.aspx</a></p>
<p><i>20 minute presentation followed by 20 minute discussion</i></p>	<div style="background-color: #cfe2f3; padding: 2px;"><b>Practical perspectives: Building justified public confidence</b></div> <p>Intelligence agencies have been around long before Data Protection Authorities (DPAs) existed. Many have specific oversight bodies with a tightly prescribed mandate. What scope is there for building links between domestic agencies with privacy and data protection responsibilities, and between such agencies across jurisdictions?</p> <p><b>Cheryl Gwyn, Inspector-General of Intelligence and Security, New Zealand (NZ):</b> Cheryl combines her previous experience as a senior legal official in government with more recent work as the key oversight officer for intelligence services in a period of intense public scrutiny and controversy. She has brought a new transparency into performing the IGIS role and has been active in engaging internationally with peer oversight bodies and domestically with other accountability bodies including the Privacy Commissioner.</p> <p>Cheryl was appointed as Inspector-General of Intelligence and Security in May 2014. She was formerly Deputy Solicitor-General at the Crown Law Office, and has previously been a partner at two law firms. She has also been a Deputy Secretary for Justice as well as Acting Solicitor General and Chief Executive at Crown Law.</p> <p><a href="http://www.igis.govt.nz/about/">http://www.igis.govt.nz/about/</a></p>

<p><i>20 minutes followed by 20 minutes discussion</i></p>	<p><b>Shining a light: Transparency reporting</b></p> <p>Some DPAs have a specific role in respect of law enforcement or security. DPAs that have no such role will nonetheless have jurisdiction over telecommunications providers, online platforms, banks and other rich sources of information for law enforcement and intelligence agencies. Is there scope for DPAs to perform a more active role in promoting openness and transparency to help ensure democratic and legal accountabilities are brought to bear? This session would be built around IWGDPT paper on transparency reporting which includes a road map for action by relevant stakeholders.</p> <p><b>Ira Rubinstein, NYU School of Law (USA).</b> Ira is an academic with involvement in civil society projects promoting transparency. He was the author of a 2013 paper for the Centre for Democracy &amp; Technology entitled ‘Systematic Government Access to Personal Data: A Comparative Analysis’.</p> <p>Ira is a Senior Fellow at the Information Law Institute, New York University School of Law. His research interests include Internet privacy, electronic surveillance law, big data, and voters' privacy. Rubinstein lectures and publishes widely on issues of privacy and security and has testified before Congress on these topics on several occasions. Ira recently completed a research report on systematic government access to personal data for the CDT and has also published on Big Data and on Privacy by Design. Prior to joining the ILI, Rubinstein spent 17 years in Microsoft's Legal and Corporate Affairs department, most recently as Associate General Counsel in charge of the Regulatory Affairs and Public Policy group. From 1998-2001, he served on the President's Export Council, Subcommittee on Encryption. He has also served on the Editorial Board of the IEEE Security and Privacy Magazine. In 2010, he joined the Board of Directors of the Center for Democracy and Technology.</p> <p><a href="https://its.law.nyu.edu/facultyprofiles/profile.cfm?section=bio&amp;personID=30084">https://its.law.nyu.edu/facultyprofiles/profile.cfm?section=bio&amp;personID=30084</a></p>
<p><i>40 minutes</i></p>	<p><b>DPA discussion</b> (total assigned discussion time 110 minutes, can be distributed in different ways)</p>