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**Report of Short Term Scientific Mission at HeLEX Centre for Health, Law and Emerging Technologies, University of Oxford. Reference: COST-STSM-ECOST-STSM-IS1303-141116-078864**

This is to report on the activities during my Short Term Scientific Mission (STSM) at the HeLEX Centre for Health, Law and Emerging Technologies at the University of Oxford, United Kingdom, in November/December 2016. I would like to thank the HeLEX team represented by Professor Jane Kaye for welcoming me, and COST Action CHIP ME for making this STSM possible.

The topic of the STSM was “Genomics and personalized medicine: Governance models and legal framework for accessibility and privacy”.

As outlined in the Memorandum of Understanding, COST Action CHIP ME WG1’s year two core questions and deliverable dealt with ICT solutions for dynamic consent and research subject participation, while the year three core questions and deliverable relate to governance models and the legal framework for ensuring data security and the privacy of research subjects. The aim of the STSM was to bridge these topics together and foster collaboration to contribute to and further the legal data privacy research on these topics. This was achieved by focusing on six main tasks:

- 1) In collaboration with HeLEX researchers, I organized a seminar on Nissenbaum’s concept of contextual privacy. Associate Professor Donald J. Willison at the University of Toronto gave a webinar to HeLEX researchers and CHIP ME members from four countries. Following Willison’s presentation, we discussed Nissenbaum’s theory, and how we may utilize these concepts in our work. This also extended into more general data protection law discussions.
- 2) I gave a presentation of my PhD project and of third party access to biobanks and genetic databases, with a focus on the upcoming European Union General Data Protection Regulation’s privacy by design obligation and dynamic consent as a possible solution to some of the challenges faced. The presentation was followed by a very fruitful discussion with HeLEX researchers.
- 3) Throughout the STSM, I was able to gain insight into Professor Kaye and her colleagues’ work, which is highly relevant to my PhD thesis, but where similar research has not been conducted in Norway. This was clearly of great importance to my further work, and I look forward to further collaboration with HeLEX researchers.

- 4) I provided thorough feedback on the paper “Dynamic Consent: a potential solution to some of the challenges of modern biomedical research” (first author: Isabelle Budin Ljøsne), which is WG1’s year two deliverable. HeLEX researchers similarly provided feedback and editing. I am happy to report that the paper has now been accepted for publication in BMC Medical Ethics’ special issue on Translation in healthcare.
- 5) I provided feedback on the paper “The challenges of the expanded availability of genomic information. An agenda-setting paper” (first author: Pascal Borry). The intention is for the paper to be part of the Action’s final deliverable, and it will be submitted to the Journal of Community Genetics CHIP ME special issue.
- 6) WG1’s year three deliverable is a paper following the conference “Genetic data in public research databases: Which governance mechanisms should apply?” that we organized in Bolzano, Italy in April 2016. Having collected the co-authors contributions, and discussed the direction of the paper with WG1 in Leuven and Vienna, I sat down with HeLEX researcher and CHIP ME member Jessica Bell to discuss, rewrite and edit the regulatory section of the paper “Deposit of Individual Level Genetic Data in Public Research Databases: Ethical, Legal and Societal Implications”. After further feedback and editing, I am very pleased to report that the legal section of WG1’s year three deliverable is now submission ready. We aim to submit the paper to the European Journal of Human Genetics in 2017.

Thank you for this STSM opportunity.

Sincerely,  
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