

# 28

## May 2019

Tuesday

### LECTURE

CHL - Centre  
4, rue Ernest Barblé  
L-1210 Luxembourg  
**Room: Amphitheatre**

**11.30-12.30pm**

### MEET THE SPEAKER\*

Light snacks provided  
LIH, 1A-B, rue Thomas Edison  
L-1445 Strassen  
**Room: Curie/Pasteur (3<sup>rd</sup> floor)**

**12.45-2.00pm**



\*Registration is mandatory to meet the speaker by sending an email to [tania.zamboni@lih.lu](mailto:tania.zamboni@lih.lu)

# Patients, trust and ethics in information privacy in e-health - from FAIR to FAIR Health

### ABSTRACT

One of the fundamental principles of science and e-health is reproducibility, the idea that a discovery is valid only if any scientist in any lab can conduct the same experiment under the same conditions and obtain the same results. Provenance information, which keeps track of history of biological material and data, is a fundamental component in reproducibility and reliability. The known problem of under-utilization of data and biological material from biorepositories as potential resources for medical research has been the focus of discussion for more than a decade. Recently developed guidelines for improved data availability and reusability, the so-called FAIR Principles (1) (Findability, Accessibility, Interoperability, and Reusability), are important, but likely to address only parts of the problem. In this talk we argue that biological material and data should be viewed as a unified resource. This approach would facilitate access to complete provenance information, which is a prerequisite for reproducibility and meaningful integration of the data. A unified view also allows for optimization of long-term storage strategies, as demonstrated in the case of biobanks. We propose an extension of the FAIR Principles to include additional components:

1. Quality aspects related to research reproducibility and meaningful reuse of the data. Provenance information describing all steps.
2. Incentives to stimulate effective enrichment of data sets and biological material collections and its reuse on all levels.
3. Privacy respecting approaches for working with the biological material and data (2).

These FAIR-Health principles (3) should then be applied to both the biological material and data. For e-Health, all of these components called FAIR-Health are fundamental prerequisites for effective reuse of the biological material and data. Most of the current knowledge on diseases as well as available diagnostic assays and drugs are based on investigation of biological sample and data.

1|Wilkinson, MD, Dumontier, M, Aalbersberg, JJ, et al. The FAIR Guiding Principles for scientific data management and stewardship. 2016; Sci Data. 15:3160018. doi: 10.1038/sdata.2016.018  
2|Litton, JE. "We must urgently clarify data-sharing rules". Nature 2017; 541:437  
3|Holub P, Kohlmayer F, Prasser Fet al. Enhancing Reuse of Data and Biological Material in Medical Research: From FAIR to FAIR-Health, Biopreservation and Biobanking. 2018; 23. doi: 10.89/bio.2017.0110.



### SPEAKER

## Prof Jan-Eric Litton

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### HOSTS:

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### INVITED BY:

Prof Paulo Veríssimo  
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