

Newsletter

November 2014

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Partner profile

FORTH – Hellas



Ethics Advisory Board Meeting

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Various representatives from the FP7 **EURECA project** met in Brussels this June to present issues and solutions encountered with regards to data protection and informed consent, gaining feedback and insight from European experts in the legal field.

In attendance from the board were Dr Solvita Olsena, President of the European Association of Health Law, and Prof Henriette Roscam-Abbing, Editor of the European Journal of Health Law.

Many of the discussions focussed around the approach each clinical project partner took towards ensuring data protection, patient

education and gaining informed consent within the context of their own country's legislation. The meeting highlighted that there are three main aims in sharing patient healthcare record data: clinical care, secondary re-use and prospective research.

One of the key ethical issues that cropped up lay at the heart of the issue was in taking a human rights approach to data, and balancing treating patient information like any other type and as deeply private information.

The relative merits of 'blanket' versus 'dynamic' informed consent were weighed, with a look at Oxford University's Centre for Health, Law and Emerging Technologies (**HeLeX**) and their **Dynamic Consent Project**.

This issue is echoed in a recent **ruling by the British Medical Association** to make the new care.data system opt-in rather than opt-out, with GP John McGough commenting "This data is information collected from GP records. It is the illnesses, the hopes, confidences and fears of our patients".

EU health and data protection laws hold many nuances and complexities, differing from country to country. In spite of this, many fundamental issues hold true and it these that **ecancer**, as the **EURECA** project's dissemination partner, will communicate in the form of patient and doctor-orientated educational videos. These will assist in getting across the key message involved surrounding personal data, data protection and informed consent.

Overall the EU reviewers acknowledged delays caused by privacy issues, but warmly praised the project's legal and ethical framework.



Driving Excellence in Integrative Cancer Research

The Evaluation Workshop held at the premises of FORTH, in Heraklion, Greece, on Friday, June 13th, 2014 had the main aim to evaluate four tools developed in the context of the INTEGRATE project: the Patient Screening tool “Decima”, the Cohort Selection tool “Nona”, the Central Review of Pathology Images tool and the Analytical Platform tools.

INTEGRATE is another FP7 project in which Breast International Group (BIG) and other partners are also involved in addition to the EURECA project.

A panel of experts coming from around the world and representing potential end-users of these tools was invited to participate to the event. The panel comprised 2 oncologists, 1 research nurse, 3 bioinformaticians and 2 pathologists.

Throughout the workshop, qualitative and quantitative tests for tools’ evaluation were scheduled on parallel tracks. The tests usually consisted in an introductory part in which the scenarios and the functionalities of the

tools were explained, followed by demos and sessions in which the tools were tested by the potential end users using real, anonymized patients data.

The tests were usually followed by discussions aimed at gathering constructive feedbacks from the experts. The experts were also given two short questionnaires: “Questionnaire A”, based on the ISO/IEC standard and focused towards end users, and “Questionnaire B”, consisting in a software usability test (SUS).

The experts confirmed the relevance of the use cases for which the four tools were developed and overall gave a positive feedback regarding the tools’ utility and functionality. The evaluation workshop also resulted in valuable suggestions for their improvement and their future development and deployment.

To learn more about INTEGRATE and the partners involved in this FP7 project, visit: www.fp7-integrate.eu

The Foundation for Research and Technology-Hellas (**FORTH**), established in 1983, is one of the largest research centers in Greece with well-organized facilities, highly qualified personnel and a reputation as a top-level research foundation worldwide. The Foundation, with headquarters in Heraklion, includes six Research Institutes in different parts of the country.

The Institute of Computer Science is a major national research centre partly funded by the General Secretariat for Research and Technology of the Hellenic Ministry of Education and Religious Affairs. The mission of **FORTH-ICS** is to perform high quality basic and applied research, to promote education and training, and to contribute to the development of the Information Society, at a regional, national, and European level. Since its establishment, **FORTH-ICS** has had a long history and recognized tradition in conducting basic and applied research, and playing a leading role, in Greece and internationally, in the field of Information and Communication Technologies.

Role in EURECA

FORTH is involved in most of the work packages of the project and is the leader of WP8: Q&A, evaluation and validation, being in charge of organizing the evaluation and validation of the project. **FORTH** has also a significant contribution to the definition of the architecture, the development of the semantic interoperability environment and is responsible for the two of the demonstrators of the **EURECA** software services, the Personal Medical Information Recommender and the Patient Diary demonstrators.

