A Virtual Research Environment for International Adrenal Cancer Research

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INTRODUCTION

For many research areas, the need to collaborate across organizational and in certain cases national boundaries is essential. This is especially the case when dealing with rare diseases where a lack of data, information and/or sharing of expertise can cause delays in progressing the understanding and potential diagnosis/treatment of such diseases. Research into adrenal tumours and understanding their different molecular mechanisms and in turn development of targeted personalized treatments is one such area where co-ordination of international cancer efforts is essential. The European Network for the Study of Adrenal Tumours - Structuring clinical research on adrenal cancers in adults (ENS@T-CANCER – www.ensat-cancer.eu) project has been funded by the European Union to establish a state of the art Virtual Research Environment (VRE) supporting all aspects of international research and collaboration into the aetiology, diagnosis and establishing optimal treatment strategies for patients with adrenal cancer. In developing this platform it is essential that access to clinical and biological data (samples) is strictly enforced according to ethical arrangements.

AIMS

ENS@T-CANCER is a 5-year project that covers the breadth and depth of post-genomic biomedical research platform requirements covering establishment of a range of clinical databases of individuals with different forms of adrenal cancer and their associated treatments (and responses to treatments); biobanks for storing and labeling/tracking of biosamples from patients to be used by biomedical (omics) researchers; visualization support for improved understanding and analysis of the forms of tumours and their potential metastases, and importantly, support for large scale clinical trials where patient cohorts are recruited and used to test out the impact of targeted treatments based upon their genetic profiling. The project is truly international with 16 clinical and biomedical partners from across Europe and all software support for the VRE undertaken at the University of Melbourne. The project has already applied for and had ethical approval for the work and clinical and biological data sharing is now already taking place.

APPROACH

This presentation describes the background to the project as a whole and outlines the current work in progress on development of the VRE. We show how the VRE is already used for several major clinical trials and how over 1300 patients have been included into the system covering all adrenal tumour molecular subtypes. We also outline how all of the software required to conduct a major clinical trial has been completed, and is now used to actively recruit patients (with over 175 patients already included for a trial involving a particularly rare tumour type).

DISCUSSION

This paper outlines the goals of the ENS@T-CANCER project and outlines the on-going implementation work. We show how security-oriented information can be collected and tracked through the VRE including supporting collection of clinical data sets and their linkage with associated bio-samples in an ethically-driven framework. We also outline how it is expected that this project will shape many related efforts around the Parkville Precinct where clinical and biological matchmaking services across a range of clinical research areas are to be supported.

REFERENCES


ABOUT THE AUTHORS

Anthony J. Stell is the primary software engineer on the ENSAT-CANCER project. He has been involved in numerous major clinical/biomedical projects whilst working at the National e-Science Centre at the University of Glasgow including the MRC funded VOTES project, the EU funded AvertIT project and several others. He joined the Melbourne eResearch Group in May 2011 to work on the ENSAT-CANCER project.
Prof. Richard O. Sinnott is Director of eResearch at the University of Melbourne. Before this he was the Technical Director of the National e-Science Centre at the University of Glasgow; Deputy Director of the Bioinformatics Research Centre (also in Glasgow) and the Technical Director of the National Centre for e-Social Science. He has been involved in an extensive portfolio of e-Science projects in the UK, Europe and now in Australia.