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Final Copy of Case Study

Status:

Laureate

Year:

2013

Organization Name:

BioGrid Australia

Organization URL:

www.biogrid.org.au

Project Name:

National Bowel Cancer Screening Program

Please select the category in which you are submitting your entry:

Health

Please provide an overview of the nominated project. Describe the problem it was intended to solve, the technology or approach used, how it was innovative and any technical or other challenges that had to be overcome for successful implementation and adoption. (In 300 words or less.)

Governments are now adopting evidence-based policies, bringing greater transparency to how these programs impact citizens' well being. BioGrid's web-based federated platform uniquely identifies and ethically integrates data collected about an individual across multiple institutions. The platform securely links patient level clinical, biospecimen, genetic and imaging data across institutions, jurisdictions and diseases to enable improved research and clinical outcomes. Authorised researchers dynamically query de-identified data that can be combined and analysed utilising SAS statistical analysis software through BioGrid. A key challenge was in setting up collaboration agreements between researchers and institutions to link their databases to a federated platform. This complex agreement was challenging to achieve, however, now it enables a streamlined approach to data sharing where data contributors retain full control over their data. A key project has been informing the Government's National Bowel Cancer Screening Program where people aged 50-70 are offered a free test every five years. BioGrid enabled the analysis of data from more than 1,200 bowel cancer patients from

19 sites around Australia. The analysis produced showed the government that early diagnosis of bowel cancer not only significantly improved the chances of patient survival, it reduced the cost of treatment per patient. Sir Gustav Nossal, Professor Emeritus, Department of Pathology, University of Melbourne: "Amongst the biggest problems that investigators face are data collection, data storage, analysis, & statistical analysis. A second order of problems is concerned with ethics and privacy, and the amazing thing about BioGrid is that it addresses all of those things." Prof. Tony Burgess, Laboratory Head, Structural Biology, Walter Eliza Hall Institute of Medical Research: "It clearly speeds up the time to finish a trial, find out whether the drug's going to be effective and therefore shorten the time to actually using the drug in a clinic."

When was this project implemented or last updated? (Please specify month and year.) Has it incorporated new technologies and/or other innovations since its initial deployment? (In 300 words or less.)

The BioGrid collaborative model was leveraged between 2009 and 2012 for research on the effectiveness of the National Bowel Cancer Screening Program (NBCSP) in Australia. Research outcomes assisted the Australian government to announce in the May 2012 Federal Budget to extend the program with \$50M over 4 years. The program extension now includes 50-70 year olds; previously it only accommodated 55-65 year olds. During 2011-12 BioGrid upgraded to SAS Enterprise Business Intelligence Server Version 9.2 (from 9.1.3), which enabled the introduction of Enterprise Guide Client Version 4.3. This SAS upgrade provided more sophisticated stored procedures and a more user-friendly web reporting interface in SAS Web Report Studio Version 4.3. This version of Web Report Studio has provided enhanced graphic features and productivity for users. Researchers analysed the cost-effectiveness of the NBCSP utilising SAS data analytics software. The research showed that annual bowel cancer treatment costs in Australia was likely to increase four-fold to \$1 billion over 10 years by 2011, strengthening the economic case for expanding the NBCSP. Due to the cost of expensive new therapies treating stage 3 (more advanced) cancers tripled from \$25,000 in 1999 to \$75,000 and for stage 4 (most advanced), the cost has significantly escalated 10 fold from \$6,000 to \$61,000. By screening leading to the detection of early stage cancers which can be dealt with by surgery alone, the substantial cost of treating later stage cancers, including the use of expensive chemotherapy drugs, are avoided. Data available through BioGrid was able to show the cost effectiveness of screening. 1 Tran B, et al. A preliminary analysis of the cost-effectiveness of the National Bowel Cancer Screening Program demonstrating the potential value of comprehensive real world data. Intern Med J

If this is a previously submitted project that has been significantly updated and/or expanded, please describe the nature of the update here. (In 300 words or less.)

In 2008, BioGrid Australia participated in the Computerworld Honors Program under the name of Melbourne Health. BioGrid was one of the 200 organisations chosen to be at the Medal Awards Ceremony and Gala Dinner that year. This submission was in relation to a project called BioGrid Australia under the category Healthcare sponsored by IBM for the federation technology provided by IBM for BioGrid's federated data platform. The 2013 submission features an update focusing on the use of SAS advanced analytical

solutions applied to the federated platform, in particular research relating to the National Bowel Cancer Screening Program in Australia.

Is implementation of the project complete? If no, please describe the project's phases and which phase the project is now in. (In 300 words or less.)

The 2011-2012 research informed the 2012 federal budget announcement of \$50 million to extend the National Bowel Cancer Screening Program for another four years. The initial extension of the program will see Australians screened every five years, from the age of 50. It will then be progressively extended further so that people are screened every two years. The research that has been undertaken with BioGrid's technology is to inform the government with sufficient relevant data for funding the National Bowel Cancer Screening Program. Because it is a government-funded project, research is ongoing and although the lobbying component is completed, the funding will be reassessed in four years. Therefore research will again need to be conducted and presented to the government to provide evidence-based research to inform the funding for the next phase of the project.

Please provide at least one example of how the technology project has benefited a specific individual or organization. Feel free to include personal quotes from individuals who have directly benefited from the work. (In 300 words or less.)

With BioGrid's federated technology platform plus SAS' analytical tools, researchers are now able to easily and quickly analyse data to inform treatment outcomes. This means information about greater numbers of patients can be combined, leading to more effective and powerful research. Since its success BioGrid has been receiving interest from global pharmaceutical companies, as nothing like BioGrid's multi-site data collaboration exists elsewhere. Dr Daniel Thurley, MD Regional Medical Director, Asia Pacific, Roche Products Pty Ltd: "Roche Products and BioGrid began collaborating in 2009 on the TRACC project, a prospective study of the treatment for 1000 patients with metastatic colorectal cancer. Roche has incorporated insights gained from the project to inform clinical trial development, allowing to further explore optimal treatment of patients with metastatic colorectal cancer. Roche values this local collaboration which enhances medical knowledge and improves the quality use of medicines, enabling tangible improvements in the health, quality of life and survival of patients. Partnering with BioGrid allows both clinicians and Roche to gain insight into the real-life treatment of Australian patients with mCRC which will ultimately improve understanding of mCRC care." A/Prof Desmond Yip, Director, Medical Oncology Unit, The Canberra Hospital, Australian National University Medical School: "BioGrid is a very powerful IT platform that provides the ability to collect and analyse data on cancer patients across a large number of institutions across Australia to provide real world information on patterns of care. This enhances our ability to obtain large datasets for research easily and solves issues of cross-jurisdictional privacy and confidentiality. We are very proud to be part of this important collaboration. One of our major research interests is in gastrointestinal oncology, this will enable us to further a project looking at the treatment of elderly patients with advanced colorectal cancers."

Would this project be considered an innovation, a best practice or other notable advancement that could be adopted by or tailored for other organizations and uses? If yes, please describe that here. (In 300 words or less.)

BioGrid supports the demand for governments to provide greater transparency on programs in an evidence-based approach. BioGrid's impact on public health is significant, as they are operating in the way in which e-health in Australia will operate in the future. In the case of the National Bowel Cancer Screening Program, the implications are obvious: Bowel Cancer is the second most common cause of cancer related deaths in Australia. With BioGrid's linkage technology, research indicated that early detection through screening increases the chance of successful treatment and long-term survival improves significantly. Tanya Plibersek, Australian Federal Health Minister said, "The extension of the bowel screening program to biennial screening has the potential to reduce colorectal cancers by 15-25% and prevent between 300-500 Australian deaths annually." "Fully implemented, the National Bowel Cancer Screening Program could save 30 lives a week," Cancer Council Australia CEO, Professor Ian Olver said. "This analysis adds to the current weight of evidence that early detection is key to higher survival rates. It also strengthens the case for encouraging maximum numbers of eligible people to participate in the screening program." This innovation in the health sector is streamlining the data analysis process to allow more comprehensive and efficient research activities. Previously, the time taken for researchers to gather data from different sources, standardise it in the same format and acquire the ethics approvals was quite extensive, however, BioGrid is enabling this to be done almost instantaneously, reducing the time for researchers and facilitating more effective research. BioGrid is unique in its multisite data collaboration on a global scale; nothing like this exists elsewhere and as a result, global pharmaceutical companies have expressed interest in BioGrid's enabling technology.

If there are any other details that the judges should know about this project, please note them here. (In 300 words or less.)

A future area of interest for BioGrid is disease co-morbidity: the effect of one or more diseases on a patient in addition to his or her primary disease. A cancer patient, for example, may have a number of co-morbidities, such as hypertension or diabetes, and given drugs for each of them. There has been little research on how to effectively treat patients with multiple diseases. Using data available through BioGrid, researchers might find the same patient presenting for different diseases at different institutions and be able to analyse these data further. A/Prof. Kate Drummond, Neurosurgeon, The Royal Melbourne Hospital and Research Domain Coordinator, Cancer, The University of Melbourne: "Another really good example is a Neurosurgeon PhD researcher who has been able to really use aspects of two different databases, the epilepsy database and the brain tumour database, and bring those together on a really useful project of tumour associated epilepsy." Dr Mark Colson, Senior Staff Specialist Anaesthetist, The Geelong Hospital: "In effect it automates the whole ID identification process. The local ethics committee should no longer have those concerns about the integrity of data security." Prof. Tony Burgess, Laboratory Head, Epithelial Biochemistry Laboratory, Ludwig Institute for Cancer Research (since May 2012, Laboratory Head, Structural Biology, Walter Eliza Hall Institute of Medical Research): "Previously, you'd have to employ two, three or four people to gather the data you would like, hence you save three or four



salaries over the period of a year for 500 patients. So the research will become more and more cost effective with BioGrid." Sir Gustav Nossal, Professor Emeritus, Department of Pathology, The University of Melbourne: "I'm excited about the future of clinical research. When I look at the contribution that can be made by BioGrid I get even more excited."