The Need for a Victorian Translational Research Platform

Maureen Turner, CEO, BioGrid Australia Ltd
Translational Research

- Transforms laboratory, clinical, and population studies into routine clinical care
- Clinicians aim to reduce cancer incidence, morbidity, and mortality whilst optimising safety and cost-effectiveness
- Research crucial to address needs of cancer prevention, diagnosis, treatment and follow-up
The Need in Victoria

- To be internationally competitive cancer research must be efficient and sustainable

- Several entities that measure the effects of cancer and support research

  - Victorian Cancer Registry
  - Victorian Cancer Biobank
  - BioGrid Australia

- Victorian Cancer Agency (VCA) recognised the need for an integrated platform to support cancer research
The Need in Victoria

- In 2010 VCA commissioned independent review of cancer research community needs and existing capabilities
- Conclusion was to form a cohesive coordinated integrated platform for cancer data and information services
- Concept was to implement staged integration with biospecimens and clinically annotated data coming together initially
Integrated Platform Approach

- Single platform for Victorian cancer research community
- Support VCA funded research projects
- Establish links with state cancer registry and other research driven registries
- Collaborate with cancer trials groups
- Explore increasing data collected through legislative changes to the Cancer Act
Solution for Victoria

- Absence of established enterprise wide technology solutions
- Affordable solution that can accommodate existing and new data collections
- Flexible and scalable solution
- Address ethics, privacy, security, access
**Problem**

- Hospital A: Oncology, Biospecimen, Surgery, Pathology
  - Inconsistent access control
  - Inconsistent ethics approval
  - Uncontrolled sensitive data
  - Difficult to merge data

- Hospital B: Oncology, Biospecimen, Surgery, Pathology

**Solution**

- Single access control (online)
- Single ethics approval
- Match patients across sites
- De-identified data
- Uniformly formatted data

- Government
- BioGrid
- Hospitals A, B, C, D, E, Research F, G
BioGrid Australia

- Leading not-for-profit federated IBM technology platform providing authorised access to de-identified data for research purposes

- Core capabilities
  - Data governance and security
  - Scalable federated platform
  - Controlled online access system

- Key services
  - Institution ethics and connectivity
  - Database linkage
  - Data interrogation, analysis and reporting
BioGrid Member Collaborators

- Austin Health
- Peter Mac
- ACT Health
- Alfred Health
- Radiation Oncology Victoria
- Western Health
- UNSW
- Walter + Eliza Hall Institute of Medical Research
- PENINSULA HEALTH
- Melbourne Health
- Southern Health
- Adelaide Health Service (Central Northern Adelaide Health Service)
- Latrobe Regional Hospital
- Northern Health
- Ballarat Health Services
- Baker IDI Heart & Diabetes Institute
- easternhealth
- Bendigo Health
- The University of Melbourne
- Ludwig Institute for Cancer Research
- St V
- The Royal Children's Hospital Melbourne
- Goulburn Valley Health
- Barwon Health
- ROYAL HOBART HOSPITAL
Solution utilising BioGrid

- Automation of patient de-identification to overcome privacy issues
- Allocation of unique ID (USI) for record linkage
- Web-based project application process for requesting ethical and data custodian approval
- Single point online access to de-identified data and analysis tools
- Connect any type of database to the platform (e.g. SQL, Access, DB2, Filemaker Pro)
Ethics, Privacy and Security

- Ethics approval at each participating institution
  - BioGrid linkage methodology and processes
  - Institution implementation of BioGrid methodology
  - Connected databases (amendment for subsequent)

- Ethics states patient consent not required as data is de-identified and is for secondary use (patient opt-out)

- Specific project approval process includes ethics approval for data access
Ethics, Privacy and Security

- Health data always kept separate from identifying data

- Data governance and security
  - Unique subject identifier encrypted
  - Regular security audits
  - Robust user management
  - Data queries tracked and logged

- Data available to authorised users in de-identified form only for research purposes
BioGrid (Platform) does NOT

X collect data (data custodians do)
X own the connected data
X store data (not a data warehouse)
X allow unauthorised access to data
X conduct research (enables it)
BRAF Mutation in Bowel Cancer

- Patients identified using data in BioGrid
  Selected evenly distributed subgroups based on age, gender, stage and tumour site (right, left or rectal)
- Matched to specimen ID, specific tissue requested
- Specimen samples tested for BRAF mutation
- BRAF results, clinical data and biospecimen data linked through BioGrid, analysis performed
- Patients given appropriate chemotherapy based on BRAF mutation test result

Integrated Platform Benefits

- Enhances the research community's resources
- Data custodian control
  - Link their data to other data in platform
  - Use the analysis and reporting tools
  - Retain full control over access to data
- Patient privacy remains protected
- Robust data governance and data security
- Offer uniformly formatted data through SAS tools
- Streamlined application process
- Access solutions for researchers and industry
Progress re Solution for Victoria

- May 2012 state government budget included funding for
  - Continuation of the Victorian Cancer Agency to support translational cancer research
  - Development of an integrated cancer research platform that builds on and links existing research infrastructure

- Department of Health has commenced the planning phase
The Future for Victoria

Integration of cancer information and biospecimens will enable Victoria to:
- Reduce the impact of cancer in community
- Improve our performance in cancer care
- Advance our research capacity internationally

Support other state and federal funded translational cancer research initiatives:
- Victorian Comprehensive Cancer Centre
- Olivia Newton-John Cancer and Wellness Centre
- Monash Comprehensive Cancer Consortium

Innovative way to address research needs
Thank you

How to get more information about BioGrid

www.biogrid.org.au

P: +61 (0)3 9342 3167

enquiries@biogrid.org.au

BioGrid Australia acknowledges its supporters
Australian Government Department of Innovation, Industry, Science and Research
Victorian Government Department of Business and Innovation
Victorian Cancer Agency
Picchi Brothers Foundation