Advancing health research through collaboration

RESEARCH REPORT 2011

BIOGRID AUSTRALIA

Health through information

BIOGRID MEMBERS

ACT Health
Canberra Hospital

Adelaide Health Service (Central Northern Adelaide Health Service)
Royal Adelaide Hospital
The Queen Elizabeth Hospital
Lyell McEwin Hospital

Alfred Health
The Alfred
Caulfield Hospital
Sandringham Hospital

Austin Health
Austin Hospital
Heidelberg Repatriation Hospital

Ballarat Health Services
Ballarat Base Hospital
Queen Elizabeth Centre

Barwon Health
Geelong Hospital

Bendigo Health
Bendigo Hospital

Eastern Health
Angliss Hospital
Box Hill Hospital
Healesville Hospital
Maroondah Hospital

Goulburn Valley Health
Goulburn Valley Hospital

Latrobe Regional Hospital

Ludwig Institute for Cancer Research

Melbourne Health
The Royal Melbourne Hospital

Northern Health
The Northern Hospital

Peninsula Health
Frankston Hospital
Rosebud Hospital

Peter MacCallum Cancer Centre

Radiation Oncology Victoria

Southern Health
Monash Medical Centre, Clayton
Monash Medical Centre, Moorabbin
Casey Hospital
Dandenong Hospital

St Vincent's Hospital, Melbourne

Tasmanian Government Department of Health and Human Services
Royal Hobart Hospital
Launceston General Hospital

The Royal Children's Hospital

The Royal Women's Hospital

The University of Melbourne

The University of New South Wales

The Walter and Eliza Hall Institute of Medical Research

Western Health
Western Hospital
Sunshine Hospital
The Williamstown Hospital

BioGrid member names and associated institutions as at 31 December 2011.

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ABOUT BIOGRID

BioGrid Australia Limited is a leading data sharing technology company providing a secure infrastructure that advances health research by linking privacy-protected and ethically approved data among a wide network of health collaborators.
BioGrid links real-time de-identified health data across institutions, jurisdictions and diseases to assist researchers and clinicians improve their research and clinical outcomes.
The web-based infrastructure provides ethical access while protecting both privacy and intellectual property.

BioGrid was established in 2003 with the foresight of the Bio21 Cluster collaboration as the Molecular Medicine Informatics Model. State and Federal Governments have enabled the establishment then expansion of the infrastructure over three funding phases. The most recent funding from the Victorian State Government Department of Innovation, Industry and Regional Development (now known as Department of Business and Innovation) leveraged the infrastructure to develop the Australian Cancer Grid.

In 2009 BioGrid became an independent not-for-profit company and is now owned by 25 collaborators representing 41 hospitals and research organisations across five states and territories.

BioGrid's core specialist services include:

- Infrastructure support and development
- Data connection ethics expertise
- Data connection, linkage and integration
- Web-based data access application system
- Data querying, interrogation, analysis and reporting
- Dataset creation and development

As health research and planning becomes more complex, the need for collaboration significantly increases. BioGrid's web-based infrastructure has the capacity to uniquely identify and ethically integrate data collected about a patient across multiple institutions.

BioGrid has the capability to link data with other datasets, produce tailored reports for auditing and reporting and provide statistical analysis tools to conduct more advanced research analysis.

Over the past 12 months, further expansion of the Australian Cancer Grid and activity across other disease areas, has contributed to an increase in privacy-protected patient records linked to BioGrid of 205,400 at 31 December 2011.

For more information on how BioGrid works, what data is linked to BioGrid and how to access data, go to www.biogrid.org.au.

OUR VISION

Integrating health and research data to facilitate improved health outcomes.

OUR MISSION

Providing a technology platform for the ethical integration of data from individuals, health services, industry, research organisations and governments for research to reduce the burden of disease and improve human health.

SUPPORTED BY

A Victorian Government initiative — Victoria The Place To Be
Department of Business and Innovation

Victorian Cancer Agency
Linking research and patient care

Australian Government
Department of Innovation, Industry, Science and Research

CEO'S REPORT

On behalf of BioGrid Australia, it gives me great pleasure to present the 2011 BioGrid Australia Research Report. This year's report provides research progress to date and outlines the valuable work BioGrid does to facilitate health research in Victoria and Australia.

The Board and executive management team have continued to focus on financial sustainability for BioGrid post the Australian Cancer Grid funding. During the year, the Victorian government committed interim funding for 2011–12 during which time BioGrid is working with state government agencies supporting the establishment of an integrated translational research platform for the cancer community in Victoria.

In 2011, under the leadership of the Victorian Cancer Agency (VCA), state funded organisations, the Victorian Cancer Registry, the Victorian Cancer Biobank and BioGrid Australia explored how they could work together in a more integrated way to better support the research sector and the Victorian Government's Cancer Action Plan. A working party (which consulted with the sector and government) was formed by the VCA and in October 2011 recommended the full integration of the three organisations. A funding proposal supporting this recommendation is currently being considered by the Victorian government.

The establishment of an integrated cancer research platform leverages the substantial work that has been done by BioGrid in developing the Australian Cancer Grid (ACG), a project funded by the Victorian Department of Innovation, Industry and Regional Development (now known as Department of Business and Innovation). The ACG Project was successfully completed in June 2011, on time, on budget, with project milestones achieved. Expansion of the ACG and activity across other disease areas, has contributed to an increase in privacy-protected patient records linked to BioGrid (205,400 at 31 December 2011). The ACG Project established BioGrid's reputation for facilitating privacy-protected health research. It has enabled research outcomes that are translating into changed clinical practise and treatment.

The strategic direction of the business continues to focus on further developing data linkage in major cancers such as lung, breast, prostate and bowel cancer. Ongoing discussions with key translational research initiatives, such as the Victorian Comprehensive Cancer Centre, the Monash Comprehensive Cancer Consortium and the Olivia Newton-John Cancer and Wellness Centre, have facilitated potential future opportunities for BioGrid's specialist expertise in data linkage and management.

In the coming year, BioGrid will be providing these specialist services to several VCA funded projects in areas of lung, prostate and bowel cancer and the Cancer 2015 project. Other disease areas such as neurology, endocrinology and cardiology are either in the process or planning to extend their data collection and research activities with assistance from BioGrid, should appropriate funding be available.

Substantial progress has been made over the past year with the Australian Institute of Health and Welfare (AIHW) regarding linkage to the National Death Index. This will allow BioGrid to obtain Australia wide death data for approved research projects. Ongoing discussions have resulted in approval of an amendment to BioGrid's data access application review procedure to comply with AIHW requirements. Currently technical work is underway to achieve data linkage.

The ongoing success of the company has largely been due to the many people who have contributed to BioGrid. Firstly on behalf of the company Board, executive management team and the member's Management Committee I would like to thank the Victorian government for their ongoing engagement with BioGrid and their funding of the Australian Cancer Grid until June 2011.

Since 2003 Melbourne Health has continued to act as Secretariat and home for the Australian Cancer Grid project and BioGrid. The continued support for BioGrid from the Melbourne Health executive team is greatly valued and appreciated.

I would like to take this opportunity to acknowledge and thank Mr Bob Atwill, BioGrid's Interim Chief Executive Officer to December 2011, for the strategic contribution that he made to the company during his two years with BioGrid. Both Bob and I are indebted to the executive management team, A/Prof Peter Gibbs (Clinical Director), Ms Julie Johns (Data Utilisation Manager), Dr Suzanne Kosmider (Project Manager) and Mrs Naomi Rafael (Technology and Systems Manager) for their commitment and passion to the ongoing development of BioGrid. The contributions and cooperative work of the Australian Cancer Grid Project Board, the Member Management Committee and the Scientific Advisory Committees over the past year has also been a great support to BioGrid.

Finally, I would like to thank all the BioGrid staff for their generous commitment to BioGrid's vision and mission. The past year has been a busy and challenging time for BioGrid as the organisation works with other key cancer research capabilities towards the establishment of an integrated translational research platform in Victoria. We look forward to working closely with the cancer community, the Victorian Cancer Agency and the state government to make this vision a reality in the coming year.

I trust you enjoy reading the report and finding informative how BioGrid facilitates collaborative research.

Ms Maureen Turner
Chief Executive Officer, BioGrid Australia

RESEARCH HIGHLIGHTS

Centre of Analysis of Rare Tumours: CART-WHEEL.org

Since its launch in April 2010 by Professor Sir Gustav Nossal, the CART-WHEEL.org rare tumour database has attracted more than 260 registrants and 100 people have returned their consent forms for the use of their clinical information for future research.

Funded by the Victorian Cancer Agency, the first project utilising the CART-WHEEL.org database will attempt to validate the patient self-entered data via CART-WHEEL.org with original source medical data. This project is currently recruiting patients; the results are keenly anticipated.

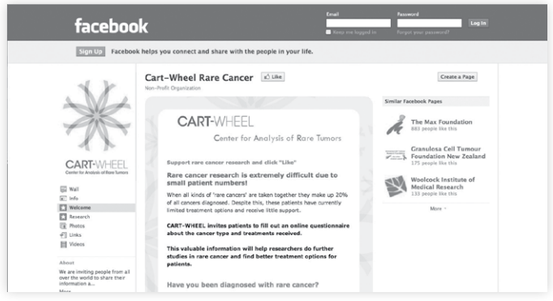
The Picchi Brothers Foundation is supporting a research fellow and this has facilitated the commencement of other rare tumour projects. One project is targeting a rare subset of ovarian cancer and is an important preliminary study to support a larger international collaborative project. The international project will determine the gene expression of this poorly understood high-grade subset of mucinous ovarian cancer with the aim of clarifying treatment options for women with this rare but highly lethal disease.

CART-WHEEL.org is also facilitating another study in small cell cancer of ovary by the Translational Genomics Research Institute and Van Andel Research Institute, of which both are collaborating sites investigating the molecular/genetic pathways driving this rare but aggressive disease mainly affecting young women.

Many international gynae-oncologists have taken active interest in the potential utility of the CART-WHEEL.org rare tumour database as a platform for future collaborative work on rare gynaecological cancers. CART-WHEEL.org was recently introduced in an international gynaecological journal[1].

As part of promotional activities, CART-WHEEL.org has embraced social media by creating Facebook and Twitter accounts with daily cancer news and information updates. Cancer forums have also been utilised to spread the word of CART-WHEEL.org to the wider cancer community. Proof of principle projects utilising the CART-WHEEL.org data and social networking approaches will continue to drive consumer usage of CART-WHEEL.org.

[1] Bae S, Friedlander M, Scott C. **CART-WHEEL.org can facilitate research into rare gynaecological tumors.** *Int J Gynaecological Cancer.* In Press. 19 May 2011.



CART-WHEEL.org Facebook page.

Researchers first to develop a multi-SNP risk prediction model for newly diagnosed epilepsy patients

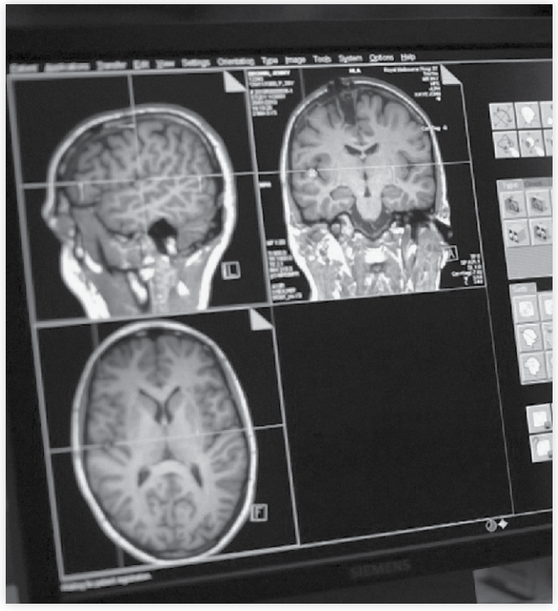
Determining the optimal treatment for patients with newly diagnosed epilepsy is problematic. Slave Petrovski and Professor Terry O'Brien were the first to develop a multi-SNP risk prediction model to predict the likelihood that a newly diagnosed epilepsy patient will respond to the most common anti-epileptic drugs. Following this research, clinical parameters such as a patient's pre-treatment mood disorder was also found to predict their response to epilepsy treatment.

Their findings have important clinical translation as they suggest that treatment of any neuropsychiatric disorder in parallel with anti-epileptic therapy could improve the control of seizures in patients newly diagnosed with epilepsy[1].

BioGrid Australia plays an important role in managing the data and facilitating the research efforts of the pharmacogenomics team. Their research into the field of epilepsy pharmacogenomics has been presented at over a dozen national and international scientific meetings, resulting in an international patent[2], and has won numerous achievement awards.

[1] S Petrovski, C E I Szoeke, N C Jones, M R Salzberg, L J Sheffield, R M Huggins, T J O'Brien (2010) **Neuropsychiatric symptomatology predicts seizure recurrence in newly treated patients.** *Neurology* 75: 11. 1015-1021 Sep

[2] Slavé Petrovski, Cassandra E Szoeke, Leslie J Sheffield, Wendy D'souza, Richard M Huggins, Terence J O'Brien (2009) **Multi-SNP pharmacogenomic classifier is superior to single-SNP models for predicting drug outcome in complex diseases**. *Pharmacogenet Genomics* 19: 2. 147-152 Feb



Magnetic Resonance Imaging Scan.

BioGrid enabled data supporting continuation and expansion of a National Bowel Cancer Screening Program in Australia

Bowel cancer is a significant public health issue in Australia. Screening for bowel cancer with faecal occult blood testing (FOBT) has been proven to save lives by diagnosing cancer at an early stage, when the likelihood of cure is high. Clinical trials have demonstrated that such screening reduces deaths from bowel cancer by 15–30%, equating to almost 1,000 lives saved per year. The current Australian National Bowel Cancer Screening Program (NBCSP) is limited to specific age groups rather than the broader population. Little evidence is available to assess if it is having the desired impact. The cost effectiveness of such a program was also unknown.

Impact on stage at diagnosis

BioGrid is supporting clinicians to capture a comprehensive dataset on patients with bowel cancer. Through multi-site data linkage an adequate sample size has been analysed to compare the outcomes for those diagnosed by the NBCSP versus those diagnosed when symptoms are detected.

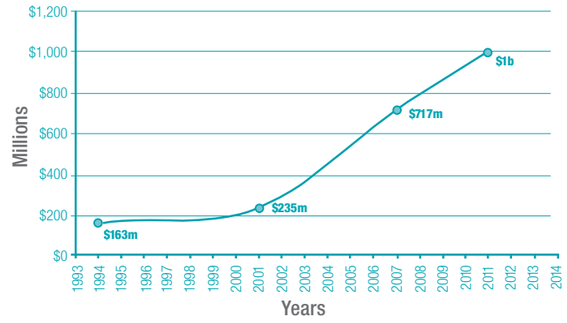
Stage of Cancer Diagnosis	NBCSP	Symptoms
A	**40%**	**14%**
B	25%	31%
C	25%	24%
D	**3%**	**15%**

Cost of treating bowel cancer

Data linked through BioGrid has enabled a comprehensive analysis of the cost of treating bowel cancer according to the stage at which the cancer was diagnosed. Compared to 1999 estimates the cost of treating early stage cancer in 2010 is largely unchanged whereas the cost of treating advanced cancer has escalated dramatically.

Stage of Cancer Diagnosis	$cost 2010	$cost 1999
A	**23,100**	**17,100**
B	63,500	33,400
C	80,000	25,800
D	**97,300**	**6,300**

New treatment options that benefit people with advanced bowel cancer bring with it significant public health costs. Analysing the forecasted expenditure, the estimate for the national cost of treating bowel cancer will be one billion dollars in 2011.



Rapidly escalating cost of treating bowel cancer.

Data linked through BioGrid has demonstrated that despite the limited scope of NBCSP, it is leading to earlier diagnosis of bowel cancers and this earlier diagnosis is directly leading to increased survival from this disease. Additional analysis related to the increasing cost of treating advanced bowel cancer creates a compelling argument for the cost effectiveness of screening.

This research project is currently in submission for publication.

Research findings inform Head and Neck cancer treatment

The Head and Neck module of the Australian Comprehensive Cancer Outcomes and Research Database (ACCORD) at BioGrid is now in its fourth year of use, headed by Associate Professor David Wiesenfeld. This data collection tool has been invaluable for clinical research into Head and Neck cancers at The Royal Melbourne Hospital. The database captures all disciplines involved in the care of patients with various Head and Neck malignancies.

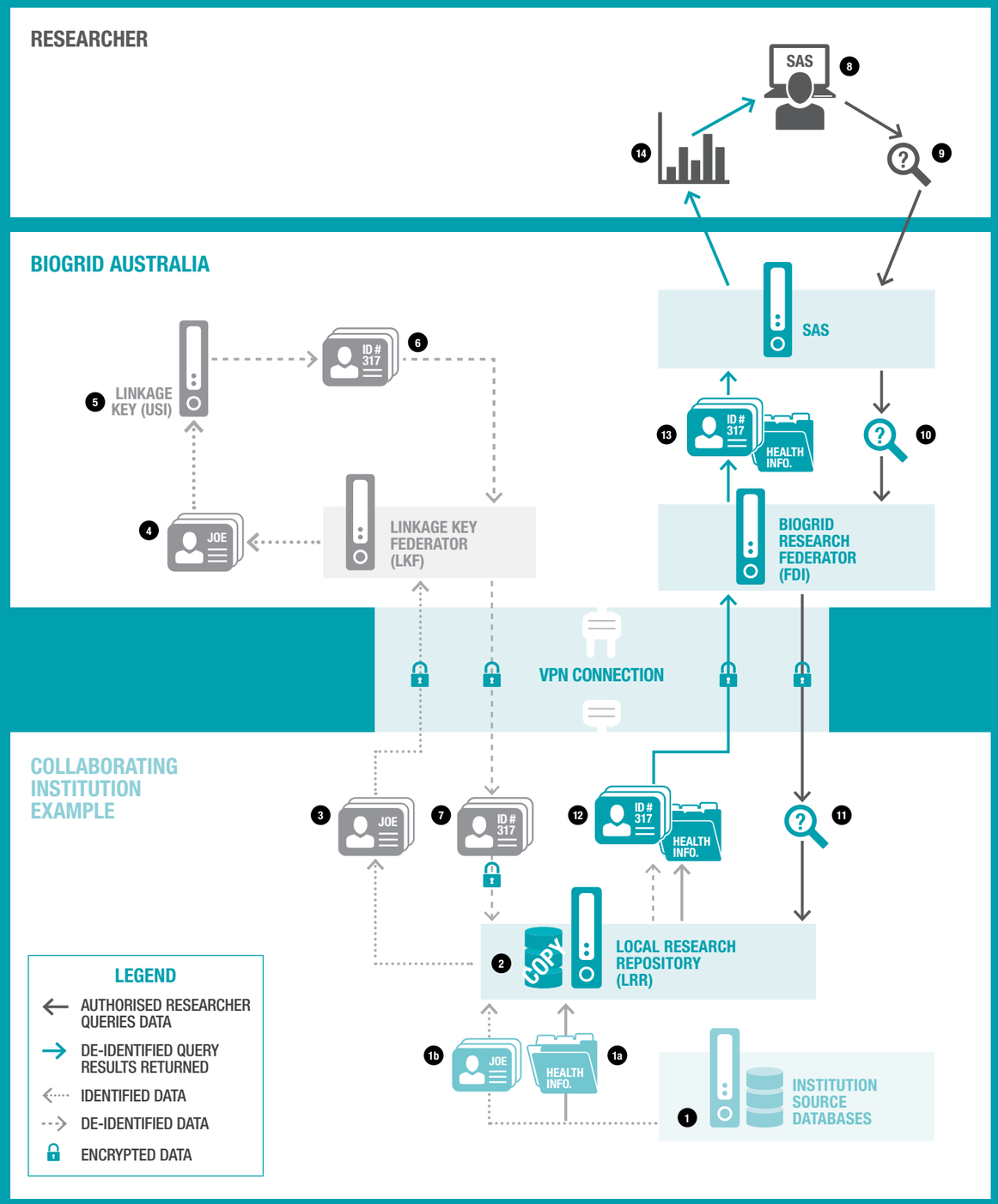
A project examining surgical outcomes for cancers of the tongue identified a subset of patients more likely to have local tumour recurrence. The research findings have resulted in suggested alternative surgical techniques and additional treatment to reduce this[1]. Adenoid cystic carcinoma is a rare salivary gland malignancy. A review of records over a 22-year period confirmed that tumour size at diagnosis is the most important predictor of outcome[2].

Utilising the BioGrid analytical software tools to interrogate the ACCORD data has allowed research into the outcomes and risk factors for patients with Head and Neck tumours.

[1] Matthew J Lin, Anthony Guiney, Claire E Iseli, Malcolm Buchanan, Tim A Iseli (2011) **Prophylactic Neck Dissection in Early Oral Tongue Squamous Cell Carcinoma 2.1 to 4.0 mm Depth.** *Otolaryngol Head Neck Surg* 144: 4. 542-548 Apr

[2] A F Deangelis, A Tsui, D Wiesenfeld, A Chandu (2011) **Outcomes of patients with adenoid cystic carcinoma of the minor salivary glands.** *Int J Oral Maxillofac Surg* Mar

HOW BIOGRID WORKS



HOW BIOGRID WORKS

DIAGRAM REFERENCE KEY

1. Patient information is recorded in one or more data sources (i.e. databases, spreadsheets), which are stored on a collaborating institution's computer network. This information comprises clinical health information data and identifiers.

1a. Clinical health information data are the collection of facts and opinions about an individual's health and wellbeing. Treatment details are an example of clinical health information data.

1b. Identifiers are the data items, which identify the individual who is described within a patient record. A patient's name is an example of an identifier.

2. The patient information is copied into replica data sources, which are stored on the collaborating institution's Local Research Repository (LRR), on a nightly basis or frequency agreed by the collaborating institution.

3. A limited set of identifiers from each new patient record are sent from the replica data sources to BioGrid Australia's Linkage Key Federator (LKF) via a secure encrypted Virtual Private Network (VPN) connection.

4. The Linkage Key Federator (LKF) forwards the identifiers to BioGrid Australia's Linkage Key server. This server hosts the Unique Subject Identifier (USI) database.

5. The identifiers are compared with the USI database's records to establish whether data about the patient already exists within a BioGrid-linked data source.

   If a match is found for a patient's data, the patient has previously been allocated a USI. If no match is found for a patient's data, the patient's set of identifiers and a new USI are written to the USI database.

6. The USIs for the matching and non-matching patients are sent back to the LKF.

7. The USIs are sent back to the LRR via a secure encrypted VPN connection and stored with their associated clinical health information data.

8. Once authorised access via the BioGrid Australia Data Access Application System has been provided to the researcher, they can commence querying the de-identified data they have approval to access.

9. The researcher submits a data query to BioGrid Australia's statistical analysis (SAS) computer via the Internet.

10. The SAS computer forwards the query to the FDI.

11. The FDI requests the specified data from each of the relevant LRRs via a secure encrypted VPN connection.

12. The clinical health information data and USIs from applicable patient records are sent to the FDI via a secure encrypted VPN connection. These data are combined into a temporary table. The table is removed from the FDI upon completion of the query.

13. The SAS computer reads and processes data from the temporary table.

14. The SAS computer presents the results of the query to the researcher.

CLINICAL DIRECTOR'S REPORT

Being involved with BioGrid since its inception, as a founding clinical researcher, and now more recently as Clinical Director, my role has been to generate increasing engagement from clinicians and industry to develop data collection and linkage across a broad spectrum of diseases, with the long-term aim of improving clinical outcomes for patients. It has been very encouraging to see that over the past 12 months there has been an increase in research outcomes across several disease areas whilst data collection continues to steadily increase.

In my role as Clinical Director, I provide oversight to the three BioGrid Scientific Advisory Committees (SAC): Cancer, Life Sciences and Pharmaceutical. The role of the Cancer and Life Sciences SACs is to lead and oversee the rapidly expanding and evolving science and research activities of BioGrid, including reviewing and approving data access requests from researchers. Meeting quarterly throughout the year, the Cancer and Life Sciences SACs comprise representatives from member organisations and affiliates who have expertise in particular disease areas. The Pharmaceutical SAC, also meeting quarterly, oversees the validity of commercial activities of the company to ensure projects are aligned with BioGrid's strategy without compromising any of our core values. Members of the advisory committee include member clinicians and researchers as well as external commercial expertise.

The ongoing collaborative study between BioGrid and Roche Products has continued to provide insight into how clinicians choose from the multiple potential treatment options available for patients with advanced bowel cancer. Pleasingly, along with increasing involvement of clinicians in both the public and private sector in Victoria, the first interstate site (Canberra) has been linked and data collection is either initiated or about to begin at additional sites in Tasmania, New South Wales and Queensland, which will make this a truly national project. The first of many anticipated research papers related to this activity has been drafted and will shortly be submitted. Feedback from Roche has been very positive and with accrual of the initial 1,000 patients across Australia likely to be completed toward the end of 2012, discussions are underway regarding expanding this project to include additional questions across a significantly larger number of patients.

The number of tumour streams collecting multi-disciplinary and comprehensive data continues to expand. Highlights include the ongoing research output of the head and neck tumour group which has produced multiple publications in the last 12 months and the initiation of data collection for hepatocellular carcinoma (HCC) across seven major Melbourne centres, with longer term plans to move to a national HCC database. New initiatives continue and in 2012 a testicular cancer dataset and database will be established, initially at three sites in Melbourne with plans to engage with sites across Australia.

During the year endocrinologists from six hospitals across three states obtained industry support to enhance the BioGrid Diabetes Survey Database with a module that enables clinicians to collect data on patient usage of insulin pumps. The new module has been installed at participating hospitals; following collection of these new data items, collaborative projects will commence to answer important research questions relating to insulin pump usage.

An exciting development is the establishment of international links, with the first publications due in 2012 from combining data from Melbourne centres linked through BioGrid with data from MD Anderson Cancer Centre in Houston. Additional projects are underway which will build on this initial collaboration. Conversations are underway with researchers at additional US centres and with the Princess Margaret Hospital in Toronto, where both colorectal cancer and testicular cancer data is likely to be combined with data through BioGrid in the next 12 months.

BioGrid is working with state government agencies to support the establishment of an integrated translational research platform in Victoria. In time, data linkage across clinical data, biospecimens, registry data, biomarkers, genomics and imaging will provide a rich source of information for clinical research that will enhance the efficiency of biomarker discovery and validation research.

I would like to take this opportunity to acknowledge the commitment and contribution of the Scientific Advisory Committees over the past year. I would also like to thank all the clinical leaders and researchers for their hard work and commitment during the year, and the BioGrid team members for their ongoing support.

Detailed reports on achievements and activity for 2011 across cancer and other disease areas can be found in the following pages of this report.

Associate Professor Peter Gibbs
Clinical Director, BioGrid Australia

RESEARCH REPORTS: CANCER

BONE AND SOFT TISSUE (SARCOMA)

Dr Jayesh Desai is the BioGrid Bone and Soft Tissue tumour stream leader. Dr Desai is a Medical Oncologist at The Royal Melbourne Hospital and Peter MacCallum Cancer Centre and senior Research Staff at the Ludwig Institute for Cancer Research. He is the Chair of the Australasian Sarcoma Study Group (ASSG), the national cooperative group for sarcoma research and trials.

Background

Sarcomas are a diverse group of malignant tumours that develop from bone and soft tissues (fat, muscle, nerves and blood vessels). Although rare; they comprise about 1% of adult and 15% of pediatric malignancies. The morbidity and community impact of sarcomas is significant given the high proportion of younger people affected compared to most other solid tumours. For example it has been estimated that 17 years of life are lost per sarcoma patient, three times the rate of bowel or breast cancer.

Progress and Challenges

Data collection is now established at each of the planned ASSG sites and the past 12 months has focused on making this data available for reporting and analysis. At present, all sites do not have data linkage through BioGrid, so a temporary solution of a periodic extract will allow data to be combined from all sites. Leveraged funding and support for ongoing data collection through the ASSG will continue into 2012.

There have been some modifications to the ACCORD[1] Sarcoma module to allow specific fields to be entered for a pulmonary mastectomy project and improve some other areas of data collection. Data is continuing to be collected at all sites in Victoria, New South Wales, Queensland, South Australia, Western Australia and Australian Capital Territory using the ACCORD database or equivalent. Data on over 3,000 patients has now been collected.

Funding for data collection at each site has been provided by ASSG supported by a grant through Cancer Australia, with matched funding provided by the sites. A Sarcoma Database Users Group has been formed and data managers attended a training meeting coordinated by BioGrid in May 2011, where members met and discussed data collection processes at each site, reporting requirements and issues for resolution. Members received 'hands-on' training for SAS Web Report Studio (reporting) and how to extract or link data from ACCORD into MS Access. A clear challenge identified early in the development of the sarcoma database initiative related to the complexity of quality data collection given this is really a diverse set of diseases. Referral of patients to major centres of care, with an ongoing shared-care arrangement with local clinicians adds to the challenge of tracking patient outcomes.

Future Directions

High quality clinical and epidemiological data, mapping patterns of care across all centres will be available at all sites over the next 12 months. BioGrid linkage will be critical to enabling this process. Discussions are ongoing for paediatric data collection, and to address specific issues with the AYA population. Further such prospective studies are in development.

[1] Australian Comprehensive Cancer Outcomes and Research Database

BREAST

Associate Professor Clare Scott is the BioGrid Breast tumour stream leader. A/Prof Scott is a Medical Oncologist at The Royal Melbourne Hospital and Laboratory Head at The Walter and Eliza Hall Institute of Medical Research.

Background

Breast cancer is the most common invasive cancer among Australian women and the second most common cancer causing death after lung cancer. It is uncommon in males. Growing older is the most common risk factor: about 13% of new cases are among women aged 20–44, 61% in women aged 45–69 and 26% among women over 70. Women of all ages need to understand the importance of finding and treating breast cancer early.

Fifteen per cent of all breast cancers are advanced at diagnosis. Women whose cancer is diagnosed when it is contained in the breast, have a 90% chance of surviving five years compared with 20% five-year survival when the cancer has spread at diagnosis.

Progress and Challenges

There are several projects at a state level directly linked to the breast tumour stream.

1. The Cancer Council Victoria (CCV) along with Western and Central Melbourne Integrated Cancer Service (WCMICS) has developed a Victorian Consensus Dataset (VCDS) for the Breast tumour stream. This published/online dataset (http://www.cancervic.org.au/downloads/cec/VCDS -project/VCDS-Breast-Data-Set.pdf) will provide the opportunity for data to be collected in a uniform and standard manner across Victoria.
2. BioGrid has developed an ACCORD[1] module for Breast cancer data collection, which uses standards set in the VCDS dataset. This module is web based and includes fields to capture data in Multidisciplinary Team Meetings. Prospective data will be collected at the three sites involved in the module's development and testing (Austin Hospital, Box Hill Hospital and Monash Medical Centre) and the database will be available to any other BioGrid member sites keen to collect breast data.
3. The Cancer Council Victoria's RUTH database is being used at the Royal Melbourne Hospital and the Royal Women's Hospital in Melbourne. RUTH is now in use for collection of data, with active multi-disciplinary meeting capability. The data terms collected by both RUTH and the ACCORD module are closely aligned so data can be combined for analysis.

Future Directions

- To continue to develop the Breast ACCORD module with functionality for generation of letters to GP's;
- Use of the BioGrid electronic chemotherapy prescribing module, with linkages to EviQ, which will be released to member sites in 2012.
- The availability of clinical annotation for tissue specimens held by diagnostic laboratories and tissue banks for ethically approved projects.

[1] Australian Comprehensive Cancer Outcomes and Research Database

CENTRAL NERVOUS SYSTEM

Associate Professor Kate Drummond is the BioGrid Central Nervous System tumour stream leader and a Consultant Neurosurgeon at The Royal Melbourne Hospital.

Background

Central Nervous System (CNS) tumours comprise a wide variety of tumour types and data is collected on all patients having neoplastic brain and spinal lesions removed, with tissue also collected and banked. Of these tumour types, glial tumours and metastases are both common and are associated with a poor prognosis, and thus are a particular focus. Data and tissue collected on cerebral metastases has obvious synergy for data linkage with other primary cancer databases through BioGrid and has been the subject of recent publications.

Progress and Challenges

Web-based electronic data collection continues however obtaining follow-up and survival data continues to be a challenge, as many patients return to regional health services for ongoing care after their centralised neurosurgical treatment. Expansion of data linkage possibilities will be important in this area. The data collected continues to evolve as diagnostic and treatment paradigms change and thus continuous updates are required.

The CNS database now contains over 2,500 patients and is being used for a number of collaborative projects looking at biomarkers in malignant glioma, the characteristics of long-term survivors from glioblastoma multiforme, tumour-associated epilepsy and treatment pathways in patients with lung cancer and brain metastases. Abstracts have been accepted at national and international meetings and initial publications have been accepted. A number of Australian groups have expressed an interest in contributing to the database, but funding and manpower remain significant issues for those groups who do not routinely collect tumour data.

Future Directions

As diagnosis and treatment of CNS tumours evolve, so does the dataset. An upgrade will be planned in 2012 as well as continued expansion into other Australian sites. As RMH moves into the Victorian Comprehensive Cancer Centre era, the important role of BioGrid in data collection and linkage will need to be developed.

Publications and Presentations

1. Tie J, Lipton L, Desai J, Gibbs P, Jorissen RN, Christie M, Drummond KJ, Thomson BN, Usatoff V, Evans PM, Pick AW, Knight S, Carne PW, Berry R, Polglase A, McMurrick P, Zhao Q, Busam D, Strausberg RL, Domingo E, Tomlinson IP, Midgley R, Kerr D, Sieber O. KRAS mutation is associated with lung metastasis in patients with curatively resected colorectal cancer. *Clin Cancer Res* 17(5):1122-30, 2011.
2. Field K, Rosenthal MA, Yilmaz M, Gibbs P, Drummond KJ. Novel features that impact the outcome of patients with glioblastoma multiforme: multivariate analysis from a comprehensive dataset. Poster presentations at Medical Oncology Group of Australia ASM, Adelaide, August, 2011; European Association of Neurosurgical Societies Annual Meeting, Rome, October, 2011; European Cancer Congress Annual Meeting, Stockholm, September, 2011; Society for Neuro-Oncology Annual Meeting, California, November, 2011.

CHRONIC LYMPHOCYTIC LEUKAEMIA

Dr Constantine Tam is the BioGrid Chronic Lymphocytic Leukaemia (CLL) tumour stream leader. Dr Tam is a Haematologist at St Vincent's Hospital Melbourne, and a member of the CLL Australian Research Consortium (CLL-ARC), a collaborative body of enthusiastic CLL clinicians and researchers dedicated to finding the cure for CLL. Dr Tam's responsibilities within the CLL-ARC are to facilitate the establishment of a comprehensive, multi-centre clinical data network and to develop the next generation of treatments for CLL to be tested in clinical trials in Australia.

Background

Chronic Lymphocytic Leukaemia (CLL) is a type of slow growing leukaemia that affects developing B-lymphocytes (specialised white blood cells). Under normal conditions they produce immunoglobulins (also called antibodies) that help protect our bodies against infection and disease.

In people with CLL, lymphocytes undergo a malignant (cancerous) change and become leukaemic cells. CLL is the most common adult leukaemia in Australia (with the diagnosis made in 718 patients each year[1]), and yet little is known about its cause, and it is not curable with current technology.

For many people CLL remains stable for many months and years and has little if any impact on their lifestyle or general health. Around 50 percent of people diagnosed with CLL never require any treatment for their disease and can survive for many years despite their diagnosis. For others, the leukaemic cells multiply in an uncontrolled way. It is not known why the leukaemia is so indolent in some patients, and aggressive and life-threatening in others. More research is required to understand the genetics of CLL, in order to find weaknesses in the cancer that can be exploited by new drugs. By better understanding what causes the leukaemia to be aggressive and what its weaknesses are, we hope to construct treatment programs that can cure CLL.

Progress and Challenges

Historically patient datasets have been collected in many research institutions (e.g. St Vincent's Hospital and Royal North Shore Hospital) but standard datasets have never been defined, and these datasets have never been linked or analysed in a systematic manner. BioGrid will facilitate the linkage of a standard dataset using ACCORD[2] and other databases to make data available to researchers and clinicians in a de-identified manner.

The CLL module in ACCORD has been installed with data currently being collected at St Vincent's Hospital as the lead site for this collaborative project. Funding support for data entry continues to be a challenge across the interested CLL-ARC hospitals, and until this issue is resolved, progress will be limited.

Future Directions

Once the CLL module is active at St Vincent's Hospital, the historical data at this site will be entered into ACCORD as a final check on the function and integrity of the system. The ACCORD module will then be rolled out to interested CLL-ARC sites in order to establish a nationwide, comprehensive network.

Initial research projects will be devoted to understanding the epidemiology of CLL within the Australian population and how differing treatment practices influence major outcomes such as response to chemotherapy, side effects and survival. We envision that the availability of a large data network will then facilitate and coordinate basic and clinical CLL research in Australia.

[1] Source: Leukaemia Foundation website: www.leukaemia.org.au
[2] Australian Comprehensive Cancer Outcomes and Research Database

COLORECTAL

Associate Professor Peter Gibbs is the BioGrid Colorectal cancer tumour stream leader. A/Prof Gibbs is a joint Laboratory Head at the Ludwig Institute for Cancer Research and Senior Staff Specialist at The Royal Melbourne and Western Hospitals.

Background

Colorectal cancer remains the second most common cancer affecting men and women in Australia, and the second leading cause of cancer related death.

Progress and Challenges

Research

During 2011 data through BioGrid has made significant contributions to many areas of colorectal cancer research. While considerable progress has been made in treating patients with advanced colorectal cancer, the biggest impact on survival is likely to come from defining an individual's risk (6,7) and from earlier diagnosis through screening, which does need to be cost effective (9). Improving a clinician's ability to predict outcomes, considering not only tumour (1,2,5,11), but also patient related factors (10), and the impact of these on any intervention will help to substantially improve outcomes. For any area of translational research enriching patient populations to be studied is critical to optimising the return on investment into translational research (1). Improving the quality of care is vital, including optimal initial pathologic assessment (3) as is ensuring the outcomes of new therapies benefit patients in routine clinical care (4). For the first time data through BioGrid has been linked with data from international sites, resulting in a joint project with MD Anderson Cancer Centre (5).

Sites

This year has seen an expansion of the number of sites collecting colorectal cancer data and the range of research activities enabled by this collection, with data now entered on well over 5,000 patients. Accelerating participation in colorectal data collection by medical oncologists has been an increasing engagement with industry, particularly with a project supported by Roche that captures comprehensive data on the management of patients with advanced cancers. Data from multiple interstate sites is now being contributed to this project, which ultimately should engage clinicians from every state and territory in Australia. Several additional industry sponsored data collection projects are well advanced in development.

Grants

An NHMRC project grant will explore the value of circulating tumour DNA as a prognostic marker in patients with locally advanced rectal cancer. Data for this project is being collected and linked with support from BioGrid, with the Victorian Cancer Biobank enabling the collection of required tumour and blood samples. A project exploring two novel biomarkers in stage II colon cancer, funded by an international industry collaborator is well underway. Another project, funded by an academic partner in the US will explore a novel marker of response to irinotecan, a commonly used chemotherapy drug in advanced bowel cancer. A joint project with CSIRO, funded by an NHMRC development grant, was also initiated this year.

Future Directions

A new direction in 2012 will be several blood biomarker projects, funded by industry grants where samples will be collected from patients treated in routine care with standard protocols, with the collection and analysis of outcome data being supported by BioGrid. Work continues on an electronic chemotherapy prescribing tool (which generates prescriptions and collects data), linked with EviQ, which should be ready for distribution to any interested sites in the coming year. A pilot project combining data through BioGrid with data from Cancer Care Ontario is in development, and will examine the differences in treatment of metastatic colorectal cancer.

Publications

1. Tie J, Gibbs P, Lipton L, Jorissen R, et al. Optimizing Targeted Therapeutic Development: Enriching the Colorectal Cancer Patient Population for the BRAFV600E Mutation. *Int J Cancer.* 128;2075-84:2011
2. Tie J, Lipton L, Desai J, Gibbs P, et al. KRAS mutation is associated with lung metastasis in patients with curatively resected colorectal cancer. *Clin Cancer Res.* 17;1122-30:2011
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4. Kosmider S, Hsiang T, Yip D, et al. Radioembolization in Combination with Systemic Chemotherapy as First-Line Therapy for Liver Metastases from Colorectal Cancer. *JVIR* 22;780-6:2011
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7. Spain SL, Carvajal-Carmona LG, Howarth KM, et al. Refinement of the associations between risk of colorectal cancer and polymorphisms on chromosomes 1q41 and 12q13.13. *Hum Mol Genet.* 2011 Nov 10. [Epub ahead of print]
8. Merriel RB, Gibbs P, O'Brien TJ, et al. BioGrid Australia facilitates collaborative medical and bioinformatics research across hospitals and medical research institutes by linking data from diverse disease and data types. *Human Mutation* 2011;32:1-9. [I.F. 6.887]
9. Tran B, Keating CL, Ananda S, 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. *IMJ.* Accepted July 2011
10. Field K, Faragher I, Gibbs P. The cost of cancer care – considering the value of caring for the elderly. *NEJM.* 365;675:2011
11. Bae S, Tie J, Desai J, Gibbs P. MSI status is critical to analysis of survival for stage II colon cancer. *J Clin Oncol.* Accepted October 2011

GYNAECOLOGY

Dr Sumitra Ananda is the BioGrid Gynaecological tumour stream leader. Dr Ananda is a Medical Oncologist at The Royal Women's Hospital, Peter MacCallum Cancer Centre and Western Hospital.

Background

Gynaecological cancers include cancers of the uterus (including endometrium), ovary, cervix, vulva, vagina, placenta and gestational trophoblastic disease (pregnancy-related cancers). On average, more than 3,900 women were diagnosed with a gynaecological cancer in Australia each year, between 2001 and 2005. Gynaecological cancers were responsible for 1,562 female deaths in Australia in 2005, accounting for 9.1% of all female cancer deaths. Ovarian cancer is the most common gynaecological malignancy. A recent paper published in the Lancet reports a poorer survival for ovarian cancer in Australia compared to our counterparts in Europe, North America and Scandinavia. While treatment for ovarian cancer has advanced over the last three decades with improvement in aggressive de-bulking surgery and the use of platinum based chemotherapy, long term survival rates have changed very little. There is an urgent need to have diagnostic, treatment and outcome data for these patients in order to identify key areas for change and to ultimately improve outcomes for our patients.

Progress

The Ministerial Taskforce for Cancer (2003–2007), established by the Victorian Government provided seed funding in 2005 to initiate the Victorian Cancer Outcomes Network (VCON) project. A pre-trial commenced in June 2006 with the capture and transfer of Victorian Clinical Cancer Registration Dataset (VCCRD) data from the Oncology Unit at the Royal Women's Hospital to the Victorian Cancer Registry. The Royal Women's Hospital collects data using a database known as GeMMA. The success of the pre-trial led the Cancer Council Victoria to fund a one-year project know as the Gynaecological Oncology Project (GOP) which commenced in 2008 to expand Gynaecological data collection to the other major metropolitan and regional Gynaecological treatment centres using the GeMMA software. This enabled the Victorian Cancer Registry to expand the existing data collection to include clinical data based on the VCCRD and report on surveillance and monitoring for Gynaecological tumour stream at the population level for Victoria. The project promoted and expanded Gynaecological cancer data collection at several metropolitan health services using the GeMMA software.

BioGrid has established linkage with The Royal Women's Hospital, which is the largest provider of Gynaecological oncology care in Victoria. Data collection is ongoing and a data manager is employed to ensure data is up to date and complete when entered. The GeMMA database has been used for clinical research and in particular a few projects have been carried out in collaboration with BioGrid using BioGrid analysis and reporting tools.

Future Directions

To further establish Gynaecological data collection as part of the current BioGrid tumour streams will be the ongoing focus. BioGrid is currently in discussion with the Royal Women's Hospital to assist with upgrading the current database, which will provide greater functionality. BioGrid is also making links with other sites in Victoria to enable the utilisation of their comprehensive data for translational research purposes and linkage analysis.

Presentations

1. Ananda S, Gibbs P, Quinn M. Ovarian Cancer Survival - A single institution experience presented at ANZGOG 2011

HEAD AND NECK

Mr David Wiesenfeld is the BioGrid Head and Neck tumour stream leader and Clinical Associate Professor at The University of Melbourne. Mr Wiesenfeld is an Oral and Maxillofacial Surgeon at The Royal Melbourne Hospital with research affiliations at The University of Melbourne.

Background

The management of patients with Head and Neck tumours involves specialised, multidisciplinary medical care and input from sub-specialised allied health members including Otorhinolaryngologist Head and Neck, Oral and Maxillofacial and Reconstructive Plastic Surgeons, Medical and Radiation Oncologists, Speech Pathologists, Nutritionists and Prosthetists. Thyroid cancer is currently included in this tumour stream.

Progress and Challenges

The Head and Neck module in ACCORD[1] is now in its fifth year of use. It has been invaluable for clinical research into Head and Neck cancer at The Royal Melbourne Hospital. The appointment of Craig Love as Head and Neck Database Manager has ensured the completeness and accuracy of data entry for patients. The inclusion of Radiation and Medical Oncology data will be an ongoing project within the Victorian Comprehensive Cancer Centre.

A proud achievement for this year is the award of a WCMICS grant for the assessment of psycho-social needs for head and neck and lung cancer patients. We intend to identify the most appropriate screening tool, and incorporate it into our BioGrid Head and Neck Database.

Projects currently in progress include:

1. Analysis of patients with oral cancer, comparing the demographics and outcomes for those who are non-smokers, and non-alcohol drinkers, with those who have consumed significant amounts of tobacco and alcohol. This project has generously been supported by a grant from the Price Family Foundation.
2. Prospective correlation of radiological, clinical, and pathological assessments of tumour thickness in the anterior tongue. This project has nearly completed the accrual phase, and is expected to be published by the end of 2012.
3. Analysis of outcomes for patients managed with mid-facial cancer, including prognostic predictors and the incidence of nodal metastatic disease.
4. An assessment of Novel Biomarkers in oral cavity carcinomas utilising fresh and fixed tumour specimens in combination with researchers at the Peter MacCallum Cancer Centre.
5. Assessment of the versatility, functional and aesthetic outcome of approaches to the lower face utilising lip splitting incisions.
6. A review of progress over a 20 year period of delays in presentation and diagnosis for patients with oral cavity carcinomas.
7. A review of management and outcomes of osteoradionecrosis of the jaws.
8. Studies on the role of HPV in the development of Ameloblastoma on the jaws.
9. Determinants of radioiodine uptake after one and two-stage thyroidectomy for thyroid cancer.
10. Studies on functional reconstruction and quality of life for patients with maxillary tumours.

All of these projects rely on accurate data within our ACCORD Database. The contributions of researchers, Tim Iseli, Julie Miller, Michael McCullough, Arun Chandu, Pramit Phal, Catherine Spinou, Adrian DeAngelis, Mathew Linn, Roland Barrowman, Kendrick Koo, and Alex Bobinskas are gratefully acknowledged.

Future Directions

The challenge of spreading the use of the ACCORD Head and Neck Database to additional sites is significant and requires ongoing effort. Interest has been expressed from centres in Australia and The United States of America. The development of the database for MDT presentations, referrer communications, and as part of the patient clinical record, is an area that demands financial and intellectual support.

Publications

1. M. J. Lin, A. Guiney, C. E. Iseli, M. Buchanan, T. A. Iseli. Prophylactic neck dissection in early oral tongue squamous cell carcinoma 2.1 to 4.0 mm depth *Otolaryngol Head Neck Surg* April 2011 vol. 144 no. 4 542-548
2. R. Barrowman, P.R. Wilson, D. Wiesenfeld. Oral rehabilitation with dental implants after cancer treatment. *Aust. Dent. J.* 2011:56(2):160-165
3. A.F. DeAngelis, A. Tsui, D. Wiesenfeld, A. Chandu. Outcomes of patients with Adenoid Cystic Carcinoma of the Minor Salivary glands *International Journal of Oral and Maxillofacial Surgery* 2011: (40) 7100
4. A.F. DeAngelis, C. Spinou, A. Tsui, T. Iseli, J. Desai, D. Wiesenfeld, A. Chandu. A review of the efficacy of pre-operative chemotherapy for 15 patients with osteosarcoma of the facial bones, comparing the extent of tumour necrosis with disease control. *Journal of Oral and Maxillofacial Surgery* Online July 2011
5. T. A. Iseli, M. J. Lin, A. Tsui, A. Guiney, D. Wiesenfeld, C. E. Iseli. Are wider surgical margins needed for early oral tongue cancer? Accepted by *JLO,* March 2012
6. T. A. Iseli. A review of regional failures of patients with oral tongue cancer with and without neck dissection by depth of tumour Accepted for publication *Otolaryngology by Head & Neck Surgery Journal,* April 2011
7. J. Lo, J McNaughtan, V. Rani, D. Maric, A. Smith, M. McCullough, A. Chandu. An immunohistochemical analysis of cell cycle markers in oral mucosal dysplastic lesions treated by laser therapy. A pilot study. Accepted by *J Maxillofac Oral Surg,* 2011
8. C. Law, R. Chandra, J. Hoang, P.M. Phal. Imaging of the oral cavity – key concepts for the radiologist. Accepted by *British Journal of Radiology* October 2011

[1] Australian Comprehensive Cancer Outcomes and Research Database

HEPATOCELLULAR CARCINOMA

Associate Professor Amanda Nicoll is the BioGrid Hepatocellular Carcinoma tumour stream leader. A/Prof Nicoll is Deputy Director of Gastroenterology and Hepatology at The Royal Melbourne Hospital.

Background

Worldwide, Hepatocellular Carcinoma (HCC) is the fifth most common cancer and the third most common cause of cancer-related death.

HCC is by far the most common primary liver cancer, being responsible for 75–90% of liver cancers worldwide. While HCC remains relatively uncommon in Australia, incidence rates have been progressively rising over the last few decades, due to increased cases attributed to hepatitis C and from hepatitis B – the latter related to migration from high prevalence countries. Adding to this is the obesity epidemic and increased cirrhosis due to non-alcoholic steatohepatitis (NASH, Fatty liver disease).

HCC has well-defined risk factors, some of them amenable to modulation or eradication. The treatment of HCC is increasingly multidisciplinary and outcomes continue to improve due to advances in percutaneous therapies such as chemo-embolisation and radiofrequency and microwave ablation. While HCC responds poorly to conventional chemotherapy, biological agents that specifically target the molecular basis of neoplastic growth and metastasis are expected to make a significant impact on outcomes in coming years. Vascular endothelial growth factor inhibitors have been shown to improve survival in randomised controlled trials.

Therapy, outcomes and prognosis in HCC are intimately linked to both tumour characteristics and organ (liver) function. The lack of appropriate staging systems that recognise the unique nature of HCCs has been a significant impediment to establishing standardised treatments. The Barcelona Clinic Liver Cancer staging system captures the required details, has been widely endorsed and is increasingly used for guiding patient management and assisting patient selection into clinical trials which will add to standardisation in the future. Including this staging data along with the collection of details related to treatments used and outcomes achieved in routine practice will substantially inform optimal treatment selection and lead to improved outcomes.

Progress and Challenges

The Melbourne collaboration for the Study of HCC (MeSH) Interest Group was established in 2010 as an offshoot of the Melbourne Liver Group (MLG), and includes representatives from each of the seven Melbourne hospitals that routinely manage patients with HCC. In addition to hepatologists, it now involves clinicians from across all specialty groups involved in the management of HCC. One issue highlighted was the paucity of linked local data on the epidemiology, management patterns and outcomes of HCC patients in the light of new interventional and systemic therapies. Also discussed was the lack of a standardised approach to patient management. MeSH outlined that collaboration was needed to form a HCC Registry in Victoria to evaluate and assess the diagnosis, epidemiology and treatment of HCC in Victoria and in the future in Australia.

A further current challenge for the MeSH group is the task of involving the radiology departments of the various hospitals in the plans to link data. In order to be able to compare outcomes of different therapies for HCCs, we need to minimise the variation in techniques across all the centres. Our lead radiologist, based at the Austin Hospital, is currently devising a questionnaire to be sent to all involved radiologists to question the techniques used in RFA and TACE. This will help us to see where

the differences lie and help us to devise a protocol that can improve the uniformity of the treatments we offer our patients, and therefore help us to compare the outcomes more accurately.

MeSH has developed with BioGrid a consensus HCC module for ACCORD[1] to enable data collection across seven patient treatment sites in Victoria namely; Austin Hospital, Box Hill Hospital, Monash Medical Centre, St Vincent's Hospital, The Alfred, The Royal Melbourne Hospital and Western Hospital.

Future Directions

The ACCORD HCC database, once implemented, will establish the IT infrastructure to collect HCC data in a uniform manner that could then be installed across all HCC treatment centres in Australia. This would mean that HCC researchers would have access across geographic regions and health organisations to thousands of patient treatment records, enabling:

- Higher confidence levels in research outcomes;
- Ability to track best practices across HCC treatment sites;
- More effective human resource and funding allocation as less will be spent on data collection and more on analysis;
- ACCORD HCC, managed by BioGrid is active and running at Royal Melbourne Hospital and Western Hospital, however it is not yet operational at St Vincent's Hospital, Austin Hospital, Alfred Hospital, Monash Medial Centre and Box Hill Hospital. The implementation process has been commenced at these sites.

Presentations

Data from the ACCORD HCC database was used for a presentation at the annual meeting of the American Association for the Study of Liver Disease (AASLD): The Liver Meeting was held in November 2011 in San Francisco. An abstract entitled "Outcomes of radiofrequency ablation as primary therapy of early stage hepatocellular carcinoma – a multicentre retrospective study" by Ilana Gory, Start Roberts et al was presented as a poster.

MeSH as a group are planning a one-day symposium on HCC to be held in Melbourne in August 2013. This will be a meeting for gastroenterologists, hepatologists, surgeons, radiologists, students and researchers interested in HCC and would involve plenary sessions as well as research presentations.

[1] Australian Comprehensive Cancer Outcomes and Research Database

LUNG

Dr Matthew Conron is the BioGrid Lung tumour stream leader and Respiratory Physician at St Vincent's Hospital.

Background

Close to 2,000 Victorians die each year from lung cancer, more than from colon and breast cancer combined. Unlike other types of cancer, there has been little improvement in outcome for individuals diagnosed with lung cancer over the last 20 years. There is increasing recognition that the poor outcome of lung cancer patients is linked to a paucity of quality research in the area. In the last 12 months two statewide initiatives have been launched that will hopefully address the current deficiencies in lung cancer research. Firstly, the Victorian Lung Cancer Research Consortium (VLCRC) funded through the Victorian Cancer Agency (VCA) is focused on developing and exploiting existing biorepositories across five sites in Victoria. Secondly a Victorian Lung Cancer Registry is being developed with data currently being collected at two pilot sites. BioGrid has been involved in the development of both these projects from the early stages and will hopefully ensure they deliver maximum benefits.

Progress and Challenges

The challenges faced by researchers interested in lung cancer data linkage remain constant. One of the major issues concerning data collection is that lung cancer care occurs across multiple medical disciplines, with no one craft group having ownership of the tumour stream. Furthermore, being such a common tumour, patient care is diffused across the whole health system, with no state centre dedicated to the management of lung cancer.

Without the consolidation of care at one site within Victoria, data collection is challenging. As a result of the problems that face lung cancer data collection, little is known about variation in patient care that may occur across the state. It is hoped that the Victorian Lung Cancer Registry will fill in some of the gaps in the knowledge of lung cancer care outside the major Metropolitan hospitals.

Future Directions

It is hoped that the long awaited establishment of a registry and the VLCRC will allow the lung tumour stream to utilise BioGrid to a greater extent. Numerous projects that require data linkage have been proposed that will require resources provided by BioGrid.

MELANOMA

Professor Grant McArthur is the BioGrid Melanoma tumour stream leader. Prof McArthur is a Medical Oncologist and Head of the Molecular Oncology and Translational Research Laboratories at Peter MacCallum Cancer Centre.

Background

Melanoma is the most serious type of skin cancer, and the third most frequently occurring form of cancer in Australia. Melanoma has become a serious Public Health threat, with incidence rates currently increasing faster than any other cancer.

The latest statistics from the Cancer Council of Australia show that Australia has one of the highest rates of Melanoma in the world. Each year, over 10,300 Australians are diagnosed with Melanoma, and research published by the Cancer Council Australia estimates Melanoma treatment costs the health system $300 million each year, with young people being at particular risk; Melanoma accounts for the loss of more productive years of life than any other type of cancer.

Progress and Challenges

The Melbourne Melanoma Project (MMP) is leading programs in melanoma research across Victoria to improve diagnosis and early detection, gain more accurate tools to predict outcome and target new melanoma therapies for the patients at most risk. Peter MacCallum Cancer Centre, Victorian Melanoma Service - Alfred Hospital, the Austin Hospital and Border Oncology, are the current Melbourne Melanoma Project sites.

MMP mutually agreed standard Melanoma clinical datasets have been defined and data collection is well underway with collaborators able to access clinical information and matched paraffin embedded tissue on over 800 clinical cases. This has offered unique opportunities to study the underlying molecular and genetic changes in a large caseload of Melanomas where full clinical information is also available.

The MMP is looking to improve the performance, availability, and security of our data repository. Discussions are underway with the Melanoma Institute of Australia and the Scott Kirkbride Melanoma Research Centre to develop the first true national database for melanoma in Australia.

Future Directions

The development of a national database involving the Melanoma Institute of Australia, Peter MacCallum Cancer Centre, Victorian Melanoma Service - Alfred Hospital, the Austin Hospital and Border Oncology, and the Scott Kirkbirde Melanoma Research Centre offers a real opportunity for BioGrid to be involved in coordinated data linkage on a national level.

PITUITARY

Professor Peter Colman and Associate Professor David Torpy are the BioGrid Pituitary tumour stream leaders. Prof Colman is Director of Endocrinology and Diabetes at Royal Melbourne Hospital and A/Prof Torpy is a Senior Consultant Endocrinologist at the Royal Adelaide Hospital.

Background

Pituitary disease accounts for a diverse range of clinical syndromes resulting from the role of the pituitary as the 'master gland' regulating the function of many other endocrine glands and its proximity to other important intracranial structures, particularly those that affect vision. Tumours, which are most often benign, are frequent causes of Pituitary disease and the management options involve surgery, medication to alter tumour biology and hormone secretion and radiotherapy.

There is a need to better understand the natural history of patients with Pituitary disease as well as evaluate the effectiveness of Pituitary therapies in an Australian context. It is hoped such a database will be useful for audit/quality control purposes and also for research purposes.

Using the resources of BioGrid, three Australian hospitals are developing databases of patients treated over the past 10–15 years with an ongoing commitment to add prospective data to the database. It is hoped other hospitals will join in this initiative.

Progress and Achievements

The Royal Adelaide Hospital and The Royal Melbourne Hospital have produced a data collection tool in collaboration with several other Australian centres. The Royal Adelaide Hospital has complete data on approximately 600 patients treated over 20 years. The Royal Melbourne Hospital has added data on 800 patients. In India, Vellore Hospital, which has strong professional and educational ties to the Royal Adelaide Hospital has provided data on 200 patients. A further hospital, the Princess Alexandra Hospital in Brisbane has also joined the project, under the supervision of A/Prof Warrick Inder. The plan is to obtain a reliable picture of Pituitary disease management in Australia. A recent analysis of the prognosis of patients with cavernous sinus invasion by tumour, a generally inoperable region, has been completed by Ms Georgina Irish, medical student at the University of Adelaide, and a manuscript is in preparation.

Challenges and Future Directions

After several years, we believe that during 2012 we will have reliable real data on pituitary disease management and outcomes in Australia. The data quantity and quality will be of international importance. There are many pressing research questions that can be asked and protocols for analyses are in preparation. The collaboration of BioGrid has allowed us to reach a position where we have been able to achieve a valuable research and audit tool for pituitary disease in Australia.

Other than analyses and reporting of data the next major challenge is the development of the current data collection tool, an MS Access database, into a web-based tool that can be used at the clinic to add data from consultations and produce reports, reducing the time needed to add data as a process separate to clinical care. Meetings in October 2011 led to the involvement of a sponsor to assist development of this data collection tool and BioGrid has expressed interest in acting as the developer.

RESEARCH REPORTS: LIFE SCIENCES

RARE TUMOURS

Associate Professor Clare Scott is the leader of the BioGrid rare tumour stream. A/Prof Scott is a medical oncologist at the Royal Melbourne Hospital and a Laboratory Head at the Walter and Eliza Hall Institute of Medical Research.

Background

Utilising the BioGrid Australia infrastructure, CART-WHEEL.org is the first ethically-approved portal for consumer–driven information collection for rare tumours. Since its launch in April 2010 by Professor Sir Gustav Nossal, the rare tumour database has attracted more than 260 registrants and 100 people have returned their consent forms for the use of their clinical information for future research.

Progress and Challenges

The primary focus in 2011 was to increase the awareness of CART-WHEEL.org so that many people affected by rare tumours could participate in consumer-driven research. Dr Susie Bae, a Clinical Research Fellow with BioGrid Australia and Ludwig Institute for Cancer Research, joined the CART-WHEEL team in February 2011 to drive awareness of, and specific projects for, CART-WHEEL, funded by the Victorian Cancer Agency and The Picchi Brothers Foundation. She has been involved in reaching out to clinicians and cancer consumers throughout the year attending conferences, meetings and clinics.

Several projects have been initiated in 2011 through CART-WHEEL.org. Firstly, a project to validate the quality of patient-entered data on CART-WHEEL, was approved by the Peter MacCallum Cancer Centre Human Research Ethics Committee and completed recruitment, targeting patients affected by bone and soft tissue tumours. Data analysis is underway and the results are being prepared for publication in a peer reviewed cancer journal. CART-WHEEL.org was particularly well received by gynaecologic oncologists in 2011. Two separate studies looking at rare types of ovarian cancer, small cell cancer of the ovary and high-grade mucinous epithelial ovarian cancer, have been listed on the CART-WHEEL website. Ongoing efforts to recruit patients through appropriate channels are underway.

As part of promotional activities, CART-WHEEL.org has now embraced social media by creating Twitter and Facebook accounts with daily cancer news and information updates. Cancer forums have also been utilised to spread the word of CART-WHEEL to the wider cancer community. Many international gynaecologic oncologists have taken active interest in the potential utility of the CART-WHEEL.org rare tumour database as a platform for future collaborative work on rare gynaecological cancers, described in a publication in the international gynaecologic oncology journal[1].

Future Directions

Proof of principle projects utilising the CART-WHEEL data and social networking approaches will continue to drive the consumer usage of CART-WHEEL.org. We are planning to upgrade the CART-WHEEL website in 2012 to improve usability and access by the participants, clinicians and researchers. CART-WHEEL.org will continue to maintain a close relationship with cancer consumers and support groups to keep an open channel of communication. It is hoped that in 2012 a designated cancer consumer representative will join the team to help drive the projects.

Publications

1. [1] Bae S, Friedlander M, Scott CL. CART-WHEEL.org can facilitate research into rare gynaecological tumours. *Int J Gynecol Cancer.* 2011 21(9):1517-1519.

UROLOGICAL

Cancer can develop in any organ of the male and female urinary and male reproductive system; these cancers are known as urological. There are several types of urological cancers including, prostate, kidney, bladder and testicular. During 2012, disease stream leaders will be established for each type of urological cancer.

Background

Prostate cancer is the leading new cancer diagnosis, with incidence having risen sharply with the increasing use of PSA testing to detect early asymptomatic cancers. Prostate cancer is the second ranking cause of cancer death for men. Renal cancer is the ninth most common cancer in Australia and the fifteenth most common cause of cancer deaths. Testicular cancer is the second most commonly diagnosed cancer in young males (15–24 years) and has the best survival of any cancer type (97% at 5 years).

Progress and Challenges

The Victorian Cancer Agency is funding the Cancer of Prostate Translational Research in Victoria (CAPTIV) Collaboration, lead by Associate Professor Mark Frydenberg. The collaboration has a number of research objectives. BioGrid will be providing data linkage capability, systems advice and data analysis services.

The dataset for renal cancer is now established and fully operational at Austin Health and data continues to be collected. Discussions continue regarding an industry supported analysis of treatment and outcome of advanced kidney cancer from data linked through BioGrid.

Future Directions

Beginning in 2012 prospective data in testicular cancer will be collected for the first time. This will be supported by a half time research fellow working with clinicians interested in testicular cancer, with the intent of defining the dataset, creating a database and helping to establish data collection at major centres. Links with international efforts will be pursued.

CARDIOVASCULAR

Associate Professor Andrew Wilson is a consultant cardiologist at St. Vincent's Hospital, Melbourne and leads the Cardiovascular Research Centre at the Department of Medicine, St. Vincent's Hospital at The University of Melbourne.

Background

Cardiovascular disease, which includes all diseases and conditions of the heart and blood vessels, is the leading cause of death in Australia. The burden of cardiovascular disease, measured in terms of disability and premature death, is second only to cancer. Significantly, the direct health care expenditure for cardiovascular disease exceeds that for any other disease group in Australia[1].

Progress and Challenges

Information relating to cardiovascular disease is collected in, and held by, a number of clinics including – among others – cardiology, vascular disease and diabetes. As patients often attend a number of clinics for their care, information is often stored in multiple, separate databases. Furthermore, each clinic may collect the same or similar data fields, depending upon their requirements. This gives rise to issues of data collection efficiency as well as data quality, impacting on the ability of clinical researchers to use this information to better understand, treat and prevent cardiovascular disease.

Clinicians at St Vincent's Hospital Melbourne continue to collect cardiovascular disease information and are working with BioGrid Australia and VPAC to better integrate their clinical and hospital databases. When funding becomes available, it is anticipated that these datasets will be linked to the BioGrid Australia platform.

[1] Australian Institute of Health and Welfare 2011. Cardiovascular disease: Australian facts 2011. Cardiovascular disease series. Cat. no. CVD 53. Canberra: AIHW.

CYSTIC FIBROSIS

Professor John Wilson is the BioGrid Cystic Fibrosis (CF) disease stream leader. Prof Wilson is head of the Cystic Fibrosis service at the Department of Allergy, Immunology and Respiratory Medicine at the Alfred Hospital and on the Faculty Board of Monash University Medical School. In addition to the Alfred Hospital, the BioGrid CF stream includes Monash Medical Centre (MMC) under Associate Professor David Armstrong and The Royal Children's Hospital (RCH) under Associate Professor Phillip Robinson.

Background

Cystic Fibrosis is a devastating disease for which there is currently no cure. It affects the mucous glands of the lungs, liver, pancreas, and bowel, causing progressive disability due to multisystem failure and eventual death. However the introduction of aggressive treatment regimes has seen patient survival improve from an average of 20 to 30 years a generation ago, to the point where many patients are now surviving into their 40's and beyond.

Progress and Achievements

The main aim of the BioGrid CF group was to connect the lung function databases from the three participating sites (Alfred, MMC, RCH) to the BioGrid platform. All three centres treating CF in Victoria are connected and this has allowed a state-wide population of patient information to be available for research. It allows tracking of patient information (in de-identified form) from treatment in childhood through to treatment as an adult. These data are valuable sources for clinical researchers to answer important research questions.

The past year has seen the analysis of Lung Function data from all the three hospitals through the BioGrid platform. In addition, data for RCH covering treatment over the last 25 years has provided a rich source which is being examined for treatment trends and outcomes over time. Information includes patient admission, length of stay and co-morbidities. The impact of the introduction of newborn screening was also examined.

The use of an electronic health record has allowed bioinformatic analysis of clinical variables and their dependency on inflammatory changes in cystic fibrosis. The results are now automatically reported to the National CF Data Registry.

Challenges and Future Directions

The download of Smarthealth reporting data (electronic health record) was enabled at the Alfred during 2011. The automation of making these data available through the BioGrid platform is in progress. Smarthealth is a full clinical system for CF patients that is being installed over time at the three participating hospitals, and will contain full clinical details and patient management notes. When linked to the admissions and lung function data it will provide a valuable resource for the study of CF.

Presentations and Publications

Summary work from the application of the electronic health record and telemedicine projects was presented at the 2011 European Cystic Fibrosis Society ASM in Hamburg. The survey of capabilities in the use of eHealth technology (staff and patients) won the Best Poster prize (1). Work on the effect of the NBN on clinician use of telemedicine will be presented by the Department of Broadband, Communication and the Digital Economy in January 2012 (2).

1. Ambrose H, Braithwaite M, Wilson JW. Perceived benefits of ehealth implementations to healthcare workers and patients. *Telecommunications Journal of Australia.* 2011;61:4.
2. Monash University. Potential telemedicine benefits of high speed broadband. Canberra, Dept. of Broadband Communication and the Digital Economy; 2011.

DIABETES

Professor Peter Colman is the BioGrid Diabetes disease stream leader. Prof Colman is Head of the Department of Diabetes and Endocrinology and Head of the Endocrine Laboratory at The Royal Melbourne Hospital.

Background

Diabetes is a major health priority for the community with the incidence of both type 1 and 2 diabetes increasing at an alarming rate. This chronic disease affects 4% of the Australian population. Type 2 diabetes represents 85–90% of all cases of diabetes with the remaining 10–15% type 1 diabetes, which mainly affects children and adolescents. Treatment for both types of diabetes can be complex and there is a risk of complications affecting the heart, kidneys, eyes and nerves.

Progress and Challenges

The Diabetes stream consists of two areas – Clinical Diabetes and Preclinical Type 1 Diabetes research. The clinical diabetes area is the most active with clinical data from The Royal Melbourne Hospital (RMH), The Royal Children's Hospital (RCH), Austin Hospital and St Vincent's Hospital (SVH) continuing to accrue. The major focus of research is clinical outcomes of diabetes with emphasis on approaches to improve outcomes. The type 1 diabetes research area is extremely active, but during this period there has been limited use of this dataset.

Over the past year The Royal Melbourne Hospital data has been used extensively to evaluate diabetes outcomes (through electronic submission of data to the Australian National Diabetes Information Audit and Benchmarking). The RMH diabetes service remains one of the few centres in Australia submitting electronic data. The data is also being used to run a continuing QA process for clinic outcomes.

Two researchers are now using combined diabetes data from contributing hospitals to evaluate different aspects of diabetes care and outcomes – retinopathy, nephropathy, peripheral vascular disease, peripheral neuropathy and cardiovascular outcomes. This is an exciting development. In addition, collaboration between SVH, RMH and RCH is using data to track clinical outcomes in patients with diabetes who 'transition' from paediatric to adult care. The data continues to be used to identify people with diabetes and specific characteristics to be involved in a number of clinical trials. A recent snapshot of cardiovascular disease and diabetes is evaluating the effect of obesity on cardiovascular risk. Our major challenge is to continue to recruit researchers to work with our data and to make the interface with the data as friendly as possible.

Future Directions

There are a number of other research ideas which need further development and then funding. We need to involve more hospitals. The Royal Adelaide Hospital and Princess Alexandra Hospital in Queensland are well advanced in the process of installing and using the BioGrid Diabetes Database. During the year support from industry enabled development of a module to collect data on use of insulin pumps, and this is now operational in the BioGrid Diabetes Database. This will allow more systematised care and research in the group of patients with type 1 diabetes being treated with insulin pumps. Linking the data with State Government hospital outcomes data and the death index remains a high priority for expanding the scope of research which can be undertaken in the Diabetes disease stream.

EPILEPSY

Professor Terence O'Brien is the BioGrid Epilepsy disease stream leader. Prof O'Brien has appointments at the Department of Medicine and Department of Neurology, The Royal Melbourne Hospital and at The University of Melbourne.

Background

Epilepsy is the most common serious neurological condition worldwide. Between 5 and 10% of individuals experience a seizure during their life and 2 to 5% will develop epilepsy, defined as more than one unprovoked seizure. Mortality among those with severe epilepsy is two to three times greater than that of the general population. People with epilepsy often have one or more co-morbidities and exhibit a two to five times greater prevalence of cerebrovascular and cardiovascular disorders, gastro-intestinal disorders, pulmonary disorders, and dementia across all age groups. Psychiatric disorders are amongst the more common co-morbidities. Depression is three to ten times more frequent in those with uncontrolled epilepsy than the general population, and the overall suicide rate is five times higher. Falls, drowning, choking and burns comprise the most common causes of injury for people with epilepsy.

The outcomes of treatment for epilepsy are often unsatisfactory, and unpredictable in an individual. At least 50% of patients will not have seizures control after starting a medication for epilepsy, and at least 30% will never achieve seizure control despite trying multiple different medications. Adverse drug reactions occur in 30–40% of patients with each anti-epileptic drug tried. If women become pregnant while taking an anti-epileptic medication there is at least two to three fold increased risk of a foetal malformation, neurocognitive deficit or autism spectrum disorder.

Progress, Challenges and Future Directions

The research being facilitated by BioGrid is aimed at identifying predictors of adverse outcomes of epilepsy and its treatment which can be subsequently applied in clinical practice to improve certainty and quality of life for sufferers of this common serious condition.

The following projects are currently being undertaken:

1. *Identification of pharmacogenomic predictors of treatment outcomes in epilepsy:* We have obtained and published proof of concept data for the application of supervised learning approaches to develop a multigenic classifier for treatment outcomes in a cohort of 179 prospectively followed newly treated epilepsy patients (Petrovski et al., 2009). This cohort has now been expanded to 450 Australian patients, and is being linked to 1,200 newly treated patients from the UK. These patients have been genotyped genome-wide for >500,000 SNPs. We are in the process of developing multigenic models to predict treatment response based on this unique cohort.
2. *The outcomes of patients newly presenting with a possible seizure disorder:* This project is linking the hospital based clinical, imaging and electrophysiology data from a cohort of 3,500 patients who have been seen in First Seizure Clinics over more than a decade with comprehensive government databases to provide internationally unique comprehensive data about epilepsy, medical, psychiatric, injury, mortality and fertility data.
3. *KONQUEST study of outcomes of first substitution anti-epileptic drug therapy:* This world first study has randomised patients who have failed the first anti-epileptic drug, because of ongoing seizures or adverse drug reactions, to a new (leviteracetam) vs. older (carbamazepine or valproate). A broad range of epilepsy, side-effects, psychiatric, neurocognitive and quality of life outcomes are assessed. The study has now finished collecting data and is being written up for publication.
4. *Teratogenicity of antiepileptic drugs in pregnancy:* The Australian Pregnancy Registry (APR) has a unique opportunity to collaborate with its European equivalent to investigate the nature and cause of up to three-five times increased risk of birth defects in pregnancies where the mother was treated with an antiepileptic drug through her pregnancy. We are initiating a genome-wide investigation of antiepileptic induced birth defects, supplemented by deep sequencing of carefully selected families.
5. *Seizure outcome after surgery for epilepsy:* Individuals who have severe epilepsy that is refractory to medication may undergo surgical resection of the seizure focus. Although most patients benefit from surgery, between 20–40% of patients will continue to experience some seizures after surgery. The cause of seizure recurrence is not well understood. This project examines seizure outcome for patients who have undergone resection of a temporal lobe lesion (non-malignant) or structural abnormality. There are several lesion types commonly associated with epilepsy; each has specific characteristics that may impact on seizure recurrence after surgery.

Publications

1. Walterfang M, Choi Y, O'Brien TJ, Cordy N, Yerra R, Adams S, Velakoulis D. Utility and validity of a brief cognitive assessment tool in patients with epileptic and non-epileptic seizures. *Epilepsy and Behaviour* 2011;21:177-183. [I.F. 2.610]

   This study shows that the NUCOG questionnaire appears to correlate strongly with neuropsychological functioning in a number of key cognitive areas affected in patients with epilepsy, and appears to robustly detect memory impairment in patients with temporal lobe epilepsy.

2. Merriel RB, Gibbs P, O'Brien TJ, Hibbert M. BioGrid Australia facilitates collaborative medical and bioinformatics research across hospitals and medical research institutes by linking data from diverse disease and data types. *Human Mutation* 2011;32:1-9. [I.F. 6.887]

   BioGrid Australia is a federated data linkage and integration infrastructure that uses the Internet to enable patient specific information to be utilised for research in a privacy protected manner, from multiple databases of various data types (e.g. clinical, treatment, genomic, image, histopathology and outcome), from a range of diseases (oncological, neurological, endocrine and respiratory) and across more than 20 health services, universities and medical research institutes. BioGrid has demonstrated an ability to facilitate powerful research into the causation of human disease and the prediction of disease and treatment outcomes. This article reviews BioGrid's first seven years and how it has overcome 9 of its top 10 challenges.

3. Vajda FJE, Graham J, Hitchcock AA, O'Brien TJ, Lander CM, Eadie MJ. Foetal malformations after exposure to antiepileptic drugs in utero assessed at birth and 12 months later. *Acta Neurologica Scandinavia* 2011;124:9-12. [I.F. 2.317]

   This study found that early assessment and delayed assessment of infants for the presence of foetal malformations are complementary, with the latter resulting in finding a higher incidence of malformations. However, omission of an early post-natal assessment may result in biases because of loss of subjects to follow-up.

HUMAN VARIOME PROJECT

Professor Richard Cotton is the BioGrid Human Variome disease stream leader. Prof Cotton is the Scientific Director of the Human Variome Project.

Background

The Human Variome Project (HVP) is an international initiative to establish and maintain the standards, systems and infrastructure necessary to embed the routine sharing of genetic variation information into clinical practice. The Human Variome Project is working towards a future where the availability of and access to genetic variation information is not an impediment to diagnosis and treatment and where the burden of genetic disease on the human population is significantly decreased.

This will be done globally via a network of HVP Country Nodes and international gene/disease specific databases. HVP Country Nodes are repositories of all genetic variation identified within a single country or region. They are owned and operated by local consortiums and allow vital data to be collected and shared in a manner that complies with each country's legal and ethical requirements. These Nodes are critical to ensure the flow of data for use by healthcare professionals and clinicians in diagnosing and treating their patients.

Importantly, the HVP Country Nodes are required to pass on their information to international gene/disease specific databases. These databases are run by experts in the field and because of this, contain large amounts of high quality data about specific genetic variations, their functional effect and what they mean for patients who carry them.

Progress and Challenges

In April 2011, the Human Variome Project Australian Node (www.hvpaustralia.org.au) was launched, providing diagnostic laboratories, clinicians and genetic counsellors free access to the collective datasets of a number of Australian diagnostic laboratories. Funding for this work was provided through the National eResearch Architecture Taskforce (NeAT).

Over the past year the Human Variome Project's international activities have attracted a high level of interest and support with major contributions to the Project being made by China as well as HVP Nodes being formed in a total of 12 countries, including Malaysia, Kuwait, Greece, Korea, Egypt and Belgium.

Future Directions

In the coming months, the Human Variome Project Australian Node will be expanded to cover more diagnostic laboratories within Australia. We will also be looking to connect this rich molecular dataset with the clinical datasets available on the BioGrid platform.

INFLAMMATORY BOWEL DISEASE

Professor Finlay Macrae is the BioGrid Inflammatory Bowel Disease/ Crohn's Disease stream leader. Prof Macrae is Department Head of Colorectal Medicine and Genetics and a Gastroenterologist at the Royal Melbourne Hospital.

Background

Inflammatory Bowel Disease (IBD) is a chronic inflammatory disease of the gastrointestinal tract, comprising two major subtypes – ulcerative colitis and Crohn's Disease. The condition is common, with the cause uncertain, but it is thought to represent a disordered immune response, perhaps genetically determined, to an environmental stimulus. The microbiota of the gut is under close scrutiny at present for its role in association with the host immune response. Most therapies are targeted at controlling the immune response, with expensive biological agents now emerging as the most effective therapies.

Melbourne IBD is the professional association of "IBDologists" who share their expertise at research and educational meetings. Most centres maintain an IBD database, using one of a number of platforms. These include an IBD database which has been developed at St Vincent's Hospital and adopted by Melbourne IBD as their preferred database. To date these databases have not been linked to the BioGrid platform due to lack of resource and funding.

Progress and Challenges

At the Royal Melbourne Hospital (RMH) we continue to collect data, though even with this task we struggle due to limited resource and an expanding clinical workload. On a positive note, we have appointed a full time IBD clinical nurse specialist who is developing our database to meet IBD clinical needs. Clinicians with IBD expertise are located at the following centres: RMH: Finlay Macrae, Suresh Sivanesan, Guru Iyngkaran, Bernadette Viney; St Vincent's: Michael Kamm, Steven Brown, Mark Lust, Sally Bell and Bill Connell; Monash Medical Centre: Greg Moore; Alfred Hospital: Simon Jacobovitz and Miles Sparrow; The Royal Children's Hospital: Tony Catto Smith, Don Cameron. The aim is to allow research from the larger experience available from the multiple centres involved.

Future Directions

In the future there is the potential to link to IBDologists in IBD Australia, a well established subspecialty group of the Gastroenterological Society of Australia.

REFUGEE HEALTH

Associate Professor Beverley-Ann Biggs is the disease stream leader for Refugee Health. A/Prof Biggs is an Infectious Diseases Physician, Victorian Infectious Diseases Service (VIDS Clinic) at The Royal Melbourne Hospital and also has an appointment at The University of Melbourne working in International Health, Department of Medicine.

Background

Refugee health is an emerging specialised clinical area, with around 4,000 people of a refugee background settling in Victoria annually. Refugee patients require specific health screening for infectious diseases and nutritional deficiencies after they arrive in Australia; they typically have multiple complex health conditions and require medium to long-term follow-up. Clinical care is challenging, due to the number and complexity of their medical problems, the need for multiple screening tests and the fact most health care is delivered with the help of an interpreter. Victoria now uses a primary care model of refugee health screening; however available evidence suggests at least 50% of refugees require specialist referral. Both primary care providers and specialists must be aware of patients' results, management, medication and follow-up plans, requiring a clear flow of information to avoid duplications and improve outcomes. There are no systems currently in place that allows direct sharing of clinical information between hospitals and primary care, even though this is fundamental for coordinated care.

To date there has been extremely limited prospective data collection in refugee health, and no way of gathering population data across primary and specialist care, or collecting data on long term outcomes. Typically, by the time demographic information has been collated, the Humanitarian intake has changed, and the information is 'out of date'.

We are developing a web-based electronic health record for refugee patients across the four specialist adult and paediatric refugee clinics in Victoria. The system has been developed in collaboration with Arcitecta and will allow rapid epidemiological data collection and responsive evaluation of guidelines, practice and service delivery. We have also been awarded a Department of Business and Innovation grant (in collaboration with the University of Melbourne, Arcitecta, Precedence Health Care, Royal Children's, Dandenong, and Geelong Hospitals) to build on this system to create a web-based refugee health clinical hub, which will include a primary care/specialist interface, a patient held record/portal, and facilities for remote telehealth support for general practitioners. We intend to explore different modalities for collating data for research, including utilisation of the BioGrid system.

Progress and Challenges

The project commenced in August 2010. Over the past 12 months we have:

- Developed a prototype web-based refugee health record, and are planning to pilot it within the VIDS in the next three months.
- Received additional funds to share the record between refugee health clinics at different hospitals, and to create a GP/patient interface.

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BIOGRID
AUSTRALIA
Health through information

BioGrid Australia
ABN: 31 136 185 647

6 North, Main Building
The Royal Melbourne Hospital
300 Grattan Street
Parkville 3050
Victoria, Australia

T: +61 (0)3 9342 3167
F: +61 (0)3 9342 8548

enquiries@biogrid.org.au
www.biogrid.org.au