



**BIOGRID
AUSTRALIA**

Health through information

**BIOGRID AUSTRALIA
AND
THE AUSTRALIAN CANCER GRID**

annual report 2008–2009



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HIGHLIGHTS FOR 2008–09

- **New ACG sites implemented:** Using funding provided by the Victorian Government Department of Innovation, Industry and Regional Development (DIIRD) through the Australian Cancer Grid (ACG) project. The Victorian major regional centres have been linked to BioGrid in the past year.
- **New disease types rolled out:** The number of Cancer tumour streams has expanded to include Head and Neck, Brain, Pituitary, and Urology (Renal & Prostate).
- **ACG National Grid architecture rolled out:** Following an extensive planning period the new architecture which enables robustness on a national scale was successfully rolled out in early 2009.
- **New company incorporated:** BioGrid Australia Limited (ACN 136 185 647) a not for profit company incorporated by the members of the new BioGrid Australia Collaboration Agreement.
- **New BioGrid Australia Collaboration Agreement signed by 20 members on 11 May 2009.**
- **DIIRD approves ACG Project Funds Rollover to the end of 2010.**
- **Awards:** Two BioGrid ACG Research Fellows receive Merit Awards at 2009 Gastrointestinal Cancers Symposium USA.
- **Awards:** Dr Jeanne Tie, of the Ludwig Institute for Cancer Research Ltd (a BioGrid member) is awarded the 2009 Bradley Stuart Beller Merit Award.
- **New electronic newsletter published bi monthly, five editions in 2008–09.**
- **A new research animation to demonstrate the use of BioGrid to clinical researchers—see www.biogrid.org.au**

CHAIRMAN'S REPORT

As Chairman of the BioGrid Australia Management Committee I am pleased to introduce the annual report for the year ended 30 June 2009. I have been Chair of the Management Committee for the last four and a half years and have really enjoyed the role. From the July Management Committee meeting, Prof Tony Burgess, who is well known to the members, will be taking over as an independent Chairman. I wish Tony every success.

My personal involvement in the project will continue as I have been elected as a foundation Director of BioGrid Australia Limited and I will also remain as Melbourne Health's representative on the Management Committee.

This has been a busy and productive year of building and planning for our future. It has also seen the achievement of a number of significant milestones – we should stop and reflect on these successes:

- Establishment of BioGrid Australia Limited – the not-for-profit company that will provide the members with a streamlined governance structure and a vehicle for expansion.
- Successful negotiation with DIIRD to rollover project funding and extend their support until December 2010.
- Successful completion of the DEST (now DIISR) Phase of BioGrid.
- Delivery of quality peer reviewed and acknowledged translational research.
- Success of BioGrid on YouTube – where an explanatory animation of the project's foundations and processes proved both educational and a valuable marketing tool.

I will take this opportunity to thank a number of the people who have contributed to the BioGrid's successes.

Firstly on behalf of the Management Committee I would like to thank both the Australian and Victorian governments, through DIISR and DIIRD, respectively for their vision and generous funding support of the project.

Thanks also to the BioGrid team members and all of our clinician researchers for their hard work and dedication during the year. Special thanks to Project Director, Dr Marianne Hibbert for her dedication, enthusiasm, energy and positive attitude. The project's success is an outstanding achievement and a testament to Marianne's professional standards and commitment.

I would also like to acknowledge the contributions and cooperative work of both the Management Committee and our Scientific Advisory Committee over what has been a busy and challenging year.

For the sixth year Melbourne Health has continued to act as Secretariat, home and provided the bulk of the infrastructure support for the project. I would like to thank Linda Sorrell the Chief Executive of Melbourne Health, and Sally Campbell, Executive Director Business Development and Corporate Secretary and Professor Ingrid Winship, Executive Director Research for their keen interest and strong support for BioGrid.

The key challenge for the next year, for the new company and the Management Committee of members is to achieve financial sustainability for the project. There are significant opportunities before us to achieve a financially sustainable future.



Rob Merriel Chairman,

Chairman – BioGrid Australia Management Committee

December 2004 – June 2009

BIOGRID AUSTRALIA PROJECT DIRECTOR'S REPORT

THE YEAR IN REVIEW

The year has seen activity and successes in a number of areas. The governance change will enable a streamlined approach to foster new research and sustainability – and this is the culmination of three years of consultation planning and implementation. Thanks particularly to Richard Tate and all the corporate counsels and our lawyer Tim Clark.

The year has also seen an increase in the number of hospitals and research institutes who are engaged with BioGrid. The reach of BioGrid has extended to most Australian states with discussions continuing with potential international collaborators. The progress from site ethics approval and agreements, to the point of data being available to link to BioGrid takes time but with increasing numbers of researchers and research projects using BioGrid, the research findings are demonstrating the value in a variety of areas.

A major activity over the summer of 2008–2009 was the IT extension and upgrade to the BioGrid technology platform. The upgrade provides a robust and scalable platform for BioGrid's extension of linkage capability to a national and international service. The most obvious demonstration of this capability is the portal which includes our new web site. BioGrid now has the capability to provide secure portals to its members as required. Thank you to the BioGrid technical team, IBM and partners who implemented the upgrade at the same time as the existing platform continued to service the research needs.

The other major activity has been the progressive extension of tumour streams, with more data collection applications developed that target specific tumour streams - sarcoma, prostate, renal and head and neck have been implemented. Thank you to the clinical leaders who lead this for their tumour stream. The rare tumour web site and data collection system called CART-wheel has had significant consumer input and has been dedicated to the memory of Daniel Pollak whose mother Cynthia Pollak has been unwavering in her belief that data-driven research will enable better treatment. She has tirelessly helped in establishing this unique interface between people with rare cancer and researchers.

Finally as we embark on endeavouring to be sustainable we have many researchers who have submitted research grants using BioGrid, as well as industry engaging in funding research and services which will assist in evaluating and improving the efficiency and effectiveness of treatments. I would like to thank the many people who have helped BioGrid have a successful year: Melbourne Health, the University of Melbourne, VPAC, the BioGrid Boards, the Management Committee, the Science Advisory Committee and particularly Rob Merriel, Peter Gibbs and the BioGrid team.

Dr Marianne Hibbert

Project Director, BioGrid Australia

July 2009



HISTORY, OBJECTIVES AND OPERATION OF BIOGRID

BioGrid is a collaboration between clinical researchers studying treatment outcomes and influences such as genetic aspects of disease; epidemiologists (researchers of public health); and IT specialists. Together they have created a virtual database of clinical, genetic and other data from many different sources across hospitals and research institutes across Australian states. Researchers can use this system to help them study what factors influence disease outcomes.

The benefit to patients, or people who might become future patients, will be significant. With the identification of more genetic factors that cause diseases such as cancer, people in higher risk groups, or the general population, could have their genetic make-up tested. Those who carry genes that are associated with disease can make lifestyle choices to reduce their risks, and can undertake regular screening so if they do develop a disease such as cancer, it can be treated at an early stage. BioGrid will also help doctors to understand why particular drugs work for some patients and not others. Within one disease, one drug may suit people with one genetic profile, while another works for those with a different profile. This type of information will assist in selecting available medication in the future, as well as helping match patients with suitable clinical trials if the available drugs are unsuitable. In this way, treatment is tailored for each individual's needs.

Prevention is always better than cure. BioGrid can also help examine the factors that can help prevent disease, to evaluate programmes designed to prevent or detect disease early such as surveillance and intervention programs as well as evaluate the effectiveness and quality of health service delivery.

BioGrid has established a network that is increasingly enabling research to improve health outcomes.

OPERATIONS – HOW DOES BIOGRID WORK?

The BioGrid Australia platform provides the capability for researchers to access, integrate and link data across many environments regardless of their existing linkage and research platforms. This is the vision to establish a connection for all life sciences and the Australian Cancer Grid is the flagship. BioGrid Australia is a 'federation' of all the researchers' repositories and can integrate and link to all the participating hospitals and research centres in Australia. By providing access to the data sets, to data on clinical outcomes, administrative data, quality and audit data, biospecimen genomic data, images as well as analytical tools, this platform positions Australia with the capacity to maximise life sciences research.

Figure 1 illustrates how the BioGrid Australia system works.

1. Firstly, researchers must obtain authorisation to access data from the data custodians, the Scientific Advisory Committee and the BioGrid Australia Management Committee;
2. Source data from databases at various institutions is extracted, transformed and loaded (ETL) on a nightly basis to their respective Local Research Repositories (LRRs) which are located at the institutions;
3. The data is record-linked for the individuals using probabilistic matching and a record linkage key is assigned and stored in encrypted format at the institution;
4. Authorised researchers are then able to query and analyse the data via the Federator using SAS Enterprise Guide (querying and statistical/business analysis software);
5. The federator is an integrator for accessing data across physical boundaries;
6. The data is sent to the user via a Virtual Private Network (VPN) and secure socket layer web services in de-identified form with a record linkage key. The federator does not store health data;
7. The BioGrid Australia project is a federating technology where each participating site retains full ownership and control over their own data sources and data collection systems.

SECURITY

The security system includes a number of features. Each LRR is connected to the federator via a Virtual Private Network (VPN), which ensures data security for transmission. Views block all identifying information, allowing end users to see only the data which has been authorised in conjunction with the record linkage key. Access to these views on the federator is controlled by the database administrators by assigning database roles and defining privileges to the table/view level. All queries to the federator are tracked and monitored for audit purposes by DB2 Query Patroller Software. Access to data is de-identified.

PROTECTING PRIVACY

The BioGrid Australia platform has been achieved with rigorous attention to ethics and privacy requirements. All participating sites must obtain ethics approval to join. BioGrid Australia complies with all privacy legislation and regularly seeks independent external legal advice to ensure the project continues to comply with all relevant privacy legislation particularly as it grows and develops.

The research data is used in a de-identified, codified form, but the system allows the patient to be ethically re-identified, if required.

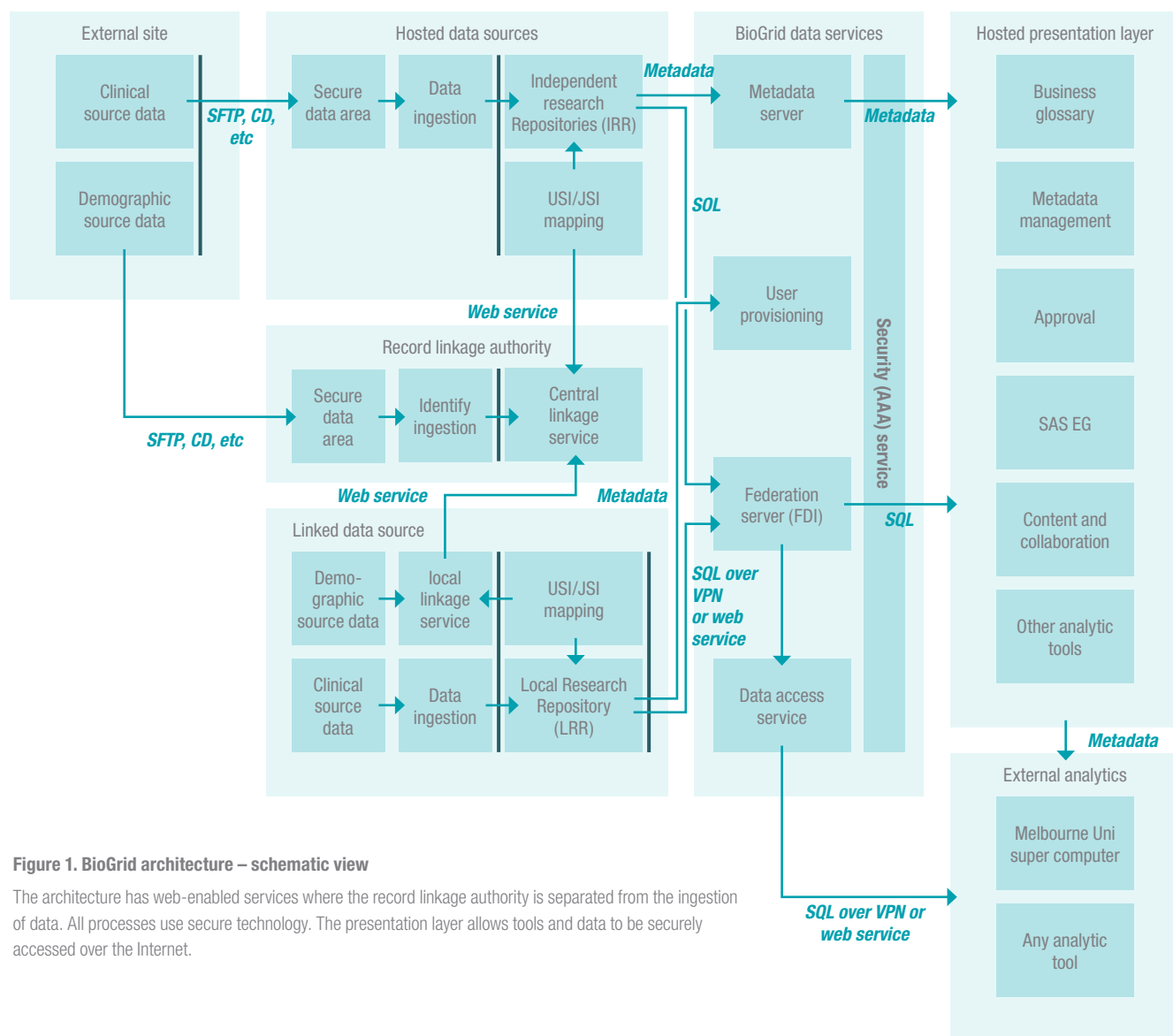


Figure 1. BioGrid architecture – schematic view

The architecture has web-enabled services where the record linkage authority is separated from the ingestion of data. All processes use secure technology. The presentation layer allows tools and data to be securely accessed over the Internet.

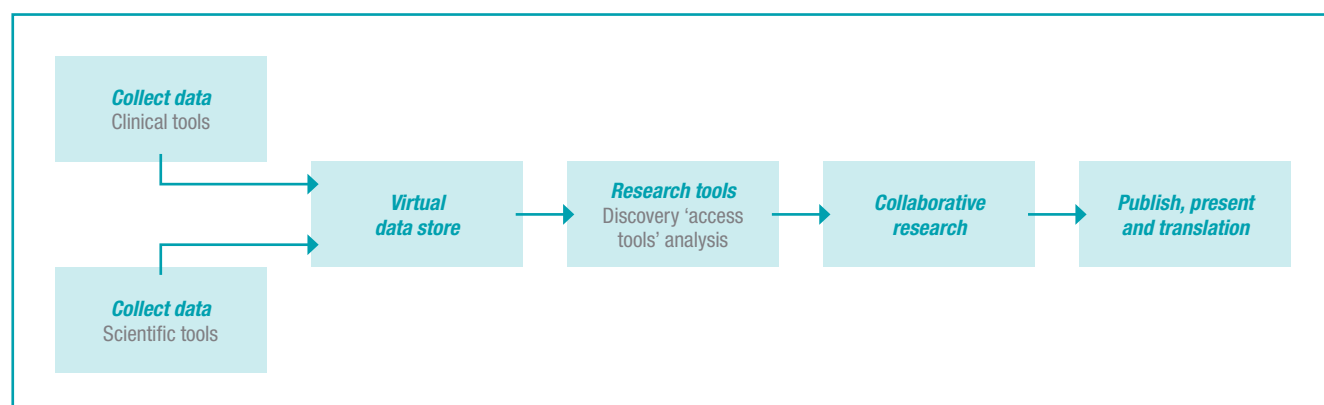


Figure 2: How BioGrid works

Data from both hospitals and research institutes are linked creating a virtual data store. Authorised users can access the de-identified data using the research tools to analyse and collaborative research. Research outcomes are then used to improve treatment and health care.

BIOGRID AUSTRALIA GOVERNANCE

GOVERNANCE CHANGE IN 2008-09

One of the key achievements during 2008–09 has been the implementation of the governance change to create the structures and processes required to support the expansion of members and data sources and to provide the foundations for the future sustainability of the BioGrid Australia data linkage platform.

A new BioGrid Australia Collaboration Agreement was signed on 11 May 2009 by 20 members of the former MMIM Collaboration Agreement (established in November 2005 following the success of the pilot phase, the agreement for which lapsed at 30 April 2009).

The BioGrid Australia Collaboration Agreement provides a governance structure for the collaborating parties in the administration of the BioGrid Australia infrastructure platform and ongoing research. It covers the management committee, financial matters, intellectual property, project management, commercialisation activities, publications, warranties, and indemnity and dispute resolution.

BioGrid Australia thanks all of the member legal counsels and others who participated in workshops and reviewed the many legal documents for their advice, support and hard work during the year.

INCORPORATION OF BIOGRID AUSTRALIA LIMITED

The members of the BioGrid Australia Collaboration Agreement incorporated a not-for-profit limited liability public company (limited by guarantee) that has been licensed by the members to operate the data linkage platform on behalf of the members of the BioGrid Australia Collaboration Agreement.

The company BioGrid Australia Limited (ACN # 136 185 647) has obtained GST registration and an ABN number enabling it to contract with a range of parties wishing to work with the BioGrid data linkage platform. An application for tax exempt status and Deductible Gift Recipient status (enabling the company to accept donations) has been approved by the Australian Tax Office.

The features of the company include:

- A separate legal existence from the new joint venture collaboration members such that the extent of any BioGrid Australia collaboration member liability will be limited to the guarantee (set at \$10.00 per member);
- A clearly defined management structure including a Chief Executive Officer (to be appointed) with the ability to execute agreements in its own right consistent with the terms of the licensing agreement.

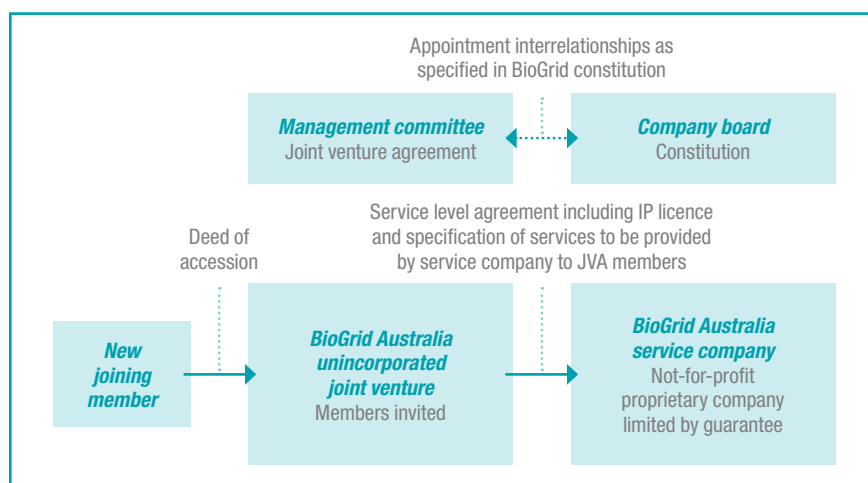


Figure 3: BioGrid governance structure

BioGrid Australia is an unincorporated Joint Venture. The management committee of members meets regularly and all members have signed the BioGrid Joint Venture agreement. BioGrid Australia are the shareholders of the BioGrid Australia Service company.

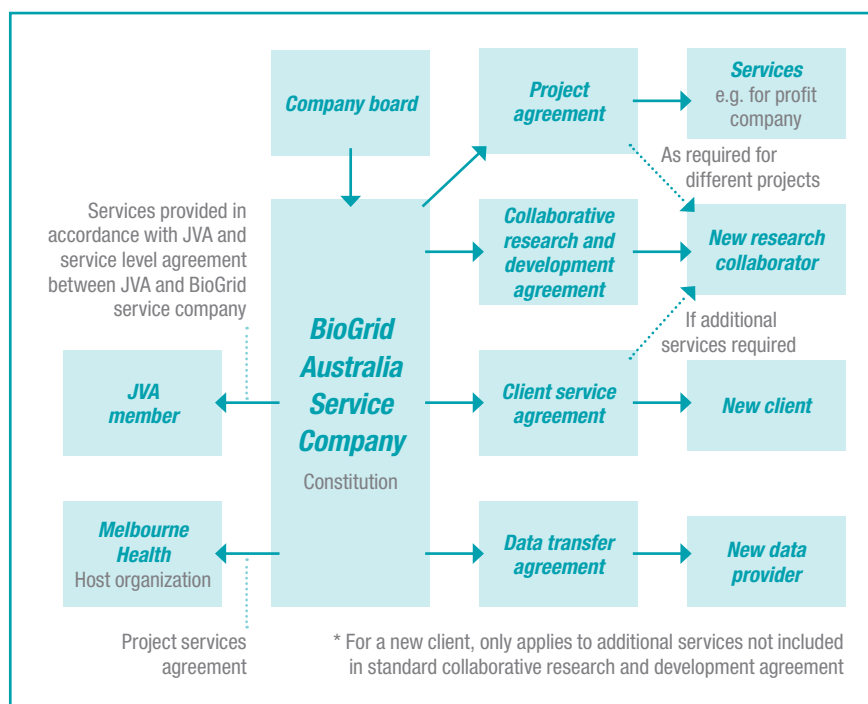


Figure 4: BioGrid Australia relationships

The BioGrid Australia Service Company is a not-for-profit company limited by guarantee. It can engage in different agreements and is governed by a Board.

BIOGRID BOARDS AND COMMITTEES

BIOGRID AUSTRALIA LIMITED BOARD AT 30 JUNE 2009

A Board of seven directors (appointed from the new collaboration members and from outside nominees with a broad range of skills and expertise) oversee the governance of the new company and meet monthly. One of the company directors reports on company activities to the monthly meeting of the BioGrid Australia Management Committee.

The company holds all necessary insurances required such as Workcover, public liability, directors and officers liability and professional indemnity etc. that are required for a not-for-profit company.

The company currently has three directors with four more to be appointed. The initial three directors are:

Professor Bryan Williams

*Chairman, Independent Representative
(Monash Research Institute)*



Mr Rob Merriel

Melbourne Health



Dr Julian Clark

*The Walter and Eliza Hall Institute
of Medical Research*



BIOGRID AUSTRALIA MANAGEMENT COMMITTEE MEMBERS AT 30 JUNE 2009

Each member of the BioGrid Australia Collaboration Agreement is entitled to nominate a full voting representative to the BioGrid Australia Management Committee which meets monthly. The committee is the governing body of the members and consists of nominated representatives of BioGrid Australia members and non voting invitees with special expertise and knowledge to contribute.

BioGrid Australia Member Institution	Management Committee Representative	
Independent Chair	Professor Antony W Burgess <i>AC FAA FTSE PhD</i> <i>Laboratory Head</i> <i>Epithelial & Biochemistry Laboratory</i> <i>Melbourne Branch Ludwig Institute</i> <i>for Cancer Research</i>	
ACT Health (The Canberra Hospital)	A/Professor Desmond Yip <i>Director</i> <i>Medical Oncology Unit</i> <i>The Canberra Hospital</i>	
Alfred Health	Prof John Wilson <i>Head of the Department of Allergy,</i> <i>Immunology & Respiratory Medicine</i>	
Austin Health	Associate Professor Paul Mitchell <i>Director of Cancer Services</i>	
	Dr Sianna Panagiotopoulos <i>Research Fellow</i>	
Ballarat Health Service	Dr Stephen Vaughan <i>Director GRICS</i>	

Bendigo Health Care Group	Dr Peter Sloan <i>Medical Director</i>	
Central Northern Adelaide Health Service (Royal Adelaide Hospital, Queen Elizabeth Hospital and Lyell McEwin Hospital)	Ms Lesley Dwyer <i>Executive Director – Operations Acute & Specialist Services</i>	
Eastern Health	A/Prof Joe McKendrick <i>Clinical Head of Haematology, Medical Oncology and Palliative Care</i>	
Goulburn Valley Health	New representative to be appointed	
Latrobe Regional Hospital	Mr Peter Craighead <i>Chief Executive</i>	
Ludwig Institute for Cancer Research Ltd	Dr Lara Lipton <i>Medical Oncologist</i>	
	Dr Jayesh Desai <i>Medical Oncologist</i>	

Melbourne Health	Mr Rob Merriel <i>Director Business Development</i>	
Peter MacCallum Cancer Centre	Prof Gillian Duchesne <i>Director Radiation Oncology</i>	
	Ms Katerina Andronis <i>Director Information Management</i>	
Southern Health	Ms Malar Thiagarajan <i>Director, Research Services and Corporate Solicitor</i>	
St Vincent's Health	A/Prof Raymond Snyder <i>Department of Oncology</i>	
The Royal Children's Hospital	A/Prof Tony Catto-Smith <i>Director Department of Gastroenterology and Clinical Nutrition</i>	
	A/Prof Philip Robinson <i>Head of CF Services Respiratory Physician</i>	

The Royal Hobart Hospital	Dr Rosemary A. Harrup <i>FRACP FRCPA</i> <i>Head of Department</i> <i>Medical Oncology/Haematology</i>	
The Royal Women's Hospital	Professor Jock Findlay <i>AO PhD DSc</i> <i>Director of Research</i>	
University of Melbourne	Terence J. O'Brien <i>MB BS MD FRACP</i> <i>James Stewart Professor of Medicine</i> <i>and Head of Department</i>	
Walter and Eliza Hall Institute of Medical Research	Dr Clare L Scott <i>MBBS PhD FRACP</i> <i>RD Wright Fellow and Medical Oncologist</i>	
Western Health	A/Prof Peter Gibbs <i>Medical Oncologist</i> <i>RMH</i>	

APPRECIATION OF FORMER MMIM MANAGEMENT COMMITTEE

The final meeting of the Management Committee of the former MMIM Collaboration Agreement was held in April 2009 and BioGrid Australia thanks all of the members for their contribution over the past years, especially the following who did not continue on with the new Management Committee:

- Prof Graham Brown
(The University of Melbourne)
- Prof Peter Colman
(Walter and Eliza Hall Institute of Medical Research & Melbourne Health)

BioGrid thanks these former Management Committee members for their commitment to good governance of the BioGrid project over the past five years.

While Mr Rob Merriel is continuing as the Melbourne Health nomination to the BioGrid Australia Management Committee, Rob has stepped down as Chair of the Management Committee due to his also being a director of BioGrid Australia Limited. BioGrid expresses its gratitude to Rob for his tireless efforts to ensure the success of BioGrid and his guidance to all over the past five years.

In June 2009 BioGrid welcomed Professor Tony Burgess of The Ludwig Institute for Cancer Research Ltd as the independent Chair of the BioGrid Australia Management Committee.

MANAGEMENT OF PHASE 3 – THE ACG PROJECT

To manage the ACG Project funds from the Victorian Government, Melbourne Health and The University of Melbourne signed an agreement in December 2006 appointing Melbourne Health as the ACG project manager until the end of 2009.

With the DIIRD rollover of ACG funds approved until the end of 2010, the agreement with Melbourne Health to be the ACG project manager has also been varied to extend to the end of 2010.

The BioGrid Australia Management Committee also receives updates on progress of the ACG project at their monthly meetings.

An ACG project steering committee body (known as the Interim Board) was formed under the terms of the 2006 agreement to oversee the project. The membership comprises two representatives each from Melbourne Health and The University of Melbourne. This body meets bi-monthly to receive progress reports from the BioGrid Australia project office and address any issues.

MELBOURNE HEALTH – UNIVERSITY OF MELBOURNE ACG BOARD MEMBERS AT 30 JUNE 2009

- Mr Rob Merriel (Chair) (Melbourne Health)
- Prof Ingrid Winship (Melbourne Health)
- Prof Terence O'Brien (The University of Melbourne)
- Prof Jim McCluskey (The University of Melbourne)



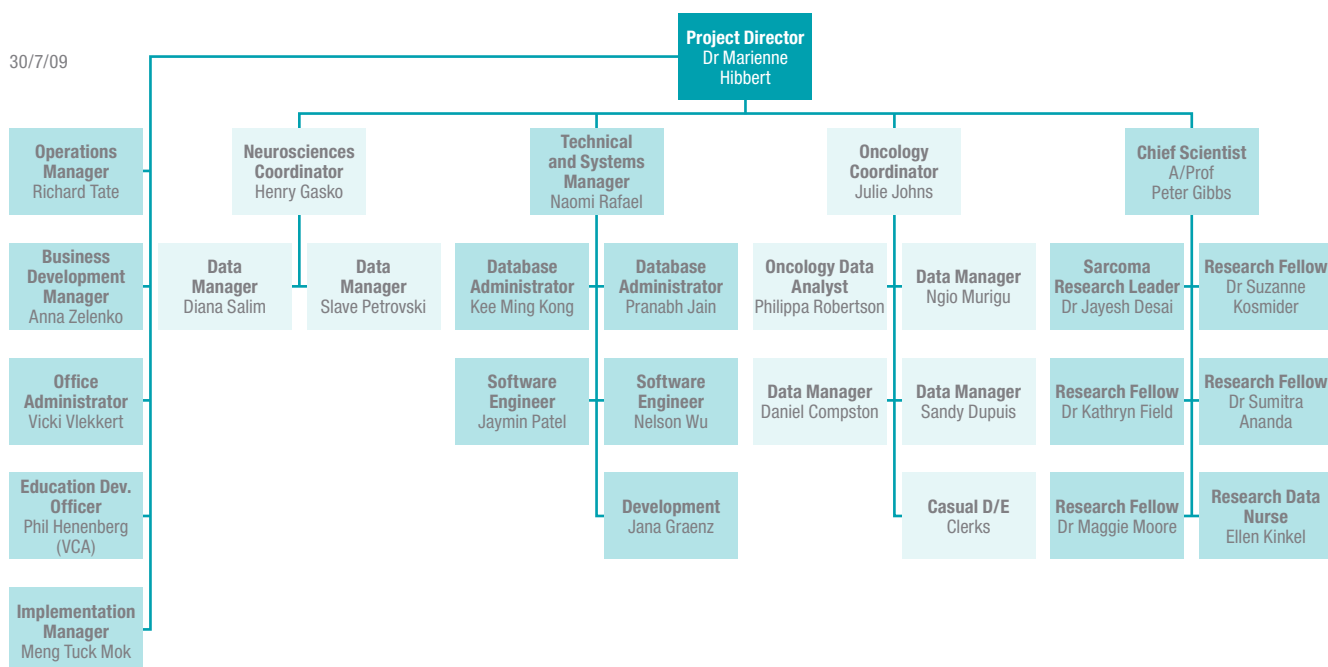
Back L–R: Terry O'Brien, Rob Merriel, Richard Tate (BioGrid Operations Manager)

Front L–R: Ingrid Winship, Marianne Hibbert, Jim McCluskey

Professor Graham Brown (The University of Melbourne) stepped down from the ACG Board during the year and was replaced by Professor Terry O'Brien. BioGrid thanks Professor Brown for his contribution to the board since its inception in 2006.

BIOGRID AUSTRALIA STAFF

The BioGrid Australia project is directed by Dr Marianne Hibbert (PhD) with project management through a number of functional areas detailed on the organisational chart below.



The increasing number of sites and disease groups to be integrated to BioGrid over 2008–09 has necessitated BioGrid Australia recruiting a number of new staff to support the workload demands of BioGrid Australia.

BioGrid Australia has welcomed the following new staff members during 2008–09:

- Mr Jaymin Patel – Research Software Engineer.
- Ms Anna Zelenko – Business Development Manager;
- Dr Maggie Moore – ACG Research Fellow;
- Dr Sumi Ananda – ACG Research Fellow;
- Ms Philippa Robertson – Oncology Research Coordinator;
- Mr Phil Henenberg – Education Manager;
- Mr Meng Tuck Mok – Implementation Manager.

WORKING WITH BIOGRID AUSTRALIA

There are a number of ways in which interested entities can work with BioGrid Australia including:

- Joining the BioGrid Australia Collaboration Agreement as a full member;
- Collaborating with BioGrid Australia using a Collaborative Research and Development Agreement (CRADA);
- Collaborating with BioGrid Australia for a limited term for a one off project using a project specific agreement.

The first two options assume an ongoing active collaboration between BioGrid and the member or collaborator with the contribution and sharing of data, the third being more suitable for a one-off data reporting project and thus usually limited in term and scope.

FULL MEMBERSHIP

This option is suitable for potential long term collaborators who will be both contributing and sharing data to join the BioGrid Australia Collaboration Agreement with a full voting seat on the BioGrid Australia Management Committee. They will also become members of the limited liability (not-for-profit) public company that has been incorporated and licensed by the Collaboration members to operate the data linkage platform.

For those wishing to join the BioGrid Australia Collaboration Agreement as full members, the steps are as follows:

1. BioGrid Australia provides the prospective member with the following documents:
 - BioGrid Australia Limited Constitution;
 - The Collaboration Agreement Establishing the BioGrid Australia Collaboration (and all Schedules and Annexure) (Collaboration Agreement);
 - An Application Form to join as a member of BioGrid Australia Limited; and,
 - Deed of Accession to join the BioGrid Australia Collaboration Agreement.
2. The prospective member completes, signs and returns to BioGrid Australia:
 - Application Form to join BioGrid Australia Limited as a Member; and
 - Deed of Accession to join the BioGrid Australia Collaboration Agreement.

3. The Management Committee (of the BioGrid Australia Collaboration Agreement) then considers the Deed of Accession signed by the prospective member.

The Management Committee is required to pass a unanimous resolution consenting to the admission of the prospective member.

4. BioGrid Australia Limited board receives and considers the Application Form to join as a member and when approved by the board enters the new member details in the BioGrid Australia Limited Register of Members.
5. BioGrid Australia invites the new member to nominate a representative to take up one position on the Management Committee that meets monthly.

NON-MEMBER COLLABORATOR

For a new prospective long term collaborator who will be both contributing and sharing data, but is unable or unwilling to join BioGrid Australia as a full member of the Collaboration Agreement, the option is to use a Collaborative Research and Development Agreement (CRADA). This enables participation in the BioGrid Australia platform as a non-member collaborator under similar terms and conditions to full members. The CRADA holder however does not have any right of representation on the Management Committee of BioGrid Australia, the overarching governance body of the BioGrid Australia members. Nor do they have membership of BioGrid Australia Limited the company licensed by the members of the BioGrid Australia Collaboration Agreement to operate the data linkage platform.

The steps to join are as follows:

1. The prospective non-member collaborator executes (i.e. signs) a Collaborative Research and Development Agreement (CRADA).
2. BioGrid Australia Limited executes (i.e. signs) the CRADA.

PROJECT AGREEMENTS

These are short term data reporting studies using a one-off project agreements limited in scope and developed in line with the requirements of the specific project at the time.

Significant legal, ethical and technical effort is required before a new site can formally join BioGrid Australia, including identification of clinical champions and key players in executive and IT areas, and visiting the sites to present information about BioGrid Australia to executive and clinical staff.

FUNDING AND ACHIEVING SUSTAINABILITY

ROLLOVER OF ACG PROJECT FUNDING

The funding provided by the Victorian Government Department of Innovation, Industry and Regional Development (DIIRD) in 2006 for the Australian Cancer Grid (ACG) project was due to expire at 30 June 2009. Fortunately DIIRD granted an extension of unused ACG funds at 30 June 2009 to the end of calendar year 2010 for which BioGrid Australia is grateful.

WORKING TOWARDS FUTURE SUSTAINABILITY

While BioGrid Australia has been pursuing a number of sustainability initiatives in the past year, a key set of milestones attached to the DIIRD extension involves working towards the practical achievement of BioGrid Australia financial sustainability in the post 2010 period when the current ACG Project roll-over funding will be exhausted.

The governance changes implemented in the past year will help support this important work, in particular the incorporation by the members of the BioGrid Australia Collaboration Agreement of a not-for-profit limited liability public company (limited by guarantee). This company is licensed by the BioGrid members to operate the data linkage platform on behalf of the members of the BioGrid Australia Collaboration Agreement.

The company will be able to contract with a range of parties wishing to work with the BioGrid data linkage platform and enter into agreements for paid data reporting studies with entities such as pharmaceutical companies.

The application for tax exempt status and Deductible Gift Recipient status enabling the company to accept donations was approved by the ATO.

SUSTAINABILITY ACTIVITIES

A number of sustainability activities have been undertaken during the past year and these are detailed below.

SUSTAINABILITY SUB-COMMITTEE

A small sub-committee of the BioGrid Management Committee was formed and this met fortnightly with BioGrid senior staff to plan and develop financial sustainability proposals and guide the work of the Business Development Manager.

Business Development Manager

A full time Business Development Manager was appointed in February 2009 to guide and develop sustainability initiatives.

Pharmaceutical Company Reporting

It is clear that there is a significant market value placed on drug related data within the pharmaceutical industry with drug companies prepared to invest substantial funds to obtain health information and market research data.

BioGrid Australia Limited is able through the data linkage platform to provide much of the data that the pharmaceutical companies are currently paying for in untimely manual collection activities. A number of such paid reporting projects have been secured during the year with marketing work continuing in this sector.

Data Custodians

Approval processes continue to be rigorous with data custodians' approval to use data being obtained. Information is only provided in aggregated form. BioGrid is establishing a Review Committee to ensure the validity of the project and ethics.

Pharmaceutical funded projects in the past year included:

- Breast cancer statistical data reporting project that will not only secure revenues but help expand the database infrastructure of BioGrid in the area of breast cancer;
- A project reporting the impact of a drug in cancer treatment;
- A large project study contract (signed in July 2009) to establish a large scale prospective colorectal cancer data collection study nationally;
- Other paid pharmaceutical funded projects are under negotiation in the areas of colorectal cancer, chemotherapy treatment and a proposal to set up a neuro-endocrine database.

Victorian Cancer Agency Grants (VCA)

BioGrid Australia has applied for and received the following grants from VCA during the year:

- Linked Data Training Development Project – BioGrid was awarded a grant from VCA to undertake this project valued at \$338,800 (including GST) and a full time Education Officer has commenced to undertake this project. This project will improve communication and training activities for the researchers and clinicians using the BioGrid platform;
- Rare Tumours Database – BioGrid was awarded a grant from VCA to undertake this innovative project valued at \$55,000 (including GST) and work has commenced on development of the internet portal and database for collection of rare tumours data. A key part of this project has included consumer consultation.

Three further Expressions of Interest submitted to VCA have progressed to Full Application status with the outcomes to be known towards the end of calendar year 2009.

Other VCA applications are in progress regarding Translational Cancer research.

We express gratitude to the VCA for its support of BioGrid in translational research activities in cancer.

NHMRC Grants Submitted

- Partnership Grant was submitted with University of Melbourne on Epilepsy and Neuropsychiatry outcomes for 3 years. Although unsuccessful, there are plans to resubmit a revised application.
- Partnership Grant was submitted with the University of Queensland on Quality and Safety reporting nationally with the outcome to be known by end of 2009.
- Five further NHMRC Project Grants were submitted in March 2009 with outcomes to be known at the end of 2009.

OTHER BIOGRID SUSTAINABILITY INITIATIVES

BioGrid Australia has been active in the development of dialogue with disease associations, community trusts and charities seeking support for BioGrid infrastructure and partnership in the development of new databases and linkage of these to the BioGrid platform in the disease areas of diabetes, epilepsy and cystic fibrosis, (with receipt of Deductible Gift Recipient status from the Australian Tax Office, the company will be able to accept donations from these bodies to support the work of BioGrid Australia in facilitating enhanced research outcomes).

Sustainability Marketing Program and Activities

Marketing Consultants were appointed to carry out a twelve month marketing campaign including development of a range of communication materials targeted to all BioGrid target markets. Currently the following items are in the design phase:

- General BioGrid folder;
- Tri-fold brochure targeted at researchers;
- Posters;
- Leaflets targeted to government, pharmaceuticals and disease associations;
- Animation targeted at clinical researchers.

BioGrid Fact Sheets with Frequently Asked Questions targeted to researchers, pharmaceuticals and disease associations have been developed by BioGrid.

BioGrid has been releasing e-news bi-monthly for all interested stakeholders and a bi-annual hard copy newsletter.

The BioGrid website is now operated from our own portal and has been completely redesigned and is updated constantly.

In the next year the following activities will be pursued to facilitate easier understanding of BioGrid services:

- Website content update to guide visitors more easily through the site;
- One page case studies to showcase the role of BioGrid in facilitating research;
- Updated list of publications;
- Podcast answering FAQ's;
- Prepared packages to approach every target market.

ACHIEVEMENTS IN 2008–09

TECHNICAL EXPANSION

Technical achievements during 2008–09 has included the following:

- Installed end to end development/test environment
- Introduced portal technology and implemented new website
- Enhanced Business Glossary Ontology software
- Enhanced perimeter security with authenticating reverse proxy and SSL
- Deployed Access Request Application software
- Established separate linkage key service
- Upgraded Linkage key (USI) server to enterprise capacity
- Upgraded Images server to double its volume
- Introduced Jira – issue and task management system
- Ingested many additional databases into BioGrid
- Connected 4 additional institutions into BioGrid (via VPN-virtual private network)
- Adoption of alternative deterministic matching tool using encryption technology to conceal patient identity
- Prepared architecture for increasing use of web services technology

NEW SITES

Sites and diseases were added to BioGrid Australia in the past year:

- Launceston Hospital (Oncology) Colorectal Cancer Data
- Box Hill Hospital (Oncology) Breast Cancer Data
- Frankston Hospital (Oncology) Lung Cancer Data
- Ludwig Institute for Cancer Research (Oncology) BRAF test results for Colorectal Cancer

New sites who have signed a Deed of Accession form to join the BioGrid Australia Collaboration Agreement as full members early next year include:

- University of NSW
- Radiation Oncology Victoria Pty Ltd

The following new sites are at various stages of in the process of joining, but are expected to join the BioGrid Australia Collaboration Agreement as full members in the next year:

- Flinders Medical Centre Adelaide
- Royal Prince Alfred Hospital Sydney
- Northern Health Victoria
- Peninsula Health
- Barwon Health for Barwon South Western Geelong Integrated Cancer Service

STAFF APPOINTMENTS

BioGrid Australia staff appointments made during the year to support the ACG program have included:

- Dr Maggie Moore and Dr Sumitra Ananda were appointed as additional ACG Research Fellows;
- Additional support staff recruited includes a Research Software Engineer, Oncology Research Analyst, Education Manager, Implementation Manager and Business Development Manager.

SCIENTIFIC ADVISORY COMMITTEE

The BioGrid Australia ACG Scientific Advisory Committee (SAC) was formed in late 2006 with A/Prof Peter Gibbs appointed as Chairman. Tumour groups reporting at the SAC have been formalised with leaders appointed to oversee work in each disease area. Work in the new tumour types to define data fields and collect data has been completed in brain, renal, head and neck, sarcoma, prostate, CLL, Upper GI with other tumour types under development. The SAC met four times in 2008–09.

New clinical data collection software developed by BioGrid Australia in the past year included the following:

- Sarcoma finalised and software deployed
- Rare tumours software designed and being tested
- Renal tumours development completed
- Prostate software designed and tested
- Chronic Lymphocytic Leukaemia software designed and being tested
- Chemotherapy version 3 under development
- HL7 repository application deployed



NATIONAL ACG GRID INFRASTRUCTURE EXTENSION

The BioGrid Australia Phase 3 project developed a plan for a national ACG grid infrastructure and during the year BioGrid Australia successfully implemented the architecture extension required to support the platform into the future.

The implemented platform is scalable, robust, responsive and reliable. The architecture solution implemented protects the privacy and security of the databases and the intellectual property of the data owners. At the same time it provides a platform for medical and other researchers to collaborate in research using remote and disparate data sets.

The main areas of accomplishment in this project were to firstly add a development environment enabling innovation and enhancement while still maintaining a reliable service in the production environment of BioGrid Australia.

Secondly, BioGrid Australia committed to the use of server virtualisation. This facilitates the fuller utilisation of the physical servers purchased, reduces space requirements and power consumption, simplifies backup plans and contributes to budgetary savings. BioGrid Australia now has 31 servers in the central BioGrid Australia infrastructure, a mix of 13 physical servers, 5 of which are virtual server hosts. These are overlayed with 17 virtual servers.

Thirdly, BioGrid Australia added new and updated components to the grid infrastructure. These included new data analysis and metadata discovery tools, SAS Enterprise Miner, IBM InfoSphere Information Analyser and IBM InfoSphere Business Glossary Anywhere. BioGrid Australia has explored and demonstrated the use of web services through a web service delivery of the record linkage service with new tools including web security, IBM Tivoli Access Manager and Directory Server. The capability to host external institutions' data sets on a BioGrid Australia server as an alternative to installing a Local Research Repository at the new site has also been established.

Finally the presentation of BioGrid Australia on the web has been professionally updated and enhanced through the introduction of the IBM Portal Express.

Security Audit

BioGrid also conducts a regular security audit of its technology and processes. This commenced in February 2009 and will be completed by the end of 2009.

RESEARCH ACTIVITIES

A key element of the ACG Project is to sponsor research that will produce early and high quality returns especially from the existing colorectal cancer and BioGrid Australia resources. These include research using colorectal cancer familial surveillance datasets collected for up to 25 years and prospective clinical data on over 5000 patients. The ability to rapidly link clinical and research data from multiple sites, and to perform sophisticated analysis through the BioGrid Australia initiative will enable projects that would otherwise be practically impossible.

The BioGrid Australia ACG project has invested \$1.0 million in three research projects from 2007 to the end of 2009 with a \$1.3 million matching contribution from CSIRO. The research is being undertaken in collaboration with key groups including CSIRO, Melbourne Health (MH), and Ludwig Institute for Cancer Research Ltd (LICR) and Flinders Medical Centre (FMC) in South Australia. BioGrid Australia will provide the data linkage infrastructure for undertaking each of these projects.

BioGrid Australia has a head agreement with CSIRO for the research projects and a specific research project agreement with each of the other parties.

The three research areas funded in the project plan with CSIRO are:

- High-risk Colorectal Cancer surveillance datasets (BioGrid Australia, RMH, CSIRO and FMC);
- Colorectal Cancer Biomarkers and outcomes in micro satellite unstable cancers (BioGrid Australia, RMH, CSIRO, and LICR);
- Comprehensive analysis of prognostic and predictive markers in Colorectal Cancer (BioGrid Australia, CSIRO and LICR).

Detailed reports for achievements and activity in each of these projects for the past year can be found in the Annual Research Report section of this report.

CONFERENCES, PRESENTATIONS, RESEARCH AND PUBLICITY

During the past year BioGrid Australia staff members have been active in promoting BioGrid Australia, the ACG Project, health informatics and health grid research as well as upgrading their knowledge and skills through participation in the following conferences, workshops and presentations.

PRESENTATIONS

Presentation	Place	Date
Australian Statistical Conference Poster titled ' <i>BioGrid Australia: A multi-institutional, multi-disciplinary research and training platform for clinical research</i> '	Melbourne	June 30 to July 3, 2008
Clinical Research Excellence	Brisbane	August 2008
Super Computing	Queenstown New Zealand	August 2008
VCOG Scientific Advisory Committee	Melbourne	September 2008
IBM Cognos Conference	Gold Coast	September 2008
Sarcoma/Haematology Group meeting at Orthopaedic Surgical Society Royal Hobart Hospital	Hobart	October 2008
NEMICS Colorectal tumour group meeting	Melbourne	November 2008
Australian Association Public Safety APCO Conference	Sydney	March 2009
IDUG Australasia ' <i>IBM WebSphere Federation Server at BioGrid Australia</i> '	Melbourne	March 2009
DOHA Colorectal Cancer Screening group	Melbourne	March 2009
Co-operative Trial Group for Neuro-oncology Annual meeting	Melbourne	March 2009
IBM Web Sphere Portal User Group	Melbourne	April 2009
ANZPAA (ANZ Policing Advisory Agency)	Melbourne	May 2009
Victorian Cervical Cytology Registry	Melbourne	May 2009
Australian Liver Association	Melbourne	May 2009
MonCan – Monash Cancer	Melbourne	May 2009
Pituitary Cancer (Acromegaly) meeting 'Introduction to BioGrid'	Melbourne	May 2009
School of Population Health	University of Melbourne	September 2008

Melbourne Health Research Week 2009

BioGrid Australia again supported The Royal Melbourne Hospital Research Week in June 2009 with a seminar featuring presentations highlighting the role of BioGrid Australia in facilitating collaborative research.

The program presented by BioGrid Australia included presentations by the following:

- Dr Kathryn Field – ‘Establishing a Brain Tumour Database’;
- Dr Sumitra Ananda – ‘Impact of the National Bowel Cancer Screening Program in Australia utilising faecal occult blood test (FOBT) screening on the diagnosis of colorectal cancer’;
- Dr Maggie Moore – ‘Rare Tumours: A new way of engaging with consumers and progressing research’.

Presentations and Posters at Western Hospital Research Week (October 2008)

BioGrid Australia was active at Western Hospital Research Week with posters presented by the following researchers:

- ‘Chemotherapy Treatments for Metastatic Colorectal Cancer – Is Evidence-Based Medicine in Practice?’ K. Field, S. Kosmider, M. Jefford, M. Michael, R. Jennens, M. Green, P. Gibbs
- ‘Determinants of Lymph Node Yield in Colorectal Cancer: Analysis of 10,082 Patients from Prospective Australian Databases’. K. Field, S. Kosmider, I. Skinner, I. Jones, U. Suthar, D. Compston, P. Gibbs
- ‘Colorectal Cancer: Linking Cancer Registry and Hospital Outcomes Databases Results in Increased Utility and Accuracy of Both Data Sets’. K. Field, S. Kosmider, J. Johns, H. Farrugia, I. Jones, S. McLaughlin, M. Chapman, M. Harold, N. Murigu, P. Gibbs
- ‘Preoperative Workup of Colon and Rectal Cancer in Australia – Marked Variation in Practice and Evidence for Inclusion of CT Chest Imaging’. S. Kosmider, K. Field, C. Oakman, S. Ananda, M. Singh, M. Moore, D. Compston, D. Stella, P. Gibbs
- ‘Impact of Diabetes Mellitus on the Development and Outcomes of Colorectal Cancer’. P. Gibbs, N. Murigu, J. Johns, S. Kosmider
- ‘Impact of the National Bowel Cancer Screening Program (NBCSP) Utilising Faecal Occult Blood Test (FOBT) Screening on the Diagnosis of Colorectal Cancer (CRC)’. S. Ananda, S. McLaughlin, F. Chen, I. Hayes, A. Hunter, I. Skinner, M. Steel, I. Jones, I. Hastie, N. Rieger, S. Shedda, P. Gibbs

Presentations and Posters at AGITG

(Australasian Gastro-Intestinal Trials Group)

BioGrid Australia researchers attended AGITG with posters presented by the following researchers:

- ‘Chemotherapy treatments for metastatic colorectal cancer – is evidence-based medicine in practice?’ K. Field, S. Kosmider, M. Jefford, R. Jennens, M. Green, P. Gibbs – runner up (2nd) prize for best young investigator poster
- ‘Determinants of lymph node yield in colorectal cancer: Analysis of 10,082 patients from prospective Australian databases.’ Field K, Kosmider S, Platell C, Reiger N, Skinner I, Jones I, Wattchow D, Chen F, Suthar U, Compston D, Gibbs P
- ‘Preoperative Investigations for Metastatic Staging of Colon and Rectal Cancer across Multiple Centres – What is Current Practice?’ Suzanne Kosmider, Damien L. Stella, Kathryn Field, Maggie Moore, Sumitra Ananda, Catherine Oakman, Madhu Singh, Peter Gibbs
- ‘Impact of Diabetes mellitus on the development and outcome of colorectal cancer’. S Kosmider, P Gibbs, N Murigu, J Johns – won best prize for young investigator poster
- ‘Impact of the National Bowel Cancer Screening Program (NBCSP) utilising Faecal Occult Blood Test (FOBT) Screening on the diagnosis of Colorectal Cancer (CRC)’. Ananda S. McLaughlin S, Chen F, Hayes I, Hunter A, Skinner I, Steel M, Jones I, Hastie I, Reiger N, Shedda S. Gibbs – 3rd prize for young investigator poster

Presentations and Posters at COSA

(Clinical Oncology Society of Australia)

BioGrid Australia researchers attended COSA with posters presented by the following researchers:

- ‘Colorectal cancer: Linking cancer registry and hospital outcomes databases results in increased utility and accuracy of both data sets’. Field K, Kosmider S, Johns J, Farrugia H, Jones IT, McLaughlin S, Chapman M, Harold M, Murigu G, Gibbs P
- ‘Electronic chemotherapy prescribing: improving clinical data collection and treatment quality’. Kosmider S, Kwong D, Field K, Desai J, Gibbs P

Presentations and Posters at ASCO GI (American Society of Clinical Oncology Gastrointestinal Cancers Symposium) – poster presentations

BioGrid Australia researchers attended ASCO GI with posters presented by the following researchers:

- ‘Initial dose reductions in colorectal cancer chemotherapy: an insight into routine clinical practice’. K Field, S Kosmider, J Desai, F Barnett, L Lim, P Gibbs – winner of Merit Award
- ‘Capecitabine in colorectal cancer: a five-year review of use in routine clinical care’. K Field, S Kosmider, J Desai, F Barnett, L Lim, P Gibbs

- *'Dose rounding of chemotherapy treatment: what is the potential impact on treatment costs and is it acceptable to oncologists?'* K Field, N Murigu, M Hibbert, P Gibbs
- *'Effect of advancing age and stage on cost of treatment for colorectal cancer'.* S Kosmider, K Field, S Ananda, P Gibbs
- *'Impact of the National Bowel Cancer Screening Program (NBCSP) utilising Faecal Occult Blood Test (FOBT) Screening on the diagnosis of Colorectal Cancer (CRC)'.* Ananda S. McLaughlin S, Chen F, Hayes I, Hunter A, Skinner I, Steel M, Jones I, Hastie I, Reiger N, Shedda S. Gibbs P

Presentations at .eResearch Australasia

Posters presented by BioGrid Australia researchers included the following:

- *'BioGrid Australia – Life Science e-research Outcomes'.* Marianne Hibbert et al.
- *'BioGrid Australia – A Service-oriented Approach for Clinical Research'.* Jason Lohrey and Steve Melnikoff

Presentation at Australian Biospecimen Network, Sydney

Dr Clare Scott (Walter and Eliza Hall Institute for Medical Research and BioGrid Australia Management Committee member) presented the following:

'Linking biospecimens to targeted therapy development and rare tumour research'.

Clare Scott

These and other presentations can be accessed on the BioGrid Australia website at <http://www.biogrid.org.au>.

PUBLICATIONS

BioGrid researchers to end of June 2009 published 67 publications (54 in Colorectal Cancer, 2 in Diabetes and 11 in Neurosciences) using data linked and collected over recent years through the BioGrid Australia data linkage platform. These research publications have highlighted the linkage of multiple databases and disease types such as diabetes and colorectal cancer.

BioGrid Australia researchers have again been active in publications during 2008–09 with further details provided later in this report. Details of all BioGrid Australia research and publications including those in 2008–09 can also be obtained from the BioGrid Australia website: www.biogrid.org.au

PUBLICITY AND PROMOTION

Publicity and promotional activities undertaken during the year included the following:

During the year BioGrid Australia has published and distributed newsletters numbers 13 and 14 each containing news, updates and articles on BioGrid Australia-related research and researchers of interest to our readers. All newsletters are on the BioGrid Australia website, with limited hard copies available from the BioGrid Australia office. With the introduction of the new electronic newsletter during 2008–09 the glossy hard copy format has been cut back to 2 editions per annum:

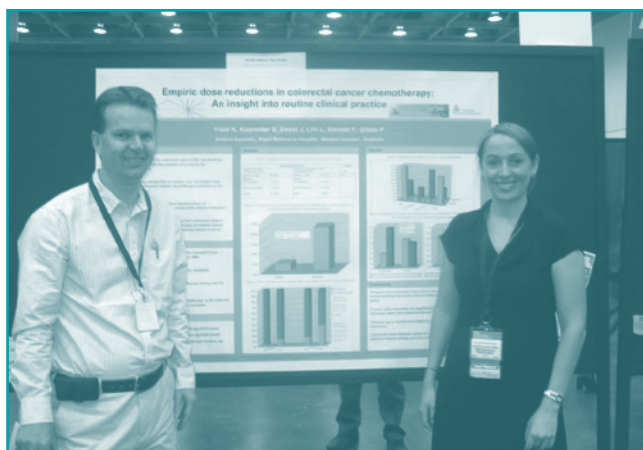
- A new bi-monthly electronic newsletter has been published with the first edition in August and five editions in 2008–09.
- The animation titled 'What is BioGrid Australia?' was released last year and has proved to be a great success.
- A new animation incorporating data collection and revaluation of data to improve patient care was released this year targeting clinical researchers.

To view all the newsletters and animations please check our website www.biogrid.org.au

BioGrid Research Fellows Honoured with Merit Awards at 2009 Gastrointestinal Cancers Symposium USA

- Dr Kosmider's study poster was titled: *'Escalating costs of treating colorectal cancer (CRC) and cost effectiveness of faecal occult blood test (FOBT) screening'*.
- Dr Ananda's study poster was titled: *'Impact of the national bowel cancer screening program in Australia (NBCSP) utilising faecal occult blood test (FOBT) screening on the diagnosis of colorectal cancer'*.
- Dr Field's three posters were titled: *'Initial dose reductions in colorectal cancer chemotherapy: An insight into routine clinical practice'*; *'Capecitabine in colorectal cancer: A five-year review of use in routine clinical care'*; and *'Dose rounding of chemotherapy treatment: What is the potential impact on treatment costs and is it acceptable to oncologists?'*

The BioGrid fellow posters were the only two Australian entrants to receive awards, so this was a significant achievement!



2009 Bradley Stuart Beller Merit Award



The Ludwig Institute for Cancer Research Limited is a member of the BioGrid Australia Collaboration Agreement.

The results of this research will be presented at the 2009 ASCO Annual Meeting in the Tumour Biology and Human Genetics Oral Abstract Session.

BIOGRID RESEARCH REPORT 2008–09

TUMOUR STREAM: BREAST



Dr Clare Scott is the leader of the BioGrid breast tumour stream.

Dr Scott is a Medical Oncologist at the Royal Melbourne Hospital and Clinician Scientist at the Walter and Eliza Hall Institute of Medical Research.

Breast cancer is the most common invasive cancer among Australian women with about a quarter of those affected under the age of 50.

2008–2009: Progress and Challenges

There are several projects at a state level that have a direct link to the breast tumour stream.

The Cancer Council Victoria (CCV) along with Western Central Melbourne Integrated Cancer Service (WCMICS) is developing a consensus dataset (CDS) for the breast tumour stream. The development of the dataset will ensure that data is collected in a uniform and standard manner across Victoria. The dataset will be the basis for any development of data collection tools for the breast tumour stream.

Establishment of breast cancer data collection systems

CCV in conjunction with WCMICS have a project to install and implement the RUTH software at four hospitals in Melbourne to assist in clinical treatment of patients. BioGrid have representation on the governance committee for the RUTH project. BioGrid is also developing a module for breast in the ACCORD data collection software system. This development will utilise the breast consensus dataset and further expand data collection for the breast tumour stream. The ACCORD breast module development will also assist in collecting clinical information for breast cancer patients.

Future Directions

To develop the Breast ACCORD module with the aim to incorporate functionality that can be useful for managing breast cancer patients:

- Generation of letters to GP; and
- Functionality to support multidisciplinary team

BioGrid will continue to work with state-wide initiatives that have clear links with the breast tumour stream and continue to work with CCV on the RUTH project and development consensus datasets.

TUMOUR STREAM: PITUITARY CANCER



Prof David Torpy (Royal Adelaide Hospital) is the leader of the BioGrid pituitary cancer stream.

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.

Brief background on Pituitary stream

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 a pituitary 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

Current collaborators include Assoc Prof David Torpy (Royal Adelaide Hospital), Assoc Prof Mark McLean (Westmead Hospital) and Prof Peter Colman (Royal Melbourne Hospital) and Dr Warwick Inder (St Vincent's Hospital, Melbourne). A common dataset for the disease has been defined and work has started to create a tool for data collection. The first complete retrospective database from a single hospital was added to the BioGrid platform in July 2009. The work is being assisted by a generous grant from Novartis to facilitate entry of historical data at each of the participating hospitals.

Challenges and Future Directions

The main challenge for the coming year is the completion of the new data collection tool, and its roll-out to all interested hospitals in Australia. This will provide a much larger cohort of cases for research than is available at any single institution, and allow significant research questions to be addressed.

TUMOUR STREAM: BONE AND SOFT TISSUE (SARCOMA)



Dr Jayesh Desai is the leader of the BioGrid Bone & Soft Tissue tumour stream. Dr Desai is a Medical Oncologist at Royal Melbourne Hospital, Peter MacCallum Cancer Centre and Ludwig Institute for Cancer Research.

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 paediatric malignancies. The morbidity and community impact of sarcomas is significantly greater given the greater proportion of younger people affected than most other solid tumours. It has been estimated that 17 years of life are lost per sarcoma patient, 3 times the rate of bowel or breast cancer.

2008–09: Progress and Challenges

Over the past 12 months, we have worked together (Peter MacCallum Cancer Centre, Royal Prince Alfred Hospital and Prince of Wales) to finalise a minimum dataset, and have developed an online database as a module in ACCORD. The database was implemented at Peter MacCallum in May 2009 and data entry has commenced. The Australasian Sarcoma Study Group (ASSG) has part-funded a program nurse, who is responsible for data entry at Peter MacCallum as part of her wider role within the sarcoma service. Data is currently being entered prospectively with approximately 170 patients from the paper trial of the dataset also to be entered.

Several interstate sites will also be using the minimum dataset and/or ACCORD to collect data; these include Royal Prince Alfred and Prince of Wales in NSW and Princess Alexandra in QLD. As these sites treat the vast majority of sarcoma patients in NSW, Victoria and QLD, it is expected that from a national perspective the level of data capture will be very high.

Dr Maggie Moore was employed as a BioGrid Fellow in February 2009 and has been involved with the ongoing development of the sarcoma tumour stream. She attends the Bone & Soft Tissue sarcoma clinic at the Peter MacCallum, and has been involved in the final stages of developing, and then testing the sarcoma database along with assisting with clinical support for the data entry team.

BioGrid and the ASSG have developed a strong collaboration over the past year, particularly as collection of clinically annotated tissue is a key performance indicator for the ASSG. There is also an ASSG database sub-group which will help coordinate data collection around Australia. The ASSG has provided initial funding for data collection in Victoria, NSW and QLD with the sites aiming to find matching funds to make ongoing data collection sustainable.

Future Directions

It is envisioned that clinically meaningful research questions will be able to be answered using information collected through the database within the next twelve months. Current research initiatives that will use the ACCORD database include a project evaluating outcomes following resection of limited pulmonary metastasis in patients with various subtypes of sarcoma. The next year should also see the NSW and QLD databases linked into BioGrid and the involvement of more interstate sites specifically Canberra, WA and SA.

TUMOUR STREAM: CHRONIC LYMPHOCYTIC LEUKAEMIA (CLL)



Dr Constantine Tam is a Haematologist at St Vincent's Hospital Melbourne, and an executive member of the Chronic Lymphocytic Leukaemia 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, multicenter clinical data network and to develop the next generation of treatment for clinical trials in CLL in Australia.

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 700 patients each year*), and yet little is known about its cause, and it is not curable with current treatment.

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.

2008–2009: Progress and Challenges

Historical patient datasets have been collected in many research institutions (e.g. St Vincent's Hospital, Royal North Shore Hospital, Sydney) but these datasets have never been linked or analysed in a systemic manner. BioGrid aims to help in the linkage of these datasets by facilitating the collection of a standard dataset using the ACCORD or other database and making the data available to researchers and clinicians in a de-identified manner. Development of the CLL module in ACCORD has begun, which has been sponsored by Roche.

The major challenge is finding common data parameters that are essential for comprehensive data collection at all sites. A final dataset was agreed on by all investigators after 2 meetings.

Future Directions

Once the ACCORD module has been finalised and tested at St Vincent's Hospital, Melbourne, it will be rolled out at Royal North Shore Hospital and Peter MacCallum Cancer Centre. Other potential sites include Flinders Medical Centre, Royal Brisbane Hospital, Sir Charles Gairdner Hospital and Gosford Private Hospital.

The 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 basic and clinical CLL research in Australia.

*Source: Leukaemia foundation website: www.leukaemia.org.au

TUMOUR STREAM: COLORECTAL



Associate Professor Peter Gibbs is the leader of the BioGrid Colorectal tumour stream. A/Prof Gibbs is a Medical Oncologist at Royal Melbourne and Western Hospitals, and Ludwig Institute of Cancer Research. He is also the Chief Project Scientist for the Australia Cancer Grid.

Colorectal cancer (CRC) is the most common internal malignancy in men and women, effecting one in 20 Australians. Of those diagnosed, almost half will eventually die from advanced disease, annually accounting for approximately 529,000 deaths worldwide.

2008–09: Progress and Challenges

Colorectal databases currently linked into BioGrid are from Royal Melbourne Hospital, Melbourne Private, Western Hospital, Western Private, Box Hill Hospital, Austin Hospital, Peter MacCallum Cancer Centre, St Vincent's Hospital, and newly linked Launceston Hospital.

A further 9 sites are contributing to the Colorectal Surgical Society of Australia and New Zealand centralised database, with work continually progressing on including remaining CSSANZ member sites via BioGrid or the central database. At that point data will be collected from every state in Australia, with New Zealand sites also likely to be participating.

Version one of an Electronic Chemotherapy prescribing module has been a success and a generic version is now in development which will encompass most tumour streams. This has improved the ease and quality of data capture.

Ethics and agreements are now in place to link in Radiation Oncology Victoria, Austin Radiotherapy and Alfred Radiotherapy data.

Achievements

Ten publications that utilised BioGrid colorectal cancer data were published in 2008, eight have been published or accepted for publication so far in 2009.

Future Directions

Sites in progress to be linked in the next 12 months include:

- Victoria: Southern Health, Peninsula, Ballarat, Northern and Geelong;
- NSW: Prince of Wales, Royal Prince Alfred, Royal North Shore, St Vincent's and Westmead;
- QLD: Royal Brisbane and Princess Alexandra.

TUMOUR STREAM: GYNAECOLOGY



Dr Sumitra Ananda is coordinating the BioGrid Gynaecological tumour stream. Dr Ananda is a Medical Oncologist and a Fellow at BioGrid.

Gynaecological cancers include cancers of the uterus (including endometrium), ovary, cervix, vulva, vagina, and placenta and gestational trophoblastic disease (pregnancy-related cancers). On average, more than 3900 women were diagnosed with a gynaecological cancer in Australia each year between 2001 and 2005. Gynaecological cancers were responsible for 1562 female deaths in Australia in 2005, accounting for 9.1% of all female cancer deaths.

Background

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 run by CCV. 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 software application and database known as GeMMA. The success of the pre-trial led to the Cancer Council Victoria to fund a one-year project known as the Gynaecological Oncology Project (GOP) which commenced in 2008 to expand gynaecological data collection to the other major metropolitan and regional gynaecological centres using the GeMMA software. This enabled the Victorian Cancer Registry (VCR) to expand the existing data collection to include clinical data based on the Victorian Clinical Cancer Registration Dataset (VCCRD) and report on surveillance and monitoring for gynaecological tumour at the population level for Victoria. The project promoted and expanded gynaecological cancer data collection at several metropolitan health services using the GeMMA software.

Future Directions

BioGrid aims to establish the Gynaecological Tumour Stream as part of their current tumour streams. The Gynaecological Oncology Project (GOP) demonstrated a need to collect clinical information for gynaecological cancers. BioGrid is making links with the Royal Women's Hospital and other sites in Victoria to enable the use of their comprehensive data for translational research. BioGrid is looking towards developing an ACCORD module to collect gynaecological cancer data.

TUMOUR STREAM: HEAD AND NECK



Clinical Associate Professor David Wiesenfeld, from University of Melbourne is the Head and Neck Tumour Stream leader. He is an Oral and Maxillofacial Surgeon at the Royal Melbourne Hospital with research affiliations at Melbourne University.

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 included in this tumour stream.

Progress and Challenges for 2008–09

The Head & Neck module in the ACCORD software continues to be used at RMH and the database is currently undergoing refinement and improvement. Speech pathology and nutrition at RMH, Southern and Alfred have given requirements for a clinically useful dataset which will be included in the upgrade.

Surgeons Peter Thompson from the Alfred, Rod Mitchell from Bendigo and Prof Robert Jones from Townsville as well as surgeons from Western Hospital have all expressed interest in using the new version of the database.

Challenges have included ensuring that the database collects all relevant patient pathways and gaining agreement from speech pathology and nutrition departments across the sites that use different terminology. The inclusion of Radiation and Medical Oncology modules has been identified as a priority.

Future Directions

The database will be demonstrated at the ANZAOMS meeting in QLD in October to highlight the usefulness of data collection and use of the ACCORD database. Data will be entered online after the refinements to the database are completed.

Future research projects include identifying and studying biological markers at the tumour margin with the Department of Physiology and School of Dental Science at the University of Melbourne, the radiological assessment of tumour thickness with the Radiology Department at RMH and a retrospective analysis of Head and Neck Tumour Imaging at Royal Melbourne Hospital.

TUMOUR STREAM: LUNG



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

Lung cancer is the most lethal cancer worldwide. It is a tumour type that frequently does not require surgical intervention and involves multidisciplinary care which has implications for thorough data collection.

2008–09: Progress and Challenges

The VCOG lung group and Integrated Cancer Services have developed a consensus minimum dataset that has been agreed by all participants. BioGrid has been involved in this process developing the data collection form for VCOG. A data dictionary is in progress and will include the newly ratified 7th Edition of the International Lung Association for the Study of Lung Cancer (IASLC) Staging system.

Collection of data involves surgeons, radiation oncologists, respiratory physicians, medical oncologists and Palliative Care Physicians. Currently there is no state-wide data collection for this common and most lethal of cancers. Currently there are 3 sites collecting lung data, with the focus being on increasing the number of collaborating sites.

Challenges have included coordinating the collection of data from all disciplines at the point of clinical care and linking to the relevant external databases relevant to lung cancer, in particular radiotherapy.

Future Directions

There are several initiatives for the lung tumour stream. Currently there are two major projects that will benefit from BioGrid resources:

- New lung cancer staging validation project;
- World lung cancer genome project.

Summary

The lung tumour stream requires state-wide data collection to further understand the clinical behaviour of this tumour type. It is hoped that the VCOG consensus lung dataset will be the catalyst for data collection.

Recent publications highlighting the value of BioGrid resources should generate interest in lung cancer data collection.

TUMOUR STREAM: MELANOMA



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

The latest statistics from the Australian Institute of Health and Welfare publication Australia's Health 2008 state that melanoma is one of the most common cancers diagnosed in Australia. As such Australia is a major contributor to the global melanoma battle.

2008–09: Progress and Challenges

Peter MacCallum Cancer Centre, Victorian Melanoma Service – Alfred Hospital and the Austin Hospital, are the initial sites comprising the Melbourne Melanoma Project.

The progress for 2008–09 is the clinical data collection occurring at Alfred Hospital, Austin and Peter MacCallum Cancer Centre. The data collected is for research and clinical activities to provide the comprehensive clinical information to complement the Melanoma Tissue Bank, in collaboration with the Victorian Cancer BioBank (VCB). Current challenges are to ensure the efficient linkage of clinical data with molecular pathology data.

The last year's highlights for the melanoma tumour stream are:

- The development of new targeted therapies for melanoma;
- Impact of clinical and genetics data on clinical trials with target therapies – BRAF inhibitors and KIT inhibitors;
- Prominent presentations at American Society Clinical Oncology.

The challenges are establishing efficient linkage of molecular pathology data and clinical data for melanoma patients, and links between the melanoma tissue banking data and clinical data for the Melbourne Melanoma Project.

Future Directions

The utilisation of project based data to look at three specific areas:

- To gain an understanding of clinical and molecular pathology data of nodular melanoma;
- Utilisation of molecular biology data for melanoma and looking for the expression of highly immunogenic molecules such as cancer testis antigen;
- Looking at the behaviour of transplant melanoma cells in mice and possible application to humans.

TUMOUR STREAM: RARE TUMOURS



Dr Clare Scott is the leader of the BioGrid Rare tumour stream. Dr Scott is a medical oncologist at the Royal Melbourne Hospital and clinician scientist at the Walter and Eliza Hall Institute of Medical Research.

The rare tumour stream encompasses over 500 malignancies and also includes rare subsets of common tumours.

2008–09: Progress and Challenges

The primary focus of the rare tumour stream over the last twelve months has been the development of the web based database known as CART-wheel. It is planned that this will be launched in 2009.

The generation of this web-based Rare Tumour Database, utilising the BioGrid Australia infrastructure, will for the first time provide an ethically-approved portal for consumer-driven information collection for rare tumours. The website has been developed with significant consumer input, particularly from Cynthia Pollak (HEARD Database) and John Stubbs (Cancer Voices Australia) to ensure that is accessible, user-friendly and relevant to consumers.

The database will serve as a tool by which researchers are able to identify larger groups of patients with a particular tumour type in order to conduct more meaningful research. It is hoped that it will also contribute substantially to identify people who may be relevant for clinical trials of novel targeted therapeutics. The web-based format will allow identification of consumer participants on an international scale, with the individual's level of involvement in the project reflecting the level of consent they have provided.

Researchers will be able to apply to BioGrid for access to the data that is collected with the scientific validity and feasibility of their request assessed by a BioGrid committee.

In concert with the database development the website will also provide a consumer information page containing relevant links to further information and support.

The generation of the website was funded by a Victorian Cancer Agency consumer grant.

Future Directions

It is anticipated that the website will be launched in 2009 and that preliminary analysis of meaningful data should be possible within the first six months.

TUMOUR STREAM: RENAL



Renal tumour stream leader Associate Professor Ian Davis is a medical oncologist and cancer immunologist. He has a clinical appointment at Austin Health and is currently an Associate Member of the Ludwig Institute for Cancer Research, Associate Professor of Medicine in the University of Melbourne and adjunct Associate Professor at Monash University. He holds a Victorian Cancer Agency Clinician Researcher Fellowship and is an honorary NHMRC Practitioner Fellow.

Renal cancer is the ninth most common cancer in Australia and the 16th most common cause of cancer death*.

Progress and Challenges for 2008–09

The dataset developed by Austin Health and Royal Melbourne Hospital has been developed as a module in the ACCORD database and is undergoing final testing before deployment. The database was developed to be used in clinics so has functionality that directs the user to complete appropriate screens, highlights incomplete pages and minimises the number of mouse clicks by using radio buttons where appropriate.

Funding from the Victorian Cancer Agency contributed to the development of this module in ACCORD and has funded a project manager to facilitate data and tissue collection at the Austin in conjunction with the Ludwig Institute for Cancer Research, the Victorian Cancer BioBank and BioGrid.

Future Directions

After initial deployment at Austin Health and Royal Melbourne Hospitals the database will be rolled out to other BioGrid sites. Potential users will be identified at current BioGrid sites, Cancer Trials Australia forums and COSA meetings.

Future research includes tissue analysis with associated clinical data.

*National Cancer Statistics Clearing House, AIHW. 2005 Data.

CYSTIC FIBROSIS



Professor John Wilson of The Alfred Hospital is the leader of the BioGrid Cystic Fibrosis (CF) stream.

Professor Wilson is head of the Department of Allergy, Immunology & Respiratory Medicine at The Alfred Hospital and on the faculty of Monash University Medical School. In addition to the Alfred Hospital, the BioGrid CF stream also includes Southern Medical Centre under Prof. David Armstrong and The Royal Children's Hospital under Prof. Philip Robinson.

Cystic Fibrosis is a devastating disease for which there is currently no cure. It affects the exocrine (mucus) glands of the lungs, liver, pancreas, and intestines, 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 for 2008–09

The main aim of the BioGrid CF project is to link the lung function databases from the three participating sites into the BioGrid system. This will allow a larger cohort of patient information to be available for research than is available at any single hospital. It will also allow tracking of patient information (in de-identified form) from pre-adult treatment at The Royal Children's Hospital through treatment as an adult at The Alfred or Southern.

The past year has seen the linkage of Lung Function data from all three hospitals through the BioGrid system. In addition, historical data from RCH for the past 25 years has been linked, and data in CF Australia format from those sites is also being linked. Information regarding patient admissions, length of stay and co-morbidities is now available for all three sites as well, and analysis regarding the effects of various levels of treatment on patient outcomes has begun.

Challenges and Future Directions

Current work is focused on obtaining data from the Smart Health System. This 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 information, it will provide a valuable resource for the study of CF. A paper is due to be presented to the CF Society meeting in September 2009 highlighting the improvements in patient survival over the past 10 years, based on information linked through BioGrid.

DIABETES – CLINICAL AND RESEARCH



Professor Peter Colman is the leader of the BioGrid Diabetes streams.

Professor Colman is head of the Department of Diabetes and Endocrinology at the Royal Melbourne Hospital and an Honorary Professorial Associate at the Walter & Eliza Hall Institute.

Diabetes is a major health priority for the community with the incidence of both type 1 and type 2 diabetes increasing at an alarming rate. Type 1 diabetes, which affects mainly children and adolescents has an incidence of 22/100,000/yr and is increasing at a rate of 3%/year. Type 2 diabetes, which affects people usually beyond their teenage years, affects 7.4% of the population. Treatment for both types of diabetes can be complex and there is a risk of complications affecting the heart, kidneys, eyes and nerves.

2008–09: Progress and Challenges

The aim of diabetes treatment is to ensure treatment targets (for glucose, blood pressure, lipids, exercise and diet) are met and that clinical screening for the earliest signs of complications (of eyes, heart, kidneys and feet) are undertaken regularly and rigorously such that treatment can be undertaken to prevent progression to clinically significant disease with subsequent negative effects on quality of life. Clinical data, which has been collected for over 10 years, has been analysed to begin to address numerous research questions regarding ideal treatments and associated outcomes. Comparison of data collected in clinics at Austin Hospital, St Vincent's Hospital, The Royal Children's Hospital and Royal Women's Hospital is underway and will continue. A web-based database has been developed to assist a number of other institutions, who wish to join the collaboration, to collect the same electronic data.

BioGrid also contains an extensive dataset related to preclinical diagnosis of type 1 diabetes. This dataset has resulted in a clinical trial, the Type 1 diabetes prevention trial in which intranasal insulin is being tested as a vaccine to prevent type 1 diabetes.

Future Directions

Clinical data from the collaborating institutions will form one of the largest and most complete datasets guiding diabetes management in the country. The involvement of further institutions will further strengthen the importance of the data for Quality of Care analysis and research into better treatments and outcomes for people with diabetes.

EPILEPSY



Professor Terence O'Brien leads the BioGrid Epilepsy Stream which includes Quality of Life studies led by Dr. Raju Yerra, and Neuroimaging led by Prof. Patricia Desmond.

Chronic neurological illnesses, such as epilepsy, multiple sclerosis and cerebrovascular disease, cause enormous physical and psychosocial impact on the individual and family involved and come at a huge cost to the community in terms of loss of productivity and economic burden. Epilepsy is the most common chronic neurological disorder, affecting ~1% of the general population.

Epilepsy research within BioGrid encompasses both basic and clinical research, from genomic studies of treatment outcomes to the studies of psychosocial outcomes.

Besides the Royal Melbourne Hospital, most other tertiary hospitals in Victoria are involved in the current research projects.

Progress and Achievements for 2008–09

Significant achievements in the past year include:

- In the field of Pharmacogenomics, work involving BioGrid has identified the world's first multigenic pharmacogenomic classifier for epilepsy treatment outcomes. This research has been published in the highly regarded journal *Pharmacogenetics and Genomics*, and was presented at the American Epilepsy Society annual conference in Seattle, December 2008. Slave Petrovski, one of the researchers on the team, has won one of only two Sir Keith Murdoch Fellowships from the American Australian Association, which will enable him to continue his PhD studies at the highly regarded Duke University Institute for Genome Sciences & Policy.
- Important work has been done linking the quality of life and neuropsychological outcomes in epilepsy patients admitted to hospital for video EEG monitoring. The study has identified risk factors that appear to be associated with negative psycho-social outcomes. These results were also presented at the American Epilepsy Society conference in Seattle and are being written up for publication.
- A study, done in conjunction with the Bone Mineral Density Unit at Melbourne Health, has investigated the bone health of epilepsy patients. The study found that patients who are on long-term anti-epileptic drug therapy have poorer bone health and a greater risk of fractures. The study was presented to the ANZ Association of Neurologists in Christchurch in May 2009 and is being prepared for publication.

INFLAMMATORY BOWEL DISEASE



Challenges and Future Directions

Exciting future projects include:

- Linking the Australian phenomics – genomics epilepsy databases with similar databases of international collaborators in the UK and Hong Kong, to allow greater power to identify genomic predictors of disease and treatment outcomes;
- Linking clinical data with imaging data in a seamless way. As well as clinical data for epilepsy patients, the BioGrid database now links all MRI images for these patients at Melbourne Health, and all PET scans done on these patients at Peter MacCallum Cancer Centre;
- Linking the current BioGrid neuroscience databases with databases from similar research programs in other parts of Australia;
- Incorporating the databases of the National Australian Register of Anti-epileptic Drugs in Pregnancy (containing information on outcomes of more than 1400 pregnancies).

Prof Finlay Macrae heads the BioGrid IBD/Crohn's Disease Stream.

Inflammatory Bowel Disease is a chronic inflammatory disease of the gastrointestinal tract, comprising two major subtypes – ulcerative colitis and Crohn's Disease. The condition is common, with a prevalence of 30 to 60/10,000 population. The cause is 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.

Brief background on IBD stream

IBD Melbourne is a sub group of IBD Australia. The group is cohesive and collaborative. Strong membership includes gastroenterologists from St Vincent's, The Royal Melbourne, The Royal Children's, Box Hill, Western, Alfred, Austin Hospitals and Monash Medical Centre. Collaborative projects have been conducted by IBD Melbourne, and more are planned with applications to the NHMRC. A group Yahoo is set up for regular member communication.

St Vincent's Hospital has had an IBD database for over 5 years which has evolved. The group favours this database for across-Melbourne use, after carefully considering the alternative national database located at the Mater in Brisbane, because of ease of use. Several sites in Melbourne have therefore installed local versions of the St Vincent's database.

Progress and Achievements

Given the utility of BioGrid, IBD Melbourne has been in discussions with BioGrid's Henry Gasko to allow the existing databases across Melbourne to be linked using the BioGrid process for the purposes of accumulating experience and reporting de-identified information. Initial steps have included discussion about how the dataset can be enhanced at this stage, especially around drug recording and side effects, pregnancy management, time stamping, phenotype description, and disease activity indices and some free text comments fields for more flexibility. With approval from St Vincent's for these changes imminent, we will be able to move to consolidate the changes and introduce a version incorporating this across BioGrid.

Challenges and Future Directions

With approval from St Vincent's for the changes to the database, we will migrate to this version at all sites and link to BioGrid.

NEUROPSYCHIATRY



Dr. Dennis Velakoulis heads the BioGrid Neuropsychiatry stream.

Dr Velakoulis is the Clinical Director of the Melbourne Neuropsychiatry Centre (MNC), a joint Centre of Melbourne Health and the University of Melbourne and is also Chair of the Electro Convulsive Treatment Committee for North Western Mental Health (NWMH).

The information collected in the course of neuropsychiatric assessments includes psychiatric, neuropsychological, functional and imaging data across a broad range of neurological and neuropsychiatric disorders. Within the research setting MNC has collected clinical, imaging and neuropsychological data on over 3000 subjects with neuropsychiatric disorders, in particular patients with psychotic illnesses.

2008–2009: Progress and Challenges

The successful incorporation of the NUCOG (Neuropsychiatry Unit cognitive screening tool) database into the BioGrid database paved the way for the integration of a much more complex dataset of neuropsychological data in the year 2008–2009. Dr. Mark Walterfang (Neuropsychiatry Unit) guided the development of the database and worked with neuropsychologists Dr Amy Scholes (Neuropsychiatry Unit), Ms Alexia Pavlis (Neuropsychiatry Unit) and Dr Deborah Leighton (The Royal Melbourne Hospital – Royal Park Campus Library) [formerly MECRS Library] to bring it to the point where data has been entered and used. Further work is proceeding to develop this database for research outputs.

The ECT database of NWMH has been linked into BioGrid in the last year. This database which includes details regarding ECT treatments and anaesthetic medications will now be linked with diagnostic and clinical outcome (psychiatric and medical) data to better understand the longitudinal course and psychiatric/medical outcomes of ECT within NWMH.

The Neuropsychiatry team (Dr. Sophie Adams) has continued its close clinical collaboration with the Epilepsy service. The Neuropsychiatry Epilepsy database now includes data on over 427 patients with focal epilepsy who have been assessed across a variety of neuropsychiatric and neurological domains.

Future Directions

The MNC's Bioinformatics development project (Ms Bridget Soulsby, Dr. Katherine Manson, Professor Chris Pantelis) aims to integrate MNC's behavioural, cognitive, neuropsychological and imaging data through the development of a flexible conceptual data model and data dictionary. This project has now been approved ethically and the initial pilot project is being planned.

STATISTICAL REPORT ON DATA AND USAGE (JUNE 2009)

Table 1: Monthly BioGrid Australia statistical report for June 2009

Sites	Databases	Tables	Sources	Columns	Records	Patients
RMH	ACCORD V1	13	1	142	27,678	8,188
	ACCORD V2	73	1	884	22,876	2,538
	Biomarkers	2	1	49	4,581	674
	Bone density	15	1	1,201	1,867	161
	BRAF	1	1	15	583	347
	CRCLIFE	15	1	91	191	78
	Diabetes (research)	52	1	1,406	342,742	11,760
	Diabetes V2 (clinical)	14	1	257	301,259	4,964
	Epilepsy	64	1	2,011	33,606	3,240
	Familial	77	1	759	72,436	8,312
	Konquest	7	1	456	1,003	105
	MS_IMED	9	1	301	4,731	374
	Oncseizure	9	1	86	90	47
	Stroke	14	1	182	4,945	4,831
	Surveillance	31	1	465	58,098	3,744
	Tissuebank	42	1	624	1,411,502	2431
	VEM	9	1	524	1,128	239
	ACCORD V2	13	1	344	15,838	1,893
WH	CRCLIFE	15	1	93	266	118
Austin	ACCORD V1	13	1	142	11,446	4,204
	ACCORD V2	13	1	337	2,522	432
	Diabetes	5	1	260	63,951	1,521
	Tissuebank	37	1	337	183,259	2,947
PMCI	ACCORD	18	1	385	25,139	5,366
	ACCORD V2	13	1	337	308	95
	Tissuebank	15	1	128	102,217	9,906
SVHM	Breast	20	1	313	36,194	5,311
	Diabetes	14	1	701	4,317	201
	Oncology	23	1	277	129,900	20,697
Bayside shared	Box Hill					
	ACCORD V2	17	1	404	3,273	396
	Breast	18	1	498	22,543	2,616
	Monash					
	ATD	4	1	31	16,707	342
	Cystic fibrosis	2	1	101	4,501	131
	Alfred					
	ATD	4	3	30	64,405	374
	Cystic fibrosis	2	1	114	9,919	374
	Stroke	2	1	63	2,694	1,282
FH	Lung	12	1	230	498	36
RCH	Diabetes	15	1	246	64,690	3,694
	Cystic fibrosis	2	1	97	22,848	4,754
	Cystic fibrosis Australia	5	1	205	8,029	328
	Cystic archived 1996–1999 RCH	3	1	110	2,510	1,595
	Cystic archived 1999–2003 RCH	9	1	276	3,629	421
	Cystic HP3000 RCH	3	1	67	13,012	1,595
DHHS	Launceston General Hospital					
	ACCORD V2	15	1	388	1,349	190
Total		707	39	14,578	2,989,213	110,275

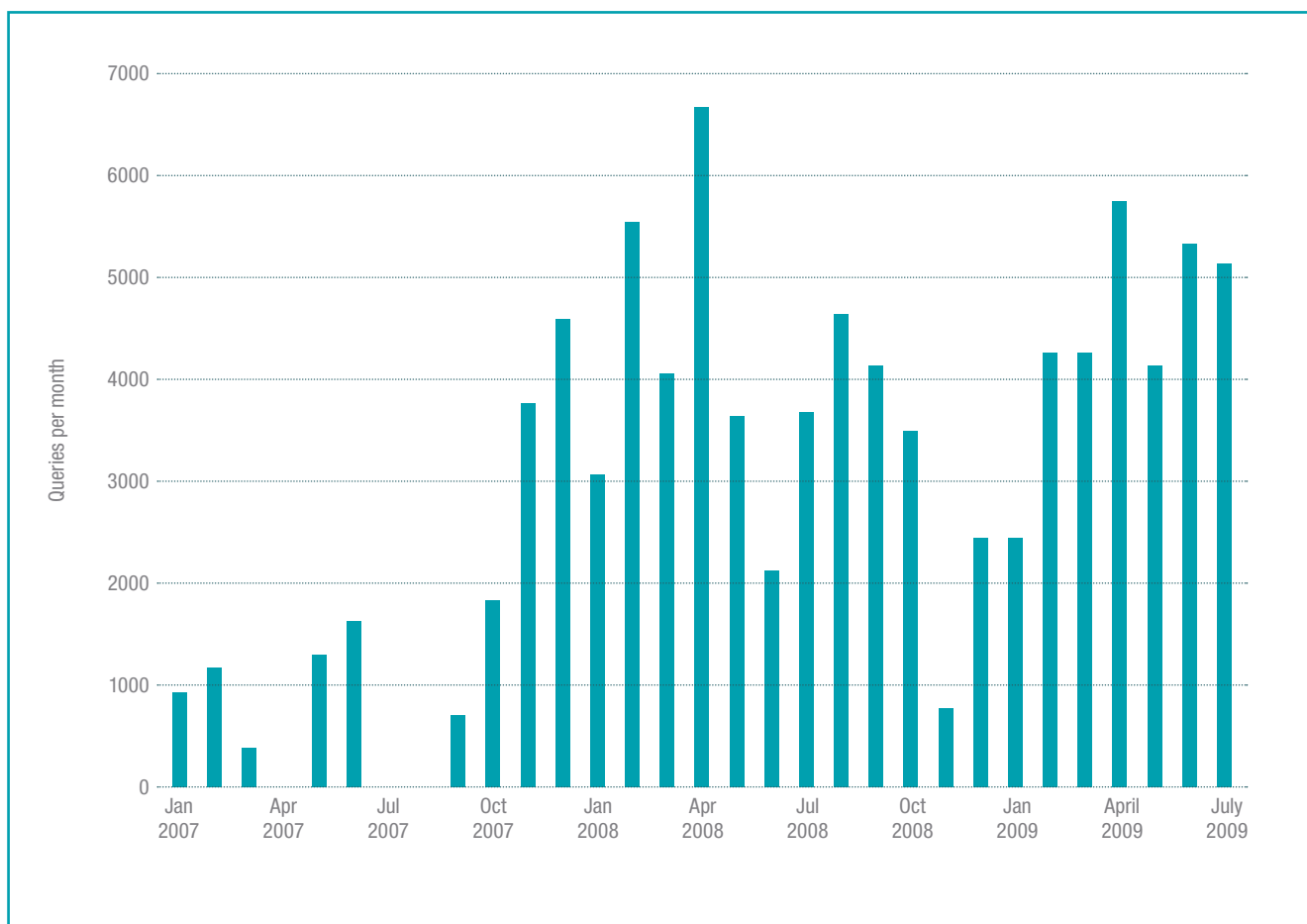


Figure 5: Queries processed by BioGrid Jan 2007 – July 2009

Note: Nov 2008 technical loss of query numbers. Dec 08 – Jan 09 upgrade of technology.

DATABASES ON THE SYSTEM

Data dictionaries are available for down loading from www.biogrid.org.au. The terms and definitions are also available from the glossary on the web site.

1. ENDOCRINOLOGY

Database Name	Group	Location	Description	Data Owner	Records (16/07/09)
Diabetes Austin	Diabetes	Austin Hospital	Diabetes data at Austin Health in Melbourne	George Jerums	1,539
Diabetes Clinical Audit RMH	Diabetes	The Royal Melbourne Hospital	Diabetes Clinical Audit data at The Royal Melbourne Hospital. Data on type and duration of diabetes, ethnicity, treatment for diabetes and other co-morbidities plus complications of diabetes, for example, the eyes, kidneys, feet	Peter Colman	4,989
Diabetes RCH	Diabetes	The Royal Children's Hospital	Diabetes data at The Royal Children's Hospital in Melbourne	Fergus Cameron	3,723
Diabetes Research RMH	Diabetes	The Royal Melbourne Hospital	The Preventative studies data has been collected from a number of studies	Peter Colman	46,818
Diabetes SVHM	Diabetes	St Vincent's Hospital (Melbourne)	Diabetes data at St Vincent's Hospital Melbourne	Glenn Ward	201

2. IMAGES

Database Name	Group	Location	Description	Data Owner	Records (16/07/09)
PETIMG PMCI	PET Images	Peter MacCallum Cancer Centre	PET scans, Radiology, at Peter MacCallum Cancer Centre Melbourne	David Binns	19,958
MRI Images RMH	MRI Images	The Royal Melbourne Hospital	MRI Images database at The Royal Melbourne Hospital	Patricia Desmond	29,715

3. NEUROSCIENCES

Database Name	Group	Location	Description	Data Owner	Records (16/07/09)
Epilepsy RMH	Epilepsy	The Royal Melbourne Hospital	Integration of Epilepsy clinical and research databases: 1. First Seizure Clinic 2. Pharmacogenetic study 3. Video EEG Monitoring 4. Comprehensive Epilepsy 5. Post Surgery List 6. PET measurements of the brain	Terry O'Brien	3,322
MSiMed RMH	Multiple Sclerosis	The Royal Melbourne Hospital	Ongoing research study of subjects admitted to the Multiple Sclerosis unit at The Royal Melbourne Hospital and other hospitals in Australia.	Helmut Butzkueven	374
NUCOG RMH	Neuro-psychiatry	The Royal Melbourne Hospital	Ongoing research study of cognitive function of patients in the Neuropsychiatry Unit, The Royal Melbourne Hospital, and other patients who undergo cognitive assessment in Melbourne Health	Dennis Velakoulis	110
Stroke Alfred	Stroke	Alfred Hospital	Ongoing study of subjects admitted to the Stroke Unit at the Alfred Hospital in Melbourne	Judith Frayne	1,289
Stroke RMH	Stroke	The Royal Melbourne Hospital	Ongoing study of subjects admitted to the Stroke Unit at The Royal Melbourne Hospital	Peter Hand	4,865

4. ONCOLOGY

Database Name	Group	Location	Description	Data Owner	Records (16/07/09)
ACCORD V1 Brain Austin	CNS Cancer	Austin Hospital	Clinical data on CNS cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Paul Mitchell	168
ACCORD V1 Breast Austin	Breast Cancer	Austin Hospital	Clinical data on breast cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Paul Mitchell	33
ACCORD V1 Breast RMH	Breast Cancer	The Royal Melbourne Hospital	Clinical data on breast cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	623

ACCORD V1 Breast WH	Breast Cancer	Western Hospital	Clinical data on breast cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	623
ACCORD V1 Haematology Austin	Haematology	Austin Hospital	Clinical data on haematology patients including sex, date of birth, date of diagnosis, pathology and staging	Paul Mitchell	1,959
ACCORD V1 Haematology RMH	Haematology	The Royal Melbourne Hospital	Clinical data on haematology patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	3,387
ACCORD V1 Haematology WH	Haematology	Western Hospital	Clinical data on haematology patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	3,387
ACCORD V1 Lung Austin	Lung Cancer	Austin Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Paul Mitchell	443
ACCORD V1 Lung RMH	Lung Cancer	The Royal Melbourne Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	1,090
ACCORD V1 Lung WH	Lung Cancer	Western Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	1,090
ACCORD V1 Melanoma Austin	Melanoma	Austin Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Paul Mitchell	369
ACCORD V1 Melanoma RMH	Melanoma	The Royal Melbourne Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	223
ACCORD V1 Melanoma WH	Melanoma	Western Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	223

ACCORD V1 Other Tumours Austin	Other Tumours	Austin Hospital	Clinical data on cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Paul Mitchell	1,052
ACCORD V1 Other Tumours RMH	Other Tumours	The Royal Melbourne Hospital	Clinical data on cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	1,627
ACCORD V1 Other Tumours WH	Other Tumours	Western Hospital	Clinical data on cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	1,627
ACCORD V1 Prostate Austin	Prostate Cancer	Austin Hospital	Clinical data on prostate cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Paul Mitchell	205
ACCORD V1 Prostate RMH	Prostate Cancer	The Royal Melbourne Hospital	Clinical data on prostate cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	518
ACCORD V1 Prostate WH	Prostate Cancer	Western Hospital	Clinical data on prostate cancer patients including sex, date of birth, date of diagnosis, pathology and staging	Peter Gibbs	518
ACCORD V2 Brain RMH	CNS Cancer	The Royal Melbourne Hospital	Clinical data on central nervous system cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Kate Drummond	1,243
ACCORD V2 Colorectal Austin	Colorectal Cancer	Austin Hospital	Clinical data on colorectal cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Andrew Bui	425
ACCORD V2 Colorectal BH	Colorectal Cancer	Box Hill Hospital	Clinical data on colorectal cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Frank Chen	415
ACCORD V2 Colorectal LGH	Colorectal Cancer	Launceston General Hospital	Clinical data on colorectal cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Hung Nguyen	190

ACCORD V2 Colorectal PMCI	Colorectal Cancer	Peter MacCallum Cancer Centre	Clinical data on colorectal cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Alexander Heriot	72
ACCORD V2 Colorectal RMH	Colorectal Cancer	The Royal Melbourne Hospital	Clinical data on colorectal cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Peter Gibbs	1,078
ACCORD V2 Colorectal WH	Colorectal Cancer	Western Hospital	Clinical data on colorectal cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Peter Gibbs	1,914
ACCORD V2 Head and Neck RMH	Head & Neck	The Royal Melbourne Hospital	Clinical data on head and neck cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	David Wiesenfeld	193
BRAF LICR	Breast Cancer	Ludwig Institute	Results of a study by the Ludwig Institute for Cancer Research on the BRAF tumour marker in Colorectal Cancer samples	Jayesh Desai	583
Biomarkers RMH	Breast Cancer	The Royal Melbourne Hospital	Results of Biomarker testing on tissue and blood. Includes demographics, sample testing institution, staging and date of sample collection and testing. Tests include CEA, MSI, EGFR etc.	Peter Gibbs	1,161
Breast Cancer BH	Breast Cancer	Box Hill Hospital	Clinical data on breast cancer patients including sex, date of birth, date of diagnosis, surgery, pathology, staging, therapy, follow up, etc.	Jacque Chirgwin	2,618
Breast Cancer SVHM	Breast Cancer	St Vincent's Hospital (Melbourne)	Clinical data on breast cancer patients including sex, date of birth, date of diagnosis, surgery, pathology, staging, therapy, follow up, etc.	Michael Henderson	5,311
CRCLIFE RMH	Colorectal Cancer	The Royal Melbourne Hospital	Survey results of colorectal cancer patients on their lifestyle. Includes smoking, alcohol, exercise and family history	Peter Gibbs	83
CRCLIFE WH	Colorectal Cancer	Western Hospital	Survey results of colorectal cancer patients on their lifestyle. Includes smoking, alcohol, exercise and family history	Peter Gibbs	121

ACCORD V2 Sarcoma PMCI	Sarcoma	Peter MacCallum Cancer Centre	Clinical data on sarcoma patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, follow up, etc.	Jayesh Desai	39
Fambiz (Familial) RMH	Familial Cancer	The Royal Melbourne Hospital	Tracks subjects with a family history of cancer – has documentation of symptoms, genetic test results, and pedigree information	Geoff Lindeman	8,404
Lung Cancer FH	Lung Cancer	Frankston Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, surgery, pathology, staging, therapy, follow up, etc.	Van Le Blanc	39
Lung Cancer SVHM	Lung Cancer	Alfred Hospital	Clinical data on lung cancer patients including sex, date of birth, date of diagnosis, surgery, pathology, staging, therapy, follow up, etc.	Matthew Conron	
Oncology SVHM	General Oncology	St Vincent's Hospital (Melbourne)	Clinical research data on cancer patients including sex, date of birth, date of diagnosis, pathology, staging, therapy, etc.	Raymond Snyder	20,839
Oncology Seizure RMH	CNS Cancer	The Royal Melbourne Hospital	Seizure history data on CNS cancer patients	Tanya Yuen	48
Pituitary Cancer RAH	Pituitary Cancer	Royal Adelaide Hospital	Ongoing database for the study of pituitary cancer and acromegaly patients, including incidence, symptoms and treatment	David Torpy	505
Pituitary Cancer RMH	Pituitary Cancer	The Royal Melbourne Hospital	Ongoing database for the study of pituitary cancer and acromegaly patients, including incidence, symptoms and treatment	Niki Maartens	645
Surveillance RMH	Familial Cancer	The Royal Melbourne Hospital	Data of the surveillance of colorectal cancer patients with a familial colorectal cancer. Includes colonoscopy results, pathology, genetic testing	Finlay Macrae	3,750
Tissue Bank Austin	Tissue Banking	Austin Hospital	Details on tissue and blood collected for the BioBank, includes data on diagnosis, tissue treatment, pathology etc.	Carmel Murone	3,032

Tissue Bank PMCI	Tissue Banking	Peter MacCallum Cancer Centre	Details on tissue and blood collected for the BioBank, includes data on diagnosis, tissue treatment, pathology etc.	Lisa Devereaux	10,131
Tissue Bank RMH	Tissue Banking	The Royal Melbourne Hospital	Details on tissue and blood collected for the BioBank, includes data on diagnosis, tissue treatment, pathology etc.	Geoff Lindeman	2,549
Tissue Bank WH	Tissue Banking	Western Hospital	Details on tissue and blood collected for the BioBank, includes data on diagnosis, tissue treatment, pathology etc.	Geoff Lindeman	2,549

5. RESPIRATORY

Database Name	Group	Location	Description	Data Owner	Records (16/07/09)
ATD Monash	Cystic Fibrosis	Monash Medical Centre	Admission Transit Discharge, Cystic Fibrosis Patients at Monash Medical Centre, Melbourne, Australia	David Armstrong	343
Cystic 3000 RCH	Cystic Fibrosis	The Royal Children's Hospital	Cystic Fibrosis patient data from 1947–1996 at The Royal Children's Hospital Melbourne	Phil Robinson	1,599
Cystic 9699 RCH	Cystic Fibrosis	The Royal Children's Hospital	Cystic Fibrosis patient data from 1996–1999 at The Royal Children's Hospital Melbourne	Phil Robinson	1,599
Cystic 9903 RCH	Cystic Fibrosis	The Royal Children's Hospital	Cystic Fibrosis patient data from 1999–2003 at The Royal Children's Hospital Melbourne	Phil Robinson	421
Cystic Fibrosis Alfred	Cystic Fibrosis	Alfred Hospital	Cystic Fibrosis data at the Alfred Hospital, Melbourne. The Data Collected is based on the CF Australia database data elements plus lung function and pathology data	John Wilson	333
Cystic Fibrosis Monash	Cystic Fibrosis	Monash Medical Centre	Lung function results including some Cystic Fibrosis patients, Monash Medical Centre, Melbourne	David Armstrong	131

Cystic Fibrosis RCH	Cystic Fibrosis	The Royal Children's Hospital	Cystic Fibrosis data at The Royal Children's Hospital, Melbourne. The data collected is based on the CF Australia database data elements plus lung function and pathology data	Phil Robinson	4,777
CysticAUST RCH	Cystic Fibrosis	The Royal Children's Hospital	Cystic Fibrosis Patient data, ACFA format, at The Royal Children's Hospital, Melbourne, Australia	Phil Robinson	329
ATD Alfred	Cystic Fibrosis	Alfred Hospital	Admission Transit Discharge, Cystic Fibrosis Patients at Alfred Hospital, Melbourne, Australia	John Wilson	375
Genetic Markers Alfred	Cystic Fibrosis	Alfred Hospital	Genetic Markers database of Cystic Fibrosis patients at Alfred Hospital Melbourne	John Wilson	530

6. OTHER

Database Name	Group	Location	Description	Data Owner	Records (16/07/09)
Bone Density RMH	Bone Density	The Royal Melbourne Hospital	Bone Density data at The Royal Melbourne Hospital, Australia	Terry O'Brien	171
Women's Health Longitudinal Study	Other	Melbourne University	This Database is a Longitudinal Study of Women's Health, capturing information on a cohort of women spanning over 13 years. Information on pathology, bone density, imaging, hormonal, cognitive measures, psychological, genetic, lifestyle, illness, socio-demographic, symptoms, violence and more are available	Cassandra Szoek	438

FINANCE – AUDITOR'S REPORT



WHK Day Neilson

INDEPENDENT AUDIT OPINION

TO: The Minister for Innovation
c/~ Department of Innovation, Industry and Regional
Development 35th Floor, 121 Exhibition Street Melbourne
3000.

AUSTRALIAN CANCER GRID

This Audit Opinion is prepared for the purposes of the Grant Agreement entered into by State of Victoria and The University of Melbourne ("the Agreement") dated 16 October 2006.

Scope

We have conducted an independent audit in accordance with Australian Auditing Standards of the attached Financial Statement of Income and Expenditure for the period ended 30 June 2008 provided to us which specifies an amount of \$2,428,601 of expenditure on the Program and an amount of \$5,500,000 as Matching Contributions towards the Program in order to express an opinion on it for the purposes of the Agreement.

Our audit involved an examination, on a test basis, of evidence supporting the amount of expenditure incurred, including all Grant funds and the amount of contributions (both cash and in kind) received. This included an examination of the financial records and receipts, and an evaluation of the policies and procedures used to calculate the expenditure of the Program and the Matching Contributions. These procedures have been undertaken to form an opinion as to whether the methodology used to calculate the expenditure and these contributions is in accordance with the Agreement, and that the figures stated are true and fair.

This Audit Opinion expressed in this report has been formed on the above basis.

Audit Opinion

We confirm that in our opinion:

- expenditure of \$ 2,428,601 has been incurred on the Program;
- the Matching Contributions to the Program are \$5,500,000 in accordance with the terms of the Agreement.

WHK Day Neilson

Martin Thompson
Principal

Date 9 October 2008

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