Bio21 Molecular Medicine Informatics Model and The Australian Cancer Grid

Annual Report 2006-2007

Annual Report

Contents

MMIM Highlights for 2006–2007

- **New sites implemented:** Funded by the Australian Government Department of Education Science and Training (DEST).
- **Continued successful implementation** of the DEST-funded MMIM project, Phase Two with new sites under development at Eastern Health (Box Hill Hospital), Southern Health (Monash Medical Centre) and St Vincent's Health Melbourne in 2006 – 2007.
- **New members:** The MMIM Collaboration now has eight members with Southern Health, St Vincent's Health Melbourne and Eastern Health joining.
- **Further members** in the process of joining the MMIM Collaboration in 2007 – 2008 include: the Royal Women's Hospital (Melbourne); the The Royal Children's Hospital (Melbourne); Royal Hobart Hospital; Canberra Hospital; Royal Adelaide and Queen Elizabeth Hospitals and Flinders Medical Centre (South Australia).
- **Funding:** Approval by the Government of Victoria of funding for Australian Cancer Grid (ACG) project for three years, agreement signed with University of Melbourne December 2006 for Melbourne Health (MH) to be MMIM ACG Project Manager until the end of 2009.
- **Awards:** MMIM honoured at the 2006 Melbourne Health Annual General Meeting when awarded the "Best of Health– Celebrating Excellence" Award in the Category – Research.
- **Committees:** MMIM ACG Scientific Advisory Committee (SAC) for Cancer formed with the establishment of eight tumour stream working groups reporting to the MMIM ACG SAC.
- **Research:** Cancer research project agreements funded under the MMIM ACG Project to the end of 2009 with CSIRO contributing $1.3 million. Research to be undertaken by Royal Melbourne Hospital, CSIRO, the Ludwig Institute for Cancer Research and Flinders Medical Centre, South Australia.

Chairman's Report

As chairman of the Bio21: MMIM Management Committee I am pleased to present the first "glossy" Bio21: MMIM annual report for the financial year 2006 – 2007.

It is gratifying, as someone who has been associated with the project since 2003, to observe how the Bio21:MMIM has grown from what was generally agreed to be a "logical idea" through the pilot project funded by the Victorian State Government's STI program and from there to the fully functional virtual research repository it is today.

The pace of growth has continued unabated in the past year, with the Bio21: MMIM building on successful completion of the pilot project, securing two significant development funding streams, firstly from the Australian Commonwealth Government Department of Education Science and Training in 2005–2006 and in the last year, from the Victorian Government through Department of Innovation, Industry and Regional Development to develop the Australian Cancer Grid.

This funding has enabled us to increase our infrastructure capacity to support the integration of new disease types, expansion to new research databases and to enable research using new data types such as digital MRI and PET images.

During the last year three new healthcare services have formally joined the Bio21: MMIM Collaboration. At least a further nine facilities, from South Australia to the ACT, NSW, Victoria and Tasmania, are poised to do so in the coming year.

At the same time, Bio21: MMIM has continued to invest in research – as evidenced by our growing publications list and recognised at the 2006 Melbourne Health Annual General Meeting, where Bio21: MMIM won the "best of health" award for achieving excellence in research.

While this continued growth and development is welcomed by the Management Committee, it has nonetheless highlighted that the current unincorporated joint venture governance arrangements are not going to be adequate to support the forecast development of project. The Management Committee has appointed external consultants to work with both Bio21: MMIM members and our collaborators to agree on changes to the current governance arrangements. A number of workshops and information forums have been held, including a working group of member corporate counsels. It is expected the new governance model will be adopted and implemented in next financial year.

Concurrent with the process of developing a new governance model Bio21: MMIM has also been exploring the optimal model for financial sustainability in the post government grant funding period, for 2010 and beyond. A small group of students from the University of Melbourne are working with team members, evaluating the appropriate balance of revenues from grants, service provision, commercial engagements and membership subscriptions. There are significant opportunities before us to achieve a financially sustainable future.

I will take this opportunity to thank a number of the people who have contributed to the Bio21: MMIM's successes.

Firstly, on behalf of the Management Committee I would like to thank both the Australian and Victorian governments, through DEST and DIIRD, respectively for their vision and generous funding support of the Bio21: MMIM.

Thanks also to our dynamic Project Director, Dr Marienne Hibbert. The best decision I have made on this project has been to appoint Marienne to lead the way. Thanks also to the Bio21: MMIM team members and all of our clinician researchers for your hard work and dedication during the year.

To my fellow Management Committee members, my thanks for your untiring work and support of the project, not only at Committee meetings, but throughout the year. In particular I would like to thank A/Prof Peter Gibbs our Chair of the Scientific Advisory Committee and Professor Graham Brown of the University of Melbourne for their support and advice during the year.

I would like to thank Linda Sorrell, the Chief Executive of Melbourne Health, who since 2003 has acted as Secretariat and provided the bulk of the infrastructure support for the project. Other key supporters at Melbourne Health have been Mrs Sally Campbell (Executive Director Business Development and Corporate Secretary), Mr Chris Gibbs (Executive Director Health Informatics) and Professor Ingrid Winship (Director of Research).

The challenge for the next year is raise the bar and deliver increasingly significant translational research outcomes and achievements that demonstrate the breadth and depth of the value of this exciting initiative.

Rob Merriel Chairman,
Bio21: MMIM Management Committee
September 2007

MMIM Project Director's Report

Introduction

The MMIM project in 2006 – 2007 has continued to grow and build on the achievements of the STI-funded pilot that was successfully completed in 2005, and which demonstrated the viability of establishing a research platform of federated and integrated data across multiple Victorian institutions and disease types.

So much so that in 2005, MMIM was awarded an Australian Government DEST grant for further development of what has become known as MMIM Phase 2. This phase will continue until the end of 2007 and will facilitate the integration in to MMIM of a further 10 hospitals/research facilities across several states as well as additional disease types: multiple sclerosis; stroke; cystic fibrosis; prostate cancer and brain cancer.

In April 2006, the Hon. John Brumby announced that the Victorian Government through DIIRD would invest a further $11.0 million in MMIM expansion until the end of 2009 to integrate 6 more Victorian healthcare sites and build the Australian Cancer Grid (ACG).

The completion of the DEST-funded phase of MMIM will be achieved parallel with the implementation of the ACG program in the period up to 2009.

Appreciation

These are busy and exciting times for MMIM and our achievements in 2006 – 2007 would not be possible without the hard work and support of many people and organisations.

First the MMIM team, the dedicated scientists, data managers and administrators who have accomplished so much.

On behalf of all at MMIM I would like to express my appreciation for the financial funding support and encouragement given to MMIM by DEST and DIIRD, without which none of this would be possible, particularly Margot Bell, Nancy Stefanovski and Michael Krien.

Thank you for all of the support and direction given to the work of MMIM by the Management Committee and in particular the Chairman Mr Rob Merriel and the MMIM driving clinicians A/Prof Peter Gibbs, A/Prof Terry O'Brien and A/Prof Peter Colman.

To the University of Melbourne and in particular Prof Graham Brown many thanks for your support, mentoring and encouragement. My thanks also to Stella Clarke of Bio:21 and especially the Bio21 Science Advisory Committee and to Prof Tony Burgess for all of your support since MMIM began.

Other groups supportive of MMIM and to which we offer sincere thanks include:

- Monash University
- Ludwig Institute for Cancer Research
- Walter and Eliza Hall Institute
- Victorian Partnership for Advanced Computing
- Cancer Council Victoria.

Finally, to all of our supportive clinicians and researchers who are fantastic and make this project happen with their unpaid work at all of the MMIM member sites and to everyone at MH where the project office is located, my thanks for all of your hard work and support over 2006 – 2007.

Dr. Marienne Hibbert
Project Director, *Bio21: MMIM Management Committee*
September 2007

History, Objectives and Operation of MMIM

Why Develop MMIM?

Advances in genomics, clinical and bioinformatics and information technology are transforming medical research. Future improvements in health care and understanding of disease processes will come, in part, from the ability of clinicians and clinical scientists to analyse complex patterns and trends that emerge from the integration of a variety of data related to a particular disease, in selected subsets of patients, often held in different databases by different organizations.

The impetus for the development of MMIM came from a recognition of the need to maximize collaborative research across Australia and internationally. The INFOMED (Europe), CaBig (USA), and Cancer Grid (UK) projects are all current initiatives that recognize the need for a platform that provides integrated data, data standards and tools. A cohesive approach between disciplines was identified so that research data collection becomes a one-time only exercise, with the data stored in such a way that it remains readily accessible, and in a format that facilitates rapid interrogation, permitting diverse research questions across various clinical disciplines and jurisdictions to be addressed.

What is Bio21: MMIM (Molecular Medicine Informatics Model)?

Bio21: MMIM is a platform and infrastructure that gives clinical researchers access to data in multiple disease types, data from disparate existing databases at multiple institutions. It does this while protecting both privacy and intellectual property.

Bio21: MMIM federates the databases stored at each site, creating a virtual repository, which can be linked with other databases such as publicly available research and genetic profiling data.

Bio21: MMIM provides a flexible and secure method for interrogating the multiple data sources, where thousands of records of patient data is record-linked across the databases and institutions. Only authorized researchers can extract subsets of data, transform where required and test hypotheses using their own analytical tools.

Key Objectives of the MMIM Project

The key objectives of the MMIM project include the following:

- To provide a platform for collaborative research that protects data privacy and intellectual property
- To provide a federation of research across multiple Australian health and research institutions and disease types that will in de-identified form be readily accessible to researchers via the internet.

MMIM will facilitate research by enabling authorized researchers to:

- conduct research with confidence that ethics, privacy, security and intellectual property issues are addressed
- collaborate with other researchers to increase the power of their research
- test multiple hypotheses without collecting their own data
- identify patient numbers suitable for clinical trials, based on clinical information or genetic profile
- research genetic factors that may influence treatment outcome (e.g. with respect to toxicity and potential benefit)
- analyse summary and statistical information across institutions and from diverse databases
- cache data retrieved from public data sources to work on locally
- join the platform and add new data sources – potentially nationally as well as linking internationally.

In addition the work program includes:

- Development of a governance structure for MMIM that will be optimal in supporting the longer-term viability of MMIM
- Development of a sustainability strategy for MMIM that will position it as a fully sustainable, nationally based research and related data linkage platform.

History of the MMIM Project

MMIM originated as a pilot in December 2003 funded by the Science, Technology and Innovation Infrastructure Grant (STI) program of the Victorian Government Department of Innovation, Industry and Regional Development (DIIRD) via the lead agency Bio21 Australia Limited with Melbourne Health (MH) appointed as the project manager.

MMIM Phase 1 integrated data across five healthcare sites (The Alfred Hospital, Austin Health, The Royal Melbourne Hospital, the Peter MacCallum Cancer Centre, and Western Hospital), with two medical research institutes (the Ludwig Institute for Cancer Research and the Walter and Eliza Hall Institute [WEHI]) also involved. The pilot successfully demonstrated the linkage of clinical research data, tissue bank and genetic information on colorectal cancer, epilepsy and diabetes from the pilot institutions.

Phase 2 of the MMIM Project was funded in August 2005 by the Australian Government Department of Education, Science and Training (DEST) with a $4.37 million grant, with the University of Melbourne as the lead agency and MH the project manager. This phase integrated data across a number of new sites in Victoria and inter-state, and added additional disease types including multiple sclerosis, stroke, cystic fibrosis, asthma, prostate cancer and brain cancer.

Future of the MMIM Project

The big news event of the year was the funding from the Victorian Government of Phase 3 of MMIM until the end of 2009 with a grant of $11.0 million through DIIRD. The Hon. John Brumby, then Minister for Innovation Industry and Regional Development, viewed the MMIM ACG project when he visited Melbourne Health in September 2006. This phase of the project is being implemented concurrently with the completion of Phase 2, with the University of Melbourne as the lead agency and Melbourne Health as the project manager.

This phase will provide support for the creation of an Australian Cancer Grid (ACG) and covers the following major components:

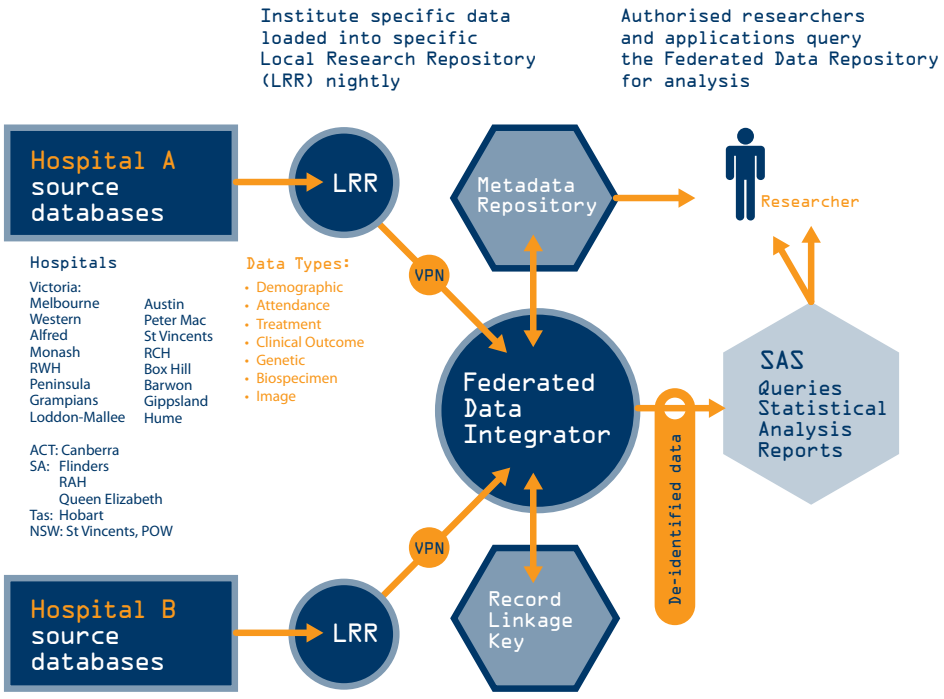
- Expand the data grid to integrate further Victorian healthcare sites, including Peninsula Health and five rural Regional Integrated Cancer Services (RICSs): Gippsland, Grampians, Hume, Loddon Mallee and Barwon South.
- Expand the research to include more tumour types across the MMIM network, in the first instance to include brain, breast, lung, sarcoma and colorectal cancer, (others are being reviewed).
- Liaise closely with other parties with an interest in the ACG, including the various Metropolitan and Regional Integrated Cancer Services, Cancer Council Victoria and the Victorian Cancer Outcomes Network (VCON) to promote efficiencies in cancer data collection, integration, reporting and research.
- Provision of a web services technology, to "future-proof" MMIM against changes in technology, and to ensure that the system is scalable to any number of sites.
- Provide research tools, and ensure that research activity occurs that will lead to early high quality outcomes.

Operations – How Does MMIM Work?

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

The diagram below illustrates how the MMIM system works:

- Researchers must obtain authorization to access the data from both the data custodians and the MMIM Management Committee.
- Source databases from various institutions are extracted, transformed and loaded (ETL) nightly to their respective Local Research Repositories (LRRs) based at the institutions.
- The data is record linked at the individual level using probabilistic matching and a record linkage key is assigned and stored in encrypted format at the institution.
- Authorized researchers are then able to query and analyse the data via the Federated Data Integrator (FDI) using SAS enterprise guide (Querying and statistical/business analysis software).
- The FDI is an integrator for accessing data across physical boundaries;
- The data is sent to the user via a Virtual Private Network (VPN) in de-identified form with a record linkage key .The FDI does not store health data.
- The MMIM project is a federated model 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 FDI via a VPN, which ensures data security for transmission. Views block all identifying information, allowing end users to see only the authorized research data in conjunction with the record linkage key. Access to these views on the FDI is controlled by the database administrators by assigning database roles and defining privileges to the table/view level. All queries to the FDI are tracked and monitored for audit purposes by DB2 Query Patroller. Access to data is de-identified and at table level only.

Protecting Privacy

The Bio21: MMIM platform has been achieved with rigorous attention to ethics and privacy requirements. All participating sites must obtain ethics approval to join. MMIM 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.

MMIM Governance and Management Committee

Governance Background

In November 2005, the five pilot participants concluded a joint venture Collaboration Agreement legally establishing the Molecular Medicine Informatics Collaboration. The organizations involved were:

- Melbourne Health
- Western Health
- Austin Health
- Peter MacCallum Cancer Centre
- Bayside Health.

This document provides governance rules for the collaborating parties in the administration of the Bio21: MMIM infrastructure and ongoing research. It covers the management committee, financial matters, intellectual property, project management, commercialization activities, publications, warranties, indemnity and dispute resolution. The documentation was prepared using external legal counsel.

Three further health services joined the MMIM Collaboration Agreement by signing and executing the Deed of Accession to the Agreement in the past year. These are:

- Southern Health (Monash Medical Centre)
- St Vincent's Health (Melbourne)
- Eastern Health Melbourne (Box Hill Hospital).

A further eight sites are in the final stages of joining MMIM. Upon signing of their Deeds of Accession, the MMIM membership will comprise 16 health care organisations in three states and one territory.

Governance Review

MMIM is currently an unincorporated joint venture overseen by a Management Committee that meets monthly at Melbourne Health. With the continued expansion of MMIM, it has become apparent that the current unincorporated governance model is inadequate to support the future growth of the project.

As part of the MMIM Australian Cancer Grid (ACG) phase of the project, the governance arrangements in place for the Phase 1 and Phase 2 of the project are therefore being reviewed in order to determine the optimal governance model for MMIM in the future.

A number of workshops have been held with MMIM members and other interested parties to help inform future options and directions for a governance model. Dr Michael Vitale from Occum Consulting and Ms Alison Hutchison from Aspex Consulting have provided valuable assistance in this work. A working group of the MMIM member legal counsels have endorsed the direction and recommendations of the consultants.

The MMIM Management Committee is kept fully informed of the progress and endorsed the recommendations of the governance review.

Planning for the Future – Sustainability

Planning MMIM financial sustainability for the post 2009 period is also underway. In 2010, the current funding ceases and a study has commenced to identify a range of revenue streams and funding models that will support future sustainability of MMIM.

MMIM Governance and Management Committee

Management of Phase 3 – the ACG Project

To manage the ACG 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.

An ACG project steering committee body (known as the Interim Board) was formed under the terms of this agreement to oversee the project during this period. The membership comprises two representatives each from MH and the University of Melbourne. This body meets bimonthly to receive progress reports from the MMIM project office and address any issues.

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

The ACG Board

The ACG Project is governed by the ACG/MMIM Project Board consisting of two representatives each from the University of Melbourne and Melbourne Health. The University of Melbourne is responsible for the funding agreement with DIIRD and has contracted Melbourne Health as the Project Manager. The ACG Board's role is to monitor the progress of the Project including: monitoring the financial position; meeting the DIIRD milestones; providing guidance relative to risk management, project issues or concerns and the MMIM Project Director attends meetings as a nonvoting member to provide project reports and advice as required. The board meets quarterly and the minutes of the meeting are provided to the MMIM Management Committee.

Board Membership 2007:

Melbourne Health:	**Mr Robert Merriel (chair)**
	Mr Chris Gibbs
Melbourne University:	**Prof Jim McClusky**
	Prof Graham Brown

MMIM Management Committee

The current committee consists of representatives of MMIM members, foundation supporters including The University of Melbourne; Walter and Eliza Hall Institute (WEHI); Ludwig Institute of Cancer Research (LICR); Monash University, and invitees with special expertise and knowledge to contribute.

MMIM Management Committee members at 30 June 2007

Mr Rob Merriel	Chair – Melbourne Health
A/Prof Peter Gibbs	LICR/Western Health
Ms Katerina Andronis	Peter Mac Cancer Centre
Dr Paul Mitchell	Austin Health
Prof John Wilson	Bayside Health
Ms Malar Thiagarajan	Southern Health
Prof Raymond Snyder	St Vincent's Health Melbourne
Dr Joe McKendrick	Eastern Health
Prof Graham Brown	University of Melbourne
Prof Don Campbell	Monash University
Prof Peter Colman	Walter and Eliza Hall Institute
A/Prof Terry O'Brien	University of Melbourne

MMIM Management Committee meeting.

Back row: Terry O'Brien, Richard Tate (MMIM Team), Michael Georgeff (Invitee), Rob Merriel, Don Campbell, Peter Gibbs
Front row: Frank Devuono (Invitee), Malar Thiagarajan, Katerina Andronis, Marienne Hibbert (MMIM team), Ray Snyder, Bill Yeadon (Invitee)
Absent: Joe McKendrick, John Wilson, Graham Brown.

Achievements in 2006-07

1. Infrastructure Expansion

Significant legal, ethical and technical effort is required before a new site can formally join MMIM, including identification of clinical champions and key players in executive and IT areas, and visiting the sites to present information about MMIM to executive and clinical staff. In addition, ongoing technical and governance tasks have also been completed in the past year.

Work undertaken to date during 2006 – 2007 on infrastructure expansion has included the following

- The following sites and diseases were added to MMIM in the past year:
  - Box Hill Hospital (Eastern Health) – colorectal cancer
  - Monash Medical Centre (Southern Health) – cystic fibrosis, tissue bank when available, colorectal cancer under discussion
  - St Vincent's Health Melbourne – colorectal cancer, breast cancer and lung cancer
  - Alfred Hospital (Bayside Health) – cystic fibrosis (although a member of MMIM in the pilot, Bayside did not have infrastructure on site).
- The following new sites are at various stages of the process, and are expected to formally join MMIM in the next six months:
  - The Royal Children's Hospital
  - Royal Women's Hospital
  - Royal Hobart Hospital
  - Royal Adelaide Hospital
  - Queen Elizabeth Hospital
  - Canberra Hospital
  - Flinders Medical Centre
  - Peninsula Health
  - Five Victorian RICS sites (Gippsland, Grampians, Hume, Loddon Mallee and Barwon South).
- Sites under discussion for connection:
  - St Vincent's Health Darlinghurst NSW.
- MMIM clinical staff appointments made during the year to support the ACG program have included:
  - A/Prof Peter Gibbs as the ACG Chief Scientist
  - Dr Suzy Kosmider as ACG Research Fellow
  - Dr Jayesh Desai as ACG Sarcoma Clinical Champion
  - Additional support staff recruited includes Oncology Data Managers and an Ontologist.
- The MMIM ACG Scientific Advisory Committee (SAC) was formed in late 2006 with A/Prof Peter Gibbs appointed as Chairman. Tumour groups reporting to the SAC have been formalized with leaders appointed to oversee work in each disease area. Work in the new tumour types to define data fields and collect data has started. (Read more under the Scientific Advisory Committee later in this report).
- The electronic chemotherapy prescribing module was developed during the year and is in test mode at Western Health with roll out to member sites planned when testing is complete.
- Technical achievements:
  - External security audit of MMIM completed
  - Hardware upgraded to provide greater redundancy
  - Business Glossary implemented to enable users to search information (Meta-data)
  - Statistical analysis and query tools upgraded to provide capacity for 50 concurrent users
  - Genetic analysis tools provided
  - Diabetes application written
  - Epilepsy applications upgraded
  - Statistical training course provided for users on using SAS and MMIM
  - Retrieval and storage of 12 years of archival MRI images and Implementation of Image storage and access system
  - Oncology application upgraded to.net (colorectal module) including chemotherapy prescribing
  - MMIM website upgraded, address is http://mmim.ssg.org.au

2. Planning a National ACG Grid Infrastructure

The MMIM Phase 3 project is developing a plan for a national ACG grid infrastructure, including the following key components:

- A transport layer using Internet protocol.
- A communications layer, which provides a uniform interface to each of the heterogeneous data sources and services.
- A metadata layer, which provides services for understanding the structure and meaning of diverse data sources and services, and for mapping terminologies and data formats from one form into another.
- The grid services which enable providers to publish and advertise their data/services; users to search, discover and query relevant data/services, and provides user authorization and secure access to data/services.
- Other work planned will include the development of optimal governance, management and access arrangements for MMIM in consultation with key stakeholders.

This work will build on the infrastructure developed to date with technical achievements in the past year outlined above. Specific achievements in the past year under this section included:

- Workshops and documentation of ACG architecture have been undertaken in 2006/2007 with a final report due to be delivered to DIIRD in October 2007.

3. Undertake Research Activities

A key element of Phase 3 will be to sponsor and fund research that will produce early and high quality returns especially from the existing colorectal cancer and MMIM resources. These include colorectal cancer familial surveillance datasets collected for up to 25 years and prospective clinical data on over 5000 patients (fresh frozen tissue is available for over 1300 of these). The ability to rapidly link clinical and research data from multiple sites, and to perform sophisticated analysis through the MMIM initiative will enable projects that would otherwise be practically impossible.

The MMIM ACG will invest $1.0 million to research three projects in the period to the end of 2009 with a $1.3 million matching contribution from CSIRO. The research will be undertaken in collaboration with key groups including CSIRO, MH, and LICR and Flinders Medical Centre (FMC) in South Australia. MMIM will provide the data linkage infrastructure for undertaking each of these projects.

MMIM has established a head agreement with CSIRO for the research projects and finalized a specific research project agreements with each of the other parties.

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

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

4. Establish New Relationships

During 2006 – 2007 MMIM has developed a number of new relationships, some of which have been formalised in agreements. These include:

- CCV and VCON

  The Cancer Council Victoria (CCV) have signed a Memorandum of Understanding (MOU) for both the Victorian Cancer Outcomes Network (VCON) and Victorian Cancer Research Tissue Bank (VCRTB) with MMIM to promote cooperation and more specifically to:

  – assist with respective project implementation as requested and appropriate

  – avoid unnecessary duplication in data capture by sharing data as appropriate

  – avoid unnecessary systems and infrastructure development.

- RACS and CSSANZ

  The Royal Australian College of Surgeons (RACS) and the Colorectal Surgical Society of Australia and New Zealand (CSSANZ) are implementing a surgical audit of CSSANZ members in South Australia. MMIM is linking the following hospitals into the MMIM Collaboration:

  – Flinders Medical Centre

  – Queen Elizabeth Hospital

  – Royal Adelaide Hospital.

  RACS, through their Adelaide office, have agreed to act for MMIM in recruiting and then implementing MMIM connectivity in these hospitals. This in turn will assist RACS and CSSANZ in accessing surgical audit data for South Australia.

  A MOU has been signed between RACS, CSSANZ and MMIM to work cooperatively in order to:

  – assist with MMIM project implementation in Adelaide

  – avoid unnecessary duplication in data capture and systems development

  – assist with CSSANZ audit project implementation.

- CSIRO

  In January 2007 MMIM signed a head agreement with CSIRO for joint funding and research collaboration with ACG of three research projects over the period until 2009 as part of the ACG research program.

  Three individual project agreements have been developed for signing by the parties involved, MH and MMIM, CSIRO, LICR and Flinders Medical Centre.

  To ensure communication and management of these projects proceeds smoothly, Dr Christine O'Keefe from CSIRO has joined the MMIM SAC.

- Monash University

  Monash University has signed an MOU with MMIM to:

  – facilitate greater involvement of its clinical, biomedical and other researchers in Bio21:MMIM projects

  – coordinate research activities involving Bio21:MMIM across Monash University so as to increase the value gained from these activities

  – provide support, strategic advice, and guidance to Bio21:MMIM management so that it can better achieve its research objectives in Victoria, nationally and internationally.

- Victorian Partnership for Advanced Computing (VPAC)

  VPAC has an agreement with MMIM to provide project management, software development, systems expertise and training resources as required. They have been involved in joint software development and architecture design.

Conferences, Presentations, Research and Publicity

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

Presentations

Presentations about MMIM and ACG were made to the following:

- Health Informatics Society of Australia AGM, Melbourne
- Victorian Health Care Association Annual Conference, Melbourne
- SAS Health IT Industry Breakfast Melbourne, a number of new ACG sites attended this meeting which was their first exposure to MMIM and the ACG project, positive feedback
- SAS User Group, Melbourne (twice)
- Australian Health and Medical 3rd Research congress
- Australian Data Managers Association Annual meeting
- Australian Cancer Registry Annual Meeting
- Presentation and paper on MMIM by the Project Director to Healthgrid 2007 in Geneva April/May 2007
- Visit and discussions with Inge Bernstein (MD, PhD) in Copenhagen regarding the European Colorectal Data Network – VEDR.: INSIGHT Information Technology Project
- Presentations and discussions with the Dr Max Wilkinson and the NCRI the National Cancer Research Institute in London, UK
- Melbourne Health Research Week–lunch time seminar sponsored by MMIM featuring three presentations by the MMIM ACG Research Fellow, two other associated clinical researchers and MMIM Steering Committee Chairman
- Medinfo Conference Brisbane paper presented and publication, August 2007
- Presentation at Canberra conference "Information Architecture in the Public Service" June 2007
- Project Director interview published in Financial Review Information Technology section June 2007
- Presentation by MMIM Chairman at BioMelbourne Network breakfast June 2007
- Presentation and chair of session at eResearch conference Brisbane June 2007.

Publicity

- During the year MMIM has published and distributed four newsletters (numbers five to eight) each containing news, updates and articles on MMIM related research and researchers of interest to our readers. All newsletters are on the MMIM website, with limited hard copies available from the MMIM office.
- MMIM is now included on the Aus Biotech web site.
- Work has also been undertaken to upgrade the website which is expected to be completed during 2007/2008.

Participation in Bioinformatics Future Planning

MMIM has been actively involved in the following planning groups:

- NCRIS 5.7 Population Health and Data Linkages Expert Advisory Group (Dr M Hibbert).
- Cancer Australia–Data Advisory Group for the Cancer Australia National Cancer Data Strategy (Dr M Hibbert).

Education and Research

MMIM Honoured at MH 2006 Annual General Meeting

At the 2006 MH Annual General Meeting MMIM was honoured to be awarded the "Best of Health – Celebrating Excellence" Award in Category – Research.

Dr Marienne Hibbert is shown along with MMIM Chair Rob Merriel and A.Prof Peter Gibbs accepting the award from the incumbent MH Chief executive Dr Peter Brennan at the MH AGM.

Rob, Peter and Marienne accepting prize from Peter Brennan

RMH Research Week 2007

MMIM was again active in supporting Royal Melbourne Hospital Research Week in mid June 2007 by sponsoring lunch for 100 attendees on 15th June 2007, followed by a seminar featuring presentations highlighting the role of MMIM in facilitating research. A number of posters from MMIM researchers were also presented.

Photo: Marienne Hibbert, Katerina Andronis and Stella Clarke at MMIM MH Research Week presentations

The program presented by MMIM included the following:

- Introduction by Rob Merriel, Chairman of MMIM Management Committee
- Epilepsy and MMIM – Using MMIM a Video Demonstration, by Dr Raju Yerra (Specialist in Epilepsy The Royal Melbourne Hospital)
- Colon Cancer and MMIM – Using ACCORD Chemotherapy Prescribing tool – Dr Suzanne Kosmider (MMIM ACG Research Fellow)
- Tissue Banking and MMIM by Dr Bruce Mann (Director of Breast Cancer Services for The Royal Melbourne and The Royal Women's Hospitals)
- New Linkages and Wrap-up by Rob Merriel

These and other presentations can be accessed on the MMIM website.

MMIM researchers have also been active in publications during 2006/2007 with further details provided later in this report. Details of all MMIM research and publications to date can be obtained from the MMIM office.

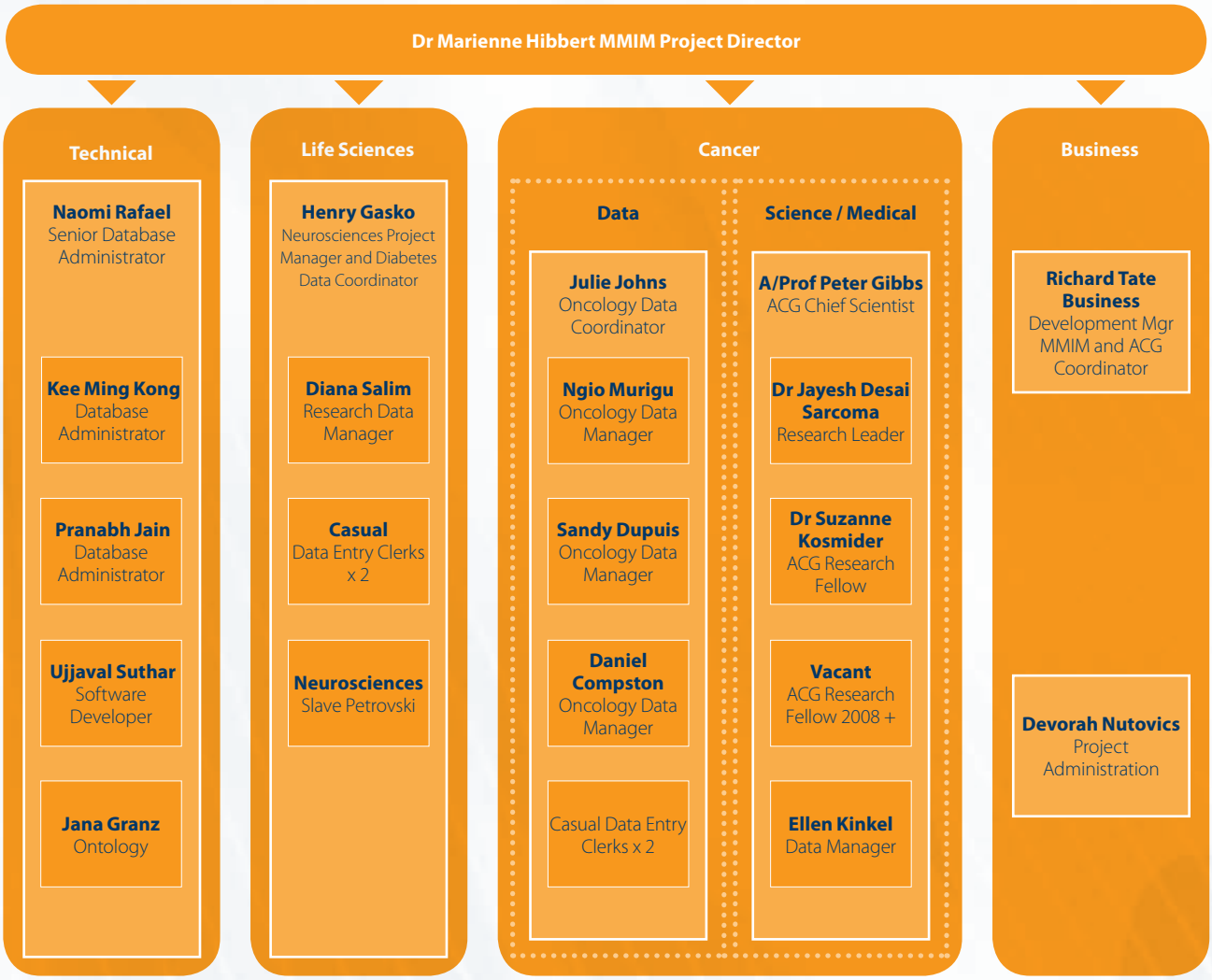
During the year a Certificate in Informatics course was developed in conjunction with the University of Melbourne.

Significant Visitors to MMIM

Significant visitors to MMIM in the past year have included Dr Carol Kovac, then General Manager Healthcare and Life Sciences IBM (USA), pictured with Marienne Hibbert and Rob Merriel. Dr Kovac who has been keenly interested in MMIM as it developed visited MH and was updated about the history, achievements and plans of the MMIM project. Dr Kovac was responsible for the strategic direction of the IBM global healthcare and life sciences business. IBM has been a significant participant in the team working on the MMIM project. Dr Kovac's visit was an opportunity for those associated with the MMIM Project to exchange views with a globally influential healthcare IT executive.

MMIM Organisational Structure

The MMIM project is directed by Dr Marienne Hibbert (PhD) with project management through a number of functional areas detailed on the organisational chart below. The coloured positions are planned but currently vacant.



The increasing number of sites and disease groups over 2006 – 2007 coupled with the commencement of the ACG project has necessitated MMIM recruiting a number of new staff to support the workload demands of MMIM over the next three years.

MMIM has welcomed the following new staff members during 2006 – 2007:

- Peter Gibbs –ACG Chief Scientist
- Suzanne Kosmider– ACG Fellow
- Jayesh Desai – ACG Sarcoma Clinical Champion
- Richard Tate – ACG Project Coordinator and Business Development Manager
- Pranabh Jain – Database Administrator
- Sandy Dupuis– Data Manager
- Slave Petrovski – Bioinformatics (part-time).

New staff members who commenced early in 2007 – 2008 include:

- Jana Granz – Ontologist
- Daniel Compston – Oncology Data Manager.

MMIM Member Profiles

Melbourne Health

Melbourne Health is a major public health provider in Victoria, Australia. It provides comprehensive acute, sub-acute and community-based health care programs to about one-third of metropolitan Melbourne's population, as well as general and specialist services to regional and rural Victorians and statewide services. Melbourne Health employs more than 7000 staff members across its services and manages more than 1000 beds in the acute, sub-acute and community sectors.

It includes:

- The Royal Melbourne Hospital – City Campus
- The Royal Melbourne Hospital – Royal Park Campus
- North Western Mental Health
- North West Dialysis Service
- Victorian Infectious Diseases Reference Laboratory.

Austin Health

Austin Health is the major provider of tertiary health services, health professional education and research in the northeast of Melbourne. Austin Health is world-renowned for its research and specialist work in cancer, liver transplantation, spinal cord injuries, neurology, endocrinology, mental health and rehabilitation.

Austin Health comprises: Austin Hospital; Heidelberg Repatriation Hospital; and the Royal Talbot Rehabilitation Centre.

Eight independent research institutions are based at Austin Health, where leading research on cancer, diabetes, respiratory disease, liver disease, heart disease, stroke, epilepsy and psychiatry is conducted.

Austin Health provides statewide services including:

- Victorian Spinal Cord Service
- Victorian Respiratory Support Services
- Victorian Liver Transplant Unit
- Child and Adolescent Mental Health Service.

Western Health

Western Health is the major provider of acute health services in the western suburbs of Melbourne, with a primary catchment in the local government areas of Maribyrnong, Hobsons Bay, Brimbank, Melton, and parts of Moonee Ponds and Hume.

A broad range of services are offered at three acute public hospitals, Western Hospital, Sunshine Hospital, and the Williamstown Hospital.

A drug and alcohol program is offered at the DASWest service and aged care at Hazledean Nursing Home.

Peter Mac

Peter MacCallum Cancer Centre (PMCC) aspires to be a comprehensive cancer centre, where critical research, world-class treatment and ongoing support are seamlessly integrated.

The main campus is situated in East Melbourne, with satellite centres at Bendigo, Box Hill, Moorabbin and the Tattersalls Cancer Centre at Epworth in partnership with Peter Mac.

PMCC has a multidisciplinary approach to cancer care through its 11 clinical service streams, where experts in diagnostic imaging, chemotherapy, radiation therapy, surgery, immunotherapy and supportive care work together to tailor treatment plans for each patient and provide the best possible outcomes at every stage of illness.

Peter Mac is one of the world's leading cancer research centres. Boasting the largest dedicated cancer research group in Australia, its scientists, clinicians, researchers and research support staff contribute more research to patient care than any other institution in Australia.

The combination of a specialist cancer hospital with a large, integrated Research Division is truly unique in this country.

Important scientific knowledge gained in the laboratory is rapidly translated into clinical care through research trials. The research program at Peter Mac is considered one of the most productive world-wide, aimed solely at cancer.

Bayside Health

Bayside Health is the main provider of health services to people living in the inner-southeast suburbs of Melbourne, and a major provider of specialist statewide services to the people of Victoria. These services are provided across the continuum of care from ambulatory, to inpatient and home and community based services.

Services are provided from three campuses: The Alfred Hospital; Caulfield General Medical Centre; and the Sandringham and District Memorial Hospital.

Bayside Health has a strong commitment to research and undergraduate and postgraduate training for medical, nursing, allied health and other support staff through its major partnerships with Monash and Latrobe Universities. It has important research and development links with the Baker Institute, the Burnet Institute and Monash University as a partner in the Alfred Medical Research & Education Precinct (AMREP).

St Vincent's Health

St Vincent's Health provides acute medical and surgical services, aged care, diagnostics, rehabilitation, allied health, mental health, palliative care and residential care.

St Vincent's Health owns and manages:

- St. Vincent's Hospital Melbourne
- Caritas Christi Hospice
- St. George's Health Service
- Prague House.

Prior to July 2002, St. Vincent's Health was known as Sisters of Charity Health Service Melbourne.

Southern Health

Southern Health provides services to an area in excess of 2,800 square kilometers in Melbourne's south-eastern suburbs with a population of over 750,000 people. The primary catchment area includes the cities of Cardinia, Casey, Greater Dandenong, Kingston and Monash. Specialist services are also provided to a rural catchment including Gippsland with a population of more than 300,000.

Southern Health provides public hospital services; aged inpatient, community and home care services; and inpatient and community mental health services to its primary and nearby catchment populations.

Services are provided through a number of hospitals and community health services:

- Casey Hospital
- Dandenong Hospital
- Kingston Centre Rehabilitation and Aged Care
- Monash Medical Centre Clayton
- Monash Medical Centre Moorabbin
- Casey Community Health Service
- Cardinia Community Health Service
- Greater Dandenong Community Health Service.

Southern Health is a centre for medical and postgraduate nurse training, postgraduate study and medical research.

Eastern Health

Eastern Health is now the second largest of Victoria's 18 public health services.

Eastern Health is the main provider of health services to people in the east, outer east and Yarra Ranges areas of metropolitan Melbourne and provides a range of acute, sub-acute, mental health and community health services from over 50 sites.

Supporting the health care needs of a geographical catchment covering approximately 2800 square kilometers, Eastern Health annually provides inpatient services to over 100,000 patients and ambulatory services to close to 600,000 patients/clients.

Eastern Health actively supports teaching, training and research in the disciplines of medicine, nursing and allied health and is affiliated with a number of universities including Monash University.

Eastern Health has five main facilities from which services are provided including:

- Angliss Hospital in Upper Ferntree Gully
- Box Hill Hospital in Box Hill
- Maroondah Hospital in Ringwood East
- Healesville and District Hospital in Healesville
- Peter James Centre in Burwood East.

In addition three new significant facilities are currently in development in the region which will become operational in 2007 – 2008:

- In Wantirna – a 60-bed facility to provide palliative care and complex care rehabilitation services.
- Yarra Ranges Health (formerly Lilydale Super Clinic) in Lilydale – delivering specialist medical services to the Yarra Ranges.
- The New Box Hill Hospital Spring Street Development – A $38.2 million development which signals for the first stage of the redevelopment of the New Box Hill Hospital. The completion of the Spring Street building importantly frees up sufficient space on the existing hospital site to enable the new Box Hill Hospital to be constructed.

Southern Health

easternhealth

Our Partners and Supporters

The work of MMIM would not be possible without the financial and in kind support of many organisations that have partnered MMIM over the past four years. Many thanks to our valued partner organisations listed below.

Scientific Advisory Committee Report

Introduction

I am pleased as Chairman to present the first annual report of the MMIM Scientific Advisory Committee for the Victorian part of the Australian Cancer Grid (SAC) in this inaugural MMIM Annual Report for 2006 – 2007.

The SAC consists of invited clinicians and researchers and was formed in June 2006 to monitor and report on the scientific rigour of MMIM research projects. The committee meets every three months with minutes of the SAC forwarded to the MMIM Management Committee.

On behalf of MMIM I would like to express my appreciation to all SAC members for the amount of time and effort they have freely given over 2006 – 2007 both within meetings and undertaken outside of the SAC.

By Associate Professor Peter Gibbs, *Chair*

SAC Members

The SAC members:

A/Prof Peter Gibbs – Chair and Colorectal Tumour Stream leader

Dr Kate Drummond – Brain Tumour Stream leader

Dr Bruce Mann – Breast Tumour Stream leader

Dr Mathew Conron – Lung Tumour Stream leader

Dr Jayesh Desai – Sarcoma Tumour Stream leader

A/Prof Grant MacArthur – Melanoma Tumour Stream leader

Dr Ian Davis – Renal Tumour Stream leader

Dr Clare Scott – Rare Tumour Stream leader

Dr Ben Solomon – Peter MacCallum Cancer Centre

Prof Bryan William – Monash Institute for Medical Research

Prof Finlay Macrae – Melbourne Health

Prof Mark Rosenthal – Melbourne Health

Dr Sherene Loi – Peter MacCallum Cancer Centre

Prof Don Campbell – Monash University

Dr Ian Jones – Melbourne Health

Dr Suzanne Kosmider – MMIM

Dr Michael Jefford – Peter MacCallum Cancer Centre

Mr Tony Costello – Melbourne Health

Prof Peter Choong – St. Vincent's Health

Dr Gregor Brown – Melbourne Health

Dr Andrew Roberts – Melbourne Health

Dr Lara Lipton – LICR

Dr Chris Hovens – University of Melbourne

Dr Marienne Hibbert – MMIM

Dr Christine O'Keefe – CSIRO

Ms Julie Johns – MMIM

Tumour Stream Reports for 2006-2007

The SAC has identified eight tumour streams each with nominated leaders who report progress to the SAC. The SAC is also the forum in which the three ACG funded research projects that will be undertaken in partnership with CSIRO, LICR and FMC are reported.

Tumour Stream: Brain

The leader of this stream is Dr Kate Drummond. Dr Drummond is a Consultant Neurosurgeon at the Royal Melbourne Hospital a senior lecturer at the University of Melbourne, and the head of Tumour Streams (Central Nervous System) at the Melbourne Comprehensive Cancer Centre.

Dr Drummond completed her MBBS at Sydney University and her neurosurgical training at Westmead Hospital, Royal North Shore Hospital, the Austin Hospital and The Royal Children's Hospital. Kate's chief interest is treatment and research in malignant brain tumours.

Team members:
Mark Rosenthal, Tanya Yuen.

Overview of tumour stream:
Early stage, RMH-centred group with a history of tissue and basic data collection, now moving into advanced stage of data collection for clinical and translational research.

Aims of the group:
To develop and refine brain tumour data collection model at RMH, extend statewide and further.

Activities/achievements:
Tanya Yuen (neurosurgery trainee) has developed a dataset for crossover complimentary project with epilepsy database.

Concept presented at the Ludwig Institute for Cancer Research Head Office in New York. Links made with a number of research institutions who can use clinical data while adding laboratory data (specifically sequencing).

Work plan for the next 12 months:
Develop Brain Tumour module in ACCORD then implement and test at RMH.

Tumour Stream: Breast

The leader of this stream is Professor Bruce Mann. Professor Mann is a Surgical Oncologist and Specialist Breast Surgeon. He is the Director of Breast Cancer Services for the Royal Melbourne and Royal Women's hospitals and a Professor of Surgery at the University of Melbourne. In addition, he is the director of advanced surgical training at the Royal Melbourne Hospital.

His surgical training was at the Royal Melbourne Hospital and Memorial Sloan Kettering Cancer Centre in New York, where he specialized in Surgical Oncology – the surgical treatment of cancer – and in particular the treatment of Breast Cancer. He is also an expert on melanoma, gastric (stomach) cancer, and sarcoma.

Team member:
Michael Henderson.

Overview of tumour stream:
This tumour stream is aligned with the Breast Tumour Streams of ICS.

Aims of the group:
To implement a consensus database for use clinically as well as for audit and research. Provision of reliable clinical information to accompany tissue bank specimens.

Short term general research questions:
What are the patterns of care in participating sites, and how do they compare with guidelines?

Long term research questions:
Activities/achievements over the last 6 months: Data cleaning, preparation of reports and data extraction at St Vincent's (by Sandy Dupuis, MMIM data manager). Success in grant application to WCMICS for a project to define a consensus minimum dataset for Breast disease across the ICS.

Work plan for the next 12 months:
- Reaching a consensus dataset across as many participating sites as possible
- Implementation and testing of the new database and training of users.

Tumour Stream: Colorectal

The leader of this stream is Associate Professor Peter Gibbs. A/Prof Peter Gibbs is a medical oncologist specialising in colorectal cancer. He divides his time between treating patients at the Western and Royal Melbourne Hospitals, and research at the Ludwig Institute of Cancer Research. He is also the Chief Project Scientist for the Australian Cancer Grid.

Team members:
Ian Jones, Sandy Herriot, Frank Chen, Rod Woods, Ian Faragher, Joe McKendrick, Ray Snyder, Andrew Hunter.

Overview of tumour stream:
Data is currently being collected and entered into Accord at RMH (n=750), MP (n=144), WH (n=1341), Box Hill (n=100), Peter Mac (n=25).

Aims of the group:
To expand to a national colorectal cancer database. Data collection has been initiated in South Australia, and is shortly to start in Canberra and several sites in Sydney.

Short-term general research questions:
See publications/abstracts. Also looking at:

- uptake of laparoscopic surgery and impact on morbidity
- outcomes in the elderly (>80 years)
- impact of initial staging
- quality of pathology reporting
- impact of obesity on cancer outcomes
- impact of exercise on cancer outcomes.

Activities/achievements over the last 6 months:

- Data collection commenced at Box Hill Hospital.
- MMIM ethics approval at three South Australian sites to collect ACCORD dataset.
- Development of online chemotherapy prescribing module.
- Publications accepted (all are in press):

1. Recognition and referral of familial colorectal cancer. *Internal Medicine Journal*. Christina Wong, Peter Gibbs, Julie Johns, Ian Jones, Ian Faragher, Eleanor Lynch, Finlay Macrae and Lara Lipton.
2. A single institution experience of adjuvant 5-fluorouracil based chemotherapy for stage iii colon cancer. *Internal Medicine Journal*. Gibbs P, Handolias D, McLaughlin S, Chapman M, Johns J, Faragher I.
3. Re: Comparing survival outcome for patients with colorectal cancer treated in public and private hospitals [letter]. *The Medical Journal of Australia*. Kosmider S, Jones I, Hayes I, Gibbs P.

- Oral presentations at MOGA
  - Colon cancer and smoking
  - Adjuvant therapy for stage II and III colon cancer
- Poster at ECCO
  - Diabetes and colon cancer
- Articles submitted
  - MMIM review – ANZJS

Work plan for the next 12 months:
Initiate data collection at:

- Freemasons/Epworth
- Canberra
- St Vincent's Sydney
- Prince of Wales

Increase data collected on co-morbidity, lifestyle and exercise.

Tumour Stream: Lung

The leader of this stream is Dr Matthew Conron. Overview of tumour stream: Lung cancer is a common, lethal cancer that will remain an important cause of cancer related mortality for many years. There are ~2,000 new cases diagnosed each year in Victoria and with close to 1,750 deaths per annum it is the most common cause of cancer related mortality. While smoking rates are now starting to fall, a decline in new lung cancer diagnoses is not expected for over 20 years. The high disease related mortality is because most patients present with incurable metastatic disease and often have other smoking-related co-morbidities that limit treatment options. Surgery, chemotherapy and radiotherapy are used with equal frequency in lung cancer care, meaning that care has not traditionally been consolidated in one area. The recent focus on a multidisciplinary approach to cancer care provides a unique opportunity to develop a clinical and translational research program. Unlike other tumour streams, lung cancer research needs to focus on improving outcomes for the large numbers of patients in whom palliative treatment rather than curative surgery is the current standard of care.

Team members:

The Lung cancer tumour group is under development.

Aims of the group:

There is a lung cancer database housed at St Vincent's Hospital that contains demographic, tumour, staging (radiological, PET and pathological), smoking, treatment and survival data on 1,000 patients. The aim of the group is to transfer data from this lung tumour database into the newly developed multidisciplinary component of the hospital's oncology database. This database will be compatible with MMIM and will then be rolled out to other sites.

Short term general research questions:

- Trial the lung cancer database to ensure accurate information transfer.
- Stratify patients on database according to a validated co-morbidity score.
- Assess feasibility of inclusion of small volume tumour specimens in molecular lung cancer projects.

Long term research questions:

- Develop an existing collaborative translational lung cancer project between PMCC and St Vincent's to include other sites
- Examine association of primary lung cancer with occupational asbestos exposure.

Activities/achievements over the last 6 months:

- Linking the Lung Cancer and Tissue Bank database to assemble full demographic, tumour, staging (radiological, PET and pathological), ECOG, smoking, treatment and survival data on 250 archived tumour specimens.
- Development of the multidisciplinary component of the St Vincent's Hospital Oncology Database (this will contain additional data fields required for MMIM).
- Collaboration with the ENT, Colorectal and Lymphoma tumour groups to develop the MDC database for these streams.

Work plan for the next 12 months:

- Data cleaning before the data transfer occurs (MMIM to assist)
- Use MMIM resources to obtain information that will allow a co-morbidity score calculated
- Linking Tissue Bank with new database.

Tumour Stream: Melbourne Melanoma Project (MMP)

The leader of this stream is Associate Professor Grant McArthur. Associate Professor McArthur is a consultant Medical Oncologist, Head of the Molecular Oncology and Translational Research Laboratories, Peter MacCallum Cancer Centre in Melbourne. He is a Fellow of the Royal Australasian College of Physicians in Medical Oncology and holds a PhD in Medical Biology. In 2004 he was awarded the Translational Research Award of the Fondation Nelia et Amadeo Barletta and in 2005 the Dunlop Clinical Research Fellowship of the Cancer Council of Victoria. Research interests include clinical trials of targeted therapeutics, GIST, melanoma, breast cancer, cell cycle control, differentiation, and functional imaging. He sits on the editorial board of Anti-Cancer Drugs.

Team members:

John Kelly, Ian Davis, Jonathan Cebon, David Speakman.

Overview of tumour stream:

Melbourne Melanoma Project aims to reduce the burden and mortality from Melanoma by integrated Clinical and Laboratory Research.

Objectives of the MMP:

- To establish a Melanoma Tissue bank by collecting samples of tissues for all stages of melanoma, in collaboration with the Victorian Cancer Biobank (VCB).
- To collect clinical and pathological information from patients undergoing treatment for melanoma in various cancer centres across Melbourne, to contribute to research in prevention and early detection.
- To understand the molecular basis of melanoma by linking molecular characteristics of melanoma tissue with the clinical and pathological features of the disease.
- To establish databases of patients with defined molecular characteristics of Melanoma that will assist in recruiting participants for clinical trials, for identifying effective molecular-targeted therapeutics.

Research questions (possible projects):

- Prognostic and clinico-pathological significance of mutations in BRAF in melanoma
- Frequency and clinico-pathological significance of mutations in KIT in melanoma
- Influence of adiposity on outcomes following definitive treatment of melanoma
- Prognostic and clinico-pathological significance of expression of NY-ESO-1 in melanoma.

Activities/achievements over the last 3 months:

- Melbourne Melanoma Project launched
- Project officer employed
- Developed clear objectives of the project; obtained sign-off by the Steering Committee
- Progress with establishment of the minimum dataset
- Progress with establishment of the Ethics approvals
- Negotiations with the Victorian Cancer Biobank (VCB)
- Grant Application to Deloitte's – Negotiations for integrating Skin and Cancer Foundation into MMP.

Work plan for the next 12 months:

- Establish ethics approvals at the initial participating sites
- Validate molecular tests to be used
- Patient recruitment
- Specimen collection
- Pilot project data analysis and report.

Tumour Stream: Rare Tumours

The leader of this stream is Dr Clare Scott. Dr Scott is a Clinician Scientist / Oncologist at the Walter and Eliza Hall Institute of Medical Research and the Royal Melbourne Hospital, studying drug resistance in breast cancer and lymphoma. Dr Scott has 10 years of experience in cancer genetics, in particular, familial breast and ovarian cancer, analysing the penetrance for breast cancer of mutations in the breast cancer predisposition genes, BRCA1 and BRCA2, in the Australian population. Dr Scott was awarded the Arnott Fellowship in Cancer Research by the Australasian College of Physicians, the Seligson Cancer Fellowship at Cold Spring Harbor Laboratory and a Laurie Strauss Leukemia Foundation Grant. She is currently an NHMRC RD Wright Fellow in the Molecular Genetics of Cancer Division at the Walter and Eliza Hall Institute.

Team member:
Jayesh Desai.

Overview of tumour stream:
To use existing MMIM infrastructure to incorporate rare tumour subtypes. Preparing HREC submission to deal with novel aspects of data collection.

Aims of the group:
To establish a rare tumour resource, enabling identification of patients with rare tumour types and subsequent data collection including clinical data and potential access to histological data/specimens. This resource would be available to clinical / laboratory researchers undertaking HREC-approved studies. A major novel advantage of this proposal is that the resource would be web-based, thus allowing interested individuals to access the database voluntarily, to provide their information and consent for its use, utilizing the established structure of MMIM/ACG.

This resource could potentially allow sufficient numbers of patients with a particular rare tumour type to be accessed, that research could be performed on a more meaningful number of cases than would otherwise be possible. Included in "rare" tumour types would be specific cancer subsets for which targeted therapy is currently under investigation, improving the identification of such rare cases, useful for both the patient and the researcher.

Short-term general research questions:
- To explore an existing dataset for HEARD (need to "acquire" the data first)
- To run as a pilot, web-based submission of details by patients/proxies both for rare tumours and for rare subtypes of tumours which are amenable to targeted therapies.

Long-term research questions:
Availability of data/biospecimens links for researchers with HREC approved studies for a wide range of rare tumour subtypes.

Activities/achievements over the last 6 months:
- Description of how the data will be received and triaged
- Preparation of an HREC submission
- Meeting and discussions with HEARD coordinator: plan for dealing with that data
- Generic data forms.

Work plan for the next 12 months:
- Submit to HREC in August
- Pilot use of the website once approved: report at 6 months and 12 months.

Tumour Stream: Renal

The leader of this stream is Dr Ian Davis. Ian Davis is a medical oncologist and cancer immunologist and is currently an Associate Member of the Ludwig Institute for Cancer Research and Associate Professor of Medicine in the University of Melbourne. He undertook his oncology training at Prince Henry's Hospital and at Austin Hospital and subsequently undertook a PhD in cancer immunology at the Ludwig Institute for Cancer Research in Melbourne. In 1995 he left Melbourne for post-doctoral research at the University of Pittsburgh Cancer Institute, including clinical work using novel biological agents and gene therapy. He returned in 1997 to take up a position with the Ludwig Institute Oncology Unit at Austin Health.

Team members:
The membership is being developed.

Overview of tumour stream:
Collection of tissue and data on patients with renal cell carcinoma.

Aims of the group:
To collect tissue and patient data prospectively with a view to developing an RCC database able to interface with ACG and ultimately with electronic medical records systems across Australia and elsewhere.

Short term general research questions:
Local experience in terms of epidemiology, patient characteristics, treatment patterns.

Long term research questions:
- Associations with other conditions
- Tissue-based studies (molecular, immunological, other).

Activities/achievements over the last 6 months:
Development of paper-based data collection sheets

Work plan for the next 12 months: Validate paper data collection sheets:
- Develop electronic database
- Move towards web-based data collection
- Integration into ACG.

Tumour Stream: Sarcoma

The leader of this stream is Dr Jayesh Desai. Dr Desai is a Medical Oncologist employed jointly through the Austin Hospital and the Ludwig Institute for Cancer Research. After completing his training in Medical Oncology at the Austin, he spent three years at the Dana-Farber Cancer Institute/Harvard Medical School in Boston (USA), where his main research focus was in the development of new drugs in cancers, particularly a new class of drugs known as molecularly-targeted agents. These are drugs designed to target the abnormal signals that many cancers rely on to grow in an uncontrolled manner.

At the Austin, Jayesh's main interests are in developing these new treatments to treat cancers, particularly gastrointestinal cancers, sarcomas and head and neck cancers. He is a member of a number of professional bodies including the Australian Gastrointestinal Trials Group and the Australian Sarcoma Group.

Team members:
Peter Choong, David Thomas, Sam Ngan, Guy Toner, Gerard Powell, Stuart Galloway.

Overview of tumour stream:
Growing clinical service, which now serves as the main referral centre for sarcomas in Victoria.

Aims of the group:
Initially to incorporate a paper-based database into our clinical practice for new patients referred to sarcoma service (pilot phase). Define appropriate fields for data collection.

Medium term (Q3, 2007) – electronic database. Incorporate retrospective data focused on answering particular research questions.

Short term general research questions:
Satisfactory data collection.

Long term research questions:
Lab-based projects/models will focus on liposarcoma, chondrosarcoma and osteosarcoma. We plan on utilising tissue from the established tissue collection, and link this to clinical data on these patient subsets.

Activities/achievements over the last 6 months:
Development of dataset and forms. Trial collection began in March 07. Data model completed.

Work plan for the next 12 months:
Develop Sarcoma module in ACCORD.

Research and Teaching Projects

MMIM is above all else concerned with facilitating a better way to undertake research across a range of datasets and disease types. The following are publications, abstracts, posters and work published and in preparation during the current year using research data derived from the Bio21: MMIM infrastructure.

If you would like to find out more about these and other Bio21: MMIM research publications prior to 2006 – 2007, please contact the Bio21: MMIM office.

- Paper/presentation for HIC 2006: 'Information Based Medicine and the Molecular Medicine Informatics Model (MMIM) Project' Bruce Ross, Lejla Hadzanovic, John Ientile, IBM Healthcare and Life Sciences, Australia, Robert Merriel, Marienne Hibbert, Melbourne Health.Abstract accepted to Australasian Biospecimen Network Meeting as part of the Australian Health and Medical Research Congress (AHMRC). M Hibbert et al.Abstract accepted at Australian Gastroenterology Week " P2X7: A New Biomarker for Colorectal Neoplasia Kaur G, Chang WY, Zhiye S, Barden, J, Cumming G, Landgren A, Macrae F. Colorectal Medicine & Genetics, and Pathology, Royal Melbourne Hospital; Biosceptre International Ltd, Sydney; Anatomy & Histology, The University of Sydney.Abstract accepted for presentation at the Australian Gastroenterology Week on Oct 14th 'Analysis of 25 years of screening for colorectal neoplasia based on moderate familial risk. Macrae FA, Slattery M, Brown GJ, St John DJB, O'Dwyer M, Budd K. Colorectal Medicine and Genetics, The Royal Melbourne Hospital, eHealth Research Centre, CSIRO ICT Centre, Brisbane.
- Abstract submitted: Familial Colorectal Cancer - How Poor is our Pick-up?". American Society of Clinical Oncology - Gastrointestinal meeting, January 2007.: LR Lipton, C Wong, P Gibbs, J Johns, I Faragher, I Jones, G Lindeman, F Macrae, E Lynch.
- Abstracts submitted: The quality of the pathology provider significantly impacts reporting of multiple prognostic factors in colon cancer." American Society of Clinical Oncology - Gastrointestinal meeting, January 2007. Authors P. Gibbs, F. Barnett, J. Moore, A. Ryan, S. Ananda, M. Croxford, N. Reiger.
- Paper presented 'Synoptic reporting in colorectal cancer'. Australian Gastrointestinal Trials Group, September 14th 2006. P Gibbs.
- Paper submitted 'A Single Institution Experience of Adjuvant 5-Fluorouracil Based Chemotherapy For Stage III Colon cancer. Faragher I, Handolias D, McLaughlin S, Skinner I, Chao M, Chapman M, Johns J, Gibbs P.
- Paper accepted: The NUCOG: validity and reliability of a brief cognitive screening tool in neuropsychiatry patients. . Mark Walterfang, Ronald Siu, Dennis Velakoulis. Australian and New Zealand Journal of Psychiatry 2006; 40: 995-1002.
- Letter submitted to the *American Journal of Gastroenterology*: Type 2 Diabetes Mellitus, Smoking and Colorectal Cancer". Authors: P Gibbs, S McLaughlin, IT Jones, I Faragher, I Skinner, M Croxford, J Johns, M Chapman, L Lipton.
- Letter submitted. "The quality of pathology reporting impacts on lymph node yield in colon cancer." *Journal Clinical Oncology*. Authors: Reiger NA, Barnett FS, Moore JWE, Neo E, Badahdah F, Ryan AJ, Ananda SS, Croxford M, Johns J, Gibbs P.
- Invited talk: "Cancer databases" Australian and New Zealand Society of Hepato-pancreatico-biliary Surgeons, Melbourne, October 26th 2006. Ian Jones.
- Invited talk: "Maximising the use of Linked Databases. Airways 2006. M. Hibbert, presented at ARACY ARC/NHMRC Research Network Workshop on Mature Australasian Longitudinal Studies of Children and Youth 21st Aug 2006.Paper submitted: Long-term outcomes of patients with localized rectal cancer treated with chemotherapy and/or radiotherapy alone due to medical inoperability or patient refusal. Lim L, Chao M, Shapiro J, Millar JL, Kipp D, Rezo A, Fong A, Jones IT, McLaughlin S, Gibbs P.
- Letter accepted: "The quality of pathology reporting impacts on lymph node yield in colon cancer". Journal Clinical Oncology. Reiger NA, Barnett FS, Moore JWE, Neo E, Badahdah F, Ryan AJ, Ananda SS, Croxford M, Johns J. Gibbs P.

Grants and Awards

Peer-Reviewed Research Grants

2006 AEDs and fracture risk
Principal Investigators: JD Wark, O'Brien TJ, Sambrook P, Hill K, Seibel M, Herkes G.
Source: National Health and Medical Research Council Project Grant 400089
Amount: $459,750

2006 Phamacogenetics of anti-epileptic drugs
Principal Investigators: C Szoeke, O'Brien TJ, Newton M.
Source: Pfizer Neuroscience Grant
Amount: $55,000

2007 Is TLE a progressive disorder? A follow-up study of neuroimaging, neurological and neuropsychiatric outcomes
Principal Investigators: Adams S, Velakoulis D, O'Brien TJ.
Source: Pfizer Neuroscience Grant
Amount: $55,000

2007 Ictal SPECT perfusion patterns in TLE: relationship to epilepsy subtype and surgical outcome
Principal Investigators: Kazemi NK, O'Brien TJ, Jackson GD.
Source: Pfizer Neuroscience Grant
Amount: $55,000

2007 Genetics and expression of P-glycoprotein and other drug transporters in pharmacoresistant epilepsy
Principal Investigators: Kwan Patrick
Co Investigators: Baum LW, Ng HK, O'Brien TJ, Poon WS, Wong LKS.
Sources: Research Grant Council (RGC) ref No CUHK4466/06M
Amount: HKD534,500 plus Clinical Research Fellowship HKD800,000
Duration: July 2007 to June 2009

2007 Factors predisposing to post-operative epilepsy in patients with supraentorial gliomas
Investigator: Tanya Yuen
Source : Royal Australian College of Surgeons
Amount: $57,000

Pharmaceutical Industry Investigator Initiated Study Grants

2006 Neuropsychiatric, neurocognitive and quality of life outcomes in patients with epilepsy treated with levetiracetam verses older AEDs as first substitution monotherapy
Principal Investigators: SR Yerra, TJ O'Brien, N Moore.
Source: UCB Pharma
Amount: $328,000

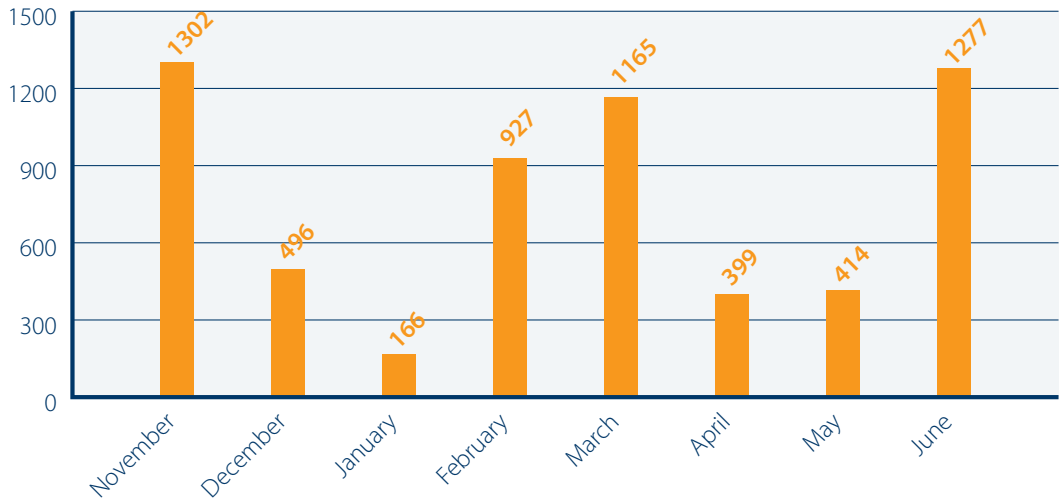
2006 KONQUEST: Keppra versus older AEDS and neuropsychiatric, neurocognitive and quality of life outcomes in treatment of epilepsy as first substitution monotherapy. Bone health and body composition substudy
Principal Investigators: R Yerra, TJ O'Brien, S Petty, JD Wark, M Seibel.
Source: UCB Pharma
Amount: $469,800 for 2006 – 2008

Usage Statistics

Statistical MMIM Report (December 2007)

Sites	Databases	Tables	Sources	Columns	Records	People (USIs)
RMH	ACCORDV1	13	1	142	271,860	5,950
	ACCORDV2_RMH	13	1	344	247,343	826
	ACCORDV2_WH	13	1	344	423,006	1,431
	BIOMARKERS	2	1	49	67,487	627
	DIABETES	59	2	1,873	12,540,882	16,098
	EPILEPSY	43	1	1,634	560,135	2,693
	FAMILIAL	57	1	585	1,519,592	6,559
	MS_IMED	5	1	165	35,070	374
	STROKE	12	1	99	286,966	3,310
	SURVEILLANCE	28	1	496	1,406,642	3,656
	TISSUEBANK	16	1	245	3,495,345	2,250
AUSTIN	ACCORDV1	13	1	142	128,692	3,134
	ACCORDV2	13	1	355	58,826	260
	DIABETES	5	1	260	1,695,172	1,521
	TISSUEBANK	36	1	338	933,440	1,603
PMCC	ACCORD	18	1	216	335,668	4,457
	ACCORDV2	13	1	299	9,031	38
	TISSUEBANK	16	1	146	1,236,217	8,935
SVHM	Breast	20	1	304	30,572	4,928
	Diabetes	15	1	719	4,317	199
	Oncology	20	1	185	119,744	16,992
BaysideShared						
– Box Hill	BoxHill ACCORDV2	13	1	337	1,920	215
– The Alfred	Alfred in progress					
– Monash	Monash in progress					
TOTAL		**443**	**23**	**9,277**	**25,407,927**	**86,056**

Queries against the system November 2006 – June 2007



Data Description
DATABASES ON MMIM SYSTEM

Please note that ALL data is de-identified

Cancer			
Database	**Description**	**Location**	**Data Owner/s**
Accord	Clinical research data on cancer patients including name, sex, DOB, date of diagnosis, pathology, TNM stage, therapy, etc.	Austin	Paul Mitchell
		Box Hill	Joe McKendrick (Oncology) and Frank Chen (CRC surgery)
		Peter MacCallum Cancer Centre	Sandy Heriot
		Royal Melbourne Hospital	Peter Gibbs
		Western	Peter Gibbs
Biomarkers	Tissue testing results for biomarkers in colorectal cancer	Royal Melbourne Hospital	Peter Gibbs
Breast	Collects surgical and oncology data on breast cancer patients, treatments, staging etc.	St Vincent's	Michael Henderson
FAMBIZ	Tracks subjects with a family history of Colon cancer- has documentation of symptoms, genetic test results, and pedigree information.	Royal Melbourne Hospital	Geoff Lindeman
Micro Array	Micro Array result in colorectal cancer.	Peter MacCallum Cancer Centre	Alex Boussioutas
Oncology Clinical Data	Clinical research data on cancer patients including name, sex, DOB, date of diagnosis, pathology, TNM stage, therapy, etc.	Peter MacCallum Cancer Centre	Michael Jefford
		St Vincent's	Raymond Snyder
Surveillance	Tracks patients who have familial risk of bowel cancer – Collects symptoms and results of screening tests, such as faecal blood tests, colonoscopy and associated histology reports.	Royal Melbourne Hospital	Finlay Macrae
Tissue Bank	Details on tissue and blood collected for the Tissue Bank, includes data on diagnosis, tissue treatment, pathology etc.	Ludwig Austin	Carmel Munroe
		Royal Melbourne Hospital/ Western Hospital	Audrey Partanen or Michelle McMahon
		Peter MacCallum Cancer Centre	Lisa Deveroux

Data Description
DATABASES ON MMIM SYSTEM (Continued)

Please note that ALL data is de-identified

Diabetes			
Database	**Description**	**Location**	**Data Owner/s**
Diabetes – Austin Repatriation Hospital	Demographic information, type of diabetes, outcomes and complications focusing on heart and renal disease.	Austin Hospital	Sianna Panagiotopoulos and George Jerums
Diabetes Clinic	Diabetes Clinical audit database includes information on type and duration of diabetes, ethnicity, treatment for diabetes and other co-morbidities and complications of diabetes (eyes, kidneys, feet)	Royal Melbourne Hospital	Peter Colman
Diabetes Research	Database of Diabetes patients and incidence of Diabetes in other members of the same family	Royal Melbourne Hospital	Peter Colman and Len Harrison
Diabetes – St Vincents Hospital	Australian National Diabetes Information Audit and Benchmarking (ANDIAB) data entered directly by the clinics since 1998 and have approximately 300–400 patients.	St Vincent's Hospital (Melbourne)	Glenn Ward
Neurosciences			
Database	**Description**	**Location**	**Data Owner/s**
eAssessments	Study of all Epilepsy patients admitted to Video EEG Monitoring at RMH integrated with two other research studies conducted into early imaging evidence for Epilepsy	Royal Melbourne Hospital	Terry O'Brien, Sophie Adams, Simon Jones
Epilepsy	Epilepsy clinical data collected during department clinical review meetings	Royal Melbourne Hospital	Terry O'Brien, Christine Kilpatrick
Illumina / SNP's (Single Nucleotide Polymorphisms)	Genetic data for selected Epilepsy patients, which has been linked to clinical and pharmacology data for these patients in order to study possibly genetic basis for pharamaco-resistance	Royal Melbourne Hospital	Terry O'Brien
MRI Images	Historical MRI scans at RMH since early 1990's – includes brain and other studies	Royal Melbourne Hospital	Patricia Desmond
Multiple Sclerosis (using the international iMEd system)	Research study of all patients admitted to Multiple Sclerosis unit at MH and other hospitals in Australia	Royal Melbourne Hospital	Helmut Butzkeuven
Stroke – MH	Study of all patients admitted to Stroke Unit at MH	Royal Melbourne Hospital	Louise Weir

Data Description
MMIM DATABASES IN PROGRESS

Please note that ALL data is de-identified

Cancer			
Database	**Description**	**Location**	**Data Owner/s**
Accord	Clinical research data on cancer patients including name, sex, DOB, date of diagnosis, pathology, TNM stage, therapy, etc.	Flinders (SA) Queen Elizabeth (SA) Royal Adelaide (SA)	Paul Hollingworth Andrew Hunter Andrew Hunter
Breast	Collects surgical and oncology data on breast cancer patients, treatments, staging etc.	Box Hill Hospital	Jacquie Chirgwin
Colorectal Cancer	Clinical research data on cancer patients including name, sex, DOB, date of diagnosis, pathology, TNM stage, therapy, etc.	Covering Monash Medical Centre, Cabrini & The Alfred	Paul McMurrick Peter Carne Roger Wales
GeMMA @ RWH	Clinical research data on cancer patients including gynecological, breast and other types.	Royal Women's Hospital server	Margot Olinski Michael Quinn
Radiotherapy database	Clinical research data on radiotherapy	William Buckland (The Alfred)	Ian Porter
Renal	Collects data from patients whose biopsies are collected for the Biopsy Bank. Clinical research data, longitudinal record, biopsy histology.	Melbourne University network server	Renae Gow
Tissue Bank	Data on tissue collected, diagnosis, storage location, research projects, tissue treatment, pathology etc.	Tissue Bank Monash Medical Centre	Pam Mamers
Endoscribe	Colonoscopy and Endoscopy results.	Royal Melbourne Hospital	Peter Pritchard
Diabetes			
Database	**Description**	**Location**	**Data Owner/s**
Diabetes – Paediatric	Clinical data on paediatric patients with type 1 diabetes.	The Royal Children's Hospital	Fergus Cameron
Gestational Diabetes	An Obstetrics database that acts as a maternity clinical research and audit tool, and includes details of Gestational Diabetes for each pregnancy. This database is based on the Australian & Diabetes in Pregnancy Society (ADIPS) format.	Royal Women's Hospital	Jeremy Oats

Data Description
MMIM DATABASES IN PROGRESS (Continued)

Please note that ALL data is de-identified

Neurosciences			
Database	**Description**	**Location**	**Data Owner/s**
Epilepsy	Menzies Institute Epilepsy data	Royal Hobart Hospital	Simon Foote
Epilepsy Quality of Life Study	Quality of Life study of Epilepsy patients, using 5 questionnaires plus demographic information	Royal Melbourne Hospital	Raju Yerra
Epilepsy – St Vincent's	Clinical Epilepsy data	St Vincent's	Mark Cook
Konquest study	Clinical study of effectiveness of a new Epileptic drug (Keppra) versus older drugs	Royal Melbourne Hospital	Raju Yerra
Multiple Sclerosis longitudinal data	Menzies Institute Epilepsy data	Royal Hobart Hospital	Simon Foote
NUCOG	Research study of cognitive function of patients in the Neuropsychiatry Unit, Royal Melbourne Hospital, and other patients who undergo cognitive assessment with the NUCOG evaluation tool in Melbourne Health	Royal Melbourne Hospital	Mark Walterfang
PET Images	Online storage of all historical PET scans done at Peter MacCallum Cancer Centre	Peter MacCallum Cancer Centre	David Binns
Stroke – Alfred	Study of all patients admitted to Stroke Unit at The Alfred	The Alfred	Judith Frayne
Cystic Fibrosis			
Database	**Description**	**Location**	**Data Owner/s**
Cystic Fibrosis	Clinical data based on the CF Australia database data elements and includes lung function and pathology data including: • RESMED – Respiratory Lab function database. • GENOTYPE – genetic data on patients • Hospital data – Admission data and Pathology results.	The Alfred	John Wilson Felicity Finlayson Libby Francis
Cystic Fibrosis	Clinical data based on the CF Australia database data elements and includes lung function and pathology data.	Monash Medical Centre	David Armstrong Teresa McIvor
		The Royal Children's Hospital	Phil Robinson Julie Smith
Cystic Fibrosis – Lab system	Respiratory function data for CF patients	Monash Medical Centre	David Armstrong Teresa McIvor Paul Guy
		The Royal Children's Hospital	Phil Robinson Julie Smith
Smarthealth Cystic Fibrosis	Clinical data on patients	Monash Medical Centre, The Alfred & The Royal Children's Hospital	John Wilson Phil Robinson David Armstrong

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Bio21 Molecular Medicine Informatics Model and The Australian Cancer Grid

Annual Report 2003