

Developing and operating clinical registries: workshop

Thursday 14th February 2013

About the workshop:

This workshop has been developed to provide insight into the design and operations of clinical quality registries. It will focus on fundamental stages and challenges often faced such as how to develop the dataset, the legal and ethical considerations of running a registry and governing the data, data security, and methods of data validation.

Who should attend:

This workshop is relevant to:

- Clinicians with an interest in developing a registry or using registry data;
- Ethics committee members or HREC staff who review applications for registries;
- Quality managers;
- Researchers with an interest in developing a registry or using registry data;
- Health Information Managers.

Venue: The Alfred Medical Research and Education Precinct (AMREP) lecture theatre, 75 Commercial Rd, The Alfred, Melbourne Vic 3004.

This is located at the closest intersection of Commercial and Punt Roads.

Workshop date: Thursday 14th February, 2013

Workshop time: 9:00am - 5:00pm
(Registration opens at 8:30am)

Work sheets will be provided via email, 2-5 work days prior.

Cost:

\$280 pp (incl. of GST) - **Workshop** only individual registration
\$195 pp (incl. of GST) - **Seminar** only individual registration
\$450 pp (incl. of GST) - **Workshop AND seminar** individual reg.*
*NB: This is a reduced rate which cannot be processed retrospectively. If you initially register in one event then wish to register for the second event, you will pay the full individual fee, separately.

Further venue details, accommodation and parking information can be found on our website at:

<http://www.med.monash.edu.au/sphpm/creps/seminars.html>

Enquiries to Catherine Pound on +61 3 9903 0891 or catherine.pound@monash.edu

We are running a seminar on registries the following day which you may like to attend...

Title: Clinical registries seminar: monitoring and improving health outcomes

Venue: AMREP lecture theatre, 75 Commercial Rd, The Alfred, Melbourne Vic 3004.

Seminar date: Friday 15th February, 2013

Seminar time: 9:00am - 5:00pm
(Registration opens at 8:30am)

Cost: \$195 per person (incl. of GST)

Please visit the website listed above to download the flyer.



Speaker and Facilitator details

(in order of appearance)

Professor John McNeil is Head of the Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, Australia, and Head of the School of Public Health and Preventive Medicine at the Alfred Hospital site. He is a Physician whose principal research interest is in the use of drugs to prevent chronic disease. Professor McNeil's department covers a broad range of research activities and hosts a number of national research centres. These include Australian coordinating centres for research in critical care and anaesthesia, several major clinical registries, cohort studies and large-scale clinical trials. His department provides a skill base in epidemiology, biostatistics and data management that underpins the clinical and public health research activities of Monash University and its major teaching hospitals.

Dr Sue Evans is Associate Director of the Centre of Research Excellence in Patient Safety (CRE-PS) and Head of the Clinical Registry Unit at Monash University. Sue has a keen interest in improving measurement of quality in health and manages a number of large clinical registries operating across Victoria. She leads a number of research projects exploring how best to use data to monitor quality of care.

Ms Renee Best is currently working within the School of Public Health and Preventive, Monash University, as the coordinator of the Breast Device Registry. Previous to this she consulted with Healthcare Management Advisors which involved evaluating federal and state government programs, conducting Hospital service plans, implementing workplace health promotion programs, and development of strategic directions for policy review. For four years Renee undertook immunology research with Imperial College London.

Ms Angela Brennan is a Registered Nurse who undertook post-graduate studies in Critical Care. She has had extensive project management experience within clinical and academic environments. She also has extensive experience in cardiovascular registry management, particularly those related to cardiac procedures for revascularisation in patients with coronary artery disease and has been the coordinator for the Melbourne Interventional Group (MIG) registry since commencing at CCRE in 2004. In 2009, Angela was the co-project manager of the Australian Cardiac Procedures Registry (ACPR) pilot project and currently she is overseeing the Victorian Cardiac Outcomes Registry (VCOR) project.

Associate Professor Lynn Gillam is Associate Professor in Health Ethics in the School of Population Health at the University of Melbourne, and Academic Director of the Children's Bioethics Centre at the Royal Children's Hospital Melbourne. Her research interests are in paediatric clinical ethics and research ethics. She is Chair of the University of Melbourne Human Research Ethics Committee.

(continued overleaf)

Developing and operating clinical registries: workshop

Thursday 14th February 2013

Speaker profiles

Mr David Morrison is the Systems Development Manager for the Clinical Informatics and Data Management Unit (CIDMU) at Monash University. He has spent the last nine years working in Clinical Informatics. He has been instrumental in developing the Clinical Registry Platform Architecture that conforms to ISO 27001 standards and is an author of “Quality Clinical Registries” technical standards on behalf of the Australian Commission on Safety and Quality in Health Care (ACSQHC). David leads a team of one Business Analyst, thirteen Software Developers and three Database Analysts. He and his team have developed and continue to maintain over 30 quality clinical registries.

Dr Chris Bain is inaugural Director of Health Informatics at Alfred Health in Melbourne. In this role he is responsible for the corporate reporting environment, including the Alfred Health Information Grid and its attendant services. His career interests reside in the area of management information provision and Management Information Systems for healthcare managers across the entire healthcare spectrum. Chris is passionate for systems improvement in all healthcare settings and the requirement for health systems to integrate clinical care with data collection. He has been instrumental in developing systems to enable data to be extracted from multiple existing clinical information systems for use by clinical registries. He would like to extend this work to include liaising with vendor providers to see critical data fields incorporated into software for deployment at the Alfred Hospital and other hospitals using mainstream information packages.

Dr Amanda Zatta is a NHMRC Peter Doherty Research Fellow in the Transfusion Research Unit, operating within the Critical Care Division at the Department of Epidemiology and Preventive Medicine, Monash University. She was the Project Manager of the Australian and New Zealand Haemostasis Registry which collected 10 years of data on the administration of activated recombinant factor VII for treatment against critical bleeding in patients. More recently, Amanda is establishing a Massive Transfusion Registry (MTR) in Australia and New Zealand with the support of the Transfusion Outcomes Research Collaborative, which is a partnership between the Australia Red Cross Blood Service and Monash University and an educational grant from CSL Biotherapies and more recently, support from the New Zealand Blood Service. The aim of the registry is to collect data on the incidence, clinical contexts and outcomes of critical bleeding events that require a massive transfusion.

Ms Peta McLaughlin is the Project Co-ordinator for the Victorian Lung Cancer Registry (VLCR). Peta has previously worked in project management and research within both the health and media sectors in Australia and the UK. She has experience in a broad range of public health projects, with particular interest in patient safety and quality improvement. Peta has recently been involved with the development and implementation of clinical quality registries and is currently involved with the overall project co-ordination and development of the pilot of a population-based lung cancer clinical quality registry.

Ms Liddy Griffith is the Research and Operations Manager of the Data Management & Analysis Centre (DMAC) at The University of Adelaide. Liddy is also the Data Manager of the Australian Orthopaedic Association’s National Joint Replacement Registry (AOA NJRR). Liddy has extensive experience in data management of clinical trials, cohort studies and registries, including coordinating data collection at a national level and undertaking validation work to ensure high quality data.

Mr Geoff Sims is a Consultant Statistician and is the Data Manager for the Australian Cystic Fibrosis Data Registry which was established in 1998 through Cystic Fibrosis Australia (CFA) and modelled on the American Cystic Fibrosis Foundation Patient Registry. The registry monitors the demographics, morbidity and mortality of the CF population to increase awareness about CF, improve quality of patient care through comparisons of CF centres, and facilitate research. Geoff has extensive experience overseeing all aspects of the registry operation, including more recently the public reporting of outcome data. He was formerly Head of the Health Division at the Australian Institute of Health and Welfare.

Professor Joseph Ibrahim is a consultant physician in geriatric medicine and health services researcher with a principal interest in quality of care, patient safety, and the effects of extreme hot weather on the health of older persons, and is co-author of the Victorian Department of Health (Aged Care Branch) publication “Residential Aged Care Services Heatwave Ready Resource”. He is an Associate Director of the Centre of Research Excellence in Patient Safety, in the Department of Epidemiology and Preventive Medicine, Monash University, and Clinical Director of Subacute Services at the Ballarat Health Service.



Developing and operating clinical registries: workshop

Thursday 14th February 2013

Time	Area covered	Speaker and Organisation
0830	REGISTRATION	
Session 1: Clinical registries		
0900 - 0915	What are clinical quality registries?	Prof John McNeil - Monash University
0915 - 1015	Developing the minimum dataset	Dr Sue Evans, Ms Renee Best - Monash University
1015 - 1045	MORNING TEA (30 minutes)	
Session 2: Governance, ethics, and policies		
1045 - 1245	Legal considerations to running a registry: <ul style="list-style-type: none">• governance arrangements• ethical considerations• policies	Dr Sue Evans, Ms Angela Brennan - Monash University A/Prof Lynn Gillam - The University of Melbourne
1245 - 1330	LUNCH (45 minutes)	
Session 3: Data security and validation protocols		
1330 - 1415	Data security, privacy, and data transfers	Mr David Morrison, Monash University Dr Chris Bain - Alfred Health
1415 - 1500	How good is my data? Working examples of validating data	Dr Amanda Zatta, Ms Peta McLaughlin - Monash University Ms Liddy Griffith - The University of Adelaide
1500 - 1530	AFTERNOON BREAK (30 minutes)	
Session 4: Focus Groups (you will attend one of the following and sign up on the day)		
1530 - 1615	1. Exploring the ethical implications	Ms Angela Brennan - Monash University
	2. Information technology challenges for registries	Mr David Morrison - Monash University
	3. Using registry data to improve quality of care	Dr Sue Evans - Monash University Mr Geoff Sims - Geoff Sims Consulting Pty Ltd
1615 - 1700	Summing up	Prof Joseph Ibrahim - Monash University
1700	CLOSE	

Developing and operating clinical registries: workshop

Thursday 14th February 2013

REGISTRATION FORM - please complete all sections



Please email registration information (via attached pdf or within an email) to catherine.pound@monash.edu.

DELEGATE DETAIL/S:

Delegate 1

Title Other	Prof / Dr / Mr / Mrs / Miss	First name	Surname
Phone		Email	
Position		Organisation	

Delegate 2 (if applicable)

Title Other	Prof / Dr / Mr / Mrs / Miss	First name	Surname
Phone		Email	
Position		Organisation	

COST: (please tick or mark the appropriate box)

<input type="checkbox"/>	\$280 per person (incl. of GST)	Workshop only individual registration
<input type="checkbox"/>	\$195 per person (incl. of GST)	Seminar only individual registration
<input type="checkbox"/>	\$450 per person (incl. of GST)	Workshop AND Seminar individual registration NB: This is a reduced rate which cannot be processed retrospectively. If you initially register in one event then wish to register for the second event, you will pay the full individual fee, separately.

PAYMENT METHOD:

<input type="checkbox"/>	Credit card	Please visit the following website to pay online http://ecommerce.med.monash.edu.au/product.asp?pid=335&cID=8&c=152322 You will AUTOMATICALLY receive a tax invoice/receipt.
<input type="checkbox"/>	On INVOICE Complete only if you wish to be invoiced	Contact person _____ Company ABN _____ Phone _____ Postal address _____ _____ _____ Email address _____

NB: The registration process is complete once payment has been received and noted by Catherine, at which time a registration confirmation email will be sent to you.

Terms and Conditions: Refunds will NOT be given if inability to attend is advised two (2) days prior to the workshop. Requests for refunds at any other time will be considered on an individual basis. Please note, a colleague is always welcome to attend in your place.

Enquiries and forms to Catherine Pound:

Email: catherine.pound@monash.edu / Ph: 03 9903 0891

Finance office use only M15001 / 3165959 CREPS Workshops