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Highlights 2015

2015 was the first full year of operation for UNSW Australia’s Centre for Big Data Research in Health (CBDRH). Three new Unit Heads (A/Professor Georgina Chambers, Professor Sallie Pearson, A/Professor Claire Vajdic) and their teams joined the Centre over 2015, bringing us to a critical mass that will begin to drive delivery of our ambitious vision.

The Centre is the first Australian research centre dedicated to health research using big data. Our aim is to maximise the productive use of all possible sources of health big data in order to enhance the health and well being of Australians and the global community.

“Big data” have no agreed definition, but the term is in general applied to data that by virtue of their size and/or complexity pose challenges to traditional methods for management and analysis. In health, such data include the millions of records that are generated routinely by health services, real-time clinical data captured at the point-of-care, genomic data produced in research and clinical settings, and health-related data generated by the population at large through technologies such as wearable devices and social media. We sit at a key point in history, where big data are poised to become a dominant driver in what happens in health and health care.

To ensure that our research has real impact, we are committed to an approach of research co-creation, which brings together academics, consumers, clinicians, and service and policy organisations to frame relevant research questions, create research designs that apply to real-world contexts, and commit to implementing the research and its findings more broadly. We are privileged to have many enthusiastic partners in our work, including government agencies, health organisations from the public, private and not-for-profit sectors, research funders, clinicians, health consumers and community members.

We operate as a hub for collaborative interdisciplinary research, methodological development and training, providing opportunities for researchers from diverse backgrounds to come together, share insights, experiment with new approaches, form new partnerships and train new generations of researchers. In particular, we aim to foster the rapid implementation of new methods from disciplines including mathematics, statistics and computer science into practical applications within health. We are actively fostering a broad community of researchers who are adept in advanced analytic methods, agile in adopting new techniques, and who embody best practices in data security and privacy protection.

Centre highlights in 2015 included the official launch of the Centre by the NSW Minister for Health, The Hon. Jillian Skinner MP, on 4 May 2015, and the commencement of our seminar series, with seminars delivered by Professor John Quackenbush (Harvard University), Professor Andrew Morris (University of Edinburgh), Dr Tim Churches (The Sax Institute) and A/Professor Marni Brownell (University of Manitoba).

With new staff joining the Centre progressively through 2015, our research outputs ramped up over the year. Research highlights included the award of two NHMRC project grants, one NHMRC Partnership Project Grant and one NHMRC Early Career Fellowship to Centre investigators, more than 70 peer-reviewed papers published by Centre researchers, and 3 PhDs submitted. Professor Sallie Pearson was recognised for her research leadership in the post-market surveillance of cancer medicines with the award NSW Premier’s Outstanding Cancer Research Fellow. More detail of these achievements is provided in subsequent sections of this report.
Official launch

The Centre was officially launched by the NSW Minister for Health, The Hon. Jillian Skinner MP on 4 May 2015. The launch was attended by 130 people from organisations including the Australian Bureau of Statistics, Australian Commission on Safety and Quality in Health Care, Australian Institute of Health and Welfare, NSW Bureau of Health Information, Cancer Institute NSW, Clinical Excellence Commission, Healthdirect Australia, Intel Australia, Intersect, National Heath Performance Authority, NPS MedicineWise, NSW Ministry of Health, the Population Health Research Network and the Cancer Council NSW.

Launching the Centre, Minister Skinner said “This opportunity is limited only by our skills in analysing and translating this data into better health and outcomes. This Centre fills a crucial research role in this new data-driven era of quality healthcare”.

Two distinguished international guests also spoke at the launch.

Professor Andrew Morris, the Chief Scientist for Health in Scotland and Director of the Farr Institute@Scotland, who has used the findings of big data research to drive health reform, said that combining research with care and education and launching large scale collaborations could result in dramatic gains for health systems as well as individual patients.

Professor John Quackenbush from Harvard University, an authority on analysing and interpreting the vast amounts of data being provided by the genomics revolution, told the launch that the key challenge facing this research was not how to collect and store data, but how to bring it together in a meaningful way to address fundamental problems in health.

Videos of the launch, and also of seminars presented by Professor Andrew Morris and Professor John Quackenbush are available on the CBDRH website: https://cbdrh.med.unsw.edu.au/event-videos

From L to R – Mr Peter Noble (Vice-President, UNSW), Prof Peter Smith (Former Dean, UNSW Medicine), The Hon. Jillian Skinner (NSW Minister for Health), Prof Louisa Jorm (Director, UNSW CBDRH) and Prof Terence Campbell (Deputy Dean, UNSW Medicine)
“Healthcare is the last industry to be transformed by the information age”

Professor Andrew Morris

“This Centre represents precisely the type of investment that is needed to drive both research and practical application in today’s data-rich world”

Professor John Quackenbush
Centre overview

“Big data” refers to datasets whose size or complexity is beyond the ability of traditional methods and tools to capture, store, manage, and analyse. Big data in health and medicine are generated through operating the health system (e.g. medical service claims), clinical care (e.g. hospital records, primary care records), laboratories (e.g. imaging data, pathology records, genetic testing) and research studies (e.g. clinical trials, observational studies), to support disease prevention, control (e.g. disease notifications) and survivorship, and by individuals themselves (e.g. “life logging”). This type of ‘real-world’ data is growing rapidly and will continue to expand exponentially for the foreseeable future.

There is enormous potential to inform improvements in the effectiveness, safety and efficiency of health care by bringing these data together, and using them for research to understand the determinants of disease risk, target therapies to those who will benefit most, compare the effectiveness of alternative preventative and therapeutic interventions, and model the health and economic impacts of interventions and policies. Recognising this potential, research that will lead to “better models of care and services that improve outcomes, reduce disparities, increase efficiency and provide greater value” is listed first among the new national research priorities for health\(^1\). Moreover, it is estimated that effective use of big data could also deliver reductions to national health care expenditure of around 8 percent\(^2\) which would translate to more than $11 billion annually in Australia.

The Centre for Big Data Research in Health (CBDRH) is a world-first research centre that is focused on delivering this value. The Centre supports UNSW Medicine’s Thematic Research model in which key research themes (Neuroscience, mental health and addiction; Infectious disease, immunity and inflammation; Cancer; Non-communicable diseases) are supported by cross-cutting enabling capabilities including ‘Big data in health’.

Vision

The power of “big data” is harnessed to transform the prevention and management of disease, and the delivery of health services.

Mission

To maximise the productive use of all possible sources of health big data in order to enhance the health and well being of Australians and the global community.

Values

- **Excellence**: Our research is scientifically rigorous and of high quality
- **Innovation**: We use creative and novel approaches in study design, analysis techniques and reporting
- **Impact**: Our high impact research benefits population health and the health care system
- **Leadership**: We are influential in the health data science field and aim to be regarded as a world leader
- **Collaboration**: We develop and maintain open and respectful relationships with research partners, the community, and each other

Functions


• Foster and develop innovation in health data science
• Undertake high impact, high-quality and multi-disciplinary health and medical research using big data
• Facilitate the rapid translation of research findings into health improvements and better value in health care
• Build multi-disciplinary capacity in health research using big data
• Promote public, clinical and policy awareness of the health and societal benefits of research using big data

Research units
While the Centre has broad expertise that spans multiple health domains and the capability to address any health issue that can be informed through research using large-scale electronic data, it has a longstanding reputation as world leaders in thematic areas that correspond to its four internal research units:

• **Health Services and Outcomes Unit**: undertakes research to identify variations and disparities in the use, outcomes and costs of health services, investigates the factors that drive these, and evaluates the outcomes of health policies and programs.

• **National Perinatal Epidemiology and Statistics Unit (NPESU)**: conducts national epidemiological, health services, policy and health economic research in reproductive, perinatal and maternal health.

• **Cancer Epidemiology Research Unit**: performs genetic epidemiology and population-based health record linkage studies aimed at understanding the causes and consequences of cancer.

• **Medicines Policy Research Unit**: conducts research regarding the judicious use, safety, costs and cost-effectiveness of prescribed medicines.
Staff list 2015

Maria Arriaga, Research Assistant  
Georgina Chambers, Associate Professor and Director, NPESU  
Sharon Chow, Coordinator  
Kathleen Falster, Visiting Fellow  
Michael Falster, Research Fellow  
Louise Francis, Centre Manager  
Amy Gibson, Research Fellow  
Mark Hanly, Research Fellow  
Katie Harris, Biostatistician  
Alys Havard, Research Fellow  
Lisa Hilder, Senior Project Officer  
Nusrat Homaira, Senior Research Officer  
Sadia Hossain, Research Assistant  
Peter Hull, Senior Research Officer  
Jolie Hutchinson, Biostatistician  
Louisa Jorm, Professor, Director CBDRH and Head, Health Services and Outcomes Unit  
Mikaela Jorgensen, Research Fellow  
Maarit Laaksonen, Senior Research Fellow  
Renate Le Marsney, Data Manager  
Alan Macaldowie, Senior Research Officer  
Amy Monk, Project Manager  
Melisa Litchfield, Data Manager  
Sanja Lujic, Lecturer in Biostatistics  
Donna Maxwell, Administrative Officer  
Michele Partridge, Administrative Officer, NPESU  
Sallie Pearson, Professor and Head, Medicines Policy Research Unit  
Deborah Randall, Research Fellow  
Penny Terry, Project Coordinator  
Bich Tran, Research Fellow  
Danielle (Duong) Tran, Research Fellow  
Claire Vajdic, Associate Professor and Head, Cancer Epidemiology Research Unit  
Marina van Leeuwen, Research Fellow  
Jennifer Walsh, Project Coordinator
Research students 2015

Bilal Ahmed
Topic: Utilisation of Antihypertensive Drugs During Pregnancy and the Risk of Adverse Outcomes for Mothers and their Children
Primary Supervisor: Dr Alys Havard
Co-Supervisor(s): Prof Louisa Jorm

Jonathan Brett
Topic: Pharmacoepidemiology and low value care
Primary Supervisor: Prof Sallie Pearson
Co-Supervisor(s): A/Prof Adam Elshaug, Prof Nicholas Buckley

Benjamin Daniels
Topic: Big Data to Real World Evidence Around HER2-Targeted Cancer Therapies
Primary Supervisor: Professor Sallie Pearson
Co-Supervisor(s): Professor Nicholas Buckley

Michael Falster
Topic: Understanding the roles of individuals, context and service availability in preventable hospitalisations in NSW, Australia
Primary Supervisor: Prof Louisa Jorm
Co-Supervisor(s): Prof Alastair Leyland

Caroline Joyce (thesis submitted August 2015)
Topic: The relationship between anxiety and depression in the onset of, and recovery from, coronary heart disease
Primary Supervisor: Dr Kathryn Nicholson Perry
Co-Supervisor(s): Dr Alys Havard, Prof Ian Wilson

Evelyn Lee
Topic: Embryo screening techniques
Primary Supervisor: Assoc Prof Georgina Chambers
Co-Supervisor(s): Dr Michael Costello

Sanja Lujic
Topic: Comorbidity and Multiborbidity in New South Wales: Prevalence, Trajectories and Implications for Healthcare Utilization and Costs
Primary Supervisor: Prof Louisa Jorm
Co-Supervisor(s): Prof Judy Simpson

Lisa McCallum (thesis submitted August 2015)
Topic: Pertussis in New South Wales mothers and children: epidemiological studies using linked administrative data
Primary Supervisor: Prof Louisa Jorm
Co-Supervisor(s): Prof Peter McIntyre, A/Prof Bette Liu

Holger Möller
Topic: Inequalities in unintentional injuries between Aboriginal and non-Aboriginal children in New South Wales
Primary Supervisor: Prof Louisa Jorm
Co-Supervisor(s): Prof Rebecca Ivers and Dr Kathleen Falster
Stella Setumba Nalukwago
Topic: Economic Evaluation of Offender health programs
Primary Supervisor: Tony Butler (Kirby)
Co-Supervisor(s): Assoc Prof Georgina Chambers (CBDRH), Marian Shanahan (NDARC)

Deborah Randall (thesis submitted July 2015)
Topic: Multilevel modelling of routine data to investigate individual and contextual influences on disparities in myocardial infarction rates and outcomes for Aboriginal people
Primary Supervisor: Prof Louisa Jorm
Co-Supervisor(s): Prof Alastair Leyland

Andrea Schaffer
Topic: Quality use of medicines in Australia: Using administrative databases to explore utilisation and best practice research methods
Primary Supervisor: Prof Sallie Pearson
Co-Supervisor(s): Prof Nicholas Buckley
Staff profiles

Health Services and Outcomes Unit

Louisa Jorm
Professor Louisa Jorm is the Foundation Director of the Centre for Big Data Research in Health at UNSW Australia, and heads the Centre’s Health Services and Outcomes Unit. From 2007 until November 2014, she was Foundation Professor of Population Health and Director of the Centre for Health Research at the University of Western Sydney, and Principal Scientist at the Sax Institute. Prior to this, she spent more than 15 years in service and government roles, including 10 years as Director of the Centre for Epidemiology and Research in the NSW Department of Health.

Louisa is an Australian leader in public health and health services research using routinely collected data and linked data, including hospital inpatient, mortality, perinatal and Medicare (MBS, PBS) data. Her research has addressed topics including measuring health system performance, evaluating health policies and services using “natural experiments”, evaluating the impact of policies and services on early childhood development, and targeting interventions to improve Indigenous health outcomes. She has played a leading role in the establishment of major infrastructure and capacity for “big data” health research in Australia, including the NSW/ACT Centre for Health Record Linkage, the Population Health Research Network, the 45 and Up Study and the NSW Biostatistical Officer Training Program. She led the development of the Secure Unified Research Environment (SURE), a facility that benefits researchers nationally by providing secure remote access to linked health data. Her work has had numerous policy impacts, e.g.: driving changes to reporting of national public health performance indicators; informing national guidelines for management of acute coronary syndrome in Indigenous people; and shaping national policy regarding access to linked Commonwealth data and publicly funded health data for research.

Louisa is a high-profile advocate for more and better use of routinely collected health data, including a recent commentary published in The Australian, participation in the 2015 Zunz Lecture “The promise of big data” broadcast by Radio National as part of its “Big Ideas” series, appearing as a witness before the Senate Select Committee on Health in 2015, and role as a discussant at a Consumers Health Forum workshop about using routinely collected data to enhance consumer outcomes while still protecting their rights to privacy.

Louisa represents the NHMRC on the international Public Health Research Data Forum convened by the Wellcome Trust. She was an invited participant in the inaugural meeting of the Australia-US Science and Technology Joint Commission Steering Committee meeting in Washington DC in 2011. Louisa is a member of the Boards of the NSW Bureau of Health Information and Scientia Clinical Research and of the Australian Burden of Disease Study Expert Advisory Group.

Since 2011, Louisa has been awarded $10.3m in grant funding from the NHMRC, National Heart Foundation and Scottish Chief Scientist’s Office, including $1.5m as CIA. She is CIA of current NHMRC Project and Partnership Project grants and CI on a further two NHMRC Project grants. She has undertaken commissioned research for the NSW Clinical Excellence Commission, the Australian Commission on Safety and Quality in Health Care, HealthDirect Australia and various Local Health Districts. Louisa has authored 59 peer-reviewed publications since 2011, more than half of these first-authored by her students and postdocs. Her publications have been cited >1450 times since 2011. She has given invited plenary presentations at 4 international and 11 national conferences since 2011.

Since 2011, Louisa has supervised 6 PhD candidates (4 as principal supervisor) and 3 Honours candidates to completion. She is currently supervisor of 4 PhD candidates and 4 early career postdoctoral researchers.
Kathleen Falster
Dr Kathleen Falster is an epidemiologist with interest and expertise in epidemiologic methods, cohort and cross-sectional studies, analysis of linked data, managing and manipulating large and complex datasets, and the health of disadvantaged populations.

Kathleen is currently an NHMRC Early Career Fellow with the National Centre for Epidemiology and Population Health at the Australian National University and the Sax Institute. She is also a Visiting Fellow with the Centre for Big Data Research in Health at the University of New South Wales. Her current research focuses on health and development outcomes in Aboriginal children using data from cohort studies and linked administrative datasets.

Kathleen is a Chief Investigator and the Study Director of the NHMRC-funded 'Seeding Success' study that aims to identify factors that promote positive early childhood health and development in Aboriginal children using linked, cross-sectoral population datasets. She has also collaborated with the Indigenous Health Outcomes Patient Evaluation (IHOPE) study since 2010.

Michael Falster
Michael Falster is a Biostatistician and Research Fellow at the Centre for Big Data Research in Health (CBDRH) at UNSW Australia. Michael has over 10 years' experience working in public health, biostatistics and epidemiological research, and is currently project coordinator on the Assessing Preventable Hospitalisation InDicators (APHID) Study, an NHMRC funded partnership grant using linked data to explore contributors to geographic variation in 'preventable' hospitalisations.

Michael's work and interests are characterized by finding innovative statistical methods for quantifying and exploring variation in health and health care, such as: multilevel models for deconstructing geographic variation in health inequalities and outcomes; data visualizations exploring temporal patterns of health events; spatial methods for identifying and analyzing hospital patient catchments; and data algorithms for characterizing longitudinal patterns of healthcare use. Having a background in health, policy and statistics, Michael is interested in translating complex statistical methods and findings towards a policy audience.

Amy Gibson
Dr Amy Gibson is an epidemiologist and Research Fellow who conducts analyses using linked health data and participates in public health policy projects. She joined the Centre for Big Data Research in Health in 2014, and is currently drafting the data governance framework for the UNSW Australia E-Research Institutional Cloud Architecture (ERICA).

She is also an investigator on two linked data projects; one examining the incidence and clinical outcomes of meningococcal disease in children; and the other evaluating outcomes following calls to healthdirect Australia, a telephone-based health care triage and advice service. Amy completed her PhD on mortality associated with maintenance treatments for opioid dependence at UNSW in 2009 and her MPH (University of Sydney) in 2004.

Amy is particularly interested in the use of large administrative health data sets for research, including their analysis, and the policies and governance of their use. She has worked with a range of data sets including hospital admissions, emergency department presentations, mortality data, notifiable conditions, perinatal data, telephone triage data and registrations for maintenance pharmacotherapies for the treatment of opioid dependence. She has experience in a range of public health fields including drug and alcohol dependence, paediatric communicable disease and telemedicine.

Mark Hanly
Dr Mark Hanly is an Associate Research Fellow in the Health Services and Outcomes Unit, Centre for Big Data Research in Health. In his role as statistician on the Seeding Success
project, Mark is responsible for managing, preparing, and analysing the linked administrative datasets used in the study. Mark joined the CBDRH from the University of Bristol, where he completed his PhD in Advanced Quantitative Methods for the Health and Social Sciences. His doctoral research focused on novel approaches to correct for nonresponse bias in large household surveys. He also holds a MSc in Applied Social Research from Trinity College Dublin.

As a social statistician, Mark’s broader research interests lie on the intersection between the collection and analysis of data pertaining to people’s everyday lives, across a range of domains, including health, gerontology, education, and early childhood development. Methodologies of interest include: sampling and household surveys; data linkage; sequence and event history analysis, with applications to longitudinal data; multilevel modelling, used to study hierarchical effects arising in the context of clustered data; best practice approaches for addressing missing data; techniques for program evaluation in the context of non-random rollout and uptake of services; and modern approaches to version control, which promote collaborative and reproducible research.

Alys Havard
Dr Alys Havard is a Senior Research Fellow in the Centre for Big Data Research in Health at the University of New South Wales (UNSW). She was awarded her PhD in 2011, and since then she has been supported by an NHMRC Early Career Fellowship followed by a National Heart Foundation Future Leader Fellowship.

Alys’ primary research interest is in using linked administrative datasets for tobacco control research and for examining the utilisation and safety of prescription medications. She has a growing national profile as an expert in research using large-scale routinely collected health data, and in particular, these data linked together to create longitudinal person-based records. She leads the first project to obtain Commonwealth Pharmaceutical Benefits Scheme (PBS) data linked to administrative data from other jurisdictions (NSW and WA) since arrangements for cross-jurisdictional data linkage were established in Australia. This NHMRC-funded project investigates the utilisation and safety of medications during pregnancy. It has brought together 10 different data collections, resulting in a linked dataset containing almost 35 million records belonging to over 2 million individuals. She is also currently undertaking a fellowship project of similar scale in which she is examining the safety of pharmacotherapies for smoking cessation in the general population.

Nusrat Homaira
Dr Nusrat Homaira is a medical epidemiologist with 10 years working experience in the field of epidemiological and population health research. Much of her work has evolved around outbreak investigations, establishing surveillance for communicable diseases and estimating burden of childhood disease using low cost novel methodologies. Nusrat’s expertise includes aetiological epidemiology of childhood infectious respiratory diseases. She is interested in understanding the complex interrelationship between communicable and non-communicable respiratory diseases and how it is modified by environmental factors with a particular interest in the contribution of early childhood viral infections on chronic respiratory morbidity. Prior to coming to UNSW, she worked as Assistant Scientist, Centers for Communicable Diseases at the International Centre for Diarrhoeal Disease Research, Bangladesh (icddr,b).

Mikaela Jorgensen
Dr Mikaela Jorgensen is a Research Fellow at the Centre for Big Data Research in Health at UNSW. She is project coordinator for Seeding Success, a study aiming to identify factors that contribute to positive early childhood health and development in Aboriginal children using linked population-based health, welfare and education data.
Mikaela completed her PhD in 2014 while working as a research officer with the Cancer Epidemiology and Services Research group at the University of Sydney. Her research included using linked routinely collected health datasets to examine disparities in the care and outcomes of older adults with colorectal cancer in NSW. She has a background in speech pathology and community aged care.

Sanja Lujic
Ms Sanja Lujic is a Lecturer in Biostatistics at the Centre for Big Data Research in Health at UNSW. She has BSc(Hons I), MStats and MBiostats and is currently completing her PhD.

Sanja is an experienced senior biostatistician who specialises in analysing complex linked administrative datasets. She has been involved in numerous research projects involving both small- and large-scale datasets, including randomised controlled trials. Her analysis expertise spans methods for analysing survey, cross-sectional, longitudinal, as well as clustered/hierarchical datasets. Sanja’s research interests include health services research, population ageing, multimorbidity, data linkage methods and the use of routinely linked administrative datasets in statistical modelling.

Deborah Randall
Deborah Randall is a Research Fellow in the Centre for Big Data Research in Health. Deborah holds a BSc (Psych), and MBiostat and has submitted her PhD. Deborah is a senior biostatistician with specialist training and expertise in survey methods, analysis of linked administrative data and multilevel modelling. Her primary research interests are in using linked administrative data to monitor health outcomes and health inequalities. She also has extensive experience as a researcher in the areas of drug and alcohol, cardiovascular disease and Aboriginal health. She has high-level data management and analytic skills, including experience analysing large population health datasets, linked data, cohort study and cross-sectional survey data.

Deborah has analysed datasets including the National Nutrition Survey, BreastScreen Register, NSW Admitted Patient Data Collection and NSW Perinatal Data Collection. She has extensive experience in report development, including setting up the programming infrastructure for the Clinical Excellence Commission report Quality of Healthcare in NSW: A Chartbook.

Bich Tran
Dr Bich Tran joined the Centre for Big Data Research in Health in 2015 as an Associate Research Fellow. Her current project is to investigate indicators of potentially preventable hospitalisation and readmission. She will use data from the 45 and Up Study and linkage to other health records including the NSW Admitted Patient Data Collection to identify admissions and Medicare Australia for non-hospital medical attendances/services.

Bich spent 2 years prior to her current position at the Centre for Health Research based at the University of Western Sydney where she also analysed large-scale linked data. She did her postdoc at the Queensland Institute of Medical Research with the focus on sun, vitamin D and health. Dr Bich Tran obtained PhD in Medicine from the Garvan Institute of Medical Research in 2010. Her thesis was to develop clinico-genetic models to predict osteoporotic fracture risk. She was awarded the prestigious Young Investigator Award by the American Society of Bone and Mineral Research in 2007; and a travel grant by the Australian and New Zealand Bone and Mineral Society at the completion of her PhD.

Danielle Tran
Dr Danielle Tran is a Research Fellow in epidemiology and health services research. She has expertise in using large-scale linked datasets for research on utilisation and outcomes of health services and interventions, chronic diseases and patient safety. She uses complex
statistical analyses to assess independent effects of patient and health services factors on health outcomes.

Currently, Dr Tran is undertaking projects to investigate the utilisation and safety of smoking cessation pharmacotherapies and other medications during pregnancy, evaluate patient compliance and health outcomes following 1.4 million calls to the national healthdirect telephone triage service, and assess the use of primary care and quality of care among people with diabetes.

National Perinatal Epidemiology and Statistics Unit

Georgina Chambers
Associate Professor Georgina Chambers is the Director of the National Perinatal Epidemiology & Statistics Unit (NPESU), a leading source of statistical and epidemiological research to inform policy, community discussion and decision-making on the health and wellbeing of mothers and babies in Australia.

Georgina is a leading international expert on the epidemiology and health economics of assisted reproductive technologies (ART). Her qualifications include a PhD, an MBA, a BAppSci(MLS), and a Grad Diploma(IT). Georgina has built a significant research career in perinatal epidemiology, policy analysis and health economics. She established the first research group dedicated to policy and economic analysis of ART in 2010 and has received two Category 1 Grants (as CIA) to support this group. She has significant experience in leading data linkage projects, including on the health outcomes of ART conceived children. She undertook a number of policy analyses as they relate to IVF, including publications on the impact of changes to the Extended Medicare Safety Net, access to IVF by socioeconomic groups, impact of affordability on clinical practice and child outcomes.

Georgina’s work informs (inter)national policy and the public debate on funding of fertility treatments, providing information and advice to government bodies (Australia, UK, Canadian governments) on policies related to fertility treatments. She is a member of the International Committee Monitoring Assisted Reproduction (ICMART).

Georgina has been CIA on two Category 1 grants on health economics and epidemiology of fertility treatments (NHMRC Project 2016-18, ARC Linkage 2010-14). Since 2011, she has received $5.6 million in Category 1 funding and $1.1 million in Category 2 funding (AIHW, NSW Health, New Zealand Government, Fertility Society of Australia, Australian Fertility Medicine Foundation).

In the last 5 years Georgina has authored 30 epidemiology and health economic publications in perinatal health, including 20 peer-review articles (>750 citations since 2011), a book chapter and 8 government reports. Georgina is also senior author of the Australian Institute of Health and Welfare (AIHW) Australian Mother and Babies 2012, which the national statistical report on women giving birth in Australia and neonatal outcomes, and leads significant components of the National Maternity Data Development Project (NMDDP) including the maternal mortality data linkage project to be published in April 2016. She is a regular invited speaker at conferences (12 invited speaking appointments since 2011) and frequently speaks with the media on subjects pertaining to her research and fertility policy. Her paper ‘Socioeconomic disparity in access to IVF’ was awarded Best Clinical Paper at the Fertility Society of Australia 2015 meeting and will be presented as plenary paper at the British Fertility Society Scientific Meeting in 2017.

As NPESU Director, Georgina supervises 3 academic and 8 professional staff. She currently supervises 4 higher degree students.
Sharon Chow
Sharon Chow is the Coordinator for the Australian and New Zealand Neonatal Network (ANZNN), a registry that monitors the care of high risk newborn infants in Australia and New Zealand. The ANZNN is based at the National Perinatal Epidemiology and Statistics Unit (NPESU), in the Centre for Big Data Research and the School of Women's and Children's Health, Faculty of Medicine. Sharon Chow has skills in database management, validation and analysis in SQL Server.

Katie Harris
Dr Katie Harris is a Research Fellow in Biostatistics in the National Perinatal Epidemiology and Statistics Unit, Centre for Big Data Research in Health, UNSW and course coordinator for Reproductive and Perinatal Epidemiology and Statistics, School of Women's and Children's Health, Faculty of Medicine, UNSW.

Katie has gained extensive experience as a biostatistician, specialising in statistical techniques such as multilevel modelling, longitudinal data analysis, functional data analysis and relative survival analysis, and is highly competent with the statistical software package R. Current research interests are in Assisted Reproductive Technology and Maternal and Perinatal outcomes at birth.

Lisa Hilder
Dr Lisa Hilder is a Senior Project Officer. Following medical undergraduate training and internship she went to in India where she co-ordinated field work for a study pre-school nutritional status using anthropometric data. Lisa went on to postgraduate clinical training in obstetrics, gynaecology and sexual health. In 1987 she was a research visitor in the Demography at LHSTM before undertaking formal qualifications in epidemiology. Lisa was a lecturer in the Department of Epidemiology at the Royal London Hospital Medical School and later a Senior Research Fellow in the Department of Midwifery at City University in London, where she was awarded a University Research Prize for a national record linkage study of NHS Numbers for Babies data with birth registration data that made gestational age at birth available for the first time for statistical reporting.

Lisa’s research focus has remained centred on the effective use of routinely collected data and record linkage. Since returning to Australia in 2008 I have worked full time as a Perinatal Epidemiologist on national perinatal reporting and record linkage studies.

Sadia Hossain
Sadia Hossain is a Research Assistant for the Australian and New Zealand Neonatal Network (ANZNN). The ANZNN is based at the National Perinatal Epidemiology and Statistics Unit (NPESU), in the Centre for Big Data Research and the School of Women’s and Children’s Health, Faculty of Medicine. Sadia assists in regular data management, preparation of data for research requests and publication of reports.

Jolie Hutchinson
Jolie Hutchinson is a Biostatistician in the National Perinatal Epidemiology and Statistics Unit within the Centre for Big Data Research in Health. Prior to this she worked with linked administrative data exploring the impact of perinatal mental health policies for an NHMRC Partnership grant with the Department of Psychiatry, School of Medicine (UNSW) and NPESU in collaboration with colleagues at the University of Western Australia and Deakin University. She has also worked in perinatal health at University of Sydney (Centre for Perinatal Health Services Research).

Jolie has a first class honours in statistics from Adelaide University and is currently enrolled in Masters of Biostatistics at Sydney University.
**Renate Le Marsney**

Renate Le Marsney is a Data Manager for the Australian and New Zealand Neonatal Network (ANZNN) with a focus on the follow up outcomes for infants born extremely preterm. The ANZNN is based at the National Perinatal Epidemiology and Statistics Unit (NPESU), in the Centre for Big Data Research and the School of Women's and Children's Health, Faculty of Medicine. Renate has skills in managing data for a large population registry using SQL Server.

**Amy Monk**

Dr Amy Monk is a Registered Midwife and Registered Nurse with extensive research and clinical experience in midwifery, perinatal health and maternity services. Amy joined the NPESU in 2015 and is the project manager for the NPESU components of the National Maternity Data Development Project.

Amy was recently awarded a PhD from the University of Sydney. Her thesis was entitled "Evaluating Midwifery Units (EMU): a prospective cohort study of freestanding midwifery units in New South Wales, Australia" and was funded by the National Health and Medical Research Council. Her other qualifications include a Bachelor of Nursing (Hons) from the University of Sydney, for which she was awarded the University Medal in 2003, and a Graduate Diploma (Midwifery) from the University of Technology in 2006.

**Alan Macaldowie**

Alan Macaldowie is a Senior Research Officer in the National Perinatal Epidemiology and Statistics Unit, Faculty of Medicine, UNSW. He is currently the data manager of Australia and New Zealand Assisted Reproduction Database (ANZARD). Alan has completed a Bachelor of Science in Science with Management Studies from Napier University. His current research interests and areas of expertise include perinatal/reproductive medicine and assisted reproductive technology.

**Cancer Epidemiology Research Unit**

**Claire Vajdic**

A/Professor Claire Vajdic is a population health researcher specialising in cancer epidemiology. She was awarded her PhD in 2002 and appointed Head of the UNSW Cancer Epidemiology Research Unit at the Centre for Big Data in Health Research in 2015. She leads a program of research on the causes and consequences of cancer with a focus on outcomes that inform the direction of basic science research and impact public health policy and clinical practice.

Claire is an internationally recognised expert on the environmental and genetic risk factors for lymphoma, cancer risk in immune dysregulation, and malignancies associated with sun exposure. She has a track record of successful high-level collaboration with specialists from a range of clinical, biological, population health and computational disciplines. These studies have enhanced strategies for cancer prevention and early detection in high-risk groups. For example, her data on cancer risk in people with HIV infection and kidney transplants directly informed the draft 2016 Australian *Clinical Management Guidelines for the Prevention for Cervical Cancer*. She is PI of the NSW non-Hodgkin lymphoma study and member of the GWAS working group of the international lymphoma Consortium (InterLymph). Multidisciplinary work within the InterLymph Consortium has resulted in the discovery of new gene variants for non-Hodgkin lymphoma risk, recognised by 3 *Nature Genetics* and 2 *Nature Communications* papers. These seminal discoveries have generated multiple ongoing secondary analyses of which Claire is an active collaborator. Within the Consortium she is currently leading one, and collaborating in three, international pooled analyses of
gene-environment interactions in collaboration with the National Cancer Institute, City of Hope & University of Southern California. She is also a member of the InterLymph Genetics of NHL and Skin Cancer Working Group. She is the current Chair of Cancer Council NSW Advisory Committee for Internal Research and The Bright Alliance Data Governance Committee. She is a current member of AIHW’s Cancer Monitoring Advisory Group and Data Integration Advisory Committee, the NSW Health Ethical Aspects of Data Linkage Working Group, and the Cancer Council NSW Cancer Research Committee. Organising committee member, 2016 Sydney Cancer Conference.

Claire has been awarded a total of $8.6m in competitive grants, $4.7m as CIA, and $5.9m in the last 5 years. Most of these grants (80%) are tier-one. The projects are large-scale, with a trajectory of increasing research innovation, cross-disciplinary collaboration, and international reach. She held NHMRC CDFs Level 1 and 2, 2008-2011 and 2012-2015.

Claire has a career total of 5 book chapters and 104 original articles, 9 review articles, 10 scientific communications; 59 in the last 5 years. Her Scopus citations have more than doubled from 2205 to 4637 over the last 5 years. In the last 5 years she has been invited to write 6 review articles/chapters and give 12 presentations, including at IARC, and two chapters (cutaneous and ocular melanoma; non-Hodgkin lymphoma) in the authoritative textbook *Cancer Epidemiology and Prevention* (4th Edition, Oxford University Press, in press Feb 2016).

Claire has supervised 2 PhD and 5 Honours students to completion, and is currently supervising 1 PhD student and 2 NHMRC Postdoctoral Fellows. All PhD students obtained competitive top-up awards. She was Prince of Wales Clinical School Postgraduate Coordinator (2009-2012). Claire taught Cancer Epidemiology within the UNSW Masters of Public Health program (2008-2015).

**Maria Arriaga**

Maria Arriaga is a PhD candidate and a Research Officer in the Cancer Epidemiology Research Unit at the Centre for Big Data Research in Health. In her PhD she studies the relative importance of lifestyle-related risk factors for rarer cancers in Australia. This involves application of disease burden measures to pooled data from seven Australian cohort studies, linked to the National Death Index and Australian Cancer Database, and Australian National Health Surveys.

Maria is experienced in literature searches and reviews, data management and harmonisation, and is currently gaining experience in statistical analysis of linked longitudinal data. Prior to starting her PhD, Maria completed a Bachelor of Science at the School of Pharmacy and Biochemistry, University of Buenos Aires, Argentina and a Masters in Science of Medicine (HIV/STD) at the School of Medicine, University of Sydney. She also has 8 years of experience as a Clinical Project Coordinator at the Kirby Institute, UNSW.

**Peter Hull**

Peter Hull is a Senior Research Officer with the Centre for Big Data Research in Health and the Centre for Social Research in Health. Peter has a BSc (Psych) and a BPsysch (Hons) both from Macquarie University. He has experience in computerised and online data collection and data management.

**Maarit Laaksonen**

Dr Maarit Laaksonen is a Senior Research Fellow in the Cancer Epidemiology Research Unit at the Centre for Big Data Research in Health. She is a biostatistician with 12 years’ national and international experience in the field of epidemiology and public health. Her main research focus is on the development of novel, more accurate disease burden measures and their application to big data in health to inform priorities for reducing the burden of cancer and related multi-morbidity. She holds NHMRC and Cancer Institute NSW Early
Career Fellowships, and leads an NHMRC project evaluating the population-level relevance of the risk factors for cancer in Australia.

Maarit has expertise in analyses and meta-analyses of cohort, case-control and nested case-control studies, survival models and competing risks. She is experienced in carrying out research on several diseases, including cancer, type 2 diabetes, cardiovascular diseases, and mental health disorders, and wide range of both traditional and novel risk factors related to lifestyle, environment, and genes. At UNSW, she has developed expertise in the analysis of large linked primary and secondary health datasets, aimed to inform prevention, treatment and costs of cancer.

**Marina van Leeuwen**

Dr Marina van Leeuwen is a cancer epidemiologist whose research interests include the epidemiology of lymphomas, germ cell tumours, and other young adult cancers; cancer in immune-deficient populations; late adverse treatment effects; and cancer survivorship. She is experienced in the analysis of large-scale, population-based linked health data sets.

**Jennifer Walsh**

Jennifer Walsh is the Study Coordinator for the AGOG (Australian Genomics and Clinical Outcomes of Glioma) Epidemiology Study. With BSc and MPH qualifications, Jennifer has extensive experience as a Project Manager working on surgical outcome intervention studies as well as large scale epidemiological cancer studies at the University of Sydney and Cancer Council Victoria.

In her current position as Study Coordinator, Jennifer is responsible for developing study protocols and policies, coordinating participant recruitment as well as data collection and management.

**Medicines Policy Research Unit**

**Sallie Pearson**

Professor Sallie Pearson is a leading authority in the conduct of population-based research using routinely collected health data, particularly studies examining the use and impact of prescribed medicines in routine clinical care. She heads the Medicines Policy Research Unit, Centre for Big Data Research in Health, UNSW Australia. She is also the Scientific Director the NHMRC Centre of Research Excellence in Medicines and Ageing. Sallie completed her doctoral training at the University of Newcastle, Australia, in 1998 and was the inaugural Postdoctoral Fellow in Pharmaceutical Policy at Harvard Medical School from 2000-2001. She returned to Australia in 2002 where she worked as a private consultant to the WHO Collaborating Centre in Pharmaceutical Policy, Boston, and the Australian Health Insurance Commission (now the Department of Human Services). She returned to full-time academic research in 2006 to establish her independent research group; since that time her team has received continual competitive grant and fellowship funding. Sallie was recognised for her research leadership in the post-market surveillance of cancer medicines in 2015 with the award NSW Premier’s Outstanding Cancer Research Fellow.

Sallie’s research to date has been dominated by high-quality studies on the post-market surveillance of prescribed medicines. Her program has contributed to the field by: 1) providing much needed evidence about the use and impact of prescribed medicines outside clinical trial conditions; 2) understanding the intended and unintended consequences of pharmaceutical policy decisions on the way in which individuals and the broader population access medicines; 3) demonstrating the utility of large-scale linked routine data collections to conduct health service research and contribute to clinical and policy practice; 4) advancing
the methodology relating to the use of routine data collections for pharmacoepidemiological research.

Sallie’s research has been published in leading general medical and specialist journals including *Lancet Oncology, Journal of Clinical Oncology, Annals of Oncology, Medical Journal of Australia, Pharmacoepidemiology and Drug Safety*. It has also been the subject of numerous editorials and disseminated in the popular press. Her research was cited by Professor Ian Olver, Chief Executive Officer of Cancer Council of Australia at the time of publication in the *MJA* as ‘demonstrating the potential benefits of post-marketing research for the Australian health care system’. Sallie also generates research with clinical and policy impact. For example, her pivotal research evaluating the use of targeted cancer agents in routine clinical practice has been used by the PBAC with respect to the listing of other targeted agents for public subsidy. In addition, the outcomes of Sallie’s research (published in *Archives of Internal Medicine*) addressing the discriminatory effects, by race, of a physician surveillance program formed part of the testimony on the importance of universal drug coverage in the Massachusetts Health Reform. The testimony was successful in overturning government plans to omit drug coverage for lower income enrollees in ‘minimal plans’. This work also forms part of the core curriculum in the Harvard Medical School PhD in Health Policy.

Sallie receives regular requests to consult with government organisations on matters pertaining to pharmacoepidemiology and data linkage for population health research including her role as a research advisor to NPS MedicineWise and recent invitation to present at the Senate Select Committee on Health public hearing on big data and data linkage. She is actively engaged in a range of quality use of medicines and health data linkage committees and advisory groups including: Chair, NSW Population Health Services Research Ethics Committee; Chair: NSW Ministry of Health, Ethics and Data Linkage Working Group; Member, Research Advisory Group, Department of Health and Human Services (custodian of Pharmaceutical Benefits and Medicare benefits data); Member, Drug Utilisation Sub-Committee of the Pharmaceutical Benefits Advisory Committee; and Member, Sydney Catalyst Translational Cancer Research Consortium: T2 Working Group.

Sallie is CI on $12 million in competitive grants and fellowships from NHMRC, Cancer Australia, Cancer Institute NSW since 2011: $18 million career total. Sallie has presented on 50 occasions at international meetings and workshops.

Since 2006 Sallie has supervised, or is currently supervising, ten Postdoctoral Fellows, seven PhD students, and more than ten honours students. All PhD students have gained NHMRC or APA postgraduate scholarships and many of her students and fellows have won research awards at national and international meetings.

**Melisa Litchfield**

Melisa Litchfield is the Data Manager for the Medicines Policy Research Unit at the Centre for Big Data Research in Health. She has over 15 years experience working in public health research, epidemiology and program delivery.

As Data Manager she is responsible for the overall management of the large, linked datasets administered by the unit. Her responsibilities include research governance and ethics, data storage and security, data manipulation and analysis using SAS software.

She has considerable experience in managing cohort studies including the Concord health and Ageing in Men Project (CHAMP) and international collaborations such as the Genes, Environment and Melanoma (GEM) Study.
Research funding 2015

Health Services and Outcomes Unit

New Grants awarded - 2015


Ongoing Grants - 2015


2. Havard A. The risk of cardiovascular events, seizures and psychiatric conditions associated with use of smoking cessation pharmacotherapies: a population-based study. *National Heart Foundation Future Leader Fellowship* 2015 ($519,925)


5. Havard A. The health impact of smoking in subgroups of Australians. *NHMRC Early Career Fellowship* 2011 ($290,032)

6. McNamara B, Eades S, Jorm L, Preen D, Jones J, Joshy G, Gubhaju L, Shepherd C, McCaulay D. Defying the odds': Exploring the impact of perinatal outcomes, maternal social and health outcomes and level of culturally appropriate service availability on the health of Western Australian Aboriginal infants and children. *NHMRC Project Grant* 2014 ($634,886)


National Perinatal Epidemiology and Statistics Unit (NPESU)

New Grants awarded – 2015


Ongoing Grants - 2015

1. New Zealand Ministry of Health: Assisted reproductive technology in New Zealand 2012 report ($24,000)
2. AIHW: National Maternity Data Development Project (NMDDP) Phase 2: 2015-2016, ($400,000)
3. AIHW: NPESU Core Work Program 2015-2016 ($65,000)
4. AIHW National Maternity Data Development; Maternity Models of Care Data Collection Tool: 2015-2016 ($135,000)
5. AIHW: Population Burden analysis of low birth weight by indigenous status and IECB birthweight, antenatal care and smoking data ($14,800)
6. Australian Fertility Medicine Foundation Donation: 2015-2016 ($60,000)

Cancer Epidemiology Research Unit

Ongoing Grants - 2015

3. Vajdic, Severi, McDonald, Nowak, Rosenthal, Drummond, Walker, Jeffree. Risk and prognostic factors for glioma in Australia. *Cancer Australia Priority-driven Collaborative Research Scheme* 2012 ($600,000)
4. Giles, Vajdic, Prince, Harrison, Joshua, Campbell. The epidemiology of multiple myeloma in Australia (EMMA). *NHMRC Project Grant* 2012 ($1,445,512)
5. Vajdic C. Cancer epidemiology in high-risk populations and complex cancers. *NHMRC Career Development Fellowship* 2012 ($432,568)


### Medicines Policy Research Unit

#### New Grants awarded – 2015


#### Ongoing Grants - 2015


5. Schaffer A. Post-market surveillance of medicine-related adverse events: Using linked administrative databases to explore outcomes and best-practice research methods. *NHMRC Postgraduate Scholarship 2014*


7. Daniels B. Big data to real-world evidence: Informing pharmaceutical policy decisions around targeted cancer medicines. *NHMRC Postgraduate Scholarship 2015*

8. Pearson S. Post-market surveillance of cancer medicines: Generating evidence for clinical policy practice using linked health administrative data. *Cancer Institute NSW Career Development Fellowship 2013* ($150,000)


14. Pearson S, Charles C. Do changes in chemotherapy dose and increased toxicity explain poorer survival outcomes in advanced cancer patients with systemic inflammation? *Sydney Catalyst Seed Funding Grant 2015* ($50,000)

15. Blanch B. Prescribed medicine misuse in Australia. *University of Sydney Postgraduate Award 2013*
Publications 2015

Health Services and Outcomes Unit

Papers published in peer-reviewed journals


27. Gibson A, Jorm L, McIntyre P. Using linked birth, notification, hospital and mortality data to examine false positive meningococcal disease reporting and adjust disease


**Published Reports**


**National Perinatal Epidemiology and Statistics Unit (NPESU)**

**Papers published in peer-reviewed journals**


**Letters 2015**


**Government Reports 2015**


Cancer Epidemiology Research Unit

Papers published in peer-reviewed journals


**Medicines Policy Research Unit**

**Papers published in peer-reviewed journals**


Cancer Epidemiology. 2015 Jun 19;pii:S1877-7821(15)00043-0. doi: 10.1016/j.canep.2015.02.007.


Published Abstracts

Conference presentations 2015

Health Services and Outcomes Unit


4. Jorm LR. Translating data into disease prevention and better care. Future Health Summit 2015, Melbourne, 2015 [Invited speaker, TED style talk].

5. Falster MO, Jorm LR, Leyland AH. Visualising linked health data to explore service use around preventable hospitalisations. The 11th Annual 45 and Up Collaborators Meeting, Sydney, November 2015 [Invited plenary presentation].


7. Falster, MO. Key findings from the APHID (Assessing Preventable Hospitalisation InDicators) Study, National Health Performance Authority, February 2015 [Invited presentation].


10. Falster MO, Jorm LR, Leyland A. Visualising linked health data to explore service use around preventable hospitalisations. The Farr Institute International Conference 2015, St Andrews UK 2015 [Poster presentation].

11. Falster, MO. The APHID Study: Assessing Preventable Hospitalisation InDicators. Sydney Local Health District Public Health Observatory, April 2015 [Invited presentation].


20. Tran DT, Gibson A, Randall D, Havard A, Byrne M, Robison M, Jorm L. *Compliance with healthdirect telephone triage recommendations among older patients*. 45 and Up Study Collaborators’ Meeting, the Sax Institute, Sydney, November 2015.

**National Perinatal Epidemiology and Statistics Unit (NPESU)**


5. Harris, K. Recording and Measuring the Outcome of an Assisted Reproductive Technologies (ART) Cycle: The ANZARD Database. *START (Start-up Training in Assisted Reproductive Technology) course*, November 2015 [Oral presentation].

**Cancer Epidemiology Research Unit**

1. Vajdic CM. The epidemiology of tumours induced by viruses. ViM Annual Scientific Meeting, Katoomba, April 2015 [Invited oral].


4. Vajdic CM. Genomic determinants of susceptibility to basal cell carcinoma. *Inaugural melanoma and skin cancer special interest group (MELSIG) mini-symposium*. Sydney, July 2015 [Invited oral].


6. Vajdic CM. Local and statewide issues in biobanking. Sydney, May 2015 [Invited panel member].


9. Vajdic CM. Immunology and Infection session chair. *InterLymph Annual Scientific Meeting June 2015, Holland.*


**Medicines Policy Research Unit**


5. Pearson S. Building capacity in pharmacoepidemiology research in Australia. St Vincent’s Hospital Therapeutics Centre. UNSW, Sydney Australia 2015.