

IPDLN 2020 Conference
 Virtual Workshop Program | 1 – 6 November 2020

Sunday 1 November 2020, UTC Time

Timing	Session
<p>LIVE 10:00 PM, Sunday 1 November, UTC Time</p> <p>5:00 PM, Sunday 1 November, Toronto Time 10:00 PM, Sunday 1 November, London Time 9:00 AM, Monday 2 November, Sydney Time</p> <p>Duration: 4 Hours</p>	<p>Short Course: Using Data Linkage for Research : An Introduction and Primer (session 1 of 2)</p> <p>Facilitator: Stuart Kinner and Jesse Young</p> <p>Bios: Professor Stuart Kinner is Head of the Justice Health Unit at the University of Melbourne, and Head of the Justice Health Group at the Murdoch Children’s Research Institute. He is experienced in longitudinal studies, multi-sectoral data linkage, randomised controlled trials, program evaluation, policy analysis, systematic review, and meta-analysis. He has produced >250 publications and attracted >\$24 million in research and consulting funds, mostly from nationally competitive schemes. Stuart Chairs Australia’s National Youth Justice Health Advisory Group, and the WHO Health in Prisons Programme Technical Expert Group. He is a member of the WHO Steering Group on Prisons Health.</p> <p>Dr Jesse Young is a NHMRC Emerging Leadership Fellow in the Justice Health Unit at The University of Melbourne specialising in psychiatric epidemiology with expertise in data linkage methodology. He is a member of the Australian Institute for Health and Welfare’s National Prisoner Health Information Committee and Technical Expert Group. Since 2014, Dr Young has authored a book chapter and 47 peer-reviewed publications; led reports commissioned by state and national government departments; and discussed his research on national TV and radio. His research has informed international clinical guidelines for the treatment of substance use disorder and the prevention of overdose.</p> <p>Short Course Overview: The workshop is intended as an introduction to data linkage, for individuals who have limited experience or training but either (a) are involved in managing or overseeing data linkage projects, and/or (b) wish to be developing competency in using data linkage for research. Attendees will develop an appreciation of the key</p>

	<p>technical and governance issues surrounding linkage and use of administrative data for research purposes. Those wishing to develop high-level competency will be encouraged to pursue further training. This workshop is designed for policy makers, researchers, managers, analysts, and others working in the public sector with an interest in developing an awareness of the lifecycle of linked data research. This includes:</p> <ul style="list-style-type: none"> • Learning about administrative data • Understanding the process of linking and accessing data in Australia • Applying linked data to real-world problems • Generating evidence and contributing to a body of knowledge. <p>There is no requirement for prior training or experience, however basic familiarity with research methods is an asset.</p>
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Monday 2 November 2020, UTC Time

Timing	Session
<p>LIVE 8:00 AM, Monday 2 November, UTC Time</p> <p>3:00 AM, Monday 2 November, Toronto Time 8:00 AM, Monday 2 November, London Time 7:00 PM, Monday 2 November, Sydney Time</p> <p>Duration: 2 Hours</p>	<p>Workshop: Repeatable Research Forum (session 1 of 2)</p> <p>Facilitator: Daniel Thayer</p> <p>Bio: Dan Thayer is a Senior Data Scientist who leads research software development for the SAIL Databank, based in Swansea University, Wales, UK. He directs a development program that includes standardized processes for data cleaning and transformation; tools to enable repeatable analysis; software to manage research knowledge; data quality reporting; and automation of data provision processes. In addition, he is a co-investigator on a number of applied research projects, including major pan-European projects EUROlinkCAT, investigating outcomes of congenital anomalies, and CONCEPTION, studying medication safety in pregnancy. He is also part of the operational management team of the SAIL Databank, leading on disclosure control. With a background as a software engineer, he has an interest in applying software development methods in an academic research environment and training researchers in best practices for writing code and working with data.</p> <p>Workshop Overview: It is widely recognized that enabling documentation, sharing and reuse of research methods is critical to maximizing the benefit of the wealth of population data available. Replication is key to raising the quality of and confidence in research findings. Cross-centre studies increase power to study rare events, and they can also</p>

	<p>mitigate bias found in a single data source. Enabling researchers to use methods created by others facilitates rapid, efficient research and enables continuous improvement rather than reinventing the wheel. The umbrella term “repeatable research” covers a toolbox of techniques used to meet these goals. The goals of this workshop are to:</p> <ul style="list-style-type: none"> • raise awareness of different development activities happening across our network; • introduce researchers who may not be familiar with these techniques to key concepts; • signpost them to relevant tools and approaches; and • identify possibilities for better coordination and collaboration. <p>In this workshop we will consider the state of the art in four areas: Electronic Phenotyping – Defining clinical concepts measured in data. Common Data Models – An approach to enabling sharing methods and tools. Repeatable analysis – Tools to enable rapid implementation and repeatability of standard data preparation and analysis methods. Repeatable reporting -- Techniques to facilitate repeatability in generation of outputs, including tools such as markdown.</p>
<p>LIVE 10:00PM, Monday 2 November, UTC Time</p> <p>5:00 PM, Monday 2 November, Toronto Time 10:00 PM, Monday 2 November, London Time 9:00 AM, Tuesday 3 November, Sydney Time</p> <p>Duration: 4 Hours</p>	<p>Short Course: Using Data Linkage for Research : An Introduction and Primer (session 2 of 2)</p> <p>Facilitator: Stuart Kinner and Jesse Young</p> <p>Bios: Professor Stuart Kinner is Head of the Justice Health Unit at the University of Melbourne, and Head of the Justice Health Group at the Murdoch Children’s Research Institute. He is experienced in longitudinal studies, multi-sectoral data linkage, randomised controlled trials, program evaluation, policy analysis, systematic review, and meta-analysis. He has produced >250 publications and attracted >\$24 million in research and consulting funds, mostly from nationally competitive schemes. Stuart Chairs Australia’s National Youth Justice Health Advisory Group, and the WHO Health in Prisons Programme Technical Expert Group. He is a member of the WHO Steering Group on Prisons Health.</p> <p>Dr Jesse Young is a NHMRC Emerging Leadership Fellow in the Justice Health Unit at The University of Melbourne specialising in psychiatric epidemiology with expertise in data linkage methodology. He is a member of the Australian Institute for Health and Welfare’s National Prisoner Health Information Committee and Technical Expert Group. Since 2014, Dr Young has authored a book chapter and 47 peer-reviewed publications; led reports commissioned by state and national government departments; and discussed his research on national TV and radio. His research has informed international clinical guidelines for the treatment of substance use disorder and the prevention of overdose.</p>

Workshop Overview:

The workshop is intended as an introduction to data linkage, for individuals who have limited experience or training but either (a) are involved in managing or overseeing data linkage projects, and/or (b) wish to be developing competency in using data linkage for research. Attendees will develop an appreciation of the key technical and governance issues surrounding linkage and use of administrative data for research purposes. Those wishing to develop high-level competency will be encouraged to pursue further training. This workshop is designed for policy makers, researchers, managers, analysts, and others working in the public sector with an interest in developing an awareness of the lifecycle of linked data research. This includes:

- Learning about administrative data
- Understanding the process of linking and accessing data in Australia
- Applying linked data to real-world problems
- Generating evidence and contributing to a body of knowledge.

There is no requirement for prior training or experience, however basic familiarity with research methods is an asset.

Tuesday 3 November 2020, UTC Time

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<p>LIVE 8:00 AM, Tuesday 3 November, UTC Time</p> <p>3:00 AM, Tuesday 3 November, Toronto Time 8:00 AM, Tuesday 3 November, London Time 7:00 PM, Tuesday 3 November, Sydney Time</p> <p>Duration: 2 Hours</p>	<p>Workshop: Repeatable Research Forum (session 2 of 2)</p> <p>Facilitator: Daniel Thayer</p> <p>Bio: Dan Thayer is a Senior Data Scientist who leads research software development for the SAIL Databank, based in Swansea University, Wales, UK. He directs a development program that includes standardized processes for data cleaning and transformation; tools to enable repeatable analysis; software to manage research knowledge; data quality reporting; and automation of data provision processes. In addition, he is a co-investigator on a number of applied research projects, including major pan-European projects EUROLINKCAT, investigating outcomes of congenital anomalies, and CONCEPTION, studying medication safety in pregnancy. He is also part of the operational management team of the SAIL Databank, leading on disclosure control. With a background as a software engineer, he has an interest in applying software development methods in an academic research environment and training researchers in best practices for writing code and working with data.</p>
<p>LIVE</p>	<p>Workshop: Parent-Offspring Record Linkage for Population based health research (Session 1 of 2)</p>

<p>3:00PM, Tuesday 3 November, UTC Time</p> <p>10:00 AM, Tuesday 3 November, Toronto Time 3:00 PM, Tuesday 3 November, London Time 2:00 AM, Wednesday 4 November 2020 Sydney Time</p> <p>Duration: 3 Hours</p>	<p>Facilitator: Lisa Lix</p> <p>Bio: Dr. Lisa Lix is Professor and Canada Research Chair at the University of Manitoba. Her interests include health services research methodology, quality of administrative health databases, analysis of longitudinal data, and chronic disease surveillance approaches. Dr. Lix collaborates widely on projects about population health and the association between chronic disease and quality of life outcomes. She Her recent interests lie in exploring 40+ years of Manitoba’s administrative health data and family linkage methods to examine its utility for chronic disease multigenerational studies. She works closely with the Public Health Agency of Canada to advance the Canadian Chronic Disease Surveillance System and with Health Data Research Network Canada to improve the environment for cross-jurisdictional data linkage studies.</p> <p>Workshop Overview: This workshop will introduce participants to intergenerational chronic disease studies, which link parent and offspring health history information from routinely-collected administrative data. Intergenerational studies, which are conducted in only a few research centres worldwide, provide a unique ability to study the role of biological factors, shared environments, and heritability on offspring chronic disease risk at the population level. The workshop aims are:</p> <ul style="list-style-type: none"> • To facilitate interdisciplinary discussions about priority research areas in parent-offspring record linkage studies; • To identify challenges and opportunities for international, multi-site intergenerational chronic disease studies; and • To introduce early-career investigators and trainees to intergenerational health research and facilitate their connections with established scientists
<p>LIVE</p> <p>11:00 PM, Tuesday 3 November, UTC Time</p> <p>6:00 PM, Tuesday 3 November, Toronto Time 11:00 PM, Tuesday 3 November, London Time 10:00 AM, Wednesday 4 November, Sydney Time</p> <p>Duration: 4 Hours</p>	<p>Workshop: Methods and Approaches for Optimising the Use of Linked Data in Indigenous Health Research</p> <p>Facilitator: Bridgette McNamara, Sandra Eades, Marcia Langton</p> <p>Bios: Professor Sandra Eades is the Dean of Medicine at Curtin University. In 2003, she was Australia's first Aboriginal medical doctor to be awarded a Doctorate of Philosophy (The University of Western Australia). Sandra is now internationally recognised as a leading researcher in the epidemiology of Indigenous health in Australia. Sandra also serves as Chair of the NHMRC’s Principal Committee Indigenous Caucus, in Australia. Currently, Sandra leads a</p>

NHMRC Centre for Research Excellence focused on Aboriginal child and adolescent health, and a MRFF Million Minds Mission program of research focusing on improving mental health care access for young Aboriginal people.

Professor Marcia Langton AM is an anthropologist and geographer, and is the Foundation Chair of Australian Indigenous Studies at The University of Melbourne. She has produced a large body of knowledge in the areas of political and legal anthropology, Indigenous agreements and engagement with the minerals industry, and Indigenous culture and art. In 1993, she was made a member of the Order of Australia, in recognition of her work in anthropology and the advocacy of Aboriginal rights. Her 2012 Boyer lectures titled, *The Quiet Revolution: Indigenous People and the Resources Boom*, is one of her many contributions to public debate. Her role in the Empowered Communities project under contract to the Department of Prime Minister and Cabinet, and as a member of the Expert Panel on Constitutional Recognition of Indigenous Australians, are evidence of Marcia's academic reputation, policy commitment and impact, alongside her role as a prominent public intellectual.

Dr Bridgette McNamara is a Senior Research Fellow in the Indigenous Epidemiology and Health Unit, Centre of Epidemiology and Biostatistics at The University of Melbourne. Awarded her PhD in 2009, her subsequent research has examined the determinants of health and wellbeing among Aboriginal and Torres Strait Islander people across the life-course, using total population linked health and administrative data and large cohort data. She currently leads the *Defying the Odds* study into early childhood morbidity and mortality among Aboriginal children in WA.

Workshop Overview:

This workshop will focus on processes, methods and overcoming challenges in the use of linked data for Indigenous health research, from a research perspective. This workshop will draw on expertise of Indigenous and non-Indigenous research leaders to present and discuss successful methods for optimising the use of linked data in mixed method study designs across a range of topics in Indigenous health. By the end of this workshop, participants will learn about and be able to discuss:

1. Broader issues related to the governance of data generated by and about Indigenous Australians, including the holding, controlling and processing of data, and its classification of as a proprietary asset.
2. Successful methods of engaging and partnering with Aboriginal and Torres Strait Islander community leaders and organisations in research programs involving linked data analysis.
3. Strengths of mixed method designs for working with the perspectives, priorities and concerns of Aboriginal community-controlled health services and policy agencies.
4. Understanding the value, the gaps and limitations, and data quality of linked administrative data about Aboriginal and Torres Strait Islander people.
5. Specific methodological approaches to address challenges of working with population-based linked data for Indigenous health research (Indigeneity, different patterns of service usage and access based on location and social circumstances).

6. Responsible and ethical reporting of findings from linked data.

Wednesday 4 November 2020, UTC Time

Timing	Session
<p>LIVE 8:00 AM, Wednesday 4 November, UTC Time</p> <p>3:00 AM, Wednesday 4 November, Toronto Time 8:00 AM, Wednesday 4 November, London Time 7:00 PM, Wednesday 4 November, Sydney Time</p> <p>Duration: 2 Hours</p>	<p>Workshop: Exporting Federated Data Science and Analysis, Governance and Technology Approaches</p> <p>Facilitator: Simon Thompson and David Ford</p> <p>Bios: Simon Thompson is a systems architect with many years' experience in the NHS and academia. He is the Chief Technology Officer of a large team of talented, diverse skilled software developers. Simon leads the innovation, design, development and implementation of all SAIL technical system developments. He is responsible for delivering the technical workstream for Swansea as part of the UK network of health e-research centres of excellence.</p> <p>David Ford is Professor of Health Informatics and leads the Health Informatics Group at College of Medicine in Swansea University, Wales, UK. He is Director of the Administrative Data Research Centre (ADRC) Wales, an £8 million investment by the Economic and Social Research Council (ESRC) as part of its Big Data initiative and is Deputy Director of a the Centre for Improvement in Population Health through E-records Research (CIPHER), part of the Farr Institute of Health Informatics Research, funded by a consortium of top UK research funders led by the Medical Research Council (MRC).</p> <p>David is also Director of the eHealth Industries Innovation (ehi2) Centre, developing links between academia, the NHS, and business within the UK and internationally. He is also University Director of NHS Wales Informatics Research Laboratories, created through a collaboration between the College of Medicine, Swansea University and NHS Wales Informatics Service, the national programme for NHS IT for Wales. The Research Laboratories provide state-of-the-art facilities to design, prototype, test and evaluate innovative new information technologies for use in improving health and healthcare.</p> <p>David is joint lead of the Health Information Research Unit for Wales (HIRU), which develops new ways of harnessing the potential of routinely collected information collected in health and other settings. HIRU's main product is the SAIL Databank, an internationally recognised data linkage resource formed from a wide variety of routinely collected data from across Wales.</p>

	<p>David is a Fellow of the Royal Society for the Encouragement of the Arts, Manufactures and Commerce (FRSA) and past Chairman and a current Director of MediWales, a membership organisation representing the medical technology sector of Wales. David is a member of numerous committees and national bodies relating to health informatics and health-related research. He has received research grants and consultancy contracts valuing over £35m over recent years.</p> <p>Workshop Overview: The wide spread adoption of trusted research environments has brought massive advantages and benefits. However, this has led to increased siloing of data holdings with a complex mixture of differing governance models, most of which prevent data release or movement. The workshop objectives are to explore current approaches, constraints, governance models enable federating access to large siloed collections in order to accelerate data science. Attendees will both gain an understanding of the current approaches available and their perspective strengths/weaknesses. The key benefit is the ability to meaningfully shape the direction of development for these emerging technologies and ensure that they do not lose sight of the end user utility and are able to deliver against a data science use case that clearly increases the power of research beyond what is achievable today.</p>
<p>LIVE 3:00PM, Wednesday 4 November, UTC Time</p> <p>10:00 AM, Wednesday 4 November, Toronto Time 3:00 PM, Wednesday 4 November, London Time 2:00 AM, Thursday 5 November, Sydney Time</p> <p>Duration: 3 Hours</p>	<p>Workshop: Parent-Offspring Record Linkage for Population based health research (Session 2 of 2)</p> <p>Facilitator: Lisa Lix</p> <p>Bio: Dr. Lisa Lix is Professor and Canada Research Chair at the University of Manitoba. Her interests include health services research methodology, quality of administrative health databases, analysis of longitudinal data, and chronic disease surveillance approaches. Dr. Lix collaborates widely on projects about population health and the association between chronic disease and quality of life outcomes. She Her recent interests lie in exploring 40+ years of Manitoba’s administrative health data and family linkage methods to examine its utility for chronic disease multigenerational studies. She works closely with the Public Health Agency of Canada to advance the Canadian Chronic Disease Surveillance System and with Health Data Research Network Canada to improve the environment for cross-jurisdictional data linkage studies.</p>

Thursday 5 November 2020, UTC Time

Timing	Session
<p>LIVE 8:00 AM, Thursday 5 November, UTC Time</p>	<p>Workshop: Using Common Data Models in the Real World</p> <p>Facilitator: Douglas IR Boyle, Nicole Pratt, Daniel Capurro</p>

3:00 AM, Thursday 5 November, Toronto Time
8:00 AM, Thursday 5 November, London Time
7:00 PM, Thursday 5 November, Sydney Time

Duration: 2 Hours

Bios:

Douglas IR Boyle (PhD, BSc Hons) is an Associate Professor and Academic Specialist in the Department of General Practice, Melbourne Medical School with a specialty in Health Data Science. He is also the Academic Convenor for the University of Melbourne Petascale Campus Initiative and Chair of the University Expert Group on Research Data Management. He has degrees in Computer Studies and Microsystems (BSc, Dundee, Scotland), and Health Informatics – Data Acquisition (PhD, Dundee, Scotland). He is the founding Director of the University of Melbourne, Health and Biomedical Informatics Centre Research Information Technology Unit (HaBIC R2), Project Lead for the Australian Health Research Alliance, Transformational Data Collaboration and a Fellow of the Australian Institute of Digital Health.

A/Prof Pratt is an expert in biostatistics and pharmaco-epidemiology, specialising in the development of methodologies to study the effects of medicines and medical devices in linked health-care datasets. She is Deputy Director of the Quality Use of Medicines and Pharmacy Research Centre, University of South Australia. Nicole made significant contributions to medication safety surveillance, developing analysis software and pioneering a distributed network model to allow it to be implemented globally. Her research includes knowledge generation and quantification of harms from medicines and devices and has led to TGA safety warnings, changes in practice and changed guidance for medicine use. For the last five years Nicole has worked collaboratively with OHDSI (Observational Health Data Sciences and Informatics) and has helped to develop a comprehensive framework for analysing linked observational healthcare data at-scale. LEGEND (Large-scale Evidence Generation across a Network of Database) aims to generate real world evidence on the effects of medical interventions using best-practice statistical methodology to support clinical decision making.

Dr Daniel Capurro is a MD trained in Internal Medicine and holds a PhD in Biomedical and Health Informatics from the University of Washington in Seattle. Dr Capurro's main interest is to develop methods to improve the use of clinical data for research. This includes the use of electronic health records and the data collected in them. Dr Capurro has extensive applied experience in health informatics since he was the Chief Medical Information Officer for Chile's Catholic University university healthcare network (2 hospitals, 11 clinics) during 4 years and he founded the Chilean National Centre for Health Information Systems, a 5-university initiative to implement healthcare information interoperability standards and to develop the health informatics workforce in the Chile.

Workshop Overview:

The objectives of this workshop are to describe the philosophy of Common Data Models (CDMs), what they look like and their place in the research continuum, especially in the context of real world health data linkage. This workshop will focus on how researchers can adopt a CDM approach to facilitate the generation of large-scale real-world evidence from their data sources. As a result of this workshop participants will understand the concept of

	<p>Common Data Models, how they can map data to a CDM framework and how to use vocabularies within the CDM to standardise content data to facilitate international studies.</p>
<p>LIVE 3:00 PM, Thursday 5 November, UTC Time</p> <p>10:00 PM, Thursday 5 November, Toronto Time 3:00 PM, Thursday 5 November, London Time 2:00 AM, Friday 6 November, Sydney Time</p> <p>Duration: 2 Hours</p>	<p>Workshop: Exporting Federated Data Science and Analysis, Governance and Technology Approaches (repeat)</p> <p>Facilitator: Simon Thompson and David Ford</p> <p>Bio: Simon Thompson is a systems architect with many years’ experience in the NHS and academia. He is the Chief Technology Officer of a large team of talented, diverse skilled software developers. Simon leads the innovation, design, development and implementation of all SAIL technical system developments. He is responsible for delivering the technical workstream for Swansea as part of the UK network of health e-research centres of excellence.</p> <p>David Ford is Professor of Health Informatics and leads the Health Informatics Group at College of Medicine in Swansea University, Wales, UK. He is Director of the Administrative Data Research Centre (ADRC) Wales, an £8 million investment by the Economic and Social Research Council (ESRC) as part of its Big Data initiative and is Deputy Director of a the Centre for Improvement in Population Health through E-records Research (CIPHER), part of the Farr Institute of Health Informatics Research, funded by a consortium of top UK research funders led by the Medical Research Council (MRC).</p> <p>David is also Director of the eHealth Industries Innovation (ehi2) Centre, developing links between academia, the NHS, and business within the UK and internationally. He is also University Director of NHS Wales Informatics Research Laboratories, created through a collaboration between the College of Medicine, Swansea University and NHS Wales Informatics Service, the national programme for NHS IT for Wales. The Research Laboratories provide state-of-the-art facilities to design, prototype, test and evaluate innovative new information technologies for use in improving health and healthcare.</p> <p>David is joint lead of the Health Information Research Unit for Wales (HIRU), which develops new ways of harnessing the potential of routinely collected information collected in health and other settings. HIRU’s main product is the SAIL Databank, an internationally recognised data linkage resource formed from a wide variety of routinely collected data from across Wales.</p> <p>David is a Fellow of the Royal Society for the Encouragement of the Arts, Manufactures and Commerce (FRSA) and past Chairman and a current Director of MediWales, a membership organisation representing the medical technology sector of Wales. David is a member of numerous committees and national bodies relating to health</p>

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