

## 2016 International Population Data Linkage Conference

24-26 August 2016  
Wales, United Kingdom

[www.ipdlnconference2016.org](http://www.ipdlnconference2016.org)

### Linking Data - Improving Lives

**Pre-Conference Workshops**  
22-23 August 2016

**Main Conference**  
24-26 August 2016

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In collaboration with



Administrative Data  
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**Swansea University**  
Prifysgol Abertawe

Conference proceedings  
published by



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# Acknowledgements

The conference committee for the 2016 International Population Data Linkage Conference thanks the conference sponsors for their generous support.

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# Welcome to the 2016 International Population Data Linkage Conference

It is with the greatest of pleasure Wales welcomes you to the **International Population Data Linkage Network (IPDLN) Conference 2016.**

This event builds upon a history of wonderful IPDLN conferences across the globe and it is both an honour and a privilege for Swansea to host it this year.

Wales, a small nation, has distinguished itself both in the UK and internationally, by being at the forefront of efforts to make health and administrative data systematically available for research for a number of years. Its work has been heavily informed by the work of others across the world, and there is no doubt that the IPDLN and its past conferences have made this possible, providing the opportunities to learn of the exciting advances, techniques and approaches taken by others. The strong connections we have made have lasted, and it is a pleasure to help continue this process for the benefit of all in our growing community.

This year's conference has been influenced significantly by the data linkage landscape in the UK and it has been a pleasure to work with two very significant research entities in the UK to deliver the event - The Farr Institute of Health Informatics Research, a health-orientated research collaboration funded by a consortium of UK's health research funders led by the Medical Research Council, and the Administrative Data Research Network, funded by the UK's Economic and Social Research Council. Working together with the



IPDLN, we have attempted to bring you a stimulating, informative and hopefully useful programme of scientific talks, rapid fire sessions and multimedia posters. We are particularly excited by the wonderful keynote speakers that have agreed to give up their time to address us. We have also tried to make your time in Wales enjoyable as well as informative and so there is a varied set of social activities to accompany the science, designed to give you a taste of Wales.

As many of you will know, organising a conference is a very significant undertaking and I need to acknowledge the many who have worked tirelessly to bring things together. In particular, the conference's International Scientific Committee members, volunteers from across health and social science research communities both in the UK and internationally; the local organising team, led by Stephanie Lee; Swansea University for providing its new beachfront located

Bay Campus for our use; and our sponsors, who's contributions have been so vital.

But most importantly, I would like to thank you - whether you are an invited speaker, giving a talk or poster, or are attending as a delegate. What makes these conferences so special is the people one meets, the connections we make, and the things that we learn from others. We hope you take advantage of the opportunities the event offers, to move things forward in your own world and to help build our worldwide community.

We hope you enjoy!

**David V Ford**

Professor of Health Informatics, Swansea University Medical School

Chair of the International Population Data Linkage Conference 2016 and Current Director of the International Population Data Linkage Network



# Committees

## International Scientific Committee



### Chair of the International Scientific Committee and Conference

**Professor David Ford**  
Current Director of the International Population Data Linkage Network, Professor of Health Informatics  
Swansea University Medical School, UK



**Athanasios Anastasiou**  
Lecturer in Health Data Science  
Swansea University Medical School, UK



**Professor Marcos Ennes Barreto**  
Assistant Professor  
Federal University of Bahia, Brazil



**Professor Chris Dibben**  
Director  
Administrative Data Research Centre Scotland, UK



**Professor Mika Gissler**  
Professor  
National Institute for Health and Welfare, Finland



**Dr Catharine Goddard**  
Manager  
The Farr Institute of Health Informatics Research, UK



**Dr Zisis Kozlakidis**  
Researcher  
University College London, UK



**Professor David Martin**  
Deputy Director  
Administrative Data Research Centre England, UK



**Associate Professor Kimberlyn McGrail**  
Associate Professor  
University of British Columbia, Canada



**Associate Professor Rebecca Mitchell**  
Associate Professor  
Australian Institute of Health Innovation, Australia



**Dr Goran Nenadic**  
Reader  
University of Manchester, UK



**Dr Dermot O'Reilly**  
Senior Clinical Lecturer  
Administrative Data Research Centre Northern Ireland, Northern Ireland



**Professor Sallie Pearson**  
Head, Medicines Policy Research Unit  
Centre for Big Data Research in Health, Australia



**Michael Schull MSc MD FRCPC**  
President, CEO and Senior Scientist  
University of Toronto, Canada



**Professor Tjeerd van Staa**  
Professor of Health eResearch  
University of Manchester, UK

## Local Organising Committee

The Local Organising Committee members are based within the Health Informatics Group at Swansea University Medical School.



### Chair of the Local Organising Committee

**Stephanie Lee FCIM Chartered Marketer**  
Head of Marketing & Communications  
Swansea University Medical School, UK



### International Population Data Linkage Network Manager

**Sharon Hindley**  
Content Marketing  
Swansea University Medical School, UK

**Michael Bale** Graphic, Web & Mobile App Design and Development  
**Nick Corlett** Administrative Support  
**Lynsey Cross** Public Engagement  
**Cynthia McNerny** Information Governance  
**Chris Orton** Logistics Planning - Pre-conference Social Activities  
**Jeffrey Peng** Web Development  
**Cathrine Richards** Press and Media Relations  
**Simon Thompson** Mobile Application  
**Sarah Toomey** Events Management

And members from Swansea University's Conference Services and Campus Catering.

## PhD/Early Career Researcher Summer School Planning Committee

The PhD/Early Career Researcher Summer School is hosted by The Farr Institute of Health Informatics Research.

**Athanasios Anastasiou** Swansea University Medical School, UK  
**Catharine Goddard** University of Dundee, UK  
**Colin McCowan** University of Glasgow, UK  
**Georgina Moulton** The University of Manchester, UK  
**Paul Taylor** University College London, UK

# Workshop Coordinators & Facilitators

The conference committees for the 2016 International Population Data Linkage Conference thank the workshops' coordinators and facilitators for the time and effort they have put into creating and facilitating the workshops programme.

**Athanasios Anastasiou** Swansea University Medical School, UK  
**Mahmoud Azimaee** ICES Central, Canada  
**Amitava Banerjee** University College of London, UK  
**Joanne Demmler** Swansea University Medical School, UK  
**James Farrow** SA.NT DataLink, University of Sydney, Australia  
**Elizabeth Ford** Brighton and Sussex Medical School  
**Richard Fry** Swansea University Medical School, UK  
**Abraham George** Kent County Council, UK  
**Catharine Goddard** University of Dundee, UK  
**Pia Hardelid** UCL Institute of Child Health, UK  
**Richard Jackson** Kings College London, UK  
**Kerina Jones** Swansea University Medical School, UK  
**Jonathan Kennedy** Swansea University Medical School, UK

**Arron Lacey** Swansea University Medical School, UK  
**Lisa Lix** ICES Central, Canada  
**Colin McCowan** University of Glasgow, UK  
**Kimberlyn McGrail** University of British Columbia, Canada  
**Anne McKenzie** The University of Western Australia, Australia  
**Hannah Moore** UCL Institute of Child Health, UK  
**Georgina Moulton** The University of Manchester, UK  
**Rachel Reeves** UCL Institute of Child Health, UK  
**Rainer Schnell** City University London, UK  
**Paul Taylor** University College London, UK  
**Pennie Taylor** Journalist and Health Communications Specialist, UK  
**Dan Thayer** Swansea University Medical School, UK  
**Shang Ming Zhou** Swansea University Medical School, UK

# Keynote Speakers



## Mauricio L Barreto

Oswaldo Cruz Foundation-FIOCRUZ, Brazil

### The 100 million Brazilian linked data and data centre

Wednesday 24 August 2016 | 08:15 - 08:45

Mauricio L. Barreto MD, MPH and a PhD is a Brazilian epidemiologist. His research interests includes the social and environmental determinants of infectious diseases, allergy and asthma and the evaluation of the impact of large social and health interventions on population health. He has coordinated large research projects, including the “100 million Brazilian cohort” focused on the study of the social protection policies on health and other outcomes (education, work etc.). This project creates great challenges on assembling, linkage, processing, analysis and governance of administrative data in the Brazilian context. Mauricio has participated in several scientific and health policies advisory boards and he has published over 360 peer-reviewed scientific papers in international journals. He is an Honorary Senior Researcher of the National Research Council-Brazil (CNPq), fellow of the Brazilian Academy of Sciences and The World Academy of Sciences(TWAS), Honorary Professor at the LSHTM-UK, Editorial consultant of the Lancet and up to February 2011 Editor-in-Chief of Journal of Epidemiology and Community Health.



## Adalsteinn D Brown

University of Toronto, Canada

### Political and policy arguments for Integrated Data

Friday 26 August 2016 | 14:30 - 15:00

Adalsteinn (Steini) Brown is the Director of the Institute for Health Policy, Management and Evaluation and is also the Dalla Lana Chair in Public Health Policy and the Head of the Division of Public Health Policy at the Dalla Lana School of Public Health, University of Toronto. He is a Scientist in the Li Ka Shing Knowledge Institute at St. Michael's Hospital. Past roles include the Assistant Deputy Minister for Strategy and Policy at the Ontario Ministry of Health and Long-term Care and for Science and Research at the Ontario Ministry of Research and Innovation. He received his undergraduate degree from Harvard and his doctorate from the University of Oxford, where he was a Rhodes Scholar.



## Peter Christen

Australian National University, Australia

### Advanced computational and privacy methods for data linkage

Friday 26 August 2016 | 08:15 - 08:45

Peter Christen is a Professor at the Research School of Computer Science at the Australian National University. Before moving to Australia, he received his Diploma in Computer Science Engineering from ETH Zurich in 1995 and his PhD in Computer Science from the University of Basel in 1999.

His research interests are in data mining and data linkage, with a special focus on privacy-preserving techniques and computational challenges of data linkage. He has published over 130 articles in these areas, including in 2012 the book “Data Matching” published by Springer. He is the principle developer of the Febrl (Freely Extensible Biomedical Record Linkage) open source data cleaning, de-duplication and data linkage system.



## Gun Peggy Knudsen

Norwegian Institute of Public Health, Norway

### Registries, cohorts and biobanks - Research for better health

Wednesday 24 August 2016 | 08:45 - 09:15

Gun Peggy Knudsen is a geneticist with a PhD in epigenetics. She is Executive Director of the division for Health Data and Digitalisation at NIPH. The division has expertise in the research and management of health registries, population health studies, biobanks and IT/e-health/digitalisation. The division conducts registry-based research and health analysis, as well as genetic and other research related to biobank material. The division also has expertise in bioinformatics. She is responsible for co-ordinating health registries, IT / e-health and health studies / biobank across the institute. She has extensive experience in administrating research projects, both epidemiological and genetics projects, and has in depth knowledge of the cohort data, the biological material and previous and ongoing genetics projects based on material at NIPH.



## Ronan Lyons

The Farr Institute of Health Informatics Research, UK

### The Farr Institute: distributed multi-disciplinary team science in action

Wednesday 24 August 2016 | 13:30 - 14:00

Ronan is Professor of Public Health at Swansea University, Honorary Consultant in Public Health with Public Health Wales NHS Trust and an adjunct professor at Monash University, Australia.

He is Director of the Farr Institute Centre for Improvement of Population Health through E-records Research (CIPHER), Director of the National Centre for Population Health and Wellbeing Research, Co-Director of the DECIPHER UK Public Health Research Centre of Excellence and Co-Director of the Secure Anonymised Information Linkage (SAIL) databank, the national privacy protecting research infrastructure for Wales. The focus of Ronan's research is the use of routine data in cohorts, trials and in the evaluation of natural experiments and complex interventions. He led the development of the total population Wales Electronic Cohort for Children as a platform for the evaluation of interventions and policies. He is also involved in linking data to support a number of UK cohorts and cross cohort initiatives, including leading on the development of the analysis platform for the MRC's Dementias Research Platform UK that will bring together data from 33 cohorts, utilising the UK Secure eResearch Platform (UKSeRP).



## Christine M O'Keefe

CSIRO Data61, Australia

### Privacy, Governance & Public Acceptance in Population Data Linkage for Research

Thursday 25 August 2016 | 08:15 - 08:45

Christine is a Senior Principal Research Scientist in CSIRO Data61, and an Adjunct Professor in the School of Mathematical Sciences at the University of Adelaide. She is a Fellow of the Australian Mathematical Society and the Institute for Combinatorics and its Applications. Prior to joining CSIRO in 2000, Christine held academic positions at Adelaide University and the University of Western Australia.

The University of Adelaide awarded Christine a BSc with Honours in Pure Mathematics in 1982 and a PhD in Pure Mathematics in 1988. She also gained an MBA from the Australian National University in 2008. Christine was awarded the Australian Mathematical Society Medal 2000 for distinguished research in the Mathematical Sciences and the Hall Medal of the Institute for Combinatorics and its Applications 1996 for outstanding contributions to the field. She was included on the National Pioneer Womens' Hall of Fame Signature Quilt, A Patchwork of Empowerment.



## Dermot O'Reilly

Administrative Data Research Centre Northern Ireland, Northern Ireland

### The Administrative Data Research Network (ADRN): Better Knowledge, Better Society

Thursday 25 August 2016 | 13:30 - 14:00

Dr Dermot O'Reilly is a Senior Clinical Lecturer with the Centre for Public Health at Queen's University Belfast with an interest in social epidemiology. He is the Director of the Administrative Data Research Centre in Northern Ireland (ADRC-NI), one of four such centres recently created to facilitate access to, and linkage of, administrative data in the UK. He also helped establish the Census-based Northern Ireland Longitudinal Study (NILS) and is Operational Director of NICOLA the Northern Ireland Cohort for the Longitudinal Study of Ageing.



## Kári Stefánsson

deCODE Genetics, Iceland

### Genetics of Common/Complex Traits

Friday 26 August 2016 | 13:30 - 14:00

Kári Stefánsson, M.D., Dr. Med. has served as President, Chief Executive Officer and a Director since he founded deCODE genetics in August 1996. Dr. Stefánsson was appointed the Chairman of the Board of Directors of deCODE genetics in December 1999. From 1993 until April 1997, Dr. Stefánsson was a professor of Neurology, Neuropathology and Neuroscience at Harvard University. From 1983 to 1993, he held faculty positions in Neurology, Neuropathology and Neurosciences at the University of Chicago. Dr. Stefánsson received his M.D. and Dr. Med. from the University of Iceland and is board-certified in neurology and neuropathology in the United States. He has published numerous articles on the genetics of common/complex diseases and has been among the leaders of the world in the discovery of variants in the sequence of the human genome that associate with the risk of common/complex traits. Dr. Stefánsson was chosen by Time magazine as one of the 100 most influential men of the year for 2007 and by Newsweek as one of the 10 most important biologists of the 21 century. He was the recipient of the Jakobus Award 2007, The World Glaucoma Association Award for present scientific impact 2007, The European Society of Human Genetics Award 2009, and The Andre Jahre Award 2009.



# International Population Data Linkage Network Meetings

## Entities and identities within the IPDLN: Are we a distinct discipline?

**Wednesday 24 August 2016, 12:30 to 13:30**  
**The Great Hall, Room GH001, Ground Floor**

### Context

Part of the conversation at the 2015 International Population Data Linkage Network meeting in St. Andrews centred on what differentiates us and our Network. We clearly have a strong sense of professional kinship, but also a desire for clarity on what binds us, what our shared purpose is, and how the IPDLN can best support all of us. This workshop is an opportunity to move one specific aspect of this conversation forward: Are we developing a new scientific discipline? If so, what is it, and what are its boundaries?

### Background

Based on the 2015 discussion and some further background work that has taken place in the interim, Population Data Science is one potential term for the discipline encompassing and distinguishing our work. The following ideas are put forward as discussion openers:

### What is it?

Population Data Science is a multi-disciplinary field aimed at obtaining population-level insights by maximising the use of big data pertaining to the lives of individuals, and turning it into information to make a positive impact on citizens and society.

### What does it do?

Population Data Science encompasses all activities that relate to privacy-sensitive big data that focuses mainly (though not exclusively) on individuals, including: data storage and management; architectures and infrastructures; legal and regulatory issues; privacy-protection methodologies; data and linkage quality; analytical advances; accessing distributed data; using big data; linking to emerging/complex data types; outcomes research; public involvement and engagement; capacity building; and delivering and measuring impact.

### What does it use?

Population Data Science uses technology to develop infrastructures and analytical solutions to manage, curate and provide secure access to big data using proportionate control measures for data privacy and utility. It makes use of multiple sources and types of big data, in standalone or linked forms. This includes the use of structured micro-data, image, free-text, spatial, omic, wearable device, social media and other emerging data types.

### Who is involved?

Population Data Science includes professionals from multiple disciplines including computer science, information governance, systems architecture, data management, software development, data analytics, privacy-protection methodologies, data mining, research methodologies, epidemiology, statistics, public engagement, etc.

### Plan

This will be an interactive session, exploring whether and how Population Data Science should be defined, the benefits and drawbacks of pursuing defining a discipline, what should be included and excluded from any definition, and what opportunities and responsibilities would be implied. We will leave the workshop with clear and explicit next steps.

Participants will be asked to suggest short definitions from their work area: this can be in free text, in the form of a Haiku <https://en.wikipedia.org/wiki/Haiku> or other short poem or illustration. Feel free to work on these in advance of the workshop! Prizes will go to the most popular of these submissions.

This workshop is open to all conference delegates.

### Organisers

Kimberlyn McGrail: [kim.mcgrail@ubc.ca](mailto:kim.mcgrail@ubc.ca)  
Kerina Jones: [k.h.jones@swansea.ac.uk](mailto:k.h.jones@swansea.ac.uk)

## International Population Data Linkage Network Members Meeting

**Thursday 25 August 2016, 12:30 to 13:30**  
**The Great Hall, Room GH011, Ground Floor**

**Open to all IPDLN Members**

## Collaboration Wall Post – Share expertise – Collaborate

Collaboration Wall is a place where delegates can arrange to meet others to discuss opportunities for collaboration. It's open to everyone from all levels and areas of work to do with Big Data and Data Linkage: research, analysis, methodological developments, technical work, information governance, public engagement, management, communications, capacity building, measuring impact, and more.

### Rationale and IPDLN role

Although we see many people at conferences, we may not always have the opportunity to find out enough information about each other's areas of expertise for building collaborations. The recent IPDLN survey showed that members are keen to increase collaborative opportunities both regionally and internationally, and that the IPDLN could take a more active role in facilitating cross country collaborations. The majority (over 50%) of respondents (N=68) felt that resource sharing/ best practice, knowledge exchange and facilitating collaborations were very important, with less than 10% considering these points not to be important. Collaboration Wall is a way for the IPDLN to promote increased collaborative working.

### How does it work?

Delegates at the conference will be able to post the following information on the IPDLN Conference App Activity Stream, and to return at convenient times to view the posts periodically:

- Interest/skill areas
- Expertise being sought
- Name
- Organisation
- Email address
- Other details (optional)
- Availability to meet during the conference
- Responses to other delegates' posts

### Getting started

Anyone planning to attend the conference is welcome to send their details (as above) in advance of the meeting so that they can be used to pre-populate the Collaboration Wall on the first day.

### Feedback

Everyone is welcome to provide feedback on Collaboration Wall:

- Should it be available as a standing item on the IPDLN website?
- How can it be improved?
- To let us know if it led to contact with a potential collaborator

### Organiser

Kerina Jones: [k.h.jones@swansea.ac.uk](mailto:k.h.jones@swansea.ac.uk)

# Pre-Conference Workshops Programme at a Glance

## Sunday 21 August 2016

12:30 - 15:00	Arrival and Registration open 📍 School of Management
13:30 - 15:00	Lunch 📍 The Core Campus Food Court
15:00 - 18:00	Check In open for Bay Campus accommodation
18:00 - 19:00	Dinner 📍 The Core Campus Food Court
19:00 - 22:00	<b>WELCOME AND INTRODUCTION FOR PHD/EARLY CAREER RESEARCHER WORKSHOPS</b> 📍 52 Degrees Café/Bar



## Monday 22 August 2016

08:00 - 08:30	Breakfast 📍 The Core Campus Food Court	
08:30 - 09:00	Registration 📍 School of Management	
09:00 - 10:30	<b>Reproducible Report Writing with R Studio</b> Dr Joanne Demmler 📍 School of Management, Room 111, First Floor	<b>Ice Breaking Session (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor
10:30 - 11:00	Break, Morning Tea and Coffee	
11:00 - 12:30	<b>Machine Learning</b> Dr Jonathan Kennedy 📍 School of Management, Room 111, First Floor	<b>Querying Data in Online Services via REST (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor
12:30 - 13:30	BBQ Lunch on the Beachfront (weather permitting)	
13:30 - 15:00	<b>SAS®-based Tools to Automate Quality Assessment of Population-based Administrative Data</b> Prof Lisa Lix 📍 School of Management, Room 117, First Floor	<b>Locating and Using Data Sources (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor
15:00 - 15:30	Break, Afternoon Tea and Coffee	
15:30 - 17:00	<b>Learning Health Systems: The Only Way to do Translational Bioinformatics?</b> Dr Amitava Banerjee 📍 School of Management, Room 111, First Floor	<b>Data Analysis workshop (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor
18:00 - 19:00	Dinner 📍 The Core Campus Food Court	
19:00 - 22:00	Optional Networking 📍 52 Degrees Café/Bar	

## Tuesday 23 August 2016

08:00 - 08:30	Breakfast 📍 The Core Campus Food Court		
08:30 - 09:00	Registration 📍 School of Management		
09:00 - 10:30	<b>“Words, words, words!” Governance and Technical Challenges in Healthcare Text De-identification forEHR Research</b> Richard Jackson 📍 School of Management, Room 111, First Floor	<b>Technical and Methodological Solutions to Maximise the Benefit of Linked Data (Session 01)</b> Dan Thayer 📍 School of Management, Room 112, First Floor	<b>Getting the Public Involved with your Research (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor
10:30 - 11:00	Break, Morning Tea and Coffee		
11:00 - 12:30	<b>Linking Infectious Disease Laboratory Data for Research</b> Dr Pia Hardelid 📍 School of Management, Room 111, First Floor	<b>Technical and Methodological Solutions to Maximise the Benefit of Linked Data (Session 02)</b> Dan Thayer 📍 School of Management, Room 112, First Floor	<b>Writing for the Public (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor
12:30 - 13:30	<b>VISIT TO BLAENAVON INDUSTRIAL LANDSCAPE</b>		BBQ Lunch on the Beachfront (weather permitting)
13:30 - 15:00	The coach departs at 13:00		<b>Public Engagement Workshop (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor
15:00 - 15:30	Break, Afternoon Tea and Coffee		
15:30 - 17:00	<b>Final Data Analysis Workshop (PhD/ECR)</b> 📍 School of Management, Room 011, Ground Floor		
18:00 - 19:00	Dinner 📍 The Core Campus Food Court		
19:00 - 22:00	Optional Networking 📍 52 Degrees Café/Bar		

Attendance at lunch on Sunday is by booking only

Breakfast for residential delegates only

Attendance at dinner is by booking only or included for delegates signed up to the all-inclusive package

The visit to Blaenavon includes a guided tour followed by a Welsh banquet dinner at Cardiff Castle. The trip is included in the pre-conference workshops and all-inclusive packages. A packed lunch will be provided which can be collected from the Core Campus Food Court from 12:30 - 13:00 on the day of the trip. The Coach will return to the bay campus at 20:00.





# Main Programme at a Glance

## Wednesday 24 August 2016

07:00 - 17:30	Registration Desk Open
07:00 - 17:30	Multimedia Posters Open
07:00 - 08:00	Networking, Morning Tea and Coffee
08:00 - 08:15	<b>OPENING REMARKS</b>
08:15 - 08:45	<b>KEYNOTE</b> <b>The 100 million Brazilian linked data and data centre</b> Mauricio L Barreto Senior-Scientist & Professor of Epidemiology Federal University of Bahia - UFBA, Brazil
08:45 - 09:15	<b>KEYNOTE</b> <b>Registries, cohorts and biobanks - Research for better health</b> Gun Peggy Knudsen Director Health Data and Digitalisation, Norwegian Institute of Public Health, Norway
09:15 - 09:45	<b>Linkage of health insurance data to the Netherlands TwinRegister</b> Gerard van Grootheest GGZ INGEEST and VU Medical Center Amsterdam, Netherlands
09:45 - 10:00	<b>PLENARY DISCUSSION</b>
10:00 - 10:30	Break, Morning Tea and Coffee
10:30 - 12:30	<b>PARALLEL SESSION 1</b> (Page 14)
12:30 - 13:30	Lunch and <b>MULTIMEDIA POSTER PRESENTATIONS</b>  <b>ENTITIES AND IDENTITIES WITHIN THE IPDLN: ARE WE A DISTINCT DISCIPLINE?</b> IPDLN workshop open to all 📍 The Great Hall, Room GH011, Ground Floor
13:30 - 14:00	<b>KEYNOTE</b> <b>The Farr Institute: distributed multi-disciplinary team science in action</b> Ronan Lyons Director of The Farr Institute & Professor of Public Health at Swansea University Medical School, UK
14:00 - 15:30	<b>PARALLEL SESSION 2</b> (Page 16)
15:30 - 16:00	Break, Afternoon Tea and Coffee
16:00 - 18:00	<b>PARALLEL SESSION 3</b> (Page 18)
18:00 - 19:00	<b>WELCOME DRINKS RECEPTION AND FINGER BUFFET</b>
19:00 - 20:00	<b>WELSH CULTURAL SHOW &amp; ENTERTAINMENT</b>

All announcements, keynotes and plenary sessions will take place in the Great Hall Auditorium on the first floor.

Multimedia posters and their presentations will be at the touch screen displays which are spread out over the East and West galleries on the first floor of the Great Hall.

Refreshments and lunch will be served on the first floor.

## Thursday 25 August 2016

07:00 - 17:30	Registration Desk Open
07:00 - 17:30	Multimedia Posters Open
07:00 - 08:00	Networking, Morning Tea and Coffee
08:00 - 08:15	Announcements
08:15 - 08:45	<b>KEYNOTE</b> <b>Privacy, Governance &amp; Public Acceptance in Population Data Linkage for Research</b> Christine M O'Keefe Senior Principal Scientist in CSIRO Data61 & Adjunct Professor in the School of Mathematical Sciences, University of Adelaide, Australia
08:45 - 09:05	<b>For the greater good? Patient and public attitudes to use of medical free text data in research</b> Elizabeth Ford Brighton and Sussex Medical School, UK
09:05 - 09:25	<b>Privacy-Preserving Record Linkage: An international collaboration between Canada, Australia and Wales</b> Conrad Pow Institute for Clinical Evaluative Sciences, Canada
09:25 - 09:45	<b>PUBLIC PANEL DISCUSSION</b> (Members of the public)
09:45 - 10:00	<b>PLENARY DISCUSSION</b>
10:00 - 10:30	Break, Morning Tea and Coffee
10:30 - 12:30	<b>PARALLEL SESSION 4</b> (Page 20)
12:30 - 13:30	Lunch and <b>MULTIMEDIA POSTER PRESENTATIONS</b>  <b>INTERNATIONAL POPULATION DATA LINKAGE NETWORK MEMBERS MEETING</b> Open to all members 📍 The Great Hall, Room GH011, Ground Floor
13:30 - 14:00	<b>KEYNOTE</b> <b>The Administrative Data Research Network (ADRN): Better Knowledge, Better Society</b> Dermot O'Reilly Director for the Administrative Data Research Centre Northern Ireland & Senior Clinical Lecturer with the Centre for Public Health, Queen's University Belfast, Northern Ireland
14:00 - 16:00	<b>PARALLEL SESSION 5</b> (Page 22)
16:15 - 17:00	<b>RAPID FIRE PRESENTATIONS</b> (Page 26)
17:00 - 17:30	Break, Afternoon Tea and Coffee
17:30	<b>COACHES DEPART FOR GALA DINNER AT CAERPHILLY CASTLE</b>
19:00 - 22:30	<b>GALA DINNER AND ENTERTAINMENT</b>

## Friday 26 August 2016

07:00 - 17:30	Registration Desk Open
07:00 - 17:30	Multimedia Posters Open
07:00 - 08:00	Networking, Morning Tea and Coffee
08:00 - 08:15	Announcements
08:15 - 08:45	<b>KEYNOTE</b> <b>Advanced computational and privacy methods for data linkage</b> Peter Christen Professor at the Research School of Computer Science, Australian National University, Australia
08:45 - 09:05	<b>Maternal weight gain between pregnancies and childhood body mass index - using sibling analysis to address confounding by shared lifestyle</b> Steve Turner University of Aberdeen, Scotland, UK
09:05 - 09:25	<b>Improving primary care prescribing safety using routine data for intervention and evaluation: four trials in 500+ practices</b> Bruce Guthrie University of Dundee, Scotland, UK
09:25 - 09:45	<b>Using Linked Administrative Data to Examine the Educational Outcomes of Children in Care in Manitoba</b> Marni Brownell Manitoba Centre for Health Policy, University of Manitoba, Canada
09:45 - 10:00	<b>PLENARY DISCUSSION</b>
10:00 - 10:30	Break, Morning Tea and Coffee
10:30 - 12:30	<b>PARALLEL SESSION 6</b> (Page 24)
12:30 - 13:30	Lunch
13:30 - 14:00	<b>KEYNOTE</b> <b>Genetics of Common/Complex Traits</b> Kári Stefánsson President, Chairman, CEO and Co-founder deCODE genetics, Iceland
14:00 - 14:20	<b>High resolution data from everyday life: coproducing a technically robust and engaging sensing platform</b> Matthew Machin & Lamiece Hassan Health eResearch Centre, The University of Manchester, UK
14:20 - 14:30	<b>PLENARY DISCUSSION</b>
14:30 - 15:00	<b>KEYNOTE</b> <b>Political and policy arguments for Integrated Data</b> Adalsteinn Brown Director of the Institute of Health Policy, Management and Evaluation, University of Toronto, Canada
15:00 - 15:30	<b>CLOSING REMARKS &amp; AWARDS PRESENTATION</b>
15:30	Tea and Coffee <b>CONFERENCE CLOSE</b>



# Oral Sessions

## Parallel Session 1

Wednesday 24 August 2016 | 10:30 - 12:30

	Analytical Approaches to Distributed Data	Data Linkage Quality	Advanced Analytics	Privacy Regulation Governance	Linking Emerging Data Types	Capacity Building
Room	GH043	GH001	GH037	GH029	GH049	GH014
Session Chair	Christine Roberts	Tom Clemens	Tjeerd van Staa	David Martin	Rebecca Mitchell	Elizabeth Wall-Wieler
10:30 - 10:50	<p>Early onset preeclampsia: using population data to assess recurrence risk and adverse pregnancy outcomes</p> <p>Christine Roberts Kolling Institute, University of Sydney</p>	<p>Match quality of a linkage strategy based on the combined use of a statistical linkage key and the Levenshtein distance to link birth to death records in Brazil</p> <p>Kenneth Rochel de Camargo Universidade do Estado do Rio de Janeiro, Brazil</p>	<p>Comparison of Risk Adjustment Methods in Patients with Liver Disease Using Electronic Medical Record</p> <p>Mingshan Lu University of Calgary</p>	<p>Evaluation of advanced techniques for multi-party privacy-preserving record linkage on real-world health databases</p> <p>Peter Christen Research School of Computer Science, The Australian National University</p>	<p>Linking Hospital and Tax data to support research on the economic impacts of hospitalization</p> <p>Claudia Sanmartin Statistics Canada</p>	<p>Teenage pregnancy: The impact of maternal adolescent childbearing and older sister's teenage</p> <p>Elizaberth Wall-Wieler University of Manitoba</p>
10:50 - 11:10	<p>Methods for enhancing the reproducibility of clinical epidemiology research in linked electronic health records: results and lessons learned from the CALIBER platform</p> <p>Spiros Denaxas University College of London</p>	<p>Secure Privacy Preserving Record Linkage of Large Databases by Modified Bloom Filter Encodings</p> <p>Rainer Schnell City University, London</p>	<p>Privacy protected text analysis in DataSHIELD</p> <p>Rebecca Wilson University of Bristol</p>	<p>Young people's views about consenting to data linkage: Findings from the PEARL qualitative study</p> <p>Andy Boyd ALSPAC, University of Bristol</p>	<p>Describing the Linkages of the Citizenship and Immigration Canada Permanent Resident Data and Vital Statistics—Death Registry to Ontario's Administrative Health Database</p> <p>Astrid Guttman Institute for Clinical Evaluative Sciences</p>	<p>Linking education and health data to examine the characteristics of children prescribed antipsychotic medication</p> <p>Sinead Brophy The FARR Institute CIPHER</p>
11:10 - 11:30	<p>Combining Propensity Score and Random Coefficient Modelling as an Approach to Analyse Complex Longitudinal Data</p> <p>Stefan Clos NHS Tayside / University of Dundee</p>	<p>A population-based study comparing multiple sclerosis clinic users and non-users in British Columbia, Canada</p> <p>Kyla McKay University of British Columbia</p>	<p>The seasonality and effects of temperature and rainfall on Campylobacter infections</p> <p>Abdelmajid Djennad Public Health England</p>	<p>Zone design for statistical disclosure control in administrative and linked microdata</p> <p>James Robards ESRC National Centre for Research Methods, University of Southampton</p>	<p>Predicting who applies to Public Housing using Linked Administrative Data</p> <p>Aynslie Hinds University of Manitoba</p>	<p>Trends in admissions for acute respiratory infections in children: an inter-country comparison between Western Australia and England</p> <p>Hannah C Moore Wesfarmers Centre of Vaccines and Infectious Diseases, Telethon Kids Institute, The University of Western Australia</p>
11:30 - 11:50	<p>The Health and Economic Impacts of Structural Energy Performance Investments in Wales: An Evaluation of the Arbed Programme</p> <p>Rhodri Johnson Swansea University Medical School</p>	<p>Comparing identification of children and young people with a life limiting condition from cause of death with use of an ICD-10 coding framework applied to routine clinical data</p> <p>Stuart Jarvis University of York</p>	<p>Weighted multiple imputation of ethnicity data that are missing not at random in primary care databases</p> <p>Tra M Pham Department of Primary Care &amp; Population Health, University College London, and The Farr Institute of Health Informatics Research, London</p>	<p>Programmatically encrypting data linkage fields at a project level within the Secure Anonymised Information Linkage (SAIL) databank</p> <p>Richard Noyce Swansea University Medical School</p>	<p>The utility of historical electoral roll records and their effect on the association of regularity of GP contact and potentially preventable diabetic hospitalisations</p> <p>Rachael Moorin Curtin University</p>	<p>New Zealand's Integrated Data Infrastructure (IDI): Value to date and future opportunities</p> <p>June Atkinson University of Otago Wellington</p>
11:50 - 12:10	<p>The Nascent Pan-Canadian Real-world Health Data Network (PRHDN)</p> <p>Michael J Schull Institute of Clinical Evaluation Sciences</p>	<p>Considerations of response bias and value in linking an existing longitudinal cohort study with national health record data</p> <p>Joanne Allen School of Psychology, Massey University, New Zealand</p>	<p>Application of natural language processing methods to extract coded data from administrative data held in the Scottish Prescribing Information System</p> <p>Clifford Nangle The Farr Institute, Scotland</p>	<p>Establishing data linkage between welfare and health data in the UK: Overcoming barriers to linking government datasets</p> <p>S Vittal Katikireddi MRC/CSO Social &amp; Public Health Sciences Unit, University of Glasgow</p>	<p>Do socially complex patients seek primary care from clinics specifically designed to meet their needs?</p> <p>Alan Katz Manitoba Centre for Health Policy, University of Manitoba</p>	<p>PATHS Data Resource: A population-based suite of linkable administrative records and metadata for population health research</p> <p>Nathan C. Nickel Manitoba Centre for Health Policy</p>
12:10 - 12:30	<p>IMECCHI-DATANETWORK: empowering knowledge generation through international data network</p> <p>Marie-Annick Le Pogam Institute of Social and Preventive Medicine, Lausanne University Hospital, Switzerland</p>	<p>Record Linkage Methodology for the Social Data Linkage Environment at Statistics Canada</p> <p>Colin Babyak Statistics Canada</p>	<p>Development of data-driven framework for automatically identifying patient cohorts from linked electronic health records</p> <p>Shang-Ming Zhou Swansea University Medical School</p>	<p>Multi-agency data linkage- How to and lessons learnt through the Western Australian Developmental Pathways Program</p> <p>Nicholas de Klerk Telethon Kids Institute, Perth, Western Australia</p>	<p>Generation Scotland: using data linkage for longitudinal studies</p> <p>Archie Campbell Generation Scotland / University of Edinburgh</p>	<p>Record linkage augments cancer ascertainment in HIV cohorts in South Africa</p> <p>Julia Bohlius Institute of Social and Preventive Medicine, University of Bern, Switzerland</p>



Parallel Session 2

Wednesday 24 August 2016 | 14:15 - 15:35

	Analytical Approaches to Distributed Data	Data Linkage Quality	Advanced Analytics	Privacy Regulation Governance	Linking Emerging Data Types	Capacity Building
Room	GH043	GH001	GH037	GH029	GH049	GH014
Session Chair	Michael Schull	Chris Dibben	David Martin	Chris Smith	Rod Middleton	Simon Thompson
14:15 - 14:35	<p>An Investigation of Variation in Emergency Admission Rates between New Zealand General Practices: a national database linkage study</p> <p>Hywel Lloyd BPAC NZ and Department of General Practice &amp; Rural Health, University of Otago, Dunedin, New Zealand</p>	<p>Design and evaluation of probabilistic record linkage methods supporting the Brazilian 100-million cohort initiative</p> <p>Marcos Barreto Federal University of Bahia (UFBA), Salvador, Bahia, Brazil</p>	<p>Using Bayesian Model Averaging to Analyse Hierarchical Health Data: model implementation and application to linked health service use data</p> <p>Behrooz Hassani-M ISCRR, Monash University</p>	<p>Designing a privacy-preserving protocol to support transient and purpose-specific data linkages</p> <p>Chris Smith University of Leeds</p>	<p>Codifying unstructured data: A Natural Language Processing approach to extract rich data from clinical letters</p> <p>Rod Middleton Farr Institute CIPHER</p>	<p>Dementias Platform UK (DPUK) Portal</p> <p>Simon Thompson Swansea University Medical School</p>
14:35 - 14:55	<p>CHA2DS2-VASc Calculations in Patients with Atrial Fibrillation receiving oral anticoagulants in Scotland: an analysis of linked administrative data</p> <p>Samantha Alvarez-Madrado University of Strathclyde</p>	<p>Record Linkage Project Process Model</p> <p>Richard Trudeau Statistics Canada</p>	<p>Survival to Diabetes by age, gender and BMI category</p> <p>Kelly Nock &amp; Kerry Bailey We Predict Ltd</p>	<p>Suicide Prevention through Shared Information</p> <p>Lloyd Balbuena Department of Psychiatry, University of Saskatchewan</p>	<p>Linking the Australian Childhood Immunisation Register to population-based perinatal datasets to assess coverage in at-risk groups</p> <p>Hannah C Moore Wesfarmers Centre of Vaccines and Infectious Diseases, Telethon Kids Institute, The University of Western Australia</p>	<p>Novel Tools Supporting Knowledge Translation for Public Health Practice in British Columbia, Canada</p> <p>Jenny Sutherland Public Health Agency Canada</p>
14:55 - 15:15	<p>Identification and validation of myocardial infarction and stroke outcomes at scale in UK Biobank</p> <p>Christian Schnier UK Biobank, The University of Edinburgh</p>	<p>The inpatient, outpatient and social care costs associated with atrial fibrillation in Scotland: a record linkage study</p> <p>Giorgio Ciminata Health Economics and Health Technology Assessment (HEHTA) University of Glasgow</p>	<p>The impact of regular GP visits on diabetic potentially preventable hospitalisations</p> <p>David Youens School of Public Health, Curtin University</p>	<p>Using administrative and claims data in the GNC-study –how to overcome legal restrictions</p> <p>Janett Powietzka Institut für Sozialmedizin und Gesundheitsökonomie (ISMG) Med</p>	<p>Psychiatric research platform within SAIL - Linkage of prospectively ascertained phenotypically rich and genetic data to routinely collected anonymised records</p> <p>Ann John and Joanna McGregor Swansea University Medical School</p>	<p>The impact of the Population Health Research Network on linked data research capacity in Australia</p> <p>Felicity Flack University of Western Australia, Population Health Research Network</p>
15:15 - 15:35		<p>Real-time linkage: when is near enough good enough?</p> <p>Katie Irvine Centre for Health Record Linkage, NSW Health, Australia</p>	<p>Reusable, set-based selection algorithm for matched control groups</p> <p>Daniel Thayer SAIL Databank, Swansea University Medical School</p>	<p>PDisclosure and Data Linkage</p> <p>Andrew Turner D2K Research Group, University of Bristol</p>	<p>Creating a platform for collaborative genomic research</p> <p>Mark Smithson Digital Health Labs</p>	<p>Population-based estimates of the effectiveness of pneumococcal vaccination in Australia</p> <p>Heather F Gidding University of NSW and National Centre for Immunisation Research and Surveillance, Sydney Australia</p>

Parallel Session 3

Wednesday 24 August 2016 | 16:00 - 18:00

	Data Linkage Quality (A)	Data Linkage Quality (B)	Advanced Analytics	Privacy Regulation Governance	Linking Emerging Data Types	Capacity Building
Room	GH043	GH001	GH037	GH029	GH049	GH014
Session Chair	Michael Schull	Peter Jones	David Martin	Tjeerd van Staa	Aaron Lacey	Megan Bell
16:00 - 16:20	High quality linkage using Multibit Trees for privacy-preserving blocking <b>Adrian Brown</b> Curtin University	A data linkage strategy for producing census and population statistics from administrative data <b>Peter Jones</b> Office for National Statistics	Differences in the breast cancer diagnostic process across stage groups in Ontario, Canada <b>Patti Groome</b> Queen’s University, Kingston, Ontario, Canada	Can censoring of research outputs be automated to ensure robust data protection? <b>Kelly Nock &amp; Kerry Bailey</b> We Predict Limited	Data safe havens to combine health and genomic data: benefits and challenges <b>Arron Lacey</b> Swansea University Medical School	Severe parental mental illness is associated with lower school readiness in offspring: A linked data study <b>Megan Bell</b> Telethon Kids Institute, University of Western Australia, Perth, Australia
16:20 - 16:40	Assessing the impact of different grouping methods: time to rethink and regroup? <b>James Boyd</b> Curtin University	Investigating the relationships between chronic ill health and educational outcomes in children <b>Michael Fleming</b> University of Glasgow	Distilling data – A flexible method for producing research-ready Electronic Health Records <b>Alex Hacker</b> The Nuffield Department of Population Health, University of Oxford	A Federated Data Linkage Strategy to Support Population Health Research in Canada <b>Tanya Flanagan</b> Canadian Partnership Against Cancer	Statins therapy and mortality among new long-term care residents in Ontario, Canada: the contribution of clinical assessment data to a population-based cohort study <b>Susan Bronskill</b> Institute for Clinical Evaluative Sciences (ICES)	Increasing research capacity with ICES Data & Analytic Services (DAS) <b>Lisa Ishiguro</b> Institute for Clinical Evaluative Sciences (ICES)
16:40 - 17:00	The effect of cross-jurisdictional linked hospital and death data on estimating risk-adjusted grouped hospital standardised mortality ratios in Australia <b>James Semmens</b> Curtin University	Autism Spectrum Disorders and Assisted Reproductive Technology: Massachusetts 2004-2010 Population-based Results from Data Linkage Efforts <b>Milton Kotelchuck</b> Mass General Hospital for Children, Harvard Medical School	Colonoscopy resource availability and colonoscopy utilization in Ontario, Canada <b>Colleen Webber</b> Queen’s University, Kingston, Ontario	Furthering the idea of proportionate governance in British Columbia <b>Kim McGrail</b> Centre for Health Services and Policy Research, Population Data BC, The University of British Columbia	The causes of serious injuries to crew on UK commercial fishing vessels: An investigation combining free-text and coded data <b>Steven Naylor</b> The Health and Safety Laboratory	Genetic parameters for periodontal disease: an analysis of electronic dental treatment records linked to pedigree, genomic, sociodemographic and clinical data <b>Mairead L Bermingham</b> Centre for Genomic and Experimental Medicine, Institute of Genetics and Molecular Medicine,, University of Edinburgh
17:00 - 17:20	Modelling Diagnostic Validity Estimates from Administrative Health Data <b>Kristine Kroeker</b> University of Manitoba	Profile Matching of Brazilian Birth and Mortality Records where microcephaly is recorded <b>Antony Peter Stevens</b> Coordenação Geral de Informações e Análise Epidemiológica	Incremental Interactive Record Linkage using Human Intelligence Tasks (HITs) <b>Hye-Chung Kum</b> Texas A&M University	Privacy protected graphical functionality in DataSHIELD <b>Demetris Avraam</b> University of Bristol	Title: It’s a big, BAD World- the UK picture of Big and Administrative Data <b>Joanne Webb</b> Administrative Data Service, Administrative Data Research Network	Is Cancer Diagnosis Following Emergency Admission Due to Patient Delay or Systems Failure: New Insights from a Comprehensive Primary Care Dataset <b>Michael Yule</b> University of Aberdeen
17:20 - 17:40		Using weighted hospital service area networks to explore variation in preventable hospitalisation <b>Michael Falster</b> Centre for Big Data Research in Health, UNSW Australia	Breaking the problem into pieces: pre-clustering on-the-fly with the NGLMS <b>James Farrow</b> Farrow Norris / SANT DataLink	Automated de-identification of clinical free-text <b>Azad Dehghan</b> The Christie NHS Foundation Trust	Social Housing and Health in Manitoba <b>Mark Smith</b> MCHP	Probabilistic Linkage of Two National Databases to Study Emergency Care and Hospital Readmission in Children who Survive Traumatic Injury <b>Tellen D Bennett</b> University of Colorado School of Medicine, USA



Parallel Session 4

Thursday 25 August 2016 | 10:30 - 12:30

	Data Linkage Quality (A)	Data Linkage Quality (B)	Applied Projects	Privacy Regulation Governance	Advanced Analytics	Public Engagement
Room	GH043	GH001	GH037	GH029	GH049	GH014
Session Chair	Andrew Morris	Dermot O'Reilly	Sallie Pearson	Chris Dibben	Tjeerd van Staa	Catharine Goddard
10:30 - 10:50	<p>Panning for gold: finding medical treatment data in insurance records</p> <p>Daniel Avery University of Oxford</p>	<p>How do you measure up? Methods to assess linkage quality</p> <p>James Boyd Curtin University</p>	<p>Data linkage and statistical modelling to provide stratified risk assessment for HAI</p> <p>Kim Kavanagh University of Strathclyde</p>	<p>Balancing Privacy and Utility in Secondary Data Use to Inform Policy</p> <p>Xinjie Cui Alberta Centre for Child Family and Community Research, Canada</p>	<p>Advanced methods for linking complex historical birth, death, marriage and census data</p> <p>Peter Christen Research School of Computer Science, The Australian National University</p>	<p>Public understanding of, and attitudes towards, data linkage in research</p> <p>Gwenllian Moody and Fiona Lugg South East Wales Trials Unit, Cardiff University</p>
10:50 - 11:10	<p>Linking Federal Administrative Records to Respondents and Nonrespondents in Household Surveys: A Case Study</p> <p>Joseph Sakshaug University of Manchester and German Institute for Employment Research</p>	<p>Viral aetiology of acute lower respiratory infections in a birth cohort of Western Australian children</p> <p>Hannah C Moore Wesfarmers Centre of Vaccines and Infectious Diseases, Telethon Kids Institute, The University of Western Australia</p>	<p>Alcohol-related injury admission trends in adolescents: A comparison between Western Australia and England</p> <p>Scott Sims Telethon Kids Institute</p>	<p>K-Anonymity Based Privacy Risk Budgeting System for Interactive Record Linkage</p> <p>Hye-Chung Kum Texas A&amp;M University</p>	<p>Data-driven drug safety signal detection methods in pharmacovigilance using electronic primary care records: A population based study</p> <p>Shang-Ming Zhou Swansea University Medical School</p>	<p>Social and geographical inequalities in school starting age in Australia: a population data linkage study</p> <p>Mark Hanly UNSW Australia</p>
11:10 - 11:30	<p>Bringing more science to the art of linkage: Using positive predictive value of weight and outcome sets to reduce subjectivity in probabilistic linkage</p> <p>Brent Hills Population Data BC</p>	<p>Implementing privacy-preserving record linkage: welcome to the real world</p> <p>Adrian Brown Curtin University</p>	<p>Child Injury: Does home matter?</p> <p>Cate Cameron Menzies Health Institute Queensland, Griffith University, Australia</p>	<p>Multiple operating models for data linkage: A privacy positive</p> <p>Katie Irvine Centre for Health Record Linkage, NSW Health, Australia</p>	<p>Low-density lipoprotein cholesterol and atrial fibrillation; A Mendelian randomization study using UK-Biobank data</p> <p>Michail Katsoulis Farr Institute of Health Informatics Research/ University College London</p>	<p>Out of the mouths of researchers: experiences of involvement</p> <p>Anne McKenzie The University of Western Australia</p>
11:30 - 11:50	<p>Using linked records to improve National estimates of hospital admissions for coronary heart disease (CHD)</p> <p>Derrick Lopez School of Population Health, The University of Western Australia</p>	<p>Conducting Population Health Intervention Research using Linked Databases: An Evaluation of Home Visiting Programs for At-Risk Families</p> <p>Marni Brownell Manitoba Centre for Health Policy, University of Manitoba</p>	<p>Using probabilistically linked data to investigate the burden of Respiratory Syncytial Virus (RSV) in children &lt;5 years of age on secondary care in England</p> <p>Rachel Reeves The Farr Institute</p>	<p>From a culture of caution to a culture of confidence: facilitating the good governance of administrative data in the UK</p> <p>Leslie Stevens ADRC Scotland, J Kenyon Mason Institute for Medicine, Life Science and the Law, University of Edinburgh School of Law</p>	<p>Improving the Accuracy of Length of stay Risk Adjustment Models using Linked Data</p> <p>Tolu Sajobi University of Calgary</p>	<p>The ADRN and the public's voice: making administrative data available for research while gaining public trust</p> <p>Ilse Verwulgen Administrative Data Research Network</p>
11:50 - 12:10	<p>Business datasets and record linkage: Correlates of linkage and estimating risks of non-linkage biases</p> <p>Jamie Moore Department of Social Statistics and Demography and ADRCE, University of Southampton</p>	<p>Effect of sampling period on the numbers of children and young people with a life limiting condition in stable, unstable, deteriorating and dying stages</p> <p>Stuart Jarvis University of York</p>	<p>Case definitions for common mental health disorders among adolescents using electronic primary care data: a comparison with self-reported data from ALSPAC</p> <p>Rosie Cornish School of Social and Community Medicine, University of Bristol</p>	<p>Preserving Privacy in the Face of Clients with Different Data Needs Using the NGLMS</p> <p>James Farrow Farrow Norris / SANT DataLink</p>	<p>Developing a checklist to inform data linkage study designs for health technology assessments: a case study linking the Cardiac Rhythm Management (CRM) register to the Secure Anonymised Information Linkage (SAIL) Databank</p> <p>Ruth Louise Poole Cedar, Cardiff &amp; Vale University Health Board</p>	<p>Educational outcomes are predictive of mental health diagnoses in adolescence</p> <p>Janice Wong Telethon Kids Institute, School of Psychology, University of Western Australia</p>
12:10 - 12:30	<p>Geocoding routinely collected administrative data to measure access to alcohol outlets in Wales</p> <p>Richard Fry Farr Institute CIPHER</p>		<p>The impact of cycle proficiency training on cycle-related behaviours and accidents in adolescence: findings from ALSPAC, a UK longitudinal cohort</p> <p>Alison Teyhan University of Bristol</p>	<p>Transforming children's futures: the challenges and benefits of using data linkage to improve the planning of children's services within Scotland</p> <p>Harriet Waugh Scottish Government</p>	<p>Data linkage of Psychiatric and Maternity data to investigate the pregnancy outcomes of women with Non-affective Psychosis in Scotland</p> <p>Paula McSkimming Robertson Centre for Biostatistics, University of Glasgow</p>	<p>#BritainBreathing: Codesigned citizen science to map seasonal allergy symptoms across the UK</p> <p>Lamiece Hassan The University of Manchester</p>

Parallel Session 5

Thursday 25 August 2016 | 14:15 - 15:55

	Data Linkage Quality (A)	Data Linkage Quality (B)	Applied Projects	Linking Emerging Data Types	Delivering and Measuring Impact	Public Engagement
Room	GH043	GH001	GH037	GH029	GH049	GH014
Session Chair	Andrew Morris	Dermot O-Reilly	Zisis Kozlakidis	Chris Dibben	John Wright	Ros Moran
14:15 - 14:35	<p>Understanding the coverage of Statistics New Zealand's Integrated Data Infrastructure</p> <p>Gareth Minshall Statistics New Zealand</p>	<p>Linking strategies and biases when matching cohorts to the National Pupil Database</p> <p>Tarek Mostafa University College of London</p>	<p>Comparison of child mortality by characteristics at birth in England and in Sweden using linked administrative data</p> <p>Ania Zylbersztejn UCL Institute of Child Health &amp; Farr London</p>	<p>Obtaining structured clinical data from unstructured data using natural language processing software</p> <p>Arron Lacey Farr Institute CIPHER</p>	<p>Yin and yang: why big data needs little data</p> <p>John Wright Bradford Institute for Health Research</p>	<p>The DASSL or Data Access, Storage, Sharing and Linkage Model &amp; Proposals for an Enabling Data Environment for Health and Related Research in Ireland</p> <p>Rosalyn Moran Health Research Board, Dublin</p>
14:35 - 14:55	<p>CHERISH: Understanding Suicide Clusters tHrough ExploRIng Self Harm behaviours</p> <p>Marcos del Pozo Banos Population, Psychiatry, Suicide and Informatics (PPSI), Swansea University Medical School</p>	<p>Introducing the PRIDAL model for linking routine health and identifiable patient reported questionnaire data</p> <p>Mark Rhys Kingston Swansea University Medical School</p>	<p>Opportunities for post-market surveillance of high cost medicines in Australia: Observing trastuzumab-treated women from early through late stage HER2-positive breast cancer (HER2BC)</p> <p>Benjamin Daniels Medicines Policy Research Unit, Centre for Big Data Research in Health, University of New South Wales</p>	<p>Investigating Orthopaedic Surgical Prophylaxis Changes and Post-operative Acute Kidney Injury (AKI) in NHS Grampian – a Test Case for NHS Scotland</p> <p>Eilidh Fletcher NHS National Services Scotland</p>	<p>Cautionary accounts in the use of health equity measures from linkable administrative data in population health intervention research</p> <p>Nathan C. Nickel Manitoba Centre for Health Policy</p>	<p>Patient Engagement as a Component of a Learning Healthcare System: A case study using small area rate variation research in Nova Scotia, Canada</p> <p>Adrian Levy Dalhousie University/Maritime Strategy for Patient Oriented Research (SPOR) SUPPORT Unit</p>
14:55 - 15:15	<p>The Impact of Pre-existing Health Conditions on Cost of Recovery after Workplace Injury: Insight from population-based data linkage in the State of Victoria, Australia</p> <p>Behrooz Hassani-M ISCRR, Monash University</p>	<p>Using family relationships to improve consistency of identification of Aboriginal people in linked administrative data</p> <p>Alison Gibberd University of Sydney</p>	<p>The paradox of invasive therapy following non-ST-acute coronary syndrome in older higher risk patients: A population level study in South Wales 2000-2014</p> <p>Majd Protty Cardiff University</p>	<p>The Canadian Statistical Demographic Database Research Project: Exploring Potential Use of Administrative Data to Support the Canadian Census Program</p> <p>Sylvain Cloutier Statistique Canada</p>	<p>Emergency department attendance after telephone triage</p> <p>Amy Gibson Centre for Big Data Research in Health, UNSW Australia</p>	<p>Involving People with Lived Experience of Homelessness in Electronic Health Records Research</p> <p>Rob Aldridge The London Farr Institute, University College London</p>
15:15 - 15:35	<p>Chronic Disease Case Definitions for Electronic Medical Records: A Canadian Validation Study</p> <p>Lisa Lix University of Manitoba</p>	<p>Impacts of Alternative Billing Claims on Hypertension Prevalence and Mortality Estimates in Alberta, Canada</p> <p>Hude Quan Community Health Science, University of Calgary</p>	<p>Influence of early life exposure to social disadvantages on deliberate self-harm (DSH) among children of parents with mental health disorders</p> <p>Janice Wong Telethon Kids Institute, the University of Western Australia</p>	<p>Looked after children and access to dental services and oral health in Scotland: a national data-linkage study (LAC-DENTAL)</p> <p>Alex McMahon University of Glasgow Dental School</p>	<p>Quantifying the fatal and non-fatal burden of Stroke and its modifiable determinants using routine Scottish healthcare datasets</p> <p>Grant Wyper and Ian Grant Information Services Division, National Services Scotland</p>	<p>Public attitudes to data linkage and sharing</p> <p>Joanne Given Administrative Data Research Centre Northern Ireland</p>
15:35 - 15:55	<p>Validating Earnings in the German National Educational Panel Study – Do Interviewers Have an Impact on Measurement Accuracy?</p> <p>Manfred Antoni Institute for Employment Research (IAB)</p>	<p>One for all, all for one - Establishing a standard linkage methodology for integrated health analytics at the Canadian Institute for Health Information</p> <p>Philippe Poitras Canadian Institute for Health Information</p>	<p>Does access to health services influence the diagnostic pathway and outcome from cancer: analysis of a linked dataset</p> <p>Melanie Turner University of Aberdeen</p>	<p>Using Twitter to mine sleep related information from people who declare a diagnosis of a psychotic disorder</p> <p>Natalie Berry University of Manchester</p>		



Parallel Session 6

Friday 26 August 2016 | 10:30 - 12:30

	Applied Projects (A)	Applied Projects (B)	Capacity Building	Data Linkage Quality	Advanced Analytics (A)	Advanced Analytics (B)	Delivering and Measuring Impact (A)	Delivering and Measuring Impact (B)
Room	GH037	GH029		GH049		GH043	GH001	GH014
Session Chair	Martin Heaven	Sallie Pearson		Chris Dibben		Kerina Jones	Marni Brownell	Athanasios Anastasiou
10:30 - 10:50	Data linkage of routinely collected electronic health records to characterise risk factors associated with antibiotic resistance in urinary isolates: an exemplar of NHS Scotland's Infection Intelligence Platform  Kim Kavanagh University of Strathclyde	Collateral benefits: Unintended consequences of the Roots of Empathy program  Randy Fransoo Manitoba Centre for Health Policy, University of Manitoba		Supplementing linked datasets with meaningful meta-data to enable high quality research  Shivani Padmanabhan and Ellen Cameron Clinical Practice Research Datalink (CPRD), Health and Social Care Information Centre (HSCIC)		Treating heterogeneity and uncertainty in data integration: study on Brazilian healthcare databases  Marcos Barreto Federal University of Bahia (UFBA), Salvador, Bahia, Brazil	No Strings Attached: Evaluating an Unconditional Prenatal Income Supplement Using Linked Administrative Data  Marni Brownell Manitoba Centre for Health Policy, University of Manitoba	Social outcomes associated with alcohol-related diagnoses: a population-based analysis using linked administrative data  Nathan C. Nickel Manitoba Centre for Health Policy
10:50 - 11:10	Determining breast cancer recurrence following completion of active treatment: A novel approach using linked administrative health data  David Preen School of Population Health, The University of Western Australia	Local variation in the use of out-of-home care in England: analysis of linked administrative data  Louise Mc Grath-Lone Administrative Data Research Centre for England, UCL Institute of Child Health		Measuring medication adherence: standardized definitions are needed to allow for comparisons  Hude Quan University of Calgary		Real world persistence, adherence and switch-over across anticoagulants in atrial fibrillation-a national population-based study  Amitava Banerjee Farr Institute of Health Informatics Research, University College London	Quantifying morbidity attributable to traumatic injury using a population-based matched cohort in Australia  Rebecca Mitchell Australian Institute of Health Innovation, Macquarie University	Answering questions posed by health system stakeholders using linked administrative health data at the Institute for Clinical Evaluative Sciences (ICES)  Erika A Yates Institute for Clinical Evaluative Sciences
11:10 - 11:30	Identifying superusers of health services with mental health and addiction problems  Jacqueline Quail Health Quality Council (Saskatchewan)	Using record linkage to assess the impact of late presentation for care and treatment on short-term mortality among HIV-infected adults in rural South Africa  Chodziwadziwa Kabudula London School of Hygiene & Tropical Medicine		Defining 'sensitive' health status: a systematic approach using health code terminologies  Andy Boyd ALSPAC, University of Bristol		Evaluating the Completeness of Physician Billing Claims: A Proof-of-Concept Study  Lisa Lix University of Manitoba	PEAC Events: identification of Predictable, Expensive, Avoidable, and Cardinal events within a learning health system  David Whyatt University of Western Australia	Evaluating the impacts on health outcomes of Welsh Government funded schemes designed to improve the energy efficiency of the homes of low income households  Sian Morrison-Rees Swansea University Medical School
11:30 - 11:50	The Western Australia Population-based Burn Injury Project: Using record linkage to examine long-term effects of burn injury  James Boyd Curtin University	Trajectories through child protection and education: Patterns, timing and causality  Fernando Lima Telethon Kids Institute		The Housing Regeneration and Health Study  Sarah Rodgers The Farr Institute, Swansea University Medical School		Probabilistic Record Linkage (PRL) advances between Surveillance Data and HES datasets using the Expectation-Maximization (EM) algorithm  Nikolaos Panagiotopoulos Public Health England (PHE)	Using population data linkage to make the invisible, visible: patterns and trends in mortality for Victorian born Aboriginal compared with non-Indigenous Victorian infants  Jane Freemantle University of Melbourne	Evaluating the care received by patients with oesophago-gastric (OG) cancer: the richer picture provided by linked datasets  Christian Brand London School of Hygiene and Tropical Medicine / Royal College of Surgeons
11:50 - 12:10	The effect of in utero exposure to alcohol, tobacco and cannabis on educational attainment in adolescence: findings from ALSPAC, a UK cohort study  Alison Teyhan University of Bristol	Using linked health survey and Census data to understand transitions to institutional care among Canadian seniors  Claudia Sanmartin Statistics Canada		Identification of falls subgroups through semantic similarity analysis  Muhannad Almohaimeed The University of Manchester		Effect of an Intensive Multi-Modal Intervention for Attention-Deficit Hyperactivity Disorder (ADHD) on Equity in Children's Health and Educational Outcomes  Mark Smith MCHP	Neonatal and infant readmissions for late preterm and early term babies in Ontario and England: a cohort study using linked population-level healthcare data  Katie Harron London School of Hygiene and Tropical Medicine	Using Linked Data to Explore the Relationship Between Walking-Friendliness of Neighbourhoods, Physical Activity and Body Mass  Nancy Ross McGill University
12:10 - 12:30	Secure Research at scale  Simon Thompson Swansea University Medical School							Assessment of morbidity and fatal outcomes of Acute Coronary Syndrome in Scotland  Grant Wyper University of Strathclyde

# Rapid Fire Sessions

Thursday 25 August 2016 | 16:15 - 17:00

	Data Linkage Quality (A)	Data Linkage Quality (B)	Analytical Approaches to Distributed Data	Linking Emerging Data Types	Public Engagement	Privacy Regulation Governance	Capacity Building	Delivering and Measuring Impact	Applied Projects	Advanced Analytics
Room	GH043	GH001	GH037		GH011	GH029	GH049		GH014	
Session Chair	Marcos Barreto	Samantha Turner	Zisis Kozlakidis		Alison Paprica	Dan Thayer	Athanasios Anastasiou		Sallie Pearson	
16:15 - 16:19	Barriers to high quality coding of hospital chart information to administrative data: A qualitative study  Kelsey Lucyk University of Calgary	Phenotyping congenital anomalies in England and Scotland: a comparison of three coding clusters using retrospective hospital data  Linda Wijlaars UCL Institute of Child Health	Creating reproducible dynamic reports using data from the Secure Anonymised Information Linkage (SAIL) Databank  Ting Wang SAIL Databank, Swansea University Medical School		General Public Views on Uses and Users of Administrative Health Data  Alison Paprica Institute for Clinical Evaluative Sciences	Linking survey responses and administrative records without respondent consent to link; a discussion paper  Dermot O'Reilly Queens University Belfast	Small area variation in the utilization of common medical tests and consultations in Ontario, Canada  Colleen Webber Queen's University, Kingston, Ontario, Canada		Bibliometric Analysis to Scan and Scrape New Datasets: It's all about that BASS  Karen Tingay Swansea University Medical School	
16:19 - 16:23	Under-coding of secondary conditions in coded hospital health data: impact of co-existing conditions, death status and number of codes in a record  Mingkai Peng University of Calgary	Understanding NHS hospital admissions in England, Scotland and Wales: data linkage to the King's College Military Cohort Study  Daniel Leightley King's College Centre for Military Health Research	CanIMPACT: Understanding complexities, variation, and disparities in the breast cancer care continuum in Five Canadian provinces using administrative data  Patti Groome Queen's University, Kingston, Ontario, Canada		How sick is Austria? – A decision support framework for different evaluations of the burden of disease within the Austrian population based on different data sources  Barbara Glock Vienna University of Technology - Institute for Analysis and Scientific Computing	Institute for Clinical Evaluative Sciences (ICES) Exploratory Data & Analytic Services Private Sector Pilot Project  Michael J Schull Institute for Clinical Evaluative Sciences	Integrated KT 2.0: The next generation of teamwork  Randy Fransoo Manitoba Centre for Health Policy, University of Manitoba		Early mortality from external causes in Aboriginal mothers: a retrospective cohort study  Jenny Fairthorne Telethon Kids Institute	
16:23 – 16:27	Developing and Validating Electronic Medical Record Based Case Definitions for Liver Diseases and Comorbidities  Mingshan Lu University of Calgary	Using consented health record linkage in a longitudinal cohort study  Karen Tingay Swansea University Medical School	High school graduation – the impact of older siblings' educational achievement  Elizabeth Wall-Wieler University of Manitoba		Health data on public trial: To what extent should patients control access to patient records?  Mary Tully HeRC/Farr Institute, University of Manchester	Clinical Text De-identification and Other Large Scale Processing Tasks in Resource Constrained Environments  Richard Jackson King's College Centre	In Utero Exposure to Antihypertensive Medication During Pregnancy and Neonatal and Child Health Outcomes  Catherine Fitton University of Aberdeen		Using Canadian data linkage to investigate the socioeconomic patterning of hospital burden for childbirth  Sarah M Mah Department of Geography, McGill University	
16:27 - 16:31	Policies to Optimize Physician Billing Data in Academic Alternative Relationship Payment Plans: Practices and Perspectives  Hude Quan Community Health Science, University of Calgary	The impact of administrative dataset characteristics on clerical review: A Tasmanian case study  Nadine Wiggins Menzies Institute for Medical Research, University of Tasmania	The Canadian Chronic Disease Surveillance System: The Benefits and Challenges of a Distributed Model for National Disease Surveillance  Lisa Lix University of Manitoba		Protocol for implementing the concept of citizen scientists for HealthWise Wales: a national population study  Julia Townson Cardiff University	Bespoke linkage of Public Health England laboratory data on gastrointestinal infections to the Clinical Practice Research Datalink: Ethics approval and a study proposal  Oluwaseun Esan NIHR Health Protection Research Unit in Gastrointestinal Infections, University of Oxford	Gaps in Health and Wealth: The relationship between trends in income inequality and breastfeeding inequalities  Nathan C. Nickel Manitoba Centre for Health Policy		Maternal age and child development outcomes at age five in Australian Aboriginal and non-Aboriginal children: a population data linkage study  Mark Hanly Centre for Big Data Research in Health, UNSW Australia	
16:31 - 16:35	Unified Health Database Creation: 125 Million Brazilian Cohort from Information Systems of Hospital, Outpatient, Births, Notifications and Mortalities  Ramon Pereira Federal University of Minas Gerais (UMFG)	The impact of social care expenditure at the end of life: a novel linkage study in Scotland  Claudia Geue University of Glasgow	Primary care contact before and after emergency hospitalisation in children in English NHS hospitals: a linked administrative data study  Linda Wijlaars UCL Institute of Child Health		Monitoring medication uptake in difficult asthma – qualitative analysis  Sean MacBride-Stewart NHS Greater Glasgow and Clyde	Can We and Should We Produce a model for Emergency Admissions derived from Primary Care Data?  Kerry Bailey Swansea University Medical School	Methodological research priorities for data sciences: Report from The International Methodology Consortium for Coded Health Information (IMECCHI)  Rachel Jolley IMECCHI, O'Brien Institute for Public Health, University of Calgary		Outcomes in Paediatric Intensive Care Units for Children with Life-Limiting Conditions: A national data linkage study  Lorna Fraser University of York	
16:35 - 16:39	Data linkage to develop a mortality outcome measure for patients with sepsis  Andrea Patton University of Dundee	How do you interpret a billion primary care records?  Martin Heaven Farr Institute CIPHER	Linking the Diagnostic Imaging Dataset (DID) to Hospital Episode Statistics (HES) – improving and understanding the diagnosis of lung cancer  David Kennedy Cancer Research UK		Identifying superusers of health services with mental health and addiction problems: Putting the Canadian Institutes of Health Research Strategy for Patient Oriented Research into action  Jacqueline Quail Health Quality Council (Saskatchewan)	Information Management at the Institute for Clinical Evaluative Sciences (ICES): Moving from Identifiable Data to Coded Data  Lisa Thurairasu Institute for Clinical Evaluative Sciences (ICES)	Using record linkage to demonstrate the benefits of maternal influenza immunisation in Western Australia  Nicholas de Klerk Telethon Kids Institute, University of Western Australia		The impact of dementia and other comorbidities on increased risk of subsequent hip fracture following hip fracture in Australia: a competing risk approach  Lara Harvey Neuroscience Research Australia	
16:39 - 16:43	Timeliness of recording in the Clinical Practice Research Datalink (CPRD) – an initial step in the implementation of near real-time vaccine safety surveillance  Andreia Leite London School of Hygiene and Tropical Medicine	An Investigation into the Impact of Disability on Employment in Wales using linked data  Aideen Ahern School of Management, Swansea University	Linking hospital and immigrant landing data to understand patterns of hospital use among refugees in Canada  Claudia Sanmartin Statistics Canada			iConsent an Electronic Consent Platform with the MS Register  Rod Middleton Swansea University Medical School	Disseminating findings from the Data Analysis with Privacy Protection for Epidemiological Research (DAPPER) workshop  Becca Wilson D2K Research Group, University of Bristol		Investigating antimicrobial prescribing pattern before the development of CDI using data linkage  Jiafeng Pan University of Strathclyde	
16:43 - 16:47	The Impact of the Choice of Data Source in Record Linkage Studies Estimating Mortality in Venous Thromboembolism  Arlene Gallagher Clinical Practice Research Datalink (CPRD)	Linking the English Cancer Patient Experience Survey to Cancer registration: relating patient experience to outcomes, a step towards better services and outcomes  Anna Fry Cancer Research UK / National Cancer Registration and Analysis Service	Investigating the incidence of youth mental health problem by merging person register and school level class room survey data  Marko Merikukka National Institute for Health and Welfare, Finland			Custodian Controlled Data Repository - supporting the timely, easy and cost effective access to linked data  Christopher Radbone & Suzi Adams SA NT DataLink	Long term health effects of NEET experiences: evidence from a longitudinal analysis of young people in Scotland  Chris Dibben University of Edinburgh		Hospital admissions in children who had pelvic/lyceal dilation detected on ultrasound scan during pregnancy: an e-cohort study  Shantini Paranjothy Cardiff University	
16:47 - 16:51							Transient Ischaemic Attack 999 Emergency Referral (TIER): a cluster randomised feasibility trial facilitated by data linkage  Martin Heaven Swansea University Medical School			
16:51 - 16:55							Business Intelligence System for Government and the Community  Christopher Radbone SA NT DataLink			

# Multi-media Poster Presentations

Wednesday 24 August 2016 | 12:55 - 13:19

Station 1			
Poster	Theme	Poster Details	Presentation Time
1	Linking to Emerging Data Types	Clinical Validation of the UKMS Register Minimal Dataset utilising Natural Language Processing Rod Middleton, Swansea University Medical School	13:00 - 13:04
2	Data and Linkage Quality	ICD-11: towards better capture of quality and safety events in hospital Danielle Southern, Univerisity of Calgary	13:05 - 13:09
3	Data and Linkage Quality	Multinational Population-Based Health Surveys Linked to Outcome Data: An Untapped Resource Stacey Fisher, Ottawa Hospital Research Institute	13:10 - 13:14
4	Data and Linkage Quality	Displaying Linkage Success Statistics to Identify Systemic Errors Brent Hills, Population Data BC	13:15 - 13:19
Station 2			
Poster	Theme	Poster Details	Presentation Time
5	Data and Linkage Quality	Processing of heterogeneous MS register data within the EUREMS project Tina Meißner, University Medical Center, Georg-August-Universität Göttingen, Germany	12:55 - 12:59
6	Data and Linkage Quality	Investigation and reporting of Data Quality within and between linked SAIL datasets Sarah Rees and Arfon Rees, SAIL Databank, Swansea University Medical School	13:00 - 13:04
7	Data and Linkage Quality	Validation of dementia coding in hospital admissions, death and primary care data Tim Wilkinson, University of Edinburgh	13:05 - 13:09
8	Data and Linkage Quality	The ELASiC (Electronic Longitudinal Alcohol Study in Communities) project Ashley Akbari, Farr Institute CIPHER	13:10 - 13:14
9	Delivering and Measuring Impact	Characteristics associated with residential aged care, respite and transitional aged care placement for older people following an injury-related hospitalisation in Australia Rebecca Mitchell, Australian Institute of Health Innovation, Macquarie University	13:15 - 13:19
Station 3			
Poster	Theme	Poster Details	Presentation Time
10	Linking to Emerging Data Types	Linking Genomic Data with Phenotypes Derived from Electronic Health Records Phil Appleby, Georg-August-Universität Göttingen, University of Dundee	12:55 - 12:59
11	Linking to Emerging Data Types	An Integrated Genomics and Clinical Resource for Data-Driven Health Services Policy and Practice Decisionmaking Mary McBride, British Columbia Cancer Agency	13:00 - 13:04
12	Applied Projects	Mortality rates in people with intellectual disabilities Jessie Oyinlola, Clinical Practice Research Datalink	13:05 - 13:09
13	Linking to Emerging Data Types	Managing Emerging Data Types in the NGLMS James Farrow, Farrow Norris / SANT DataLink	13:15 - 13:19

Station 4			
Poster	Theme	Poster Details	Presentation Time
14	Linking to Emerging Data Types	Financial wellbeing of older workers following injury – research utilising Statistics New Zealand’s Integrated Data Infrastructure Rebecca Lilley, Injury Prevention Research Unit, University of Otago	12:55 - 12:59
15	Capacity Building	Exploring the Impact of Health Insurance on Health Care Utilization and Outcome Using Electronic Medical Record Data Mingshan Lu, University of Calgary	13:00 - 13:04
16	Linking to Emerging Data Types	Discharge Communication and Patient Involvement are Associated with Unplanned Hospital Readmissions: Results from a Validated Hospital Experience Survey Rachel Jolley, Community Health Science, University of Calgary	13:05 - 13:09
17	Data and Linkage Quality	Building a high quality data linkage spine using a targeted approach to clerical review Nadine Wiggins, Menzies Institute for Medical Research, University of Tasmania	13:10 - 13:14
18	Capacity Building	Tomorrow’s Health Data Scientists in the Making: 2 Years of Training & Capacity Building Activities with the Farr Institute Athanasios Anastasiou, The Farr Institute	13:15 - 13:19
Station 5			
Poster	Theme	Poster Details	Presentation Time
19	Privacy, Regulation & Governance	Child Health Clinical Outcome Review Programme: Health Care Utilisation, Care Pathways and Educational Status in Children and Young People with Adolescent Mental Health problems with a focus on Self harm, Eating Disorders and Anxiety and Depression Sophie Wood, Cardiff University & Swansea University	12:55 - 12:59
20	Privacy, Regulation & Governance	Qualitative content analysis for international comparison of data usage agreements Christian Haux, University of Heidelberg	13:10 - 13:14
21	Privacy, Regulation & Governance	Big Data, Big Responsibility! Building best-practice privacy strategies into a large-scale neuroinformatics platform Brendan Behan, Ontario Brain Institute	13:15 - 13:19
Station 6			
Poster	Theme	Poster Details	Presentation Time
22	Public Engagement	Adolescent pregnancy termination and childbearing – the impact of an older sister’s pregnancy outcome Elizaberth Wall-Wieler, University of Manitoba	12:55 - 12:59
23	Public Engagement	What are the causes of death of patients with tuberculosis? Multiple causes of death in a cohort of cases and a research proposal of presumed causes Rejane Sobrino Pinheiro, Federal University of Rio de Janeiro	13:00 - 13:04
24	Public Engagement	Previous hospital admissions in risk adjustment for mortality of elderly patients admitted with hip fracture Rejane Sobrino Pinheiro, Federal University of Rio de Janeiro	13:05 - 13:09
25	Public Engagement	Public Attitudes to Integrated Data in New Zealand Anna McDowell, Statistics New Zealand	13:10 - 13:14
26	Public Engagement	The importance of gaining the public’s confidence to use administrative data for public benefit in social science research Judith Knight, Administrative Data Research Network	13:15 - 13:19



Station 7			
Poster	Theme	Poster Details	Presentation Time
27	Advanced Analysis	<b>Comparing a primary care dataset with a questionnaire based health survey</b> Mark D Atkinson, Swansea University Medical School	12:55 - 12:59
28	Advanced Analysis	<b>Linkage of health care claims data and apps data: The ADVOCATE oral health care dashboard</b> Frank Gabel, Heidelberg University	13:00 - 13:04
29	Advanced Analysis	<b>Data visualisation to support decision making and equitable healthcare service provision</b> David Whyatt, University of Western Australia	13:05 - 13:09
30	Advanced Analysis	<b>Multiple Correspondence Analysis is a Useful Tool to Visualize Complex Categorical Correlated Data</b> Jacqueline Quail, Health Quality Council (Saskatchewan)	13:10 - 13:14
31	Advanced Analysis	<b>Diseases and Geographic Variation: Are we missing the whole picture?</b> Gareth John, NHS Wales Informatics Service	13:15 - 13:19

Station 8			
Poster	Theme	Poster Details	Presentation Time
32	Applied Projects	<b>Midlife and late-life blood pressure and vascular dementia: a population based observational study</b> Mingkai Peng, University of Calgary	12:55 - 12:59
33	Applied Projects	<b>Constructing episodes of inpatient care: How to define hospital transfer in hospital administrative health data?</b> Mingkai Peng, University of Calgary	13:00 - 13:04
34	Applied Projects	<b>The effect of ultraviolet radiation on birth weights and gestational length in a scottish birth cohort</b> Tom Clemens, University of Edinburgh	13:10 - 13:14
35	Linking to Emerging Data Types	<b>Reliability of geneological cemetery records in ascertaining vital status in an historical cohort study</b> Stella May Gwini, Monash University	13:15 - 13:19

Station 9			
Poster	Theme	Poster Details	Presentation Time
36	Data and Linkage Quality	<b>Data linkage in social care: a pilot project</b> Alison J Orrell, Bangor University	12:55 - 12:59
37	Data and Linkage Quality	<b>Record linkage improves assessment of interpregnancy interval (IPI)</b> Christine Roberts, Kolling Institute, University of Sydney	13:00 - 13:04
38	Data and Linkage Quality	<b>The Yin &amp; Yang of Data Management - Four intractable contradictions and their harmonious resolutions</b> Alex Hacker, The Nuffield Department of Population Health, University of Oxford	13:05 - 13:09
39	Data and Linkage Quality	<b>Validation and Vindication: Enhancing the quality of Electronic Health Record (EHR) outcomes in a large prospective study biobank</b> Sam Sansome, The University of Oxford	13:10 - 13:14
40	Applied Projects	<b>Trends in Place of Death in Children who died after discharge from Paediatric Intensive Care Units : A national data linkage study</b> Lorna Fraser, University of York	13:15 - 13:19

Station 10			
Poster	Theme	Poster Details	Presentation Time
41	Linking to Emerging Data Types	<b>Canadian data sources on ethnic classifications: Contemporary and historical developments in heterogeneity</b> Kelsey Lucyk, University of Calgary	12:55 - 12:59
42	Data and Linkage Quality	<b>Analysing the daily, weekly and yearly cycles of births and their implications for the NHS using linked data</b> Gill Harper, City University, London	13:00 - 13:04
43	Data and Linkage Quality	<b>Linking child travel routes and routine health data</b> Amy Mizen, DECIPHer Swansea University	13:05 - 13:09
44	Capacity Building	<b>Supporting Multidisciplinary Analytic Skills: An Innovative Training Platform for Capacity Building</b> Ann Greenwood, Population Data BC	13:10 - 13:14
45	Data and Linkage Quality	<b>Cancer recording in patients with type 2 diabetes in primary care and hospital admission data</b> Shivani Padmanabhan, Clinical Practice Research Datalink	13:15 - 13:19

## Thursday 25 August 2016, 12:55 - 13:19

Station 1			
Poster	Theme	Poster Details	Presentation Time
46	Data and Linkage Quality	<b>Does quality of primary care vary across delivery models</b> Alan Katz, Manitoba Centre for Health Policy, University of Manitoba	12:55 - 12:59
47	Capacity Building	<b>Social Data Linkage Environment</b> Richard Trudeau, Statistics Canada	13:00 - 13:04
48	Data and Linkage Quality	<b>Effect of incomplete registration at general practices on the annual prevalence of treated asthma</b> Mohammad Al Sallakh, Swansea University Medical School	13:10 - 13:14
49	Data and Linkage Quality	<b>Preparing linked population data for research: cohort study of prisoner perinatal health outcomes</b> Lisa Hilder, University of New South Wales, Australia	13:15 - 13:19

Station 2			
Poster	Theme	Poster Details	Presentation Time
50	Data and Linkage Quality	<b>Linking AWPS and CARIS data to estimate perinatal mortality in Wales due to congenital anomalies</b> David Tucker, Public Health Wales	12:55 - 12:59
51	Data and Linkage Quality	<b>First steps in demonstrating an impact on health service use of the Welsh Government Supporting People homelessness prevention programme using linked administrative data</b> Sarah Lowe, Knowledge and Analytical Services, Welsh Government	13:00 - 13:04
52	Data and Linkage Quality	<b>Adherence and persistence of subcutaneous biologics delivered through homecare services to a cohort of patients with rheumatoid arthritis</b> Samantha Alvarez-Madrado, University of Strathclyde	13:05 - 13:09
53	Data and Linkage Quality	<b>Assessing the accuracy of probabilistic record linkage of social and health databases in the 100 million Brazilian cohort</b> Marcos Barreto, Federal University of Bahia (UFBA), Salvador, Bahia, Brazil	13:10 - 13:14

54	Data and Linkage Quality	<b>The comparative analysis of the welfare attitude in accordance with the dual status of taxpayer and welfare recipient by using data linkage</b> Miae Oh and Hyunsoo Choi, Korea Institute for Health and Social Affairs	13:15 - 13:19
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Station 3			
Poster	Theme	Poster Details	Presentation Time
55	Data and Linkage Quality	<b>A process-driven platform to manage datasets for research</b> Gordon McAllister, Farr Institute, University of Dundee	13:00 - 13:04
56	Linking to Emerging Data Types	<b>Secure provision of unconsented radiological imaging for research</b> Gordon McAllister, Farr Institute, University of Dundee	13:05 - 13:09
57	Capacity Building	<b>Impact of mindfulness for people with arthritis</b> Sinead Brophy, Swansea University Medical School	13:10 - 13:14
58	Data and Linkage Quality	<b>A suggestion on how to include calendar dates in Bloom Filters</b> Antony Peter Stevens, Coordenação Geral de Informações e Análise Epidemiológica	13:15 - 13:19

Station 4			
Poster	Theme	Poster Details	Presentation Time
59	Delivering and Measuring Impact	<b>The use of multi-sourced linked datasets in evaluating the Emergency Medical Retrieval and Transfer Service (EMRTS) CYMRU</b> David Rawlinson, EMRTS Cymru, NHS Wales & Swansea University Medical School	12:55 - 12:59
60	Applied Projects	<b>Incidence, risk factors, and adverse short term perinatal and maternal outcomes associated with singleton breech presentation at delivery in Northern Tanzania</b> Uyonyimoo M Mchaki, Kilimanjaro Christian Medical University College	13:00 - 13:04
61	Delivering and Measuring Impact	<b>Treatment choices for managing glucose control in impaired renal function: Interim Results</b> Gareth Davies, Swansea University Medical School	13:05 - 13:09
62	Delivering and Measuring Impact	<b>The Impact of Asthma on congenital anomalies, prematurity, birth centiles and infant feeding: retrospective population cohort analysis 2004-2010</b> Gareth Davies, Swansea University Medical School	13:10 - 13:14
63	Applied Projects	<b>The healthcare costs of heart failure during the last five years of life: A retrospective cohort study</b> Helen Strongman, Clinical Practice Research Datalink	13:15 - 13:19

Station 5			
Poster	Theme	Poster Details	Presentation Time
64	Privacy, Regulation & Governance	<b>Creating a Single Application and Approval Process to Enable Research; an example using CPRD Primary Care Data and Public Health England Cancer Registry Data</b> Sophia Amjad, CPRD	12:55 - 12:59
65	Delivering and Measuring Impact	<b>Virtual visits: Friend or foe of patient-centred care?</b> Kim McGrail, Centre for Health Services and Policy Research, Population Data BC, The University of British Columbia	13:00 - 13:04
66	Delivering and Measuring Impact	<b>Developing population segments with different levels of complexity and primary health care needs: An analysis using health administrative data in British Columbia, Canada</b> Kim McGrail, Centre for Health Services and Policy Research, Population Data BC, The University of British Columbia	13:05 - 13:09

67	Delivering and Measuring Impact	<b>Harnessing multiple data sources to good program planning for Rural US Veterans</b> Teresa Hudson, University of Arkansas For Medical Sciences, College of Medicine and VA Center for Mental Healthcare and Outcomes Research, Little Rock Arkansas USA	13:10 - 13:14
68	Applied Projects	<b>In adults with multimorbidity, does the provision of social care services have an effect on the use of primary care and secondary care health services?</b> David Henderson, University of Glasgow	13:15 - 13:19

Station 6			
Poster	Theme	Poster Details	Presentation Time
69	Advanced Analysis	<b>Integrating text analytics and statistical modelling to analyse kidney transplant immune suppression medication in registry data</b> Ghada Alfattni, The University of Manchester	12:55 - 12:59
70	Advanced Analysis	<b>Identifying Household Level Risk Factors for Unintentional House Fire Incidents, Injuries and Fatalities</b> Samantha Turner, Swansea University Medical School	13:00 - 13:04
71	Advanced Analysis	<b>Risk of mortality following discharge from Critical Care</b> Angharad Walters, Swansea University Medical School	13:05 - 13:09
72	Advanced Analysis	<b>Trends in prevalence, incidence, health system use and cost by persons with dementia in Ontario from 2004 and 2013: a population-based study</b> Susan E Bronskill, Institute for Clinical Evaluative Sciences (ICES)	13:10 - 13:14
73	Advanced Analysis	<b>Linked Data Paves the Way to Improved Health Care</b> Rachel Hemeon, Canadian Institute for Health Information	13:15 - 13:19

Station 7			
Poster	Theme	Poster Details	Presentation Time
74	Advanced Analysis	<b>Wait times and patterns of care in the colorectal cancer diagnostic interval</b> Colleen Webber, Queen's University, Kingston, Ontario	12:55 - 12:59
75	Advanced Analysis	<b>Exploring health events around preventable hospitalisations through visualisation of linked health data</b> Michael Falster, Centre for Big Data Research in Health, UNSW Australia	13:00 - 13:04
76	Advanced Analysis	<b>Longditudinal Study of Type-2 Diabetics – Do the morbidly obese really have better outcomes?</b> Kelly Nock & Kerry Bailey, We Predict Limited	13:05 - 13:09
77	Delivering and Measuring Impact	<b>Visibility in health statistics: a population data linkage study more accurately identifying Aboriginal and Torres Strait Islander Births in Victoria, Australia, 1988-2008</b> Jane Freemantle, University Department of Rural Health, Faculty of Medicine, Dentistry and Health Sciences, the University of Melbourne	13:10 - 13:14
78	Data and Linkage Quality	<b>Born a bit too early: A study of early planned birth and child development at school age</b> Christine Roberts, Kolling Institute, University of Sydney	13:15 - 13:19

Station 8			
Poster	Theme	Poster Details	Presentation Time
79	Data and Linkage Quality	<b>Are There Long-term Academic Benefits of Full-Day Kindergarten? A Population-Based Analysis</b> Marni Brownell, Manitoba Centre for Health Policy, University of Manitoba	12:55 - 12:59
80	Data and Linkage Quality	<b>New Zealand Longitudinal Census development</b> Gareth Minshall, Farr Institute, Statistics New Zealand	13:00 - 13:04
81	Applied Projects	<b>Effect of short interdelivery interval between the first and second pregnancies in adolescence on low birth weight</b> Claudia Coeli, Universidade do Estado do Rio de Janeiro, Brazil	13:05 - 13:09
82	Applied Projects	<b>Abuse and neglect in children with disabilities: risk varies by type of disability</b> Scott Sims, Telethon Kids Institute, University of Western Australia	13:10 - 13:14
83	Privacy, Regulation & Governance	<b>A UKSeRP for SAIL: striking a balance</b> Kerina Jones, SAIL Databank, Swansea University Medical School	13:15 - 13:19

Station 9			
Poster	Theme	Poster Details	Presentation Time
84	Analytical Approaches to Distributed Data	<b>The relationship between maternal race-ethnicity, immigrant status and country of birth and the risk of having a child with autism spectrum disorder in Western Australia</b> Jenny Fairthorne, Telethon Kids Institute	12:55 - 12:59
85	Analytical Approaches to Distributed Data	<b>Methods of defining hypertension in electronic medical records: validation against national survey data</b> Mingkai Peng, University College of London	13:00 - 13:04
86	Analytical Approaches to Distributed Data	<b>Causes of death in the decade after hospitalisation for injury during adolescence: a study using linked hospital admissions and death registrations data</b> Annie Herbert, Swansea University Medical School	13:05 - 13:09
87	Analytical Approaches to Distributed Data	<b>Patient-level data linkage across ambulance services and acute trusts: assessing the potential for improving patient care</b> Sophie Clark, The London Ambulance Service	13:10 - 13:14
88	Analytical Approaches to Distributed Data	<b>An International Cross-cohort Harmonization and Data Integration Initiative towards Achieving Statistical Power and Meaningful Results</b> Tanya Flanagan, Canadian Partnership Against Cancer/ Maelstrom Research	13:15 - 13:19

Station 10			
Poster	Theme	Poster Details	Presentation Time
89	Linking to Emerging Data Types	<b>Linking the Diagnostic Imaging Dataset (DID) to cancer registration data – improving understanding of diagnostic imaging in lung and ovarian cancer</b> Anna Fry, National Cancer Registration and Analysis Service (NCRAS - PHE) / Cancer Research UK	12:55 - 12:59

# Visitor Information

## Venue Access

### Car Parking

Conference delegates and those staying in the Bay Campus accommodation can park on campus.

There are 600 parking spaces at the Bay Campus to include staff parking, disabled spaces and 100 pay and display spaces. If all campus car parking spaces are full, there is a visitor pay & display car park on the immediate left hand side of the University entrance. The charges are:

Up to 2 hours	£1.50
Up to 4 hours	£2.50
8am – 6pm	£3.50
6pm – 8am	£1.50

Parking in unauthorised areas or failure to display a valid Temporary Parking notice will result in the issue of a parking fine.

SAT NAV - The Swansea University Bay Campus postcode is SA1 8EP.

## Accommodation

All residential guests have been allocated rooms in Talacharn (building no.12 on the campus map on page 38) and Llansteffan (building no.15 on the campus map on page 38). Check-in will be possible from 14:00 on the day of arrival.

### Room Key Collection Points

**Guests arriving prior to Monday 22 August 2016:**

Keys will be available in the Tower and Information Centre St Modwen Reception Desk (building no.9 on the campus map on page 38). Security will be present during the evening for late check in.

**Guests arriving on Monday 22 August & Tuesday 23 August 2016:**

Keys will be available in the Tower and Information Centre St Modwen Reception Desk (building no.9 the campus map on page 38). Security will be present during the evening for late check in.

**Guests arriving on Wednesday 24 August 2016:**

Keys will be available from the main conference registration desk in the entrance of The Great Hall (building no.6 on the campus map on page 38) between 07:00 - 17:00. Guests arriving after 17:00, keys will be available in the Tower and Information Centre St Modwen Reception Desk (building no.9 the campus map on page 38). Security will be present during the evening for late check in.

**Guests arriving post Wednesday 24 August 2016:**

Keys will be available from the Tower and Information Centre St Modwen Reception Desk (building no.9 the campus map on page 38). Security will be present during the evening for late check in.

All delegates have a single ensuite bedroom. The following items are provided in the rooms:

- Bed linen
- 2 towels (1 bath towel & 1 hand towel)
- Mini toiletries (shampoo, conditioner & soap)
- A hospitality tray (kettle, coffee & tea)

*Please note that the bedrooms do not have televisions, hairdryers or irons.*

When Checking out, please return your room keys to the Tower and Information Centre St Modwen Reception Desk (building no.9 the campus map on page 38).

### Complimentary Breakfast

Breakfast for residential delegates will be served in The Core (building no. 9 on the campus map on page 38) each morning between 06:30 to 08:00.

### Use of Gym Facilities

All residential conference participants are entitled to use the Swansea University Bay Campus Sports Centre Uni-Gym facilities. In order to use the gym, proof of induction at another sports facility will be required. Please show conference badge and room key as identification, at the Sports Centre Reception Desk.

## Registration

### Pre-Conference Workshops Registration Desk

The pre-conference workshops will be held in the School of Management building (building no. 7 on the campus map on page 38). The registration desk is positioned in the atrium and will be open as follows:

Sunday 21 August	12:00 - 19:00
Monday 22 August	08:30 - 19:00
Tuesday 23 August	08:30 - 19:00

### Main Conference Workshops Registration Desk

The main conference will be held at The Great Hall (building no.6 on the campus map on page 38). The registration desk is positioned in the entrance foyer and will be open as follows:

Wednesday 24 August	07:00 - 17:00
---------------------	---------------

Thursday 25 August	07:00 - 17:00
Friday 26 August	07:00 - 14:00

### Conference Guide

The conference will **NOT** be printing and distributing hard copies of the conference guide onsite so please either print or download the conference programme in advance from the website.

### Conference App

The conference app – IPDLC 2016 (available for both IOS and Android) will be available for download in August prior to the conference. It will enable delegates to view the full programme including the details of the sessions and abstracts on handheld devices.

### Cloakroom Facilities

The cloakroom for the pre-conference workshops is located in room 43 on the ground floor of the School of Management (by the registration desk positioned in the atrium).

The cloakroom for the main conference is located on the ground floor of The Great Hall (Room GH018 on page 40).

The cloakrooms are open at the following times:

**School of Management:**

Monday 22 August	08:00 - 17:00
Tuesday 23 August	08:00 - 17:00

**The Great Hall:**

Wednesday 24 August	07:00 - 18:00
Thursday 25 August	07:00 - 17:30
Friday 26 August	07:00 - 16:30

## Food and Drink

Complimentary refreshments and lunches are provided at scheduled times during the 5-day conference as part of the delegate package.

### Pre-Conference Workshops

- Refreshments will be served in the Ground Floor Coffee Shop, School of Management
- BBQ lunches will be served at the Bay Campus beachfront located to the rear of the Great Hall (if weather permits). Should the BBQs not go ahead due to bad weather then lunch will be served in The Core (building no. 9 on the campus map on page 38).
- A packed lunch will be provided to those who are joining the coach tour to Blaenavon, followed by a complimentary Welsh banquet at Cardiff Castle in the evening.



### Main Conference

- Refreshments and lunches will be served in the Great Hall Galleries located on the first floor where the Multimedia Poster stations are situated.
- The Welcome Drinks Reception and Finger Buffet taking place in the Great Hall on the 24 August from 18:00 is open to all conference delegates to attend.

### Optional Extra Dining at the Bay Campus (not included in the delegate package)

#### The Core

The Core will be open during the evenings for anyone wishing to dine on campus. This modern, food court-style dining space serves a variety of options from traditional home comfort dishes to more exotic options. Dinner can be pre-booked via the registration page <https://intranet.swan.ac.uk/OnlineStore/Products/Details/1070> Click here to view the menu [http://www.swansea.ac.uk/medicine/research/researchthemes/patientpopulationhealthandinformatics/ehealth-and-informatics-research/pdfuploads/Lunch\\_&\\_Dinner\\_Menus.pdf](http://www.swansea.ac.uk/medicine/research/researchthemes/patientpopulationhealthandinformatics/ehealth-and-informatics-research/pdfuploads/Lunch_&_Dinner_Menus.pdf)

24 August	19:30 - 20:30
25 August	18:30 - 19:30

#### 52° Café Bar

The Bar at the 52° Café serves delicious light bites and a mouth-watering selection of chef's specials plus beers and wines from around the world

21 to 25 August open from 19:00 to 23:00

#### The Great Hall Café Bar and Restaurant

The Great Hall Café Bar and Restaurant offers an excellent menu of sandwiches, salads, sharing platters and tapas using only the finest, freshest, locally sourced ingredients. They also serve a selection of coffees and soft drinks as well as fine wines and award-winning beers.

24 to 25 August open from 19:00 to 23:00

### Wi-Fi

Wi-Fi is available free of charge for delegates throughout the conference venue from most wireless enabled devices.

#### Access using Eduroam

The JANET Roaming Service is designed to provide roaming network access between participant sites in the UK education and research sectors for staff and students. Swansea University is a participating member of the JANET Roaming Service and so allows visitors from participating institutions to use our Eduroam wireless network.

To use this facility, it is necessary to configure your device for wireless use in your home institution before bringing it to Swansea. If this has been done, delegates can connect to Swansea wireless with no further configuration or registration necessary.

*Note that support for Eduroam should be provided by your home institution's IT staff.*

Further details on the JANET Roaming Service can be found here: [www.ja.net/services/authentication-and-authorisation/janet-roaming.html](http://www.ja.net/services/authentication-and-authorisation/janet-roaming.html)

#### Access using the venue Wi-fi

For delegates who are not visiting from an Eduroam institution, there will be a straight forward access to a wireless network available to most wireless enabled devices. Log in details for the wireless network will be disseminated upon arrival at the conference.

### Accessibility

Many visitors to the Bay Campus may have special requirements and details of the services provided are listed below:

#### Access

There is level access throughout the Venue and via all entrance gates. Lifts are available within all buildings to access higher levels.

#### Parking

A limited number of Disabled Parking bays are available situated in the visitor's car park at the front of the campus. For more information please contact us by email: [info@ipdln.org](mailto:info@ipdln.org)

#### Toilets

Wheelchair friendly toilet facilities are located on the west & east side of the venue on both floors.

#### Assistance

The Conference Team are trained to assist delegates with disabilities and will be more than happy to assist where possible.

#### Guide Dogs

Guide Dogs are permitted within the Venue. Should your dog require water then please ask a Conference Team member and we will do our best to assist.

#### Induction Loops

All of the venue breakout rooms have a mixture of hearing loops and infra facilities.

Induction Loop systems have been installed to the following areas:

- The Great Hall Bar Area
- The Great Hall Galleries Area

### First Aid

During conference hours you will find

Justin Biddle, the dedicated conference first aider, stationed daily at the conference registration desk in the main foyer of the Great Hall.

For medical emergencies during conference hours please call 333 using the nearest landline telephone that you will find in all of the breakout rooms.

### Tesco Express

You will find a Tesco Express store located on Bay Campus.

Visit [www.tesco.com/store-locator/uk/](http://www.tesco.com/store-locator/uk/)

### Cash Point

You will find a cash machine for withdrawals within easy walking distance of the Great Hall and School of Management located outside the Tesco Express store.

### Useful Local Telephone Numbers

Taxis:	
Data Cabs Swansea	01792 474747
Yellow Cabs	01792 644446

*Please Note: Please instruct the driver that your destination is the new Bay Campus on Fabian Way and not Singleton Campus.*

Police (non-emergency number)	101
Ambulance Service	999

### Complimentary Shuttle Bus Service

The conference provides shuttle bus service on 24, 25 & 26 August to transport conference delegates between the conference venue and the following hotels:

- Towers Hotel & Spa
- Hotel Ibis Swansea
- Premier Inn Swansea Waterfront
- Village Hotel Swansea

### Public Bus Service

#### Getting from Swansea University Bay Campus to Swansea City Centre by First Cymru Bus

**Number 8:** Runs every 30 minutes between 08:30 - 18:30 on the weekdays. The bus stop is adjacent to The Great Hall (within The Bay Campus).

**Number 10:** Runs every hour between 08:00 - 18:00 on the weekdays. The bus stop is adjacent to The Great Hall (within The Bay Campus).

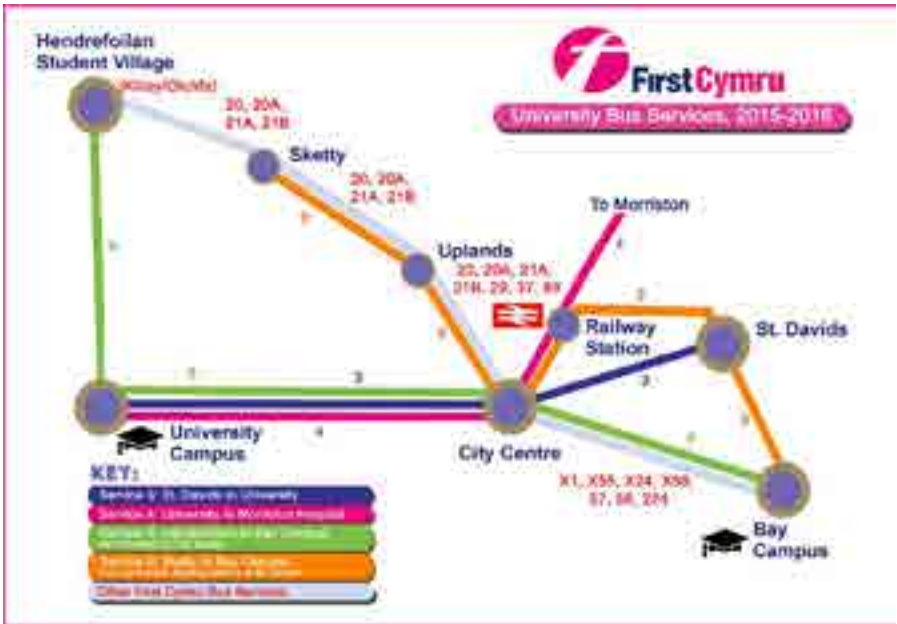
**Number X1:** Runs every hour between 07:15 - 20:38 on the weekdays. The bus stop is located on Fabian Way (on the main road by the entrance of The Bay Campus).

**Number X3:** Runs every hour between 09:00 - 17:19 on the weekdays. The bus

### Timetable for Shuttle Bus Service

Depart from	Wednesday 24 August	Thursday 25 August	Friday 26 August
<b>Towers Hotel &amp; Spa</b>	07:15	07:15	07:15
Arrive at Bay Campus	07:30	07:30	07:30
<b>Mariott Hotel (Marina)</b>	07:00	07:00	07:00
<b>Premier Inn Waterfront</b>	07:10	07:10	07:10
<b>Village Hotel</b>	07:15	07:15	07:15
<b>Hotel Ibis</b>	07:20	07:20	07:20
Arrive Bay Campus	07:30	07:30	07:30
Return to all Hotels	20:30	17:30	15:30
<b>Depart Bay Campus</b>			

### Public Bus Services and Routes:



stop is located on Fabian Way (on the main road by the entrance of The Bay Campus).

**Number X10:** Runs every hour between 06:00 - 17:25 on the weekdays. The bus stop is located on Fabian Way (on the main road by the entrance of The Bay Campus).

#### To visit the Mumbles, a charming fishing village situated at the Western end of Swansea Bay

**Numbers 2, 2A, 2B, 2C:** Using the bus services listed above alight at Swansea City Centre Bus Station and take one of the number 2 buses at Stand W into Mumbles.

**Number 224:** Runs every hour between 06:56 - 17:33 on the weekdays. The bus stop is located on Fabian Way (on the main road by the entrance of The Bay Campus) and will take you to Mumbles with no change.

To plan your journey around Swansea City, please visit the Public Transport Journey Planner website [www.swansea.ac.uk/sustainability/travel/bus](http://www.swansea.ac.uk/sustainability/travel/bus)

A day ticket to travel by First Cymru Bus will cost £4.20.

### Swansea Restaurants

#### British

The River House [www.riverhouse.co.uk/](http://www.riverhouse.co.uk/) No Sign Bar <http://nosignwinebar.com/>

#### Chinese

The Star Bar & Restaurant [https://www.tripadvisor.co.uk/Restaurant\\_Review-g186466-d5603858-Reviews-Star\\_Bar\\_Restaurant-Swansea\\_Swansea\\_County\\_South\\_Wales\\_Wales.html](https://www.tripadvisor.co.uk/Restaurant_Review-g186466-d5603858-Reviews-Star_Bar_Restaurant-Swansea_Swansea_County_South_Wales_Wales.html)

#### Continental

La Braseria <http://www.labraseria.com/> Mosaic <http://www.mosaicswanseauk.com/>

#### French

Pant-y-Gwydr <http://www.pantgygydr.co.uk/> Bouchon de Rossi <http://www.bouchonderossi.co.uk/>

#### Indian Fusion

Rasoi Waterfront <http://rasoiwaterfront.co.uk/>

#### Italian

Mama Mia! <http://www.mymammamia.com/> Pizza Express <https://www.pizzaexpress.com/swansea> Coast Italia <http://www.coast-italia.co.uk/>

#### Japanese

Nishimura <http://nishimura.co.uk/menu/>

#### Latino

Las Iguanas <http://www.iguanas.co.uk/book-now/swansea>

#### Middle Eastern

Awa Grill House - <https://www.facebook.com/pages/Awa/234255053392301>

#### Portuguese

Madeira Restaurante <http://www.madeirarestaurantswansea.co.uk/>





# Swansea University Bay Campus

## Key


- 1 Energy Safety Research Institute (ESRI)
- 1.1 Oracle II
- 2 Institute of Structural Materials (ISM)
- 3 Engineering East
- 3.1 Service Good Yard
- 4 Engineering Central
- 5 Bay Library
- 6 Great Hall
- 7 School of Management
- 8 Student Residences
- 8 Students' Union
- 9 Tower Information Centre (TIC)
- 9 Estates and Facilities Reception
- 9 St Modwen Student Living Reception
- 9 My Uni Hub
- 12 Talacharn Residence
- 15 Llansteffan Residence





Car Parking	Food Court	Sports Reception/Hall/Gym	Outdoor Sports Facilities
Bus Stops	Bar/Café	Baby Changing Facilities	Site of Special Scientific Interest
Taxis	Café	Crèche	Site of Special Scientific Interest Parking
Cycle Park	Vending	Shop	TIC Entrance
Bank	Showers	Launderette	


# Great Hall Floor Plan


Key


Registration


Toilets


Elevators/Lifts

Poster Stations

Café Bar & Restaurant

Terrace

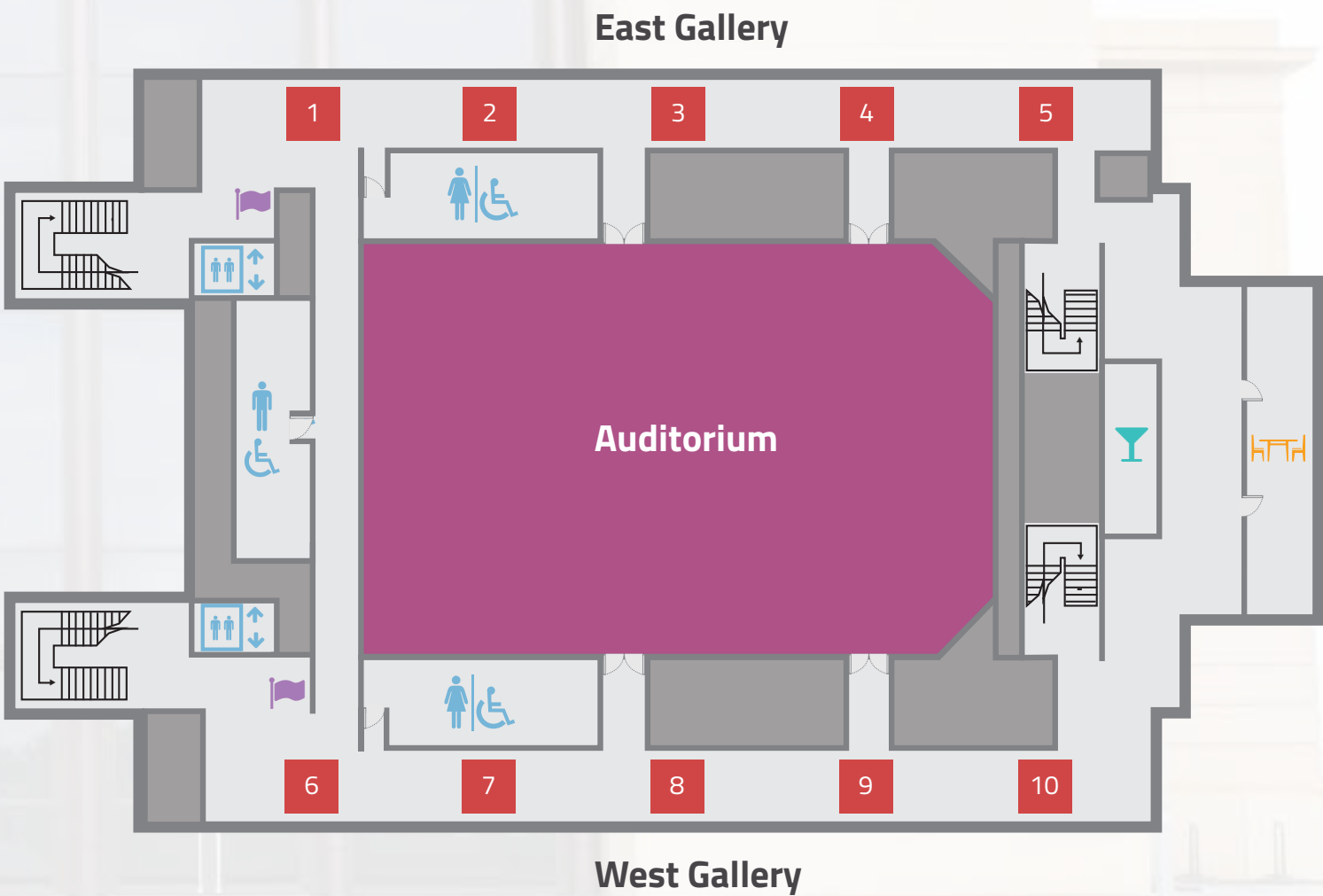
Sponsor

Buzzwire & Crane Grabber Games

## Ground Floor



## First Floor



Please Note: Indicated areas may be subject to change at short notice



# Social Activities

## The Giant Buzzwire Game

Play the all-time favourite buzzwire game and whoever completes the course in one go wins a prize and gets to stay on the leaderboard throughout the conference!

Look out for the Giant Buzzwire Game at the conference!

## Welcome Reception

The opening of the conference will be marked by an evening drinks reception with finger buffet and a light-hearted Welsh cultural show to be held at The Great Hall Gallery and Auditorium. All conference delegates are welcome to attend.

## Gala Dinner

The conference Gala dinner will be held at the impressive fourteenth-century Great Hall at Caerphilly Castle - the largest castle in Wales, and the second-largest in Britain after Windsor Castle. Caerphilly Castle covering 30 acres, is one of the grandest surviving castles in the medieval Western world that is built by Earl Gilbert de Clare in 1268. It was a highpoint in medieval defensive architecture with its massive gatehouses and water features, the first truly concentric castle in Britain constructed in the 13th century.

The Gala dinner at Caerphilly Castle includes admission to the castle, complimentary pre-dinner drinks (served on an unlimited basis of 40 minutes), and a five course meal with wine and coffee. The bar at the venue will be open for the duration of the evening if you wish to purchase your own drinks. You will be entertained by Wynne Evans, a Welsh tenor known for his role in the GoCompare.com insurance adverts on television in the United Kingdom and he was cast as the opera singer Ubaldo Piangi in the 25th Anniversary celebratory production of Andrew Lloyd Webber's The Phantom of the Opera at the Royal Albert Hall.

The conference Gala dinner is an unmissable opportunity to network with peers in a relaxed atmosphere, whilst discovering the outstanding natural beauty of the South Wales hills and valleys and its historical sites.

## Blaenavon Industrial Landscape (UNESCO World Heritage Site of Wales) & Welsh Banquet at Cardiff Castle

(Available for pre-conference workshops' delegates only)

Blaenavon Industrial Landscape was inscribed as a World Heritage Site by UNESCO in 2000 in recognition of the exceptional testimony to the dynamic forces that drove the Industrial Revolution that is told through the areas heritage assets. Major sites such as Blaenavon Ironworks and Big Pit, together with the wider landscape with its relicts of mineral exploitation, manufacturing, transport and settlements together tell the story of the iron and coal industry that was pre-eminent in south Wales in the 19th century.

The visit includes a guided tour followed by a Welsh banquet

at Cardiff Castle, a medieval castle and Victorian Gothic revival mansion located in the city centre of Cardiff, Capital of Wales.

## See Wales Tours

Swansea and the surrounding area is one of the most beautiful and interesting parts of Wales. After a data linkage packed day at IPDLN 2016, you might want to let your hair down, recharge your batteries and explore your surroundings

So, for those who were unable to get a Gala Dinner ticket in Caerphilly Castle, don't despair as we have some fantastic options to keep you busy on the evening of the 25th August!

Have a browse at the options opposite and if you, or your accompanying delegate, would like to join any of the specially designed activities, please visit our website to book:

[ipdlconference2016.org/Programme/SocialActivities](http://ipdlconference2016.org/Programme/SocialActivities)

## Welsh Whisky & the Brecon Beacons National Park: The Real Taste of Wales

On this experience of Wales a taste of the good life is guaranteed. From the coast to the mountains your route will take you from Swansea up to the Brecon Beacons National Park with two outstanding visits to get your taste buds tingling.

The Welsh Whisky Centre is at the foothills of the national park and it'll be where you'll find a village with liquid gold - whisky flavoured. Called Penderyn this exceptional Welsh single malt whisky, which is also the name of this quaint place, will be the focus of your distillery tour and will allow you to discover (and taste) one of the country's proudest exports. You'll find Brecon Gin, Brecon Five Vodka and Merlyn Cream Liqueur delighting your senses too – all made at the same place.

Next to the uplands of South Wales which are dominated by a mountain range now called the Brecon Beacons National Park. So, as the setting sun silhouettes the hills, you'll be soaking in the scenery of a land torn by glaciers and nibbled by sheep to visit your next place ... for a hearty Welsh dinner!

A fine night of Welsh food and drink awaits at a locally renowned restaurant, Pen-Y-Cae, nestled in a Welsh valley of green, green grass.

## Dylan Thomas' Swansea: The Actor's Walking Tour

(With Performance Actors!)

This unique, lively and entertaining Dylan Thomas Walking Tour is a chance to walk in the footsteps of Dylan Thomas through his "ugly, lovely town", the city of Swansea. Absorb the iconic streets and corners of the city where he celebrated the characters of his youth through many works of poetry and prose. You'll be in the company of local actors along the tour who'll perform many of his famous poems in the very places that inspired him.

Follow your guide as you walk to these places that inspired this fun, quirky, irksome poetry and prose. Visit such familiar

places as Captain Cat's Statue, Dylan Thomas Square, Swansea Museum, Wind Street, Salubrious Passage, Castle Square, St Mary's Church, Old Evening Post Building, Three Lamps, Kardomah Café, High Street, BBC Building, No Sign Bar and the Queens Hotel. Your accompanying actors will bring these places to life!

We'll start and finish at one of these local "haunts" too where you'll sample the local ales and enjoy fantastic Welsh food with a dining experience to remember. All of this whilst revelling in the almost unchanged surroundings from the time of the great Welsh wordsmith.

## Tour of Gower Peninsula, Wales. Britain's 1st Area of Outstanding Natural Beauty

A tour of the stunning Gower Peninsula with its golden sandy beaches, rugged coastline and prehistoric wonders. A perfect evening awaits to discover Wales. Gower is Britain's first designated Area of Outstanding Natural Beauty and by the end of the evening you'll see why.

With fantastic views of the coast from cliff tops, coastal path walks and ancient stone-age discoveries this excursion will delight all newcomers to Wales.

The main highlights are walking the coastal path and a visit to the highest village on the peninsular Rhossili where you'll have the chance to explore the 'serpent in the sea' and take in the spectacular view of Rhossili Bay; Trip Advisor's 10th Best Beach in the World.

You'll dine here too at the evocative sounding name Worms Head Hotel with its famous Bar Helvetia, so named from the shipwreck on the beach below. A typical range of local hearty dishes awaits, such as traditional battered fish, chips and mushy peas, home-cooked pies, locally sourced lamb, beef and fish dishes plus a selection of Welsh delicacies such as Welsh Rarebit and Pembrokeshire Crab.

Plenty of chance to take a walk on this tour too and soak in the scenery as you dine. To quote a famous Welsh poet "What is this life if, full of care, we have no time to stand and stare".

## Welcome to Wales - A Taste of Gower

For Accompanying Delegates and Families  
Welcome to Wales and welcome to Gower! Join us for a brief but perfect excursion to the famous beaches and bays of south Wales and an Area of Outstanding Natural Beauty called Gower. It's a huge peninsula near the city of Swansea and famed for its natural wonders, giving you many aspects of the whole of Wales in one special place. You'll get the chance of discovering some breath taking cliff top views and coastal paths whilst being guided by a professional tour guide from See Wales Tours

Enjoy the delights of Mumbles – a quintessential seaside town, Langland Bay – a bay for the rich and famous, and surfers paradise at Caswell Bay. Walk, swim (if you like!) and have an ice cream or two – essential!





Supporting cutting-edge  
health informatics research  
across the UK



## Who We Are

The Farr Institute is a UK-wide research collaboration involving 21 academic institutions and health partners in England, Scotland and Wales. Publically funded by a consortium of ten organisations led by the Medical Research Council, the Institute is committed to delivering high-quality, cutting-edge research using 'big data' to advance the health and care of patients and the public.

The Farr Institute aims to position the UK as a world leader in health informatics research through scientific discovery and the enhancement of patient and public health. By analysing data from multiple sources and collaborating with the government, public sector, academia and industry, the Institute will unleash the value of vast sources of clinical, biological, population and environmental data for public benefit, preventing disease through:

- Earlier diagnosis of disease
- Safer and more effective treatments
- More effective integrated pathways
- A greater understanding of how to use NHS funding most effectively
- Driving clinical research
- Precision Medicine – understanding the genetic and molecular basis of disease
- Public health research



[www.farrinstitute.org](http://www.farrinstitute.org)

Visit [www.farrinstitute.org](http://www.farrinstitute.org) for more information

# What We Do

The Farr Institute does not own or control data but analyses data to better understand the health of patients and populations in six ways:

## Research

Performing pioneering inter-disciplinary research with large and complex data

## Skills

Developing skills, talent and expertise in the health informatics research community and providing tools for collaborative working.

## Methods

Enabling new datasets and developing new infrastructure, methods, technologies, and standards for health informatics research.

## Regulation and Ethics

Working with the owners and controllers of data to support the safe use of patient information for medical research across the UK, championing data protection, confidentiality and privacy.

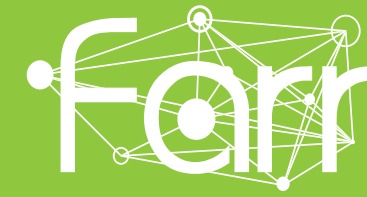
## Public Engagement

Engaging with the public to demonstrate the benefits of using health data in research and to encourage the support of secure and trusted access to patient information

## Creating Partnerships

Bringing together government, public sector, academia and industry to foster relationships and establish best practices for innovation, discovery and impact in health data science.

The Farr Institute is proud to be a part of the UK's vision to become a global leader in health data science by accelerating the understanding of disease and improving health and care for patients and the public.



The Farr Institute of Health Informatics Research

The Farr Institute of Health Informatics Research is funded by:



Visit [www.farrinstitute.org](http://www.farrinstitute.org) for more information







An ESRC Data Investment

# The Administrative Data Research Network



# Do you have an idea for research that needs administrative data?

Get in touch with our Helpdesk via [help@admn.ac.uk](mailto:help@admn.ac.uk) or +44 (0) 1206 87 3435



## Looking for devolved government or regional data?

Contact one of our Administrative Data Research Centres:

- ▶ England: [adrce@soton.ac.uk](mailto:adrce@soton.ac.uk)
- ▶ Northern Ireland: [adrcni@qub.ac.uk](mailto:adrcni@qub.ac.uk)
- ▶ Scotland: [adrc-s@ed.ac.uk](mailto:adrc-s@ed.ac.uk)
- ▶ Wales: [ADRCWales@swansea.ac.uk](mailto:ADRCWales@swansea.ac.uk)

# Join the Royal Statistical Society

And become a member of an active community of producers and users of statistics who work together to promote the role that statistics and data analysis play in society.

## ABOUT US

— We are a **charity** which promotes statistics, data and evidence for the public good; we are one of the world's leading learned societies and the only UK professional body for all statisticians. Our main category of membership – **fellowship** – is open to all who have an interest in statistics and data analysis; formal qualifications are not necessary and you don't need to live in the UK (around a quarter of our 8000+ members live overseas).

Become a member today and help us achieve our vision of '**A world where data are at the heart of understanding and decision-making.**'

## Improving knowledge

- All fellows receive a print copy of **Significance**, our bi-monthly magazine which covers statistical topics and news in a thought-provoking and entertaining way. The Significance website gives members exclusive online content and the iOS and Android apps also give free access to current issues of the magazine. The full back catalogue is also available to members online



- Our **Journal of the Royal Statistical Society** keeps members updated on leading methodologies, novel solutions and statistics applied to social issues. You'll receive electronic access (both online and through the iOS/Android app) to one of the three series as part of your membership package (additional series can be purchased at the cost of £42 per year per series).

### The three series are:

- **Statistics in Society (Series A)** focusing on statistics applied to social issues in all disciplines which take people as their subject matter
- **Statistical Methodology (Series B)** which publishes work at the leading edge of methodological development, with an emphasis on relevance to statistical practice
- **Applied Statistics (Series C)** which publishes papers dealing with novel solutions to real life statistical problems. The subject matter covers the range of interdisciplinary fields, eg industry, agriculture, genetics, medicine and physical sciences

- Our **Webinar series** is a popular channel for our international membership to improve knowledge. The Journal webinars feature selected papers from the Journal with authors presenting their work followed by a discussion. Our Professional Statisticians' Forum also runs regular webinars, open to all members
- All fellows receive the fortnightly **members-only e-bulletin** offering an easy to read digest of statistical news and opinion, plus the latest jobs



## Having a voice

- Through our **member-led policy work**, our members have a voice. Whether it's influencing education policy, working with the press on how to report statistics or responding to consultations, our members are able to influence decision makers and make a real impact on the role of data in society
- Our members are also encouraged to **write for our publications and websites** and talk at careers events, at schools, at seminars in parliament and at other professional events about the importance of statistics and the role of the RSS
- Members who are users of statistics are invited to participate in an **online forum** where they can share experience and knowledge with one another and with those who produce statistics
- Every year we select and train a small number of early career statisticians to present statistics to the public, becoming our **statistical ambassadors**

## Sharing best practice

- We are the largest UK networking organisation for statisticians. Our **150+ meetings** a year give our members plenty of opportunities to share best practice and meet others from different industries, sectors and areas of the UK. Meetings are either free or offered at a discount to members
- For our members who can't attend all our meetings, we record a number of them which are then available on our website as **free podcasts or videos**; there are also a number of online forums
- Fellows receive a discount to attend the **RSS Annual International Conference**: the only conference in the UK which brings together all statisticians and users of data
- We encourage our members to participate in our **Statisticians for Society** programme, enabling our members to offer their time pro bono to good causes



## Other benefits

- Using the collective buying power of the membership, we have a comprehensive **discount scheme** offering savings on a range of items from travel and car hire to cinema tickets and restaurants. The scheme also offers cashback at many high street brands and discounts on professional and business services and insurance
- Free access to the **Fellows' Suite** at our office in London
- 20% discount on **room hire** at our office in London
- 20% discount to **advertise** on our popular jobsite
- A dedicated online members' area, **My RSS**, where you can access online benefits and update your profile for the searchable Fellows Directory
- Discounts from a range of **publishers**

## Professional development

- Members enjoy discounts to attend our popular **short training courses** that aim to meet the needs of both statisticians and users of statistics
- Fellows with a degree (or equivalent) in statistics and/or relevant experience are invited to apply for one of our two **professional awards**: Graduate Statistician or Chartered Statistician. Both are acclaimed worldwide as a benchmark for professional statisticians and bring further exclusive membership benefits
- If you're an early career statistician, we have an active group which helps members **develop their careers** in statistics and data analysis

## Fees

The standard annual subscription rate for fellows is £132 or £122 if paying by Direct Debit. If you are from an Economically Developing Area, are a student, retired or a new graduate, then a concessionary rate of £66 (or £61 if paying by Direct Debit) is available.

Fellow membership runs from January to December. We accept applications throughout the year: if you join before the end of August, you'll be sent all copies of Significance and the Journal that you've missed in that year and other benefits will start immediately. If you join from September onwards the following year's subscription rate will be used and all membership benefits will start immediately.





## FREE e-Student and e-Teacher membership

We offer FREE online membership to students and teachers anywhere in the world. Students need to be in either full or part-time education from A Level (or equivalent) onwards and teachers need to be teaching in schools and further education colleges.

We have created these **FREE** membership categories because we want to support students with their learning and encourage them to enter statistical and data analytical careers and we recognise that teachers play an essential role in influencing and delivering statistical education.

e-Students and e-Teachers will receive most of the benefits described here except we can only offer discounts on selected events and meetings. You also won't be eligible for the printed copies of **Significance** nor our **Journals**, although you can enjoy free access to Significance online and through the iOS and Android apps. Teachers will also have priority access to our resources for teachers, including the Guy Lecture for Schools and careers promotion materials.

e-Student membership will last for as long as you remain a student. After you have completed your course, you can move into the paid category of fellow membership that enables you to enjoy the full range of membership benefits. But if you'd like access to this full package of benefits while you are a student, we offer a concessionary discount of 50% on the fellow membership fee.



### Royal Statistical Society

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www.statslife.org.uk

Become a member of the RSS today and help us achieve our vision of 'A world where data are at the heart of understanding and decision-making.'

Join online today: [www.rss.org.uk/membership](http://www.rss.org.uk/membership)

## ◆ About SAGE ~ Secondary Analysis to Generate Evidence

**SAGE** is a data and research platform where research data, and at a later stage, administrative and community service delivery data related to child and youth development, health and well-being are stored, cleaned, catalogued, managed and potentially linked for secondary research and policy uses.

State-of-the-art technical infrastructure and governance processes for the secondary use of data are provided to ensure privacy, security and ethical use. Outcomes for Alberta's children, youth, families and communities will be improved through using and combining data in new ways to inform social, educational and health policy, practice and service planning.

**SAGE** is not just a passive data repository, but a comprehensive research platform to support novel research in health and social applications. The platform aims to support a broad array of activities to increase the value of data assets deposited with **SAGE**. **SAGE** is leveraging **The Centre's** infrastructure and proven expertise in the following areas to not just build bridges to new research, but to extend it to real-world impact.



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www.research4children.com



## ◆ About The Alberta Centre for Child, Family and Community Research (The Centre)

**The Centre** exists to improve well-being by leading, creating, enabling and mobilizing research and evaluation for evidence-informed policy and practice.

**The Centre** was established as a not-for-profit corporation in 2003 and is a partnership between Alberta's universities, the community and the Government of Alberta. By funding, synthesizing, generating and mobilizing evidence, **The Centre** enables an in-depth understanding of the factors that contribute to the well-being and health of our children.

Our well-developed and coordinated agenda, that is both cross-sectoral and cross-ministerial, addresses the broad needs of the healthy development and futures of children, families and communities throughout Alberta.





## The Centre's Mission

Develop and integrate evidence to inform, identify and promote effective public policy and service delivery to improve the well-being of children, families and communities in Alberta, Canada and internationally.

### WE ARE:

- **BRIDGE BUILDERS**
- **TRANSLATORS**
- **EVIDENCE SEEKERS**
- **A GO-TO ORGANIZATION**
- **TRUSTED**
- **PATH BUILDERS AND ENABLERS**



## Evidence Generation

*The Centre's* evidence generation and knowledge mobilization efforts involve working with all of the Government of Alberta's partnering ministries. *The Centre* staff are familiar with the broad spectrum of current and emerging government priorities and information needs as they relate to the well-being of children, families and communities. So, it is common practice to include cross-ministerial representation on most research and evaluation project advisory committees.

In order to be policy relevant, evidence needs to be produced in a timely manner. *The Centre* responds by working quickly and closely with government staff to clearly define the pertinent questions that require evidence-based answers. Decisions are then made on the best means or methods to generate knowledge to adequately address the questions.

*The Centre* also develops continuums of evidence that build on thematic research priorities. Gap analyses are routinely conducted on existing collections of research evidence to identify key areas or questions that require further investigation. The results of program evaluations, for example, are used to develop research questions to generate increased knowledge based on initial findings.

There are major challenges in being able to provide evidence of value to policy development since it requires capacity in both policy and academic worlds to deeply understand each other's context and situations.

*The Centre* integrates a capacity building approach into knowledge generation.

## Our Core Functions

- Engage in research, evaluation, communication and knowledge mobilization
- Conduct, fund and build capacity in applied research
- Link, analyze and manage data
- Manage resources and strategic relationships
- Measure and communicate our impact and value

## The Child and Youth Data Laboratory (CYDL)

LINKING ADMINISTRATIVE DATA ACROSS GOVERNMENT OF ALBERTA MINISTRIES TO BETTER UNDERSTAND THE LIFE TRAJECTORIES OF CHILDREN AND YOUTH AND THE IMPACT OF POLICY DECISIONS.

Our Government of Alberta partnering ministries believe, like *The Centre*, that data can play an important role in better decision-making and better outcomes. That's why these they are working with the Child and Youth Data Laboratory (CYDL) to explore how cross-ministry, linked and anonymized data can ensure continuous improvement. Through on-going surveillance, monitoring and analysis of data, policies, prevention and intervention strategies can be enhanced.



## Knowledge Mobilization

*The Centre's* ability to inform and support policy begins with a collaborative process to identify key issues and develop useful researchable questions. Supporting policy is dependent on having relationships and networks among Ministers and senior civil servants as well as knowledge of how the policy process actually works.

At *The Centre*, knowledge mobilization is part of the research project process from the point of inception to the release of findings. End users are the backbone of every project. Because of this, the uptake of knowledge and learning throughout a project increases.

*The Centre* plays an important role in making evidence available to policy and program decision makers.

Sometimes this role is supporting the conduct of specific research to inform a particular policy need; and sometimes it's helping to broker relationships behind the scenes.

*The Centre* collaborates with its partners to develop events such as workshops and symposiums.

*The Centre* began broadcasting its events via videoconferencing in 2005 and webcasting in 2006. Today, with little or no marketing budget, *Centre* events have been viewed by over 100,000 around the world.

*The Centre's* popular web presence receives visits from around the world and features thousands of reports of high quality information and knowledge resources as well as recordings of hundreds of presentations and links to other entities.





Data  
Discovery  
Better Health

# TURNING EVIDENCE INTO IMPACT

Over **400** research, data and clinical experts across Ontario

The **largest** repository of Ontario's health-related data

**Research-ready** data sets, accessed over the Internet

**For more than twenty years,** ICES has been leading cutting-edge research that makes policy better, health care stronger and people healthier.

## A growing research community

Our network of satellite campuses connects centres of research excellence across the province, supporting collaboration and giving more researchers access to valuable data.



1992

ICES opens its doors on the campus of Toronto's Sunnybrook Health Sciences Centre on April 1.

1994

ICES publishes first practice atlas, *Patterns of Health Care in Ontario*, raising public awareness of the challenges of delivering a wide range of health services.

1996

**Sore Throat Score** co-developed by ICES researchers leads to a 25% reduction in unnecessary antibiotic prescriptions.

Highlights over the years

1997

**Patient decision-making aids are produced** for women facing breast cancer treatment and considering hormone replacement therapy.

2001

**ICES researchers help develop** the Registry of the Canadian Stroke Network and evaluate a new strategy for stroke care in Ontario.

2002

**Launch of Enhanced Feedback for Effective Cardiac Treatment (EFFECT)** project — the world's first randomized trial of report cards measuring hospital performance.

2007

**ICES extends its geographical reach** with the opening of its first satellite site at Queen's University.

2009

**ICES forges new partnerships** with the Chiefs of Ontario and the Métis Nation of Ontario to study chronic diseases among Aboriginal peoples.

2010

**The Ontario Cancer Data Linkage Project (cd-link)** is an innovative first step toward wider distribution of risk-reduced coded ICES data.

2014

**ICES Data & Analytic Services** begins to provide knowledge users with access to research-ready linked health administrative data and analytic tools through a secure virtual desktop infrastructure.

2015

**In partnership with several provincial ministries**, ICES releases a baseline scorecard for Phase 1 of Ontario's Comprehensive Mental Health and Addictions Strategy, focusing on system performance for children and youth.

World-class research. Real-world results.

ICES connects the best and the brightest scientific talent with a rich repository of health data. The resulting insights and recommendations are used by governments and health care providers to guide decisions and develop policy. ICES research is organized into seven major programs:

Cancer

Examines the delivery of cancer services across the continuum of care from screening through end-of-life care and survivorship.

Kidney, Dialysis & Transplantation

Develops new high-quality information to prevent kidney disease and its complications and improve the lives of those receiving dialysis and organ transplants.

Cardiovascular

Focuses on measuring and improving the quality and effectiveness of cardiovascular care in Ontario, as well as the treatment of strokes and risk factors for chronic diseases.

Mental Health & Addictions

Generates knowledge to improve mental health and addictions services. Some areas of interest include the delivery of and access to services, as well as social determinants of health.

Chronic Disease & Pharmacotherapy

Examines the epidemiology, management and outcomes of chronic illnesses, as well as the safety and effectiveness of prescription drugs and drug insurance policies.

Primary Care & Population Health

Explores the accessibility and effectiveness of primary health care and issues in population health to inform policy and primary care reform models.

Health System Planning & Evaluation

Investigates issues in health services, including spending, public reporting, and service quality across many types of care.





## Information is the foundation of everything we do

The **ICES data repository** is among the world's largest holdings of secure, linkable data sets.

### Notable features

Includes historical records for over 18 million Ontarians

All data are encoded, with a unique ICES key number for every individual

Data can be linked at the individual patient level

### At ICES, privacy matters

We are deeply committed to protecting the information that we collect and use. ICES is recognized as an international leader in data security.



### ICES Data & Analytic Services (DAS)

ICES provides enhanced data access to researchers.

#### Services include:

Access to research-ready data sets through a secure web portal

Tools, support and advice on analytics

Data analysis and reports

Find out more  
[DAS@ICES.ON.CA](mailto:DAS@ICES.ON.CA)



### OUR MISSION

Research excellence resulting in trusted evidence that makes policy better, health care stronger and people healthier.

### OUR VISION

To be a world-leading institute where data and discovery improve health and health care.

### OUR VALUES

**Excellence** — demonstrated by the quality, innovation and rigour of our work

**Integrity** — expressed through independence, transparency and impartiality

**Relevance** — by providing high-value, timely results that are responsive to health priorities

**Collaboration** — through effective partnerships, accessible data and a spirit of openness

**Respect** — exemplified by responsible stewardship, inclusiveness and appreciation of each other

## Making vital information more accessible

ICES publications help identify issues of concern and equip decision makers with the evidence they need to influence change.

ICES strives to ensure that the results of our research do not languish on library shelves but are promptly translated into changes in health policies and practices for the benefit of all Ontarians.



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Visit us online to download our publications and sign up for news and announcements.

[ICES.ON.CA](http://ICES.ON.CA)



Data  
Discovery  
Better Health

# UK SECURE eRESEARCH PLATFORM

UKSeRP



Swansea University  
Prifysgol Abertawe

**Health Informatics Group**  
Swansea University Medical School



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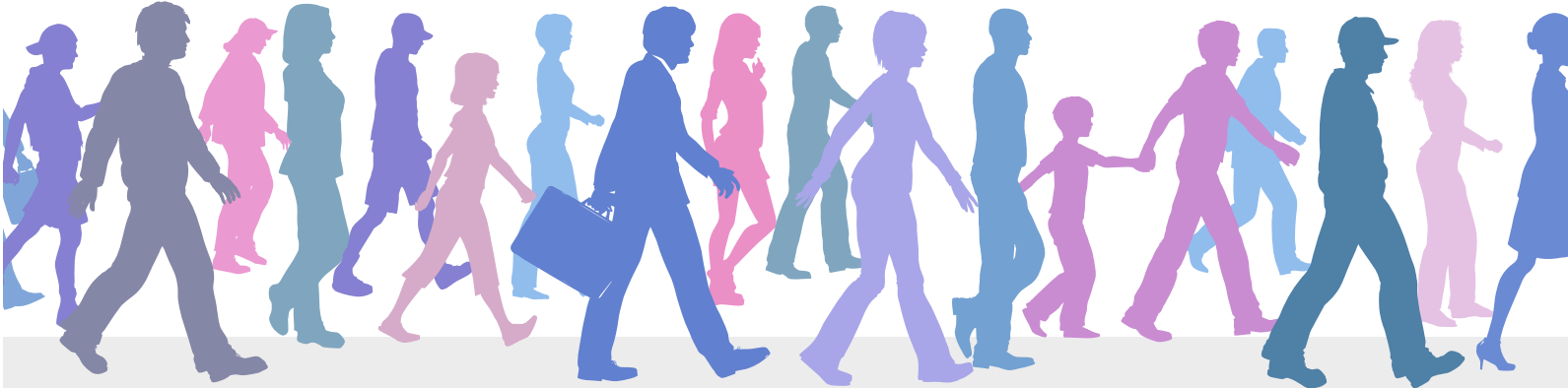
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# DATA SHARING: WHY SHOULD WE SHARE DATA?

It is common practice for organisations to routinely collect and hold data on their clients, patients, research subjects or other individuals, and many make good use of their own data to conduct research. But increasingly, and particularly in light of an increasing demand for access to data from the research community along with current and impending statutory obligations to do so, there is greater emphasis on organisations sharing their data safely and anonymously for research purposes to improve the lives of the wider population.

There is no doubt that by leveraging the power of shared data and opening up access to masses of data that would not otherwise be accessible for research, the enormous potential to drive insight is unlocked for the benefit of society. Data sharing stimulates new ideas and areas for research and increases the potential for collaboration, particularly on larger national scale research projects.

Organisations that were previously limited to using only their own data can benefit from collaborating and sharing data with approved partners, both from within their own organisations or more broadly across industry sectors, giving access to a much wider pool of vital information. In doing so data owners will realise the full potential of their own data to benefit the wider research community and society.



## DATA LINKAGE - HARNESS THE POWER OF RELATIONAL DISCOVERIES

The ability to link multiple sources of data together that relate to e.g. a particular individual, a geographical location or an event, brings a new dimension to answering research questions. Data linkage allows researchers to use existing collections of extensive data that has been routinely collected and stored to identify patterns across entire populations to give a much broader picture. Previously unnoticed relationships can be identified giving greater depth of clarity and understanding that wouldn't otherwise be possible from analysis using a single source of data alone. Using existing data is far more cost effective than having to collect the equivalent data through other methods such as surveys, and is overall far less intrusive.

## UKSeRP - SHARE AND LINK DATA SAFELY AND SECURELY

UKSeRP is a high powered, safe and secure e-research platform. It allows data owners and researchers to store, access, share, analyse and link data at scale in a governed environment whilst maintaining full control of the data at all times.

UKSeRP is the perfect solution for any organisation that has accumulated a large amount of data, that intends to share that data for the purposes of research and long term benefit to society, and that wants to do so in the most secure and safe way possible to reduce associated risks.

# WHO SHOULD USE UKSeRP?

Organisations such as the NHS and Health Boards, Government Departments and Academic Centres in particular would all benefit from using UKSeRP.



## HEALTHCARE

Hospitals and health care systems routinely collect and hold large amounts of data on their patients through health records and there is strong emphasis on the need to share data in order to continually improve upon the services provided to patients and accelerate the research process to deliver improvements in healthcare.

Research using shared and linked data can provide insight into areas that can be developed to provide more efficient services, offer improved care and treatments to patients, enhance the patient experience, enhance existing services and develop new ones, and ensure a more considered distribution of provisions and co-ordination of services.

Key to successful data sharing and data linkage for the healthcare sector is the trustworthy use of patient data and patient privacy. UKSeRP provides the mechanism to exchange data between healthcare organisations (or other relevant external organisations) whilst providing a safe, secure and governed environment to ensure that patient data is safeguarded with confidence.

Access to the data is strictly controlled by the data custodians and to respect data protection rights and ensure anonymity. UKSeRP uses international best practice to de-identify your data with a variety of different approaches e.g. using trusted third parties that protects data owners and individuals alike.



## LOCAL AND CENTRAL GOVERNMENT

Government departments are keen to harness the potential of using administrative data for research to identify opportunities where resources can be re-directed for the greater welfare of society. Public agencies that already hold large amounts of data and wish to share it would benefit from proportional use of appropriately shared data to improve the welfare of individuals, enhance administrative processes and procedures for users, identify and recover cases of fraud and other financial losses that can be redirected back into public services, and to produce more accurate official statistics. The benefits to society could be further enhanced if data were not only shared between public agencies, but also between public agencies and other sectors such as health and social care to give greater depth of understanding to research questions.

Governments recognise the compelling arguments for the benefits of sharing and using administrative data for research and statistics to develop policies and services that will benefit society in a more targeted way. To progress proposals for improving the availability of administrative data in safe settings for valuable research it is essential to establish a code of practice for collecting and storing data, creating suitable controls for sharing data and, arguably most importantly, ensuring safe guards to protect the identity of individuals and organisations through effective de-identification. UKSeRP is an all-encompassing solution that effectively addresses all of these important factors to make data sharing and data linkage possible.



## ACADEMIC RESEARCH

It is widely agreed that access to shared research data not only improves the quality and frequency of new research but also the fact that reusing 'old' data for new research questions facilitates innovation, as far less time and effort is expended on collecting data leaving more time for answering research questions. Add to this the fact that networking and collaboration opportunities increase when data is shared through increased visibility among peers in the academic community. However, sharing data between academic institutions, although widely supported and acknowledged as a great enabler to scientific progress, is not yet widely practiced.

The issues hindering data sharing amongst the Academic community are numerous and complex ranging from data owners retaining control of the data, secondary users ability to understand and interpret others' data sets, concerns surrounding the security of storing data, ensuring de-identification of sensitive data, the quality of data if it is to be shared, and having access to a data sharing process that is simple to use.

UKSeRP is a complete solution created to solve such issues and opens the way to safe, secure data sharing and data linkage in an uncomplicated manner requiring minimum time and effort.

Naturally, control and ownership of the data in terms of who exactly will be using it are important concerns, and UKSeRP ensures that any access to the data is strictly controlled by the data owner to ensure appropriate and agreed use for further research. Best practice approaches to de-identification deal with any legal uncertainty surrounding data sharing, especially when

researchers are working with sensitive data.

The data management facilities include automatic analysis of the data for quality assessment, and a comprehensive metadata cataloguing system that enables interoperability and removes any effort on the part of the data owner to have to explain the content of the data. It allows permitted users to make sense of data sets and prevents misinterpretation without any additional assistance being required from the data owner.

Previous problems that are typically associated with the physical act of sharing data, such as how and where will researchers using the owner's data store and protect it, are no longer a concern as data stored in a UKSeRP provides complete reassurance of being contained within a robust, accredited and highly regulated environment.

UKSeRP simplifies the data sharing and linkage processes in a safe yet accessible environment making it easy for Academics to embrace and engage with the practice of sharing data without the need for technical skills.



# UKSeRP: A COMPLETE SOLUTION FOR DATA SHARING AND DATA LINKAGE IN A SAFE, SECURE AND CONTROLLED ENVIRONMENT

## A COMPLETE PRE-INSTALLED SOFTWARE SUITE An All-In-One Solution

Designed to be very user friendly, UKSeRP is really quick to set-up and operate without the need for any specialist technical skills or training. Having a complete solution takes away the need to acquire separate pieces of software to do different jobs making this a convenient and low cost alternative.

Each organisation's particular security considerations that require specialist solutions to meet specific needs will benefit from the bespoke design and implementation service to create a tailored product specifically to meet those requirements.

To get started we will work closely with you to gain a full understanding of your requirements so that we can set up your very own UKSeRP.

Once established, data owners can begin to upload and prepare their data, create projects, set up user accounts and make the necessary preparations to start sharing the data.

Researchers or analysts can then ask you for an online account and, if you approve, you can easily create them a secure desktop so they can access a range of statistical research software and start to use the data you have agreed to make available.

## ACCESS CONTROLS AND PERMISSIONS Data Owners Retain Full Control

With UKSeRP the data custodians retain complete ownership and remain in full control of their data at all times with the ability to define roles and to set preferred access controls and project permissions to ensure that particular data sets are accessed only by pre-approved individuals as defined by you. Not only does this give complete confidence in the knowledge that your data remains private and protected, but also it significantly reduces reputational risk in an increasingly transparent 'business' environment.

Further to this, storing and using data in a governed environment is also very reassuring for stakeholders, so by demonstrating high levels of security around your data and data usage, you will certainly increase your credibility.

## SECURE REMOTE ACCESS Continuous Access from Anywhere in the World

All organisations holding sensitive data want to ensure that it is protected at all times and it is imperative that such data is not physically moved from one place to another due to the high level of risk. At the same time, it is important that the right people can access the data they need to without hindrance in order to conduct research quickly and effectively. UKSeRPs' solution to this conundrum is its secure remote access facility.

Approved users can access data from any desktop from anywhere in the world at any time, or from an established 'safe zone' if preferred, so that research activity isn't restricted. This highly secure yet agile approach means that not only can collaborative teams constantly capitalise on new opportunities with ease, but equally importantly, sensitive data is never sent to anyone ever again offering organisations complete protection from associated risks. Secure remote access is particularly attractive to dispersed research teams as it reduces costs, and having such flexibility enhances the work life balance for employees leading to long term staff retention.

UKSeRP simplifies the process of sharing data in the most secure, low risk way eliminating geographical limitations of access to data and the need to compromise security previously associated with moving data around.

UKSeRP offers a coherent environment that is specifically designed to support and simplify the process of not only sharing data but also linking data easily and effectively.

## GOVERNED ENVIRONMENT Protection For You and Your Data

Already pre-approved as an accredited platform for HSCIC (Health and Social Care Information Centre) data sharing framework agreements, the ISO27001 'kite mark' and regular audits and inspections gives your programme increased credibility with enhanced security. Additionally, full audit trails of use are available upon request at any time.

So not only does UKSeRP protect your organisation from reputational risk of potential data compromises by storing data in an accredited and highly regulated environment, it also facilitates the re-use of person based data to satisfy increased public awareness, reduces the time it takes to gain necessary approvals, and enhances cooperation, agreement and data sharing.

## STATE-OF-THE-ART DATA LINKAGE Gain New Insights from the Data

UKSeRP has a world class data linkage mechanism at the push of a button. The fully automated probabilistic data linkage system eliminates all of the technical challenges typically associated with linking data (with optional manual inspection and tuning if required). This will effectively reduce time spent on projects by performing fast and accurate data linkage on demand.

This advanced technology brings with it the ability to create new complex datasets more easily than ever before to increase research insight. UKSeRP makes easy work of using and linking your own data which not only increases the value of your existing data, but will also save you the time and expense of collecting primary data. By linking your data the process has the added advantage of highlighting any irregularities and improving the quality and consistency of your data for research.

## GETTING STARTED

### SET UP A UKSeRP



Tell us exactly what you need and we will create a UKSeRP to the required size and scale

### DATA OWNERS UPLOADING DATA ETC.



Upload, analyse, catalogue and de-identify your data and set access controls ready for use

### RESEARCHERS ACCESSING DATA



Allow researchers access to the data through their secure remote desktop

# ALL THE ESSENTIAL FEATURES FOR YOUR PROJECTS

## SIMPLE USER INTERFACE Upload Data Easily

UKSeRP gives users a straightforward way to migrate large amounts of data into a highly regulated secure environment for peace of mind. An easy to use system, it requires no specialist technical skills or training thereby reducing technical problems and allowing the focus to remain on the research question. By eliminating the need for manual processing you can avoid lengthy delays to your projects and enjoy reduced associated costs.

## DATA QUALITY ANALYSIS Cleaning the Data

Once data has been uploaded into UKSeRP, it can be automatically analysed in order to highlight any anomalies in the data such as missing fields or whether any fields are corrupted etc. giving you the opportunity to improve the quality of your data before use. This ensures that you produce precision data to reduce errors and mistakes that would otherwise affect the research results.

## METADATA CATALOGUING Making Sense of the Data

Once data has been uploaded into UKSeRP and cleaned for irregularities, how can you make sense of such a massive amounts of data and source the right data sets for your research questions?

The answer lies in the semi-automated metadata cataloguing system that has been built with the user in mind to eliminate the need for training and associated costs. No-one knows more about the content of the data being uploaded than the owners who are best positioned to augment the data sets with descriptors of what each dataset contains. Approved users can then quickly identify data sources that can be linked for specific research questions with ease and increase productivity.

Being able to catalogue the contents of your data is a great way to increase potential collaborations by sharing the descriptors of your data in an uncomplicated format. The metadata catalogue allows you to attach supporting documentation to your datasets giving researchers additional intelligence to quickly select the most appropriate data sets for their projects when they need them and to stimulate new research activities.\* Access to view metadata catalogues when sourcing the right data reduces the time it takes to source data and helps to prevent costly delays associated with acquiring new data.

## DATA DE-IDENTIFICATION Anonymising the Data

When sharing person based data with pre-approved research partners, the data can be rendered de-identified by removing personal details such as names, addresses etc. in order to keep each individual anonymous. This ensures complete privacy and protection of individuals' data whilst still allowing it to be shared and used for research.

UKSeRP uses international best practice to de-identify your data, whilst allowing others safe and secure access for research. This is a very efficient process with a variety of different approaches to de-identification e.g. using trusted third parties that protects data owners and individuals alike.

## WIDE RANGE OF ANALYTICAL TOOLS Analysing the Data

UKSeRP comes with a wide ranging suite of analysis tools so that users have access to tools they are already familiar with without the need to learn anything new whilst taking full advantage of using new powerful software. UKSeRP ensures you are using the tools best suited for each job with the added advantage of a lower cost of ownership.

## WIDE RANGE OF DATA STORAGE TECHNOLOGIES Manage, Store and Process the Data

It is important to have the right type of data storage for your specific requirements and budget and UKSeRP offers the flexibility to choose the most appropriate option from DB2, SQL Server, PostgreSQL, Hadoop or NoSQL. Having instant access to various storage options that are fully managed and maintained requires no involvement on your part saving both time and money, and allows you to concentrate your efforts entirely on your project knowing that your data is safe and secure.

## DIVERSE FORMS OF DATA Store and Analyse with Ease

UKSeRP is a robust, large scale high performance data storage and analysis platform for large complex data sets. There is scalable infinite capacity for data to be stored in a safe neutral shared environment that has the capability to integrate diverse forms of data from multiple record systems for analysis with ease.

## LARGE SCALE HPC CAPABILITY Solve Larger Problems with the Data

HPC, or High Performance Computing, is essential for large scale data-intensive analysis requiring fast, reliable and efficient processing power. Whatever the size of your project or programme, UKSeRP is completely scalable and customisable to your specific requirements to empower innovation and advance discoveries faster. UKSeRPs' highly scalable HPC also gives the added advantage that you only pay for what you need to process large complex datasets giving you real value for money.

## CUSTOMISABLE OPTIONS Only Use What Your Project Requires

If you are still unsure whether a complete off-the-shelf solution is right for your projects, organisation and budget, then you'll be pleased to know that UKSeRP has a wide variety of customisation options available to suit your project including a variety of multi-modal add-ons for different data types (e.g. genetics, imaging etc.)

It is possible to incorporate your own software or systems within UKSeRP negating the need to spend time and money on training, and it is an expandable, flexible and reconfigurable solution that grows with your project as it develops over time.

Whilst you remain in full control of your own data, you can also enjoy the convenience of ownership whilst only paying for what you actually need keeping your costs as low as possible.



# HOW TO GET STARTED

If you would like to know more about UKSeRP and how to get started please contact us for more information.

Contact the UKSeRP Service Centre:  
[info@UKSeRP.co.uk](mailto:info@UKSeRP.co.uk)

