## EXPLOITING EXISTING DATA FOR HEALTH RESEARCH 2011 CONFERENCE PROGRAMME

Times	Friday 9 <sup>th</sup> September 2011			
11.00-12.50 pm	REGISTRATION and BUFFET LUNCH (Lower College Hall)			
12.50-1.00 pm	WELCOME: Chris Dibben (Buchanan Building) University of St Andrews and Director of the Longitudinal Studies Centre – Scotland			
1.00-2.00 pm	KEYNOTE: Professor Sir Rory Collins (Buchanan Building) Clinical Trial Service Unit, University of Oxford "Effective strategies for identifying and phenotyping health outcomes"			
	SESSION 1a (Value 1 Pharmacovigilance)	SESSION 2a (Methodology: Validation, classification and harmonisation)	SESSION 3a (Governance Matters : Engaging and Exploring Attitudes Part 1)	SESSION 4a (The utility of routine data in different settings)
2.00-3.30 pm	School 2	School 3	School 5	Upper College Hall
3.30.400	<ol> <li>Quantin, C., Velten, M., Huet, F., Benzenine, E., Dupoux, A., Hamadi, A., Farrington, C.P. and Tubert-Bitter, P. Pediatric vaccine pharmacoepidemiology: a validation study of febrile convulsions identification from French automated hospital databases</li> <li>Mesher, D., Kealy, R., Offman, J., Edwards, R., Aigret, B., Pinney, E., Sestak, I., Cuzick, J. and Sasieni, P. The use of hospital episode statistics data in reporting of safety data from long-term follow-up studies</li> <li>Sun, P.C., Black, C., Helms, P.J. and McLay, J.S. Paediatric pharmacovigilance: Signal generation from linked NHS administrative data</li> <li>Kirby, B., Simpson, C., Helms, P., Bennie, M., Wood, R., Sweetland, M. and McLay, J. Data linkage for pharmacovigilance</li> </ol>	<ol> <li>McGilchrist, M., Verheij, R., Sathanandam, S., Hernandez-Santiago, V., Khan, N., Wilson, N., Visscher, S. and Sullivan, F. Data comparability: the comparison of data provenances</li> <li>Franklin, M., Putman, K., Hayre, J., Eden, M., Rodgers, S., Longridge, E., Boyd, M., Morris, C., Avery, T. and Elliott RA. Compiling a unified dataset of NHS resource use by extracting data from GP patient records</li> <li>Judson, A. (on behalf of SDRN) Validation of diabetes classification in SCI-DC</li> <li>Bellia, C., Bressi, M., Copello, F. and Griffo, R. Classification and geographical distribution of population affected by heart disease in Liguria region by integrating electronic health records</li> </ol>	<ol> <li>Aitken, M., Cunningham-Burley, S. and Pagliari, C. Public attitudes and responses to proposed governance mechanisms</li> <li>Luchenski, S., Reed, J., Sasaki, K., Marston, C., Majeed, A. and Bell, D. Electronic health records for healthcare improvement and research: understanding the hopes and concerns of patients and the public</li> <li>Braunack-Mayer, A.J., Duszynski, K.M., Xafis, V., Gold, M.S., Street, J., Thomson, C. and Berry, J.G. Data linkage and public acceptance: is notification sufficient?</li> <li>Hopf, Y.M., Bond,, C.B., Haughney, J. and Helms, P.J. Data linkage for paediatric pharmacovigilance: views from Scottish Caldicott Guardians</li> </ol>	1. Jorm, L. Increasing the policy impact of epidemiological research using linked health data  2. Douglas, M. The use of routinely collected data and record linkage for research  3. Kernthaler, J. and Judson, A. Improving the utilization of community prescribing data  4. Hannah, X. and Cronin, D. The English Medical Record Linkage System
3.30-4.00 pm		TEA/COFFEE (Lov	wer College Hall)	1

<sup>\*</sup>Note, the underlined speaker in the first paper in each session will also be the session chair

Times	Friday 9 <sup>th</sup> September 2011				
4-5 pm	KEYNOTE: Sir Harry Burns (Buchanan Building) Chief Medical Officer for Scotland "A vision for reducing poverty associated chronic ill health in Scotland and globally?"				
	SESSION 1b (Ethnicity and gender)	SESSION 2b (Methodology: Record linkage)	SESSION 3b (Governance Matters: Engaging and exploring attitudes Part 2)	SESSION 4b (Older people)	
5-6.30 pm	School 2	School 3	School 5	Upper College Hall	
	<ol> <li>Feng, Z. and Dibben, C.         Ethnic groups:stability, changes and health inequalities in Scotland – an analysis using the Scottish Longitudinal Study     </li> <li>Ferrante, A.         Using health data to determine gender and race differences in the risk factors associated with delinquency: a linkage-based, population-level study of Western Australian children     </li> <li>Bansal, N., Brewster, D., Bhopal, R. and Steiner, M.         Ethnic variations in breast screening invitation and uptake in Scotland: The Scottish Health and Ethnicity Linkage Study     </li> <li>Thiede, M. and Latza, U.         Gender specific analysis of occupational diseases of the low back caused by carrying, lifting or extreme trunk flexion     </li> </ol>	1. Randall, S. Data cleaning in record linkage  2. Randall, S. Improving linkage quality – post-linkage automatic quality checks  3. Hermansen. S.W. Developing and using composite similarity functions in automated data linkage  4. Larney, S. and Burns, L. Aliases as a methodological challenge in undertaking data linkage with criminal justice populations	1. Brown, L., Campbell, R., Boyd, A. and Macleod, J. What young people think about the use of "their" data in research: qualitative study of individuals with different levels of participation in the Avon Longitudinal Study of Parents and Children (ALSPAC) study  2. Scobie-Scott, E., Bond, C. and Helms, P.J. Is the use of linked routinely acquired NHS data for pharmacovigilance in children acceptable to parents and young people  3. Rate, A. Completing the link – consumers, community and data linkage	<ol> <li>McCowan, C., Magin, P., Clark, S. and Guthrie, B. Psychoactive prescribing in older patients living in care or at home</li> <li>Yu, N., Donnan, P.T., Marwick, C., Lockhart, M., McGuigan, C. and Davey, P. The elderly, antibiotic prescribing, care home residence and Clostridium difficile – how are they related?</li> <li>Donnan, P.T., Barnett, K., McCowan, C., Guthrie, B. and Sullivan, F. Development of a risk prediction tool for entering a care home in those aged 65 and over in a Scottish population</li> <li>McGrail, K.M., Lilly, M.B., McGregor, M.J., Broemeling, A-M., Salomons, K., Peterson, S., McKendry, R. and Barer, M.L. Assisted living and the use of other health care services: a descriptive study</li> </ol>	
6.30 pm	International Health Data Linkage Network - Beer and wine discussion and social evening (Lower College Hall) http://www.ihdln.org/				

<sup>\*</sup>Note, the underlined speaker in the first paper in each session will also be the session chair.

Times	Saturday 10th September 2011			
9.00-10.30 am	SESSION 1c (Cancer and cardiovascular disease)  School 2  1. Walker, J. and Wild, S.H. Type 2 diabetes and relative mortality from cardiovascular disease and four common cancers in Scotland  2. Shah, A., Diggens, N., Stiller, C., Murphy, D., Passmore, J. and Murphy, M.F.G. What influences place of death and hospital care for children who die of cancer? The English experience 1999-2006  3. Clark, D., Brewster, D.H., Tucker, J.S., Fleming, M., Morris, C., Stockton, D.L., Lloyd, D.J., Bhattacharya, S. and Chalmers, J.W.T. Risk of skin cancer after neonatal phototherapy: retrospective cohort study  4. Kelly, M., Sharp, L., Dwane, F., Kelleher, T. and Comber, H. Factors predicting hospital length-of-stay and readmission after colorectal resection: a population-based study	SESSION 2c (Birth and early life)  School 3  1. Fleming, M., Ajetunmobi, T., Whyte, B., Morris, C., Nolan, C. and Chalmers, J. Investigation of observed increases in breastfeeding rates in deprived areas  2. O'Leary, C., Bourke, J., Leonard, H., D'Antoine, H., Bartu, A., Watson, L., Stanley, F. and Bower, C. Using data linkage to estimate the rate of cerebral palsy and intellectual disability in children of mothers with an alcohol-use disorder  3. Reilly, R., Paranjothy, S., Beer, H., Brooks, C.J., Fielder, H. and Lyons, R. Birth outcomes following treatment for precancerous changes to the cervix: a population based record linkage study  4. Gardner, E., Casson, K., Dolk, H. and Gray, A-M. An exploratory analysis of the sociodemographic characteristics of married versus unmarried mothers using the Northern Ireland Longitudinal Study and Record Linkage of several routinely available health and socio-demographic data sets	SESSION 3c (Governance Matters: Consent)  School 5  1. Siede, L. Informed consent and population data for research  2. Jones, R.G., Johnson, O.A., Clamp, S.E. and Gillott, R.G. Unlocking the ethical challenges in consenting patients to allow access to GP records for research  3. Bridges, S. The methodological and ethical considerations of obtaining informed consent to data linkage in three national surveys  4. de Klerk, N. Some non-technical aspects of data linkage – consumer and community support and engagement	SESSION 4c (Routine data and health economics)  Upper College Hall  1. Geue, C., Briggs, A., Lewsey, J. and Lorgelly, P. Population ageing in Scotland: implications for healthcare expenditure using linked SLS-SMR01 data  2. Husain, M.J., Macey, S., Brophy, S., Pinder, L., Atkinson, M.D., Cooksey, R., Phillips, C.J. and Siebert, S. HERALD (Health Economics using Routine Anonymised Linked Data) protocol paper  3. Macey, S. Assessing the excess health service utilisation and direct medical costs following injury  4. Guo, J. and Konetzka, R.T. How does home health care avoid institutional care? evidence from Medicaid Linkage Data
10.30-11am	TEA/COFFEE (Lower College Hall)			
11-12 noon  *Note the underli	KEYNOTE: William Lowrance (Buchanan Building)  Consultant in Health Research Ethics and Policy, La Grande Motte, France  "Privacy and genomic research"			

<sup>\*</sup>Note, the underlined speaker in the first paper in each session will also be the session chair

Times	Saturday 10th September 2011			
	SESSION 1d (Safety and readmissions)	SESSION 2d (Methodology: Bias and missing data)	SESSION 3d (Routine data for understanding health services 1)	SESSION 4d (Diabetes and obesity)
12noon -Ipm	1. Taylor, C. Scottish patients at risk of readmission and admission: an example of the use of linked prescribing data in Scotland  2. Moore, H.C., de Klerk, N., Richmond, P.C., Blyth, C.C., Smith, D.W., Keil, A.D. and Lehmann, D. Population-based data linkage of hospital morbidity and laboratory data to investigate aetiology of respiratory infections in children  3. Lone, N.I., Rowan, K.M., Walsh, T.S., Wild, S.H. and Murray, G.D. Readmissions to intensive care units in Scotland: epidemiology, risk factors and outcomes colorectal resection: a population-based study	School 3  1. Harron, K., Wade, A., Gilbert, R., Muller-Pebody, B., Parslow, R., Hartley, J. and Goldstein, H. Avoiding bias in the analysis of linked health data  2. Clough-Gorr, K.M., Schmidlin, K., Spörri-Fahrni and Zwahlen, M. The challenge of unlinked deaths in health research: an example from the Swiss National Cohort (SNC) Study  3. Boyd, A., Macleod, J. and Golding, J. Using linkage to health and social administrative records to quantify the response rate to initial recruitment in the Avon Longitudinal Study of parents and children (ALSPAC) and assess possible bias associated with non-response	School 5  1. Biggin, K., Stewart, A., Gray, S. and Bailie, K. Patterns and trends in blood transfusion  2. Feng, Y. Health professionals' motivation and income in the UK NHS: longitudinal record linkage  3. Tagg, S., Hart, S. and Moffat, G. Estimating the value of recruiting more organ donors	<ol> <li>Upper College Hall</li> <li>Stephens, J.W., Carmen, J.E., Brooks, C.J., Lyons, R.A., Ford, D.V., Price, D.E. and Bain, S.C.         Is better HBA1c associated with more glucose strip prescribing?     </li> <li>Anwar, H., Fischbacher, C.M., Leese, G.P., Lindsay, R.S., McKnight, J. and Wild, S.H.         Assessment of the under-reporting of diabetes in hospital admission data: a study from the Scottish Diabetes Research Network</li></ol>
1-2 pm	LUNCH (Lower College Hall)			

<sup>\*</sup>Note, the underlined speaker in the first paper in each session will also be the session chair

Times	Saturday 10th September 2011			
2-3.30 pm	SESSION 1e (Routine data for RCT 1)  School 2  1. Sullivan, F. and McGilchrist, M. The TRANSFORM and EHR4CR projects: EU initiatives to transform clinical trial conduct  2. Mackenzie, I. Record linkage in the SCOT and FAST trials  3. McConnachie, A., Walker, A., Robertson M., Cobbe, S.M., Packard, C. and Ford, I. Use of record linkage to conduct a trial economics evaluation: results from the long- term follow-up of WOSCOPS  4. Lloyd, S., Stott, D., Sattar, N., Briggs, A., Packard, C. and Ford, I. Long-term follow-up of the PROSPER trial using record linkage	SESSION 2e (Methodology: Record linkage)  School 3  1. Knowles, R., Hutchinson, R., Spragg, R., Langan, P., Dezateux, C., Kehoe, D. and Castillo, F. A secure virtual environment to support research involving identifiable patient data: the SHARE collaboration with industry  2. Endel, F., Endel, G., Filzmoser, P., Weibold, B. and Katschnig, H. Health service record linkage in a situation of multiple social health insurance institutions: the case of Austria  3. Ferrante, A. and Boyd, J. Introducing a shareable methodology for evaluating data linkage software and systems  4. Meagher, N., McGrail, K. and MacNeil, C. Demonstrating the value of record linkage	SESSION 3e (Governance Matters: Regulation and Risk 4)  School 5  1. Laurie, G. and Sethi, N. On the quest for good governance: SHIP's approaches to tackling obstacles  2. Willison, D. and Gibson, E. Governance toolkit for use of personal information for health research  3. Flack, F. Information governance and the Population Health Research Network  4. Willison, D. and Emerson, C. The many faces of privacy-related risk	SESSION 4e (Measuring patterns and burden)  Upper College Hall  1. Donnan, P.T., Cochrane, L. and Glasier, A. Patterns of use and discontinuation rates of progestogen-only injectable contraception (DepoProvera®) and the risk of fractures in a record-linked population study  2. Turner, S., Lyons, R., Rodgers, S. and Hall, R. Identifying household level risk factors for experiencing a house fire incident, death, or injury in Wales  3. Pinder, L.M., Macey, S.M., Thomas, G., Lyons, R.A. and Snooks, H.A. Emerging geographical variations of non fatal poisoning emergencies in Wales: a retrospective study optimised with data linkage  4. Bauer, J., Arnott, I., Paterson, H., Nicholls, R.J., Crowe, A., Knight, A., Clark, D., Springbett, A., Bridger, P., Yen, L., Hodgkins, P. and Dunlop, M. Using linked administrative data to assess the disease burden of diverticular disease in Scotland
3.30-4 pm		TEA/COFFEE	(Lower College Hall)	

<sup>\*</sup>Note, the underlined speaker in the first paper in each session will also be the session chair

Times	Saturday 10th September 2011			
	SESSION 1f (Routine data for understanding health services 2)  School 2	SESSION 2f (Methodology)	SESSION 3f (Governance Matters: Different Perspectives and Case Studies)  School 5	SESSION 4f (Birth outcomes)  Upper College Hall
4-5.30 pm	1. Maramba, I.C., Ford, D.V., Noble, J.G., Osborne, L.A., Jones, K.H., Middleton, R.M. and Lyons, R.A.  The UK Multiple Sclerosis (MS) register pilot: linking data from multiple sources  2. Katschnig, H., Endel, G., Endel, F., Filzmoser, P. and Weibold, B.  Identifying psychiatric patients' pathways of care: linking service use data for psychiatric and non-psychiatric services for the total population of a province of Austria  3. Glauert, R. and Stanley, F.  Developmental pathways in WA Children Project: new initiatives and outcomes  4. MacDonald, A.  Understanding patient pathways through unscheduled care services	1. Fleming, T.J., Scott, D.J.A., Murray, C., Mitchell, D.C., McCabe, C. and Baxter, P.D.  Linking the National Vascular Database to hospital episodes statistics for long term mortality follow up  2. Bourke, A. and Dattani, H.  Data linkage of THIN electronic primary care data and Hospital Episode Statistics (HES)  3. Bettencourt-Silva, J.H., De La Inglesia, B., Donell, S.T. and Rayward-Smith, V.J.  Extracting patient-centric data from a NHS secondary care centre: a Methodology and Case Study  4. Heaven M.L., Lyons, R. and Jadar, L.  Development of a methodology for determining prevalence of long term neurological conditions using primary care data	1. Roy-Toole, C Regulating medical database research in the United Kingdom: a cautionary tale based on the English experience  2. Neinaber, A. Exploiting existing data for health research: a view from the developing world  3. Churches, T., Jorm, L., Rao, S., Khoo, J. and Farrow, J. Djinn in a bottle: a secure, remote-access data analysis laboratory for research using linked health data  4. Gillott, R.G., Jones, R.G., Johnson, O.A. and Clamp, S.E. The readiness of UK primary care records to facilitate clinical trials research: a feasibility study	1. Gunn, L.H., Dattani, N., Macfarlane, A. and Garg, P. Preterm birth and infant mortality rates among births to Black African and Caribbean women in England and the United States  2. Datta-Nemdharry, P., Dattani, N. and Macfarlane, A. Country of birth of mother and rates of preterm births and low birthweight in England & Wales of babies of African and Caribbean ethnicity  3. Dattani, N., Macfarlane, A. and Datta-Nemdharry, P. Linkage of birth registrations and NHS numbers for babies data to hospital records on maternity for England and Wales, 2005-06
7 pm-Midnight		CONFERENCE DINNER and CEILI	DH (Lower College Hall/Upper College H	all)

<sup>\*</sup>Note, the underlined speaker in the first paper in each session will also be the session chair

Times	Sunday 11th September 2011				
9-10.00 am	KEYNOTE: Prof. Paul Burton (Buchanan Building)  Professor of Genetic epidemiology, University of Leicester  "DataSHIELD and DataSHaPER: harmonized analysis of individual-level data without sharing the data"				
	SESSION 1g (Diabetes and cardiovascular disease)	SESSION 2g (Vaccines and surveillance)	SESSION 3g (Governance Matters)	SESSION 4g (Routine health data systems)	
10-11.30 am	School 2	School 3	Upper College Hall	School 5	
	<ol> <li>Looker, H.C.         Intensive management and low HbA1c in type 2 diabetes: a nationwide study     </li> <li>Livingstone, S. On behalf of SDRN</li> </ol>	1. <u>King, C.</u> , Hasnat, R., Garcia-Alvarez, A., Holmes, A. and Aylin, P. <i>Linking of routine administrative databases</i> within an English academic health science centre to support the creation of a	Workshop - What makes research/researchers trustworthy? An invitation to contribute your views'	1. Springbett, A., Pavis, S. and Ward, H. SHIS-R: Development of a technical infrastructure to support record linkage and data access for researchers in Scotland	
	Cardiovascular disease risk in the Type 1 diabetes populations of Scotland: continuing high risks even in the absence of renal disease	syndromic surveillance tool for healthcare associated infections  2. Lone, N.I., Simpson, C.R., Ritchie, L.D.,	<ul> <li>Welcome and Overview</li> <li>Overview of SHIP governance work to date and key issues to address</li> </ul>	2. <u>Bass, J.</u> , Lam, E., White, P. and Garfield, C. Extending data linkage to include familiar links: link management, on-screen genealogical editing, and unexpected benefits	
	3. Nyangoma, S. and Cromie D Diabetic retinopathy at diagnosis in Type 2 diabetes in Scotland	Robertson, C., Kavanagh, K., Sheikh, A. and McMenamin, J. Seasonal Influenza Vaccine Effectiveness (SIVE) Study: methodological challenges of	<ul> <li>Overview of SHIP focus group findings: the importance of trust</li> </ul>	3. Shih, SF., Chen, L., Yang, WC. and Kuo, K.N. Establishment of surveillance system for birth	
	4. <u>Simpson, C.R.</u> , Buckley, B.S., McLernon, D.J., Sheikh, A., Murphy, A. and Hannaford,	using linked data to assess vaccine effectiveness	<ul> <li>Questions for discussion</li> </ul>	defects: strategies of linking health data sets and challenges of system integration	
	P.C.  Five year prognosis in an incident cohort of people presenting with acute myocardial	3. <u>Samad, L.</u> , Cortina-Borja, M., El Bashir, H., Sutcliffe, A.G., Marven, S., Cameron, J.C., Lynn, R. and Taylor, B.	10.30 a.m. Tea/Coffee/ Muffins/Cupcakes	4. Thuemmler, C., Buchanan, W., Bell, D. and Fan L DACAR platform for eHealth Services Cloud	
	infarction	Intussusception in children: use of record linkage to validate the national incidence prior to the introduction of rotavirus	<ul><li>Small group discussions</li><li>Feedback from groups and</li></ul>		
		vaccines in the UK 4. Gallagher, N. and O'Reilly, D.	discussion		
		Prescription data as a surveillance tool for diabetes morbidity: record linkage with Census data	<ul> <li>Reflection and summing up</li> </ul>		
11.30-12 noon		TEA/COFFEE (	Lower College Hall)		

Times	Sunday 11th September 2011			
12 noon – 1.10 pm	SESSION 1h (Routine data for RCT 2)  School 2  1. Turner, E.L., Martin, R.M., Donovan, J.L., Metcalfe, C., Noble, S., Lane, A., Verne, J., Oliver, S., Hamdy, F.C., Neal, D.E. and Macleod, J. Evaluating the potential of electronic data linkage for trial outcome CAPture: the eCAP study, feasibility phase  2. Breen, C., Shakeshaft, A., Slade, T., D'este, C., Mattick, R. and Petrie, D. Using routinely collected data to assess alcohol-related crime in a community based cluster RCT  3. Elders, A., Glazener, C. and McPherson, G. Is record linkage the answer? The effectiveness of using hospital admissions data for clinical trial follow-up: an example from a long-term urogynaecological study	SESSION 2h (Methodology: Textual analysis and data mining)  School 3  1. Lyttleton, O. Data mining of text fields  2. Zhou, S-M., Lyons, R.A., Demmler, J.C., Hyatt, M., Atkinson, M.D., Paranjothy, S. and Gravenor, M.B. Investigation of data mining methods and epidemiological models in examining the relationship between childhood health maternal health, socioeconomic status and educational achievement  3. Lim Choi Keung, S.N., Tyler, E., Taweel, A., Arvanitis, T.N., Delaney, B. and Hobbs, R.F.D. A vocabulary controlled approach to querying heterogeneous patient data repositories for reuse in clinical research	SESSION3h (Health inequalities)  School 5  1. Rodgers, S.E., Demmler, J.C., D'Silva, R. and Lyons, R.A.  Anonymously linking health data for individuals to high resolution map data to explore environmental health inequalities  2. Dougall, N.J., Lambert, P., Maxwell, M. and Dawson, A.  Modelling health and social risk factors for suicide in Scotland: a 30 year record linkage study. A Data Management in the e-Social Sciences (DAMES) project  3. Olajide, D. and Eberth, B.  Modelling the time to incidence of smoking-related diseases: a sample selection approach using linked hospitalisation data	SESSION 4h (Governance and methodology joint session - Privacy and matching)  Upper College Hall  1. Durham, E., Yuan, X., Kantarcioglu, M. and Malin, B. Evaluating privacy-preserving field comparison methods for linking medical records  2. Schnell, R. Cryptographic long-term stable identification keys for record linkage in longitudinal research  3. Stevens, A.P. Does the dice coefficient have a null distribution?
1.10-1.40 pm	TEA/COFFEE/SANDWICHES/TRAY BAKE  DEPART			

<sup>\*</sup>Note, the underlined speaker in the first paper in each session will also be the session chair