



<b>DRAFT AGENDA</b>	
<b>WORKSHOP ON HEALTH DATA GOVERNANCE – STRATEGIES TO MAXIMISE BENEFITS AND MINIMISE RISKS</b>	
<b>OECD Conference Centre, 2 rue Andre Pascal, Paris, 20 May 2015</b>	
9:00 -9:30	Morning Coffee
9:30-9:35	<b>Opening Remarks</b> – Francesca Colombo, OECD
9:35-9:45	<b>Access to data and privacy: OECD experiences</b> – Jillian Oderkirk, OECD
9:45 -11:00	<i>High Value Health Information Systems – Utilising and Linking Electronic Data</i>  <b>Moderator: Fabrizio Carinci, Professor of Health Systems and Policy, University of Surrey, UK</b>
	<ul style="list-style-type: none"> <li>• Jeremy Veillard, VP Research, Canadian Institute for Health Information, Canada – <i>Developing national data for health care improvement</i></li> <li>• John Hoyt, Executive VP, HIMMS Analytics, USA - <i>Data use for high performing hospitals</i></li> <li>• Sun Min Kim, Commissioner for Health Care Quality, Health Insurance Review and Assessment Service, Korea - <i>Evaluating health care quality and performance</i></li> <li>• Max Köster, Director, Department of Statistics and Comparisons, National Board of Health and Welfare, Sweden - <i>Open comparisons of health care performance</i></li> <li>• Unto Häkkinen, Research Professor, THL, Finland and Lead Investigator, EuroHOPE - <i>Measuring health care outcomes and efficiency across countries</i></li> </ul> <p><b>Questions and Answers</b></p>
11:00 -11:30	Morning Break
11:30-12:30	<i>Panel on Safeguards for Privacy-Protective Data Use</i>  <b>Moderator: Robert Gellman, Privacy and Information Policy Consultant, USA</b>
	<ul style="list-style-type: none"> <li>✓ Legislative safeguards to protect privacy and enable data use</li> <li>✓ Embedding privacy protection at all steps</li> <li>✓ Project approval processes and ethical review</li> <li>✓ Best practices in data de-identification</li> <li>✓ Accreditation of health data processors</li> </ul> <p>Panellists:</p> <ul style="list-style-type: none"> <li>• Tania Di Iorio, Legal Consultant, Sereatrix s.n.c., Italy</li> <li>• Peter Knight, Deputy Director, Research Contracting, Information Intelligence and Stakeholder Engagement, Department of Health, England</li> <li>• Pēteris Zilgalvis, Head of Unit, eHealth and Well Being, DG Connect, European Commission</li> <li>• Warren Richter, Chief Information Officer, Australian Institute for Health and Welfare</li> </ul> <p><b>Group Discussion and Lessons Learned</b></p>
12:30-13:30	Lunch



13:30 -14:30	<p><b><i>Panel on Data Sharing and Access to Data for Monitoring and Research</i></b></p> <p><b>Moderator: Lies van Gennip, Director, National IT Institute for Health Care (NICTIZ), Netherlands</b></p> <ul style="list-style-type: none"> <li>✓ Opening access to health data</li> <li>✓ Using technology to improve secure data access</li> <li>✓ Access to data for commercial researchers</li> <li>✓ Fostering a multi-country research environment</li> </ul> <p>Panellists:</p> <ul style="list-style-type: none"> <li>• Jacques Huguenin, Head, Health Care Statistics, Federal Statistical Office, Switzerland</li> <li>• Emily Jefferson, Co-Director, Farr Institute of Health Informatics, University of Dundee, Scotland, UK</li> <li>• Toshiro Kumakawa, Director, Department of Health and Welfare Services, Japan</li> <li>• Michael Schull, President and CEO, Institute for Clinical Evaluative Sciences, Ontario, Canada</li> <li>• Michael van den Berg, National Institute for Public Health and the Environment, Netherlands</li> </ul> <p><b>Group Discussion and Lessons Learned</b></p>
14:30 -15:30	<p><b><i>Panel on Public Communication and Transparency</i></b></p> <p><b>Moderator: Ronni Gamzu, Ministry of Health, Israel and Consultant, OECD</b></p> <ul style="list-style-type: none"> <li>✓ Communicating about data availability and access</li> <li>✓ Consulting and communicating about data governance</li> <li>✓ Engaging stakeholders in data development and use</li> </ul> <p>Panellists:</p> <ul style="list-style-type: none"> <li>• Päivi Hämäläinen, Director, Department for Information, National Institute for Health and Welfare (THL), Finland</li> <li>• David Knight, Director, Information Strategy, Department of Health, England</li> <li>• Jan Mainz, Professor of Quality Improvement, University of Southern Denmark</li> </ul> <p><b>Group Discussion and Lessons Learned</b></p>
15:30 - 16:00	Afternoon Break
16:00 – 17:30	<p><b><i>Round table on best practices in health data governance</i></b></p> <p><b>Moderator: Niek Klazinga, OECD</b></p> <p><b>Discussion of Best Practices to Advance Privacy-Protective Data Use</b></p> <p><b>Group Discussion and Round Table</b></p>
17:30 – 17:40	<b>Closing Summary – OECD</b>
17:40 - 18:30	Cocktail Reception



# **OECD Workshop on Health Data Governance**

**OECD Conference Centre, Paris 16th**

## **Who's Who**

## Fabrizio Carinci

Professor of Health Systems and Policy, University of Surrey, UK



Fabrizio Carinci, Italian Australian, is a biostatistician with 25 years of experience at the interface of evidence based medicine and statistics, health information systems, policy and the academia. He has worked for Universities across the globe, including Harvard, Monash and Surrey, as well as research institutes, governmental organizations (a former senior officer of the Italian Ministry of Health) and international organizations including the OECD, WHO Europe, and the European Commission. An early pioneer of privacy-enhanced, distributed statistical meta-analysis of linked health databases, he has conceptualized a specific approach, the BIRO system (Best Information through Regional Outcomes) designed and implemented in two subsequent EU projects: BIRO and EUBIROD (2005-2012). He is currently Professor of Health Systems and Policy at the School of Health Sciences, University of Surrey and a Member of the Bureau of the OECD Health Care Quality Indicators Project and the Advisory Panel on Health Information infrastructure (APHII). Through these roles, he aims to contribute to strengthening health systems performance evaluation and improving access to high quality health information for a range of stakeholders, including decision makers, health professionals and citizens.



## **Robert Gellman**

### **Privacy and Information Policy Consultant, USA**

Robert Gellman is a privacy and information policy consultant in Washington, D.C. He advises large and small companies, for-profit and non-profit organizations, trade associations, government agencies, and advocacy organizations how to develop, analyze, implement, and maintain policies for personal privacy and fair information practices. Specialty areas include privacy policy for health, the Internet, and the homeless; freedom of information, and other information policy areas. A graduate of the Yale Law School, Gellman has worked on privacy issues for more than 40 years. He spent 17 years on the staff of a Subcommittee in the House of Representatives of the U.S. Congress responsible for privacy, freedom of information, health record confidentiality, and other information policy matters. He served as a member of the Department of Health and Human Service's National Committee on Vital and Health Statistics (1996-2000), a federal advisory committee with responsibilities for health information infrastructure matters, and he chaired the Privacy and Confidentiality Subcommittee for two years. He is the author of numerous columns, conference papers, congressional reports, and scholarly articles on privacy and other information policy issues. Many are available at [www.bobgellman.com](http://www.bobgellman.com).



## **Päivi Hämäläinen**

**Department for Information, and Senior  
Consultant, National Institute for Health and  
Welfare (THL), Finland**



PhD, MD, MA, Specialist of Public Health and General Medicine. She is works at the National Institute for Health and Welfare (THL) as leading expert. THL is a state authority, research and development organization under the Ministry of Welfare and Health. THL is responsible for health and welfare statistics, classifications and other information structures and the operational governance of the national eHealth and eWelfare implementation. Päivi Hämäläinen has 15 years of experience from clinical practice in primary and specialised care and over 10 years experience in project management and administration. Dr. Päivi Hämäläinen is/has been involved in several Finnish national and also international data management and eHealth activities, such as planning and the construction of the Finnish national EPR, the Board of Directors of EHTEL, patient safety groups and different OECD, EU and Nordic Council Health working groups among others. Her scientific work is from the fields of health care, including eHealth, and also public health and Informatics.



## Unto Häkkinen

**Research Professor, THL, Finland and Lead Investigator, EuroHOPE**



Unto Häkkinen is Research Professor in National Institute for Health and Welfare (THL) in Finland. He is working at the Centre for Health and Social Economics (at THL). He has been a Finnish co-ordinator in many international comparisons and a project director in EuroHOPE (European Health Care Outcomes, Performance and Efficiency) -project funded by European Commission.

His academic and applied research has mainly focused on health economics and topics related to it covering topics such as: cost, financing and outcome of health services, equity in health and health care, demand and utilisation of health care, payment systems in health care, health care reforms, allocation of health care resources, regional variation of health care, hospital productivity, care of the elderly and register-based analyses of costs and outcomes in health care.



## **John P. Hoyt**

**VP, HIMMS Analytics, USA**



John P. Hoyt is Executive Vice President, HIMSS Analytics at HIMSS, a global, cause-based, not-for-profit organization focused on better health through information technology (IT). HIMSS leads efforts to optimize health engagements and care outcomes using information technology. HIMSS represents approximately 52,000 individuals, of which more than two-thirds work in healthcare provider, governmental and not-for-profit organizations across the globe, plus over 600 corporations and 250 not-for-profit partner organizations, that share this cause. Mr. Hoyt is responsible for providing executive leadership and direction to HIMSS Analytics worldwide where he also provides direction for all Stage 6 and Stage 7 validations and derivative research.

Throughout his healthcare career, Hoyt has been instrumental in defining business and IT strategy as well as selecting, implementing and integrating mission-critical healthcare information systems across the enterprise. Before joining HIMSS, Hoyt served as a hospital Chief Operating Officer and twice as a Chief Information Officer with various healthcare organizations accumulating in over 22 years of hospital executive committee leadership experience. Mr. Hoyt served in consultancy practices, including: IBM Healthlink Services and First Data Health Systems Group.

Hoyt holds a BSBA in Economics from Xavier University in Cincinnati, Ohio, and an MHA from St. Louis University in Missouri. He is a HIMSS Fellow and a Fellow and active member of the American College of Healthcare Executives (ACHE).





## Emily Jefferson

**Co-Director, Farr Institute of Health Informatics, University of Dundee, Scotland, UK**



Dr Emily Jefferson read Biochemistry at the University of St Andrews before moving to attain a PhD in the more computational field of Bioinformatics at the University of Dundee. After a post-doc in Bioinformatics, Emily left academia to work in the banking sector for a large software company as a Project Director. Emily then took a career break to solo cycle from New Zealand to the UK over 1 year.

Emily chose to return to work in an area she feels passionate about and joined the University of Dundee in Oct 2012. She has a combined role as the Director of the Health Informatics Centre (HIC), Co-director of the Farr Institute @Dundee and also Senior Research Fellow of Health Informatics. Emily has responsibility for the overall management, technical direction and leadership for a team of software developers and data analysts within HIC and those co-located within specific research groups. HIC manage ~130 data linkage projects per year.



## Sun Min Kim

**Commissioner for Health Care Quality,  
Health Insurance Review and Assessment  
Service, Korea**



Sun Min Kim, M.D. Ph.D. graduated Seoul National University School of Medicine in 1989. After finishing the specialist course of family medicine in 1996, she has been involved in health services research as a professor of Hallym University School of Medicine and Korean Health Industry Development Institute. Since 2006, she has worked for Health Insurance Review and Assessment Service(HIRA) of Korea, which is the major independent purchasing organization within Korea's single unified National Health Insurance system. Within HIRA, she is engaged in the quality assessment and pay for performance affairs for the health care institutions including hospitals and primary care facilities. HIRA's quality assessment is based on the well-organized health information technologies. In addition, she has been a vice-chair of OECD Health Care Quality Indicator Project expert group as well as the Korean focal point of the expert group.



## **Toshiro Kumakawa**

**Director, Department of Health and Welfare Services, Japan**



Toshiro Kumakawa, MD,MBA,PhD is an executive senior researcher, a former director of the Department of Health and Welfare Services, National Institute of Public Health, Ministry of Health, Labour and Welfare in Japan. After graduating from the Showa University School of Medicine, he received PhD from the University of Tokyo and MBA from Graduate School of Business Sciences, University of Tsukuba. He is also abundant in experience as a clinician and certified Geriatrician, Physician, Hematologist and Occupational Physician. The concern of his research is in an evidence based health policy and strategic management on various systems, as well as human resource development. Recently his research focuses on practical use of big data in a comprehensive healthcare system. He is a member of Bureau of OECD HCQI experts Group, a member of an advisory group to develop an OECD recommendation on the use of personal health data, a member of WHO / World Bank UHC Measurement Working Group, a member of Expert Panel of the Equitable Access Initiative (EAI), a member of WHO / OECD HQI Network in Asia Pacific Region and a member of the Asia Pacific Observatory on Health Systems and Policies (APO).



## **David Knight**

**Director, Information Strategy, Department of Health, England**



David Knight leads on information policy at the Department Of Health. Since joining the Department in 1996, having previously worked in the NHS, David has led on a wide range of issues including coordinating patient safety policy in Europe for the UK 2005 Presidency of the EU, taking legislation through Parliament, leading work to improve the quality of NHS maternity and neonatal care and, more recently, drafting the Government's Information Strategy for health and social care in England.



## **Peter Knight**

**Deputy Director, Research Contracting,  
Information Intelligence and Stakeholder  
Engagement, Department of Health, England**



Peter is a Deputy Director, in the Research and Development Directorate at the Department of Health with responsibility for policy and delivery of Research Contracting, Information Intelligence and Stakeholder Engagement.

Peter joined the Department in April 2010 having established the Research Capability Programme in 2008 that established a secure research data service (Clinical Practice Research Datalink) now operated by the MHRA.

Prior to this, Peter as a Managing Director and interim Chief Executive at Winchester and Eastleigh Health NHS Trust he helped put the NHS Trust on the map as one of the first to switch over to the NHS Care Records Service.



## **Jan Mainz**

**Professor of Quality Improvement, University of Southern Denmark**



Jan Mainz is professor of Quality Improvement and Health Services Research at Aalborg University Hospital and adjunct professor at University of Southern Denmark. He is Deputy Director of Psychiatry in Region North Denmark.

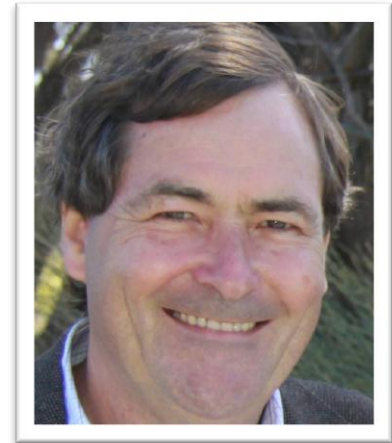
Jan Mainz is the Danish representative in the OECD Health Care Quality Indicator Project since 2002 and member of the OECD Bureau. He is also member of WHO's Advisory Committee of the WHO Report on Safety and Quality of Health Care Services.

From 1999 to 2005 he was President of The Danish Society for Quality in health care and from 2003 to 2005 President of The European Society for Quality in Health. His main research activities relates to quality improvement and quality management, health services research and patient empowerment.



## Warren Richter

**Chief Information Officer, Australian  
Institute for Health and Welfare**



Warren Richter is the Australian Institute of Health and Welfare's (AIHW) Chief Information Officer, responsible for the AIHW's ICT, business transformation and data integration programs.

Warren began his professional career as a statistician at the Australian Bureau of Statistics where he became interested in the design and development of statistical infrastructure, including data and metadata management and online analytical processing software. He has long experience as a chief executive in the private sector and as a senior executive in the public sector. He holds Master of Science (IT) and Bachelor of Economics degrees.



## Michael Schull

**President and CEO, Institute for Clinical Evaluative Sciences,  
Ontario, Canada**



Michael Schull MSc, MD, FRCPC

Dr. Schull is President and CEO at the Institute for Clinical Evaluative Sciences, and Professor in the Department of Medicine at the University of Toronto. His research focuses on health service utilization, quality of care and patient outcomes as they relate to emergency care, and the study of interventions designed to reduce emergency department waiting times. His studies use administrative datasets and linkages with clinical data, and examine the causes and consequences of emergency department overcrowding, variations in patient waiting times, and pre-hospital care. He is currently working with other researchers and health system decision-makers to evaluate policy interventions designed to reduce emergency department waiting times, and innovative ways to better integrate health care between hospital and community providers. Dr Schull practices as an Emergency Medicine specialist at Sunnybrook Health Sciences Centre in Toronto.





## Michael van den Berg, PhD

**National Institute for Public Health and the Environment, Netherlands**



Michael van den Berg, PhD, is a sociologist and health services researcher. His main research interests are quality of care, performance indicators, health systems and primary care. Michael works at the National institute for Public Health and the Environment (RIVM) in the Netherlands and at the Academic Medical Center (University of Amsterdam). Since five years, he has been the project leader of the Dutch Health Care Performance Report. He participates in several international research projects. Michael represents the Netherlands in the Health Care Quality Indicators expert committee of OECD.



## **Dr. Lies van Gennip**

**Director, National IT Institute for  
Health Care (NICTIZ),  
Netherlands**

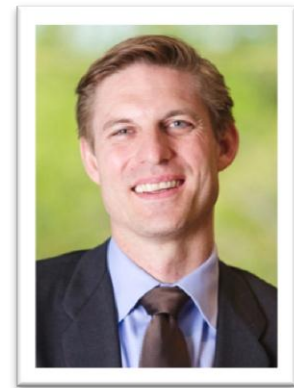


Dr. E.M.S.J. (Lies) van Gennip has a PhD in Biology (1988) with honours at the Leiden University. From 1989-1996 she worked at HISCOM (at the time Dutch market leader in hospital information systems) on technology assessment of (amongst others) PACS and Medical and Nursing information systems. From 1996-2002 she worked for TNO (Dutch institute for applied science), on quality assurance of hospitals and public health. During that period she was involved in the establishment of the hospital accreditation system in the Netherlands (NIAZ) and she was the first CEO of NIAZ until 2002. From 2002-2006 she was the first CEO of the Dutch-Flemish accreditation system for higher education. From 2006-2012 she was CEO of the Dutch centre for tobacco control STIVORO. From 1st November 2012 she is CEO of Nictiz, National IT Institute for Healthcare.



## Jeremy Veillard

**VP Research, Canadian Institute for Health Information, Canada**



Jeremy Veillard, PhD, is CIHI's Vice President of Research and Analysis and an assistant professor (status only) at the University of Toronto's Institute of Health Policy, Management and Evaluation. He is also President of the Canadian Association for Health Services and Policy Research (CAHSPR) for 2013–2015.

Dr. Veillard has expertise in health policy development and health system reform, as well as in evaluation and health system performance measurement, and he has extensive professional experience in the health sector in both Europe and Canada. Dr. Veillard was the regional adviser for health policy and equity at the World Health Organization (WHO) Regional Office for Europe from 2007 to 2010.

Dr. Veillard's previous experience includes leading work on the Health Results Team at the Ontario Ministry of Health and Long-Term Care, serving as a policy advisor at the WHO/EURO in charge of hospital reforms and working as a hospital administrator in France.

Dr. Veillard has a PhD in health systems research from the faculty of medicine of the University of Amsterdam (Netherlands) and two master's degrees.



## Pēteris Zilgalvis

**Head of Unit, eHealth and Well Being, DG  
Connect, European Commission**



Pēteris Zilgalvis is the Head of Unit for eHealth and Well Being in DG Communications Networks, Content and Technology (CNECT) and Digital Single Market “Going Local” Ambassador to Latvia in the European Commission. He was the Visiting EU Fellow at St. Antony's College, University of Oxford for 2013-14, where he is also an Associate of the Political Economy of Financial Markets Programme and is a Senior Common Room Member 2014-17. From 2005 until 2010, he was Head of the Governance and Ethics Unit, Directorate Science, Economy and Society at DG Research, European Commission. From 1997 to 2005, he was Deputy Head of the Bioethics Department of the Council of Europe, in its Directorate General of Legal Affairs, and Co-Secretary of the Intergovernmental Steering Committee on Bioethics (CDBI). In addition, he has held various positions in the Latvian civil service (Ministry of Foreign Affairs, Ministry of Environment). He was Senior Environmental Law Advisor to the World Bank/Russian Federation Environmental Management Project and was Regional Environmental Specialist for the Baltic Countries at the World Bank. P. Zilgalvis studied political science (cum laude) at the University of California, Los Angeles. At the Law Centre of the University of Southern California he obtained his JD (Doctor of Jurisprudence) and received the Darling Foundation academic scholarship. He completed the High Potentials Leadership Program at Harvard Business School. He is a member of the California State Bar. He has published over 30 publications on bioethics, economics and finance, innovation law and policy, European and environmental law in English, Latvian, and French. His most recent publication is “The Need for an Innovation Principle in Regulatory Impact Assessment: The Case of Finance and Innovation in Europe” in *Policy & Internet*



## OECD Secretariat

### Francesca Colombo

#### Head of Health Division



As Head of the OECD Health Division, **Francesca Colombo** oversees OECD work on health, which aims at providing internationally comparable data on health systems and applying economic analysis to health policies, advising policy makers, stakeholders and citizens on how to respond to demands for more and better health care. She has led projects on the performance of health systems in OECD countries, covering a wide range of topics, including quality of health care policies, health financing and the impact of private health insurance on health systems, health workforce and the international migration of doctors and nurses. She has been responsible for OECD Asian Social and Health activities with non-member countries, working with the OECD/Korea Policy Centre. Mrs Colombo is a leading international expert on health and care issues for elderly populations and also held responsibilities for co-ordinating OECD involvement at high-level meetings such as on diabetes and dementia. Prior to joining OECD in 1999, she was seconded to the Ministry of Health and Labour of Guyana as Acting Head of the Planning Unit, where she was instrumental to the implementation of financing and governance reforms of the health system, and also worked at UNCTAD. Over her career, she has travelled extensively in Europe, South America and Asia, advising governments on health system policies and reforms. Mrs Colombo holds a MSc Development Studies from the London School of Economics and Political Science (United Kingdom) and BSc in Economics and Management from Bocconi School of Economics (Italy).



## **Ronni GAMZU**

**Senior Health Policy Analyst**



Former DG of Israel health ministry (till last year), **Ronni Gamzu** besides of being a professor of Gynaecology and PhD in physiology research has graduated business and law school.

Nowadays he serves as an OECD Senior Health Policy Analyst; Focusing mainly on how to promote Healthcare Big data use as well as addressing waste issues in healthcare. In Israel he is the chair of the digital Healthcare information national council.



## Niek Klazinga

Senior Health policy analyst

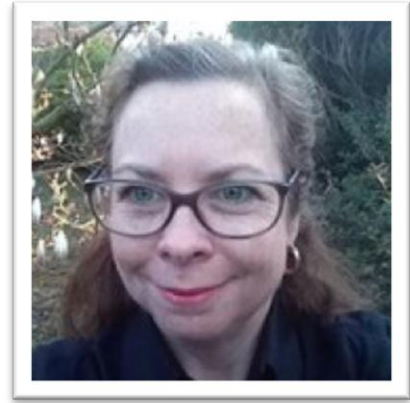


**Niek Klazinga**, MD PhD since 2005 coordinates the Health Care Quality Indicator project at the OECD in Paris. He combines this work with a professorship in Social Medicine at the Academic Medical Centre at the University of Amsterdam. Niek has been involved over the past 25 years in numerous health services research projects and policy debates on quality of care and published widely on the subject. Present commitments include a visiting professorship at the Corvinus University in Budapest, a visiting professorship at the University of Toronto, advisor to WHO, member of the global advisory council of IHI/Boston, advisor to the Canadian Institute for Health Information, member of the Outcome Framework Technical Advisory Committee of the English Department of Health, and member of the board of trustees of the Isala Clinics (Zwolle a large teaching hospital in The Netherlands) and Arkin (Amsterdam; one of the largest mental health care institutes in The Netherlands).



## Jillian Oderkirk

Senior Economist and Policy Analyst



**Jillian Oderkirk** is a Senior Economist and Policy Analyst with the Health Division of the Organisation for Economic Co-operation and Development in Paris, France. She leads a project on developing health information infrastructure including the development of electronic health record systems; the use of personal health data for health system performance monitoring and research; and the privacy and data protection challenges associated with the secondary use of data. Jillian also leads efforts to model health systems within the OECD including the development of decision-support platforms and health expenditure forecasting methods. Prior to joining the OECD, Jillian had a long career with Statistics Canada in Ottawa, Canada and was the Director of the Health Analysis Division at Statistics Canada from 2006 to 2011. Jillian has a Master's Degree in economics from McMaster University, Hamilton, Canada.

