Karolinska Institutet

SIDI
Swedish Institute for Drug Informatics

INTERNATIONAL WORKSHOP IN STOCKHOLM
JANUARY 24-25, 2019

User adapted knowledge bases and real world data in medicine and pharmacology: data acquisition, design, implementation and effects

AIMS

5. Provide state-of-the-art knowledge about design and use of knowledge bases and real world data to achieve rational drug therapy in clinical practice.

6. Strengthen research and development about decision support for patients, healthcare staff and students.

7. Highlight optimal avenues to access data and sustain open science collaboration.

8. Identify and initiate research and development partnerships.

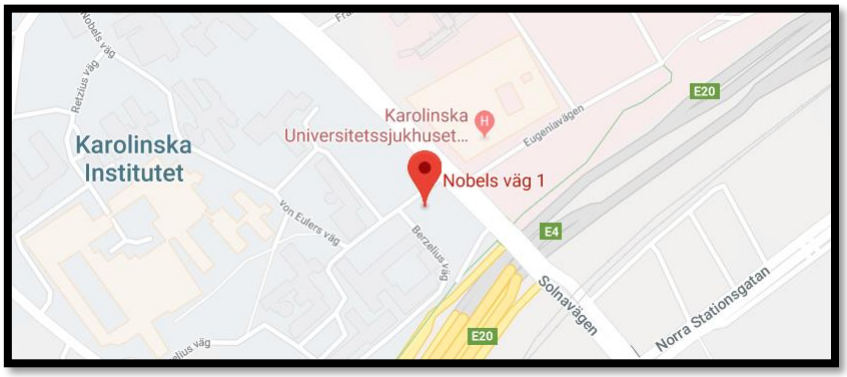
PARTICIPATION

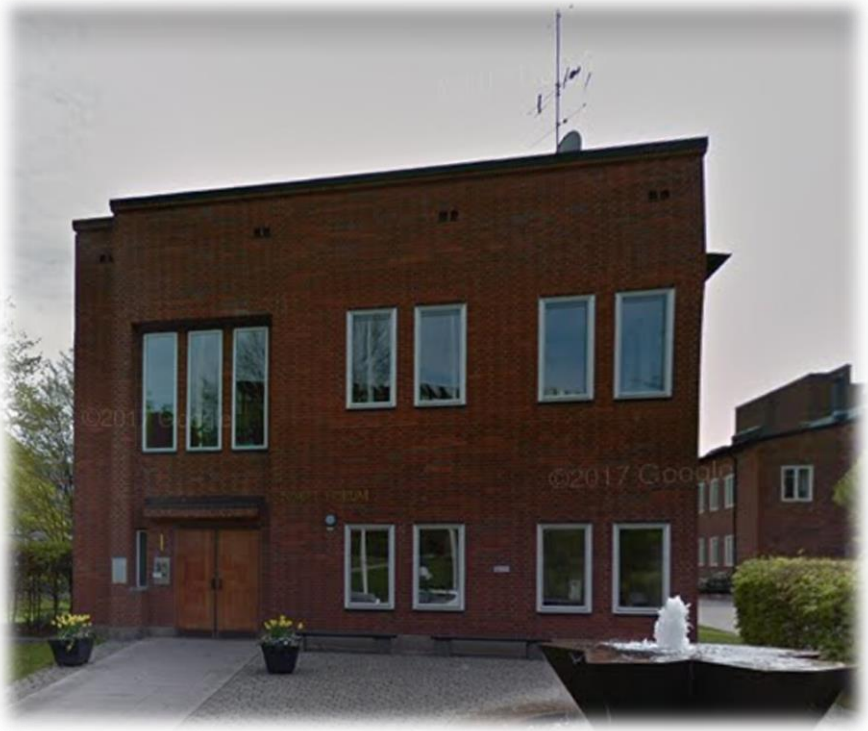
Free of charge by invitation. About 60 participating experts active in research, development, education or in healthcare services and a few policy makers.

Organizing scientific committee

Lars L Gustafsson, KI and SIDI Sweden (Chair)
Paul Cohen, SIDI, Sweden
Marja-Liisa Dahl, KI, Sweden
Dina Demner-Fushman, NLM, USA
Birgit Eiermann, Inera Ltd and KI, Sweden
Daniel Rodriguez, SIDI, Sweden
Robert Vander Stichele, University of Ghent, Ghent, Belgium
Executive secretary Yvonne Elliman, KI, Sweden (yvonne.elliman@ki.se)

Venue: Nobel Forum, Nobels väg 1, Karolinska Institutet, Solna





Video cast of the meeting (not live!!) will be openly available after the meeting at: https://ki.se/en/labmed/live-broadcast-from-the-international-research-workshop-24-25-jan-2019.

At the same website you will find pdf-format of the program and information about the meeting and after the meeting presentations.

Wifi at the Venue:
user name:ki-guest, password: Stockholm18

Thursday January 24, 2019

11:00 – 12am	Registration at site (Nobel forum)
12:00 – 1pm	Lunch
1 – 1:15pm	***Welcome address*** President, professor Ole Petter Ottersen Karolinska Institutet Stockholm, Sweden
1:15 – 1:20pm	***Background and aims*** Professor Lars L Gustafsson Karolinska Institutet and SIDI (Swedish Institute for Drug Informatics) Stockholm, Sweden
1:20 – 3:55pm	***PART 1*** ***USER ADAPTED KNOWLEDGE BASES AND REAL WORLD DATA: contents, data acquisition, structural and technical perspectives*** (25 – 35 minutes for each presentation, including 5 minutes for questions/comments)
1:20 – 1:25pm	***Chair and introduction*** Professor Robert Vander Stichele University of Ghent Ghent, Belgium

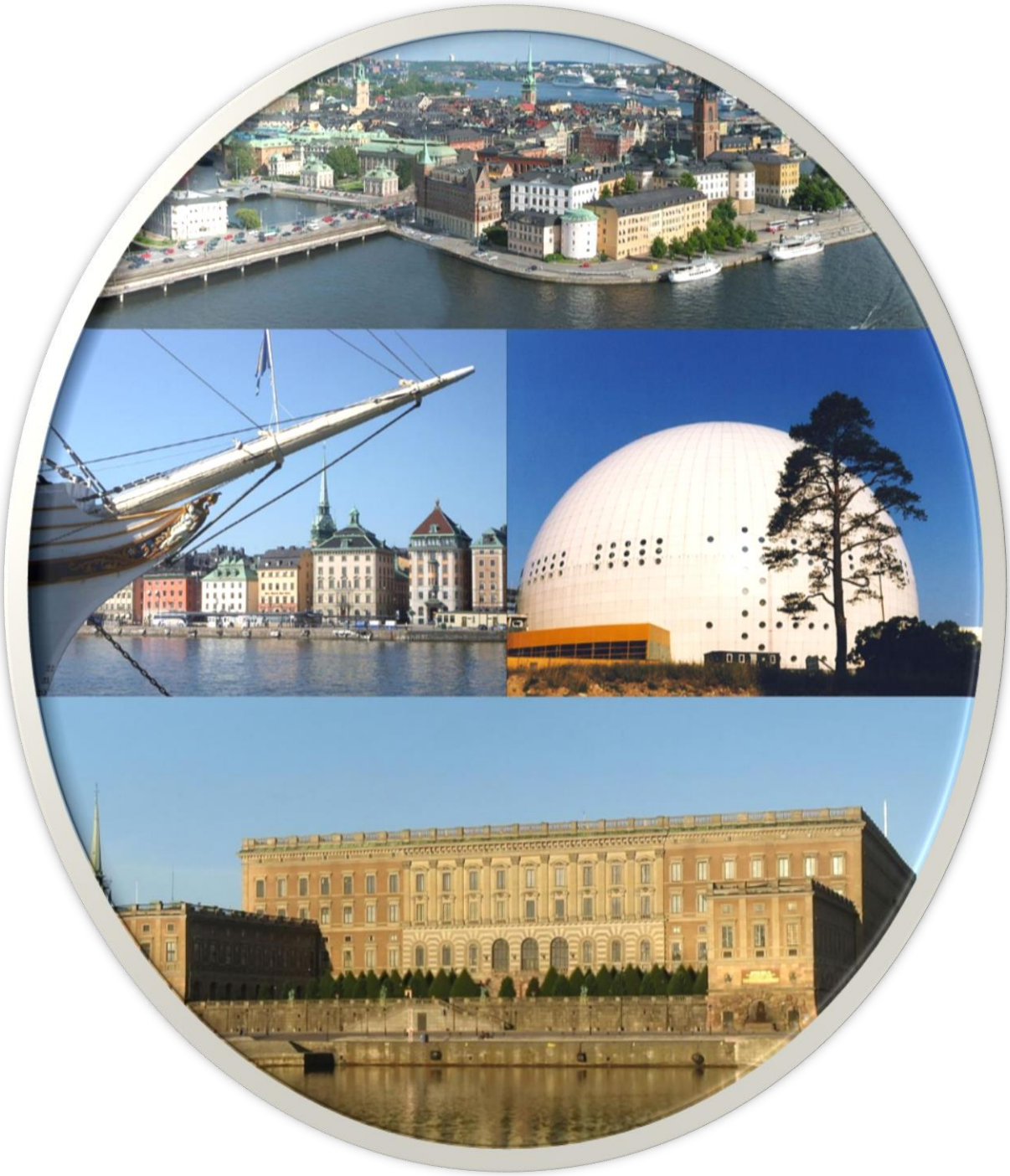
1:25 – 2pm	***Technical breakthroughs in multimodal data access under time-critical conditions*** Associate professor and CEO Johanna Björklund Umeå University and Codemill Ltd Umeå, Sweden
2 – 2:30pm	***Breakthroughs for user adapted medical and pharmacological knowledge bases in health-care and for patients*** Investigator Dina Demner-Fushman National Library of Medicine (NLM) Bethesda, United States
2:30 – 2:55pm	***Adapting real world data for use in decision support in healthcare and for patients: the example of adverse drug reactions.*** Professor Panagiotis Papapetrou Stockholm University Stockholm, Sweden
2:55 – 3:25pm	Coffee and tea
3:25 – 3:50pm	***Contents, design and effects of knowledge bases for medical practice and education: the Duodecim experience.*** Research Director Ilkka Kunnamo Duodecim Medical Publications Ltd Helsinki, Finland
3:50 – 3:55	***Conclusions*** Robert Vander Stichele
3:55 – 5:10pm	***PART 2*** ***AVENUES TO BUILD USER ADAPTED KNOWLEDGE BASES AND COLLECT REAL WORLD DATA IN MEDICINE: focus on drug therapy*** ***Chairs:*** Professor Ylva Böttiger (SIDI Stockholm and Linköping University, Linköping, Sweden) and professor Hervé Le Louet, CIOMS, Paris/Geneva
	Discussion based on presentations and comments on day 1 ***Participants:*** Professor David W Bates (Harvard University, Boston, United States) Johanna Björklund Dina Demner-Fushman Ilkka Kunnamo Dr. Ulrika Nörby (Stockholm Healthcare Region and Lund University, Stockholm and Lund, Sweden) Panagiotis Papapetrou
5:10 – 5:15pm	***Mini-summary of the day*** Health policy analyst Ane Auraaen OECD Paris, France
7 – 9:30pm	***OFFICIAL SIGNING OF COLLABORATIVE AGREEMENT AND WORKSHOP DINNER*** Nobel Forum, Nobels väg 1, Karolinska Institutet, Solna ***Entrance Gallery*** Welcome drink Signing of collaborative agreement between IUPHAR (International Union of Basic and Clinical Pharmacology, Secretary general Michael Spedding) and Karolinska Institutet (President Ole Petter Ottersen) ***Dining rooms upstairs*** (reserved seats, see program) Official workshop dinner

Friday January 25, 2019

8:30 – 8:35am	***Introduction of the day:*** Dr. Marine Andersson Karolinska Institutet and SIDI Stockholm, Sweden
8:35am – 12	***PART 3*** ***USE OF KNOWLEDGE BASES AND REAL WORD DATA IN PRACTICE: EXAMPLES AND PREREQUISITES*** (25 – 35 minutes for each presentation including questions and comments)
8:35 – 8:40am	***Introduction by chairs*** Professor Marja-Liisa Dahl Karolinska Institutet, Stockholm, Sweden Software engineer Paul Cohen SIDI, Stockholm, Sweden
8:40 – 9:15am	***Effective implementation of medical knowledge bases for rational drug therapy*** David W Bates
9:15 – 9:45am	***User-friendly design of interfaces of CDSS (clinical decision support system) enhancing patient-healthcare interactions*** Professor Sabine Koch Karolinska Institutet Stockholm, Sweden

9:45 – 10:15am	***Implementation of decision support for chronic patients targeting needs among patients and healthcare staff*** Researcher Hanna M Seidling Heidelberg University Hospital Heidelberg, Germany
10:15 – 10:45am	Coffee and tea
10:45 – 11:10am	***Integrating Patient reported quality of life Ourcome Measures (PROMs) into cancer care in Scotland: vision and early scientific results*** Professor Marion Bennie University of Strathclyde Glasgow, Scotland
11:10 – 11:35am	***Importance of rapidly accessible real world data for the implementation of new therapies: the example of effectiveness and safety of Non-vitamin K Oral Anticoagulants (NOACs)*** Professor Paul Hjemdahl Karolinska Institutet Stockholm, Sweden
11:35 – 12	***Panel and workshop discussion including remarks by Chairs***
12 – 1pm	Lunch
1 – 3:05pm	***PART 4*** ***NEW WAYS TO ACCESS DATA, COLLABORATE AND ENSURE FUNDING*** (Presentations 20-25 minutes each, including 5 minutes for questions and comments)
1 – 1:05pm	***Chairs and introduction*** Sabine Koch and Chief technical Officer (CTO) Daniel Rodriquez, SIDI, Stockholm, Sweden
1:05 – 1:30pm	***Possibilities and limitations to deliver user adapted knowledge bases for rational prescribing in Sweden*** Dr. Birgit Eiermann Inera Ltd and Karolinska Institutet Stockholm, Sweden
1:30 – 1:50pm	***The advantages of open knowledge data bases in medicine: the perspective by National Library of Medicine*** Dina Demner-Fushman
1:50 – 2:10pm	***Building and maintaining the GUIDE to pharmacology, immunopharmacology and drugs for malaria (www.guidetopharmacology.org): a global collaborative knowledge base involving 500 experts*** Associate professor Steve Alexander University of Nottingham Nottingham, United Kingdom
2:10 – 2:25pm	***The situation in United states for open access and sustainable funding*** (no questions***)*** David W Bates
2:25 – 2:40pm	***Sketch of the situation in Europe for open access and sustainable funding*** (no questions) Robert Vander Stichele
2:40 – 3:05pm	***Discussion and remarks on the way forward***
3:05 – 5:00pm	***PART 5: Group work*** ***COLLABORATIONS FOR OPEN DATA: USE OF HEALTH RECORDS DATA, THE WEBB AND KNOWLEDGE BASES***
3:05 – 3:10pm	***Chairs introduce group work*** David W Bates and Marion Bennie

3:10 – 4:10pm	***Work in five groups, about 10 persons each. Coffee and tea during group work***
4:10 – 5pm	***Presentations of group work (4 minutes each group) and discussions***
5 – 5:05pm	***Conclusions*** David W Bates and Marion Bennie
5:05 – 5:15pm	***Closing reflections*** Birgit Eiermann and Lars L Gustafsson



A workshop identifying new avenues for research and collaboration to provide knowledge bases and real world data in medicine and pharmacology for rational prescribing in healthcare. Experts in the field are participating by personal invitation. The workshop is organized by Division of Clinical Pharmacology at Karolinska Institutet and SIDI (Swedish Institute for Drug Informatics, www.sidi.se promoting

access to independent drug information and IT-support). The event is supported so far by *Swedish Research Council* (VR) and the independent foundations *NEPI* (Swedish Foundation for Pharmacoepidemiology, www.nepi.net). *SIDI* and *Foundation for Clinical Pharmacology and Pharmacotherapeutics* (Sweden). An international follow-up meeting as well as publication of a meeting report in a scientific journal are envisoned. **We will ask all participants to agree to make the presentations and discussions at the meeting openly available by video casting over internet after the meeting.**

Minipresentation of speakers and chairs

Ane Auraaenn: Ane is a health policy analyst at OECD (Organization for Economic Cooperation and Development) in Paris with an educational background in social economics, health economics and in public health. She works with the economics and health policy implications of patient safety and health care coverage using cross-country comparisons of real world and outcome data.

Steve Alexander*:* Associate professor in Molecular Pharmacology at University of Nottingham, United Kingdom. His research interests include signaling pathways associated with G-protein coupled receptors and the turnover of the endogenous ligands, which act through them. Of particular interest is the endocannabinoid system, which lead to a term as President of the International Cannabinoid Research Society in 2015. He is Senior Editor of the British Journal of Pharmacology and of the Concise Guide to Pharmacology. He chairs the Nomenclature Committee of pharmacology and biochemistry of G-coupled receptors. He is active in the IUPHAR (International Union of Pharmacology and Clinical Pharmacology). These roles link to a Wellcome Trust grantholder capacity for the online data bases initiative "*Guide to Pharmacology.org"* and *"Guidetoimmunopharmacology.org"*, which are an expert-driven guide to pharmacological targets and substances that act on them. He is one of the founding members.

Marine Andersson*:* Pharmacist, PhD at Karolinska Institutet and Karolinska University Hospital Stockholm, Sweden with years of experience from drug information services. Marine is active in research and development related to design, use and impact in clinical care of the drug-drug interaction knowledge base (Janusmed). Board member of SIDI (Swedish Institute of Drug Informatics).

David W Bates*:* Professor in medicine at Harvard Medical School and in health policy and management at the Harvard Chan School of Public Health. He is an international leader in research and implementation on health information technology solutions to improve safety and quality of healthcare, in particular with clinical decision support. He has published over 800 scientific papers and is the Chief of the Division of General Internal Medicine at Brigham and Women´s Hospital in Boston. He has held numerous positions of trust and received many awards including the Morris F. Collen Award of Excellence from the American Medical Informatics Association in 2016.

Marion Bennie: Professor of Pharmacy and Pharmacoepidemiology, University of Strathclyde and Chief Pharmacist at NHS (National Services Scotland). Marion's joint post allows her to implement an evidence base to better inform the safe and effective use of medicines in clinical practice. The clinical focus of her research is infection, cardiovascular and cancer including large dataset evaluation to understand evolving patterns of use of medicines in clinical practice and the impact of tailored clinical decision support tools/health interventions. She holds several strategic leadership positions in academy and healthcare nationally and internationally in health data research, informatics and on cancer medicines outcome programs. She chairs the European Drug Utilization Research Group (EURO-DURG).

Johanna Björklund*:* Associate Professor at Umeå University, Sweden. She leads a research group in multimodal analysis. She is also the co-founder of the companies CodeMill Ltd, Smart Video Ltd and Accurate Player Ltd, which deliver media technology to customers world-wide. She has received several scientific and industrial awards. She is named as one of Sweden's most promising entrepreneurs under 40.

Ylva Böttiger: Professor of clinical pharmacology at Linköping University, Sweden. She has years of research, clinical services and teaching in Rational Use of Medicines, in particular on design, editing and delivery of knowledge bases such as the drug-drug interaction database SFINX/Janusmed

Interaction. Presently she chairs EACPT (European Association of Clinical Pharmacology and Therapeutics) and is board member of SIDI (Swedish Institute for Drug Informatics).

***Paul Cohen**:* Software engineer with years of experience from IT-companies and major initiatives and healthcare institutions developing and implementing e-health services in Sweden. Paul has worked with IT-solutions of drug information services for more than a decade. He is co-founder and present board member of SIDI (Swedish Institute for Drug Informatics).

***Marja-Liisa Dahl**:* Professor of clinical pharmacology at Karolinska Institutet and Chief physician at Department of Clinical Pharmacology at Karolinska University Hospital, Stockholm, Sweden. Years of experience of research, teaching and clinical services for rational use of medicines focusing on understanding genetic and non-genetic factors for variability in drug response. She is the Medical Director of the Janusmed Drug-Drug Interaction database used across healthcare institutions in Sweden.

***Dina Demner-Fushman**:* Nina is a medical doctor and computer scientist working as investigator at the National Library of Medicine in Bethesda, United States. She leads research in information retrieval and natural language processing allowing development of clinical decision support that link evidence (test and images) to patients´ data. She has a special interest in providing correct and safe information to the public and patients. Dina has been a NLM leader for several projects on information extraction for clinical decision support. She has published more than 180 scientific articles and book chapters. Dina has received NIH Award of Merit.

***Birgit Eiermann**:* Pharmacist with *a* PhD in clinical pharmacology. Coordinator at Inera Ltd (a company owned by the Swedish Association of Local Authorities and Regions responsible for e-health services) and researcher at Division of clinical pharmacology at Karolinska Institutet, Stockholm Sweden. Years of experience in research and development of knowledge bases to promote rational use of medicines in Sweden and internationally. First director (2002-2009) for the development and implementation of the drug-drug interaction database SFINX in Sweden and Finland.

***Lars L Gustafsson**:* Professor of clinical pharmacology at Karolinska Institutet, Stockholm Sweden. He has years of experience of research and development of knowledge bases and provision of drug information services in clinical pharmacology. Co-founder of SIDI (Swedish Institute of Drug Informatics) and initiator and leader of national and international task forces and research collaborations on e-health and Rational Use of Medicines. Since decades research in tropical clinical pharmacology and on genetic control of drug therapy.

***Paul Hjemdahl**:* Professor of clinical pharmacology at Karolinska Institutet Stockholm, Sweden. He has years of experience of basic and clinical research on cardiovascular drug therapy. In recent years, interest in developing methods to monitor quality of prescribing and use of cardiovascular drugs based on multiple sources such as quality registers, medical record data and health registers. Since decades, Paul has been a leader in developing and implementing guidelines for rational prescribing and sound ethical approaches in clinical research.

***Sabine Koch**:* Professor of health informatics at Karolinska Institutet and Director of the Health Informatics Centre, Stockholm, Sweden. She is president of International Medical Informatics Association (IMIA) and Chief Editor of the journal *Methods of Information in Medicine*. Sabine has established an international master program in health informatics given jointly by Karolinska Institutet and Royal Institute of Technology, Stockholm. She has a broad interest in health informatics including models for collaborative care, human factors/usability, evidence-based decision support and information visualization for enhanced decision-making.

***Ilkka Kunnamo**:* He is a general practitioner and researcher. Ilkka is Research Director for EBM Guidelines at Duodecim Medical Publications. It is an organization funded and owned by the Finnish Medical Association. He is a co-founder of their IT-based systems proving evidence based recommendations. He is an adjunct professor in general practice at University of Helsinki, Finland.

Hervé Le Louët: He is professor of clinical pharmacology at University Paris-Est Creteil and physician specialized in hepatology. Hervé is head of pharmacovigilance coordination in Paris metropolitan region holding several expert positions on drug regulatory and safety issues nationally and internationally. Hervé is past president of the International Society of Pharmacovigilance. Presently he is president of CIOMS (council for International Organizations of Medical Sciences), a non-profit organization advancing public health through guidance on health research with headquarter in Geneva.

***Ulrika Nörby**:* Pharmacist holding a PhD in reproductive epidemiology (fetal effects of maternal drug exposure) at University of Lund, Sweden. She has also long experience as a medical editor. Ulrika is since decades involved in major initiatives to develop and evaluate impact of practice directed drug information. She is as Director of the knowledge base "*Drugs and Birth Defects*" available to health care professionals and patients across Sweden.

***Ole Petter Ottersen**:* President of Karolinska Institutet Stockholm, Sweden since 2017 and of the University of Oslo, Norway 2009-2017. Professor in neuroscience with research focusing on synaptic structure and function and on the molecular mechanisms underlying water transport in brain. Recently engaged in global health much inspired by experience gained as Chair of the Lancet-University of Oslo Commission on Global Governance for Health (2012-2017). Ole Petter served as panel leader of ERC Advanced grants from start to 2012 and is now chairing ERC synergy grant panel (life science). He has served on multiple scientific and healthcare boards and has been the Chief Editor of Neuroscience (2006-2009). For more than a decade he has been involved in promoting scientific and educational collaborations between universities across borders.

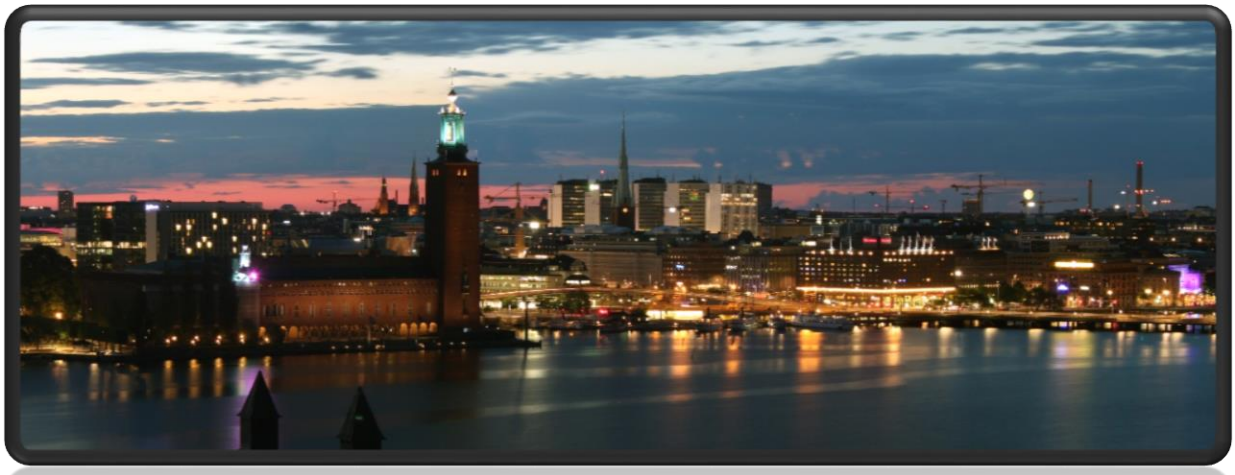
***Panagiotis Papapetrou**:* Professor in computer science at The Department of Computer and Systems Sciences at Stockholm University, Sweden and also adjunct professor at Aalto University, Finland. His area of expertise and main research interest is in algorithmic data mining with particular focus on mining and indexing temporal data and healthcare data and complex data including learning and interpreting information in electronic health records. Panagiotis received his PhD in Computer Science at Boston University in Unites States in 2009. He was a post-doctoral researcher at Aalto University during 2009-2013. He was lecturer at University of London during 2012-2013. He is board member of the Swedish Al Society and Editor of the Data Mining and Knowledge Discovery Journal. He is the scientific leader of a project on data mining of adverse drug events documented in electronic health records.

***Daniel Rodriguez**:* Software engineer with years of experience in designing and developing IT-related solutions for regional and national healthcare institutions in Sweden. He has worked with drug informatics solutions to achieve rational use of medicines for more than two decades. He is a co-founder of SIDI (Swedish Institute for Drug Informatics) and serves on its board and as SIDí´s Chief Technical Officer (CTO).

***Hanna M Seidling**:* Pharmacist and PhD. She is presently head of clinical pharmacy services at Department of Clinical Pharmacology and Pharmacoepidemiology at the University Hospital in Heidelberg, Germany. She is trained at university hospitals in Geneva, Heidelberg and Boston. Her research interests include development, implementation and evaluation of clinical decision support systems as well as strategies to increase patient safety and prevent medication errors.

***Robert Vander Stichele**:* A practising general practitioner since years and combined with specialization also in clinical pharmacology. Robert is professor in clinical pharmacology at University of Ghent, Belgium. His research, education and clinical services include understanding variability in use of medicines across institutions and disciplines. He has initiated and acted as leader, including Chief Information Officer and Editor-in-chief, for several national and international initiatives to provide evidence based recommendations and knowledge at point of care. He has a special interest in health and drug informatics.

40 other leading Swedish and international experts active in research, development, clinical practice and evaluation of knowledge base and use of real world data in medicine participate. Some policy and decision makers are invited to this workshop.



CONTACT INFORMATION
Yvonne Elliman (yvonne.elliman@ki.se), mobile phone +46 70 425 83 15
Lars L Gustafsson (lars-l.gustafsson@ki.se), mobile phone +46 70 601 26 14