



**Karolinska
Institutet**



SIDI

Swedish Institute for Drug Informatics

AGREEMENT

INTERNATIONAL EXPERT WORKSHOP ON USER ADAPTED KNOWLEDGE BASES AND REAL WORLD DATA IN STOCKHOLM JANUARY 24-25, 2019

I will participate in this workshop at Karolinska Institutet.

(Jointly organized by Division of Clinical Pharmacology at Karolinska Institutet and SIDI, an independent public foundation).

I allow any presentation of mine and any comments during the discussions to be video casted and openly made available by the organizing institutions after the meeting. It is planned that meeting proceedings will be available as videos at the home page of Department of Laboratory Medicine at Karolinska Institutet.

I also allow that (if I have contributed) my presentations will be made available in the produced online video cast material and as pdf-files that can be downloaded from the organizations home pages.

I am glad to inform that I am willing to share my contributions at the workshop to promote open science.

Stockholm January 2019

(Name)

(Title)

.....
.....

Name and address of Institution

REGISTERED PARTICIPATING EXPERTS

International expert workshop January 24-25, 2019 at at Karolinska Institutet, Stockholm

USER ADAPTED KNOWLEDGE BASES AND REAL WORLD DATA IN MEDICINE AND PHARMACOLOGY

SPEAKERS AND MODERATORS		WORK GROUP	DINNER TABLE
Stephen Alexander <i>Associate professor</i>	University of Nottingham Nottingham United Kingdom steve.alexander@nottingham.ac.uk	3	4
Marine Andersson , <i>PhD, MScPharm</i>	Karolinska University Hospital Department of Clinical Pharmacology Stockholm Sweden marine.andersson@sll.se	1	7
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Mia von Euler <i>Associate professor, MD</i>	Karolinska University Hospital Department of Clinical Pharmacology Stockholm Sweden mia.von.euler@ki.se	3	5
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INVITED DINNER GUESTS

Johanna Ackemar <i>International Coordinator</i>	International Office Karolinska Institutet Stockholm Sweden johanna.ackemar@ki.se	No	2
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Dag Larsson <i>Member of Parliament, MP</i>	Swedish Parliament Stockholm Sweden Stockholm dag.larsson@riksdagen.se	No	1
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Anna Nilsson Vindefjärd <i>Secretary General</i>	Research!Sweden Stockholm Sweden forskasverige.anna@gmail.com	No	1
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Barbro Westerholm <i>Member of Parliament, MP</i> <i>Professor</i>	Swedish Parliament Stockholm Sweden barbro.westerholm@riksdagen.se	No	1
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EXECUTIVE ADMINISTRATION

Yvonne Elliman	Division of Clinical Pharmacology Department of Laboratory Medicine Karolinska Insitutet Stockholm Sweden yvonne.elliman@ki.se	No	No
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EXPERT WORKSHOP: User adapted knowledge bases and real world data in medicine and pharmacology

TOPICS FOR GROUP WORK

GROUP 1:

Group room in Nobel Forum Gallery close to main entrance

User adapted knowledge bases: how to become helpful and used in CDSS for healthcare staff and patients?

Guiding questions

1. What are the optimal strategies for user adaptation and how can professional end-users and patients be engaged in development and follow-up of value?
2. Are there existing or emerging smart tools for continuous feed-back and contact between end-users and knowledge base producers?
3. Should integration of knowledge bases be mandatory and if so, who should mandate it and what should the mandate look like?
4. How should the clinical benefits of knowledge bases be investigated and who should be responsible?
5. What are the risks, benefits and recommended agreements with commercial parties interested in developing apps and other tools of disseminating knowledge base information?
6. Should knowledge bases be hosted by scientific/academic communities?

Members of group

Petra Thürmann, chair	Peter Alvinsson, rapporteur	Marine Andersson
David W Bates	Paul Cohen	Birgit Eiermann
Jonas Ekström	Werner Hackl	Per Nydert
Ludvig Petersson	Annikki Roos	

GROUP 2:

Group room 2 in Nobel Forum Gallery close to Wallenberg auditorium

Access to real world data for medical research and clinical practice

Guiding questions

1. How do we ensure access to real world data and how can data be shared internationally?
2. Characteristics of good examples where access to real world data in clinical practice have had major impact on health and/or healthcare outcome?
3. Do you have examples of knowledge bases that could be created based on real world data?
4. How to optimally organize and maintain access, storage, visualization and analysis of real world data in research and clinical practice?
5. What are the ethical challenges and solutions in using real world data in clinical practice and research?

Members of group

Marion Bennie, chair	Thomas Cars, rapporteur	Ana Auråen
Nils Feltelius	Patrik Georgii-Hemming	David Herron
Mona Heurgren	Paul Hjemdahl	Gun Peggy Knudsen
Panagiotis Papapetrou	Max Petzold	

GROUP 3:

Front part of Wallenberg Auditorium

Global network collaboration to establish standards and provision of basic and clinical drug information

Guiding questions

1. To what extent can the “Identification of Medicinal Products” initiatives by EMA and FDA be the basis for defining standards for essential information/data about medicines (molecular, basic and clinical drug)?

www.fda.gov/ForIndustry/DataStandards/ucm612442.html,
www.ema.europa.eu/en/human-regulatory/overview/data-medicines-iso-idmp-standards-overview

2. In what areas can universities and expert societies (i.e. IUPHAR and pharmaceutical associations) have an impact in defining and maintaining standards and in provision of essential drug information?
3. What expertise, collaborative structure and networking tools can ensure high probability of success of global collaboration?
4. What initiatives and steps are required to ensure that the needs of standards and provision of drug information for patients and health care staff are provided in resource strained countries?

Members of the group

Michael Spedding, chair	Tora Hammar, rapporteur	Steve Alexander
Ylva Böttiger	Johan Holm	Bror Jonzon
Rikard Lövström	Daniel Rodriguez	Christopher Southan
Robert Vander Stichele	Mia von Euler	

Group 4:

Back part of Wallenberg auditorium

Scientific and healthcare opportunities and challenges for knowledge bases/data access making a difference for chronic patients

Guiding questions

1. What are the most promising opportunities for applications focused on the needs of healthcare staff treating/caring chronic patients today?
2. What are the most promising opportunities for applications focused on the needs of patients and guardians today?
3. What are the most important barriers and challenges to be handled in order to implement “low-hanging fruits” of knowledge bases and IT-tools?
4. Which chronic diseases and conditions should gain most from implementing good IT-tools and knowledge bases?

Members of group

Johanna Björklund, chair	Agostino Chiaravalloti, rapporteur	Jan Kilhamn
Dina Demner-Fushman	Lars L Gustafsson	Sabine Koch
Tomas Mora Morrison	Ulrika Nörby	Katharina Schmidt Mende
Hanna Seidling	Anders Sylvan	

Group 5: Gallery at top floor

Needs, feasibility and methods to define an international guideline/
accredited practice to build, maintain and use knowledge bases for
CDSS for healthcare staff and patients

Guiding questions

1. What are the critical properties of a guideline/accreditation practice in order to be used in a proper way?
2. What guidelines and accreditation practices exist today that can be built upon?
3. What steps and processes are needed and what representatives/competens are suited to develop such a guideline/
4. What body/bodies are best suited to publish and maintain a guideline/
accreditation practice/accreditation practice?
5. What are the roles of research bodies and global academic societies (such as IUPHAR and CIOMS)?
6. What good examples exist for financing of development, maintenance and distribution of knowledge bases in different countries?

Members of group

Lembit Rägo, chair	Charlotte Asker-Hagelberg, rapporteur	Marja-Liisa Dahl
Werner Hackl	Maria Häggglund	Mikael Hoffmann
Ilkka Kunnamo	Synnöve Lindemalm	Tero Shemeikka
Mattias Schindele	Eva Wikström Jonsson	

DINNER SEATING

TABLE 1

Lars L Gustafsson, David W Bates, Johanna Björklund, Marja-Liisa Dahl, Dina Demner-Fushman, Anders Gustafsson, Dag Larsson, Hervé Le Louet, Jan Nilsson, Ole Petter Ottersen, Michael Spedding, Barbro Westerholm.

TABLE 2

Johanna Ackerman, Charlotte Asker-Hagelberg, Patrik Georgii-Hemming, Lembit Rägo, Mattias Schindele

TABLE 3

Peter Alvinsson, Petra Thürmann, Eva Wikström Jonsson, Rickard Lövström, Ulrika Nörby, Paul Cohen, Ilkka Kunnamo

TABLE 4

Stephen Alexander, Marion Bennie, Jonas Ekström, Mikael Hoffman, Maria Hägglund, Anna Nilsson Vindejärd, Max Petzold

TABLE 5

Ylva Böttiger, Agostino Chiavarolotti, Mona Heurgren, Bror Jonzon, Jan Kilhamn, Panagiotis Papaetrou

TABLE 6

Ane Auråen, Thomas Cars, Synnöve Lindemalm, Daniel Rodriguez, Tero Shemmeika, Christophe Southan, Robert Vander Stichele

TABLE 7

Marine Andersson, Tora Hammar, Werner Hackl, Anders Sylvan, Paul Hjemdahl, Per Nydert, Gun Peggy Knudsen

Travel to and from the Nobel forum venue. (2 options)

If you are staying in a hotel in the centre of Stockholm:

1) Take the commuter train from Stockholm City train station towards Märsta or Upplands Väsby. Exit at the following station, which is Stockholm Odenplan. At the station, follow the signs Utgång/Exit Odenplan. When outside the station, face the church and you will have the busses on your left-hand side. Bus number 67 will take you to Karolinska University Hospital. If you are staying in a hotel at Odenplan, you are already in the area of the bus square.



Bus stop at Odenplan.

2) Take the underground (metro) from Stockholm City (main station) to St. Eriksplan (exit Torsgatan) and from there you can take a bus (several options, including number 3) to Karolinska Institutet (Eugeniavägen).



Bus stop at Karolinska Institutet (at the left) and Karolinska University Hospital

Travel around Stockholm

Commuter cards can be purchased at SkyCity central station, located between terminal 4 and 5, or at the main station (Stockholm city) in town. When buying the ticket please tell the staff you will be using commuter trains/metro/buses for the duration of your stay. They can recommend the best card to buy.