



UPPSALA
UNIVERSITET

Department of Public Health and Caring Sciences

Annual Report 2015

Avsändare/Fastställd av Johan Hallqvist 2016-05-12

Introduction

The Department of Public Health and Caring Sciences employs 200 persons, of which there are 11 professors and 26 senior lecturers. The yearly economic turnover is approximately 150 million SEK.

The Department of Public Health and Caring Sciences has extensive responsibilities in the teaching of nursing students, medical students, master of public health students and graduate students. The research questions addressed within the department of Public Health and Caring sciences covers a broad spectrum of issues ranging from contemporary hot public health issues on the political agenda to pertinent issues of molecular biology related to important public health problems. They take advantage from a truly multi-disciplinary collaboration, involving cooperation with other departments of the university and other universities in Sweden and around the world. The Department is also the host of two Centres; the Centre for Disability Research and the Centre for Research Ethics and Bioethics. Further, the strategic research program U-CARE is hosted by the research group Clinical Psychology in Healthcare at the department.

Education

There were about 2860 students registered at the department in 2015, in terms of funding corresponding to about 810 full time students. About 930 registered students were educated in the Nursing programme, 1090 in the Medicine programme, 70 in the Master-programme in Public Health and about 640 in separate courses. Through well-established collaboration with several universities abroad and different exchange programmes nursing students and teachers were able to get international experience. Contract education conducted by the Department additionally hosted approximately 50 registered students.

Research

The Department of Public Health and Caring Sciences is commissioned by the Disciplinary Domain of Medicine and Pharmacy at Uppsala University

to perform scientific research in Caring sciences, Diet, nutrition and metabolism, Family medicine and clinical epidemiology, Geriatric research, Preventive research, and Social medicine. During 2015 there were 300 peer-reviewed scientific publications from researchers affiliated to the department. The yearly average during the last ten years is 230 but there is an increasing trend during later years. There were 14 dissertations, a somewhat greater number than the yearly average during the last decade. During 2015 the department had 88 registered doctoral students engaged in thesis projects.

The research activities are organized in eleven research groups; Caring Sciences, Research Ethics and Bioethics, Clinical Nutrition and Metabolism, Clinical Psychology in Healthcare, Disability and Habilitation, Family Medicine and Preventive Medicine, Geriatrics, Health Economy, Health Services Research, Life Style and Rehabilitation in Long Term Illness, and Socio-medical Epidemiology.

Caring Sciences

The research has a multidisciplinary and multiprofessional perspective. The focus is on clinically relevant problems in the health care sector. There are two research themes; reproductive health, and quality of care and patient safety.

In reproductive health the aim is to enhance preconception health and care among women and men by i) developing, implementing and evaluating a counselling tool, called the Reproductive Life Plan, in clinical health care settings ii) developing, launching and evaluating a preconception information package on the internet, and as a mobile application for the general population to access and use, iii) and study ethical and gender issues related to preconception care. Also prevention of cervical cancer and the implementation of HPV-vaccination in school health have been investigated. The group collaborate with the international PrePreg network.

The quality of care and patient safety investigates different aspects of the quality of care and patient safety at micro- and meso levels in both hospital and community settings, *i.e.* hospital acquired pressure ulcers and infections, communication and the ageing population.

Centre for Research Ethics and Bioethics (CRB)

The Centre for Research Ethics & Bioethics (CRB) is an interfaculty centre that was established in 2008. CRB is a multi-disciplinary research environment with senior and junior staff from ethics, philosophy, medicine, nursing, economics, law and other fields. Their research questions arise in close collaboration with other researchers, scientists and clinicians. CRB investigates the ethical, philosophical and legal aspects of biomedical research and clini-

cal practice. Roughly, their research profile can be divided in three: bioethics, clinical ethics and research ethics, with four profile areas that stand out: biobanks and registries, neuroethics and neurophilosophy, risk research and nursing and caring.

With support from BBMRI.se, CRB publishes the Biobank Perspectives newsletter with current issues in ethics and law, that reaches approximately 4.000 subscribers. They also run the Ethics Blog and the Swedish sister blog “Etikbloggen” that reaches both the scientific community and the public. CRB is responsible for the Swedish Research Council’s website CODEX with rules and guidelines for research. In 2015, they arranged a workshop on Epigenetics as the meeting point between nature and nurture. The event brought together epigenetics, neuronal epigenesis, social science and the humanities to discuss these issues for the first time.

Clinical Nutrition and Metabolism

At Clinical Nutrition and Metabolism (CNM) top international and partly world leading research is performed (KOF11) to evaluate the role of nutrition for prevention and treatment of non-communicable diseases including cardiovascular disease, type 2 diabetes and other age-related disorders. During 2015 several important grants have been approved (*e.g.* Swedish Research Council) and a number of news-breaking papers have been published including fatty acid effects on abdominal fat deposition, dietary fat biomarkers and CVD risk, on muscle function (*e.g.* importance of sarcopenia in aging), and on dietary patterns and risk for dementia and other health hazards. Researchers at CNM are highly interactive with media and the outside society.

Clinical Psychology in Healthcare

The group houses the strategic research program U-CARE and the U-CARE-portal. The Portal is the only Swedish generic infrastructure to support research on online self-care, care, and psychological treatment. The Portal consists of two parts; a technical solution ‘software’ and interventions including, but not limited to text, multimedia material, cognitive and physical exercises, forum, chat, and questionnaires. The group conducts research on: the clinical efficacy and cost-effectiveness of online interventions; how online interventions should be designed to maximize their clinical efficacy; cognitive, economic, and psychological determinants and consequences of somatic disease for patients and significant others; and how sustainable systems should be designed to support online interventions. The research meets the healthcare challenges ahead, has potentially a high impact on the society and economy, and is cross-disciplinary involving Economics, Implementation Sciences, Information Systems, and Psychology. The group consists of

many young and talented scientists and is highly interactive with the surrounding society.

Disability and Habilitation

Research activities focus disability as a function of the interplay between a person's health condition and his or her physical, social and societal environment. There are three main research tracks: 1) the development and test of assessment methods, interventions and documentation in services for people with disabilities, 2) the significance of received targeted support for self-perceived health, and 3) participatory research. All tracks highlight the facilitating and restraining aspects of the environment, as well as the participation and perspectives of persons with disabilities, professionals and significant others.

Family Medicine and Preventive Medicine

The research in Family Medicine emanates from the multidisciplinary perspective of primary health care and is conducted by a large group of researchers throughout the Uppsala-Örebro region. The research activities have eleven different themes.

The research group continues to produce about 70 to 80 scientific articles per year in a wide range of scientific areas. The number of collaborations with Swedish researchers is high and international collaboration is increasing.

Much work has been carried out during 2015 to make the vision of an academic primary health care center come true.

Geriatrics

The main areas of research are molecular studies of dementia as well as clinical and epidemiological research in these and other age related diseases, such as cardiovascular and renal disorders. Cellular and transgenic models of Alzheimer's disease, Parkinson's disease and Lewy body dementia are used to understand mechanisms of abnormal protein aggregation in the brain and to develop new biomarkers and disease-modifying therapies. An important research tool is to develop new methods for molecular imaging, *i.e.* positron emission tomography (PET). The group applies a broad repertoire of experimental techniques, *e.g.* molecular biology, biochemistry, histology and behavioural analyses in our research. Clinical and epidemiological studies of dementia and successful ageing are also performed.

Health Economic Research Group

The Health Economic Research Group was initiated during 2013 as a part of Health Economic Forum of Uppsala University (HEFUU), aiming at increased collaboration between different Departments at the University. The research group's major research project will contribute to the development of robust methods for comparative effectiveness studies in clinical practice using mainly existing data for the evaluations, *i.e.*, medical records and registries.

The group has made progress during the year in order to assure critical collaboration partners for its first project, *i.e.*, a proof-of-concept study which will illustrate the methods by evaluating the effectiveness and cost-effectiveness of NOAC in clinical practice. The research group has also made progress during the year in order to understand the populations preferences regarding using these existing data. And finally, the group has contributed to health economic strategies for other projects, and supervised master students, and PhD students. Finally, the group also continues to contribute to the education of the faculty and the students in health economics. For example, the first master course in health economic evaluations at advanced level was offered fall 2015. Over 50 students applied for the course, but only 20 could be admitted. In the future, it would be advisable to consider accepting more students in order to advance the faculty's accumulated skill in health economic evaluations.

Health Services Research

Health Service Research (HSR) adopts three contrasting but interconnected perspectives; at care provision - organisational - and system level. The Uppsala group is engaged in research at all three levels with focus on governance and implementation, intra-organisational control, inter-organisational relations and patient relations. More specifically, current study objectives include development of exploratory models for differences in public and private care, identification of barriers for implementation of different reforms as well as identification of facilitators for high quality and patient safety care. The group is multidisciplinary and the researchers have different professional backgrounds such as medicine, psychology, nursing and political science.

Life Style and Rehabilitation in long term illness

The group *Lifestyle and rehabilitation in long term illness* was formed during 2015. Various projects are ongoing and planned within the group and most projects are cross-disciplinary randomized controlled intervention studies focusing on lifestyle (*e.g.* physical exercise, stress management, nutri-

tion) in cancer patients. The aim is to find evidence-based interventions for changing life styles factors to decrease the burden for the patients and care givers during and after cancer treatments, cost-effective rehabilitation programs and more person-centered health care.

Sociomedical Epidemiology

The main objective of the work of the research group is to analyze factors that influence health and the effectiveness of medical and health interventions in different population groups. The main fields of the research programme are to evaluate the quality and equity in medical care and health system interventions for vulnerable groups.

Uppsala May 12, 2016

Johan Hallqvist
Head of Department

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Organization

Head of Department

Professor Johan Hallqvist

Deputy Head of Department

Professor Karin Sonnander

Department Board

Carina Ahlstedt, Teacher and Researcher Representative

Ulrika Winblad Spångberg, Teacher and Researcher Representative

Mats G Hansson, Teacher and Researcher Representative

Anna Höglund, Teacher and Researcher Representative

Henrik Edlund, Technical and Administrative Representative

Jennifer Drevin, Graduate Student Representative

Karin Nordin, Teacher and Researcher Representative, Deputy

Ulf Risérus, Teacher and Researcher Representative, Deputy

Lena Hedlund, Teacher and Researcher Representative, Deputy

Ulf Holmbäck, Teacher and Researcher Representative, Deputy

Maria Peippo, Technical and Administrative Representative, Deputy

Åsa Andersén, Graduate Student Representative, Deputy

Catarina Dahlqvist, Protocol

Professor Emeriti

Marianne Carlsson

Urban Rosenqvist

Björn Smedby

Kurt Svärdsudd

Bengt Vessby, adj Professor Emeritus

Claes-Göran Westrin

Directors of Graduate Studies

Mats G Hansson, Head
Margaretha Eriksson
Barbro Wadensten

Directors of Undergraduate Studies

Carina Ahlstedt, Head
Karin Björkegren, Deputy Head
Päivi Adolfsson
Berit Thoudal
Ulrika Winblad Spångberg

Director of Clinical Issues

Lars Lannfelt

Professors and Research Groups Leaders

Bengt Arnetz
Tommy Cederholm
Louise von Essen
Lena Gunningberg
Johan Hallqvist
Mats G Hansson
Lars Lannfelt
Per Kristiansson
Karin Nordin
Karin Sonnander
Tanja Tydén
Ragnar Westerling
Ulrika Winblad

Adj Professors, Guest Professors and adj Senior Lecturers

Theo van Achtenberg
Annika Bardel
Hans Basun
Lena Ring
Thorne Wallman

Address List

Department of Public Health and Caring Sciences
(Institutionen för folkhälso- och vårdvetenskap, IFV)

Address: The department is situated at three different locations:

- BMC, Entry A11, Husargatan 3
- Dag Hammarskjölds väg 14B
- The Rudbeck Laboratory, Dag Hammarskjölds väg 20

E-mail address: `firstname.lastname@pubcare.uu.se`

Aarts Clara

Adolfsson Päivi

Aguilar Ximena

Ahlby Bitte

Ahlstedt Carina

Al Adhami Maissa

Alfonsson Sven

Almandoz-Gil Leire

Ancillotti Mirko

`fornamn.efternamn@crb.uu.se`

Ander Malin

Andersén Åsa

Anderzén Ingrid

Arnetz Bengt

Arnetz Judith

Arving Cecilia

Ax Erika

Bardel Annika

Basun Hans

Berglund Erik

Berglund Marie

Bergström Joakim

Bjerg-Bäcklund Rie

Björkegren Karin

Boberg Anton

Boger Marike

Bordas Kata

Boström Linn

Brantnell Anders

Bratteby Tollerz Linda

Bäcklund Linus

Bäckström Josefin

Carli Cheryl
Carlsson Maria
Cato Linda
Cederblad Maria
Cederholm Tommy
Cernvall Martin
Dahlqvist Catarina
Daryani Achraf
Demmelmaier Ingrid
Drevin Jennifer
Edlund Henrik
Ekmark-Lewén Sara
Eriksson Helène
Eriksson Leif
Eriksson Margaretha
Eriksson Stefan förnamn.efternamn@crb.uu.se
Eriksson-Öhman Solveig
Erlandsson Anna
Evers Kathinka förnamn.efternamn@crb.uu.se
Fagerström Johansson Jenny
Fang Xiaotian
Farisco Michele förnamn.efternamn@crb.uu.se
Fernow Josepine förnamn.efternamn@crb.uu.se
Flynn Terry förnamn.efternamn@crb.uu.se
Fredriksson Mio
Frejd Karin
Fridlund Malin
Furberg Elisabeth
Giedraitis Vilmantas
Godman Nathalie
Godskesen Tove förnamn.efternamn@crb.uu.se
Gottvall Maria
Grandahl Maria
Grönqvist Helena
Gumucio Gatica Astrid
Gunningberg Lena
Gustafsson Gabriel
Gutierrez Arenas Omar
Hagström Anneli
Hallqvist Johan
Hansson Mats Gunnar förnamn.efternamn@crb.uu.se
Hedlund Lena
Hedström Mariann
Henriksson Anna

Herrick Ylva
Holm Marta
Holm Sara förnamn.efternamn@crb.uu.se
Holmberg Fabian
Holmbäck Ulf
Horne Ian
Howard Heidi förnamn.efternamn@crb.uu.se
Hovén Emma
Hovstadius Eva
Hultin Lisa
Hultqvist Greta
Hurtigh Liljestam Anna
Hägglund Maria
Höglund Anna förnamn.efternamn@crb.uu.se
Igelström Helena
Ihse Elisabet
Ingelsson Martin
Isaksson David
Isaksson Stina
Jalmsell Li förnamn.efternamn@crb.uu.se
Jansson Håkan
Jobs Elisabeth
Josefsson Karin
Kaminsky Elenor
Karlsson Ann-Christin
Karlsson Johanna
Karlsson Mikael
Kihlbom Ulrik förnamn.efternamn@crb.uu.se
Kilander Lena
Kindström Dahlin Moa
Kirsebom Marie
Kjellberg Sören
Koochek Afsaneh
Kristiansson Per
Kukkola Laura
Kumar Boddeti Santosh
Lagerkvist Johanna
Langenskiöld Sophie
Lannfelt Lars
Lantz Christine
Larsson Kjerstin
Lindahl Norberg Annika
Lindgren Marcus
Lindström Veronica

Ljungman Lisa
Lugnet Kerstin
Lundberg Annie
Lundberg Pranee
Lundin Birgit
Lytsy Per
Lyxell Anna
Lögde Ann
Mankell Anna
Marcusson Rose-Marie
Marklund Matti
Marnell Harriet
Martinsson Carl Magnus
Mascalzoni Deborah förnamn.efternamn@crb.uu.se
Masterton Malin
Matar Amal förnamn.efternamn@crb.uu.se
Mattsson Elisabet
Mattsson Susanne
Mazzoni Anne-Sophie
Mellberg Nina
Miller Karin
Modin Karin
Mohammadi Elham
Månsson Ann
Nihlén Fahlquist Jessica förnamn.efternamn@crb.uu.se
Nikitidou Elisabeth
Nordin Karin
Norinder Camilla
Norlund Fredrika
Normark Lena
Olsen Malin
Ohlsson Anna
Olsson Erik
Olsson Fredrik
Olsson Roger
Paulsson Do Ulrica
Peippo Maria
Persson Annica
Persson Emma
Pettersson Mona förnamn.efternamn@crb.uu.se
Pingel Ronnie
Puranen Arvid
Pöder Ulrika
Ramji Rathi

Ring Lena	förnamn.efternamn@crb.uu.se
Riserus Ulf	
Ronsten Barbro	
Roshanai Afsaneh	
Rosqvist Fredrik	
Rostami Jinar	
Saletti Anja	
Sallin Karl	förnamn.efternamn@crb.uu.se
Schmidt Meta	
Segerdahl Pär	förnamn.efternamn@crb.uu.se
Sehlin Dag	
Sjögren Per	
Sonnander Karin	
StAAF Anita	
Stenhammar Christina	
Stenlund David	
Stern Jenny	
Sundbom Renée	
Svanberg Ann-Carin	
Swenne Leo Christine	
Syvänen Stina	
Söllvander Sofia	
Tegler Helena	
Tengblad Siv	
Thoudal Berit	
Thörnqvist Eva	
Tirkkonen Leena	
Toft Teolinda	
Tomasoni Mattia	
Traneus Charlotte	
Tyden Tanja	
Törmä Johanna	
Umb-Carlsson Öie	
Wadensten Barbro	
Wallert John	
Wallman Thorne	
Veldwijk Jorien	förnamn.efternamn@crb.uu.se
Vengberg Sofie	
Westerling Ragnar	
Viberg Jennifer	förnamn.efternamn@crb.uu.se
Wickström Östervall Linne	förnamn.efternamn@crb.uu.se
Wikman Anna	
Winblad Spångberg Ulrika	
Volgsten Helena	

von Berens Åsa
von Essen Louise
Wångdahl Josefin
Åberg Anna Cristina
Åhs Annika
Åkerman Eva

Associated Researchers

Adamsson Viola
Andersson Sven-Olof
André Malin
Annerbäck Eva-Maria
Arakelian Erebouni
Ax Erika
Berglund Britta
Bernsten Cecilia
Bernsten Sveinung
Björkman Ingeborg
Bogefeldt Johan
Bojner Horwitz Eva
Bröms Kristina
Burell Gunilla
Butler Stephen
Carlsson Marianne
Cederblad Maria
Cederholm Jan
Cedervall Ylva
Dahlström Tobias
Edlund Birgitta
Ekstrand Maria
Eldh Catrine
Englund Lars
Engström Maria
Engström Sevek
Engvall Gunn
Ernesäter Annica
Falkeborn Margareta
Forsberg Joanna
Glad Johan
Godskesen Tove
Gottvall Andér Maria
Gulliksson Mats

Gustavsson Catharina
Halford Christina
Hallström Björn
Hanning Marianne
Hjelmblink Finn
Holmström Inger
Hovén Emma
Hänni Arvo
Höyer Lundh Marie
Ingvoldstad Charlotta
Inthorn Julia
Janeslätt Gunnel
Jansson Stefan
Johansson Gunnar
Johansson Hans-Erik
Johansson Lars Age
Johansson Birgitta
Johansson Gunnar
Johnsson Linus
Kallings Lena
Kaminsky Elenor
Karlström Britta
Kristofferzon Marja-Leena
Kunkel Stefan
Lampic Claudia
Larsson Jan
Larsson Kjerstin
Lindahl Annika
Lindberg Maria
Lindberg Magnus
Lindstedt Helena
Lisspers Karin
Löfvander Monica
Magnusson Kristina
Makenzius Marlene
Mamhidir Anna-Greta
Muntlin Åsa
Mårtensson Gunilla
Nerpin Elisabet
Nilsson Lars
Nilsson Annika
Nordgren Lena
Olai Lena
Oscarsson Marie

Peterson Magnus
Pless Mia
Reine Ieva
Rissanen Ritva
Roshanai Afsaneh
Rytter Elisabeth
Röing Marta
Rönnemaa Elina
Sahlin Charlotte
Salles Arleen
Sanner Margareta
Schwan Åke
Silén Marit
Skytt Bernice
Smedman Annika
Star Kristina
Stålhammar Jan
Ställberg Björn
Svalastog Anna-Lydia
Swartling Malin
Svärdsudd Kurt
Terner Annika
Thorell Eva
Tiblom Ylva
Torstensson Thomas
Wahlström Rolf
Wallander Marie-Ann
Vaegter Keld
Vég Aniko
Vessby Bengt
Westerberg Josefin
Wiberg Bernice
Wiholm Clair
Wijk Katarina
Zethelius Björn
Åberg Anna Cristina
Åhsberg Elizabeth
Ålander Ture

Doctoral Students

Ahlqvist, Kerstin
Ahlstedt, Carina

Alfonsson, Sven
Almandoz Gil, Leire
Alsharari, Zayed
Ancillotti, Mirko
Ander, Malin
Andersén, Åsa
Andersson, Caroline
Ax, Erika
Bendrik, Regina
Berg, Peter
Berglund, Erik
Bjurling-Sjöberg, Petronella
Björk, Anne
Björn, Catrine
Boström, Linn
Brantnell, Anders
Carlsson, Tommy
Do Paulsson, Ulrica
Drevin, Jennifer
Fang, Xiaotian
Farisco, Michele
Franzon, Kristin
Godskesen, Tove
Grandahl, Maria
Grape Viding, Christina
Gustafsson, Gabriel
Hagerman, Heidi
Haraldsson, Johanna
Hedman, Maria
Hellerstedt Börjesson, Susanne
Hellström, Charlotta
Henriksson, Anna
Iggman, David
Isaksson, David
Isaksson, Stina
Jalmsell, Li
Kalliokoski, Paul
Karlsson, Bo
Karlsson, Lars
Karlsson, Mikael
Kerstis, Birgitta
Kirsebom, Marie
Knudsen, Kati
Lavén, Sofia

Lindgren, Anne
Ljungman, Lisa
Lännerström, Linda
Martinell, Mats
Matar, Amal
Mattsson, Susanne
Nikitidou, Elisabeth
Nordlöf, Hasse
Norlund, Fredrika
Ohlsson, Anna
Olsson, Erika
Pettersson, Mona
Phoosuwan, Nitikorn
Pålsson, Ylva
Randmaa, Maria
Roos, Charlotte
Roshanay, Afsane
Rosqvist, Fredrik
Sallin, Karl
Skoglund (fd Bergh), Elisabeth
Sobestiansky, Sigvard
Stern, Jenny
Stolt, Ragnar
Sundgren, Elisabeth
Söderberg, Jenny
Söderström, Lisa
Söllvander, Sofia
Tegelberg, Alexander
Tegler, Helena
Toft, Teolinda
Törmä, Johanna
Wallert, John
Wandin, Helena
Vengberg, Sofie
Viberg, Jennifer
Widarsson, Margareta
von Berens, Åsa
von Celsing, Anna-Sophia
von Granitz, Heléne
Wångdahl, Josefin
Åkerman, Eva
Östlund, Ann-Sofi

Centres

During 2015 the Department of Public Health and Caring Sciences was the host of two Centres; the Centre for Disability Research, and the Centre for Research Ethics and Bioethics.

Centre for Disability Research (CDR)

(www.cff.uu.se)

Director: Karin Jöreskog

The Centre for Disability Research was established in 1988 to coordinate disability issues in various subject areas at the faculties at Uppsala University and to interact with society on issues related to disability research. The aim is to disseminate information about research and to stimulate long term acquisition of knowledge about issues involving disability by enhancing the flow of information among teachers, researchers, and doctoral students as well as interested parties outside the university (p. 52).

Centre for Research Ethics and Bioethics (CRB)

(www.crb.uu.se)

Director: Mats G Hansson

The Centre for Research Ethics & Bioethics (CRB) is an interfaculty centre that was established in 2008. CRB is a multi-disciplinary research environment with senior and junior staff from ethics, philosophy, medicine, nursing, economics, law and other fields. Our research questions arise in close collaboration with other researchers, scientists and clinicians. We investigate the ethical, philosophical and legal aspects of biomedical research and clinical practice and publish the results of our research in international peer-reviewed scientific journals and in books. Roughly, our research profile can be divided in three: bioethics, clinical ethics and research ethics, with four profile areas that stand out: biobanks and registries, neuroethics and neurophilosophy, risk research and nursing and caring (p 56).

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About 50 students were registered in contract education and 88 doctoral students were registered in the department.

First-cycle courses and study programs

Courses in the Medicine Programme

Medical education in Uppsala means early patient contact.

Throughout the program the students train patient relations, examination and other clinical skills in primary care. They also answer ethical and scientific questions in the course Professional Skills and Communication, which starts as early as the first semester.

The program involves the integration between biological basis and clinical science, but also the integration between basic science and clinical subject areas. This means that the theoretical parts are studied in context, not as separate courses.

A new subject is interprofessional education. The first semesters all students from the nursing, physiotherapy and medical programs all work together in reflective exercises concerning patient, doctor, staff and relatives encounters.

Semester 1: *Introduction course*, 3 credit points

Semester 1: *Professional Skills and Communication 1*, 2.5 credit points

Semester 2: *Professional Skills and Communication 2*, 2.5 credit points

Semester 3: *Professional Skills and Communication 3*, 2.5 credit points

Semester 4: *Professional Skills and Communication 4*, 2.5 credit points

Semester 4-11: *Leadership training*, 4 credit points

Semester 5: *Geriatrics*

This course covers gerontology, Alzheimer's disease and other neurodegenerative dementia disorders, various aspects on frail elderly patients

with multiple co-morbidities and poly-pharmacy, falls, delirium and other geriatric syndromes, orthogeriatrics, stroke rehabilitation and palliative care, during a total of three weeks.

Semester 1-11: *Medical Ethics and Medical Law*, 3 credit points

The course extends over the entire program. The different elements are related to the other courses that students take during the current period. Each session includes either a half or a full day. The course involves close collaboration with various clinical specialties, including group exercises based on actual patient cases that are either presented by the participating teacher/doctor or generated by the students themselves. Group discussions are integrated with lectures. The course is examined with an individual moral case deliberation.

Semester 11: *Family Medicine*, 6.5 credit points

Theoretical education is mixed with seminars for two weeks and the students have practical training in managing patients by themselves in a health care centre for another two weeks.

Tutor education -- supervising students at health care centres

Doctors are trained in supervising students at the health care centre. Each course lasts three days.

Courses in the Nursing Program

The Nursing Program covers 180 credit points. (Nursing Methods I and II, Ill Health and Prevention of Ill Health I, Nursing and Medical Science in Public Health Practice and Primary Health Care, Nursing and Medical Science in Geriatrics and Elderly Care, Scientific Methodology and Thesis in caring science). The first three semesters of the new Nursing Program ran in 2015. The new Nursing Program has students based in both Uppsala and Gotland. The teachers Anita Staaf and Eva Hovstadius were awarded the Nursing Students' pedagogical prize in 2015 for excellent teaching standards.

Separate courses at the first-cycle level

The following courses are offered as separate courses at the first-cycle level: Culture and Health, Trends in Global Health, Motivational Interviewing in Health Promotion, Disability Living Conditions and Participation (introductory course), Impairment and Disability (advanced course), Nursing Care Planning and Quality Improvement, Bachelor's Thesis in Caring Sciences, Health Politics and Health Economics, Introduction to Theory of Science with Focus on Medical Research, Public Health, Methods in Public Health C, Public Health, Especially Health Pedagogy.

Contract education

The course *Working with Disease-prevention Methods in Practice*, 7.5 credits, is given as a contract education in cooperation between primary care in Uppsala county and the Department of Public Health and Caring Sciences. Participants are professional nurses, dieticians and physiotherapists in primary care. The course includes the National Board of Health national guidelines for disease prevention practices regarding tobacco use, hazardous use of alcohol, insufficient physical activity and unhealthy eating habits. Methods and tools for working with unhealthy habits in an evidence-based manner for individuals and groups are taught. Working under improvement model is done to implement national guidelines for disease prevention in the clinical practice.

The course *Research Ethics for Medicine and the Life Sciences*, 4 credits, is open for researchers, doctoral students and professionals from Universities, Research Institutes, Government agencies, NGO's and companies. The course runs over ten weeks and covers nine themes. During the last week, participants share what they have learned with colleagues at their home institutions. The training will develop participants' ability to identify ethical aspects of research work, and to do something about them. It provides the basic tools to identify and assess central ethical aspects and offer updated and research-based information, important issues and concepts. We also provide a resource bank of instructions, forms, guidelines and principles.

This is an online course with video-lectures and texts to read, but the course is designed to be interactive. Each lecture is followed by an online quiz and readings that should be discussed in a forum where everyone takes part. Each week participants complete a challenge and there are three e-meetings where texts are discussed. All the material is available online. The course is very structured but allows students to plan their time around other work. There is individual feedback on all written assignments and from fellow students in the discussion forum.

Second-cycle courses and study programs

Postgraduate Diploma in Specialist Nursing with focus on District nurse

Postgraduate Diploma in Specialist Nursing with focus on District nurse, 75 credit points – Pharmacology related to Diseases and the Extended Role of the District nurse, Nursing Care and Public Health in Adults and Elderly in Primary Health Care, Nursing Care and Public Health in Children and Ado-

lescents at Child Health Centres and Schools, Nursing Care in Children and Adolescents with Common and Specific Conditions, Advanced Studies in Primary Health Care Nursing.

Postgraduate Diploma in Specialist Nursing with focus on care of elderly

Postgraduate Diploma in Specialist Nursing with focus on care of elderly, 60 credit points (Geriatrics, Pharmacology and Gerontological Nursing, Gerontology and Nursing Focused on Healthy Ageing, Dementia and nursing care).

Postgraduate Diploma in Specialist Nursing with focus on oncology care

Postgraduate Diploma in Specialist Nursing with focus on oncology care, 60 credit points and 30 credit points at our department: Psychosocial Cancer Care I and II, Palliative Care I and II.

Separate courses

The following courses are offered as separate courses at the second-cycle level: Research Designs, Methods and Statistics in Public Health, Public Health Ethics, Theories in Caring Sciences, The Organization and Management of Swedish Health Care, Health Promoting Management, Diet, Nutrition and Public Health, Equity in Health, Clinical Nutrition and Energy Balance, Psychosocial Cancer Care, Palliative Care, Challenges in Global Health, Community Interventions, Neuroethics, Behavioural Medicine with Applications to Lifestyle-Related Health Problems, Dementia and Nursing Care - Basic Course for Nurses, Caring Sciences, Degree Project, Advanced Course C, Public Health C, Degree Project, Scientific Methodology II, and Supervision.

Master in Public Health

Two years of full-time studies, 120 credit points, started in year 2007.

The modules are: Public Health (advanced level, 15 credit points), Research Designs, Methods and Statistics in Public Health (advanced level, 15 credit points), Behavioural Medicine with Applications to Lifestyle-Related Health Problems (7.5 credit points), Community Interventions (7.5 credit points), Organisation and Management of Swedish Health Care (7.5 credit points), Equity in Health (7.5 credit points), Diet, Nutrition and Public Health (7.5 credit points), Public Health Ethics (7.5 credit points), Health

Promoting Management (7.5 credit points), Thesis (advanced level, 30 credit points).

The aims of the program are to increase knowledge, understanding and skills in public health and public health work. This means that students will be competent both in further research and in practical strategic public health initiatives. An important profiling of the program is a focus on health promotion interventions at individual and community levels, design and evaluation of public programs and analysis of the management of the Swedish health care system.

Third-cycle course and study program

Doctoral courses and study programme

In the beginning of the year 2015, 75 doctoral students were in education and during the year 14 of them have past their theses and 13 new applicants have been admitted to studies at the doctoral level.

Different research groups at the department are taking part in the training courses in the theory components of the doctoral education. In the obligatory courses at the Faculty of Medicine, members from *Centre for Research Ethics & Bioethics* are involved in “The introduction to scientific research” (7.5 ECTS, given two times a year). The *Centre for Research Ethics & Bioethics* is also responsible for the course “Research Ethics and Philosophy of Science” (1.5 ECT, given two times a year). *Family Medicine and Preventive Medicine* participated in “Medical epidemiology” (1.5 ECT, given once a year). The research group *Clinical psychology in healthcare* is responsible for two courses “Implementation of complex interventions in healthcare” (7.5 ECT, given once a year).

The *Centre for Research Ethics & Bioethics* is also responsible for doctoral courses given at other faculties at Uppsala University: “Research Ethics for Science and Technology” (2 ECTS, given three times a year).

To give new doctoral students a good introduction to their doctoral studies the directors of doctoral studies in IFV set up a two days “*Introduction course*” where all the research group leaders give lectures in their own special research areas; the intention is also to offer the students opportunity to meet the senior ones. The doctoral students give a short presentation of their own research as well. Beside this, the doctoral students are given basic information on goals, rules and regulations, among all annual follow-up, the half-time review, the different research seminars, the obligatory registration of publication in DiVA, the organization of Uppsala University as a whole, specifically the Faculty of Medicine and our own department. An important item of the course for the new doctoral students is the meeting with the older PhD students.

Education project

An overview of the total set of courses in Public Health started, and a new structure and content were developed.

International activity

We have well-established collaboration with universities abroad within several exchange programmes for nursing students on undergraduate level, nursing students on advanced level in different specialties, and teachers. The main programmes are Erasmus Plus for European countries, Nordplus (Nordlys for the Scandinavian and Baltic countries and Danosfi for the Nordic countries), and Linnaeus-Palme and Minor Field Study for developing countries such as Ethiopia, Mozambique, Tanzania, Thailand, Uganda, and Vietnam. The students also have the opportunity to do clinical practice/internship in countries outside Europe such as South Africa, Tanzania, Thailand, Uganda, and Vietnam.

We have complied with the international strategies of Uppsala University. The number of our students studying abroad has increased every year. In 2015 about 45 of them studied abroad during 1-12 weeks, while 9 foreign students visited our department during 4-12 weeks. Six of our teachers taught abroad during 1-3 weeks; one visited Metropolitan University College, Copenhagen, for teaching in an intensive course supported by Nordplus, two participated in the European Academy of Caring Sciences and the Nordic/European Conference, "Exploring care for human service professions: Caring Science", Copenhagen, one visited Makerere University, Uganda, within the Linnaeus-Palme Exchange Programme, and two visited Mahidol University, Thailand, for participation in workshop "Capacity Building in Reproductive Health" supported by the Swedish Foundation for International Cooperation in Research and Higher Education. One teacher from Makerere University, Uganda, taught in our department during 3 weeks as a part of the Linnaeus-Palme Exchange Programme. The exchange programmes have given students and teachers knowledge, experiences, international contacts and global perspectives which are valuable for their personal development and careers as well as for their universities.

Dissertations 2015

- **Ax, Erika.** Dietary patterns: Identification and health implications in the Swedish population
- **Godskesen, Tove.** Patients in clinical cancer trials: Understanding, motivation and hope
- **Grandahl, Maria.** Prevention of human papillomavirus in a school-based setting
- **Hellström, Charlotta.** Adolescent gaming and gambling in relation to negative social consequences and health
- **Iggman, David.** Dietary fatty acids and cardiometabolic risk: Influence on lipoproteins, insulin resistance and liver fat
- **Isaksson, Stina.** The child's best interest: Perspectives of gamete recipients and donors
- **Jalmsell, Li.** Towards good palliation for children with cancer: Recognizing the family and the value of communication
- **Kerstis, Birgitta.** Depressive symptoms among mothers and fathers in early parenthood
- **Kirsebom, Marie.** Mind the gap: Organizational factors related to transfers of older people between nursing homes and hospital care
- **Nordlöf, Hasse.** Prerequisites and possibilities for manufacturing companies to prioritize and manage occupational health and safety
- **Stern Jenny.** Preconception health and care: A window of opportunity
- **Söllvander, Sofia.** Amyloid-beta Protofibrils in Alzheimer's Disease: Focus on Antibodies, Inflammation and Astrocytes
- **Widarsson, Margareta.** Journey from pregnancy to early parenthood: Perceived needs of support, fathers involvement, depressive symptoms and stress
- **Östlund, Ann-Sofi.** Motivational interviewing in primary care: Nurses' experiences and actual use of the method

Caring Sciences

Research group leader professor Tanja Tydén, chair

All teachers including the professors are to a high degree engaged in education on undergraduate-, master- and doctoral level. The education mainly concerns courses in caring sciences within the nursing and advanced nursing programs and within the master program in Public Health. Some teachers are also engaged in teaching within other departments at Uppsala University.

Our research in Caring Sciences emanates from a multi-scientific perspective including preventive, supportive, caring, and rehabilitative actions. Our research group is studying clinically relevant problems in the health care sector. Resources within the health care system for support to the individuals and their families are of great interest.

In 2015, the Caring Sciences group had following two research themes:

- Reproductive health
- Quality of care and patient safety

The theme that we call *reproductive health* investigates different aspects related to fertility issues and having children in the future. The background to this is that parental age when having a first child in Sweden has increased by five years the past four decades. The aim of this research program is to prevent infertility and HPV-related cancer.

We have ongoing studies at antenatal- and IVF-clinics in the Uppsala-Örebro region. We investigated health and lifestyle prior to conception, during pregnancy and one year after delivery. Our main research questions are: Is pregnancy planning associated with life style changes? Is pregnancy planning associated with factors such as age and education?

In an RCT-study we measure the effects of a new approach (The reproductive Life Plan) of contraceptive counseling. The main research questions are: Is it possible to increase women's knowledge about fertility and their attitudes to plan pregnancies earlier in life with help of the Reproductive Life Plan-approach? What are the midwives' experiences and needs of this new approach of contraceptive counselling? We collaborate with Örebro University and with 30 clinics for contraceptive counseling in Örebro Coun-

ty Council. We also continue with research collaboration with our international PrePreg group.

Further, we have a study in Thailand; Knowledge, belief and acceptance related to HPV vaccination among parents in Thailand.

Another focus is to gain a deeper understanding of experiences and needs following a prenatal diagnosis of congenital heart defect. The focus is on information and support to pregnant women and their partners to acquire knowledge to enhance informed decision making regarding whether to continue or terminate the pregnancy.

Prevention of cancer related to Human papilloma virus (HPV) is also studied. Sweden introduced a school-based human papillomavirus (HPV) vaccination programme in 2012. Some of our research questions are: What attitudes and experiences do school nurses have regarding the school-based HPV vaccination programme? Why do parents refuse or accept to vaccinate their daughter?

An ongoing RCT-study in School Health investigates the outcome of an intervention on HPV vaccination status and about primary prevention of HPV.

We also collaborate with Mahidol University Thailand regarding HPV vaccination.

Together with the PrePreg-network we planned the 3rd European Congress in Preconception Health and Care to be held in Uppsala February 2016.

The theme that we call *quality of care and patient safety* investigates different aspects of the quality of care and patient safety at micro- and meso levels in both hospital and community settings.

The aim of one research program is to reduce the incidence of patients with hospital-acquired pressure ulcers. In 2015, an RCT was conducted to evaluate the effect of a new innovative method, the Continuous Bedside Pressure Mapping System, on the incidence of pressure ulcers in a geriatric hospital ward. Experiences from the multidisciplinary team were also gathered through qualitative interviews. Furthermore, to investigate sustainability a three-years follow up of an implementation study (evidence based pressure ulcer prevention) is ongoing. Another research program is infection control including hospital-acquired infections following coronary artery bypass graft procedures and the concept “Vårdkamraten” (electronic monitoring system for hand disinfection), which is under development.

Communication is studied from the perspective of postoperative handover between healthcare personnel in an anaesthetic clinic (SBAR) and primary care nurses' experiences and actual performance of motivational interviewing with patients. Furthermore, evidence based practice is studied in different contexts such as airway management in anaesthesia care and standard care plans related to stroke and intensive care.

An ageing population is one of the greatest healthcare challenges of today. Factors related to transfers of older people between nursing homes, emergency department and hospital care have been identified, as well as older peoples' perceptions of dignity, well-being, autonomy and participation.

The work environment for nurses affects patient safety. Therefore, a qualitative interview study is planned to identify factors for registered nurses' intention to stay/intention to leave their position at surgical and medical wards. Another project connected to work environment, ending in 2016, had the overall aim to gain knowledge of registered specialist nurses' and assistant nurses' work in operating departments and of what factors they consider to be important for attractive work.

Members of the group during 2015

Aarts Clara, RN, PhD, associate professor, senior lecturer
Bäckström Josefin, RN, PhD, lecturer
Gunningberg Lena, RN, PhD, professor
Hedström Mariann, RN, PhD, senior lecturer
Karlsson Ann-Christin, RN, PhD, senior lecturer,
Leo Swenne Christine, RN, PhD, senior lecturer
Lundberg Pranee, RNM, PhD, associate professor, senior lecturer
Pöder Ulrika, RN, PhD, senior lecturer
Svanberg Ann-Carin, RN, PhD, lecturer
Tydén Tanja, RNM, PhD, professor, chair
Volgsten Helena, RNM, PhD, senior lecturer
Wadensten Barbro, RN, PhD, associate professor, senior lecturer

Lecturers fulltime or part time

Adolfsson Päivi
Ahlby Bitte
Cederblad Maria
Carlsson Marianne
Eriksson Leif
Eriksson-Öhman Solweig
Fagerström Johansson Jenny
Frejd Karin
Godman Nathalie
Hedlund Lena
Holm Marta
Hovstadius Eva

Hultin Lisa
Jobs Elisabeth
Kjellberg Sören
Lantz Christine
Lugnet Kerstin
Lundin Birgit
Lögde Ann
Marnell Harriet
Miller Karin
Lena Nordgren
Norinder Camilla
Normark Lena
Pettersson Mona
Anja Saletti
Schmidt Meta
StAAF Anita
Stenlund David
Thoudal Berit
Thörnqvist Eva

Associated researchers

Edlund Birgitta, RN, PhD, associate professor, senior lecturer
Ekstrand Maria
Engström Maria
Kristofferzon Marja-Leena
Lindberg Magnus
Lindberg Maria
Magnusson Kristina
Mamhidir Anna-Greta
Mårtensson Gunilla
Nilsson Annika
Oscarsson Marie
Skytt Bernice
Stenhammar Christina
Silén Marit
Westerberg Jacobsson Josefin
Tibblom Ehersson Ylva
Åhsberg Elisabeth

PhD students

Bjurling-Sjöberg Petronella
Björn Catrine

Carlsson Tommy
Drevin Jennifer
Grandahl Maria
Hedman Maria
Kerstis Birgitta
Kirsebom Marie
Knudsen Kati
Pålsson Ylva
Randmaa Maria
Roos Charlotte
Stern Jenny
Widarsson Margareta
Östlund Ann-Sofi

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Dissertations 2015

- **Maria Grandahl**
Prevention of Human Papillomavirus in a school-based setting. PhD, Medical sciences. Uppsala University, 2015.
- **Birgitta Kerstis**
Depressive Symptoms among Mothers and Fathers in Early Parenthood. PhD, Medical sciences. Uppsala University, 2015.
- **Marie Kirsebom**
Mind the gap: *Organizational factors related to transfers of older people between nursing homes and hospital care*. PhD, Medical sciences. Uppsala University, 2015.
- **Jenny Stern**
Preconception Health and Care: A Window of Opportunity. PhD, Medical sciences. Uppsala University, 2015.
- **Margareta Widarsson**
Journey from Pregnancy to Early Parenthood: *Perceived Needs of Support, Fathers’ Involvement, Depressive Symptoms and Stress*. PhD, Medical sciences. Uppsala University, 2015.
- **Ann-Sofi Östlund**
Motivational Interviewing in Primary Care: Nurses' experiences and actual use of the method. University of Gävle, Faculty of Health and Occupational Studies, Department of Health and Caring Sciences. Uppsala universitet, 2015.

Awards 2015

Tanja Tyden received the Uppsala County prize for good clinical research.

Agencies that support the research work/Funding (SEK)

Medicine and Pharmacy, UU and Campus Gotland”	300 000
Vetenskapsrådet	100 000
ALF-medel	800 000
LÖF (Landstingets Ömsesidiga Försäkringsbolag)	100 000
Frimurarstiftelsen	200 000
STINT ”Initiative grant”	148 000
RFR-medel	150 000

International collaboration

- The PrePreg-Network
- Trustee of the European Pressure Ulcer Advisory Panel (board member)
- Member of European Academy of Caring Science
- European Academy of Caring Science (EACS), Core member
- International Co-coordinator for Nordic countries (Nordplus network: Norlys), European countries (Erasmus), and Linnaeus-Palme (Vietnam), Department of Public Health and Caring Sciences, Uppsala University
- International coordinator for African countries especially Uganda and Tanzania
- Member of Scientific Board of Investigación y Educación en Enfermería Research and Education in Nursing
- Guest professor Theo van Achterberg, professor chair of the Centre for Health Services and Nursing Research and of Quality of Care at KU Leuven, Belgium
- Guest Lecturer, Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand
- Guest Researcher, Department of Nursing, Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy, Ho Chi Minh City, Vietnam
- Guest Researcher, School of Economics, Sukhothai Thammathirat Open University, Thailand
- Guest Lecturer, Makerere University, Colledge of Health Sciences, Kampala, Uganda
- Member of the Editorial board for the Journal: Nursing Research and Education

- Guest Researcher, Early rehabilitation of cancer patients at the Department of Oncology and Medical physics, Haukeland University hospital, Bergen, Norway

National commissions

- Expert group – Pressure Ulcer/Patient Safety – The Swedish Association of Local Authorities and Regions
- Advisor to Vice Chancellor concerning gender equality
- Fellow of Royal Academy of Science in Uppsala
- Member of the research board, Swedish Cancer Society
- Member of Pool of External Experts, Medicine and Care, The Swedish Council for Higher Education, Swedish International Cooperation Agency (SIDA)
- Member of the Board for Stiftelsen InDevelops u-landsfond
- Special mandate for Swedish National Agency for Higher Education. Evaluation of pediatric nurse specialist education in Borås, 2012
- Member of the Scientific Board of Investigación y Educación en Enfermería: Research and Education in Nursing (ISSN_p: 0120-5307, ISSN_e:2216-0280)

Invited speakers 2013-2015

- The Danish Council of Ethics, Ministry of Health
- School nurses Conference, Borås
- Boston University

Centre for Disability Research (CDR)

The Centre for Disability Research (CDR) was established in 1988 to coordinate disability issues in scientific fields represented at the faculties at Uppsala University and to interact with the wider community on issues relating to disability research. The Centre is placed at the Faculty of Medicine and administratively associated with the Department of Public Health and Caring Sciences.

During the year CDR continued functioning as the coordinator for the Swedish Network of Disability Researchers. On 16 April, around forty researchers from all over Sweden gathered for a network meeting in Uppsala.

The agenda included a presentation of UU, a tour of Museum Gustavianum and a lecture by Therése Fridström Montoya of the Department of Law. This was based on her thesis on the rights of people with intellectual disabilities in legal contexts, including their right to personal self-determination.

Also on the agenda was a presentation of the work being done by the nominations committee in preparation for the election of Swedish members of the board of NNDR (Nordic Network on Disability Research).

NNDR was founded in Denmark in 1997 and since then has arranged the biennial international research conference held in one of the Nordic countries. This means that the conference returns to each country every ten years. In 2017, the conference will be held in Sweden for the second time. The national network will be responsible for the conference arrangements while financial responsibility rests with the local organiser (Örebro University). Karin Jöreskog and Karin Sonnander are part of the team working on the conference, called *NNDR 2017*. Their presentation of information about the upcoming conference was also on the agenda of the network meeting.

In addition, there was a progress report from MFD (the Swedish Agency for Participation) on the work being done on the 2016 research proposition. This was followed by a discussion.

Within the framework of ongoing activities at CDR, eight lectures were organised in 2014 for the purpose of disseminating information about ongoing research into disability at Uppsala University. We have seen a steady increase in the number of people attending the lectures.

Four editions of the newsletter *Research om funktionshinder* (Current Disability Research) have been published. The newsletter represents Swedish research on disability issues.

More subscriptions have been switched from printed newsletters to digital format (PDF) newsletters and new subscribers were added during the year. The newsletter had a circulation in 2015 of 4500, of which 1600 were for the digital-format publication. In addition to the newsletter, the office sends information to an e-mail network with 800 addresses.

The CDR homepage (www.cff.uu.se) presents information about activities at CDR, its board members, lecture and course programmes, *etc.* The newsletter *Research om funktionshinder pågår* (Current Disability Research) is available in PDF format. All issues from the start in 1992 are available.

The Board of the Centre for Disability Research

Professor Karin Sonnander, (Disciplinary Domain of Medicine and Pharmacy) chairperson

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Professor Anders Rydberg (Disciplinary Domain of Science and Technology), vice chairperson

PhD Faculty of Technology, Kjartan Halvorsen, (Disciplinary Domain of Science and Technology) (until 30-06-2015)

Professor Rafael Lindqvist (Disciplinary Domain of Humanities and Social Science).

PhD Faculty of Humanities and social Sciences, Lotta Lerwall (Disciplinary Domain of Humanities and Social Science)

PhD student Therese Fridström Montoya (until 30-06-2015)

PhD student Marie S  pulchre (from 01-07-2015)

Former Senior lecturer, Sonja Calais van Stokkom (The Swedish Disability Federation)

Director Research and Development, Mia Pless (Uppsala County Council)

Managing Director, Marie Palmgren (Municipalities in Uppsala County)

Agencies supporting CDR work/funding

Funding has been received for 2015 for the newsletter *Research om funktionshinder p  g  r* (Current Disability Research). The financiers are:

- Norrbacka-Eugenia Foundation SEK 162 000
- Sunnerdahl Handicap Fund Foundation SEK 162 000
- S  vstaholm Foundation SEK 96 000
- Swedish Council for Health, Working Life and Welfare (FORTE) SEK 250 000

Funding has been received for the Swedish Network for Disability Research from:

- Swedish Council for Health, Working Life and Welfare (FORTE) SEK 250 000

Research collaboration

On 27 November, a half-day was set aside for doctoral students at UU to look into how care/assistance receivers can take part in research. Two people with experience in this area were invited to give a lecture on the subject. They were from CASE – the Centre for Aging and Supportive Environments at Lund University. In addition to discussions about the topic, the half-day provided a meeting place for doctoral students from various scientific disciplines and subject areas.

On 28 June, the Swedish Disability Federation and the Centre for Disability Research at Uppsala University ran a seminar entitled *How can research policy set about disability issues?* The starting point was the new government research policy proposition planned for 2016. Those attending discussed the question of how disability issues can be given more space in research policy.

Public outreach

The Uppsala Network

The Uppsala Network is an e-mail network for individuals with either a personal or a professional interest in research on disabilities. Information reaching the CDR is forwarded to the network's ca. 470 recipients. Recipients include researchers, representatives of care and social caring operations, personnel, relatives of individuals with disabilities, civil servants in county, municipal, or state administration, and other interested parties.

Homepage

The CDR *homepage* (www.cff.uu.se) presents information about the Centre, board members, lecture and course programmes, *etc.* The newsletter *Research om funktionshinder pågår* (Current Disability Research) is available in PDF format. All issues from the start in 1992 are now available. The homepage is updated frequently and has many visitors.

Lectures

Each semester, CDR arranges a number of *lectures* for the purpose of disseminating information about on-going research and making it available to individuals both at Uppsala University and in the wider community. In 2015 eight lectures were arranged, and we have seen an increase in the number of people in the audience.

The newsletter *Forskning om funktionshinder pågår*

(Current Disability Research)

The launching of the newsletter was a way of meeting an expressed need from the Swedish disability organisations, who asked for easily accessible written information on current disability research. The newsletter is published by the CDR, Uppsala University. However, the content is not limited to research activities from Uppsala University but includes disability research from all over Sweden. As of a few years ago, the introduction of every article is written in easy-to-read Swedish. Every issue is available as a PDF document, to be found on the website of the Centre for Disability Research, Uppsala University. Those interested in a particular topic or looking for a special article can search all published issues on the website, using keywords (in Swedish). The current number of recipients is 4500, 2900 of whom subscribe to a printed version and 1600 subscribe to a PDF document distributed by e-mail. Many subscribers are workplaces, so there is reason to believe that the newsletter is made available to and is read by multiple individuals. The newsletter is also circulated widely. Hence, the newsletter is read by considerably more people than the subscribers. The audience is varied and includes, besides a significant number of disability researchers, national, regional and local governmental agencies, universities and university colleges, libraries, schools, non-governmental organisations, workplaces and individual employees in local government organisations, persons with a personal interest in the field, national newspapers and media, *etc.* Most recipients are Swedish, although there are also subscribers in the Scandinavian countries.

Centre for Research Ethics & Bioethics (CRB)

Director: Professor Mats G. Hansson

The Centre for Research Ethics & Bioethics (CRB) is a multi-disciplinary research environment with senior and junior staff from ethics, philosophy, medicine, nursing, economics, law and other fields. Our research questions arise in close collaboration with other researchers, scientists and clinicians. We investigate the ethical, philosophical and legal aspects of biomedical research and clinical practice and publish the results of our research in international peer-reviewed scientific journals and in books.

Roughly, our research profile can be divided in three: bioethics, clinical ethics and research ethics, with four profile areas that stand out: biobanks and registries, neuroethics and neurophilosophy, risk research and nursing and caring.

Bioethics is a multi-disciplinary endeavour. We reflect on issues in health care and science and our research provides updated knowledge for courses in neuroethics, bioethics and public health ethics.

Our research in *clinical ethics* looks at health care situations and the people in them. The research is carried out in close collaboration with health care professionals and provides updated knowledge for courses in medical and nursing ethics and training of medical doctor and nursing students.

Our *research ethics* research includes a focus on regulation studies and publication ethics. We run the Swedish Research Council's website with rules and guidelines for research. We run mandatory courses for PhD students in medicine, pharmacy, science and technology at Uppsala University. We also offer online research ethics training for medicine and the life science. We are also looking at legal issues, informed consent, privacy and incidental findings, particularly in association with biobanks and registry research.

Profile areas

Biobanks and registries

For many years, researchers at CRB have provided constructive advice on how to deal with ethical and legal aspects of research using human tissue material and personal data. What we do is sometimes referred to as ELSI-research, which stands for ethical, legal and social issues. We are looking at ethical frameworks and policy, regulatory aspects of biobank and registry research, informed consent, ethical review, integrity concerns, trust, genetic testing, incidental findings, commercialization, public and patient perceptions. We also look at some of the more specific issues that arise in connection with rare disease research, and biobank research involving children.

We collaborate with biomedical scientists and publish our findings in peer reviewed journals. We have looked at ethical frameworks and policy, regulatory aspects of biobank and registry research, issues relating to informed consent, ethical review, integrity concerns, trust, genetic testing, incidental findings, commercialization, public and patient perceptions, rare diseases and issues related to children, biobanks and genetics.

We are part of the BBMRI-ERIC ELSI common service and run ELSI services for the Swedish counterpart, BBMRI.se (Biobanking and Biomolecular Resources Research Infrastructure) where, among other things, we publish our newsletter Biobank Perspectives regularly and comment recent developments on the Ethics Blog. We are also involved in BiobankCloud, a 7th Framework project aiming to build the first open and viable platform-as-a-service (PaaS) for storage and analysis of digitized genomic data where CRB is part of a work package focusing on regulatory and ethical requirements for data storage and analysis. We are responsible for work packages within BT-Cure (Be The Cure), an IMI (Innovative Medicines Initiative) project with 33 partners from both academia and industry focusing on Rheumatoid arthritis (RA) and RA-like diseases and two 7th Framework projects: Euro-TEAM (aiming towards early diagnosis and biomarker validation in arthritis management) and RD-CONNECT (building an integrated platform connecting registries, biobanks and clinical bioinformatics for rare disease research).

We have also been part of a number of projects that are now completed: AutoCure, BBMRI-LPC and CCPRB for example.

Neuroethics & Neurophilosophy

Adequate applied research must be based on solid theory. We use a conceptual approach to neuroethics and neurophilosophy, focusing primarily on fundamental research questions concerning consciousness, human identity, and the self. Roughly, our research can be divided into fundamental neuro-

ethics/neurophilosophy (the ‘neuroscience of ethics’), and applied neuroethics/neurophilosophy (the ‘ethics of neuroscience’).

We are developing a theoretical framework for neuroethics to make analysis of practical issues fruitful. We are developing a theoretical framework for neuroethics to make analysis of practical issues fruitful. We examine the concepts that neuroscience uses and the impact that neuroscientific language and categories has on ethics and society

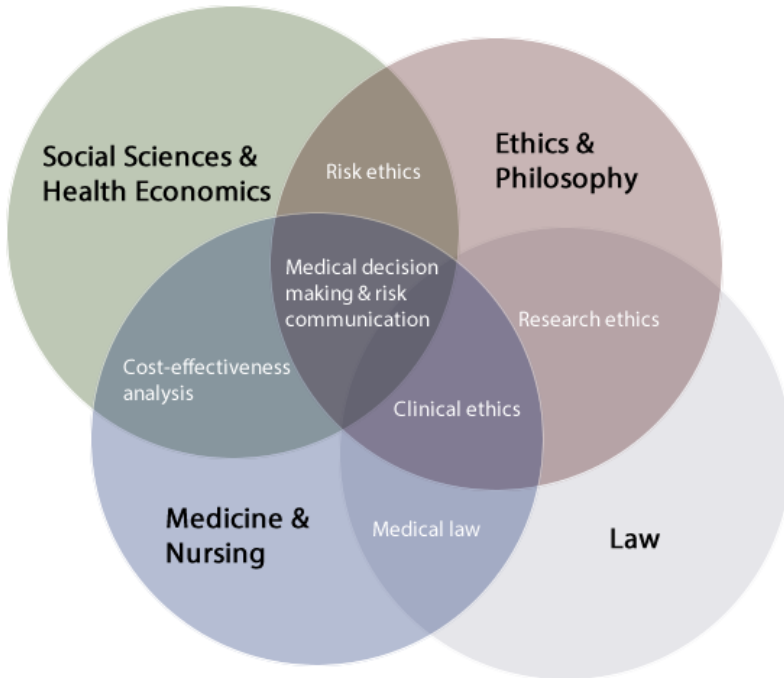
We investigate applications of neuroscience and ethical assessments of neuroscientific research. Current PhD projects look at how we can use neuroimaging and other methods to understand how the mind works in people who can’t use their behaviour to communicate and what it is like to be unconscious. We are also part of the European Community (FET) Flagship Human Brain Project where we look at the ethical and social questions that are raised when we model the human brain, for example by simulation.

The CRB neuroethics research team is an international, multi-disciplinary group. Our backgrounds allow us to approach these issues from theoretical, philosophical, social, bio-political and clinical perspectives. We collaborate closely with neuroscientists to understand the ethical and philosophical questions that neuroscience brings. We have long standing collaborations with Collège de France and the Pasteur Institute in Paris, and the Centro de Investigaciones Filosóficas (CIF) and the Institute of Cognitive Neurology (INECO) in Buenos Aires. We also work with Universidad Central de Chile, Coma Research Group in Liege, the Canada Research Chair of Mind, Brain Imaging and Neuroethics in Ottawa, the Neuroethics Group of the Pellegrino Center for Clinical Bioethics of the Georgetown University in Washington DC, the Bioethics Unit of the Italian National Institute of Health in Rome, the KTH Royal Institute of Technology in Stockholm and the Karolinska University Hospital in Stockholm.

Risk research

Risks are often difficult to interpret and communicating risk information is challenging. How people perceive risk depends on several factors, like their education and health literacy. Despite this, we have to take decisions based on risk information all the time. Lay people, patients, policy makers and health care professionals have to value risk information to decide whether or not to use certain medical treatments, preventive interventions or technology. So in the end, risks concern all of us and it is crucial that risks are communicated clearly to the entire population.

Our research is multi-disciplinary and we use methods from health economy, mainly discrete choice experiments (DCE), and best-worst scaling to capture the complexities of people’s preferences, adding different perspectives to our expertise on risk communication and medical decision making:



Currently, we are looking at the health related decisions that individuals make where they have to interpret difficult concepts and understand risk. This is hard, especially when probabilities become very small. Our research deals with the management of genetic risk information, whether researchers should disclose incidental findings in biobank research, arthritis risk communication, antibiotic resistance, cardiovascular risk communication in primary care, and people's preferences and perceptions when it comes to risk for heart and lung disease.

Nursing and caring

Nursing ethics is concerned with the moral dimensions of nursing practice while the ethics of care is a normative ethical theory. For many years CRB has developed these fields from different angles. We have used qualitative studies to describe and explore the kinds of ethical dilemmas nurses encounter in their day-to-day work and how they solve them. Other studies have investigated the role of ethical guidelines in the building of ethical competence in nursing practice and in priority setting.

The focus in nursing ethics research is on the relationship between the nurse and the person receiving care. A central question is what the nurse can do for the person in need of care and how a respectful meeting could take place, despite the asymmetry in the relationship between nurse and patient.

Nursing ethics focuses more on developing caring relationships than on broader ethical principles. The concept of ‘caring’ has priority over the concept of ‘curing’ and how a person should ‘be’ rather than how they should act is stressed. As a result, virtue ethics have often been elaborated within the framework of nursing ethics.

The concept of ‘care’ is often defined as a practice, but at the same time as a value and an ideal that can guide normative judgments and actions. This tradition is often contrasted with duty based (deontological) and consequentialist (utilitarian) ethics. It argues for embodied relations and emotions to be part of moral judgments.

Several PhD projects have looked at different aspects of care. Two theses were defended in 2015: One with a family perspective on palliative paediatric oncology and another on why parents participate in phase I and phase III clinical cancer trials. An ongoing project is looking at clinical and ethical perspectives on DNR (do-not-resuscitate) decisions in oncology and haematology care.

Centre staff 2015

CRB is a multi-disciplinary group. Here, 33 people from ethics, philosophy, law, economy, medicine, nursing, physiotherapy, social pharmacy, genetics, neuroscience and other fields come together.

During 2015, two PhD students defended their theses and moved on to other positions. Li Jalmzell continues her oncology training and Tove Godsken is now a lecturer at Gävle University. She is also an associated researcher at CRB. Omar Gutierrez Arénas, post-doc in the Neuroethics research team, left the group, as did Terry Flynn, Senior Researcher in Mind the Risk who contributed expertise on DCE’s and best-worst scaling, methods we use in several projects. To replace his competence, Jorien Veldwijk was recruited. She wrote her doctoral thesis on DCE’s and during 2016 will offer training for CRB staff in the use of this method.

Jessica Nilhén Fahlquist has leave of absence from the end of 2015. She is replaced by Elisabeth Furberg (recruited in 2015) and Karl Persson de Fine Licht (recruited in 2015, starting in February 2016).

List of staff (in alphabetical order):

Mirko Ancillotti, PhD student

Mirko Ancillotti joined CRB in September 2013 and started his PhD in February 2016. In 2014-2015 he worked on a research project on biology. He holds a degree of Master of Arts in Philosophy from the University of Pisa in 2012. His Master thesis regarded John Harris’ influence on contemporary

bioethical debate on cloning and enhancement. Mirko Ancillotti is also assistant editor of the CODEX website with rules and guidelines for research.

Stefan Eriksson, Senior Lecturer in Research Ethics

Stefan Eriksson also serves as editor of the Swedish Research Council's website CODEX. He is also an Associate Editor at BMC Medical Ethics. Stefan Eriksson is indexed and can be followed at Research Gate. He has over 90 publications listed, including 3 books, his H-index is 12 and his most prominent articles have been cited over 400 times (as calculated by Research Gate in November 2015).

Stefan Eriksson's research interests are autonomy and informed consent, the regulation of research, and publication ethics. In 2013 he published the first comprehensive monograph on publication ethics ("Publiceringsetik", Studentlitteratur) together with his colleague Gert Helgesson.

Stefan Eriksson is 2016 serving as expert in the public inquiry on how to investigate misconduct and also 2016-17 an ethics expert in the Swedish initiative for increased Swedish participation in SwafS.

Kathinka Evers, Professor of Philosophy

Kathinka Evers leads the CRB neuroethics research team. She is a co-director of the EU Flagship Human Brain Project. Her main research focus is neuroethics and the neural basis of consciousness and she teaches an advanced level course in neuroethics. Kathinka Evers conducted her doctoral studies in philosophy at Balliol College, University of Oxford, at the Research School of Social Sciences, Australian National University, Canberra, and at Lund University, Sweden, where she received her doctoral degree in 1991. She has been a research fellow at Balliol College, University of Oxford (1994); at the Department of Philosophy and Human Rights Centre, University of Essex, Colchester (1996-97); invited professor at the University of Tasmania, Hobart (1999), at École Normale Supérieure, Paris (2002), and at Collège de France, Paris (2006-7). For six years (1997-2002) she was the Executive Director for the Standing Committee on Responsibility and Ethics in Science (SCRES) of the International Council for Science (ICSU). She is also division leader for ethical and societal implications of the EU-flagship Human Brain Project. Kathinka Evers has recently been appointed Honorary Professor at Universidad Central de Chile.

Michele Farisco, PhD Student

Michele Farisco is part of CRB's neuroethics research team. He was recently appointed Associate Professor of Moral Philosophy in Italy. He holds a degree in Philosophy from University of Naples "L'Orientale" in 2003, a PhD in "Ethics and Anthropology: History and Foundation" from University of Lecce in 2008 and a Master degree in Biolaw from the University of Rome "Lumsa" in 2009. He spent time on an exchange grant from the European

Neuroscience and Society Network within the European Science Foundation joining the Coma Science Group of the University of Liège (Belgium). He is the head of the "Science and society" research unit of Biogem Genetic Research Centre in Ariano Irpino (Italy). He is the author of three books and several articles about posthuman philosophy and philosophical, ethical and legal implications (ELSI) of genetics and neuroscience.

Michele Farisco is currently working on his second PhD about the neuroscience of disorders of consciousness (from laboratory to clinics). He will study the ethical and legal issues emerging from neuroscientific investigation of Disorders of Consciousness and related technological applications. The project is a part of the European Union flagship Human Brain Project.

Josephine Fernow, Co-ordinator

Josephine Fernow has worked with research dissemination and communication for fifteen years. She co-ordinates activities and manages CRB's external and internal communications. Josephine Fernow holds a BA in Cultural Anthropology and Sociology, and has studied biomedical ethics, marketing and communications. She has organized several international multi-disciplinary conferences and was responsible for the first BBMRI HandsOn: Biobanks (an annual conference arranged by national BBMRI-nodes) in 2012 where she developed an interactive session where researchers and industry together help participants follow the route biobank samples take: from consent and collection through storage and analysis to outcomes in terms of ethics and trust, health economy, drug development, clinical practice.

Terry Flynn, Senior Researcher

Terry Flynn was Senior Researcher in Medical Decision Making at CRB between January and June 2015. He is a globally renowned expert in discrete choice modelling generally and the best-worst scaling technique specifically, co-authoring the definitive book (Cambridge University Press). His research interests include the treatment of risk in medical decision making, quality of life (particularly in older people and children), end-of-life decision making, valuing unpaid care and treatments in a variety of clinical areas.

He obtained his PhD in 2002 in the economics of cluster randomized controlled trials in Bristol, UK, and also worked in Sydney with the world experts in choice modelling for 5 years. His h-index is currently 25 and his citations are increasingly rapidly due to the innovative nature of his research streams.

Elisabeth Furberg, Deputy Senior Lecturer in Medical Ethics

Elisabeth Furberg is also lecturer in philosophy at the University of Gothenburg. Broadly, her research interests include applied philosophy and ethics, bioethics, personal identity, value theory and philosophy of meaning. Her PhD in Practical Philosophy at Stockholm University 2012 discussed the

moral legitimacy of advance directives and living wills, mainly in relation to theories of personal identity over time. One of her more recent research projects aimed to provide practical guidance in deciding how a publicly funded health care system ought to prioritise in health care.

In recent years Elisabeth Furberg has also initiated a national network for women in philosophy (SWIP-Sweden). The goal of this network is to improve gender parity in philosophy.

Tove Godskesen, Associated Researcher

Tove Godskesen received her PhD at CRB in August 2015. Her thesis is entitled *Patients in Clinical Cancer Trials: Understanding, Motivation and Hope*.

Currently, she is a Senior Lecturer in nursing at Gävle University College and associated researcher at CRB.

Omar Gutierrez Arenas, Postdoc

Omar Gutierrez Arenas was as part of CRB's neuroethics research team between January and December 2015. He is involved in the Human Brain Project. He holds a BSc in Biochemistry and an MSc in Enzymology from the University of Havana, Cuba. After obtaining a PhD in Uppsala University on modelling enzyme kinetics, he began a series of postdoctoral studies in different areas of Neuroscience. First at the University of Miami designing and implementing novel cell based assays and data analysis pipelines for high content analysis of CNS neurons in culture. This was followed by a postdoc at the Department of Computational Biology at the KTH Royal Institute for Technology where he is building models of intracellular signalling cascades in neurons. He is involved in the Human Brain Project's Initial Brain Models work package led by Jeanette Hellgren-Kotaleski and the Conceptual and Philosophical Issues work package led by Kathinka Evers from CRB.

Omar Gutierrez Arenas builds quantitative models for the dynamics of intracellular signalling cascades in CNS neurons and their effect on the electrical activity of these cells. As part of CRB, he works on a detailed dissection of how these and also other reticular representations of upper levels of organization in the brain (*e.g.* neuronal networks) map the target biological object, or what is currently known about it. Which known components are included/left out and why? How do these choices affect the explanatory capacity of the model and its iterative improvement?

Mats G. Hansson, Centre Director & Professor of Biomedical Ethics

Mats Hansson is the director of the Centre for Research Ethics & Bioethics and has conducted extensive research in biomedical ethics as principal investigator in several multi-disciplinary research projects dealing with issues ranging from ethical, social and legal aspects of the implementation of genetic diagnosis in clinical practice and the use of human tissue materials in

research, to clinical and medical ethics. He holds an undergraduate degree in biology (1974) and a doctoral degree of theology (1991). Mats Hansson is Professor of Biomedical Ethics, funded by Uppsala University and the Uppsala County Council together. He also works as a clinical consultant at Akademiska sjukhuset (Uppsala University Hospital).

Sara Holm, Researcher

Sara Holm joined CRB in August 2014. She is a physiotherapist and defended her thesis on children and adolescents with pain in primary care in May 2014. She is currently looking at the use of pretend play for children with cancer.

Heidi Carmen Howard, Senior Researcher

Heidi C. Howard received her undergraduate and doctoral degrees in Biology from McGill University (Montréal, Canada). The focus of her PhD was neurogenetics and it culminated in the cloning of the gene for Andermann Syndrome (ACCPN), a rare neuropathy primarily present in the founder population of Québec. She continued her genetics training in psychiatric genetics at the Centre for Genomic Regulation in Barcelona (Spain) and at the Douglas Hospital in Montréal (Canada).

With an Erasmus Mundus fellowship, she completed the Erasmus Mundus Master of Bioethics programme in 2008 and since then, with the support of the European Commission FP7 Marie Curie Career Development Awards (2009-2011; 2011-2013) she has been working on the ethical, legal and social issues (ELSI) related to genetics and genomics as well as biobanking at KULeuven (Belgium) and Inserm (France).

In the autumn of 2013 she spent a semester as assistant professor at the Radboud University Medical Centre (Netherlands). Her main areas of research are the ethical, legal and social aspects of direct-to-consumer genetic testing, public health genomics, genomic medicine, new genomic technologies, participant-centric research initiatives and the translation of genomics from the laboratory to the clinic.

Heidi Carmen Howard is also an invited scholar at the Centre of Genomics and Policy at McGill University (Montréal, Canada) and a member of the Public and Professional Policy Committee of the European Society of Human Genetics.

Anna T. Höglund, Senior Lecturer in Nursing Ethics and Gender Studies

Anna T. Höglund has worked extensively on the question of ethical competence for health care practitioners. Related research areas are moral distress in clinical settings and prioritization in health care. She has also published substantially on the topic of gender and ethics. She holds an undergraduate degree in Arts (1997) and a doctoral degree in Theology (2001) from Uppsala University. She became Associate Professor of Ethics in 2006.

Julia Inthorn, Associated Researcher

Julia Inthorn joined CRB in February 2014 as guest researcher from the Department of Medical Ethics and History of Medicine, University Medical Center Göttingen. Her stay was two months research fellowship funded by the German Academic Exchange Service (DAAD).

Julia Inthorn is part of Mind the Risk and an Associated Researcher at CRB. Her current research projects focus on genetic risk information and preconceptional genetic carrier screening. Her research interests are in the field of genetic testing and genetic screening, intercultural bioethics and empirical ethics. Julia Inthorn holds a master in Mathematics and a doctoral degree in Philosophy. She has also worked and published on ethical issues at the end of life, power and autonomy and biopolitics.

Ulrik Kihlbom, Senior Lecturer in Medical Ethics

Ulrik Kihlbom teaches ethics to medical students and is responsible for an advanced level course on public health ethics. His research interests cover bioethics in general, the methodology of applied ethics and metaethics. His PhD in Practical Philosophy at Stockholm University 2002 discussed the formulation and tenability of Ethical Particularism. Before joining CRB in 2009, Ulrik Kihlbom collaborated with us on clinical ethics in a project on monitoring and improving ethical and medical praxis in perinatal medicine. He has taught philosophy and medical ethics at Stockholm University and most recently at Örebro University where he was head of the Philosophy unit.

Moa Kindström Dahlin, Researcher

Moa Kindström Dahlin joined CRB in February 2015. She holds a LLD in public law from Stockholm University. Her thesis *Mental Health Law – Interests, Rights and Principles* (2014) is a critical analysis of the Swedish mental health law system from a rights-perspective.

As a legal scholar, Moa Kindström Dahlin has her basis in legal theory and emphasizes the interaction between law and other fields of knowledge. She has a particular interest in the relation between law and ethics, specifically questions regarding autonomy and integrity. She has written mostly on mental health law but focuses on public law generally and is specifically interested in human rights for vulnerable groups, e.g. people with decreased decision-making capacity; children, elderly people and persons with mental disabilities. Moa Kindström Dahlin is one of the researchers in the multidisciplinary project *Expertise, evidence and ethics in decisions regarding psychiatric compulsory treatment* at University of Gothenburg and Centre for Ethics, Law and Mental Health (CELAM).

At CRB she works with the BBMRI-ERIC ELSI Common Service and teaches medical law to students in nursing and medicine.

Sofia Lavén, PhD Student

Sofia Lavén joined CRB in September 2011 and started her PhD studies in January 2012. She is specialized in Family Medicine and works at Samariterhemmetts Vårdcentral in Uppsala. Sofia Lavén holds a degree in Medicine from Uppsala University (2000) and a license to practice (2002).

Sofia Lavén was on leave of absence part of 2015.

Anna-Sara Lind, Associate Professor of Public Law

Anna-Sara Lind joined CRB in September 2011 to work with the legal aspects of research conducted on human tissue samples within BBMRI.se and BBMRI-LPC. Anna-Sara Lind is Associate Professor of Public Law and Senior Lecturer at the Department of Law at Uppsala University and is tied part-time to CRB.

She is editor of our newsletter Biobank Perspectives: Current issues in ethics and law.

Deborah Mascalzoni, Senior Researcher

Deborah Mascalzoni joined CRB in April 2013. She holds a PhD in Bioethics from the Faculty of Law at Bologna University and has worked extensively on ELSI issues related to biobank and registry research, especially the population based CHRIS project at the Center of Biomedicine, European Academy (EURAC).

Deborah Mascalzoni has been teaching ethics at the 'Claudiana' University of Roma in Bolzano. She is a member of the Ethical board of South Tyrol and the local health system ethical board of Bolzano as well as the Telethon Advisory Board. She is involved in the WIKI platform of BBMRI.IT, a member of the BRIF project and a member of the ethical group of the International Genetic Epidemiological Society (IGES). Her main research interests are genetics and new technologies, informed consent, patient communication, privacy & data sharing and the role of stakeholders in medicine.

Currently, Deborah Mascalzoni is working on rare diseases in RD-Connect and rheumatoid arthritis within Euro-TEAM and Be the Cure. She is also involved in BBMRI.se.

Amal Matar, PhD Student

Amal Matar is a graduate of Ain Shams University Medical School in Cairo. She holds a Master of Science in Biotechnology from the American University in Cairo, and completed the Middle East Research Ethics Training Initiative Certificate Program in International Research Ethics at the University of Maryland in 2012.

In her PhD project Amal Matar is studying ethical issues concerning pre-conception genetic screening, as it raises general concerns of genetic testing

and counselling, and the handling of information and risk assessments. It also raises questions surrounding parental decision-making process and consent procedures, and concerns about screening programs. A central question to the project is how preconception genetic screening accentuates and influences parenthood and pregnancy.

Jessica Nihlén Fahlquist, Deputy Lecturer in Medical Ethics, Researcher

Jessica Nihlén Fahlquist research focuses on applied ethics, and she has a particular interest in notions of moral responsibility. She has published articles in public health ethics, risk ethics, the ethics of technology and environmental ethics. She received her PhD in Philosophy at the Division of Philosophy at the Royal Institute of Technology in Stockholm in 2008.

Jessica Nihlén Fahlquist is currently on leave of absence.

Mona Pettersson, PhD Student

Mona Pettersson started her PhD studies in September 2010. She is a registered nurse (1991), a teacher in health care for Upper Secondary School (2002) and holds a Master of Medical Science (2008). She works part time as lecturer in the Nursing Programme.

Arvid Puranen, PhD Student

Arvid Puranen's PhD work will investigate communication between patients and health professionals regarding the risk of cardiovascular and pulmonary disease. The project aims to increase the understanding of patients' preferences for risk communication, their perception of risk, and the effects of communicating risk. The project is collaboration between CRB and the Health Economics group (led by Sophie Langenskiöld) at the Department of Public Health and Caring Sciences. It is funded by the Swedish Heart-Lung Foundation and will focus on participants in SCAPIS (Swedish CardioPulmonary bioImage Study). Methodologically, the project will rely on discrete choice experiments, survey data, and qualitative work.

Arvid Puranen holds a Medical degree (Uppsala University, 2014), a license to practice (2015) as well a bachelor degree in Economics (Uppsala University, 2014) and a bachelor degree in Mathematics (Virginia Tech, 2007).

Jane Reichel, Professor of Administrative Law

Jane Reichel is a professor in Administrative Law at the Faculty of Law at Uppsala University and is since 2011 tied part-time to CRB. She is currently vice dean and chairman of the research committee at the Faculty of Law.

Jane Reichel's research focuses on the ongoing processes of globalization and Europeanization and its effect on administrative law, the legal discipline dealing with public authorities and their role in the society as well as their

relations with individuals. Administrative matters can no longer be addressed solely within one nation state at the time. In her research Jane addresses how this development affects the role of authorities and how administrative rules are to be applied in an international context. How can administrative ideals of efficiency, transparency and legal certainty in decision-making be achieved? How can command and control over administration function in a network of agencies acting beyond the state? An area of specific interest is cross-border data protection, especially medical research and biobanks. The ability of new technology to collect, store and share large amounts of information gives rise to opportunities and challenges, which necessitates administrative solutions that apply across borders.

Lena Ring, Adjunct Professor in Quality of Life Research in Health Care
Lena Ring became Adjunct Professor in 2013. Her research focus is on Patient Reported Outcomes (PRO) studies, *e.g.*, Quality of Life at the Medical Products Agency (MPA). She has worked extensively on incorporation the patient perspectives into outcomes assessments in relation to the evaluation of treatment and care of patients. Specific research areas are Quality of life Assessments in clinical oncology practice and patient-provider communication. She has also published substantially on the topic of patient reported outcomes, such as quality of life assessments both quantitative and qualitative studies. She holds an undergraduate Master's degree in Pharmacy (1993) and a doctoral degree in Pharmaceutical Services Research (1999) from Uppsala University. She did her post-doc as a Marie Curie Fellow at the Department of Psychology at Royal College of Surgeons in Ireland (2002-2004). She became Associate Professor of Pharmaceutical Outcomes Research in 2007.

Pär Segerdahl, Associate Professor of Philosophy
Pär Segerdahl investigates notions of nature and animal in animal ethics, animal welfare and philosophy, as well as in contemporary culture more generally. He holds a PhD in theoretical philosophy from Uppsala University (1993). He was a guest researcher at the Centre for Gender Research at Uppsala University from 2007-2009, and since 2013 he works part time there in the project "Becoming 'human': gender theory and animals in a more-than-human world". Pär Segerdahl became associate professor of theoretical philosophy at Åbo Akademi Univeristy in 1998 and Uppsala University in 2001. He currently develops new ideas for research on how our ethical outlook changes when the world changes, for example, when new biotechnology emerges. All his work concerns, in one way or another, the question what philosophy is and what it means to philosophize. Pär Segerdahl is involved in research communication for the BBMRI.se (Biobanking and Biomolecular Resources Research Infrastructure Sweden) and editor of The Ethics Blog and Etikbloggen. He is also a member of The Nordic Wittgenstein Society.

Arleen Salles, Associated Researcher

Arleen Salles is Director of the Neuroethics Programme at CIF (Centro de Investigaciones Filosóficas) and associated to CRB. She is part of our Neuroethics research team and involved in the Human Brain Project's ethics and society research. Her ongoing research focuses upon human identity and the impact that some neuroscientific findings could have on what it means to be human and on what typical human traits are; the neuroscience of moral decision-making, and privacy issues raised by neuro-imaging.

Karl Sallin, PhD Student

Karl Sallin is part of CRB's neuroethics research team. He is a paediatric resident at Astrid Lindgren Children's Hospital, Karolinska University Hospital. He is on the hospital's Ethics committee and a member of the Swedish Society of Medicine's Ethics committee. Karl Sallin holds a degree in Philosophy from the University of Cambridge where his main foci were on the philosophy of mind, language and mathematics. In his clinical work Karl Sallin has been involved with children suffering from Resignation Syndrome (RS). RS is a severe condition in asylum-seeking refugee adolescents most notably resulting in a seemingly unconscious state.

Karl Sallin's PhD project is part of the European Flagship Human Brain Project.

Anna Lydia Svalastog, Associated Researcher

Anna Lydia Svalastog has worked primarily on questions about cultural heritage and religion. She has conducted extensive studies on how images structure personal life and wrote her PhD thesis on reproduction and heterosexuality. Post doc projects have analysed how medical ethics structures risk handling procedures for plant science, and how research history and national politics have structured academic teaching and academic theories about Sámi people's history and culture. Anna Lydia Svalastog holds a doctoral degree in Theology, History of Religion from Uppsala University (1998), and became Associate Professor in religious studies at Umeå University (2005).

Anna Lydia Svalastog is currently looking at bioethical concerns regarding native people, and at the relation between public debate, cultural history and myths, and public opinion. She is a member of the research network Bio-objects and their boundaries, governing matters at the intersection of society, politics and science, and UppSam. She co-ordinates the research network Culture Health and Bioethics, and the ad hoc group Riekkis.

Anna Lydia Svalastog is a full Professor of Social Work at the Østfold University College in Norway.

Jorien Veldwijk, Researcher

Jorien Veldwijk joined CRB in October 2015. She holds a Masters' degree in Public Health as well as in Clinical Epidemiology. Before starting her PhD she worked as a researcher at the Dutch National Institute for Public Health and the Environment. During that time she was involved in several research projects regarding the consequences of overweight among children, partly in collaboration with the World Health Organization. During her PhD she used Discrete Choice Experiments (DCEs) to determine individuals' preferences and their decision-making behaviour regarding public health initiatives. She obtained her PhD in May 2015 and was appointed assistant professor at the University Medical Center Utrecht where her research continued to be focused on behavioural economics. Currently she continues working in the same research field using DCEs both at CRB and as a Senior Researcher at the Dutch National Institute for Public Health and the Environment.

Linnea Wickström Östervall, Researcher

Linnea Wickström Östervall joined CRB in December 2014. She is an Economist, and received her PhD from Stockholm University in September 2014. Her thesis deals with antibiotics use. Effective antibiotics are a finite common resource. Institutions, such as welfare benefits, preferences, altruism or time preferences, as well as limited attention or ignorance may matter to the possibility to curb overexploitation of effective antibiotics. In her theses, she studied antibiotics use from these perspectives in a field experiment and on register data, exploiting a natural experiment.

Her current research is focused on health inequality and preferences for informational privacy.

Jennifer Viberg, PhD Student

Jennifer Viberg is interested in different methods to investigate peoples stated preferences, especially how to balance peoples preferences against other ethical values. Her PhD project is looking at the ethical issues concerning disclosure of incidental (or secondary) findings to research participants in genetic research. Disclosure of health related information such as blood pressure, lung function, cholesterol and blood sugar is uncontroversial and common practice, but there is debate in the biobank community on whether or not to disclose genetic risk information, and especially incidental findings.

Jennifer Viberg's first two studies have a theoretical perspective on the arguments for and against disclosure, and whether offering participants to express their preferences would solve the issue. She is currently conducting empirical studies using both qualitative and quantitative methods to capture participants' preferences when it comes to genetic risk information, for example using Discrete Choice Experiments to calculate participant's trade-offs between different features of genetic risk information and to see if there are any differences between groups.

Jennifer Viberg holds an MA in Rehabilitation Science from Mid Sweden University. She is a licensed Prosthetist and Orthotist. Before starting her PhD, she was teaching at Jönköping University. She is currently involved in the IMI-funded BT-Cure project on Rheumatoid Arthritis, Mind the Risk and BBMRI.se.

Visiting scholars 2015

Louiza Kalokairinou is a PhD Fellow of the Research Foundation Flanders (FWO) at the Centre for Biomedical Ethics and Law at KU Leuven.

She holds an LLM in Intellectual Property Law and an Erasmus Mundus Master of Bioethics. Her research interests revolve around ethical, legal and social aspects of genetics and genomics and the patentability of biotechnological inventions.

Her PhD project on the ethical and legal aspects of Direct-to-Consumer Genetic Testing is supervised by Pascal Borry at KU Leuven and Heidi C. Howard at CRB. She is visiting CRB between May and June 2015.

Álvaro Mendes is a post-doc fellow at i3S - Institute for Health Research and Innovation, CGPP, University of Porto, Portugal. He holds a PhD in Health Sciences and Technology and a degree in clinical psychology. His research interests are in the field of genetic counselling and on the ethical and social aspects of genomics. His current research addresses the communication of genetic risk information within families. He visited CRB in November and December 2015 in the scope of a Short-Term Scientific Mission of the CHIPME COST Action (IS1303).

Publications 2013-2015

A characteristic feature of our inter-disciplinarity is that we publish both in scientific journals, often together with researchers from other disciplines, and in monographs. The monograph format is customary in philosophy and humanities and it allows for more in depth analysis of conceptual issues. In fact only publishing in shorter articles would be a little irregular from the perspective of philosophers. Our monographs are often published in established series and always scrutinized in a peer review.

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Basic funding and agencies that support research

CRB is an inter-faculty centre with basic funding from all disciplinary domains (Medicine and Pharmacy: 1.500.000; Science and Technology: 1.879.544; Humanities and Social Sciences: 306.007 SEK). The mandatory courses we offer for PhD Students is funded by the disciplinary domains (Medicine and Pharmacy: 140.000; Science and Technology: 160.000 SEK). Two researchers receive research funding for Caring Sciences from the Faculty of Medicine: Sara Holm 100.000; Anna T. Höglund: 200.000 SEK). We also have a connection to the Uppsala County Council, who pays 50 % of Mats G. Hansson's salary (772.335 SEK). One of our PhD Students (Sofia Lavén) is wholly paid by the County Council (salary not part of our budget). In total, this **basic funding amounts to 5.400.886 SEK**.

External funding 2015 (100.000 SEK and above):

The Swedish Research Council (Vetenskapsrådet)	3 678 000
<i>CODEX (website for rules and guidelines for research)</i>	500 000
<i>BBMRI.se</i>	2 968 000
<i>Health inequality: advancing measurement, explanation, and policy process</i>	210 000
European Union	4 450 000
<i>BBMRI-ERIC</i>	1 570 000
<i>The Human Brain Project</i>	1 100 000
<i>B3Africa</i>	638 000
<i>RD-Connect</i>	1 142 000
The Swedish Foundation for Humanities and Social Science (Riksbankens Jubileumsfond)	1 881 000
<i>Mind the Risk</i>	1 541 000
<i>Epigenetics as the Meeting Point Between Nature and Nurture (workshop)</i>	340 000
AFA Insurance	244 000
<i>Improving the ethical climate in psychiatry outpatient clinics</i>	244 000
The Swedish Agency for Health and Care Services Analysis (Vårdanalys)	1 000 000
<i>When is it worth it? – Informational privacy in health care and research</i>	1 000 000
The Swedish Cancer Society (Cancerfonden)	500 000
<i>Quality of life assessments in clinical practice</i>	500 000
Total 2015	11 753 000

Ongoing research

We are part of several European projects, for example the Flagship Human Brain Project. We are also part of several 7th framework projects dealing with biobank and registry research. We are running a six year international network collaboration funded by the Swedish Foundation for Humanities and Social Sciences (Riksbankens Jubileumsfond):

1. BBMRI.se: Biobanking and molecular resource infrastructure of Sweden
2. BBMRI-ERIC: Biobanking and BioMolecular resources research infrastructure

3. BBMRI-LPC: Large prospective cohorts
4. Be The Cure: (BT Cure) for Rheumatoid Arthritis
5. B3Africa: Bridging Biobanking and Biomedical Research across Europe and Africa
6. CHIP ME (Citizen health through public private initiatives)
7. Euro-TEAM: Towards Early diagnosis and biomarker validation in Arthritis Management
8. Health inequality: advancing measurement, explanation, and policy process
9. Human Brain Project
10. Mind the Risk: Managing genetic risk information
11. Pretend play
12. Publication ethics
13. Quality of life assessments
14. RD-Connect
15. Research regulation
16. Self management of hypertension

PhD projects: The PhD students at CRB have come from a variety of backgrounds: Medicine, nursing, philosophy, health economy, biology and political science. We offer a multi-disciplinary research environment and make sure students have a group of supervisors to help them develop their projects. In 2015, two PhD students defended their theses: Tove Godskesen (August) and Li Jalmzell (September). Two new PhD students were recruited: Arvid Puranen who will look at cardiopulmonary risk communication and Mirko Ancillotti, who will look at ethical aspects of antibiotic resistance. Jennifer Viberg defended her half-time report in September 2015.

17. Cardiovascular risk communication in primary care
18. Cardiopulmonary risk communication: participants understanding and preferences
19. The neuroscience of disorders of consciousness: from laboratory to clinic
20. DNR decisions within oncology and haematology care. Clinical and ethical perspectives
21. Ethical and public health considerations of conventional and peptide-based antibiotics
22. Ethical issues in preconception genetic screening
23. How should incidental findings in biobank research and genome sequencing studies be handled?
24. What is it like to be unconscious? Perspectives from Philosophy and Neuroscience with special regards to Resignation Syndrome
25. Factors associated with participation in phase 1 and phase 3 oncology trials

26. Paediatric palliative oncology in a family perspective

R&D projects/investigations: The Swedish Agency for Health and Care Services Analysis (Vårdanalys) has commissioned work to explore preferences on informational privacy in health care and register data among the general public as well as for groups of patients with prolonged illness:

27. Informational privacy in health care and research

Project descriptions

BBMRI.se: Biobanking and molecular resource infrastructure of Sweden

BBMRI.se is a national effort for efficient and automated collection of biological material funded by the Swedish Research Council (Vetenskapsrådet).

There are a number of ethical and legal aspects of research conducted on human tissue samples that need to be addressed in a professional and constructive manner. The proposed new act on biobanks, existing laws on personal data and public access to information and secrecy, exert an influence on what can and can't be done with biobanks and data. A major obstacle for researchers is that laws in part overlap, but provide slightly different answers to some questions and fail to address certain aspects of research activities. This poses major challenges for the scientific community in their strife to produce knowledge that can benefit patients

CRB's role in BBMRI.se - ELSI service: Our commitment in BBMRI.se includes providing ELSI service to the research community. We are part of a larger network of people with expertise in different legal and ethical fields.

ELSI Services include:

- Advice on specific ethical issues for researchers, for example how to interpret Swedish legislation on data protection or ethical review in relation to specific projects.
- Investigations of ethical and legal issues associated with biobank and registry-based research. The results are published in reports and peer-reviewed publications.
- Dissemination of research in bioethics and law to the research community through our Biobank Perspectives newsletter and the Ethics Blog.
- Training on ELSI issues and research ethics.
- Participation in research projects where we can assume responsibility for ELSI work packages and part of an integrated approach.

- Providing preparatory material to help guide universities, research consortia and research funders in their dialogue with governmental agencies on referrals or policy documents.
- Exchange of information and discussion with policy makers and the public, for example through the Ethics Blog (available both in English and Swedish).

Large projects involving international partners often require help from European nodes, where national laws are covered by national experts. We are building a network for this within the BBMRI-ERIC ELSI common service, a so called “help desk for ethics check”.

We handle Swedish projects within BBMRI.se. We prefer to get involved early on to be able to predict the ethical and legal issues that could arise. The best option is for us to handle a separate ELSI work package, but in smaller projects an integrated approach is sometimes better.

Collaborators:

- Mats G. Hansson, Professor of biomedical ethics
- Jane Reichel, Professor of Administrative Law
- Anna-Sara Lind, Associate Professor of Public Law
- Pär Segerdahl, Associate professor of theoretical philosophy
- Jennifer Viberg, PhD Student

BBMRI-ERIC: Biobanking and BioMolecular resources research infrastructure

BBMRI-ERIC is a European Research Infrastructure Consortium, or 'ERIC', for biobanking. Part of this work is providing a common service for the ethical, legal and societal issues.

BBMRI-ERIC is a joint European platform for biobanking that will provide a workable research infrastructure to process, share and store human biological samples, including associated medical data.

One of the biggest hurdles for biobank research today is the differences in regulatory frameworks for biobanking within the EU.

This ELSI service facilitates and supports cross-border exchanges of human biological resources and data attached for research uses, collaborations and sharing of knowledge, experiences and best practices.

The CRB team consists of:

- Mats G. Hansson, Professor of biomedical ethics
- Heidi C. Howard, PhD Neurogenetics
- Moa Kindström Dahlin, LL.D public law

The service is directed by Anne Cambon Thomsen at the French national centre for scientific research (CNRS) and co-directed by Mats G. Hansson at CRB, Marialuisa Lavitrano from the Milano-Bicocca University and Jasper Adriaan Bovenberg, founder of the Legal Pathways Institute.

BBMRI-LPC: Large prospective cohorts

This project has received funding from the European Union's Seventh Framework Programme for research; technological development and demonstration under grant agreement no 313010. BBMRI-LPC is coordinated by Markus Perola at Helsinki University.

Large prospective cohort (LPC) studies are considered the most reliable study design to elucidate causes of human disease, as the design minimizes several major sources of errors in etiological studies and is the only study design that can follow how genes and environment interact over time in the development of human diseases.

The need for collaboration, harmonization and, where possible, standardization becomes vital when the “omics” field is moving to using the LPC-based study design. Sufficiently large study sets of this type can only be achieved by close collaboration between the different large population cohorts in Europe and elsewhere. The project will build a network connecting the established large-scale biobanks to new European biobank initiatives, connecting to relevant European and International organizations.

CRB's role in BBMRI-LPC: We are engaged in the work package providing solutions facilitating fair, transnational access to samples and data to researchers in sorting out the ethical and legal issues regarding transnational access to samples and data.

The CRB team consists of:

- Mats G. Hansson, Professor of Biomedical Ethics
- Anna-Sara Lind, Associate Professor of Public Law
- Jane Reichel, Professor of Administrative Law
- Jennifer Viberg, BSc, MA, PhD Student

Be The Cure: (BT Cure) for Rheumatoid Arthritis

BT-Cure has received funding from the IMI call on Inflammation – Translational Research and Adaptive Immunity. The project has 33 partners. It is co-ordinated by Professor Lars Klareskog, Karolinska Institutet and Professor Tom Huizinga, Leiden University Medical Centre.

BT-Cure (Be The Cure) focuses on Rheumatoid arthritis (RA) and RA-like diseases. The development of new therapeutic agents against Rheumatoid arthritis (RA) and RA-like diseases requires a dynamic interaction between studies in humans and in animal models of disease.

BT-Cure aims to advance this parallel work and bring it to a new level by recognising (1) the need for recognition of pre-symptomatic and emerging disease in humans; (2) the heterogeneous nature of human RA and RA-like diseases; (3) the need for new alignments between several animal models and the variants of human RA and RA-like disease and (4) the potentials that an increased understanding of adaptive immunity provides for better prevention, therapy and eventual cure of RA.

With these tools at hand, we will be able to use new understanding of aetiology and early pathology of human disease for a program aimed at early and curative treatment of human RA and RA-like diseases.

CRB's role in BT-Cure: We are part of a subproject on ethics in the work package (WP5) on ethical issues and dissemination, led by Professor Steffen Gay, University Hospital Zürich. The ethics subproject will address ethical aspects of the project and foster patient participation.

The PhD project "How should incidental findings in biobank research and genome sequencing studies be handled?" is a part of CRB's work package.

The CRB team consists of:

- Mats G. Hansson, Professor of Biomedical Ethics
- Deborah Mascalonzi, PhD Bioethics, Senior researcher
- Jennifer Viberg, PhD student

BioBankCloud - Scalable, Secure Storage of Biobank Data (STREP)

This project ran between 2012-2015 and has received funding from the European Union's Seventh Framework Programme for research; technological development and demonstration under grant agreement no 317871. It is coordinated by Dr. Jim Dowling (jdowling@kth.se) KTH – Royal Institute of Technology, Sweden

The price for sequencing human genomic data has reduced significantly. Since 2004, the cost has halved every 4 months. There are massive amounts of data approaching and the storage, analysis and interconnection of data has now become the bottleneck in biobank research.

The scale of the storage requirements needed for genomic information is huge – a single human genome requires analysis of three billion base pairs. The analysis requires both a massive parallel computing infrastructure and

data-intensive computing tools and services to perform analyses in reasonable time.

BibankCloud aims to build the first open and viable platform-as-a-service (PaaS) for storage and analysis of digitized genomic data. The project will provide solutions to the problems of secure storage and efficient analysis of massive amounts of biomedical data and also make inter-connection of biobanks possible.

The BiobankCloud PaaS framework will be designed to run primarily on private cloud platforms. It will be built on open-source projects for big data and provide added features to those projects. The platform will be designed in cooperation with BBMRI.eu.

Ethical issues: CRB's role in the Biobank Cloud: CRB is part of a work package on Regulatory and ethical requirements for data storage and analysis run by Jan-Eric Litton at Karolinska Institutet. Together, we will provide a framework of legal and ethical regulations that enable the BiobankCloud to operate under controlled conditions. This framework will consider the different levels of legal protection in the EU member states.

- Create guidelines for personal data protection
- Design an informatics model for personal data protection
- Design a flexible mechanism for adoption changes in legislation
- Define a legal framework for collaboration with industry
- Design an object model for biobank data sharing
- See if it is possible to develop a user friendly "Disclosure Filter" designed to ensure that connecting the biobanks satisfies data subject requirements and restrictions on EU, national, and institutional levels

Building the PaaS framework: To build the first open platform-as-a-service (PaaS) for Biobanking, and inter-disciplinary team has been assembled, with competencies in different fields of research. The group has:

- Biobanking expertise from Karolinska Institutet and Charité University Hospital
- Bioinformatics expertise from Humboldt University
- Systems and security expertise from KTH Royal Institute of Technology and the University of Lisbon.

The CRB team consists of:

- Mats G. Hansson, Professor of Biomedical Ethics
- Jane Reichel, Professor of Administrative Law

B3Africa: Bridging Biobanking and Biomedical Research across Europe and Africa

This project has received funding from the European Union's Horizon 2020 programme. It is a CSA Action to bridge European and African biobanking and biomedical research.

B3Africa is a partnership with two strategic aims: One is to create a harmonised ethical and legal framework between European and African partner institution. The second is to provide an "out-of-the-box" informatics solution for data management, processing and sharing that works with limited Internet access.

B3Africa is co-ordinated by the Swedish University of Agricultural Sciences. Partners include BBMRI-ERIC, Karolinska Institutet, Uppsala University, and University of the Western Cape, Makerere University, Stellenbosch University, and International Agency for Research on Cancer, International Live Stock Research Institute, Medizinische Universität Graz and the Institute of Human Virology Nigeria.

CRB's Role in B3Africa: Work package 1, led by Jane Reichel, is tasked with drafting the ethical and legal framework. The framework is built on two pillars; the first sets out common ethical and legal threshold rules for all partners to abide by in order to use the informatics solution, based on the informed consent and ethical approval. This part will build on previous work conducted within European and international research collaborations, for example BBMRI-ERIC, H3Africa and Global Alliance for Genomics and Health. The second pillar focuses on cross-border sharing of data and samples, where Council of Europe and EU law requirements for transfer of data and sample will play an important role.

The CRB team consists of:

- Jane Reichel, Professor of Administrative Law is leading the ethical and legal work.
- Deborah Mascalonzi, PhD Bioethics, Senior Researcher.

CHIP ME (Citizen health through public private initiatives)

CHIP ME is a COST Action (number IS1303). COST is supported by the EU RTS Framework Programme, the Council of European Union and ESF.

We are part of CHIP ME, a community of researchers and stakeholders to promote public-private initiatives in public health genomics.

Chip me has three working groups: Research & Ethics, Genomics & Markets, and Science & Values.

Dr Heike Felzmann from the National University of Ireland Galway is action chair of CHIP ME, with Professor Pascal Borry from KU Leuven as Action vice Chair.

The CRB team consists of:

- Heidi C. Howard, PhD Neurogenetics, Senior Researcher
- Deborah Mascalzoni, PhD Bioethics, Senior Researcher

Euro-TEAM: Towards Early diagnosis and biomarker validation in Arthritis Management

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement FP7-HEALTH-F2-2012-305549.

Euro-TEAM is coordinated by Christopher Buckley at the University of Birmingham. Uppsala University with Mats Hansson and the CRB team working with ethical and legal issues associated with biobank and registry research is partner of EURO-TEAM and will work with issues related to risk communication.

Euro-TEAM aims towards early diagnosis and biomarker validation in arthritis management. An ideal intervention in a chronic inflammatory disease such as Rheumatoid Arthritis (RA) would be a preventive one.

In order to develop preventive strategies and therapies two key developments need to occur: (1) Biomarkers need to be identified that can be used to predict an individual's risk of developing RA. (2) Modifiable disease mechanisms need to be identified and characterized in the early phases of disease.

The key objective of the TEAM consortium is to specifically identify diagnostic biomarkers and disease mechanisms operating during the transition from health to rheumatoid arthritis. The consortium will achieve this by developing a collaborative, integrated programme of work that links researchers with key SMEs involved in biomarker development to produce a "personalized predictive bioprofile" for patients destined to develop RA.

A separate work package will address issues on risk communication, with these objectives:

- To understand the current perspective of individuals in different pre-RA phases about: (1) RA; (2) the meaning and perception of "risk" and "risk assessment"; (3) the utility of predictive tests in the context of RA; (4) their willingness to undergo predictive tests for RA.
- To develop strategies and tools for communication with and education of individuals in different pre-RA phases about: (1) the different stages of RA and the prognosis of RA; (2) the role of interacting biomarkers in prediction of the development of RA; (3) how lifestyle and behaviour

factors affect the risk of developing RA and how these can / should be modulated.

- To assess the impact of these communication and education strategies on an individual's willingness to undergo predictive tests and their subsequent behaviour.
- To disseminate information from this project to relevant stakeholders.

The CRB team consists of:

- Mats G. Hansson, Professor of Biomedical Ethics
- Deborah Mascalconi, PhD Bioethics, Senior Researcher

Health inequality: advancing measurement, explanation, and policy process

This project is funded by the Swedish Research Council (Vetenskapsrådet) between 2015-2018. Project PI is Ulf Gerdtham, Professor of Health Economics at Lund University School of Economics.

Health inequality persist in Sweden and other countries, and in particular the major knowledge gaps concerning measurement of and the causal driving forces behind health inequality as well as impact of public policy on health inequality. These gaps represent barriers that prevent decision-makers to design cost-effective policy actions to mitigate the persistent health inequality.

This project will uncover knowledge gaps and push forward the research front on health inequality. It will also indicate what is achievable in terms of reduced inequality if appropriate policies were adopted and through what type of actions. Our vision is that this project will result in a major breakthrough in the analysis of health inequality that has puzzled researchers and decision-makers for decades.

The overall aim of the project is to establish an interdisciplinary research program on social-related health inequality. The breadth and depth of the project will enable identification and quantification of the driving forces on the health inequality and advance the analysis of cost-effectiveness of targeted policy.

CRB's role in the project: Linnéa Wickström Östervall is involved in an experimental sub-project on exercise, commitment contracts, socioeconomic factors, time preferences and self-control. The aim is to analyse the role of individuals' health-related behaviour on health inequality.

While much research focuses on inequality in health outcomes, inequality in risk factors and health behaviour is also important. A promising new way to affect health behaviour, related to behavioural economics, is to use what is known as "nudges". The idea behind nudging is that better knowledge about people's judgments and decision-making allows for tailored adaptations –

small changes – in the decision situation, thereby making it easier for people to make choices consistent with their long-term goals of *e.g.* exercising regularly, or more frequently, to become fit and healthy. In this sub-project we will design and perform a field experiment on creating long-lasting exercise habits, testing various nudges.

- Linnea Wickström Östervall, PhD, Health Economics
- Ulf Gerdtham, Professor of Health Economics, Lund University School of Economics and Management
- Erik Wengström, Associate Professor, Lund University School of Economics and Management

Human Brain Project

The Human Brain Project (HBP) is a European Community Flagship Project of Information and Computing Technologies (ICT) within the framework of the Future Emerging Technologies (FET) vision. It is coordinated from École polytechnique fédérale de Lausanne (EPFL), Switzerland.

The project engages over 100 research groups in and outside Europe. It is organized around three complementary research areas:

- Future Neuroscience
- Future Medicine and
- Future Computing

The project will develop six ICT platforms. These are dedicated respectively to *Brain Simulation, High Performance Computing, Neuroinformatics, Medical Informatics, Neuromorphic Computing* and *Neurorobotics*.

Aims of the Human Brain Project: Simulating the human brain is a huge computational challenge, and the first goal of HBP is to build an integrated system of the six ICT-based research platforms, providing neuroscientists, medical researchers and technology developers with access to highly innovative tools and services that can radically accelerate the pace of their research. Expected outcomes include simulations of the brain that reveal the chains of events leading from genes to cognition; simulations of diseases and the effects of drugs; early diagnoses and personalised treatments; and a computing paradigm that captures the brain's cognitive capabilities. Overall, the HBP aims to reach an *integrated* understanding of the brain.

CRB in the Human Brain Project: Ethics and Society: CRB is part of HBP through Professor Kathinka Evers who leads the philosophical research within the HBP. She is director of the Subproject 12, "Ethics & Society", and a member of the HBP's Internal Advisory Board.

Visit the HBP website

Two PhD projects are also part of HBP: The neuroscience of disorders of consciousness: from laboratory to clinics (PhD Student: Michele Farisco)

and "What is it like to be unconscious? Perspectives from Philosophy and Neuroscience with special regards to Resignation Syndrome" (PhD Student: Karl Sallin).

Mind the Risk: Managing genetic risk information

Mind the Risk is a six year international network collaboration with scientists and researchers from Uppsala, Birmingham, Göttingen, Manchester, Milano and Stockholm funded by Riksbankens Jubileumsfond (The Swedish Foundation for Humanities and Social Sciences). Mind the Risk is coordinated by the Centre for Research Ethics & Bioethics (CRB) at Uppsala University.

Biomedical research is constantly finding new ways to detect genetic variation and link the findings to diseases and to the effects of various drug treatments. The amount of information that it produces keeps increasing, but we are still not sure how to manage it.

There are pressing ethical concerns and a need to improve clinical practice. Mind the Risk is an international, multi-disciplinary research project that runs over six years. Together, we will provide philosophical and conceptual framework that together with historical and socio-cultural analyses of concerns about risk information, empirical investigations of risk perceptions and preferences and ethical analyses may guide regulation and management of genetic and related risk information in various settings.

We are working to

- Develop a conceptual framework for genetic risk information and management.
- Assess perceptions and evaluations of genetic risks in different stakeholder groups
- Assess the ethical, psychological and social implications of the provision of risk information from genetic and related technologies.
- Explore new forms of communication and information, and develop tools to improve communication skills regarding genetic risk information.

Today major efforts are made concerning genetic information technology. The aim is to reach a better clinical application of the results and to provide the foundation for a deeper ethical analysis.

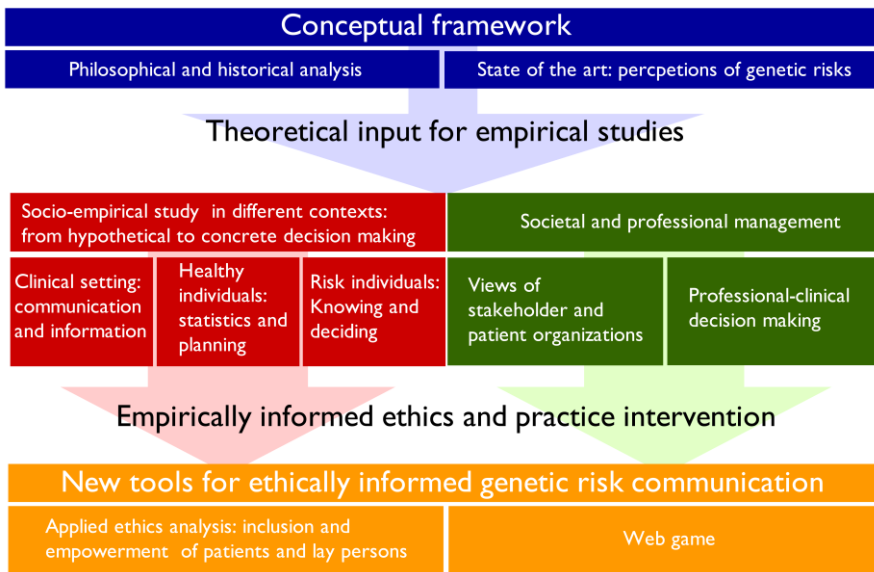
We are approaching the problem from philosophy, psychology, medicine, and health economics and will also include empirical studies of risk research. The goal is to support health care, patients and policy makers in their evaluation and handling of genetic risk information.

The project has allowed for a more in-depth discussion about questions surrounding uncertainty and how this relates to genetic risk. Discussions

revolve around understanding how different disciplines consider the relationship between these concepts and how this understanding impacts the use of the terms.

The multidisciplinary nature of the project has also raised the issue of the utility and impact of theoretical papers versus empirical papers (and for the latter, qualitative versus quantitative) to help shape our discussion on risk. Obviously, we do not want or expect one answer to this issue, but remain vigilant regarding these (perceived and real) divides in order to ensure that they do not block progress.

How we work:



Each of the seven partners has one lead principal investigator responsible for the research tasks of that group:

Uppsala University: Centre for Research and Ethics and Bioethics (CRB)

- **Mats G. Hansson** is Professor of Biomedical Ethics and Director of CRB. He received his first degree in biology 1974 and a doctoral degree in ethics 1991. He has over 100 original publications including three monographs and has led several multi-disciplinary projects in bioethics. He co-ordinates Mind the Risk.
- **Heidi Carmen Howard** is senior researcher at CRB with a PhD in neurogenetics and an MA in bioethics. Heidi Carmen Howard is also an invited scholar at the Centre of Genomics and Policy at McGill University (Montréal, Canada) and a member of the Public and Professional Policy Committee of the European Society of Human Genetics.

- **Ulrik Kihlbom** is senior lecturer in medical ethics at the Centre for Research Ethics & Bioethics. He teaches ethics to medical students and is responsible for an advanced level course on public health ethics. His research interests cover bioethics in general, the methodology of applied ethics and metaethics.
- **Sofia Lavén** is a medical doctor and PhD student at CRB. She will not be funded by the program but her project on cardiovascular risk information in primary health care brings additional competence to the project.
- **Jessica Nihlén Fahlquist** is a senior lecturer at CRB. She also works as a postdoctoral researcher at the Philosophy Section at Delft University of Technology in the Netherlands. Jessica's research focuses on applied ethics, and she has a particular interest in notions of moral responsibility.
- **Arvid Puranen** is a PhD student at CRB. His project aims to increase the understanding of patients' preferences for risk communication, their perception of risk, and the effects of communicating risk. He holds a Medical degree (Uppsala University, 2014), a license to practice (2015) as well a bachelor degree in Economics (Uppsala University, 2014) and a bachelor degree in Mathematics (Virginia Tech, 2007).
- **Jennifer Viberg** is a licensed Prosthetist and Orthotist and PhD Student at CRB. She is involved in the IMI-funded BT-Cure project on Rheumatoid Arthritis and [BBMRI.se](http://www.BBMRI.se). She started her PhD studies in April 2012. Her PhD project is looking at the ethical issues concerning disclosure of incidental (or secondary) findings to research participants in genetic research.

Georg-August-Universität, Göttingen: The Department of Medical Ethics and History of Medicine

- **Silke Schicktanz** is full professor of cultural studies and ethics of biomedicine. She focuses in her research on the mutual relationship of cultural and ethical discourses of biomedicine. This includes the socio-empirical and theoretical comparison of localised discourses in bioethics, particularly on genetic testing.
- **Julia Perry** is a research assistant with a background in medical sociology and gender studies. In her research she focuses on medical knowledge of lay people and the physician-patient communication process.
- **Sabine Wöhlke** is post doc researcher with a PhD in cultural anthropology. Her main interests are ethical and cultural aspects of genetic testing and predictive genetic testing as well as qualitative socio-empirical research in the field of patient-physician communication and shared decision making. She was the scientific coordinator of the project: Socio-empirical and ethical analysis of patients' expectations and attitudes to-

ward prognostic tests based on biomarkers in rectal cancer therapy (KFO 179/2) (funded by the DFG).

- **Manuel Schaper** is a research assistant with a background in cultural anthropology, gender studies and social and economic psychology.

The Interdisciplinary Research Center on Decision Making Processes in Milano:

- **Gabriella Pravettoni** is full professor of Cognitive Science at the University of Milan and Director of IRIDe. Her main interests include the study of cognitive processes, decision-making, patient empowerment and health psychology.
- **Ilaria Cutica** graduated in Psychology at the University of Turin in 1997; in 2001 she got a PhD in Cognitive Science at the same University with a research on the neuropragmatics of communication. In 2005 she got a Master in Cognitive Psychotherapy, from the Italian Society for Behaviour and Cognitive Therapy. She has been assistant professor in General Psychology from 2005 to 2011 at the Faculty of Psychology of the University of Turin; since 2011 she is assistant professor in General Psychology at the University of Milan, where she teaches courses of Cognitive Psychology. Her research interests are concerned with pragmatics of communication in healthy adults, in brain injured patients and in deaf individuals, and with communication in medical settings, patients empowerment and medical decision making
- **Alessandra Gorini**, PhD, has a research position at the University of Milan where she teaches Cognitive Psychology and related disciplines and conducts researches about the decision-making processes in medical environments.
- **Serena Oliveri**, PhD, is a Post-Doc researcher in Cognitive Psychology and Decision-Making processes at the University of Milan and a member of the Applied Research Unit for Cognitive and Psychological Science at the European Institute of Oncology (IEO). Her research interests focus on medical decision making, risk analysis related to genetic information, effects on cognitive functions of cancer treatments and cognitive enhancement. She is author of several scientific papers published on indexed peer-reviewed international journals.

University of Manchester: The Centre for Health Economics, Institute of Population Health

- **Katherine Payne** is Professor of Health Economics. She was awarded a personal chair in health economics in August 2010. She is also a qualified pharmacist and a member of an NICE appraisal committee. Professor Katherine Payne has over 100 publications, over 16 years' experi-

ence as an academic health economist and an international reputation for the economics of genetic technologies and services.

- **Caroline Vass** holds a BSc in Economics and an MSc in Health Economics from the University of Birmingham. She is expected to complete her PhD from the University of Manchester in September 2014. Caroline's PhD involves investigating the framing of risk attributes in DCEs.
- **Andrea Manca** is a Professor of Health Economics in the Team for Economic Evaluation and Health Technology Assessment, part of the Centre for Health Economics at the University of York. Andrea holds an MSc in Health Economics (1998) and a PhD in Economics (2005), both awarded by the University of York.
- **Fiona Ulph** is lecturer in Qualitative Methods at the University of Manchester. She holds a PhD in Psychology from the University of Nottingham. Her research interests include how people assimilate genetic risk information into their lives, the communication of genetic information to parents and children following newborn screening and how new screening technologies are understood by the public.

University of Birmingham & Sandwell & West Birmingham Hospitals NHS Trust

- **Rebecca Jayne Stack**, BSc MBPsS MSc PhD, is a Psychologist with an expertise in Behavioural Medicine and Health Service Research. She has experience and expertise in a range of qualitative methodologies and metasynthesis of qualitative research. Her expertise is in understanding personal decision making surrounding decisions to seek help and the use of pharmacotherapy.
- **Karim Raza**, BMBCh, FRCP, PhD is a Reader in Clinical Rheumatology and Honorary Consultant Rheumatologist at the University of Birmingham and Sandwell and West Birmingham Hospitals NHS Trust. His research interests relate to the earliest phases of rheumatoid arthritis including approaches to the prediction of outcome and strategies to improve access to care for patients with early arthritis. He is deputy coordinator of an EU FP-7 program (Euro-TEAM: Towards Early Arthritis Management) defining biomarkers of outcome and patient perspectives on these in individuals at risk of RA.
- **Marie Falahee**, postdoc

University of Maastricht: Department of Technology and Society Studies, Faculty of Arts and Social Sciences

- **Frederic Boudier** is Assistant Professor at the Faculty of Arts and Social Sciences, Maastricht University, in the Department of Technology and Society Studies (Netherlands) and Research Associate at the King's Centre for Risk Management (UK). Since 2003 he has developed policy

oriented research on risk communication and risk regulation, in a range of sectors including pharmaceuticals, biotechnology and Health and safety. In 2009-2010 he was National Expert at the European Medicines Agency. He has over 30 original publications.

Sophiahemmet University College

- **Susanne Georgsson Öhman** RNM, PhD, is a senior lecturer at Sophiahemmet University College and affiliated to Karolinska Institutet, Department of women's and children's health. Her main field of research is informed choice and experiences of prenatal examinations.

Karolinska Institutet

- **Erik Iwarsson**, MD, PhD, Clinical Genetics is associated professor at Karolinska Institutet, Department of Molecular Medicine and Surgery. His special field of interest is foetal diagnosis.

Pretend play

This is a pilot project funded by The Swedish Childhood Cancer Foundation (Barncancerfonden). In December 2015, we received a grant of 900.000 SEK from Barncancerfonden to continue this and make it a large-scale project.

Recent reviews show that children seldom participate in consultations and decisions regarding their care. There are disagreements between health care professionals on whether children should be involved or not.

Studies indicate that by being more active children's understanding of their illness might improve and their pain may be reduced. According to the UN Declaration of children's rights, every child has a right to acquire knowledge and skills for communication, enabling them to relate to the world around them in their own unique way.

This pilot project aims:

- To explore the usability of pretend play for increasing children's engagement in care situations
- To investigate whether pretend play can contribute to increased communication skills and a broader behavioural /emotional repertoire in care situations
- To examine the clinical ethical implications regarding involvement of children and their families in paediatric oncology care

The CRB team consists of:

- Mats G. Hansson, Professor of Biomedical Ethics

- Sara Holm, PhD, Researcher
- Anna T. Höglund, Associate Professor of Ethics
- Lena Ring, Adjunct Professor in Quality of Life Research in Health Care

Collaborators outside CRB

- Sandra Russ, Professor of Psychology, Case Western Reserve University, Cleveland
- Monika Bullinger, Professor of Medical Psychology, University of Hamburg
- Gustaf Ljungman, Associate Professor of Paediatric Oncology at Uppsala University and Uppsala University Hospital

Publication ethics

Science publications are important for scientific work and for scientific merit. In recent years the publication system has begun to change rapidly. For example, more weight given to impact and citations, the emergence of a fraud industry, and new forms for publishing (such as open access or with repositories) and peer review (such as pre-publication or post-publication review) give rise to new questions and challenges. In publication ethics we ponder these changes and how to deal with them and their consequences.

The CRB team consists of:

- **Stefan Eriksson**, Associate Professor of Research Ethics

Quality of life assessments in clinical practice

This project started in 2012 and has received funding from the Swedish Cancer Society (Cancerfonden)

Assessments of patients QoL/HRQoL are increasingly used in clinical trials, but rarely in clinical practice. To systematically monitor cancer patients with QoL/HRQoL instruments in clinical practice can be a way to individualize care, enhance patient-physician communication (with regard to psychosocial concerns), inform clinical decision-making and improve patients' outcomes. This project started in 2005 and is funded by The Swedish Cancer Society.

The main aim is to evaluate the effectiveness of QoL instruments as means of individualizing cancer care and treatment. We want to explore differences related to cancer patients QoL and to doctor-patient communication. This project consists of a recently completed psychosocial randomised study focusing on the benefits from regular assessments of Quality of Life (QoL) and Health-related Quality of Life (HRQoL) during patient care in daily oncology practice.

Objectives of special interests are:

- To evaluate the effectiveness of QoL/HRQoL instruments as means of individualizing cancer care and treatment, focusing on the influence on satisfaction with care, communication and patient management (*e.g.* medical decisions and referrals).
- To identify appropriate instruments for this purpose, the cancer specific instrument EORTC-QOL-C30 or/and the individualized instrument SEIQoL-DW
- To identify the minimally important difference (MID) for SEIQoL and EORTC-QOL-C30
- To explore the experiences of, and attitudes towards the clinical usefulness and the implementation of QoL/HRQoL assessments among patients and health care personnel.

The project now enters the final phase. Data collection has been completed and the on-going focus is to finalize the data set and to perform analysis as well as write up more publications. The most recent publications have focused on qualitative aspects of the study, which is very important as a foundation for the quantitative analysis. However, now when the data collection is completed we are performing the main quantitative analysis to answer the main research question evaluating the effectiveness of QoL/HRQoL instruments as means of individualizing cancer care and treatment.

The CRB team consists of:

- Lena Ring, Adjunct Professor of Quality of Life Research in Health Care

Collaborators:

- Hanna Fagerlind, PhD, PhD, Department of Pharmacy, Uppsala University.
- Bengt Glimelius, Professor, Department of Radiology, Oncology and Radiation Science, Uppsala University.
- Mathilde Hedlund-Lindberg, PhD, Department of Neurobiology, Care Sciences and Society (NVS), Karolinska Institutet
- Åsa Kettis, Associate Professor, Planning division, Uppsala University

RD-Connect

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 305444.

RD-Connect is coordinated by Hanns Lochmüller at Newcastle University. The ELSI work package is led by Mats Hansson with the biobank and registry team at CRB in collaboration with Pauline McCormack and Simon Woods at PEALS in Newcastle, and Monica Ensini at EURORDIS in Paris.

RD-Connect aims to build an integrated platform connecting registries, biobanks and clinical bioinformatics for rare disease research.

Despite examples of excellent practice, rare disease (RD) research is still mainly fragmented by data and disease types. Individual efforts have little interoperability and almost no systematic connection between detailed clinical and genetic information, biomaterial availability or research/trial datasets.

The project will build on and transform the current state-of-the-art across databases, registries, biobanks, bioinformatics, and ethical considerations to develop a quality-assured and comprehensive integrated hub/platform in which complete clinical profiles are combined with -omics data and sample availability for RD research.

CRB's role in RD-connect: We are responsible for a separate work package will address ethical, legal and social issues (ELSI) with the following objectives:

1. Develop best ethical practices for balancing patient-related interests associated with RD research using databases/registries, biobanks and omics databases in global networks of clinicians and researchers.
2. Engage with relevant stakeholders, *e.g.* patient organizations and patient groups, clinical and research networks, legislators and policymakers, pharma industry.
3. Develop a proposal for an expedient regulatory framework for linking of medical and personal data related to RD on a European and global level.

Mission statement: WP6 will provide constructive contributions based on sound research in order to facilitate collaboration between scientists and different stakeholders when linking and sharing data and biomaterials for the benefit of patients with rare diseases while respecting their integrity and encouraging their active participation,

WP6 will acknowledge and explore ethical issues with rare disease patient interests in mind in order for RD-Connect to be a vehicle for identifying concerns and solutions of great significance also for other disease areas and for the development of personalised medicine.

Contact at CRB:

- Mats G. Hansson, Professor of Biomedical Ethics
- Deborah Mascialoni, PhD Bioethics, Researcher
- Jennifer Viberg, BSc, MA, PhD Student

Research regulation

Difficulties in regulation are an interesting study object, not only for researchers, but also for legislators, professional organizations and the society

at large. Future developments of regulation should rest on a comprehensive and thoughtful approach to science regulation.

Ethical concerns are increasingly taking on a legal form might create a situation where a procedure of legal interpretations replaces ethical reflection. And the number of professional guidelines, research ethics codes and legal regulations has increased tremendously in the last few years.

The aim of this research is to investigate to what extent the current regulation of life sciences conform to basic rational demands on a legitimate regulative system and suggest how a regulative system for the life sciences best can meet those standards of rationality.

This research focuses on rational regulation. In research ethics and bioethics there is a clear trend towards more collaboration between law and ethics. This has been described as a juridification process. Regulation has been seen both as a solution and a problem and it has been questioned whether our regulative system is legitimate.

Legitimacy in a regulative system can be seen both as a function of meeting certain basic requirements on how the various rules and guidelines are created and designed, and as a function of how the system is perceived by those administering or being affected by it.

In a previous project, "Are codes and guidelines the right way to go? On ethical competence in medical practice", we investigated the concept of "ethical competence" within the field of medical practice and research and the importance of ethical guidelines (of various forms) in the development of such competence is studied. Stefan Eriksson has also worked with scholars involved in ABIS, Linköping, pondering the feasibility of a right not to know (as suggested by various ethical guidelines), with Gert Helgesson on various issues, with Erik Sundström on norms affecting epidemiological research, and with Anna-Lydia Svalastog on the requirement for anonymity in research. Much of the work on science regulation has been poignantly expressed in a recent article with Linus Johnsson.

The CRB team consists of:

- Stefan Eriksson, Associate Professor of Research Ethics

Self management of hypertension (Developing and evaluating an interactive mobile phone system to support self-management of hypertension)

This project started in 2010 and is supported by the Swedish government's strategic investment in health and care research and by the University of Gothenburg.

Hypertension remains being an important risk factor for cardiovascular disease and the burden of this disease is quite severe when it comes to having an impact on daily life. Despite a profound evidence base for a combined medication and lifestyle intervention and despite guidelines and education programmes only one third to one quarter of people receiving treatment for hypertension reach a well-controlled blood pressure well controlled. Factors explaining this might be that 50% of persons receiving treatment for hypertension do not adhere to treatment and that life-style adjustments in general are hard to maintain. An increased understanding among patients as well as health care personnel of the interrelationships between blood pressure, symptoms, medication use, side-effects, life-style and well-being may support the self-management of hypertension including medication adherence and treatment effect.

Increased interaction and effective communication between health care providers and the patient may support self-management of hypertension. Self-reports systems can be a tool to facilitate adherence to hypertension treatment, and improve the management of hypertension by engaging the patient as an active partner in care. Recent reviews conclude that self-monitoring appears to be useful in care and is likely to lead to a reduction in cardiovascular events and mortality. In this project, we plan to use mobile phone technology to do this.

Aims: This research programme will develop and evaluate the feasibility, utility and effectiveness of an interactive mobile phone-based system for use in supporting patients in their efforts to self-manage their hypertension treatment. The self-management system we will use is person-centred, where the patient is actively involved in the treatment and care.

An interdisciplinary group of researchers will have a participatory orientation while working together with persons with hypertension and health care professionals in the development process. CRBs role is to contribute with expert knowledge in patient-reported outcomes approaches and measurements. The program consists of four phases:

- Phase 1: Exploring patients' and health care professionals' experiences of high blood pressure and antihypertensive treatment
- Phase 2: Design and pilot testing of a mobile phone self-management system
- Phase 3: Analysis of patient self-reports and patient/professional experiences using the interactive mobile phone self-management system
- Phase 4: Evaluating patient- nurse/physician consultations using the interactive mobile phone self-management system

More information

<http://www.gpcc.gu.se/english/> and <http://www.letstudio.gu.se/>

The CRB team consists of:

- Lena Ring, Adjunct Professor of Quality of Life Research in Health Care

Collaborators:

- Karin Kjellgren, Professor, University of Gothenburg and Linköping University (Principal Investigator)
- Ulrika Bengtsson, PhD Student, University of Gothenburg
- Inger Hallberg, PhD, Post doc, University of Gothenburg
- Åsa Mäkitalo, Professor, University of Gothenburg
- Dick Kaperowski, Associate Professor University of Gothenburg
- Stefan Höfer, Associate Professor, University of Innsbruck

PhD projects

Cardiovascular risk communication in primary care

This PhD project started in 2012. It is funded by the Uppsala County Council (Primärvården, Landstinget i Uppsala län).

Cardiovascular diseases are the major cause of disease and death. Risk for cardiovascular disease is determined by a combination of lifestyle and genetic factors. General practitioners on a daily basis discuss these risks and the benefits and risks of treatment or care with their patients. In such risk communication the role of the general practitioner is to help the patient make a well informed decision.

The aim of the project is to study cardiovascular risk communication in primary care. The main focus is on how general practitioners value and communicate lifestyle as well as genetic risk factors. The first part of the project is a qualitative study, focus group interviews with Swedish general practitioners, with the aim of gaining knowledge of their experience and strategies for communicating cardiovascular risk in every day consultations. The second part of the project is a discrete choice experiment (DCE). Based on the results of the focus group interviews scenarios, attributes and levels for the DCE will be developed.

PhD student:

- Sofia Lavén, MD, PhD Student

Supervisors:

- Mats G. Hansson, Professor of Biomedical Ethics
- Karin Björkegren, MD, PhD, Senior lecturer, Family medicine and Preventive medicine, Department of Public Health and Caring Sciences

Cardiopulmonary risk communication: participants understanding and preferences

This PhD project started in 2015 and has received funding from the Swedish Heart- Lung Foundation (Hjärt- lungfonden)

Risk information is complex. What people want to know depends on several factors. How do research participants and patients perceive risk and what are their preferences regarding communication of cardiopulmonary risk?

The Swedish SCAPIS (Swedish CardioPulmonary bioImage Study) study identifies risk factors for heart and lung disease. They will collect health information and blood samples from 30,000 people. The results of the SCAPIS study will hopefully be implemented in health care, the question then is how health care professionals should give this complex information to patients.

Aim: This project hopes to aid patients, health professionals and policy makers by exploring the SCAPIS participants understanding and preferences regarding cardiopulmonary risk communication.

PhD Student:

- Arvid Puranen, MD, BA, BSc

Supervisors:

- Sophie Langenskiöld, Senior lecturer in Health Economics, Department of Public Health and Caring Sciences, Uppsala University
- Mats G. Hansson, Professor of Biomedical Ethics, CRB

The neuroscience of disorders of consciousness: from laboratory to clinic

This PhD project started in 2014 and has received funding from the European Union Flagship Human Brain Project

The instrumental investigation and assessment of consciousness have witnessed an astonishing progress over the last years. The result of this progress is the passage from a monolithic way of looking at severe brain damages to a more graded nosology based on a quantitative assessment of consciousness and on functional neuroimaging technologies.

The so-called "neuro-technologies", especially the application of technology to the assessment and investigation of consciousness, lead to relevant and unpredicted results with important theoretical and practical consequences.

Working within the framework of the European Human Brain Project, the project aims at:

- Reviewing the recent development in the scientific explanations and description of consciousness, particularly focusing on disorders of consciousness (DOCs).
- Setting the scientific stage, that is the potential and actual clinical application of neuro-imaging for diagnosing and assessing DOCs
- Describing the theoretical and technical premises of the application of neurotechnologies (*i.e.*, "mind-reading" and "externalization of mind") for communicating with patients with DOCs
- Analysing the ethical issues emerging from the clinical application of neuroimaging technologies
- Assessing the issue of the role of uncertainty in neuroscience, particularly in neuroscientific investigation of DOCs
- Assessing the issues of pain, suffering and pleasure in DOCs both from a scientific and ethical point of view
- Outlining the high rate of misdiagnosis of DOCs emerging from the behavioural assessment of consciousness
- Setting prospects and limitations of the instrumental diagnosis of DOCs
- Analysing the ethical issues arising from the misdiagnosis of DOCs
- Suggesting improvements strategy for diagnosing DOCs

Publications:

Farisco M, Laureys S, Evers K, Externalization of Consciousness. Scientific Possibilities and Clinical Implications, in: Geyer M, Ellenbroek B, Marsden C (eds), *Current Topics in Behavioural Neurosciences*, 2014, doi: 10.1007/7854_2014_338

PhD Student:

- Michele Farisco, PhD Ethics & Anthropology, Associate Professor of Moral Philosophy, PhD Student

Supervisors:

- Kathinka Evers, Professor of Philosophy
- Stephen Laureys, MD, PhD, leader of the Coma Science Group at the Cyclotron Research Center and Department of Neurology, Sart Tilman Liège University Hospital

DNR decisions within oncology and haematology care. Clinical and ethical perspectives

This PhD started in 2010 and has received funding from the Swedish Cancer Society (Cancerfonden)

Within oncology and haematology care, patients in a terminal phase of cancer sometimes have such a poor prognosis that Coronary Pulmonary Rescue (CPR) is not considered justifiable in case of cardiac arrest.

This can lead to a DNR order to be issued by the responsible physician, implying that in case of a cardiac arrest neither basic nor advanced CPR is to be performed. DNR situations can lead to severe ethical dilemmas and moral distress among the staff.

The aim of this project is to investigate attitudes to and perceptions of ‘Do Not Resuscitate’ (DNR) orders among staff in oncology and haematology care. The need for a certain ethical competence for these decisions will be investigated. Further the experiences of education in DNR and understanding of DNR orders among students in nursing and medical school will be investigated.

The project consists of four studies:

1. In an interview study, using qualitative methodology, oncology and haematology nurses will be asked about their experiences and perceptions of DNR decisions.
2. In a similar qualitative study, physicians working within oncology and haematology will be interviewed on their experiences and perceptions of DNR decisions.
3. Based on the empirical results in study 1 and 2 an analysis of what ethical competence staff needs in order to make sound decisions concerning DNR within oncology and haematology care will be performed.
4. In a quantitative study, using a web based survey, nursing and medical students will be investigated concerning their understanding of DNR and their education on this concept.

Publications

Pettersson, M., Hedström, M., Höglund, A. (2014), Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and haematology care, *Nursing Ethics*, vol. 21, ss. 902-915

PhD Student:

- Mona Pettersson, RN

Supervisors

- Anna T. Höglund, Associate Professor of Ethics
- Mariann Hedström, Senior lecturer, Department of Public Health and Caring Science

Collaborator

- Gunnar Birgegård, Professor, Department of Medical Sciences

Ethical and public health considerations of conventional and peptide-based antibiotics

This PhD project was initiated in 2015, with official start in February 2016

The rapid development of multi-resistant bacteria is one of the largest threats to public health globally. We need a global approach to fight resistant bacteria. In spite of a growing focus on the theme by many international organizations, there is evidence for a lack of public awareness and non-compliance with prescribed or oral indications.

Several measures are needed to stop this trend, including the development of new antibiotics; antimicrobial peptides represent an alternative and complement. Patients' inclinations to use antibiotics can often be explained in local, sociocultural terms. There is an urgent need for an international commitment to decrease and optimize the use of current and new antibiotics. It should also be recognized that there is also a need for sensitive policy on a local level that permit different societies to ensure the sustainability of antibiotic drugs.

Aim: The starting point for this project is the understanding public attitudes and preferences are key to find acceptance and compliance with public health programs. The project aims to contribute indications for how Swedish society could take on one of its most ardent tasks: to ensure an efficient and fair battle against infections and to maintain modern medical procedures. More specifically:

- To investigate how the public balance benefits and risks with regard to antibiotics use, focussing on the trade-off between personal versus collective gain, and present versus future gain.
- To develop an ethical normative framework for how to employ conventional and alternative (*i.e.* peptide-based) antibiotics in Sweden.

PhD Student:

- Mirko Ancillotti, MA

Supervisors

- Stefan Eriksson, Associate Professor of Research Ethics
- Dan I. Andersson, Professor of Medical Bacteriology, Department of Medical Biochemistry and Microbiology, Uppsala University
- Jessica Nihlén Fahlquist, Deputy Senior Lecturer in Medical Ethics,

Ethical issues in preconception genetic screening

This PhD project started in 2013

Today, we are given numerous reproductive options. This is making couples feel more responsible for making the right choice: A choice that depends not only on their medical and genetic status, but also on their beliefs and their moral outlook.

Preconception genetic screening (PCS) has been offered to for families with recessive genetic diseases. It has also been offered to communities with high prevalence of severe genetic disorders (for example Ashkenazi Jews).

The tests have become more reliable and cost effective, making it possible to consider genetic screening for carrier status in populations. This has led to an ethical debate: On one hand, preconception genetic screening could increase the reproductive choices for individuals or couples and lead to enhanced reproductive autonomy. On the other hand, it is not necessarily so that more choice enhances autonomy. Too much choice can lead to moral distress. The debate has also revolved around the possible medicalization of the reproductive process that preconception genetic screening can lead to.

Aims: This project will:

- Explore the ethical issues of preconception genetic screening, taking the family's and the individual's perspective into account.
- Focus on the interface between health care providers (for example clinical geneticists and gynaecologists) and the prospective parents/family.
- Highlight the role and responsibility of family members and health care providers in the decision making process regarding preconception genetic screening.

PhD Student:

- Amal Matar, MD, MSc

Supervisors:

- Anna T. Höglund, Associate Professor of Ethics
- Ulrik Kihlbom, Senior lecturer in Medical Ethics

How should incidental findings in biobank research and genome sequencing studies be handled?

This PhD project started in 2012 and has received funding from BT-Cure, BBMRI.se and BBMRI-LPC.

This project will assess the argument for and against disclosure of incidental findings in biobank and –omics research and suggest how these findings should be handled in practice. Both philosophical analysis of basic concepts and arguments and an empirical study will be conducted. The empirical study intends to answer if research participants want to know about inci-

dental findings, and if so under what conditions do they want to know. The method for that study will be Discrete Choice Experiments, developed for health economy studies, and the primary aim is to capture the individuals' preferences in complex choice situations.

Publications:

- Viberg J, Segerdahl P, Langenskiöld S, Hansson MG, Freedom of Choice About Incidental Findings Can Frustrate Participants' True Preferences, *Bioethics*, Article first published online: 23 APR 2015 DOI: 10.1111/bioe.12160
- Viberg J, Hansson MG, Langenskiöld S, Segerdahl P, Incidental findings: the time is not yet ripe for a policy for biobanks, *European Journal of Human Genetics* advance online publication, 2014;22:437-441

PhD Student:

- Jennifer Viberg, BSc, MA

Supervisors:

- Mats G. Hansson, Professor of Biomedical Ethics
- Pär Segerdahl, Associate Professor of Philosophy
- Sophie Langenskiöld, Senior Researcher, Department of Public Health and Caring Sciences, Uppsala University

What is it like to be unconscious? Perspectives from Philosophy and Neuroscience with special regards to Resignation Syndrome

This PhD project started in 2013 and has received funding from the European Union Flagship Human Brain Project

Philosophy and neuroscience have a common interest – conceptualizing how the brain can give rise to the mind. Although significant progress in neuroscience has been accomplished pertaining to the characterization of brain functions linked to mental processes and even consciousness, philosophicaly challenging issues remain, especially with respect to accounting for the first-person perspective or the *what it is like*-aspect of consciousness.

A clinical condition resembling *Pervasive Refusal Syndrome* (the Swedish diagnostic term translated into English is *Resignation Syndrome (RS)* rose in prevalence in an astounding manner in 2004-5 among asylum-seeking refugee adolescents in Sweden. Clinical symptoms persist for months to years leaving the patients in a seemingly unconscious state characterized by flaccid paralysis and a complete lack of response even to pain. Tube-feeding is necessary and no therapeutic intervention hastening recovery is known. Little is known of the biological background of the condition.

The study of RS is, with regards to its severity, duration and lack of treatment, paramount. Exhibiting altered states of consciousness and being hitherto unexplored from the perspective of neuroscience, these patients also provide an opportunity to study the biology of consciousness. Can such findings, and others from neuroscience, help us understand how consciousness and in particular the first person-perspective can arise in the brain.

Aims: Within the framework of the European Human Brain Project, this project will

- Review recent development in the scientific explanations and description of consciousness with special focus on the conceptualization of the first person-perspective
- Explore the concepts of *understanding* and *explanation* in scientific theories in particular in the setting of contemporary neuroscience
- Explore the problem of *other minds* in relation to clinical settings involving Disorders of Consciousness, in particular RS, as well as to that of brain simulation
- Characterize RS within a neurobiological framework by analysis of resting state-activity through the use of functional Magnetic Resonance Imaging (fMRI)
- Explore possible neurobiological correlates to the observed state of unconsciousness in RS
- Relate findings from performed studies in the RS condition to the neurobiology of other conditions involving altered states and or contents of consciousness in order to contribute to a neurobiological account of consciousness

PhD Student:

- Karl Sallin, MD

Supervisors:

- Kathinka Evers, Professor of Philosophy
- Predrag Petrovic, Psychiatrist, Associate Professor, Karolinska Institutet

Mentor:

- Hugo Lagercrantz, Senior Professor, Karolinska Institutet

Factors associated with participation in phase 1 and phase 3 oncology trials

This PhD project ran between 2010-2015. It was funded by The Swedish Cancer Society (Cancerfonden).

There is a lack of both philosophical analysis and empirical support of for patient's views to guide the selection of appropriate information and consent procedures for patients with progressive cancer.

A common conception is that patients participate in order to reap benefits of their own, while the scientific objective is to benefit future patients, *i.e.* the therapeutic misconception. However, the concept of benefit is complex and there are different ways patients may perceive their participation. There is a need of empirical studies that focus specifically on the balancing of benefits and risks, the issue of voluntariness and the role of doctors and research associates in promoting patient autonomy for clinical cancer trials. In particular, there is a lack of information on these issues from the perspective of the Swedish health care system and how Swedish patients reason.

The aim of this project is to understand on what premises Swedish patients decide to participate in phase 1 and phase 3 oncology trials with emphasis on their attitudes regarding risk, own benefits and benefits for future patients. We will also investigate the implications of this understanding for information and consent procedures used when recruiting patients to such trials.

In this project we want to find answers to the following questions:

- How do cancer patients participating in phase 1 and phase 3 clinical trials perceive their participation with regard to risk, benefits (own and for future patients) and information?
- What is their perception of the role of physicians and clinical research associates with regard to recommendations to participate, success of information transfer, time assigned for making decision?
- Do they regard their participation as voluntary and on what conditions would they like to withdraw?
- Is willingness to participate related to patients' quality of life?
- How may the risk of treatment/therapy misconception be handled in association with randomized controlled clinical cancer trials?

The project consists of two parts: interviews with phase 1 trial participants and, using the results from these interviews, a questionnaire to patients who participate in phase 3 trials.

Publications:

- Godskesen T. (2015). Patients in Clinical Cancer Trials: Understanding, Motivation and Hope. Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, doctoral dissertation, ISSN 1651-6206;1112.
- Godskesen, T., Hansson, M., Nygren, P., Nordin, K., Kihlbom, U. (2015). Hope for a cure and altruism are the main motives behind participation in phase 3 clinical cancer trials. *European Journal of Cancer Care*, vol. 24, ss. 133-141 DOI

- Godskesen, T., Kihlbom, U., Nordin, K., Silen, M., Nygren, P. (2015). Differences in trial knowledge and motives for participation among cancer patients in phase 3 clinical trials. *European Journal of Cancer Care DOI*
- Godskesen, T., Nygren, P., Nordin, K., Hansson, M., Kihlbom, U. (2013). Phase 1 clinical trials in end-stage cancer: patient understanding of trial premises and motives for participation. *Supportive Care in Cancer*, vol. 21, ss. 3137-3142

PhD Student:

- Tove Godskesen, RN, PhD 2015

Supervisors:

- Ulrik Kihlbom, Senior lecturer in Medical Ethics
- Karin Nordin, Professor, Department of Public Health and Caring Sciences
- Peter Nygren, Professor, Department of Radiology, Oncology and Radiation Science

Project group:

- Mats G. Hansson, Professor of Biomedical Ethics
- Anna T. Höglund, Associate Professor of Ethics

Paediatric palliative oncology in a family perspective

This PhD project ran between 2009-2015. It was funded by the Swedish Childhood Cancer Foundation (Barncancerfonden)

In Sweden, around 250 children are diagnosed with cancer every year. Modern treatment strategies have increased overall survival that today is approaching 80 per cent. But not every child is cured. One out of five children diagnosed with a malignancy will die from the cancer. The death of the child affects the whole family: Previous research has showed that bereaved parents and siblings suffer from long-term psychological morbidity due to the death of the child.

This PhD-project focuses on palliative care and end-of-life care in paediatric oncology with a focus not only on the child, but also how different aspects in the end-of-life care affect bereaved family-members long-term.

In this project, we will

- Examine to what extent there is a shift in focus on palliative care in the departments of paediatric oncology in Sweden
- Examine which symptoms bereaved parents regard as affecting their dying child the most in the end-of-life period and if there is a relation be-

tween these symptoms and long-term psychological well-being in parents who have lost a child.

- Examine if there is a relation between treatment intensity in the child (in the form of hematopoietic stem cell transplantation) and psychological well-being in bereaved parents.
- Examine how parents and dying children communicate about death.
- Examine how children suffering from cancer view their need for information regarding diagnosis and prognosis and possible treatment-failure.
- Examine how bereaved siblings experience the death of their brother or sister.

The project is designed with as a mixed method study based on data from medical records, questionnaires with bereaved family members and interviews with children who suffer from cancer. Both quantitative and qualitative analyses will be used in different parts of the project.

Publications

- Jalmsell L, Towards Good Palliation for Children with Cancer: Recognizing the Family and the Value of Communication, 2015, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, doctoral dissertation, ISSN 1651-6206 ; 1123
- Jalmsell L, Kontio T, Stein M, Henter JI, Kreicbergs U, On the Child's Own Initiative: Parents Communicate With Their Dying Child About Death, *Death Stud.* 2014 Aug 25. DOI: 10.1080/07481187.2014.913086 [Epub ahead of print]
- Jalmsell L, Forslund M, Hansson MG, Henter JI, Kreicbergs U, Frost BM, Transition to noncurative end-of-life care in paediatric oncology: a nationwide follow-up in Sweden, *Acta Paediatrica* 2013;102(7):744-748
- Jalmsell L, Kreicbergs U, Onelöv E, Steineck G, Henter JI, Anxiety is contagious-symptoms of anxiety in the terminally ill child affect long-term psychological well-being in bereaved parents, *Pediatr Blood Cancer*, 2010;54(5):751-7.
- Jalmsell L, Onelöv E, Steineck G, Henter JI, Kreicbergs U, Hematopoietic stem cell transplantation in children with cancer and the risk of long-term psychological morbidity in the bereaved parent, *Bone Marrow Transplant*, 2011;46(8):1063-70.
- Jalmsell L, Kreicbergs U, Onelöv E, Steineck G, Henter JI, Symptoms affecting children with malignancies during the last month of life: a nation wide follow-up. *Pediatrics*, 2006;117(4):1314-20

PhD Student:

- Li Jalmsell, MD, PhD

Supervisors

- Mats G. Hansson, Professor of Biomedical Ethics

- Britt-Marie Frost, Department of Paediatric Oncology, Uppsala University Hospital (Akademiska sjukhuset)
- Jan-Inge Henter, MD, Professor. Childhood Cancer Research Unit, Karolinska University Hospital
- Ulrika Kreicbergs, RN, Professor, Ersta Sköndal University College

R&D projects/investigations

When is it worth it? – Informational privacy in health care and research

The project is commissioned by The Swedish Agency for Health and Care Services Analysis (Vårdanalys). The final report is due in spring 2017.

The current debate in Sweden concerning informational privacy in the health care setting is highly polarized. On one side the firm stance taken is that privacy protection constitutes an unwarranted hindrance to good care and medical progress. Opponents just as firmly conceive all suggested weakening of privacy protection as threats to individual rights and dignity, and in a larger perspective also to fundamental democratic values.

These opposing views underlie several ongoing policy-making processes and commissions of inquiry. The recent Swedish Government Official Report Rätt information på rätt plats i rätt tid (SOU 2014:23) proposes new legislation and IT infrastructure concerning the accessibility of medical journals, with obvious privacy implications. Regarding register based research, the SOU (2014:45) Unik kunskap genom registerforskning advocated a liberalization of how data from individuals may be collected, used and handled, while the European Parliament's suggestions for a new data protection regulation point in the opposite direction (Läkartidningen 2015). The outcomes of processes such as these have an impact on the informational privacy of patients and citizens. Yet, what is lacking in this context is empirical research on how those actually affected value and evaluate privacy as well as the potential risks and benefits involved.

The main purpose of this project is to explore preferences on informational privacy in health care and register data among the general public as well as for groups of patients with prolonged illness.

Collaborators:

- Linnea Wickström Östervall, PhD, CRB
- Mats G. Hansson, Professor of Biomedical Ethics, CRB
- Sophie Langenskiöld, Department of Public Health and Caring Sciences, Uppsala University

- Sara Belfrage, Centre for Healthcare Ethics, LIME, Karolinska Institutet and Vårdanalys

International Collaborations

We have extensive international multi-disciplinary research collaborations. Worth mentioning are:

Mind the Risk

CRB co-ordinates multi-disciplinary research collaboration on how to manage and handle genetic risk information, generated by information technology. The research is funded by the Swedish Foundation for Humanities and Social Sciences (Riksbankens Jubileumsfond) Partners include the Georg-August-Universität, Göttingen: The Department of Medical Ethics and History of Medicine, the Interdisciplinary Research Center on Decision Making Processes in Milano, University of Manchester: The Centre for Health Economics, Institute of Population Health, University of Birmingham & Sandwell & West Birmingham Hospitals NHS Trust, University of Maastricht: Department of Technology and Society Studies, Faculty of Arts and Social Sciences, Karolinska Institutet and Sophiahemmet University College and deCODE genetics.

Biobank and Registry Ethics

CRB participates in several European networks and EU-funded projects on the ethical aspects of biobanking. Currently we are part of BBMRI.se (BioBanking and Molecular Resource Infrastructure of Sweden) funded by the Swedish Research Council. We are in part responsible for an ELSI-common service for BBMRI-ERIC. We run a work package in the IMI (Innovative Medicines Initiative) funded BT-Cure, focusing on Rheumatoid Arthritis (RA) and RA-like diseases. CRB is part of a work package on regulatory and ethical requirements for data storage and analysis within BiobankCloud, a 7th Framework project aiming to build the first open and viable platform-as-a-service (PaaS) for storage and analysis of digitized genomic data. We run a work package within Euro-TEAM, another 7th Framework project aiming towards early diagnosis and biomarker validation in arthritis management. We are also responsible for a work package on ethical, legal and social issues within RD-connect, a 7th framework programme that aims to build an integrated platform connecting registries, biobanks and clinical bioinformatics for rare disease research.

Network of Ethics of Families

In 2011, CRB received funding from Riksbankens Jubileumsfond for the initiation of this international multi-centre research collaboration on family ethics together with Expertise Center Ethics of Care at University Medical Center (ECEC), Groningen University the Centre for Biomedical Ethics (CBmE), National University of Singapore and the Policy, Ethics and Life Sciences Research Centre (PEALS), Newcastle University on family ethics health and social care, a network that also includes Hilda Lindeman and James Nelson, philosophers from Michigan State University.

In June 2013 the group received funding for 3 years from the Dutch body NWO for the project Practices of Responsibility in Change that will result in a wider and stronger network, joint publications and a full research proposal.

Undergraduate Teaching

We teach nurses, doctors and engineers at Uppsala University. Our aim is to help our students develop the competence they need to identify the values that are at stake when they face ethical dilemmas in their future professions.

Ethics and law for Medicine

To practice medicine involves considerable responsibility, both from a medical, ethical as well as from a legal perspective. The main aim of the curriculum is to enhance student's ability to understand how ethical and legal issues arise within the medical practice and their critical skills in analyse ethical and legal problems, the relation between them, and to argue in for different views in particular cases.

For medical doctors, medical ethics and medical law is part of the professional training curriculum that runs through the programme from the first to the eleventh semester. Lectures and seminars are integrated with courses in medicine, and taught collectively by clinicians, lawyers and ethicists.

Nursing

Within the nurse's programme, the ethics training is distributed over the three years of the programme. The ethical dilemmas nurses face can concern the conflict between a patient's right to be autonomous and consent to care on the one hand, and the nurse's will and duty to do something good for the patient and maximize the beneficence of the actions taken on the other. The students are encouraged to reflect on different solutions and to actively take part in moral deliberations.

Ethics is an important part of the providing of good nursing care and ethical competence is crucial in a nurse's practice. To be ethically competent means being able to identify moral dilemmas and to reflect on the values involved and how they should be weighed. It also implies being able to act upon the morally preferable action.

Nursing students listen to lectures, both live and on the web, and participate in seminars where they can discuss clinical ethical dilemmas. Examination is mostly in form of written assignments and mandatory seminars.

Midwives

Within the midwife programme we lecture on for example professional ethics for midwives, abortion ethics and the ethics of pre-natal diagnostics.

Specialist nurses

In the specialist nurse programmes we offer tailored lectures for specialities such as intensive care, palliative care, primary care, psychiatric care and surgery.

Science and technology

Since 2014, we have been working together with the Biology Education Centre to integrate structured ethics teaching for students in the biology degree programmes. There is also a broader project going on to improve ethics education at all of the science and engineering programmes.

The best teaching in ethics and biology is achieved when the ethics experts from CRB work together with the biology experts. When this is done, students get the best quality in terms of ethics and state-of-the art examples from their field, for example genetics. Students get both regular lectures, during which they learn tools and ethical theories to use when they do ethical analyses. But they also have seminars and debates, in order to practice these tools. Without the practice, they would not learn how to do ethical analyses of biology on their own. The goal is that they will graduate and get a job where they can use their knowledge and experience of doing ethical analyses of their respective fields of expertise.

Advanced level courses

We offer advanced level courses in neuroethics and public health ethics that are open for anyone who meets the criteria.

Neuroethics 7,5 credits

Different types of neuroethical issues will be discussed during the course. The course focuses both on applied neuroethics, *i.e.* ethical questions that arise from neuroscientific or neurotechnological advances; and on fundamental neuroethics, *i.e.* questions concerning how knowledge of the brain's functional architecture and its evolution can deepen our understanding of human thought, including moral thought and judgment. The course also includes clinical perspectives, *e.g.* to what extent a patient with a neurodegenerative disorder suffers from reduced capacity for decision-making, or reduced autonomy, or when a person with dementia can give an informed consent to participate in scientific studies.

Public Health Ethics 7,5 credits

This course is an electable part of the master programme in public health and is open to students on advanced level students. It is offered in Swedish only.

Postgraduate Teaching

We offer postgraduate courses in research ethics for PhD students from medicine, pharmacy, social science, science and technology.

Research ethics is an important part of advanced academic learning. All sciences and academic disciplines give rise to complex ethical issues. Dealing with them requires theoretical and practical knowledge, including familiarity with relevant norms in science and society, knowledge which research ethics aims to provide. Our teaching is based on sound research and critical analysis.

We want PhD students to develop ability to engage in critical and self-reflective discussion of theoretical and practical problems in research ethics and the various solutions proposed. We try to help students reflect and learn by dialogue and participation.

Science and Technology

Researchers are expected to be able to handle the ethical questions that arise in relation to their research. The process of conducting research: data management, publishing results and collaborations with parties with vested interests holds several potential conflicts of interest that have to be handled in a wise manner and in accordance with regulations. A researcher's role as expert calls for some thought and it is important for the research community as a whole to prevent different forms of misconduct and fraud.

This is a 2 credit course that can be selected as part of the compulsory ethics curriculum for PhD students in Science and Technology. The course consists of lectures and seminar discussions of papers written by the students themselves.

Medicine and Pharmacy

This course deals with the norms of science and ethical norms in theory and practice, good laboratory and clinical practice, fraud in scientific research, animal ethics and applications to ethics committees. After the course, students should be informed about different philosophical presuppositions in scientific research, ethical guidelines for research, the theoretical basis of these guidelines, legal regulations of research, research ethics committees and about how to fill out an application form. Students should also be able to identify and analyse ethical problems raised by different kinds of research.

This is a compulsory one week course (1,5 HP) for PhD students in Medicine and Pharmacy that can be chosen instead of the integrated five week course (7,5 HP) Introduction to Scientific Research.

Social science

Ethics is not compulsory for PhD students in social science. We have offered electable courses for the faculty. In 2015 we decided to develop a course tailored for PhD students in psychology that will be offered in 2016. The course is open for students from other departments at the faculty. It will give students knowledge about general ethical problems in research. The course also aims at improving the student's ability to mobilise a sense of responsibility when faced with research ethical problems. Lectures focus on the regulation of research, fraud and misconduct in science, and authorship and publication issues.

Online training

We see a growing concern for research integrity in academic research today. Researchers and others, who handle research in one way or another, need to be able to identify ethical problems - and to do something about them. We also see that universities and funding agencies are starting to require formal training in research ethics. To meet those demands, we developed an online research ethics training for medicine and the life sciences to give some of the practical tools that people need.

We chose an online format to make it available and accessible. It is a part-time commitment that runs over ten weeks. During the last week, participant's share what they have learned with their colleagues.

The training is international, inter-disciplinary, inter-professional and interactive. We designed it to fit master students, senior researchers and everyone in between: professionals, officials from funding agencies or research ethics committees and anyone else who needs to be aware of and handle research ethics in any form.

After a course pilot in 2014, the training was launched. The training runs once a semester and we offer two training scholarships for students from low and middle income countries, where we see a need for this type of training. We continue work to see if we can find collaborating partners who are willing to offer additional scholarships to make this kind of training available in other parts of the world.

We are not doing the course for profit, but unfortunately we cannot afford to offer it for free. The fee is 1.125 Euros. Information about the training is available at www.ethicstraining.crb.uu.se.

Conferences and workshops

During 2015, we organized three open workshops: 1) Epigenetics as the meeting point between nature and nurture on March 19-20, 2) Children's Involvement in Research: from Assent to Consent on September 23-24, and 3) Reproductive ethics: Islamic perspectives.

Epigenetics as the meeting point between nature and nurture

On March 19-20, 215 registered participants from Sweden, Denmark, Finland, Iceland, Norway, the United Kingdom, Germany, France, Italy, the Netherlands, Canada, USA, Israel, Pakistan and Saudi Arabia gathered at Norrlands Nation in Uppsala to discuss epigenetics as the meeting point between nature and nurture.

On March 18, a welcome reception was held in the Chancellor's Room of Uppsala University's main building. The reception was hosted by the Vice Chancellor of Uppsala University, Eva Åkesson. Participants were also invited to a dinner on Thursday March 19 at Östgöta Nation.

One aim of the workshop was to examine the potential for a joint multi-disciplinary research programme. This report contains short summaries of all presentations at the workshop. They stirred a lot of interesting questions and discussions. Our hope is that the participants, funders and universities in Sweden and abroad will use the workshop report in order to initiate new research projects with collaborations across disciplinary borders.

There is growing evidence of the impact of non-genetic variables on gene expression, *e.g.* nutrition, maternal care/behaviour, psychosocial stress, ad-

versity and neglect in early life. Molecular epigenetic mechanisms in the cell explain how the exposure to environmental factors influences the phenotypic outcome and variability both between individuals and within an individual at different times. The environment plays an important role also in the evolving neuronal network of the brain. The organisational complexity of the brain is not only a result of gene expression but affected by the strength, selection and stabilization of synapses in a critical reciprocal interaction between the brain and its physical, psycho-social and cultural environment. The plasticity of gene expression and brain maturation in response to postnatal and adult social experiences, both with increasing evidence of trans-generational effects, suggest the evolutionary significance of these mechanisms in enabling organisms to adapt to changing environmental conditions.

Why we organized this workshop: The reversible nature of epigenetic pathways indicates a potential of developing and bringing epigenetic drugs into therapeutics but points also at the possibility of approaches focusing on the environment and the need to understand and improve psycho-social, cultural and political environments in order to reverse an unfavourable process or to be epigenetically proactive, to use a term coined by Kathinka Evers. For this we need to move beyond our own disciplinary borders.

Bioethics has seldom missed an opportunity to comment on new developments in science, however, often in a speculative manner, being uninformed about both the natural and social sciences. Changing living conditions, trying to influence behaviour or attempts of social engineering will indeed raise significant ethical issues but they need to be addressed in a disciplined manner in close collaboration with others. To be epigenetically proactive is a good idea but in order to not just be speculating we need neuroscientists, molecular biologists, ethicists and philosophers to work closely together with psychologists that can examine the behaviours and attitudes that will affect how individuals build and are affected by their environments, sociologists and anthropologists who have the tools for understanding complex social and cultural factors, epidemiologists and historians with good registries that can examine potential trans-generational effects, political scientists that can examine the societal and political implications. They, in turn, must have an open attitude and want to be informed by natural scientists.

The workshop was planned with this approach in mind. We are grateful and proud that speakers representing the cutting edge in different disciplines wanted to come. We are grateful for the support from the Swedish Foundation for Humanities and Social Sciences with its CEO Göran Blomqvist and Program Officer Fredrik Lundmark and to the Swedish Foundation for Strategic Research with its CEO Lars Hultman and Program Officer Inger Florin.

Children's Involvement in Research: from Assent to Consent

On September 23-24, RD-Connect and the Centre for Research Ethics & Bioethics (CRB) at Uppsala University arranged a workshop on children's involvement in research with a special focus on assent and consent.

RD- Connect is an EU-funded rare disease research platform that will build a permanent research facility for rare-disease data, analysis and sample sharing worldwide. The goal of this workshop was to help shape the RD-Connect guidelines and help improve both family and children's involvement and engagement in rare disease research.

Before the workshop, information was collected from patient representatives about how children involved in longitudinal studies for rare diseases experience assent and consent. Interviews were recorded and pieces of these interviews were used for displaying specific issues related to the involvement of children in research.

Participants represented several perspectives: 25 registered participants representing law, ethics, biobanking and clinical trials provided their insight into this topic with emphasis on rare disease patient's perspective. Participants from Sweden, Italy, the United Kingdom and Iceland took part to the workshop representing different national perspectives.

The outcome of this workshop has been reported by CRB in a deliverable report to RD-Connect. Two papers are currently underway and will be submitted during the first half of 2016.

Reproductive ethics: Islamic perspectives

In an attempt to correct the western bias of understanding bioethics, we hosted a one-day workshop on reproductive ethics with particular emphasis on Islamic perspectives of reproduction. The workshop aimed to create dialogue between the scholars in the field from the Middle East and Sweden. Since the Second World War, Sweden has been accepting immigrants from different parts of the world: particularly from the Middle East and Arab countries (such as Iran, Somalia, Iraq, Lebanon, Albania, Stateless Palestine and recently Syria), many of who are Muslims. Though they have the same religion in common, they come from different countries with varying cultures, traditions and creeds. There is little input of Islamic perspectives on currently practiced bioethics in Sweden and some commentators reproached the fact that bioethics is primarily dependent on western moral traditions and reasoning.

The goal was to bridge the gap between practice and theory, especially for issues that are relevant for both Swedish Muslims and healthcare personnel. We invited experts in the field to share their experience and perspectives on various reproductive issues: Gamal Serour, Professor in Obstetrics and Gynaecology, Director of International Islamic Centre for Population Studies

and Research, Al Azhar University. He is also a member of FIGO Ethics Committee and Chairman of the Egyptian Representative Committee of the Royal College of Obstetrics and Gynaecologists; Birgitta Essén, Senior Lecturer in International Reproductive Health at the Department of Women's and Children's Health at Uppsala University and Senior consultant at the Women's clinic, Akademiska sjukhuset (Uppsala University Hospital); Aje Carlbohm, Associate Professor, Faculty of Health and Society, Malmö University, Sweden. They discussed infertility, Islamic family and sexual counselling in a multicultural context and what happens when Muslim couples meet the Swedish reproductive health system. Amal Matar, PhD student at CRB, also presented an overview of the ethical issues on preconception genetic screening.

Obstetricians/gynaecologists, midwives, clinical geneticists, bioethicists, philosophers, lawyers, PhD students and others with an interest in these issues were invited. The day ended with an open lecture and discussion with Gamal Serour on ethical issues in human reproduction: religious differences, reproductive tourism, assisted reproduction and conscientious objection. The lecture was held at Uppsala University Hospital (Akademiska sjukhuset) and open to the public.

Public outreach

The Centre for Research Ethics & Bioethics runs a website (www.crb.uu.se) and two blogs (www.etikbloggen.crb.uu.se and www.ethicsblog.crb.uu.se). During 2015, the online ethics training also had its own website, www.ethicstraining.crb.uu.se (now part of www.crb.uu.se).

CRB's staff are also participating in the public debate and giving lectures in different public settings in order to disseminate research results, secure funding, encourage debate and discussion on ethical issues and learn more about public concerns and interests.

Website

CRB's official website is available at www.crb.uu.se. In 2016, the website also became available at <http://crb.uu.se>. During 2015, the online ethics training was available from a separate website. In 2016, it became part of www.crb.uu.se, but also keeps its own domain (www.ethicstraining.crb.uu.se). We run two WordPress blogs on separate subdomains, www.ethicsblog.crb.uu.se and www.etikbloggen.crb.uu.se. During 2015, work began to move the website from static html-pages to InfoGlue (publishing system used by Uppsala University). The new website was launched in February 2016.

In 2015, The CRB website had 32.371 unique visitors and 59.257 views (1.83 views per visitor). Most visitors come from Sweden (46.639 views) or from .com domains (28.097 views), followed by Germany (.de, 10.877 views), .net domains (9.443 views) and .eu domains (2.892 views), followed by .nl, .it, .org, and .edu.

In the media: The Ethics Blog and Etikbloggen

In November 2011, CRB started two ethics blogs: One in Swedish and one in English. Pär Segerdahl, Associate Professor of Theoretical Philosophy, was recruited as editor.

The blogs are part of our Swedish ELSI service and funded by BBMRI.se. The Swedish version is available at www.etikbloggen.crb.uu.se, the English at www.ethicsblog.crb.uu.se. The target groups for the blogs differ slightly: The Swedish blog comments current debate and often links to opinion pages in the daily papers, while the English version is more aimed at the scientific community and debates in the field of bioethics.

The blogs have a variety of functions. These functions are reflected in the brief self-reflective remarks that end each blog post, such as:

- “We think about bioethics”
- “Following the news”
- “We follow debates”
- “We have a clinical perspective”
- “In dialogue with the public”

The blogs keep readers updated about bioethically relevant news and allows researchers at CRB a platform to popularize their research and participate in ethical debates. The blogs explain bioethical research, comments on recent publications and current events, spreads information about CRB research and explains our ideas. We use the blogs to communicate with researchers, practitioners, politicians, and the general public. Finally, the blogs try to vitalize the ethical debate by identifying questions and perspectives that are novel, challenging and scientifically well-grounded.

Both blogs are using the WordPress platform and have increased their following, both via e-mail and WordPress. The Swedish version is shared more in social media than the English version. In 2015, we received 369 clickbacks from Facebook (compared to only 10 for the English blog). This is indicative of both the fact that the Swedish blog has both more views and visitors, but also the nature of the content and target groups. The English blog, on the other hand, has more WordPress followers.

The Ethics Blog (English) has 182 followers (97 WordPress followers and 85 e-mail followers). In 2015, the blog published 42 posts and had 5.559 views and 3.225 visits (with 1,72 views per visitor). Visitors came from Sweden

(1.398 views), USA (1.291 views), United Kingdom (498 views), followed by Canada, Germany, Italy, the Netherlands, the Philippines, Australia, Finland, Russia, India, Spain, Norway and Japan (with more than 50 views).

The most popular post was written by Pär Segerdahl and deals with morality (Morality as a problem). It had 166 views, followed by a post by Moa Kindström Dahlin on legal scholarship (All you need is law? The ethics of legal scholarship) with 154 views. The third most popular post was also by Pär Segerdahl, on laws and principles (Logical laws and ethical principles: appendices to human reasoning), with 147 views.

Etikbloggen (Swedish) has 97 followers (26 WordPress followers and 71 e-mail followers). The blog published 41 posts. It had 8.103 views and 5.170 visitors (with 1,27 views per visitor). Visitors came mostly from Sweden (6.855 views), USA (611 views) and Finland (234 views) followed by Norway, the Netherlands and United Kingdom (with above 20 views each).

The most popular post was written by Pär Segerdahl. It dealt with people's fear of GMO's (Om rädslan för genmodifierade organismer... och om etik i tiden) and had 889 views, followed by another post by him on the nature of Philosophy (Vad är filosofi) 271. The third most popular post was written by Li Jalmzell about results from her thesis work showing that children with cancer want to talk about death (Våga prata om döden med svårt sjuka barn) with 268 visitors.

Ethics blogs in print

2014 we decided to print a collection of blog posts to reach the part of our target group who are not familiar with social media. The books (Tänker om etik and Thinking about ethics) were distributed in our networks as a Christmas present, both in print and electronically. The blogs have since increased their following and we have received very positive feedback. Both books are available electronically on our website.

In 2015, the English version of the book was re-printed and distributed to 300 participants at a conference on personalized medicine arranged by BBMRI.nl where one of the sessions dealt with how the clinical and biomedical research fields (should) interact with patients and patient advocacy groups.

Public debate

Part of the role as expert is participating in the public debate. Many researchers and PhD students write for the ethics blog, but also for daily press and journals for professionals. For example:

- Mats G. Hansson, Anna-Sara Lind and others signed a debate article in Svenska Dagbladet stating that openness in research damages the chances for future patents (Öppenheten förstör chansen till patent, Svenska Dagbladet Debatt, 21 June 2015)
- A debate article on the fact that the Swedish constitution states that everyone has equal value was signed by 19 lawyers, including Moa Kindström Dahlin and Anna-Sara Lind from CRB. (Stå upp för allas lika värde – grundlagen kräver det, Dagens Nyheter Debatt, 16 September 2015).
- Stefan Eriksson was quoted on Swedish television's news website about ethics approval for research (Hemliga forskningen "borde ha etikprövats", SVT Nyheter, 16 March 2015). He was also quoted in a blog post on research ethics for Stockholm University (Forskningsetik, Rektorsbloggen Stockholms universitet, 28 January 2015).
- Jessica Nihlén Fahlquist wrote a blog post for the labour union Unionen's section on Industry and Technology about taking ethical responsibility (Att ta etiskt ansvar, Unionen, industri och teknik, December 2015), that was re-posted on the Ethics Blog in both Swedish and English. She has also taken part in the Swedish public radio's science programmes, discussing vaccines and gene editing (CRISPR) ("Lyhörda experter kan bättre övertyga vaccinskeptiker", Vetenskapsradions veckomagasin, Sveriges Radio P1, 5 November 2015, and "Första genförändrade embryot väcker debatt" in Vetandets värld, Sveriges Radio P1 24 April 2015).

Media coverage

In 2015, Tove Godskesen and Li Jalmsell defended their theses on issues that were relevant to the research community, health care professionals and the public. Together with the press office at Uppsala University, we issued press-releases that generated a lot of interest:

- Tove Godskesen's thesis on why cancer patients participate in Phase I and Phase III clinical trials was mainly picked up by professional media in Sweden and Norway (Science Nordic, Forskning.no, Läke-medelsvärlden, Life Science Sweden, Vårdfokus, Läkartidningen and Dagens Medicin), but also by daily press (Uppsala Nya Tidning) focusing on cancer patients having too much faith in trial drugs, that hope for miracles can get in the way of closure, that severely ill patients misunderstand the purpose of clinical trials, that patients have unrealistic expectations, lack knowledge and that it is important they receive correct information.
- Li Jalmsell's thesis on palliation for children with cancer in a family perspective received coverage by national public service television news and was picked up by the news agency TT, and subsequently picked up

by local news media. It also received attention by professional news media (Dagens Medicin, Onkologi i Sverige, Medical press). Headlines mostly repeated the TT message that cancer-stricken children want the truth, but some picked up other aspects, for example how to talk to children who have terminal cancer, or that children with cancer want to know more about their disease.

- Neuroethics and epigenetics also received some attention. Kathinka Evers was interviewed about Neuroethics in 3:AM Magazine in December 2015. She was also interviewed by Swedish radio's Vetenskapsradions veckomagasin in relation to the epigenetics workshop in March 2015, which also covered other aspects of the epigenetics conference.

Biobank perspectives newsletter

In 2014 we launched a newsletter on biobank ethics and law. This newsletter is mainly published electronically (both pdf and html) and is distributed via e-mail to around 4.000 recipients. The newsletter discusses biobank regulation and presents research results to the biobanking community. It is part of our ELSI-service within BBMRI.se. The newsletter has been very well received and in 2015, we published 4 issues.

The first issue (1:2015) covered the European data protection regulation, new books with collections of texts and reflections from the Ethics Blog, an anthology about the regulation of biobank research and a new type of online research ethics training for medicine & the life sciences.

The second issue (2:2015) covered the book "Information and law in transition" that deals with the legal, ethical and political concerns that new information and communication technologies create in different fields, including welfare, health and research. Anna-Sara Lind provided an update on the development of Swedish research database legislation. Mats G. Hansson introduced readers to trust based consent as a model for informed consent that could protect the integrity and interests of participants, future patients and researchers. We also wrote about a recent paper in Bioethics that discusses returning risk information to people who participate in genetic research.

The third issue (3:2015) presented a statement paper in the American Journal of Bioethics that suggests using broad consent for biobank research. We took readers through the European Union's efforts to agree on data protection and the launch of B3Africa that will bridge European and African biobanking and biomedical research. We also announced that the International Charter of principles for sharing bio-specimens and data received a recommendation from the International Rare Diseases Research Consortium IRDiRC.

In the fourth issue (4:2015), Moa Kindström Dahlin gave her perspective on the ELSI common service BBMRI-ERIC provides and how legal frame-

works are interconnected with ethical and social issues. Anna-Sara Lind gave an update about what happens now that the European Court of Justice ruled that the Safe Harbour Clause is no longer a legally valid ground for sharing data between EU and the US. We also wrote about two PhD projects looking at how participants in the Swedish SCAPIS study perceive risk information and what and how they would like to know about their potential individual risks for disease and disorders.

We are planning four issues in 2016, in the first issue, Jane Reichel gives us her view on how the EU-US Privacy Shield will ensure safe harbours for data transfer in the future. We also report how direct-to-consumer genetic testing companies lack clear consent procedures for biobanking and research. Soon, these tests might become difficult to market and offer in Europe, with the European Commission proposing changes to the European Directive on in vitro diagnostic medical devices. Readers will also be able to read about how challenges to informed consent posed by rare disease research and how RD-Connect researchers proposes to meet them. On behalf of the CHIPme COST Action network, we invite readers to a workshop on genetic data in public research databases in Bolzano, Italy in April 2016.

CODEX – Rules and guidelines for research

Together with the Swedish Research Council, we are running the CODEX website (www.codex.vr.se) with rules and guidelines for research. The site is available in both Swedish and English.

The aim is to give researchers and other interested parties access to and information on the guidelines, ethics codes and laws that regulate and place ethical demands on the research process. One can search for a specific document or ones originating from a certain author ("Rules and guidelines"). Short introductions to issues in research ethics create a certain coherence and help those looking for a quick overview ("About research ethics"). There are weekly news updates from the world of research ethics.

CODEX first and foremost addresses those who are actively involved in research, but is also tailored to the interested public. No previous knowledge is needed to understand the website's contents.

Stefan Eriksson, Associate Professor of Research Ethics, developed the site in 2000. In 2004, the Swedish Research Council became involved to ensure the website can be maintained and continue to develop. Stefan Eriksson is currently the editor and runs the site with the aid of Mirko Ancillotti.

CODEX had 98 817 unique visitors in 2015. The number of visitors clearly increased from the previous year. The weekly record is 4 435 unique visitors. Visitors are mainly from Sweden, but circa 80 countries are represented – most of them coming from Germany, the Netherlands, Italy and Finland (in that order). Swedish readers are predominantly from Universities and other schools, but also from authorities. An increasing number of visitors

bookmark CODEX: 61 % go directly to the website, in other cases via link from another website (6 %) or through a search engine (32 %). 1 453 pages link to CODEX.

Clinical Nutrition and Metabolism

Research Group Leader Professor Tommy Cederholm

Research profile

Metabolic and dietary interaction during health and disease is the research focus at CNM. Within this overall focus there are several research pathways, *i.e.* 1) clinical disease- and age-related nutrition, which includes understanding of catabolic processes, consequences and treatment related to undernutrition, cachexia and sarcopenia in hospital, elderly care and community settings, 2) preventive nutrition and metabolism, including nutritional epidemiology, obesity and metabolic intervention trials for elucidating effects on insulin sensitivity, body composition and cardio-vascular risk factors, 3) food intake and dietary patterns relation to various health outcomes mainly in elderly people from various population cohorts.

Fatty acid (FA) and carbohydrate metabolism, inflammation, dietary interventions, dietary assessment, energy metabolism, body composition measurements and implementation techniques are examples of methodology expertise. CNM has laboratories that analyze FA profiles in various tissues by gas-chromatography and measure body composition by air-displacement and bioelectrical impedance, and energy expenditure.

Members of the group 2015

	<i>Academic title</i>	<i>Professional title</i>
Tommy Cederholm	Professor	MD
Ulf Risérus, deputy	Associate professor	Researcher
Per Sjögren	Associate professor	Researcher
Brita Karlström	Professor emeritus	Dietitian
Bengt Vessby	Professor emeritus	MD
Ulf Holmbäck	Postdoc	Researcher
Anja Saletti	Postdoc	Dietitian
Afsaneh Koochek	Postdoc	Dietitian
Matti Marklund	Postdoc	Researcher
Birgit Vahlberg	Postdoc	Physiotherapist
David Iggman	PhD	MD

Johanna Törmä	PhD student	Dietitian
Sigvard Sobestiansky	PhD student	MD
Erika Olsson	Licentiat student	Dietitian
Erika Ax	PhD	Nutritionist
Fredrik Rosqvist	PhD student	Nutritionist
Zayed Alsharari	PhD student	Nutritionist
Mikael Karlsson	PhD student	Dietitian
Åsa von Berens	PhD Student	Dietitian
Elisabeth Skoglund	PhD student	MD
Roger Olsson		Lecturer/Universitetsadjunkt
Siv Tengblad		Laboratory technician
Marie Berglund		Research assistant

Partly affiliated or associated to CNM

Wulf Becker	Associate professor	Chief nutritionist
Elisabet Rytter	Postdoc	Nutritionist
Helena Bjermo	Postdoc	Nutritionist
Stefan Branth	Postdoc	MD
Anders Forslund	Postdoc	MD
Anders Sjödin	Associate professor	MD
Annika Smedman	Postdoc	
Linda Bratteby		Physiotherapist
Viola Adamsson	PhD	
Torbjörn Åkerfeldt	PhD student	MD

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Other articles 2013-2015

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Dissertations 2015

- David Iggman. *Dietary fatty acids and cardiometabolic risk*. PhD, Medical sciences. Uppsala University.
- Erika Ax. *Dietary Patterns – Identification and health implications in the Swedish population*. PhD, Medical sciences. Uppsala University

Agencies that support the work/Funding (in SEK)

The Swedish Research Council (VR)	1 150 000
The Swedish Research Council (VR)	1 000 000
FORTE	550 000
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EXODIAB strategic research grant	300 000
Uppsala County Council – ALF	1 200 000
Stockholm County Council – ALF (The OmegAD Trial)	400 000
Nestec	2 500 000
Astra-Zeneca	200 000

Research projects

On-going projects

Epidemiological studies consider nutritional, metabolic and dietary factors, with special emphasis on biomarkers of fatty acid intake, in relation to long-term clinical outcomes, *e.g.* diabetes type 2, metabolic syndrome, cardiovascular disease as well as functional limitations, cognitive dysfunction, morbidity and mortality in young old and old old populations.

Clinical trials concern understanding of 1) sarcopenic *mechanisms* during disease and senescence, as well as potential effects of designed amino acid solutions and vitamin D either alone or in combination with physical exercise, to sarcopenic old adults, and 2) fatty acid effects in type 2 diabetes and obesity. [The importance and effects of exercise and nutrition on physical activity and body composition in post stroke patients](#) are studied.

Techniques of *implementation* to improve nutritional routines in elderly care are investigated.

Intervention trials in order to understand metabolic effects of healthy Nordic diet and by providing various fat qualities *i.e.* saturated *vs.* mono- and polyunsaturated fatty acids are performed in single-center as well as in larger multi-center controlled studies in order to assess effects on insulin resistance, inflammation, body composition, liver fat and other cardiovascular risk factors.

Emphasis is laid on studying *dietary patterns* and their relation to health outcomes, like cancer, cognition and sarcopenia, but also to identify underlying dietary patterns in the Swedish population. Relations between dietary patterns and exposure to environmental toxins are studied. Telomer changes during ageing are analyzed in cohort studies.

Obesity, especially child obesity, is explored by metabolic characterization of insulin resistance, energy metabolism, and body composition. Sleep pattern effects and disturbed circadian rhythm effects on glucose metabolism are studied.

Studies are performed in *wide-spread collaboration* with other research groups locally, nationally and internationally.

Future promising research at CNM

- Understanding sarcopenia from clinical, epidemiological and molecular perspectives, and its treatment
- Implementation techniques of nutritional routines and development of assessment tools for meals in elderly care
- Dietary patterns and potential effects on development of cognitive impairment and sarcopenia
- Omega-3 fatty acid effects on epigenetic markers, mononuclear blood cell gene expression and effects on inflammation resolution
- Fatty acid effects on gene expression, insulin sensitivity, inflammation, and body composition, including lean body mass and fat distribution (ectopic fat accumulation)
- Role of diet in preventing non-alcoholic fatty liver disease (NAFLD)
- Molecular and metabolic understanding behind favorable effects of energy restriction in type 2: use of functional imaging
- Relation between carbohydrate intake and fatty acid profiles and central obesity in 60 year old community-dwelling subjects.
- Impact of structural membranes for health effects by milk products.
- Dietary patterns and exposure to environmental toxins.
- Telomere functions in ageing
- Nutritional impact on metabolomics
- Cardiometabolic, transcriptomic and epigenetic effects of a healthy Nordic diet
- Effects on well-being and physical activity by prescribed walking exercise using encouragement by SMS in patients after stroke
- Potential Vitamin D relations with health outcomes like cognition and sarcopenia in old adults
- Individualized treatment of child obesity

Clinical Psychology in Healthcare

Research Group Leader professor Louise von Essen

With the help of the Swedish Government's funding of the Uppsala University Psychosocial Care Program: U-CARE, Uppsala University has been given the possibility to support our research group. The overarching goal of our research is to promote psychosocial health among patients struck by somatic disease and their significant others, hopefully at a lower cost to the benefit of individuals and society. To reach our aims we mainly use knowledge from the academic disciplines Economics, Implementation Sciences, Information Systems, and Psychology.

Members of group and external partners 2015

Members of group

<i>Name</i>	<i>Position/s in group</i>	<i>Academic title/s</i>	<i>Department/University</i>
Professor			
Louise von Essen	Professor, Research Group Leader, Programdirector for U-CARE	Associated professor, PhD, MSc in Psychology, Licensed Psychologist	Department of Public Health and Caring Sciences, Uppsala University
Researchers			
Maria Andr� Gottvall	Researcher	PhD, Registered Nurse	Department of Public Health and Caring Sciences, Uppsala University and Red Cross University College
Erebouni Arakelian	Researcher	PhD, Registered Nurse	Department of Public Health and Caring Sciences and Department of Surgical Sciences, Uppsala

			University
Martin Cernvall	Researcher	PhD, MSc in Psychology, Licensed Psychologist	Department of Public Health and Caring Sciences, Uppsala University
Helena Grönqvist	Researcher, Research-coordinator for U-CARE	PhD, MSc in Cognitive Sciences	Department of Public Health and Caring Sciences, Uppsala University
Claes Held	Researcher	Associate professor, PhD, MD	Uppsala Clinical Research Centre, Uppsala University
Emma Hovén	Researcher	PhD, MSc in Behavioral Sciences	Department of Public Health and Caring Sciences, Uppsala University and Karolinska Institutet
Birgitta Johansson	Researcher	Associate professor, PhD, Registered Nurse	Department of Public Health and Caring Sciences and Department of Immunology, Genetics, and Pathology, Uppsala University
Annika Lindahl Norberg	Researcher, Director for U-CARE Healthcare	Associate professor, PhD, MSc in Psychology, Licensed Psychologist	Department of Public Health and Caring Sciences, Uppsala University and Karolinska Institutet
Elisabet Mattsson	Researcher	Associate professor, PhD, Registered Nurse, Registered Midwife	Department of Public Health and Caring Sciences, Uppsala University and Akademiska Sjukhuset Uppsala
Gunilla Mårtensson	Researcher	Associate professor, PhD, Registered Nurse	Department of Public Health and Caring Sciences, Uppsala University
Erik Olsson	Researcher	Associate professor, PhD, MSc in Psychology, Licensed Psychologist	Department of Public Health and Caring Sciences, Uppsala University
Jonas Sjöström	Researcher, IT-coordinator for U-CARE	PhD, MSc in Information Systems	Department of Public Health and Caring Sciences and

			Department of Informatics and Media, Uppsala University
Anna Wikman	Researcher	Associate professor, PhD, MSc in Health Psychology, MSc in Research Methods in Psychology	Department of Public Health and Caring Sciences, Uppsala University
PhD students			
Sven Alfonsson	PhD student	PhD, MSc in Psychology, Licensed Psychologist	Department of Public Health and Caring Sciences, Uppsala University
Malin Ander	PhD student	MSc in Psychology	Department of Public Health and Caring Sciences, Uppsala University
Anders Brantnell	PhD student	MSc in Political Sciences	Department of Public Health and Caring Sciences, Uppsala University
Mudassir Imran Mustafa	PhD student	MSc in Information Systems	Department of Informatics and Media, Uppsala University
Laura Kukkola	PhD student	MSc in Psychology	Department of Public Health and Caring Sciences, Uppsala University
Lisa Ljungman	PhD student	MSc in Psychology, Licensed Psychologist	Department of Public Health and Caring Sciences, Uppsala University
Ruth Lochan	PhD student	MSc in Information Systems	Department of Informatics and Media, Uppsala University
Susanne Mattsson	PhD student	Registered Nurse	Department of Public Health and Caring Sciences, Uppsala University
Hafijur Mohammad Rahman	PhD student	MSc in Information Systems	Department of Informatics and Media, Uppsala University

Anna Norén	PhD student	MSc in Economics	Department of Economics, Uppsala University
Fredrika Norlund	PhD student, Director for U-CARE Healthcare	MSc in Psychology, Licensed Psychologist, Licensed Psychotherapist	Department of Public Health and Caring Sciences, Uppsala University
Teolinda Toft	PhD student	BSc in Social Work	Department of Public Health and Caring Sciences, Uppsala University
John Wallert	PhD student	MSc in Psychology, Licensed Psychologist	Department of Public Health and Caring Sciences, Uppsala University
Emma Wallin	PhD student	MSc in Psychology, Licensed Psychologist	Department of Psychology, Uppsala University
Mattias Öhman	PhD student	MSc in Economics	Department of Economics, Uppsala University
System Developers			
Fabian Holmberg	System Developer	BSc in Computer Sciences	Department of Public Health and Caring Sciences, Uppsala University
Ian Horne	System Developer	MSc in Applied Technology	Department of Public Health and Caring Sciences, Uppsala University
Mattia Tomasoni	System Developer	MSc in Computer Sciences	Department of Public Health and Caring Sciences, Uppsala University
Research assistants			
Marika Boger	Research assistant	MSc in Psychology	Department of Public Health and Caring Sciences, Uppsala University
Marina Forslund	Research assistant	MSc in Nutrition	Department of Immunology, Genetics, and Pathology, Uppsala University
Malin	Research	BSc in Public Health	Department of Public

Fridlund	assistant	Sciences	Health and Caring Sciences, Uppsala University
Project administrator			
Kata Bordas	Project administrator	MSc in Business and Management	Department of Public Health and Caring Sciences, Uppsala University
Research partner			
Annica Persson	Research partner		Department of Public Health and Caring Sciences, Uppsala University
Master student			
Ylva Hägg Sylvén	Master student	BSc in Technology	Department of Public Health and Caring Sciences, Uppsala University

External partners

<i>Name</i>	<i>Task/s in group</i>	<i>Academic title/s</i>	<i>Department/University</i>
Researchers			
Theo van Achterberg	Researcher	Professor, PhD, MSc in Health Sciences, Registered Nurse	Department of Public Health and Primary Care, KU Leuven, Leuven, Belgium
Enrico Baraldi	Researcher	Professor, PhD, MSc in Business Administration	Department of Engineering Sciences, Uppsala University
Gunilla Burell	Researcher	Associate professor, PhD	Department of Public Health and Caring Sciences, Uppsala University
Per Carlbring	Researcher	Professor, PhD, Licensed Psychologist	Department of Psychology, Stockholm University
Maria Carlsson	Researcher	Associate professor, PhD, Registered Nurse	Department of Public Health and Caring Sciences, Uppsala University
JoAnne Dahl	Researcher	Professor, PhD, Licensed Psychologist,	Department of Psychology, Uppsala

		Licensed Psychotherapist	University
Matz Dahlberg	Researcher	Professor, PhD, MSc in Economics	Department of Economics and Institute for Housing and Urban Research, Uppsala University
Jenny Eriksson Lundström	Researcher	PhD, MSc in Information Systems	Department of Informatics and Media, Uppsala University
Paul Farrand	Researcher	Professor, PhD, BSc Psychology	College of Life and Environmental Sciences, University of Exeter, Exeter, UK
Inna Feldman	Researcher	PhD, MSc in Mathematics	Department of Women's and Children's Health, Uppsala University
Andy Gibson	Researcher	Associate professor, PhD, MSc in Sociology	Department of Health and Social Sciences, University of the West of England, Bristol, UK
Erik Grönqvist	Researcher	PhD, MSc in Social Sciences	Department of Economics and Institute for Housing and Urban Research, Uppsala University
Lena Hedén	Researcher	PhD, Registered Nurse	Department of Women's and Children's Health, Uppsala University
Fredrik Holländare	Researcher	PhD, MSc in Psychology, Licensed Psychologist	Psychiatric Research Centre, Örebro County Council
Timo Hursti	Researcher	Associate professor, PhD, MSc in Psychology, Licensed Psychologist	Department of Psychology, Uppsala University
Thecla Kohi	Researcher	Associate professor, PhD, Registered Nurse	Muhimbili University of Health and Allied Sciences, School of Nursing, Dar es Salaam, Tanzania
Per Kristiansson	Researcher	Associate professor, PhD, MD	Department of Public Health and Caring Sciences, Uppsala University
Brjánn Ljótsson	Researcher	Associate professor, PhD, MSc in Psy-	Department of Clinical Neuroscience,

		chology, Licensed Psychologist	Karolinska Institutet
Gustaf Ljungman	Researcher	Associate professor, PhD, MD	Department of Women's and Children's Health, Uppsala University
Christine Rubertsson	Researcher	Associate professor, PhD, Registered Nurse, Registered Midwife	Department of Women's and Children's Health, Uppsala University
Robbert Sanderman	Researcher	Professor, PhD, MSc in Psychology, Licensed Psychologist	Faculty of Behavioural and Social Sciences and Faculty of Medical Science, University of Groningen, Groningen, the Netherlands
Agneta Skoog Svanberg	Researcher	Professor, PhD, Registered Nurse, Registered Midwife	Department of Women's and Children's Health, Uppsala University
Joanne Woodford	Researcher	Research Fellow, PhD, BSc Psychology	College of Life and Environmental Sciences, University of Exeter, Exeter, UK
Anna Cristina Åberg	Researcher	Associate professor, PhD, Licensed Physiotherapist	Department of Public Health and Caring Sciences, Uppsala University and School of Health and Social Studies, Dalarna University
Pär Ågerfalk	Researcher	Professor, PhD, MSc in Information Systems	Department of Informatics and Media, Uppsala University
PhD students			
Anna Hauffman	PhD student	Registered Nurse	Department of Radiology, Oncology and Radiation Science, Uppsala University
Tove Kamsvåg Magnusson	PhD student	MD	Department of Women's and Children's Health, Uppsala University
Jenny Thorsell	PhD student	MSc in Psychology, Licensed Psychologist	Department of Women's and Children's Health, Uppsala University
Research assistants			
Cathrine Bonnedahl	Research assistant	Registered Nurse	Department of Immunology, Genetics, and Pathology, Uppsala University

Golden Masika	Research assistant	Registered Nurse, MSc in Nursing Sciences	Muhimbili University of Health and Allied Sciences, School of Nursing, Dar es Salaam, Tanzania
Madeleine Olsson	Research assistant	Registered Nurse	Department of Immunology, Genetics, and Pathology, Uppsala University
Susanne Sjöberg	Research assistant	Registered Nurse	Department of Immunology, Genetics, and Pathology, Uppsala University

Publications from members of group 2013-2015

2015

Publications

1. **Alfonsson, S., Olsson, E., & Hursti, T.** (2015). The effects of therapist support and treatment presentation on the clinical outcomes of an Internet based applied relaxation program. *Internet Interventions*, 2, 289-296.
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 16. van Diepen, S., Tricoci, P., Podder, M., Westerhout, C.M., Aylward, P.E., **Held, C.**, van de Werf, F., Strony, J., Wallentin, L., Moliterno, D.J., White, H.D., Mahaffey, K.W., Harrington, R.A., & Armstrong, P.W. (2015). Efficacy and safety of vorapaxar in non-ST-segment elevation ACS patients undergoing non-cardiac surgery. *Journal of American Heart Association*. [Epub ahead of print].
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Half time controls and licentiate examinations 2015

Half time controls

- Brantnell, A. Barriers and Facilitators to the Implementation of Research-Based Healthcare Innovations. 20 October 2015. Department of Public Health and Caring Sciences, Uppsala University. Main supervi-

- sor: Professor Enrico Baraldi, Co-supervisors: Professor Theo van Achterberg, Professor Matz Dahlberg, and Professor Louise von Essen.
- Mattsson, S. Health-Related Support on the Internet among People with Cancer. 19 May 2015. Department of Public Health and Caring Sciences, Uppsala University. Main supervisor: Associate professor Maria Carlsson, Co-supervisors: Associate professor Birigitta Johansson and Associate professor Erik Olsson.
 - Mustafa, M.I. Designing Sustainable Information Systems: A System Developer's Perspective in the Context of eHealth Research. 12 November 2015. Department of Informatics and Media, Uppsala University. Main supervisor: PhD Jenny Eriksson Lundström, Co-supervisors: PhD Helena Grönqvist and PhD Jonas Sjöström,
 - Norlund, F. Psychological Distress in Coronary Heart Disease - Prevalence, Treatment and Cardiovascular Prognosis. 14 September 2015. Department of Public Health and Caring Sciences, Uppsala University. Main supervisor: Associate professor Claes Held, Co-supervisor: Associate professor Erik Olsson.
 - Wallin, E. Remote Ways to Deliver Psychological Treatment for Stigmatizing Problems. 27 November 2015. Department of Psychology, Uppsala University. Main supervisor: Professor JoAnne Dahl, Co-supervisors: Associate professor Claes Held, Associate professor Erik Olsson, and PhD Thomas Parling.

Licentiate examinations

- Norén, A. "Childcare and the Division of Parental Leave" and "Does Screening Pregnant Women for Alcohol Consumption Improve Child Health?". 12 June 2015. Department of Economics, Uppsala University. Main supervisor: Professor Matz Dahlberg, Co-supervisors: Professor Louise von Essen and PhD Erik Grönqvist.
- Öhman, M. "Be Smart, Live Long: The Relationship between Cognitive and Non-Cognitive Abilities and Mortality" and "Exogenous Health Information and Individuals' Subjective Well-Being: RD Evidence from a Screening-Program for an Asymptomatic Disease". 13 februari 2015. Department of Economics, Uppsala University. Main supervisor: Professor Matz Dahlberg, Co-supervisors: Professor Louise von Essen and PhD Erik Grönqvist.

Funding during 2015 - members of group (SEK)

Strategic Research Grant for U-CARE (Louise von Essen)	10 000 000
The Swedish Research Council for Health, Working life and Welfare (Erik Olsson 1 110 000; Birgitta Johansson 943 000)	2 053 000
The Swedish Research Council (Louise von Essen 1 500 000; Birgitta Johansson 480 000)	1 980 000
The Swedish Cancer Society (Louise von Essen 800 000; Birgitta Johansson 500 000; Anna Wikman 460 000)	1 760 000
The Swedish Childhood Cancer Foundation (Louise von Essen 500 000; Annika Lindahl Norberg 250 000; Emma Hovén 500 000)	1 250 000
The Vårdal Foundation (Erik Olsson)	631 000
Other funding (Erik Olsson 407 000; Birgitta Johansson 150 000)	557 000
Disciplinary Domain of Medicine and Pharmacy (U-CARE program 1 648 000; Emma Hovén 264 000)	1 912 000
In-kind support (approximately) from the departments of: Economics; Engineering Sciences; Immunology, Genetics, and Pathology; Informatics and Media; and Psychology, Uppsala University	1 700 000

During 2015 our main activities have been

- We have provided thirteen researchers and fifteen PhD students with stimulating career opportunities.
- Seven PhD students have passed their half-time controls or licentiate examinations.
- Two reserachers have been appointed Associate professors.
- We have recruited one Associate professor.
- We have recruited two PhD students.
- We have recruited one research assistant.
- We have recruited one research partner.
- We have associated two researchers.
- We have conducted the RCTs: AdultCan; Heart; and AIDA II via the U-CARE-portal.

- We have provided the infrastructure and support to enable the RCTs: ISAK, JUNO; and U-CARE Gravid and the observational study Uppsala Pelvic Pain Study to be conducted via the U-CARE-portal.
- We have involved patients and members of the public in our activities.
- We have held the fifth meeting with the U-CARE Scientific Advisory Board and all U-CARE members.
- We have consolidated and initiated national and international cooperations.
- We have held three research seminar series including one ‘stand-up’ serie.
- We have increasingly provided education at the undergraduate and master level at the Medical faculty and Faculty of Social Sciences, Uppsala University within the areas of Clinical psychology in healthcare; Care, self-care, and psychological treatment via the internet and mobile media; and Implementation of complex interventions in healthcare.
- We have provided PhD education within the area of Implementation of complex interventions in healthcare.
- We have taken active part in the EIT health work group regarding education.
- We have implemented responsive web design features on the U-CARE-portal, to make it compatible with mobile devices.

Research projects

Title: Cancer during adolescence: Psychosocial and health economic consequences

OVERALL AIM: To investigate short- and long-term psychological and economic consequences of adolescent cancer; compare the psychological and economic situation of those struck by cancer during adolescence vs. matched controls and investigate whether there are any positive psychological consequences of adolescent cancer.

METHODS: The project has a comparative, longitudinal design with eight measurements (up to now), from one month to ten years after diagnosis. Sixty-one adolescents were included. Inclusion has finished. Data from a control group of 300 healthy persons has been collected. Participants answered questions about quality of life, anxiety, and depression. Additionally those struck by cancer answered questions about costs, disease- and treatment-related distress, whether and if so how they coped with distress, and whether they experienced any negative and positive cancer-related consequences.

FUNDING: The project started 1999 and is funded by the Swedish Cancer Society and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.

Title: Occurrence and development of posttraumatic stress among parents of children diagnosed with cancer

OVERALL AIM: To investigate short- and long-term psychological and economic consequences of childhood cancer for parents of children diagnosed with cancer.

METHODS: The project has a longitudinal design with seven measurements (up to now), from one week after diagnosis to five years after end of treatment. Two hundred fifty parents were included. Inclusion has finished. Participants answered questions about *e.g.* posttraumatic stress, emotional support, the child's medical situation, and costs.

FUNDING: The project started 2002 and is funded by the Swedish Research Council, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.

Title: BETSY: Development, testing, and evaluation of an online guided cognitive behavioral-based intervention for parents of children with cancer

OVERALL AIM: To develop, test, and evaluate the clinical efficacy and cost-effectiveness of an online, guided cognitive behavioral self-help program to parents of children with cancer.

METHODS: The clinical efficacy and cost-effectiveness is evaluated with a randomized, controlled design. Inclusion has finished. Fifty-eight participants have been randomized to immediate access to a cognitive behavioral-based intervention or a wait-list control condition with delayed access to the intervention. Participants answered questions about *e.g.* posttraumatic stress, anxiety, depression, quality of life, and costs.

FUNDING: The project started 2008 and is funded by the Swedish Research Council, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.

Title: U-CARE: AdultCan. Development, testing, and evaluation of an online guided cognitive behavioral-based intervention for adults struck by cancer

OVERALL AIM: To develop, test, and evaluate the clinical efficacy and cost-effectiveness of an online, guided psychosocial intervention for adults diagnosed with cancer.

METHODS: The clinical efficacy and cost-effectiveness is evaluated with a randomized, controlled design. Adults with prostate-, breast- or localized colo- or rectal cancer are included and randomized to immediate access to the intervention or a control condition. Inclusion is ongoing. Participants answer questions about *e.g.* posttraumatic stress, anxiety, depression, quality of life, posttraumatic growth, and costs.

FUNDING: The project started 2012 and is funded by a strategic research grant to U-CARE, the Swedish Research Council, the Swedish Cancer Society, the Swedish Research Council for Health, Working Life and Welfare, and ALF funds. Principal investigator: Professor Louise von Essen. Responsible researcher: Associate professor Birgitta Johansson. Main applicant for external funding from the Swedish Research Council, the Swedish Cancer Society, and the Swedish Research Council for Health, Working Life and Welfare: Birgitta Johansson.

Title: Barriers and facilitators to the implementation of research-based healthcare innovations

OVERALL AIM: (1) To examine the actors and factors influencing implementation of university-based healthcare innovations, prior to implementation and during implementation. (2) To understand how the actors and factors can act as facilitators and barriers for implementation prior to implementation and during implementation.

METHODS: Case study and comparative observational designs are employed. The project consists of four studies. Respondents from Sweden and US have been interviewed and the data has been analyzed with qualitative methods. Healthcare providers from Sweden and the Netherlands have answered structured questions and the data will be analyzed with quantitative descriptive methods.

FUNDING: The project started 2012 and is funded by a strategic research grant to U-CARE and the Disciplinary Domain of Medicine and Pharmacy, Uppsala University. Principal investigator: Professor Louise von Essen.

Title: U-CARE: Heart. Development, testing, and evaluation of an online guided cognitive behavioral-based intervention for adults struck by myocardial infarct

OVERALL AIM: To develop, test, and evaluate the clinical efficacy and cost-effectiveness of an online, guided psychological intervention for adults struck by a myocardial infarct.

METHODS: The clinical efficacy and cost-effectiveness is evaluated with a randomized, controlled design. Adults struck with a myocardial infarct are included and randomized to immediate access to the intervention or a control condition. Inclusion is ongoing. Participants answer questions about *e.g.*

posttraumatic stress, anxiety, depression, quality of life, posttraumatic growth, and costs.

FUNDING: The project started 2012 and is funded by a strategic research grant to U-CARE, ALF funds, the Swedish Research Council for Health, Working Life and Welfare, the Vårdal Foundation, and the Swedish Heart-Lung Foundation. Principal investigator: Professor Louise von Essen. Responsible researcher: Associate professor Claes Held. Main applicant for external funding from the Swedish Research Council for Health, Working Life and Welfare and the Vårdal Foundation: Associate professor Erik Olsson.

Title: U-CARE: YoungCan. Development, testing, and evaluation of an online guided cognitive behavioral-based intervention for young people struck by cancer during adolescence

OVERALL AIM: To develop, test, and evaluate the clinical efficacy and cost-effectiveness of an online, guided psychological intervention for young people diagnosed with cancer during adolescence.

METHODS: Feasibility aspects have been investigated with a pre-post within-group design. The clinical efficacy will be evaluated with a controlled design. Outcome measures for the controlled study are not yet decided.

FUNDING: The project started 2012 and is funded by a strategic research grant to U-CARE, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.

Title: Adherence in Psychotherapy (The AIDA studies)

OVERALL AIM: To investigate factors influencing adherence and motivation in psychotherapy. The first study investigated whether enriched treatment material presentation and/or increased frequency and quality of support increased participants' adherence to an online treatment program and to prescribed homework assignments. In a follow-up study the effect of therapy-format (online or face-to-face) on adherence and motivation was studied.

METHODS: In the first study 162 participants with problems of stress or worry went through a therapist guided internet-based applied relaxation program. Participants were randomized to either enhanced or normal intervention presentation or enhanced or normal support. The follow-up study included 100 student participants randomized to a very brief intervention delivered either via the internet or face-to face. Data collection is completed. Main outcome variables were progress through the intervention and adherence to prescribed exercises.

FUNDING: The project started 2013 and is funded by a strategic research grant to U-CARE and the Disciplinary Domain of Medicine and Pharmacy, Uppsala University. Principal investigator: Sven Alfnsson.

Title: PETRA: Development and testing of face-to-face cognitive behavioral therapy for parents of children previously treated for cancer

OVERALL AIM: To develop and test the clinical efficacy of face-to-face cognitive behavioral therapy for parents of children previously treated for cancer.

METHODS: The clinical efficacy has been evaluated with an uncontrolled, within group design where cognitive behavioral therapy was given to 15 participants. Inclusion has finished. Each participant received 10-15 sessions of face-to-face therapy. Participants answered questions about posttraumatic stress, anxiety, experiential avoidance, depression, and quality of life and unstructured interview questions about suffering.

FUNDING: The project started 2013 and is funded by the Swedish Research Council, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.

Title: A Swedish national follow-up study of physical and mental health among young adults born 1990-1992 with extremely low birth weight (<1001 g)

OVERALL AIM: To investigate the physical and mental health of a cohort of young adults born with extremely low birth-weight (ELBW).

METHODS: The participants are survivors in a national cohort of 633 consecutive live-born infants with a birth weight of < 1001 g born April 1990 to March 1992 in Sweden. 59% survived up to one year. The cohort will be compared to a matched control group born at term with normal birth weight. Participants answer questions online about mental health, transition to adulthood, educational achievement, social competence and behaviour. Long-term metabolic-, and cardio-vascular health and body composition is investigated in a subgroup living close Uppsala University hospital.

FUNDING: The project started 2014 and is *e.g.* funded by Josephine Neimans Fund 2014. Principal investigator: Consultant Neonatologist, PhD Barbro Diederholm, Department of Women's and Children's Health, Uppsala University. Co-investigator from Clinical Psychology in Healthcare: PhD Helena Grönqvist.

Title: MAYA: Development and testing of face-to-face cognitive behavioral therapy for young people diagnosed with cancer during adolescence

OVERALL AIM: To develop and test the clinical efficacy of face-to-face cognitive behavioral therapy for young people diagnosed with cancer during adolescence.

METHODS: The clinical efficacy has been evaluated with an uncontrolled, within group design where cognitive behavioral therapy was given to 11 participants. Each participant received 10-15 sessions of face-to-face therapy. Participants answered questions about posttraumatic stress, anxiety, experiential avoidance, depression, and quality of life and unstructured interview questions about suffering.

FUNDING: The project started 2014 and is funded by a strategic research grant to U-CARE, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.

Title: Myocardial Infarction and Mental Health (MIMH): Emotional distress and physical activity and its impact on major adverse cardiac events and survival after myocardial infarction 2006–2016: A register-based study

OVERALL AIM: To investigate the prevalence and the possible cardiovascular consequences of emotional distress, cognitive ability, and health behaviors among patients with a previous myocardial infarction (MI).

METHODS: Data from the Swedish quality registries of cardiovascular care (SEPHIA and RIKS-HIA), the National Patient Register, the Causes of Death Register, the Swedish Prescribed Drug Register and the Swedish Conscriptio register are collected in a cohort that have had a MI between 2006 and 2013. In the project several associations between emotional distress, cognitive ability, health behaviors, and cardiovascular morbidity and mortality are analyzed. For example the association between emotional distress and later morbidity is examined in which the mediator role of health behaviors is investigated. Another example is the role of cognitive ability at young adulthood's impact on later health behaviors and mortality.

FUNDING: The project started 2014 and is funded by a strategic research grant to U-CARE, the Swedish Research Council for Health, Working Life and Welfare, and the Vårdal Foundation. Principal investigator: Erik Olsson.

Title: Secondary Prevention in Uppsala Primary Health Care Project (SUPRIM): A randomized controlled study of stress-management treatment, based on CBT principles, to prevent

recurrent cardiovascular events in patients with Coronary Heart Disease

OVERALL AIM: To study whether self-rated emotional distress and biomarkers are affected by participation in a stress-management treatment based on CBT principles in patients with Coronary Heart Disease.

METHOD: Data from the SUPRIM project is used in which patients below 75 years were randomized either to twenty sessions of stress-management or standard care. Self-assessment of stress, vital exhaustion, anxiety and depression and biomarkers for *e.g.* inflammation were collected at five occasions during two years.

FUNDING: The project started 2014 and is funded by a strategic research grant to U-CARE. Principal investigator: Professor Kurt Svärdsudd, Co-investigators from Clinical Psychology in Healthcare: Claes Held and Erik Olsson

Title: SibCan: Development, testing, and evaluation of an internet based psychosocial intervention for adolescent and young adult siblings of young persons struck by cancer

OVERALL AIM: To develop a clinically relevant and theoretically well-founded psychosocial support model for adolescent and young adult siblings of young persons diagnosed with cancer.

METHODS: Data on siblings' experiences, psychological reactions and needs are collected through group and individual interviews, and web based communication, analysed with qualitative methods, as well as a thorough literature review. The psychosocial support model emerges in a dialogue between lived experience and theory, in a process involving researchers in psychology and information systems, psychosocial clinicians, and sibling research partners. The clinical efficacy and cost-effectiveness of the support model will be evaluated in a controlled study.

FUNDING: The project started 2014 and is funded by a strategic research grant to U-CARE, the Swedish Childhood Cancer Foundation, and the Kempe-Carlgrén fund. Principal investigator: Associate professor Annika Lindahl Norberg.

Title: ParentsCan: Development, testing, and evaluation of an online, psychological self-help program for parents of children successfully treated for cancer

OVERALL AIM: To develop, test, and evaluate an online psychological self-help program for parents of children previously treated for cancer.

METHODS: A Participatory Action Approach is used to develop the self-help program and the procedures for a controlled study in which the pro-

gram's clinical efficacy will be evaluated. The feasibility of the program and the intended procedures will be tested in a study with a pre-post within-group design.

FUNDING: The project started 2015 and is funded by the Swedish Research Council and the Swedish Cancer Society. Principal investigator: Professor Louise von Essen.

Disability and Habilitation

Research Group Leader Professor Karin Sonnander

Disability is defined as the gap between what the environment demands and the impairment or health condition of a person. Persons with disabilities often experience extensive difficulties in everyday life entailing insufficient equality and participation and significant differences in living conditions compared to the general population. Since the 1980's the medical perspective has subsequently been replaced by a bio-psycho-social perspective. Today the environment (from architecture to attitudes) has a key-role for a person's well-being, activity and participation. Specialised counselling, support, services and treatment to children, young people and adults with disabilities is provided by out-patient habilitation services. Research in Disability and Habilitation is interdisciplinary and multi-professional with a fundamental focus on the interface between the individual and his/her physical, social and societal environment. Research activities elucidate environmental aspects as facilitators and barriers for persons with disabilities *e.g.* adults with intellectual disability, mental health disorder or aphasia, children with significant developmental delay, as well as children at risk of neglect.

There are three main research tracks

1. Development and test of assessment methods, interventions and documentation in services for people with disabilities
2. The significance of received targeted support for self-perceived health
3. Participatory research

in which the facilitating and restraining aspects of the environment as well as the participation and perspectives of persons with disabilities, professionals and significant others are highlighted.

Members of the group during 2015

Päivi Adolfsson, PhD, associated researcher

Johan Glad, BA, PhD Faculty of Medicine, associated researcher

Gunnel Janeslätt, PhD Faculty of Medicine, associated researcher

Kjerstin Larsson, PhD faculty of Medicine, associated researcher
Helena Lindstedt, PhD Faculty of Medicine, associated researcher
Mia Pless, PhD Faculty of Medicine, associated researcher
Ieva Reine, PhD Faculty of Medicine, associated researcher
Karin Sonnander, PhD, professor
Helena Tegler, BA, PhD student
Annika Ternér, Med Lic, Faculty of Medicine, associated researcher
Öie Umb-Carlsson, PhD Faculty of Medicine, senior researcher
Helena Wandin, BA, PhD student

External partners

- Heléne von Granitz, PhD student, Health Service Research, Department of Public Health and Caring Sciences, Uppsala University
- Ann-Britt Ivarsson, PhD Faculty of Medicine, associate professor, School of Health and Medical Sciences, Örebro University
- Kine Johansen, PhD student, Department of Women's and Children's Health, Pediatrics, Uppsala University
- Per Lindberg, PhD, professor, Department of Psychology, Uppsala University
- Steven Lucas, PhD Faculty of Medicine, Pediatrics, Department of Women's and Children's Health, Uppsala University
- Margaretha Magnusson, PhD Faculty of Medicine, Pediatrics, Department of Women's and Children's Health, Uppsala University
- Liselotte Norling Hermansson, PhD Faculty of Medicine, Clinical Research Centre, Örebro University Hospital, Örebro
- Edward Palmer, PhD, adjunct professor, Department of Economics, Uppsala Center for Labor Studies, Uppsala University
- Kristina Persson, PhD Faculty of Medicine, Pediatrics, Department of Women's and Children's Health, Uppsala University
- Ingvor Pettersson, PhD Faculty of Medicine, senior lecturer, School of Health and Medical Sciences, Örebro University
- Anna Sarkadi, PhD Faculty of Medicine, associate professor, Pediatrics, Department of Women's and Children's Health, Uppsala University
- Barbro Wadensten, PhD Faculty of Medicine, associate professor, Caring Sciences, Department of Public Health and Caring Sciences, Uppsala University
- Ulrika Winblad Spångberg, PhD, associate professor, Health Services Research, Department of Public Health and Caring Sciences, Uppsala University

Publications 2013-15

2013

1. Bolic V, **Lidström H**, Thelin N, Kjellberg A, Hemmingsson H. (2013). Computer use in educational activities by students with ADHD. *Scandinavian Journal of Occupational Therapy*, 20 (5), 357-364.
2. **Reine, I**, Novo, M, Hammarström, A. (2013). Unemployment and ill health - a gender analysis. Results from a 14-year follow-up of the Northern Swedish cohort. *Public Health*. Mar; 127(3):214-22.
3. **Reine, I**. (2013). Does personal assistance enable people to live normal lives? *European Journal of Public Health* 23 (suppl 1): 217 (Meeting abstract).
4. **Blom Johansson, M.**, Carlsson, M., Östberg, P. & **Sonnander, K.** (2013). A multiple-case study of a family-oriented intervention practice in the early rehabilitation phase of persons with aphasia. *Aphasiology*, 27 (2): 201-226.
5. **Lindstedt, H.** & **Umb-Carlsson, Ö.** (2013). Cognitive assistive technology and professional support in everyday life for adults with ADHD. *Disability and Rehabilitation: Assistive Technology*, 8 (5), 402-08.
6. **Lidström, H.** (2013). *Computer-based assistive technology device for use by students with disabilities in mainstream schools*. In Emiliano PL et al, editor. *Assistive Technology from Adapted Equipment to Inclusive Environments AAATE Netherlands*: IOS Press; pp 565-570.
7. **Eriksson, G.**, Baum, C., Wolf, T., & Tabor Connor, L. (2013). Perceived participation after stroke: the influence of activity retention, reintegration and perceived recovery. *American Journal of Occupational Therapy* November 1, 67: 616-623.
8. Heiwe, S., Nilsson-Kajermo, K., Olsson, M., Gåfvells, C., **Larsson, K.** & Wengström, Y. (2013). Evidence-based practice among medical social workers. *Social Work in Health Care*, 52 (10) 947-58.

2014

9. **Glad, J.**, Anders Kottorp, Jergeby, U., Gustafsson, C. & **Sonnander, K.** (2014). Psychometric properties of the HOME-Inventory using Rasch analysis. *Research on Social Work Practice*, 24 (2): 235-246.
10. **Glad, J.**, Jergeby, U., Gustafsson, C. & **Sonnander, K.** (2014). Social worker and teacher apprehension of children's stimulation and support in the home environment and care-giver perception of the HOME Inventory in Sweden . *British Journal of Social Work*, 44 (8): 2218-2236.

11. **Janeslätt, G.**, Kottorp, A. & Granlund, M. & (2014). Evaluating intervention using time aids in children with disabilities. *Scandinavian Journal of Occupational Therapy*, 21 (3): 181-90.
12. **Janeslätt, G.**, **Lindstedt, H.** & **Adolfsson, P.** (2014). Daily time management and influences of environmental factors on use of electronic planning devices in adults with mental disability. *Disability and Rehabilitation Assistive Technology* (Epub ahead of print).
13. **Wandin, H.**, Lindberg, P. & **Sonnander, K.** (2014). Communication intervention in Rett syndrome: a survey of speech language pathologists in Swedish health services. *Disability and Rehabilitation* (E-published ahead of print).
14. Bertilsson, A-S., Ranner, M., von Koch, L. & **Eriksson, G.** (2014). A client-centred ADL intervention: three-month follow-up of a randomized controlled trial. *Scandinavian Journal of Occupational Therapy*, 21 (5): 377-391.
15. **Janeslätt, G.**, Jöreskog, K., Springer, L. & **Adolfsson, P.** (2014). Parents on the outside – a pilot study of a support group for parents with cognitive limitations who have lost the care of their children. *Journal of Applied Research in Intellectual Disabilities*, 27 (4): 356 (Meeting abstract).
16. Ahlström- Wallin, S. & **Janeslätt, G.** (2014). Evaluation of a new method to remediate time processing ability in children with intellectual disability (ID) in special schools. *Journal of Applied Research in Intellectual Disabilities*, 27 (4): 385 (Meeting abstract).
17. Guidetti, S., Ytterberg, C., Ekstam, L., Johansson, U. & **Eriksson, G.**(2014). Changes in impact of stroke between 3 and 12 months post stroke assessed by the SIS. *Journal of Rehabilitation Medicine*, 46: 963-968.
18. Bergström, A., **Eriksson, G.**, Asaba, E., Erikson, A.. & Tham, K. (2014). Complex negotiations: The lived experience of enacting agency after stroke. *Scandinavian Journal of Occupational Therapy* (E-published 2014/10/21).
19. **Eriksson, G.**, Lilja, M., Jonsson, H., Peterson, I. & Tatzert, V. (2014). Occupations of Elderhood. In: *Occupational Therapy, Performance, Participation and Well-Being, 4th Edition* (Eds: Christiansen, C., Baum, C. & Bass, J.). Slack Incorporated, NJ, USA.
20. **Umb Carlsson, Ö.**, Källberg, N. & Wadensten, B. (2014). Blended learning among elderly care managers inspires projects that take older people's perspectives into account. *Home Health Care Management & Practice*. (E-published ahead of print).
21. **Adolfsson, P.**, **Lindstedt, H.**, Pettersson, I., Norling Hermansson, L. & **Janeslätt, G.** (2014). Perception of the influence of environmental factors in the use of electronic planning devices in adults with cogni-

- tive disabilities. *Disability and Rehabilitation Assistive Technology* (E-published ahead of print).
22. **Janeslätt, G., Lindstedt, H. & Adolfsson, P.** (2014). Daily time management and influence of environmental factors on use of electronic planning devices in adults with mental disability. *Disability and Rehabilitation Assistive Technology* (E-published ahead of print).
 23. **Reine, I.** (2014). Inequalities in attendance allowance among people with substantial and durable disabilities. *Eur J Public Health*, Suppl 2 (Meeting abstract).
 24. **Reine, I.** (2014). Personal assistance – a prerequisite to work for persons with substantial and permanent disability? Occupational and Environmental Medicine, *BMJ*, June, 71, Suppl 114 (Meeting abstract).
 25. **Turner, A.** (2014). *Predefined Headings in a Multi-professional Electronic Health Record: Professionals' Application, Aspects of Health and Health Care and Correspondence to Legal Requirements*. Department of Public Health and Caring Sciences/Disability and Habilitation, Uppsala University, 2014. (Licentiate Thesis).

2015

26. **Turner, A., Lindstedt, H., Pless, M. & Sonnander, K.** (2015). A retrospective analysis of health, health care, and legal requirements as reflected in predefined headings in an EHR. *Electronical Journal of Health Informatics* Vol 9(1):e9 (Only E-published at www.eJHI.net)
27. Johansen K, Lucas S, Bokström P, Persson K, **Sonnander K**, Magnusson M. & Sarkadi A. (2015). 'Now I use words like asymmetry and unstable': nurses' experiences in using a standardized assessment for motor performance within routine child health care. *J Eval Clin Pract*. 2015 Oct 22. doi: 10.1111/jep.12459. [Epub ahead of print]
28. Johansen K, Persson K, Sarkadi A, **Sonnander K**, Magnusson M. & Lucas S.(2015).Can nurses be key players in assessing early motor development using a structured method in the child health setting? *J Eval Clin Pract*. Aug;21(4):681-7. doi: 10.1111/jep.12366. Epub 2015 May 11.
29. **Wandin H**, Lindberg P. & **Sonnander K.** (2015). Communication intervention in Rett syndrome: a survey of speech language pathologists in Swedish health services. *Disabil Rehabil* 37(15):1324-33. doi: 10.3109/09638288.2014.962109. Epub 2014 Sep
30. **Wandin H**, Lindberg P. & **Sonnander K.** (2015). Habiliteringspsykologen i fokus. Beskrivning av kårens sammansättning och arbetsmässiga förutsättningar – resultat från en enkätstudie. *Logopeden*, 3, 18-21.

31. **Janeslätt, G., Lindstedt, H. & Adolfsson, P.** (2015). Daily time management and influence of environmental factors on use of electronic planning devices in adults with mental disability. *Disabil Rehabil Assist Technol*, 10 (5):371-377.
32. **Adolfsson, P., Lindstedt, H. & Janeslätt, G.** How people with cognitive disabilities experience electronic planning devices. *NeuroRehabilitation*, 37: 379-392.
33. **Adolfsson, P.; Lindstedt, H.**, Pettersson, I.; Norling Hermansson, L. & **Janeslätt, G.** Perception of the influence of environmental factors in the use of electronic planning devices in adults with cognitive disabilities. *Disabil Rehabil Assist Technol* (Early on line 1-8)
34. **Janeslätt, G., Sjödin, L. & Wennberg, B.** *Tidsuppfattning och tids hantering i vardagen*. I *Arbetsterapi för barn och ungdomar* (Eliasson, A-C., Lidström, H., Peny-Dahlstrand, M (Red.), Studentlitteratur, ss 259-270.
35. Wennberg, B., Sjödin, L., Buchholz, M. & **Janeslätt, G.** *Kognitivt stöd i vardagen*. I *Arbetsterapi för barn och ungdomar* (Eliasson, A-C., Lidström, H., Peny-Dahlstrand, M (Red.), Studentlitteratur, ss 271-284.
36. Anmyr, L., **Larsson, K.** & Olsson, M. Parents' stress and coping related to children's use of a Cochlear implant: A qualitative study. *Soc Work Disab & Rehab*.DOI:10.1080/1526710X.2016.1162123
37. Andersén, Å., **Larsson, K.**, Lytsy P., Kristansson, P. & Anderzén, I. Predictors of self-efficacy in women on long-term sick leave. *Int J Rehab Res*: 38 (4): 320-6.
38. Anmyr,L., Olsson, M.,Freijd, M. & **Larsson, K.** Sense of coherence, social networks and mental health among children with a cochlear implant. *Int J Pediatr Otorhinolaryngol*: 79:610-15
39. Lytsy, P., **Larsson, K.** & Anderzén, I. Health in women on long-term sick leave due to pain or mental illness. *Int J Rehab Res*: 38 (1): 27-33.

Literature reviews

1. Arvidsson, G., Buchholz, M., Forsmark, G., Hård, A., Jacobsson, Ch., Meden, D., Sjödin, L., Wennberg, B. & **Janeslätt, G.**, (2013). *Metoder för kognitivt stöd*. Evidensbaserad habilitering, Sveriges habiliteringschefers förening, www.habiliteringschefer.se (In Swedish)
2. **Lidström, H. & Hemmingsson, H.** (2014). Benefits of the use of ICT in school activities by students with motor, speech, visual, an hearing impairment. A literature review. *Scandinavian Journal of Occupational Therapy*, 21 (4): 251-266.
3. Andersson, A., Bolinder, A-K., Eriksson, M., Holmberg Bergman, T., Iwanson-Öhman, A., Nilsson, K., Warnerbring, E., Karlsson, B. &

- Sonnander, K.** (2014). *Behandlingsinsatser för personer med intellektuell funktionsnedsättning och problemskapande beteende*. Evidensbaserad habilitering, Sveriges habiliteringschefers förening, www.habiliteringschefer.se
4. **Janeslätt, G.** & Roshanay, A.H. *Föräldraskap hos vuxna med ADHD eller autismspektrumtillstånd: konsekvenser för barnet samt metoder för stöd. Systematisk kunskapsöversikt*. Nationellt kompetenscentrum anhöriga (NKA) Barn som anhöriga, 2015:7.

Conference oral presentations and poster presentations

1. **Lidström, H.** (2013). Anpassningar i gymnasieskolan för elever av särskilt stöd – ett nytt arbetsfält för arbetsterapeuter? AT-forum, arbetsterapeuternas nationella konferens, 24-25 april, Stockholm (Oral presentation).
2. **Lidström, H.** (2013). Nya doktorers forskning: IKT ger möjlighet till delaktighet i skolan och på fritiden för barn och ungdomar med rörelsehinder. AT-forum, arbetsterapeuternas nationella konferens, 24-25 april, Stockholm (Oral presentation).
3. **Lidström, H.** (2013). Computer-based assistive technology devices for use by students with disabilities. AAATE2013, 2012th European AAATE Conference, 19-22 September 2013, Vilamoura, Portugal.
4. Andersén, Å., **Larsson K.**, Lytsy, P. & Anderzén, I. (2013). Self-efficacy in women on long term sick leave – the Vitalis project. The 11th Stress Research Conference “New Frontiers in Swedish Stress Research – what is underway?” Gothenburg (Poster presentation).
5. Lejelind, E., **Larsson, K.** & Westerlind, R. (2013). Motivational interventions for increased condom use in sexual contacts abroad, and motivators and barriers for condom use. National HIV/STI Conference, Stockholm (Poster presentation).
6. **Larsson, K.**, Vejby, S., Nehlin Gordh, C. (2013). Screening capacity of brief scanning tools for hazardous alcohol drinking in a hospital setting. The 7th International Conference of Social Work in Health and Mental Health, Los Angeles, USA (Poster presentation).
7. **Larsson, K.**, Vejby, S., Nehlin Gordh, C. (2013). Screening capacity of brief scanning tools for hazardous alcohol drinking in a hospital setting. International Conference on Health Promotion Hospitals and Health Services, Gothenburg (Oral presentation).
8. **Blom Johansson, M.**, Carlsson, M., **Sonnander, K.** (2013). Participation in recreational and social life – perceived changes in everyday life according to significant others of persons with aphasia. Poster presentation at the 4th Nordic Aphasia Conference, Gothenburg, Sweden.

9. **Turner, A.** (2013). A joint language for specific purposes, or? National Conference in Nursing Informatics, Solna (Oral presentation).
10. **Pless, M. & Sonnander, K.** (2013). Evidence-based practice in-service training and support to staff. The 2013 Nordic Conference on Implementation of Evidence-Based Practice, Linköping University (Oral presentation).
11. **Turner, A.** (2014). Gemensamt fackspråk, eller? Inget gemensamt fackspråk I den elektroniska patientjournalen. SOI Conference (Oral presentation).
12. Ivarsson, A-B., **Lindstedt, H.** & Carlsson, M. (2014). The development of the Self-Assessment of Occupational Ability: a tool to measure occupation as a medium in therapy among persons with mental disability. 16th International Congress of the World Federation of Occupational Therapist (WFOT), Yokohama, Japan (Oral presentation).
13. **Eriksson, G.** (2014). Development of a rehabilitation program for return to work after stroke. 16th International Congress of the World Federation of Occupational Therapists (WFOT), Yokohama, Japan (Oral presentation).
14. **Eriksson, G.,** Hellman, T. & Bergström, A. (2014). Towards occupation based OT. An introduction to the Occupational Gaps Questionnaire. 16th International Congress of the World Federation of Occupational Therapists (WFOT), Yokohama, Japan (Workshop).
15. **Janeslätt, G.** (2014). What is the evidence for compensatory intervention for lacking time processing ability and executive functioning? 16th International Congress of the World Federation of Occupational Therapists (WFOT), Yokohama, Japan (Oral presentation).
16. **Janeslätt, G.** (2014). Parents on the outside- a pilot study of a support group for parents with cognitive limitations who have lost the care of their children. International Association for the Scientific Study of Intellectual and Developmental Disability (IASSID), Vienna, Austria (Oral presentation).
17. **Janeslätt, G.** (2014). Evaluation of a new method to remediate time processing ability in children with intellectual disability in special schools. International Association for the Scientific Study of Intellectual and Developmental Disability (IASSID), Vienna, Austria (Poster presentation).
18. **Janeslätt, G.** (2014). Parents on the outside- a pilot study of a support group for parents with cognitive limitations who have lost the care of their children. 10th Cognitive Symposium, Redondo Beach, California, USA.
19. **Janeslätt, G. & White, S.** (2014). Building bridges to manage time. 10th Cognitive Symposium, Redondo Beach, California, USA (Workshop).

20. Johansen, K., Persson, K., Sarkadi, A., **Sonnander, K.**, Magnusson, M. & Lucas, S. (2014). Towards an evidence-based early motor development in the child health setting. Conference Inspiring Infancy, University of Groningen, Groningen, The Netherlands.
21. **Janeslätt, G.** (2015). Building bridges to manage time. Research using the assessment of time management (ATMS) and Let's get organized (LGO) in Sweden. Mental Health Taskforce, June 9th 2015. (Invited speaker).
22. **Wandin, H.**, Bartolotta, Th., Garret, S-A., Urbanowitz, A. & Cowan, E. (2015). Tools for assessment of communication in Rett syndrome. European Congress on Rett syndrome, Rome, Italy. (Oral presentation)
23. Andersén, Å., **Larsson, K.**, Kristiansson, P. & Anderzén, I. Self-efficacy, self-rated health and work ability in young adults with disabilities participating in an individual tailored vocational rehabilitation program. The European Public Health Association (EUPHA) Conference, Milano (Poster presentation)
24. **Wandin, H.** (2015). Logopeders erfarenheter av kommunikationsinsatser vid Rett Syndrom. Regional Scientific Conference-Norrskén, Östersund, Sverige

Agencies that support the work/Funding (SEK)

Swedish Council for Working Life and Social Research	1 230 000
The Sävstaholm Foundation	2 280 000
Uppsala County Council	142 000
The Norrbacka Eugenia Foundation	100 000
The Promobilia Foundation	100 000
Jämtlands County Council	300 000
The National Board of Health and Welfare	216 000
Uppsala County Council	1 230 000
Vinnova (Verifiering för samverkan, VFS)	95 000

Related tasks (members)

- Chairperson, member of the board, Centre for Disability Research, Uppsala University (Karin Sonnander)
- Member of the board of the Sävstaholm Foundation, Stockholm (Karin Sonnander)
- Chairperson, member of the board of the Carola and Erik Tengström Foundation, Uppsala (Karin Sonnander)
- National editor Scandinavian Journal on Disability Research (Karin Sonnander)
- Academic teacher trainer, Uppsala University (Öie Umb-Carlsson)

Examinations and evaluations (members)

During 2015 assignments as member of examining committee at half-time review of doctoral theses at Uppsala University, scientific review of grant application, scientific conference abstract reviews and peer reviews Disability & Rehabilitation (Karin Sonnander).

Third stream activities (members)

- Associated member of the management group, Centre for Disability, Uppsala County Council (Karin Sonnander)
- Associated member of the committee for Research and Development, Uppsala Regional Council (Karin Sonnander)
- Editor National Newsletter on Disability Research (*Forskning om funktionshinder pågår*), published by Centre for Disability Research, Uppsala University (Karin Sonnander)
- Reference group at Public Health Agency of Sweden regarding the Government's strategy for the implementation of disability policy 2011-2016 (Öie Umb-Carlsson)
- Single lectures arranged by municipalities for professionals, politicians and people with intellectual disabilities arranged by FUB The Swedish National Association for Persons with Intellectual Disability (Öie Umb-Carlsson)
- Reference group at Swedish Association of Local Authorities and Regions (SALAR) regarding av national user survey in the disability field (Öie Umb-Carlsson)

Undergraduate teaching 2015 (members)

Nursing Programme

Nursing and Nursing methods 15 Higher Education Credits: lectures, seminars and essay tutorials (Päivi Adolfsson, Helena Wandin). Seminars and examination in Scientific methods (Öie Umb-Carlsson)

Caring Science Freestanding courses

Course coordinator for Essay course in Caring Science 15 Higher Education Credits and essay tutorials (Päivi Adolfsson). Single lectures and examinations (Öie Umb-Carlsson) and essay examination (Karin Sonnander).

Master Programme in Public Health

Päivi Adolffsson acts as head of Master Programme in Public Health, and as course coordinator as well as lectures, holds seminars and essay tutorials (Community Interventions 7.5 Higher Education Credits; Public Health on advanced level 15 Higher Education Credits; Master thesis in Public Health 30 Higher Education Credits). Essay tutorials and essay examination (Karin Sonnander) and lectures and examination (Öie Umb-Carlsson).

Freestanding courses

Course coordinator including lectures and seminars (Öie Umb-Carlsson) and examination (Karin Sonnander) for the distance courses Disability, living conditions and participation- Introductory Course 7.5 Higher Education Credits and Disability, living conditions and participation - Intermediate Course - 7.5 Higher Education Credits.

Projects

1. Development and test of assessment methods, interventions and documentation in services for people with disabilities

Aphasia and communication in everyday life - experiences of persons with aphasia, significant others, speech- language pathologists, and a trial of intervention

- Participants: Monica Blom Johansson, Karin Sonnander

This project focuses the communicative rights of persons with aphasia and their ability to be active participants in their social environment and in community. In particular the significant others of persons with aphasia are in focus; how could they contribute to increase autonomy and social participation of persons with aphasia and what support they may need themselves. The aim of the project is to obtain more knowledge about how persons with aphasia, significant others and speech-language pathologists perceive the altered communication between the significant other and the person with aphasia. A second aim is to study how aphasia affects everyday life of persons with aphasia and in particular their significant others. This project also includes evaluation of an intervention in early rehabilitation phase aimed at supplying individualised information, emotional support and communication partner training to the significant other of the person with aphasia.

Aided communication between persons with Rett syndrome and their interaction partners

- Participants: Helena Wandin, Per Lindberg, Karin Sonnander

The aim is to increase the knowledge of aided communication intervention targeting people with Rett syndrome. The different studies aim at 1) examining Swedish speech and language pathologists' experiences of communication intervention, especially aided communication intervention provided to persons with Rett syndrome 2) developing and evaluating instruments that measure different communicative aspects in interaction between individuals with Rett syndrome and a close communication partner 3) evaluating an aided communication intervention targeting the social network of persons with Rett syndrome. Caregivers take an active part in designing, performing and evaluating the intervention for each individual.

Reports on implementation of evidence-based practice

- Participants: Mia Pless, Karin Sonnander

The overall aim is to report on implementation of evidence-based practice in multi-professional rehabilitation and habilitation services. A specific aim is to evaluate staffs' knowledge and use of evidence-based interventions and the implementation of Health Technology Assessment as a structured model to do this for support of continuous quality improvement.

Parents with cognitive disabilities with children in foster care: parenting role, need of support and evaluation of a support group

- Participants: Päivi Adolfsson, Karin Jöreskog, Gunnel Janeslätt
- The aim is to, by using semi-structured interviews, describe mothers and fathers with cognitive difficulties who have children in foster care: parenting role, level of participation, influence on rights of access to children and need of support. A support group will be evaluated pre- and post-intervention by focus group interviews. A separate assignment, commissioned by The National Board of Health and Welfare, constitutes a systematic literature review on parenting and interventions targeting parenting tailored for parents with ADHD or ASD (Gunnel Janeslätt and Afsaneh Hayat Roshanai).

Evaluation of using an educational toolkit about parenthood and the "Real Care Baby" among individuals with intellectual disability

- Participants: Margareta Larsson, Berit Höglund, Nina Klang, Maria Wikström, Ida Kåhlin, Rose-Marie Berglund, Lydia Springer, Gunnel Janeslätt
- The aim of this project is to evaluate the use of conversational support material "Children-what does it involve" and a Real Care Baby simulator for special school students with intellectual disability.

2. The significance of received targeted support for self-perceived health

Environmental help or hindrance?

- Participants: Helene Lidström, Gunnel Janeslätt, Päivi Adolfsson, Ingvor Pettersson, Liselotte Norling Hermansson, Helena Lindstedt

Cognitive assistive technology (CAT) prescribed to people with mental/neuropsychiatric disabilities is not used as intended. The aim is to clarify the detailed methodology of the prescribing process of CAT. What environmental factors constitute help or hindrance for individual use and perceived utility of CAT for the target group? An advisory group of four CAT users contribute to the research methodology. Forty-five CAT users answer study-specific questionnaires on environmental factors and time-management. A sample of CAT users (10-15) are interviewed about their experiences of how environmental factors influence their use and utility of electronic planning devices.

Importance of personal assistance financed by the Swedish social insurance for meeting national health objectives for men and women with serious functional impairment

- Participants: Ieva Reine, Heléne von Granitz, Edward Palmer, Karin Sonnander

The aim of this project is to analyze the significance of the state assistance benefit for the wellbeing and health of people with state personal assistance. A direct relationship is drawn to the public health objectives and the project is conducted with a gender perspective. The study will be based on cohorts from 2010 to 2015 and contains a large number of analysis variables, such as demographic and health variables, including health-related selection, participation and empowerment, labor market participation and economic factors. Identification of the mechanisms that explain the relationship between personal assistance and self-perceived health is central to the analysis

Men and women with intellectual disabilities and quality of life

- Participants: Öie Umb-Carlsson, Päivi Adolfsson

The aim is to validate the Uppsala Quality of Life Model from the perspective of women and men with intellectual disabilities. Focus group interviews are conducted with women and men with mild and moderate intellectual disability and analysed by deductive content analyses.

Nutritional support for people with different disabilities

- Participant: Päivi Adolfsson

The purpose of the project is to investigate how dieticians work with and provide nutritional support to people with disabilities.

3. Participatory research

People with intellectual disabilities as participants in the research process

- Participant: Öie Umb-Carlsson

The aim of the project is to gain experience and further knowledge in involving people with intellectual disabilities in the research process. People with intellectual disabilities are involved in validation of a quality of life model, in identifying issues of importance in a quality of life scale and in production of the research report as well as planning a follow up study of living conditions.

Family Medicine and Preventive Medicine

Research Group Leader Per Kristiansson, associate professor

The research in Family Medicine emanates from the multidisciplinary perspective of primary health care and is conducted by a large group of researchers throughout the Uppsala-Örebro region. The research activities have different themes:

- asthma, allergy and COPD
- communications skills
- diabetes and cardiovascular disease
- pain and musculo-skeletal disorders
- prevention
- reproductive health
- social insurance medicine
- symptom reporting and utilisation of pharmaceuticals
- vitamin D deficiency
- organizational factors, work stress and performance

The research group continues to produce about 70 to 80 scientific articles per year in a wide range of scientific areas. The number of collaborations with Swedish researchers is high and international collaboration is increasing.

Much work has been carried out during 2015 to make our vision of an academic primary health care center come true.

Members of the group during 2015

- **Kerstin Ahlqvist**, PhD-student
 - was approved as a part-time PhD-student in 2015. Research area concerns pregnancy induced pelvic pain. She got the Degree of Master of Medical Science in 2002 and works as a physiotherapist at the Primary Health Care in Uppsala.
- **Åsa Andersén**, PhD student
 - works in the area of vocational rehabilitation since August 2013. Her thesis is about the relation between self-efficacy, individual tailored vocational rehabilitation and employment. Åsa Andersén has training as a

nurse (Uppsala University, 2007) and a medicine master in public health (Uppsala University, 2011).

- **Malin André**, MD, PhD, associate professor
- is specialized in Family Medicine. Research in infections, priority setting and decision making.
- **Sven-Olof Andersson**, MD, PhD
- has worked as a GP in Umeå since the early 70-ties. Trained psychotherapist and Balint group leader. Thesis about general practice consultation and time, lecturer in professional development and medical psychology. Involved in evaluation of medical students' communicative ability.
- **Ingrid Anderzén**, PhD
- her research is in the area of vocational rehabilitation and Return to Work (RTW). During the year 2015 she has only worked part time at the University. Most of the time she has worked at the University Hospital in Uppsala, at the Department of Vocational Rehabilitation.
- **Eva-Maria Annerbäck**, PhD, psychotherapist, trained Social worker/reg
- is a PhD in Child and Adolescent Psychiatry, the topic of her thesis was Child physical abuse. She has continued as researcher mostly within the area of Child Maltreatment and works at Centre for Clinical research in Sörmland as Research supervisor. Is an associate researcher.
- **Bengt Arnetz**, Professor, MD, PhD
- **Judith Arnetz**, Associate professor, PhD
- **Annika Bardel**, MD, PhD, adjunct senior lecture
- works partly as a GP in Sörmland county and as lecturer at Uppsala university where she educates doctors working in health centers where the students are trained by their tutors during terms 1-4 and 11.
- **Britta Berglund**, PhD, associate researcher
- **Regina Bendrik**, physiotherapist, PhD student
- started her PhD studies in 2013 but works part time at Strömsbro Hälsocentral in Gävle. She got the Degree of Master of Medical Science in 2008 and was cerificated as specialized physiotherapist in Primary Health Care 2010.
- **Elisabeth Krefting Bjelland**, PT, PhD
- is postdoctor at Department of Obstetrics and Gynecology, Akerhus University Hospital in Norway. During her first postdoctoral project, she had a 6 months stay at the Department of Public Health and Caring Sciences to co-work with Per Kristiansson in the field of pregnancy-related pelvic girdle pain (2014). Her research interests are mainly in the field of Women's health, and she is currently studying causes and consequences of timing of menopause.
- **Anne Björk**, MD, PhD student

- joined IFV in 2010 and started her PhD studies in June 2011. She is specialized in Family Medicine and Clinical Chemistry and works as a GP at Boländernas vårdcentral in Uppsala. Anne Björk holds a degree in Medicine from Uppsala University (1984) and a license to practice (1989).
- **Karin Björkegren, MD, PhD, senior lecturer**
 - is specialized in Family Medicine. Research in B12- and folate-deficiency and musculoskeletal pain. Most of the time she has worked at the Uppsala University and part time at Flogsta Health Center as a general practitioner.
- **Stefan Blomberg, MD, PhD**
- **Johan Bogefeldt, MD, PhD**
 - is specialized in Family Medicine. Presented his thesis on low back pain in adults in 2009. Since then he has specialized in pain medicine and works full time with behavioral medicine and rehabilitation for pain patients. Current research interests are back pain epidemiology, information technology and case studies in pain patients.
- **Eva Bojner Horwitz, PhD, RPT, Reg. DMT, Associate researcher**
 - is a Cultural Health researcher, specialized in Psychosomatic medicine and a co-founder and part time Director of education at the Center for Social Sustainability, CSS, Karolinska Institutet. Her research expertise covers interventions with dance/music/theatre, embodiment, emotional regulation and learning, alexithymia, creativity, quantitative and qualitative research methods.
- **Kristina Bröms, MD, PhD**
 - is specialized in Family Medicine. Research in asthma, allergy and COPD observational studies and epidemiological studies and research in Physical Activity on Prescription to patients in primary health care.
- **Gunilla Burell, PhD**
 - graduated in the Department of Psychology, Uppsala University, and has since been conducting research within the area of stress and depression in post-myocardial infarction patients. She is lecturing master program and medical students within topics of behavioral medicine and motivational interviewing.
- **Stephen Butler, MD, FRCP(C)**
 - Research consultant to Family Medicine and Preventive Medicine Unit. Part time consultant to Pain Center, Akademiska and to Pain Center, St. Olav's Hospital, Trondheim, Norway. Trained in Internal Medicine and Anaesthesia. Recent practice primarily in pain management.
- **Lars Carlsson, MD, PhD student**
 - joined Family Medicine and Preventive Medicine as part-time PhD student in 2011. He is specialized in Family Medicine and works at Ludvika Vårdcentral in Ludvika. Lars Carlsson holds a degree in Medicine from Uppsala University (1986) and a license to practice (1988).

- **Jan Cederholm**, MD, associate professor
 - finalised his PhD studies at the Department in 1985, and became Associate Professor in 1990. He is specialized in Family Medicine and Internal Medicine, and is a retired general practitioner since 2015.
- **Lars Englund**, MD, PhD, associate researcher
- **Sevek Engström**, DD, MPH, PhD
 - is dentist with interest in Public Health. The PhD thesis was about screening for high blood pressure and diabetes, a screening between Dental Care and Primary Care. Now responsible for the Competence Centre for Health in the County Council of Västmanland. Research in the field of public health.
- **Margaretha Eriksson**, PhD
 - joined the Family Medicine 1983 as a research assistant. PhD studies 2001-2005. Since then part time assistant at Family Medicine and Preventive Medicine and part time director for post graduate studies in Public Health.
- **Göran Falck**, MD, associate professor
- **Christina Grape Viding**, RN, PhD student
 - joined the Family Medicine and Preventive Medicine 2013 and started the PhD studies in 2014. Her area of studies concerns cultural activities, *i.e.* arts, and health. Christina is a registered nurse and works at Ersta hospital in Stockholm.
- **Mats Gulliksson**, MD, PhD, associate researcher
- **Catharina Gustavsson**, RPT, PhD
 - started as doctoral student at the Department of Public Health and Caring Sciences in 2006, and is since 2011 associated researcher. Works at the Academic Primary Healthcare Centre in Borlänge and the Centre for Clinical Research Dalarna/Uppsala University.
- **Johan Hallqvist**, PhD, MD, BSc, professor in prevention research, senior physician at the Academic hospital, and head of the Department of Public Health
 - in his research he applies new epidemiological methods to study the triggering of health events and to disentangle mechanistic causal questions in social epidemiology.
- **Björn Hallström**, MD, PhD, associate researcher
- **Johanna Haraldsson**, MD, PhD student
 - joined Family Medicine and Preventive Medicine in 2014 when she started her PhD studies in sexual and reproductive health in young men. She works as a MD at Strängnäs vårdcentral and participate at the National Research School in General Practice.
- **Charlotta Hellström**, PhD student
- **Anna Hofsten**, MD, associate researcher
 - joined Family Medicine 1997 and got a degree of Licentiate 2000. She is a senior lecturer in nursing education at the University of Gävle.

- **Anna Liljestam Hurtigh**, research assistant
 - had worked together with Ingrid Anderzen in her researchproject part time (50%) during 2015.
- **Stefan Jansson**, MD, PhD
 - General Practitioner and works in the Primary Health Care in Region Örebro County. Research in diabetes mellitus, mainly type 2 diabetes, comprising diabetes prevalence, incidence, mortality trends, the effect of different treatments, and the effect of screening detection on the incidence of macro- and microvascular complications.
- **Gunnar Johansson**, MD, PhD, professor emeritus
 - thesis 1979 about magnesium metabolism. Specialist in internal medicine, nephrology and family medicine. Has worked at the University hospital, Uppsala, in the pharmaceutical industry as medical director and in primary care as general practitioner. During the last ten years the research has focused on real world evidence studies based on various registers.
- **Linus Johnsson**, MD, PhD
 - defended his thesis on biobank research, trust, and researchers' moral obligations in 2013. He holds a license to practice (2004). He is presently investigating general practitioners' perspectives on quality in their work.
- **Lena Kallings**, PhD, associate researcher
- **Paul Kalliokoski**, MD, PhD student
 - joined Family Medicine and Preventive Medicine as part-time PhD student in 2014 but as a specialist in general practice he has been interested in vitamin D since 2009, when he found vitamin D deficiency (90%) in Somali younger women in the town of Borlänge. Since then he continues in this research.
- **Bo Karlsson**, MD, PhD student
 - joined Family Medicine and Preventive Medicine as part-time PhD student in 2000. He is specialized in Family Medicine and works at Gimo Primary Health Care Centre. He holds a degree in Medicine from Karolinska Institutet (1977) and a license to practice (1979).
- **Per Kristiansson**, MD, PhD, associate professor
 - is the chair of the Family Medicine and Preventive Medicine Unit since 2011-05. Per Kristiansson is a General Practitioner and works in the Primary Health Care in Uppsala County.
- **Anne Lindgren**, Ft, PhD student
 - started her PhD studies in May 2012 and she has done her halftime seminar in June 2015. Her research area is Pelvic Girdle Pain persisting after childbirth and her clinical work and research project is performed in Sundsvall Hospital at the physiotherapy department.
- **Karin Lisspers**, MD, PhD

- specialist in family medicine at the Academic Health Care Centre in Gägnaf, Dalarna. Research in asthma and COPD observational real life studies and epidemiological studies. Boardmember International Primary Care Respiratory Group, chair professional group European Lung Foundation.
- **Linda Lännerström, RN, PhD student**
 - joined Family Medicine and Preventive Medicine when she started her PhD studies in januari 2011. She works as an organizational developer at the Primary health care Division in Eskilstuna. Linda Lännerström holds a registred nurse degree from Mälardalens University (1996) and specialist nurse degree (MSc) in District Nursing from Mälardalens University (2010).
- **Monica Löfvander, MD, PhD, associate professor**
 - associate researcher at the Family and Preventive Medicine Unit since 2012. District physician, em. Main research fields are transcultural issues, immigrant care, depressive and musculoskeletal disorders and sick leave aspects.
- **Mats Martinell, MD, PhD student**
 - started his PhD studies in 2009. His research field is diabetes and his focus lies in how clinical variables present at diagnosis can predict progression and facilitate a more individualized diabetes care. He is project leader for the ANDiU study, which is part of the Exodiab collaboration. He also works part time as a General Practitioner in Uppsala.
- **Annika Nolin, Master of Arts, research assistant**
- **Lena Nordgren, PhD, associate researcher**
 - joined the Department of Public Health and Caring Sciences in December 2012. She works at the Centre for Clinical Research Sörmland/Uppsala University in Eskilstuna.
- **Gunilla Norrmén, MD, PhD**
- **Lena Olai, RN, PhD, associate researcher**
 - works at the Dalarna University, and the main research field is elderly care. She developed the Competence Centre for elderly health care at Dalarna University.
- **Magnus Peterson, MD, PhD**
 - specialist in General Medicine and Pain Rehabilitation. Works as coordinator of Academic Primary Care in Norrtälje TioHundra AB. The position means initiating and coordinating clinical education, innovation and research in primary care in cooperation with Karolinska Institute. The position also allows time as associated researcher at Dept of Publ Health and Caring Sciences, Uppsala University. This research is mostly about pain, presently with projects about diagnostic imaging of chronic soft tissue pain.
- **Nils Rodhe, MD, PhD**

- is specialized in Family Medicine and works as a General Practitioner in Falun. Research mostly in urinary tract infections.
- **Åke Schwan**, MD, PhD, associate researcher
 - research and articles mainly in cardiovascular and infectious diseases. PhD in 1992. He has been a specialist in Family Medicine since 1981. He is now retired but works as a general practitioner half time and has some connections to and lectures at Uppsala University.
- **Jan Stålhammar**, MD, associate professor
 - is specialized in Family Medicine and works as a General Practitioner. PhD 2000 and associate professor 2014. Research mainly in diabetes epidemiology and pharmacoepidemiology. Currently involved in register studies covering heart failure, IBD, and psoriasis arthritis. Lecturer in Uppsala University.
- **Björn Stållberg**, MD, PhD
 - Research in asthma and COPD observational real life studies and epidemiological studies. He has been a specialist in Family Medicine since 1984 and finalized his PhD studies at the Department in 2008. Björn works part time as general practitioner at the Academic Health Care Centre in Gägnaf, Dalarna. He is Associate Editor for the npj Primary Care Respiratory Medicine and has been chair of the ERS General Practice and Primary Care group 2013-2015.
- **Elisabet Sundgren**, RN, PhD student
 - joined the Family Medicine and Preventive Medicine Unit in 2011 when she started her PhD studies. She is a registered nurse and works at Gävle Strand in Gävle. Elisabet holds a degree in Specialist nurse in Primary Health Care from Högskolan Gävle 2009.
- **Kurt Svärdsudd**, MD, professor emeritus
 - is now mainly working with research in the Public Health area in Uppsala and Gothenburg, analyzing research data bases, supervising PhD students, and reviewing manuscripts for scientific journals.
- **Malin Swartling**, MD, PhD
- **Eva Thorell**, MD, PhD
- **Thomas Torstensson**, RPT, PhD
 - his research covers mainly persistent pregnancy-related pelvic pain. After finished his Thesis in 2014 he has been working as a clinician at Sundsvall hospital and part-time continued as an associated researcher in supervising a PhD student.
- **Keld Vaegter**, MD, PhD
- **Anna-Sophia von Celsing**, MD, PhD student
 - joined Family Medicine and Preventive Medicine as part-time student in 2009. She is specialized in Orthopedics and works at Vårdcentralen City in Eskilstuna. Anna-Sophia holds a degree in Medicine from Karolinska Institutet, Stockholm (1984) and a license to practice (1989).
- **Rolf Wahlström**, MD, PhD

- **Mari-Ann Wallander**, PhD, associate professor
- finalised her PhD studies at the Department in 1991, and became Associate Professor in 1999. She has worked as an epidemiologist in the pharmaceutical industry and is retired since 2013.
- **Thorne Wallman**, MD, PhD, adjunct senior lecturer
- joined Family Medicine and Preventive Medicine in 1989. PhD studies 1991 and PhD in 2008. He is Adjunct Senior Lecturer since 2010 and is head of Sörmland County Council Primary Health Care Development Centre including an Academic Health Care Centre in Strängnäs/Mariefred and deputy head of Uppsala university Centre for Clinical Research Sörmland. He works as GP in Eskilstuna. He is main supervisor for two PhD-students and assistant supervisor for two PhD-students.
- **Clairy Wiholm**, PhD, associate researcher
- **Ture Ålander**, MD, PhD, associate researcher

Publications from members of the group 2015-2013

- ¹⁾ Articles from former Family Medicine
²⁾ Articles from former Preventive Medicine
³⁾ Articles from former Social Medicine

2015

1. ²⁾ Andersén Å, Larsson K, Lytsy P, Kristiansson P. Predictors of self-efficacy in women on long-term sick leave. *Int J Rehabil Res* 2015;38(4):320-26.
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- **Ställberg B and Lisspers K** – together with Blom C, Tsiglianni I, Korzh O, Teixeira P, Chavannes N. [*Ställberg B, Blom C, Lisspers K, Tsiglianni I, Korzh O, Teixeira P, Chavannes N. The prevalence of comorbidities in COPD patients and their impact on the quality of life and COPD symptoms in primary care patients-an UNLOCK study from the IPCRG. (Abstract IPCRG Scientific meeting 2015)*]
- **Ställberg B and Lisspers K** – together with Sundh J, Montgomery S, Janson C and Kämpe M. [*Sundh J, Montgomery S, Janson C, Kämpe M, Ställberg B, Lisspers K. Vad påverkar förändring av hälsostatus vid KOL i en sjuårssuppföljning? (Abstract Svenska Lungkongressen 2015)*]
- **Ställberg B and Lisspers K** – together with Sundh J, Montgomery S, Janson C, Kämpe M and Källander A. [*Sundh J, Montgomery S, Janson C, Kämpe M, Källander A, Ställberg B, Lisspers K. What influences change in health status in COPD in a seven year follow-up? Eur Respir J 2015; 46: Suppl. 59 (Abstract ERS 2015)*]
- **Ställberg B** – together with Spruit MA, Marvisi M, Coolen J, Poletti V, Gasparini S, Ställberg B, Herth FJ, Clini EM. [*Spruit MA, Marvisi M, Coolen J, Poletti V, Gasparini S, Ställberg B, Herth FJ, Clini EM. Clinical highlights from the 2013 ERS Congress in Barcelona. Eur Respir J 2014;44(1):198-206*]
- **Björn Ställberg** – together with Costa-Scharplatz M, Tambour M, Henriksson F. [*Costa-Scharplatz M, Tambour M, Henriksson F, Ställberg B. Cost-effectiveness of glycopyrronium compared to tiotropium in COPD patients from a Swedish societal perspective (Abstract). Value in Health 2013;16(7):A371-72*]
- **Kurt Svärdsudd** – have examined the Norwegian text version of a book into a Swedish one. [*Hoveliuss B (Swedish editor), Andersson C, Bardel A, Björkelund C, Borgquist L, Engfeldt P, Midlöv P, Nilsson G. Allmänmedicin (Norwegian main editor Steinar Hunskår). Studentlitteratur, 2015, 1102 pages*]
- **Eva Thorell** – have examined the Norwegian text version of a book into a Swedish one. [*Hoveliuss B (Swedish editor), Andersson C, Bardel A, Björkelund C, Borgquist L, Engfeldt P, Midlöv P, Nilsson G. Allmänmedicin (Norwegian main editor Steinar Hunskår). Studentlitteratur, 2015, 1102 pages*]
- **Mari-Ann Wallander** – together with Brobert G, Garcia Rodriguez LA, Garbe E, Bezemer ID, Layton D, Friberg L, Suzart-Woichnik K, Alderson J, Winchester C, Herings RMC, Jobski K, Schink T, Shakir S, Soriano-Gabarro M. [*Brobert G, Garcia Rodriguez LA, Garbe E, Bezemer ID, Layton D, Friberg L, Suzart-Woichnik K, Alderson J, Winchester C,*

Herings RMC, Jobski K, Schink T, Shakir S, Soriano-Gabarro M, Wallander MA. Development of a collaborative European pharmacoepidemiologic Post-Authorization Safety Study (PASS) programme examining rivaroxaban use in routine clinical practice. Meeting abstract. ISPOR 17th Annual European Congress, nov 8-12, 2014, Amsterdam, The Netherlands. Value in Health 2014;17(7):A473-A74]

- **Mari-Ann Wallander** – together with Garcia Rodriguez L, Garbe E, Bezemer I, Layton D, Suzart-Woischnik K, Brobert G, Alderson J, Winchester C, Herings R, Jobski K, Schink T, Shakir S, Soriano-Gabarro M. [*Garcia Rodriguez L, Garbe E, Bezemer I, Layton D, Suzart-Woischnik K, Brobert G, Alderson J, Winchester C, Herings R, Jobski K, Schink T, Shakir S, Soriano-Gabarro M, Wallander MA. Development of a Collaborative European Post-Authorization Safety Study (PASS) Program Examining Rivaroxaban Use in Routine Clinical Practice. 30th International Conference on Pharmacoepidemiology and Therapeutic Risk Management, October 24–27, 2014. Pharmacoepidemiol Drug Saf 2014;23(S1):459-60]*]

Dissertation 2015

- **Charlotta Hellström**. Adolescent Gaming and Gambling in Relation to Negative Social Consequences and Health. PhD, Medical sciences. Uppsala University, 2015.

Half time seminar 2015

- **Anne Lindgren**. Pregnancy-related back and pelvic pain - with special reference to cause and treatment
- **Mats Martinell**. Understanding the initial clinical presentation of type 2 diabetes and LADA – a step towards personalized medicine
- **Åsa Andersén**. Self-efficacy, vocational rehabilitation and return-to-work
- **Christina Grape Viding**. Kulturella aktiviteter och hälsa

Education

Medical Programme

- **Karin Björkegren** – director of under-graduate studies
- **Annika Bardel** – responsible for training of student tutors
- **Karin Björkegren** – responsible for terms 1 and 2

- **Per Kristiansson** – in terms 1 and 2
- **Gunilla Burell** – in terms 2 and 3
- **Bo Karlsson** – responsible for terms 3 and 4
- **Karin Björkegren** – in term 4
- **Per Kristiansson** – in term 4
- **Annika Bardel** – in term 4
- **Mats Gulliksson** – in term 4
- **Åke Schwan** – in term 4
- **Jan Stålhammar** – in term 4
- **Per Kristiansson** – responsible for supervision and examination of ”Självständigt arbete”, term 10
- **Bo Karlsson** – responsible for term 11
- **Karin Björkegren** – in term 11
- **Gunilla Burell** – “Motivational interviewing” term 11
- **Karin Lisspers** – in term 11
- **Mats Martinell** – in term 11
- **Magnus Peterson** – in term 11
- **Åke Schwan** -- in term 11
- **Björn Stållberg** – in term 11
- **Thorne Wallman** and **Anna-Sophia von Celsing** – responsible for social insurance medicine term 11

Masterprogramme in Public Health

- **Ingrid Anderzén** – responsible for the course Health Promoting Leadership
- **Gunilla Burell** – “Hälsöfrämjande ledarskap”

Doctorial course

- **Johan Hallqvist** – Medical epidemiology for PhD students

External lectures or courses

- **Karin Björkegren** – B12- and folate deficiency: how to treat? For physicians in Uppsala County Council. Two times in October 2015
- **Gunilla Burell** – external courses for physicians and nurses
- **Bo Karlsson** – courses for GPs in Uppsala County Council
- **Bo Karlsson** – course in Development of web-based educational materials for National Board for Health and Welfare
- **Björn Stållberg** and **Karin Lisspers** – have given lectures to general practitioners in national asthma/COPD educations

Research collaborations – international and national

International

- **Karin Björkegren** – LONGGERD: Långtidsuppföljning av patienter med reflux symtom. Together with researchers from Division for Family Medicine, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden, Department of surgery, Umeå University, Umeå, Sweden, Molecular Medicine and Surgery, Karolinska Institutet, Stockholm, Faculty of Health and Medicine, University of Newcastle, Newcastle, Australia, Institute of Pathology Klinikum Bayreuth, Germany, Department of Microbiology, Tumor and Cell Biology, Karolinska Institutet, Stockholm, Sweden, Stress Research Institute, Stockholm University, Stockholm, Sweden
- **Johan Hallqvist** and **Ingrid Anderzén** – IWALA: “Work and Life Academy”, (Researchers from Department Tranzo (Scientific Centre for Care and Welfare), Tilburg School of Social and Behavioral Sciences, Tilburg University, the Netherlands, National Centre for Work and Rehabilitation, Department of Medical and Health Sciences, Linköping University, Sweden, Centre for Research on Work Disability Policy, Canada, Social medicine and Social Insurance Medicine, National Centre for occupational rehabilitation, Norway and other research groups at the Department of Public Health and Caring Sciences, Uppsala University, Sweden
- **Per Kristiansson, Elisabeth Bjelland, Thomas Torstensson** and **Anne Lindgren** – LiteCure Ltd, Newark, USA
- **Per Kristiansson** – collaboration project together with professors Niels Egund and Anne-Grethe Jurik, Aarhus, Denmark for imaging of the back and pelvis in diagnosis of chronic pelvic pain
- **Per Kristiansson** and **Elisabeth Bjelland** – collaboration project together with Hilde Nordeng, Siri Vangen, Malin Eberhard-Gran for investigations on pelvic pain during pregnancy and hormonal contraceptive use with data from the Norwegian Mother and Child Cohort
- **Per Kristiansson, Elisabeth Bjelland** and **Ronnie Pingel** – collaboration project together with Siri Vangen, Malin Eberhard-Gran and Katrine Owe for investigations on pelvic pain after childbirth in a longitudinal population study with data from the Norwegian Mother and Child Cohort
- **Per Kristiansson, Elisabeth Bjelland, Anne Lindgren** and **Thomas Torstensson** – collaboration project together with Sahruh Turkmen, Jan Magnus Bjordal, Andy Wood and Bryan Pryor for investigations on laser therapy of pregnancy induced back and pelvic pain persistent after childbirth
- **Per Kristiansson, Elisabeth Bjelland, Anne Lindgren** and **Thomas Torstensson** – collaboration project together with Hilde Robinson (re-

searchers at the University of Oslo) for investigations on joint mobility and pregnancy induced back pain

- **Per Kristiansson** and **Eva Thorell** – collaboration project together with Laura Goldsmith, Gerson Weiss for investigation of physical activity and pregnancy
- **Monica Löfvander** – Oslo, Family medicine
- **Mari-Ann Wallander** – Research collaboration with Centro Español de Investigación Farmacoepidemiológica (CEIFE) has continued especially in the project on the use of prescription contraceptive methods in the UK general population. The collaboration has resulted in two peer reviewed publications during 2015 [38, 45]
- **Mari-Ann Wallander** – Research collaboration with the Boston Collaborative Drug Surveillance Program with among others Professor Susan Jick investigating the risk of mortality in patients with multiple sclerosis has resulted in one publication in Neurology during 2015 [15] and yet another publication is waiting for acceptance
- **Magnus Peterson** – Harvard Medical School for analysing the central nervous system in relation to the findings in the peripheral tissue and decreased CNS neurokinin 1 receptor availability in chronic tennis elbow.
- **Björn Stållberg** – an international cost-effectiveness study in COPD [16]
- **Karin Lisspers** and **Björn Stållberg** – International Primary Care Respiratory Group (IPCRG) - international collaboration aimed at highlighting unanswered questions on the management of respiratory diseases of importance in primary care [124]

[For number in brackets -- see “Publications 2015-2013” on page 214-236]

National

- **Gunnar Johansson** – Research collaboration with Kjell Alving and Jörgen Syk. Has received financial support from Karolinska Institutet to investigate treatment of asthma in primary health care using exhaled nitric oxide analysis [230]
- **Karin Lisspers, Björn Stållberg, Kristina Bröms** and **Regina Bendrik** – a collaboration with the Clinical Research Centre in Gävle and the Department of Medical Sciences: Respiratory Medicine & Allergology, Uppsala University; a prospective study in primary and secondary care for investigating how COPD patients with risk for exacerbations can be identified. Abstracts have been accepted IPCRG and ERS Congresses.
- **Magnus Peterson** – Karolinska Institutet and Uppsala University (The PET-project) - pain-related mechanisms in the peripheral tissue, in cooperation with the Swedish Agricultural University (SLU).
- **Björn Stållberg** – Research collaboration with the Center for Family and Community Medicine (CEFAM), at the Karolinska Institute

- **Björn Stållberg** – member of the steering committee in an asthma clinical trial
- **Björn Stållberg** and **Karin Lisspers** – members in the steering committee of a national investigation of resources for rehabilitation in COPD
- University of Gävle, Centre for Musculoskeletal Research
- Linköping University, Centre for Research on Work Disability Policy
- Centre for clinical research, CKF in County of Dalecarlia
- Academic Primary Health Care Centre of Jakobsgårdarna, Borlänge
- Centre for clinical research, CKF in County of Västmanland
- Medical faculty in University of Örebro

[For number in brackets -- see "Publications 2015-2013" on page 214-236]

Invited speakers

- **Karin Lisspers** – at an asthma symposium at the Congress of the Swedish Medical Society
- **Monica Löfvander** – Migration and Health. At Asyl och Integrationshälsan, Västerås
- **Monica Löfvander** – Migration and Health. At Mariehamns högskola, Åland, Finland
- **Monica Löfvander** – Migration and Health. At Mälardalens högskola, Västerås

National /International commissions

- **Karin Lisspers, Björn Stållberg** and **Kristina Bröms** have participated in the development of the asthma/COPD guidelines in the National Board of Health and Welfare
- **Karin Lisspers** is member of the board of International Primary Care Respiratory Group (IPCRG) and European Lung Foundation
- **Karin Lisspers** has participated in the Medical Products Agency's work with the treatment recommendations for asthma and COPD and written the chapter about diagnosis of asthma
- **Björn Stållberg** is chair of the asthma and COPD national program group at the Swedish Association of Local Authorities and Regions (SKL)

Agencies that support our work / Funding 2015 (SEK)

• Uppsala County Council (ALF)	2.330.000
• Sörmland County Council	1.509.000
• Dalecarlia County Councils	1.042.000
• Center for Clinical Research Dalarna in total 2005-2016 for the PRAXIS study and the TIE study	400 000 kr
• Vinnova and Uppsala Innovation	195.000
• Samordningsförbundet RAR, Sörmland	210.000

Research projects

Astma, allergy and COPD

- Main responsibility: Karin Lisspers and Björn Ställberg

The PRAXIS-study asthma/COPD

- Participants: Karin Lisspers, Björn Ställberg

The aim of the PRAXIS-study is to compare asthma and COPD guidelines with the actual care. The study started 2005 and is based on questionnaires and record examination. Several reports have been published.

In the first about asthma control it was concluded that in spite of treatment guidelines many patients in Swedish primary care still have insufficient asthma control. The second evaluated how often a diagnosis of COPD was confirmed with spirometry. The third report has evaluated the associations of comorbidity and body mass index with quality of life in COPD. A fourth report about sex-related differences in asthma has been published and was a part of Karin Lisspers' dissertation. A fifth report regarding dyspnoea, obstruction, smoking and exacerbations (DOSE index) and mortality has been published. A sixth report about quality of life in COPD (CCQ) and mortality has been published and a seventh about exacerbations in COPD has been published [225]. An eight report regarding asthma control has been published during 2014 [125] and a ninth about a comparison between an assessment scale and a quality of life questionnaire for COPD patients has been published [67]. A tenth manuscript about change in health status in COPD patients over seven years has been submitted.

A follow-up study started in 2012 with new longitudinal data from the cohort of asthma and COPD patients from 2005. In 2014 a new random selection of both asthma and COPD-patients was performed.

The PRAXIS-project has generated one PhD thesis 2013 (Josefin Sundh) and has receiving financial support from the county councils of the Uppsala-

Örebro Region, Uppsala-Örebro Regional Research Council, the Swedish Heart and Lung Association, the Swedish Asthma and Allergy Association, the Bror Hjerpstedt Foundation, Uppsala, and Uppsala University.

The project is led by Karin Lisspers, Björn Ställberg, Christer Janson (Professor at the Department of Medical Sciences: Respiratory Medicine & Allergology, Uppsala University) and Josefin Sundh (MD, PhD, Department of Respiratory Medicine, Örebro University).

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

International research collaboration in asthma and COPD in primary care – with data from the PRAXIS asthma/COPD study

- Participants: Karin Lisspers, Björn Ställberg

An international collaboration aimed at highlighting unanswered questions on the management of respiratory diseases of importance in primary care. This has resulted in a 2010 published Research Needs Statement from the *International Primary Care Respiratory Group (IPCRG)*.

A publication about the needs of prioritising respiratory research in primary care has also been published. They are also involved in an international research project comparing the management of COPD and asthma in primary care in different countries and promoting research collaboration, the UNLOCK study, published in 2010.

A manuscript about a comparison of COPD patients in large clinical trials and COPD patients attending primary care has been published [124]. Lisspers and Ställberg are the leads of two new research projects within UNLOCK, one about asthma and one about COPD and co-morbidities.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

The physicians' actions in the management of COPD

Björn Ställberg is involved in research collaboration with the Center for Family and Community Medicine (CEFAM), at the Karolinska Institute. The aim of this project is to study how quality of care for patients in primary care with COPD can be improved by better understanding of the prevalence, indicators, and physicians' actions.

The project is generating one PhD thesis (Hanna Sandelowsky, Karolinska Institutet, Stockholm). One publications has been published from this research collaboration and a second is accepted.

COPD rehabilitation study

Björn Ställberg and Karin Lisspers are members in the steering committee of a national investigation of resources for rehabilitation in COPD. A first paper has been published [234] and a second submitted.

[For reference numbers in brackets -- see “Publications 2015-2013” on page 214-236]

Clinical trials

Björn Ställberg has been a member of the steering committee in an asthma clinical trial published 2015 [64].

Björn Ställberg has been involved in an international cost-effectiveness study in COPD published 2015 [16].

[For reference numbers in brackets -- see “Publications 2015-2013” on page 214-236]

The ARCTIC study - Patient characterization, costs and outcomes in a COPD population based on a tailored and integrated EMR and registry data in Sweden

- Participants: Gunnar Johansson, Karin Lisspers, Björn Ställberg, Christer Janson

The purpose of this research study was to generate evidence related to COPD patients in Sweden, focusing on early diagnosis treatment, management, outcomes and costs of COPD. The study entailed three major research themes that focused on providing a better understanding of outcomes of early diagnosis and intervention for COPD, characterize costs and consequences of exacerbations and symptomatic patients, and map treatment guideline adherence and related outcomes.

This is a cohort study of COPD patients detected in primary care setting, built upon existing, pseudonymised longitudinal patient-level data from electronic medical records (EMR) combined with national health registers obtained from primary and secondary care settings in Sweden. 52 primary care centers were recruited to the study. Inclusion criteria were patients aged 40 years or above who received a diagnosis of COPD (ICD-10 J44) either in the primary care or patients who received a diagnosis of asthma (ICD-10 J45) in the primary care setting that was later verified as COPD in the hospital setting. A reference population was extracted at each centre for age and gender matching for comorbidities. Of 202,397 patients listed in the primary care centers, 18,586 eligible COPD patients were identified and the rest served as the reference population.

Seven abstracts to the forthcoming IPCRG and ERS Congresses have been done during 2015 and several manuscripts are under preparation. The study is performed in cooperation with Novartis.

Comorbidities of patients diagnosed with COPD and asthma and effectiveness of Spiromax in real life in Sweden

- Participant: Gunnar Johansson, Christer Janson

While clinical trial data has adequately demonstrated safety and efficacy, effectiveness in the real-world setting is influenced by additional factors such as device characteristics and inhaler technique. The overall purpose of this research study is to obtain real-world evidence from Swedish national registries on comorbidities that may affect handling of inhalers and devices. The objective of the study is to describe the co-morbidity patterns in asthma and COPD, in terms of age, gender, region of residence and COPD and asthma treatments. Linkage of three national health registers: Swedish Prescription Registry, Swedish Patient Registry and Swedish Cause of Death Registry will be done. The national population based cohorts in Sweden including 694,900 COPD and asthma patients. We also describe the overall health by using the uniform Charlson comorbidity index. The comorbidities will also be presented separately for COPD and asthma patients, and also for patients with both COPD and asthma documented in the registers. The study is performed in cooperation with Teva.

The NO-KOL study

- Participant: Gunnar Johansson

This study was performed at one single centre, Nyby health care centre. 40 patients with chronic obstructive pulmonary disease (COPD) were randomized to double-blind crossover treatment with an inhaled steroid (mometasone). The purpose of the study was to evaluate the effects of the treatment on exhaled nitric oxide (NO). The level of exhaled NO has been demonstrated to be a good predictor of response to inhaled corticosteroids in asthma. The role of exhaled NO in COPD has been less studied.

The treatment with inhaled mometasone significantly reduced the NO as compared with placebo. The expiratory flows measured with spirometry (FEF75, FEF50 and FEF25) were significantly improved by the steroid treatment as compared with placebo. The baseline value for NO did not predict a positive response in terms of improvements in expiratory flows. Instead, the major reduction in NO after active treatment was related to significant improvements in expiratory flows.

Results have been presented at the *European Respiratory Society (ERS) Annual Congress 2013*. Exhaled NO but not eosinophilic inflammation is reduced by inhaled corticosteroid treatment in COPD).

The project is being led by Gunnar Johansson and Kjell Alving and has received financial support from Schering-Plough.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

A retrospective database assessment of clinical effectiveness in type 2 diabetes patients treated with liraglutide from primary care centers in Sweden

- Participant: Gunnar Johansson

There is only limited data on clinical effectiveness of liraglutide when used in daily clinical practice in a broad population outside the controlled setting of a randomized clinical trial. This study is a non-interventional retrospective cohort database study to analyze de-identified, anonymous patient electronic medical record (EMR) data and registry data from various national health registers in Sweden. Data will be analyzed for patients with type 2 diabetes treated with liraglutide or sitagliptin from January 2010 to 2015. The study will be conducted in two distinct stages: The first will be to determine the clinical effectiveness of liraglutide in patients of differing baseline characteristics (ranges of BMI sub groups, duration of diabetes since diagnosis, ranges of baseline HbA1c, and across a variety of previous therapy backgrounds) in clinical practice. The second distinct stage will seek to determine the comparative effectiveness of liraglutide versus DPP-IV inhibitor therapies (sitagliptin) in clinical practice. Comparisons will be examined based on outcomes in new treated liraglutide vs. DPP-IV inhibitor (sitagliptin) patients while controlling for potential confounding factors. One manuscript has been submitted for publication. The study is performed in cooperation with NovoNordisk.

Treatment of asthma in primary health care using exhaled nitric oxide analysis

- Participant: Gunnar Johansson

A total of 187 patients with asthma at 17 primary health care centres have been included in a study. The aim is to examine whether use of exhaled nitric oxide (NO) to guide anti-inflammatory treatment can improve asthma-related quality of life in adult patients with allergic asthma. The data have been collected and are being processed. The same study is examining whether there is an association between different circulating cytokines (systemic inflammation), exhaled NO and quality of life [230].

The project is being led by Kjell Alving, Jörgen Syk and Gunnar Johansson and is receiving financial support from Karolinska Institutet.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

A retrospective epidemiological study to map outpatients with chronic obstructive pulmonary disease (COPD) and describe

COPD health care in real-life primary care during the first ten years of the 21st century – PATHOS

- Participants: Karin Lisspers, Björn Ställberg, Gunnar Johansson

This is a retrospective epidemiological study to map outpatients with COPD and describe COPD health care in real-life primary care during the first ten years of the 21st century. Data has been extracted anonymously from electronic patient records in primary care on approximately 25,000 patients. In addition, data regarding morbidity and mortality has been collected from the Hospital Discharge Register (Slutenvårdsregistret) and the Cause of Death Register and information on prescribed drugs was collected from the Prescription Register. Data on social-economic status has also been collected from Statistics Sweden (SCB).

The project is being led by Gunnar Johansson and Karin Lisspers and Björn Ställberg are members of the steering committee.

The PATHOS study is receiving financial support from AstraZeneca. The data management has been performed by Pygargus and Uppsala Clinical Research Centre. Four papers have been published [128, 150, 199, 204] from the PATHOS study and a fifth manuscript has been a part of a dissertation at the Department of Medical Sciences: Respiratory Medicine & Allergology, Uppsala University.

[For reference numbers in brackets -- see “Publications 2015-2013” on page 214-236]

Effects of a rehabilitation programme on patients with COPD or heart failure

- Participants: Karin Lisspers, Björn Ställberg

A new randomised controlled trial studying the effects on dyspnoea symptoms of a rehabilitation programme on patients with COPD and heart failure has started. This study is carried out in collaboration with Regional Research centres in Karlstad and Örebro. Karin Lisspers and Björn Ställberg are members of the steering committee. The results were presented as a poster at the ERS congress in 2015 and a manuscript is under preparation.

How can COPD patients with risk for exacerbations be identified? The TIE-study

- Participants: Karin Lisspers, Björn Ställberg, Kristina Bröms, Regina Bendrik

A new prospective study in primary and secondary care in collaboration with the Clinical Research Centre in Gävle and the Department of Medical Sciences: Respiratory Medicine & Allergology, Uppsala University started in 2013.

The aim of the study is to find clinical tools for identifying patients with risk for COPD exacerbations. This is a regional study aiming to include 600 COPD patients in the counties of Uppsala, Gävleborg and Dalarna. Recruitment started in May 2014 and patients will be studied during two years with three visits including examinations, blood analysis and questionnaires.

Two abstracts have been accepted at the IPCRG Congress in 2016, one regarding the relation between a walking-test and exacerbations with Regina Bendrik as first author and one about swallowing dysfunction in patients with stable COPD with Margareta Gonzalez Lind as first author. Three abstracts have also been submitted to the ERS congress in 2016 and several manuscripts are under preparation.

Karin Lisspers, Björn Stållberg and Kristina Bröms are members of the steering committee.

Communication skills and GP's conceptions of quality in family practice

- Participants: Annika Bardel, Sven-Olof Andersson, Linus Johnsson, Lena Nordgren, Malin Swartling, Per Kristiansson

Communication skills

Participants: Annika Bardel, Sven-Olof Andersson, Malin Swartling, Malin André, Pål Gulbrandsen, Per Kristiansson

Good communication skills have a positive impact on patient and physician encounters. Communication skills training including video supervision is therefore an important part of medical students' education. The aim of the present study, which is in the planning stage, is to train supervisors at primary health care centers communication and supervision skills to improve the communication skills among the medical students.

GPs' perceptions of quality: A Grounded Theory project

- Participants: Linus Johnsson and Lena Nordgren

Quality in family medicine is a contentious concept with clinical, ethical and political connotations, the real-world ramifications of which are considerable. The aim of this project is to develop a theory of quality in family medicine, consisting of an elucidation of the concept of quality from the point of view of general practitioners (GPs) and an empirical account of how they work toward quality. We ask:

- How is quality in family medicine conceptualised and experienced by family doctors?

- What is the main concern for GPs as they work toward quality?
- What elements characterise GPs' efforts to work toward quality?
- What are the basic social processes that can resolve the main concern?

Because of our interest in understanding the challenges to quality that GPs face, the interactions that they are party to, the meanings that the various actors ascribe to their experiences and the processes through which quality is created, we have chosen a Straussian Grounded Theory (GT) methodology. Data is generated through unstructured in-depth interviews with and observations of GPs and GP residents in their work. In accordance with GT, data generation, analysis and theory building are carried out in parallel and iteratively. Participants are recruited through various GP networks. The familiarity of with family medicine contributes to theoretical sensitivity, whereas LN has experience of GT methodology and uses her limited pre-understanding to increase openness. Member checking will be used to establish the validity of the emerging theory.

Diabetes and cardiovascular disease

- Participants: Jan Cederholm, Johan Hallqvist, Gunnar Johansson, Jan Stålhammar, Kurt Svärdsudd

Determinants for the survival of diabetes patients

This project is based on the 776 diabetes patients followed and treated at Laxå primary health care centre since 1972 and 3,880 referents from the general population matched to the diabetes cases by age, sex, and year of onset for the diabetes patients. The purpose is, firstly, to determine whether the diabetes patients have had the same decline in mortality rate as the general population, and secondly, to evaluate determinants for survival among the diabetes patients (blood glucose, blood pressure, blood lipids and others).

A first report dealing with diabetes incidence and prevalence during 30 years of follow up has been published as well as a study of mortality trends in subjects with and without diabetes during 33 years of follow up. In a third report was shown the effect of blood pressure, anti-hypertension treatment, fasting blood glucose and diabetes treatment on cardiovascular disease incidence [117].

A fourth report has been published during 2015 [36] with the aim of studying if screening of diabetes compared with clinical detection is advantageous in terms of reduced mortality and cardiovascular disease incidence. The study concluded that no reduction in total mortality or CVD outcomes was found in patients with Type 2 diabetes that was detected by screening compared with those diagnosed clinically.

The project is being led by Dan Andersson and Stefan Jansson, and has generated one PhD thesis in 2014 (Stefan Jansson. A longitudinal study of diabetes mellitus: with special reference to incidence and prevalence, and to determinants of macrovascular complications and mortality).

Financial support has been received from the Primary Health Care Research Unit, Örebro, the Örebro County Council Research Unit, Örebro University and Uppsala University.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

The Swedish National Diabetes Register (NDR)

The Swedish National Diabetes Register (NDR), since last years including more than 85% of all patients with diabetes in Sweden, forms the basis for several research projects. With the register center located in Gothenburg, one of our senior researchers, Jan Cederholm, is responsible for the statistical and epidemiological analyses as well as thesis tutorials, in cooperation with Björn Zethelius (Geriatrics), forming the Uppsala branch of the Working Group of the NDR.

The project has generated two doctoral thesis's at the University of Gothenburg, Sahlgrenska Academy, in 2010 (Katarina Eeg-Olofsson: Cardiovascular risk factors and complications in type 1 and type 2 diabetes), and in 2014 (Nils Ekström: Pharmacological treatment in patients with type 2 diabetes: benefits and risk. Epidemiological studies from the Swedish National Diabetes Register). Financial support has been received from the Swedish Association of Local Authorities, Region Västra Götaland and Uppsala University.

More than 50 articles have been published from the NDR 2002-2015, as presented at www.ndr.nu – 17 articles 2013-2015 [21, 61, 75, 76, 101, 102, 105, 121, 123, 158, 159, 178, 179, 180, 181, 182, 228].

Summaries of the risk factor control and associations with diabetic complications, coronary heart disease (CHD), cardiovascular diseases (CVD), mortality, or risk of cancer, in type 1 diabetes or type 2 diabetes, have been published in *Lakartidningen* 2009 and 2013 [178] and in reviews (*Diabetes Care*, *Eur J Cardiovasc Medicine*).

Observational NDR-studies have shown that normal weight reduced risks of CHD and CVD by 15% and 22%, as compared with overweight or obesity, and non-smoking at middle age reduced risks of CHD and CVD by 57% and 38%. HbA1c (MonoS) <52 mmol/mol (<6%) strongly reduced risk of CVD, with no increased risk at lower HbA1c values, even with longer diabetes duration or history of CVD, in type 1 and type 2 diabetes.

Other observational long-term studies showed that blood pressure (BP) <140/80 mmHg strongly reduced risk of CVD, with no significant risk differences between SBP 130-139 and 110-129 mmHg, indicating a BP treatment target 130-135/75 mmHg, is in accordance with recent guidelines from

the European Societies of Hypertension and Cardiology and the American Diabetes Association. The NDR-study was presented by ESC/ESH as one of two evidence-based references for this treatment goal. Specific statistical graphical technique was applied to illustrate in detail the variation of CVD risk across the BP distribution. Half of the patients in the NDR register still have a systolic BP ≥ 140 mmHg.

Concerning blood lipids, observational NDR-studies have shown that the ratio non-HDL/HDL cholesterol was a stronger risk factor for CHD than LDL-cholesterol. Specific statistical graphical technique demonstrated that LDL had a markedly attenuated and flattened risk effect below 2.5 mmol/l, while the risk effect was progressively decreased at lowest lipid ratio values, also showing improved HDL-cholesterol and triglycerides values with lower lipid ratio [182]. Recent guidelines from American Heart Association underline that there is no evidence-base for increased risk effect at lowest LDL targets.

A multifactorial approach to risk factor control showed that combined control of HbA1c and BP, as well as combined control of HbA1c and blood lipids, had additive effects for risk of CVD. The ratio total-to-HDL-cholesterol had a stronger effect for CVD risk than HbA1c, although HbA1c also showed a considerable effect, with no increased CVD risk (no J-shaped curve) at lowest levels of HbA1c or the lipid ratio. A summary of multiple risk effects showed that almost half (40-43%) of all cases of CHD and CVD could be prevented, if HbA1c (MonoS) >57 mmol/mol%, BP $>140/90$ mmHg, obesity and smoking could all be eliminated at the same time.

Two risk models for estimation of 5-year CVD risk in type 1 diabetes or type 2 diabetes have been published based on observational NDR-studies using multiple cardiovascular risk factors and clinical characteristics as risk predictors; the risk models have shown good validation when applied to large samples of patients with diabetes overall in Sweden. Both risk models are presented at www.ndr.nu, and can be useful for diabetes care in daily clinical practice. A study of newly diagnosed patients with type 2 diabetes showed that the estimated CVD risk has been improved during the last years [105].

A long-term observational study of patients with type 2 diabetes showed considerably increased risks for CVD and mortality with low physical activity (never or 1-2 times 30 min activities per week) compared to higher activity. Inactivity both at baseline and during the 5-year study period showed highest risks, 70% higher CVD risk and 100% higher risk of all-cause mortality [159].

Long-term development of renal complications (albuminuria and renal impairment) was predicted by higher HbA1c and systolic BP, and also by higher BMI and triglycerides. Albuminuria more than renal impairment was strongly related to risk of CVD and mortality during 5 years of follow-up [229].

An observational NDR-study of pharmacological treatment on risk for diabetic complications in type 2 diabetes, using linking with the Swedish Prescribed Drug Register, showed that metformin had lower risk than insulin for CVD and all-cause mortality, and slightly lower risk than sulphonylurea for all-cause mortality. Patients on metformin with mild-moderate renal impairment (GFR 45-60) showed no increased risk of CVD, all-cause mortality or acidosis/serious infection [180]. Another long-term study on aspirin in patients with type 2 diabetes and no previous CVD showed no decrease in risks of CVD or mortality with aspirin use, not even in patients with high predicted risk of CVD [21, 180, 181].

A large observational study on 25,000 patients with type 2 diabetes, followed for 10 years until 2009, showed no association between higher HbA1c values and risk for all cancer or specific types of cancer. However, another observational NDR-study showed a strong association between elevated BMI / obesity and increased risk for all cancer as well as increased risks for gastrointestinal, colorectal and postmenopausal breast cancer [121].

A large observational study during 7 years until 2012 in patients with type 1 diabetes showed that patients with insulin pump therapy had considerably decreased relative risk of fatal CVD and total mortality compared with patients on multiple injection therapy [61].

Another large observational study during 7 years in patients with type 2 diabetes demonstrated principal predictors of newly detected atrial fibrillation: the modifiable risk factors high blood pressure, high BMI and albuminuria, as well as histories of heart failure and CVD, height and advancing age [76].

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Cooperation with ULSAM

A recent study based on the ULSAM cohort, using 1049 male subjects aged 70 years followed for mean 9 years, showed that an index for insulin resistance, estimated with use of fasting and 2-hour glucose and insulin values at a 75 g oral glucose tolerance test (Cederholm index), was a strong predictor for development of manifest diabetes as well as for risk of CVD. This test was considerably stronger than around 20 previously established resistance indexes using either only fasting values or various values at the glucose tolerance test. Cederholm index also had a strong association with the resistance value at the insulin clamp test, and should be useful for many future clinical studies of insulin resistance [75]. The study was elaborated by Jan Cederholm in cooperation with Björn Zethelius, Geriatrics/Department of Public Health and Caring Sciences.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

All New Diabetics in Uppsala – ANDiU

ANDiU is a study on patients recently diagnosed with diabetes residing in Uppsala County. Our aims are to enhance diabetes classification by exploring clinical characteristics present at time of diagnosis, facilitate individualized diabetes care and to build a platform for diabetes research. ANDiU is funded by the Exodiab consortium, a collaboration between the Uppsala university, Lund University and the Karolinska Institute. Since launch in maj 2012 ANDiU have contributed to 7 publications [23, 33, 95, 103, 129, 130, 144]. ANDiU collaborate with ANDIS (L. Groop, Lund University) and ESTRID (S. Carlsson, J Löfvenborg, R Hjort, Karolinska Institute).

Principle investigator is Per-Ola Carlsson, Department of Medical Cell Biology, Uppsala University and project leader is Mats Martinell. Other associated researchers are Johan Hallqvist, Jan Stålhammar and Daniel Espes, Uppsala University.

[For reference numbers in brackets -- see “Publications 2015-2013” on page 214-236]

A retrospective database assessment of clinical effectiveness in type 2 diabetes patients treated with liraglutide from primary care centers in Sweden

- Participant: Gunnar Johansson

There is only limited data on clinical effectiveness of liraglutide when used in daily clinical practice in a broad population outside the controlled setting of a randomized clinical trial. This study is a non-interventional retrospective cohort database study to analyze de-identified, anonymous patient electronic medical record (EMR) data and registry data from various national health registers in Sweden. Data will be analyzed for patients with type 2 diabetes treated with liraglutide or sitagliptin from January 2010 to 2015. The study will be conducted in two distinct stages: The first will be to determine the clinical effectiveness of liraglutide in patients of differing baseline characteristics (ranges of BMI sub groups, duration of diabetes since diagnosis, ranges of baseline HbA1c, and across a variety of previous therapy backgrounds) in clinical practice. The second distinct stage will seek to determine the comparative effectiveness of liraglutide versus DPP-IV inhibitor therapies (sitagliptin) in clinical practice. Comparisons will be examined based on outcomes in new treated liraglutide vs. DPP-IV inhibitor (sitagliptin) patients while controlling for potential confounding factors. One manuscript has been submitted for publication. The study is performed in cooperation with NovoNordisk.

[For reference numbers in brackets -- see “Publications 2015-2013” on page 214-236]

Pain and musculo-skeletal disorders

- Per Kristiansson, main responsibility

Epicondylitis

- Participants: Magnus Peterson, Stephen Butler, Kurt Svärdsudd

Epidemiology, treatment and causes of tennis elbow were the aims of this project. The studies showed that a large number of treatment methods was used in primary health care, graded concentric treatment was effective and physiological processes was associated with pain in the peripheral painful tissue of the affected as compared to the healthy elbow shown by positron emission tomography (PET) [213]. In cooperation with Harvard Medical School, the central nervous system has been analysed in relation to the findings in the peripheral tissue and decreased CNS neurokinin 1 receptor availability in chronic tennis elbow was shown. The PET-project is currently expanded in cooperation between Karolinska and Uppsala University to involve animal studies of other pain-related mechanisms in the peripheral tissue. In cooperation with the Swedish Agricultural University (SLU) animal studies are conducted on animal models of pain in mast cell deficient mice. During 2014 two chapters on musculoskeletal pain were published in a clinically oriented textbook [139, 112].

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Cognitive behavioral therapy in fibromyalgia

- Participants: Bo Karlsson, Karin Björkegren, Per Kristiansson, Gunilla Burell, Fred Nyberg Kurt Svärdsudd

The effects of cognitive behavioural therapy (CBT) given to fibromyalgia patients was studied in this project by a randomised controlled study design. Fifty women with a fibromyalgia diagnosis in Mid-Sweden were randomised to one of two groups. One group received CBT for one year with the other group as control. After one year the control group also received CBT. A large number of variables was collected through questionnaires and blood samples at baseline and follow-up. The results have shown that CBT reduces distress which is mirrored by reduced levels of Substance P and Neuropeptide Y. One paper is published 2015 [40] and one is submitted. The project is generating one PhD thesis (Bo Karlsson). The project has been performed in collaboration with the section for biological research on drug dependence at Uppsala University.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Prevention

The experience of health and lifestyle habits among persons with schizophrenia

- Participants: Elisabet Sundgren, Lennart Fredriksson, Johan Hallqvist

People with schizophrenia have a high comorbidity for somatic diseases like cardiovascular diseases, metabolic syndrome, cancer and diabetes type-2 and have a higher prevalence of smoking than the general population.

As a part of Elisabet Sundgren's thesis work we are studying the experience of health and lifestyle among persons with schizophrenia. The first study was qualitative there we were studying how current smokers with schizophrenia experience health and lifestyle habits and how they experience smoking in relation to health. The second study will be a quantitative evaluation of an intervention to see what types of interventions persons with schizophrenia or other types of psychosis need to be able to change unhealthy habits.

The thesis will further include one qualitative and one quantitative study on the topic of health and lifestyle changes among persons with schizophrenia. The first paper was accepted in 2015 [67b].

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Cultural Activities and Health

- Participants: Tina Grape Viding, Eva Bojner Horwitz, Johan Hallqvist
- Cultural activities like singing, dancing, painting, acting, visiting theatres and museums, may promote health through various physiological mechanisms. In this project the physiological effects of singing will be studied. An intervention program called "Kulturpaletten" has been developed and its effects will be examined in randomized studies with first women having burnout symptoms and secondly with patients who have had surgery for colo-rectal cancer [10, 11, 12, 28, 88, 89, 90, 91, 92, 104, 156].

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Triggers of the onset of disease and other health problems

- Johan Hallqvist

The case-crossover methodology was developed at Harvard in the beginning of the 1990-ies and it opened up a new field of research; the study of risk factors with short induction periods, that is, triggers of disease. In the ongoing projects all conducted in collaboration with research groups at Karolinska Institutet we aim to identify triggers of acute health events, and to quantify their effects.

In some case-crossover projects we are applying the design to data bases extracted from Swedish National registers. In studies of *Side-effects of drugs*, the first aim is to identify harmful side-effects of pharmaceutical drug use and the second aim is to potentially develop a system for surveillance. We use a record linkage between the new drug prescription register (exposures and sometimes also outcomes) and the hospital discharge register (outcomes).

We also examine *Acute life events (like death of a close relative) as triggers of acute diseases like myocardial infarction and stroke*, in a study based on record linkage between the multigenerational register and the hospital and the cause of death registers.

TUFS (Swedish acronym for triggers of sickness absence) was a part of a thesis work and aimed at identifying non-medical triggers interacting with reduced work ability due to illness. It was based on extensive data collection from more than 1000 spells of sickness absence at six work places.

Finally *Psychoactive substances as triggers of violence* is a study based on data collection from individuals in custody in Stockholm because of criminal activities including violence (The Stockholm Social Medicine Custody Project) [170, 195, 208].

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Social epidemiology: the role of life course and social context

- Johan Hallqvist

We have earlier shown that there are inherent difficulties in the task of disentangling time-related exposure constructs like accumulation, critical period and mobility in life course epidemiology. At present we pursue further in-depth analyses of specific hypotheses related to these theoretically based mechanisms in collaboration with researchers at Karolinska Institutet. We also have a general interest in methodological issues related to the study of mechanisms behind inequalities in health and we have for example shown the importance of distinguishing between differential exposure and differential susceptibility when analyzing for example the effects of exposure to job strain. At present we explore the advantages of new methodology introduced in 2015 by Tyler VanderWeele at Harvard, that is based on the principles of counterfactuals makes use of new graphical causal modeling.

In *Life Time Health: the effect of fetal exposures, social trajectories and social transitions on health and health behavior* the aim is to study trajectories and transitions as important features of the life course and to find out how health related parameters are influenced and through which mechanisms. In this project we use the new Stockholm Public Health Cohort (SPHC) with repeated questionnaires and all kinds of register information for approx 100000 participants. In associated projects we use the SHEEP

data base to investigate the combined effects of different exposures on cardiovascular disease.

In *Pain in the body and the soul* the aim is to identify life course factors that influence psychological well-being, psychological ill-health, depression and musculoskeletal pain. This project is based at Karolinska Institutet and makes use of the new Stockholm Public Health Cohort (SPHC) and national register data bases.

Life course risk factors and socioeconomic differences in the risk of mental illness concerns risk factors like adverse marital trajectories, school failures, and criminal careers. The project is also base at Karolinska Institutet and concerns register studies on the total population of Sweden.

The other aspect concerns the social environment and macro-determinants of disease. In carefully designed studies we have contributed with further empirical evidence to the yet unresolved questions on if and how social context in terms of socioeconomic deprivation or low social capital on the aggregate level impinge on the etiology of specific individual diseases.

A project at Karolinska Institutet concerns *Social context in Swedish municipalities and juvenile delinquency*. The question is whether contextual characteristics like socioeconomic deprivation or lack of social integration influence crime rates among adolescents when individual characteristics are controlled for. Family based designs and multi-level analyses are employed on register data of all Swedes [32, 58, 78, 86, 87, 100, 106, 110, 111, 113, 171, 173, 206, 214, 218, 219, 228].

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Problem gambling among young women and men in Sweden

- Participant: Johan Hallqvist

Gambling among young people is a significant public health concern. While an understanding of the aetiology of gambling problems is crucial for prevention, there is limited knowledge about the onset of and the risk factors for problem gambling among youth. This project aims to estimate the incidence of a first episode of problem gambling and to examine some potential risk factors for problem gambling among Swedish young women and men. The focus is on psychosocial factors associated with youth problem gambling (such as social support, alcohol use, school achievement, maltreatment, and affective disorders). Three of the four studies in this project are based on Swelogs data (the longitudinal cohort and a case control study nested in the multipurpose cohort at the National Public Health Agency collected for monitoring and analysing problem gambling in the Swedish population), and one study uses data from the cross-sectional Swedish National Public Health Survey [26, 27, 188].

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Obesity care

- Participants: Jenny Söderberg, Gunilla Mårtensson, Per Kristiansson, Marianne Carlsson

The aim of this study is to affect physical activity and unhealthy eating habits, in a randomized controlled study, among people with overweight and obesity by using the Swedish National Guidelines for Methods of Preventing Disease of the National Board of Health and Welfare (Socialstyrelsen).

In addition, attitudes among primary health care staff and their reported activities regarding then National Guidelines will be described in a quantitative and a qualitative study. The data collection has started and the project will generate one PhD thesis (Jenny Söderberg). The study is funded by University of Gävle.

Physical activity in prevention and treatment of disease

Physical activity is one of the most important public health determinants, and the health care sector is highlighted as a central setting in the promotion of physical activity in the population as well as at individual level. The project consists of several studies of methods for promotion of physical activity in patients. The main method is physical activity on prescription (PaP). Previous studies have shown that this method is effective in clinical settings and increases physical activity level and self-reported quality of life, reduces risk factors and has good adherence.

There has been a positive trend in the total number of PaP prescribed in Sweden since 2007, with a yearly increase of 30-67 %. Though, only 49,000 PaP were prescribed in 2010, with large variations between different county councils and regions. However, there are no national data on current number of PaP. Consequently there is a need for improved implementation of PaP and studies on clinical practise.

Lessons from implementation of the method physical activity on prescription (PaP) to patients in primary health care in the Uppsala-Örebro region

- Participants: Lena Kallings (principal investigator), Kristina Bröms, Lars Jerdén, Catharina Gustavsson, Ann-Christin Johansson, Lars Wallin, Per Kristiansson, Mats Arne

The aim of this large study is to investigate the importance of organizational, prescriber and patient factors for implementing “Physical activity on prescription” within primary health care. The study includes five sub-studies. The study is conducted in collaboration between researchers in the counties of Dalarna, Gävleborg, Sörmland, Uppsala, Värmland and Västmanland. The study is funded by Regionala forskningsrådet in the Uppsala-Örebro region.

Data has been collected in 2014 and 2015, and is now ended. One postal questionnaire was sent to 3,600 patients. Three sub-studies (Bachelor and Master thesis) with interviews of health-care professionals have been conducted in 2015. Analysis and manuscript writing will be done during 2016.

Physical activity on prescription (PaP) to patients with osteoarthritis

- Participants: Lena Kallings, Kristina Bröms, Margareta Emtner (principal investigator) and PhD student Regina Bendrik

One RCT with FaR to patients with osteoarthritis in primary health care, started spring 2010 and one PhD student Regina Bendrik is involved in the project. All patients are included and have been tested at baseline and most of the follow-ups, the long-term follow-ups continue during 2016. The study is financially supported by Gävleborg county council and Uppsala-Örebro regional research council. Two abstracts have been accepted in 2015 and first manuscript will soon be submitted. The project is generating one PhD thesis (Regina Bendrik).

Reproductive health

- Per Kristiansson, main responsibility
- Participants: Kerstin Ahlqvist, Anna-Maria Annerbäck, Mansour Alemi, Stephen Butler, Elisabeth Krefling Bjelland, Johanna Haraldsson, Per Kristiansson, Anne Lindgren, Lena Nordgren, Ronnie Pingel, Magnus Peterson, Eva Thorell, Thomas Torstensson

Physical activity and pregnancy

- Participants: Eva Thorell, Laura Goldsmith, Gerson Weiss, Per Kristiansson

The aim of this project was to assess physical fitness in pregnancy and to evaluate its effect on perceived health, back pain, blood pressure and duration of pregnancy. Also, to evaluate the effect of serum relaxin levels on blood pressure and duration of gestation. Perceived health, diastolic blood pressure and duration of gestation were positively affected by physical fitness while no effect was shown on the incidence of back pain. The effect of physical fitness on duration of gestation and diastolic blood pressure might have clinical implications as well as the increased serum relaxin levels on miscarriages.

The project has generated four papers – one of them in 2015 [68] and one PhD thesis in 2013 (Eva Thorell. Physical fitness and pregnancy. Medical sciences, Uppsala University) and has received support from New Jersey

Medical School of Rutgers University, Örebro County Council and Uppsala University.

Chronic pelvic pain induced in pregnancy

- Participants: Thomas Torstensson, Anne Lindgren, Magnus Peterson, Stephen Butler, Per Kristiansson

This study was aimed to explore the pain mechanisms and the origin of the pain and to evaluate a short-term relief treatment in women suffering from chronic pelvic pain induced in pregnancy.

Reports of randomized controlled trials of corticosteroid treatment to the ischial spine of the pelvis decreased pain intensity and increased function are published and infer a source of pain in the pelvis. Referred pain patterns provoked on intra-pelvic landmarks were consistent with sclerotomal sensory innervation and indicate allodynia and central sensitization. This suggests that pain mapping can be used to evaluate and confirm the pain experience and contribute to diagnosis.

The project has generated four papers – two of them 2013-2015 [70, 233] and has generated one PhD thesis in 2014 (Thomas Torstensson. Chronic pelvic pain persisting after childbirth: diagnosis and implications for treatment. Medical sciences. Uppsala University).

[For reference numbers in brackets -- see “Publications 2015-2013” on page 214-236]

Swedish Pelvic Pain Study (SPPS)

- Participants: Kerstin Ahlqvist, Angela Schlager, Åsa Wiberg, Annika Holten, RoseMarie Casselbrant, Ingrid Djurback, Mansour Alemi, Christina Olsson, Lena Nilsson-Wikmar, Thomas Torstensson, Elisabeth Bjelland, Ronnie Pingel, Kristofer Rubin, Per Kristiansson

The focus of this prospective cohort study is the patho-physiologic process explaining how apparently healthy and well-trained young women within a few months of pregnancy can become severely disabled by pregnancy induced low back and pelvic pain that may persist for several years after delivery. We hypothesize that a functionally disturbed remodelling and repair of ligaments of the lowest back will be involved in the development of disabling pregnancy-induced low back pain persistent years after childbirth.

The study is a population-based cohort study of 1000 women with baseline assessment before gestational week 12 and additional assessments at gestational week 36 and 9 months after childbirth. Individual patient data are collected by means of web-based questionnaires, clinical examination and blood tests. General joint mobility, skin extensibility and biochemical markers, as a measure of fragile connective tissue, will be measured thoroughly as well as the outcome measures reported low back pain location and back pain provocation tests.

The studies started in 2014. One PhD student (Kerstin Ahlqvist) is so far involved in the project and has financial support from Regionala Forskningsrådet in the Uppsala-Örebro region, Uppsala County Council and Uppsala University.

Imaging of the back and pelvis in diagnosis of chronic pelvic pain

- Collaboration project together with professors Niels Egund and Anne-Grethe Jurik, Aarhus, Denmark

There is a great need of an imaging method to diagnose chronic pelvic pain induced in pregnancy. In the present study 500 women with back pain recruited from a back rehabilitation clinic and matched controls without pain as well as 50 men with high load of their pelvis with matched controls without such high load, will use magnetic resonance tomography (MRT) to investigate the importance of changes in the vicinity of the anterior part of the sacro-iliac joints. Initial MRT investigation has been conducted 2011 and a follow-up has started. The project has financial support from the Uppsala County Council.

Pelvic pain during pregnancy and hormonal contraceptive use

- Participants: Elisabeth Bjelland, Per Kristiansson, Hilde Nordeng, Siri Vangen, Malin Eberhard-Gran

The project was the results of collaboration with researchers involved in the Norwegian Mother and Child Cohort. The study results suggest an exogenous hormonal influence on the development of pregnancy induced pelvic pain as the reported use of progestine hormonal contraceptive was associated with a higher degree of pregnancy induced pelvic pain induced in pregnancy. An ongoing study evaluates the effect of hormonal contraceptive use and pelvic pain persisting after childbirth.

Pelvic pain after childbirth: a longitudinal population study

- Participants: Elisabeth Bjelland, Katrine Owe, Ronnie Pingel, Per Kristiansson, Siri Vangen, Malin Eberhard-Gran

The project was the results of collaboration with researchers involved in the Norwegian Mother and Child Cohort. The study showed that among women with no pelvic pain during pregnancy the occurrence of pelvic pain postpartum was lowest after planned cesarean deliveries and highest after operative vaginal deliveries. Likewise, women with planned cesarean deliveries reported lower pelvic pain severity scores after childbirth than women with unassisted vaginal deliveries.

Laser therapy of pregnancy induced back and pelvic pain persistent after childbirth

- Participants: Anne Lindgren, Thomas Torstensson, Sahruh Turkmen, Elisabeth Bjelland, Jan Magnus Bjordal, Andy Wood, Bryan Pryor, Per Kristiansson

The aim of the study is to evaluate the short and long term effect of low level laser therapy in women with pregnancy-induced chronic pelvic pain regarding functioning and pain relief in a prospective triple-blinded randomized controlled trial. The laser treatment will be applied to the sacral back by a standard laser head and to the internal pelvis by a transvaginal probe. The study is approved by the regional ethics committee and the recruitment of participants has started. This is collaboration between physiotherapists, gynecologist, general practitioner and laser manufacturer. One PhD-student (Anne Lindgren) is involved in the project which has financial support from Uppsala and Västernorrland County Councils.

Joint mobility and pregnancy induced back pain

- Participants: Anne Lindgren, Thomas Torstensson, Hilde Robinson, Elisabeth Bjelland, Per Kristiansson

General joint laxity as a reflexion of constitutional weakness of connective tissue and its association with back pain induced in pregnancy and persisting after childbirth is evaluated in a collaboration with researchers at the University of Oslo. General joint mobility may provide a foundation for development of fundamentally new targeted prevention and causal strategies of the pain condition. The project is part of a PhD project (Anne Lindgren) and has financial support from Västernorrland County Council and Uppsala University.

Sexual and reproductive health among young men

- Participants: Johanna Haraldsson, Lena Nordgren, Ylva Tindberg, Per Kristiansson

The overall aim of the study is to investigate present conditions and room of improvement for sexual and reproductive health within the primary health care of young men. The study assesses sexual and reproductive health among young men in Sweden, describes the notion of sexual and reproductive health among young men and among staff of primary health care and analyze time for yourself under confidentiality with a physician. The study is generating one PhD thesis (Johanna Haraldsson) and is receiving financial support from the Primary Health Care of Sörmland County Council and Uppsala University.

Adverse childhood experiences

- Participants: Eva-Maria Annerbäck, Tanja Tydén, Per Kristiansson

Adverse Childhood Experiences is a concept where a wide range of traumatic events during the first 18 years in life are assessed. Adverse Childhood Experiences is believed to impair a person's social, emotional and cognitive functions and is associated with increased risk of health problem, disease and premature death and has an impact on epigenetics. Information of the impact of Adverse Childhood Experiences on pregnant women's health is scarce. With use of the large "Pre-pregnancy planning" data set different aspects of outcomes during pregnancy are elucidated. Financial support is received from Uppsala County Council.

Pregnancy planning

- Participants: Jennifer Drevin, Jenny Stern, Tanja Tydén, Per Kristiansson

Many women have insufficient knowledge of reproduction including health-promoting lifestyle prior to conception and, highly educated women in particular, postpone childbearing until ages when their fertile capacity has started to decrease. To increase knowledge and action of reproductive information a randomized controlled trial is carried out.

Social Insurance Medicine

- Main responsibility: Thorne Wallman
- Participants from the group:
PhD students: Anna-Sophia von Celsing, Linda Lännerström, Lars Carlsson
Supervisors: Karin Björkegren, Margaretha Eriksson, Catharina Gustafsson, Johan Hallqvist, Inger Holmström, Ronnie Pingel, Kurt Svärdsudd, Thorne Wallman

Factors of the patient, physician and health care that affect sick leave Participants from the group

The aim of this project is to gain better knowledge of the factors of the patient, physician and health care that affect sick leave. The first study was a randomized study of the effect of early multidisciplinary assessment at a primary health care centre. Second study was a qualitative focus group study of family doctors experience of sick leave assignment after the changes in the Swedish health insurance system. The third and fourth parts of the study

analyzes the significance of motivation and effect of rehabilitation programs on persons with long-term sick leave who lose their sickness benefits.

The project has generated one paper in 2015 [14]. The project is generating one PhD thesis (Lars Carlsson).

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Determinants for return to work among sickness certified patients in general practice

The aim of this study was to analyse possible determinants of return to work and their relative impacts. A prospective cohort study of 943 patients aged 18 to 63 years, sickness certified at a Primary Health Care Centre in Sweden during 8 months in 2004, and follow-up for three years. The most significant determinants increasing time to sick leave conclusion were number of sick leave days the year before baseline, age and sick leave due to a psychiatric diagnosis (F in ICD-10).

The properties of two models for the assessment of sick leave conclusion after sickness certification were analysed. The computer-based assessment model gave more precision and detailed information on sick leave conclusion than a manual assessment model. Based on these results, three nomograms were constructed providing detailed information on the probability on sick leave conclusion [80]. The impact was studied of a multidisciplinary vocational intervention for sick leave conclusion in a high-risk group for long-term sick leave compared to a matched-control group. Sick leave declined in the high-risk group but after the intervention period there was no difference as compared to a matched-control group. Furthermore, a comparison was performed of the patients' own assessment on chance to sick leave conclusion within 6 months with the assessment of a team of rehabilitation professionals. A close correlation between the patients' own view on sick leave conclusion and the assessment of professionals' indicate the importance of including patients' view when considering length of sick leave.

The project has so far generated two published articles [157] and two in manuscripts. The project is generating one PhD thesis (Anna-Sophia von Celsing).

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Sick leave in primary health care – Registered nurses' work by telephone and patients' experiences

Participants: Linda Lännerström, Anna-Sophia von Celsing, Inger Knutsson Holmström, Thorne Wallman

The aim of this project was to describe registered nurses' experiences and work with sick leave questions by telephone. It was further to describe the

effects of an educational intervention in social insurance medicine on registered nurses' work and perceived problems with sick leave questions by telephone. The aim was also to describe, analyze and understand long-term sickness absent people's experiences of being sick-listed. Four papers have been produced whereof two are published during 2012 and 2013 [209] and two are submitted during 2015. The project is generating one PhD thesis (Linda Lännerström). Financial support has been provided by Centre for Clinical Research, Sörmland County Council and Uppsala University.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

MEDiTUNA – Vocational rehabilitation: how does it affect health and quality of life?

MEDiTUNA, including 100 women and men, is a project that studies how persons with psychiatric disability are affected by an individual placement and support intervention. Outcome measures are health, quality of life, drug consumption and sick-listing. The project started in 2013. Baseline and 6 months follow-ups are finished. One year and two year follow-ups are finished in 2015.

Research area - Absenteeism and Return to Work

- Main responsibility: Ingrid Anderzén
- Participants from the group: Ingrid Anderzén, Åsa Anderzen, Anna Liljestam Hurtigh, Kjerstin Larsson

In collaboration with the Swedish Social Insurance Administration, the Swedish Public Employment Service, and the Occupational and Environmental medicine at the Akademiska hospital in Uppsala we have projects assessing the efficacy of various innovative return-to-work strategies, including the concept "Pathway Back to Work". The aims of these projects are focusing on enhancing the pathway back to work and to identify factors that will help long-listed individuals return to the working life. We have developed and evaluated strategies to decrease sick leave and to improve the return-to-work processes. The Pathway to Work focuses on assisting people on sick leave to become more independent and to earn a living by targeting some of their health-related barriers and by providing financial support. The program has achieved national recognition as an innovative and cost-effective means to decrease sick-leave and facilitate return-to-work for people with long-term stress-related absenteeism and young people with disabilities.

The Welfare Academy – a public investment for the development of welfare

- Participants connected to Uppsala University are Ingrid Anderzén and Johan Hallqvist

The Swedish Social Insurance Agency (SSIA) take the initiative to form a welfare academy, which is a co-operative undertaking between the SSIA, other governmental agencies at the local, regional and national level, the business and research communities, Community and non-profit organizations. The purpose of the academy is to improve the support for people who have difficulty find their places in the labor market. The academy shall also organize funding for research and implementation in this area. The challenges of a developing society require co-operation in all avenues of a developing society.

The purposes of the academy are:

- Develop and promote innovations within the welfare society
- Promote implementation and utilization of evidence based methods and procedures
- Contribute to the overall development of the Swedish welfare system

The main task is to bring together researchers and practitioners, establish co-operation in developing research-based methods for decision making that can improve the support systems for people who have difficulty to find their places in the labor market and to provide knowledge-based and practical support in implementation.

The groups prioritized by the academy are recent immigrants, people with functional impairments, and prevention of work-related illness.

In August 2015 the decision was taken not to proceed with the mission to start a Welfare academy.

VITALIS – An RTC study to support women on long term sick leave to return to working life through ACT or Team evaluation

- Participants: Ingrid Anderzén, Åsa Andersén, Anna Liljestam Hurtigh, and Per Lytsy

This project started as collaboration with the Swedish Social Insurance Administration, the Swedish Public Employment Service, and the Health Care sector. Fifty-five percent of people presently sick listed in Uppsala County were during 2010 diagnosed with psychological problems, such as depression, anxiety and stress related symptoms, and/or chronic pain. The overall aim with this project was to develop, provide and evaluate accessible rehabilitation programs, for these complexes of problems, to help women on long term sick leave, to return to work.

Vitalis started in Spring 2010 and data collection were completed during 2013. Approximately 400 women on long term sick leave due to pain, stress, depression and/or anxiety symptoms, were randomized into one out of three conditions. One as a multimodal team assessment and intervention, one with a home based internet supported unimodal psychological intervention (Acceptance and Commitment Therapy) and one condition as a treatment as usual (TAU) intervention. The project will evaluate the long term effects (after one and after two years) of those two different rehabilitation packages: multidisciplinary team assessment/intervention and CBT/ACT home based/internet treatment as compared to TAU. The follow-up data collection is completed. The evaluation of the project received financial support from REHSAM (forskning om arbetsrehabilitering).

A final report has been published and two articles have been published [1, 44]. The project will also generate at least three articles in two PhD thesis (Åsa Andersén and Lars Carlsson).

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

DIRIGO 1 and 2 – "I control"

- Participants in the research team: Ingrid Anderzén, Åsa Andersén and Kjerstin Larsson. Externalers are Kerstin Ekberg, Christian Ståhl.

Dirigo 1 and Dirigo 2 are two projects funded by The European Social Fund (ESF) and was operated by The Social Insurance Office, in co-operation with The Public Employment Service and the municipality, in parts of Stockholm. In Dirigo 1 participants are employees and the aim is to create a base of competence for workers on the welfare arena, enabling them to meet and support the citizen in his/her own process.

Participants in the Dirigo 2 project are sick listed individuals, young individuals with activity compensation from The Social Insurance Office and individuals that receive their compensation through their local municipality.

The overall aims with the two projects are to support and strengthen the individual and its view on their work capacity to return to/come closer to the labor market/employment.

Together with the University of Linköping we have evaluated the projects both with quantitative measurements (data from registry and questionnaires) and qualitative methods during open ended interviews and focus-groups with service users and professionals working in the area of vocational rehabilitation.

During the evaluation process the research team have completed six work reports that have been presented for the employees in the both projects. The projects started 2012 and were completed in 2014 and final reports were presented in September 2014. The projects ended up with a conference the 5 of May 2014 in Stockholm.

The project Dirigo 2 will generate one article in a PhD thesis (Åsa Andersén).

Two final reports have been published (Dirigo 1 Slutrapport, 2014. Ståhl C & Andersén Å and Dirigo 2. Slutrapport, 2014. Ståhl C, Andersén Å, Larsson K, Anderzén I, Ekberg K).

UMiA

- Participants in the evaluation process: Ingrid Anderzén, Åsa Andersén, Kjerstin Larsson

The project UMiA was founded by the European Social Fund (ESF) and is operated by The Social Insurance Office in Stockholm. The aims of the project were to develop, and evaluate different methods and interactions in order to support and enhance the ability for young individuals with disabilities to increase their work or study capacity. About 400 individuals, age 19-29 years will participate in the project.

The evaluation consists of both quantitative measurements (data from registry and questionnaires) and an on-going evaluation (qualitative) with service users and professionals working in the area of vocational rehabilitation perspective. UMiA started 2013 and completed in 2014. Three work reports have been completed and have been orally presented in 2014 and in *The EUPHA- Conference* in Milano in October 2015 (Andersén Å, Larsson K, Kristiansson P, Anderzén I. Effects of individual tailored vocational rehabilitation in young adults with disabilities). A final report was published 2014. The project UMiA will generate one article in a PhD thesis (Åsa Andersén).

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Symptom reporting and utilisation of pharmaceuticals

- Participants: Annika Bardel, Kurt Svärdsudd, Mari-Ann Wallander

Womens utilisation of pharmaceuticals and Symptom reporting among men and women in Sweden

- Main responsibility: Annika Bardel

The purpose of this project was initially to study utilisation of pharmaceuticals among women based on a postal questionnaire sent to 4,200 women in the Uppsala-Örebro region.

Symptom reporting across age has also been tested in the consort dataset including more than 17,000 observations in men and women 25-99 years old. Analyses are finalized and one paper has been submitted to a peer reviewed journal.

We now intend to move on with further analyses of the consort dataset to examine the relationship between symptom reporting among men and women and their sick-listing, disability pension, survival and use of hospital care.

Pharmacoepidemiology

- Main responsibility: Mari-Ann Wallander

The area of pharmacoepidemiology is a fairly new branch of epidemiology and is methodologically still in its development phase. Research in this area requires access to high quality health care databases and collaboration with various academic groups in Europe and the US. The project has generated three papers in 2015 [15, 38, 45].

In 2015 the research collaboration with Centro Español de Investigación Farmacoepidemiológica (CEIFE) has continued especially in the project on the use of prescription contraceptive methods in the UK general population. The collaboration has resulted in two peer reviewed publications during 2015 [38, 45].

The collaboration with the Boston Collaborative Drug Surveillance Program with among others Professor Susan Jick investigating the risk of mortality in patients with multiple sclerosis has resulted in one publication in Neurology during 2015 [15] and yet another publication is waiting for acceptance.

[For reference number in brackets -- see "Publications 2015-2013" on page 214-236]

Vitamin D deficiency

Vitamin D deficiency among pregnant Swedish women and Somali immigrant women and new mothers

- Participants: Paul Kalliokoski and Monica Löfvander

Vitamin D deficiency leads to myopathia, weak bones, body-ache, negative fetal development and reduced capability of daily work. Paul Kalliokoski and Monica Löfvander conducted a cross-sectional study including 123 pregnant and recent mothers from Somalia (n=52) and Swedish women (n=71) living in Borlänge spring 2010 with an overall aim to explore vitamin D status, bone turnover, strength and upper leg performance.

Their first paper is published with main conclusion that 90% of the Somali women and 10% of Swedish women had a vitamin D deficiency [202]. 1/3 of the Somali women had unmeasurable levels and had very weak hands and poor upper leg performance as well as high serum levels of para-

thyroid hormone and alkaline phosphatase indicating high bone-turnover and risk of osteomalacia.

Seventy-one with insufficient or deficient levels of vitamin D was included in a subsequent treatment study with lifestyle advice and supplements of vitamin D3 and calcium during 10 months.

This year's main work for Paul Kalliokoski has been to analyze and interpret data and to write a report on the treatment study of the pregnant and new mothers from Somalia and Sweden with 25-OHD deficiency. He has also prepared and reported results on the first paper with a poster presentation on an international congress for family doctors in Istanbul, Wonca 2015 Istanbul.

A new study on vitamin D, prolonged labor and perinatal complications among the 123 (n=52 Somali) women and their children is planned. Ethical approval received.

The project is generating one PhD thesis (Paul Kalliokoski).

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Vitamin D status – among immigrated women from countries in the Middle East as compared with Swedish women and the prevalence of vitamin D deficiency and impact of musculo-skeletal parameters in elderly men

- Participants: Anne Björk, Gunnar Johansson, Andreas Kindmark, Östen Ljunggren

Vitamin D in blood has been demonstrated in studies to be low in women from countries located in the southern part of Middle East and some countries in Africa. Immigrant women from countries in the Middle East have been investigated by a physician and a dietician in terms of different aspects of their vitamin D status and possible associated diseases. They were compared with age-matched Swedish women. Results show a large difference in Vitamin D in blood has previously been demonstrated in studies to be low in women from countries located in the southern part of Middle East and some countries in Africa. Immigrant women from countries in the Middle East have been investigated by a physician and a dietician in terms of different aspects of their vitamin D status and possible associated diseases. They were compared with age-matched Swedish women. Results show a large difference in vitamin D levels with low values in many immigrant women in comparison with the Swedish women. Two papers have been published [160, 169].

Polymorphisms in the gene encoding for 25-hydroxylase have been reported to correlate with circulating levels of 25-OH vitamin D (25OHD3). It is not known if these variations also affect overall bone mineral metabolism, or bone mineral density in femoral neck, total hip and lumbar spine (BMD).

Data from the mrOs study have been analyzed. Results show a strong correlation between CYP2R1 SNPs and levels of 25-OH-vitamin D, a lack of correlation between CYP2R1 SNPs and measures of calcium homeostasis other than 25-OH-vitamin D but no difference in the distribution of fractures between the different genotypes of CYP2R1. An intriguing inverse relationship between the correlation between CYP2R1 SNPs and levels of 25-OH-vitamin D on one hand, and BMD on the other hand was seen.

During 2015 Anne Björk has also prepared her halv-time seminar. The project is generating her PhD thesis.

[For reference numbers in brackets -- see "Publications 2015-2013" on page 214-236]

Organizational Factors, Work Stress and Performance

- Participants: Ingrid Anderzén, Lars Frimanson, Per Lindberg, Thomas Karlsson, Susanne Gustafsson and Annica Strömberg

Development of Strategic Cooperation through Partnership (Step-Up)

The project intends to work together with researchers and representatives from employers (managers and HR professionals). The aim is to identify methods to be able to pay attention to signals where the risk of ill health and sickness exists among employees. The ambition is that the next step is to write a major research application in cooperation with participating companies. Researchers are involved in the structure and scientifically evaluating the effect. The project started in autumn 2015 and has had one meeting together with 16 managers from different business and organizations from Uppsala County.

Organizational Factors, Work Stress and Performance

- Participants: Ingrid Anderzén, Lars Frimanson, Per Lindberg, Thomas Karlsson, Susanne Gustafsson and Annica Strömberg

There is a clear association between psychosocial factors in the organization, stress, and performance. We develop and evaluate workplace intervention programs and look at the effects on employee health, biological stress markers, and organizational productivity. In an interdisciplinary research program we combine two fields of knowledge; social medicine and Management control systems (MCS). The purpose is to examine and explain how MCS design affects psychosocial factors in the organization, stress, and performance. This is important because MCS are used for planning and evaluation in organizations. MCS can thus be expected to influence the psychosocial

factors in organization that are associated with negative stress reactions, work-related health, and performance outcomes.

Management control systems and stress: interdisciplinary field experiments

- Participants: Ingrid Anderzén, Lars Frimanson

Management control systems (MCS) in organizations have become more complex. They measure performance on more objects, with new and more measurements, they provide information more frequent and quicker, and they are used at lower levels in organizations. But we do not know how these complex MCS influence the human body. Do they improve health, well-being and performance in organizations? Or do they make people develop insomnia, stress and other unhealthy outcomes that are economically and socially costly?

This interdisciplinary research program combines two fields of knowledge; social medicine and MCS. The purpose is to examine and explain how MCS design affects psychosocial factors in the organization, stress, and performance. This is important because MCS are used for planning and evaluation in organizations. MCS can thus be expected to influence the psychosocial factors in organization that are associated with negative stress reactions, work-related health, and performance outcomes.

Data collection was finished during year 2012 and the analyses are ongoing. A poster was presented at the *Nordisk workshop i ekonomi- och verksamhetsstyrning in Gothenburg, January 2014* (Frimanson L, Anderzén I The impact of formal performance evaluation on psychosocial and neurobiological energy: A randomized intervention study).

This project ended up in 2014 and was a collaboration with Department of Business Studies, Uppsala University, and receiving financial support from Riksbankens Jubileumsfond.

GodA - Good working environment and healthy workplaces.

Test of a model linking the work environment, employee well-being and corporate development

- Participants: Ingrid Anderzén, Per Lindberg, Thomas Karlsson, Annica Strömberg and Susanne Gustafsson

"Promoting factors" at work are supposed to promote both the individual's physical and mental health and the company's competitiveness and profitability, thus providing "healthy workplaces". Which factors act health promoting, as well as how an organization can work to promote the health of the employees while ensuring a commercially sound business, is still in its infancy. The GodA-study aims to test whether a development project orga-

nized by the so-called PATH-model (Grawitch *et al.*, 2006) results in increased employee well-being and concurrent organizational improvements.

In 2012, a pre-study in form of focus groups and individual interviews in three medium sized enterprises was undertaken. The interviews sought to examine what employees and managers considered to characterize a "good" work environment and what gives them wellbeing at work. The results from the interviews and known health and safety parameters have constituted the basis for a questionnaire with which employees of the three companies are followed for 2 years. Parallel, data concerning the companies' key indicators and internal developments are collected. One of the companies' designs its work with their internal development according to the PATH-model.

At the two-year follow-up the results from the "PATH-company" concerning the well-being of both employees and the company will be compared with the results from the other two companies designing their internal development after their own choice.

This study aims to increase knowledge about how to achieve sustainable health and wellbeing of both the individual and the company parallel. Such conditions can be assumed to save suffering for the individual and reduced costs for the company and society. This project is running in collaboration with Centre for Musculoskeletal Research, University of Gävle and receiving financial support from AFA.

Geriatrics 2013-2015

Research Group Leader Professor Lars Lannfelt

The main areas of research are molecular studies of dementia as well as clinical and epidemiological research in these and other age related diseases, such as cardiovascular and renal disorders. Cellular and transgenic models of Alzheimer's disease, Parkinson's disease and Lewy body dementia are used to understand mechanisms of abnormal protein aggregation in the brain and to develop new biomarkers and disease-modifying therapies. An important research tool is to develop new methods for molecular imaging, *i.e.* positron emission tomography (PET). The group applies a broad repertoire of experimental techniques, *e.g.* molecular biology, biochemistry, histology and behavioural analyses in our research. Clinical and epidemiological studies of dementia and successful ageing are also performed.

Members of the group

Professors

- Lars Lannfelt (chair)
- Hans Basun (adjunct)

University lecturer

- Lena Kilander (associated professor 2010)

Researchers

- Martin Ingelsson (associated professor 2009)
- Vilmantas Giedraitis
- Anna Erlandsson (associated professor 2013)
- Joakim Bergström (associated professor 2013)
- Stina Syvänen (associated professor 2013)
- Björn Zethelius (associated professor 2006)
- Anna Cristina Åberg
- Dag Sehlin
- Greta Hultqvist

Postdocs and research assistants

- Veronica Lindström
- Bernice Wiberg
- Hans-Erik Johansson
- Malin Degerman-Gunnarsson
- Ylva Cedervall
- Sara Ekmark-Lewén
- Astrid Gumucio
- Sofia Söllvander

PhD students

- Gabriel Gustafsson
- Kristin Franzon
- Xiaotian Fang
- Leire Almandoz-Gil
- Elisabeth Nikitidou

Other personnel

- Linda Cato
- Ximena Aguilar
- RoseMarie Brundin
- Käthe Ström (research nurses)

Associated professor

- Johan Ärnlöv, 2009

Dissertation 2015

Sofia Söllvander. Amyloid- β protofibrils in Alzheimer's disease. 2015

Agencies that support the work/Funding (SEK/year)

Vetenskapsrådet	3 300 000
Hjärnfonden, project grants + donators	1 500 000
Berzelii Center for Neurodiagnostics, Uppsala	2 500 000
ALF-medel, Uppsala läns landsting	4 500 000
Fakultetsmedel, Uppsala universitet	1 500 000
Parkinsonfonden	1 200 000
PET-forskning	500 000
Hjärt-kärlfonden	400 000
Wallenberg-stiftelsen	700 000
Alzheimerfonden	1 500 000
Diverse andra fonder	1 800 000

International collaborations

Harvard Medical School, NIH, University of Goettingen, University of Kuopio, University of Ulm, INSERM, Max Planck/Berlin, Swedish National Diabetes Register, DECODE, A European diabetes research collaboration, Århus University, Denmark, professor A Flyvbjerg, Odense University, Denmark, professor J Juul Holst, University of Tuebingen, University of Lisbon, Institut Pasteur de Lille, University of California San Diego, University of California San Francisco, Mental Health Research Institute, Parkville Australia, University of Oxford, University of California San Diego, University of Erlangen

Guest visits in foreign laboratories

Elisabet Ihse (with Dr E. Masliah, La Jolla, San Diego, USA 2013-15, returning to the unit 2016, financed for three years by VR)

Adjunct professors

Employee of BioArctic Neuroscience, Hans Basun, 2005-2016

Research Consortias

The research group is a member of the Berzelii Technology Centre for Neurodiagnostics, the Swedish Brain Power network and the U4 network (together with the Universities of Göttingen, Ghent and Groningen)

Engagement in the external society

- Swedish association of local authorities and regions, Stockholm. Prevent falls and fall injuries in health care (national campaign for patient safety). Stockholm, 2008 and 2011 (Anna Cristina Åberg)
- Membership of The Regional Ethics Review Board (REPN) in Uppsala (Lena Kilander, Anna Cristina Åberg)
- Chairman of the Scientific Board at the Medical Products Agency (Björn Zethelius)
- Member of the steering committee for National Swedish Dementia Registry (Lena Kilander)
- Member of the Scientific Committee of the Swedish National Diabetes Registry (Björn Zethelius)
- Member of the Steering Committee of the Center for Pharmacoepidemiology at Karolinska Institute (Björn Zethelius)
- Member of the Scientific Committee of Hjärnfonden (Lars Lannfelt)

Projects

The role of astrocytes in Alzheimer's disease

(Anna Erlandsson, PhD)

Knowledge about the cellular mechanisms behind initiation and spreading of Alzheimer's disease (AD) is still very limited. Decades of research have focused on neuronal abnormalities in AD pathology, but recently more attention has been given to the glial cells. The aim with this project is to clarify the involvement of astrocytes, the most numerous glial cell type in the brain, in AD initiation and progression and to investigate the astrocytes therapeutic potential. Our results demonstrate that astrocytes engulf large amounts of amyloid-beta ($A\beta$) protofibrils that are stored, rather than degraded by the cells. Interestingly, the accumulation of $A\beta$ protofibrils by the astrocytes results in lysosomal defects and exosome-induced apoptosis of neurons. To further elucidate the role of astrocytes in AD, we use primary cultures of astrocytes and neurons and analyze brain tissue from AD patients and transgenic mice. Moreover, we examine the possibility to increase the astrocytes degradation of $A\beta$ by antibody treatment. We believe that the $A\beta$ accumulation by astrocytes is especially important in late onset AD, since this form of the disease depends on defects in $A\beta$ degradation rather than $A\beta$ production.

Pathology and amyloid imaging in transgenic Alzheimer's disease mice

(Stina Syvänen, PhD, Dag Sehlin, PhD, Greta Hultqvist, PhD)

The over-all purpose of this project is to improve clinical Positron Emission Tomography (PET) imaging in Alzheimer's disease (AD) such that the technique can be used to monitor disease progression and therapeutic efficacy of intervention with drug candidates. The project include development of new radioligands as well as development of imaging paradigms based on already existing radioligands that target neuroreceptors believed to be involved in the pathogenesis of AD. We have recently generated a ^{124}I -labelled new imaging agent based on mAb158 by using its $F(ab')_2$ fragment conjugated to a transferrin receptor antibody, 8D3. The 8D3 moiety of the fusion protein binds to the transferrin receptor at the blood-brain barrier which acts as a transporter into the brain. Using this strategy we have increased the brain distribution of $F(ab')_2$ fragment 15-fold which was enough to generate PET images of $A\beta$ protofibrils in the living mouse brain. The focus of our present research is to further improve the brain distribution of the ^{124}I -labelled $F(ab')_2$ fragment using protein engineering and thus develop a new amyloid PET radioligand for use in the clinic. This is the first time ever, to our knowledge, that an antibody has been used as a PET-ligand for a CNS disorder.

Parkinson's disease and Lewy Body Dementia

(Assoc. Profs. Martin Ingelsson and Joakim Bergström)

The protein α -synuclein deposits as Lewy bodies and Lewy neurites inside the neurons of patients with Parkinson's disease and Lewy body dementia. Large soluble oligomeric or protofibrillar forms of α -synuclein are believed to be particularly neurotoxic for the affected brain.

By working with recombinant forms of α -synuclein oligomers / protofibrils, we are analyzing the formation and effects of such species *in vitro* and on cell models.

In particular, we are investigating how these species can impair key cellular functions and how they can spread from cell to cell and thereby cause the disease to propagate inside the brain. Moreover, we want to find out how these α -synuclein species can impair cellular degradation and perturb cellular function. We have purified toxic α -synuclein oligomers and used these as antigen to generate monoclonal antibodies. A number of highly selective antibodies have been developed and several of these have been evaluated for immunotherapy on cell and animal models for the actual diseases.

Importantly, we have found that intraperitoneal injections with one of them can lower the levels of α -synuclein oligomers/protofibrils in transgenic mice and also prolong survival in the same animals. In a current study we are evaluating if the antibody treatment can alleviate the early motor and behavioural symptoms that we recently have demonstrated in this mouse model. Moreover, we seek to adopt the antibodies in assays, such as ELISA; to be able to measure the presence of toxic oligomers / protofibrils as a novel disease biomarker for the actual disorders.

Genetics

(Assoc. Prof. Martin Ingelsson and Vilmantas Giedraitis, PhD)

We have access to a large and well characterised collection of sporadic and familial dementia patients. Using high throughput sequencing technology, we are screening for mutations in known and putative disease susceptibility genes in patients with early onset forms of frontotemporal dementia, Alzheimer's disease and Parkinson's disease. We have identified several known mutations causing early onset familial Alzheimer's disease. Furthermore, we discovered a new mutation in amyloid beta precursor protein, which we have dubbed the "Uppsala" mutation, as the family originates from this city. It is a deletion of six consecutive amino acids in amyloid- β (A β). Deletions like this have never been described in Alzheimer's disease. Currently we are investigating population frequency of this mutation and studying aggregation properties and biochemical features of mutated peptides.

We are also participating in several large international collaborations on Alzheimer's disease genetics (Lambert *et al.* 2013; Rubio-Moscardo *et al.*

2013; Escott-Price *et al.* 2014). For these studies, we are using our collection of DNA samples from sporadic Alzheimer's disease patients and healthy controls.

Clinical and epidemiological research

(Assoc. Profs. Lena Kilander, Björn Zethelius, Malin Degerman Gunnarsson, Ylva Cedervall, Anna Cristina Åberg)

The close contact between the laboratory and the Memory Clinic at Uppsala University Hospital facilitates access to appropriate clinical samples. The clinical research unit is currently categorizing patients with various dementia disorders and mild cognitive impairment regarding clinical diagnoses and Alzheimer biomarkers. This research is based on our own tissue bank with DNA, plasma and serum (approximately 2000 samples), CSF samples (n= approximately 700), and brain tissues. We previously showed that high concentrations of total tau and phospho-tau were correlated to rapid cognitive decline and death in advanced dementia, (Degerman Gunnarsson -13). In an extended follow-up (2-11 years) of this cohort, high CSF total-tau predicted institutionalization and conversion to moderate dementia (Degerman Gunnarsson -16, in press), as well as rapid deterioration in cognition and dementia-related death. Thus, CSF tau is not only markers of dementia stage and predictors of conversion from MCI to AD, but also reflect the rate of neurodegeneration and long-term prognosis, which has not been shown previously. These findings may be valuable in selecting patients to tau immunotherapy trials. Longitudinal studies of dementia patients are carried out in collaboration with the Uppsala PET-centre, using the amyloid-binding PIB ligand together with PET FDG and AD CSF-biomarkers, and with the Department of Radiology (Fällmar D, Lilja J, Velickaite V, Danfors T, Lubberink M, Ahlgren A, van Osch MJ, Kilander L, Larsson EM: Visual Assessment of Brain Perfusion MRI Scans in Dementia: A Pilot Study. *J Neuroimaging*. 2015 Sep 16. doi: 10.1111/jon.12296. [Epub ahead of print])

Population based investigations have been performed on samples from the Uppsala Longitudinal Study of Adult Men (ULSAM), a cohort of initially 2322 50-year old men followed on six occasions since 1970. We have measured plasma levels of A β as well as other proteins and evaluated their respective predictive values for development of AD. Further, the role of cerebrovascular risk factors and dietary intake of fat as predictors of AD are examined. Impaired insulin secretion at age 50 has been shown to predict the development of AD at high age. In one substudy, we are assessing mid-life and late-life predictors of healthy aging, defined as maintained cognitive and ADL functioning at age 85 years (Franzon *et al.* 2015). Measurements focusing on cognition and sarcopenia have been undertaken during 2014 on survivors at age approximately 90 years (n=145), with CT-scans of the brain, CSF

analyses and post-mortem evaluation on a fraction of the ULSAM subjects. Finally, another population based cohort of AD patients and healthy controls have been collected, in which we perform replication studies of genes that have shown association to AD within ULSAM.

One line of research aims to investigate motor function and physical activity in relation to health among elderly people. Anna Christina Åberg is studying new methods for clinical motor function assessment, as well as a potential association between motor function and subjective health aspects, such as life satisfaction and fear of falling. The research is mainly directed towards elderly with a need for rehabilitation due to multiple diseases/functional limitations, and those with specific neurological or neurodegenerative diagnoses, such as stroke or AD.

A further line of research evaluates insulin resistance in relation to later development of diabetes and cardiovascular diseases. A recent publication from the ULSAM cohort including its unique population based euglycaemic insulin clamp and oral glucose tolerance test data from the age 70 years investigations evaluated several proposed indexes and their predictive capacities and clearly showed the Cederholm Index to perform superior to other indexes compared.

Research on data in the national diabetes register (NDR) linked to several national registries is performed by Dr Björn Zethelius within the Scientific Working Party at the NDR. Project on Cardiovascular risk has developed an online tool for estimated 5-year absolute and modifiable risk for CVDs, providing potential for improvements in multifactorial treatment among primary care patients. It is an established tool in recommendations on pharmacological treatment in diabetes and hyperlipidemia. Further, he has lead the largest-ever observational study of physical activity among patients with type 2 diabetes and found that both women and men can substantially reduce the risk of cardiovascular disease and premature death by exercising regularly and recently published the largest so far study on risk factors for Atrial Fibrillation in established type 2 diabetes patients. He is also involved in ULSAM-research and international collaborations such as DECODE and DETECT consortia. The work has so far led to several publications in leading medical journals, see reference list.

Ongoing, particularly successful, research

Our translational research efforts have been very successful and we have maintained an international visibility and high quality of publications. Among the expanded and new efforts, we have a particular focus on developing better principles of imaging and diagnostics for AD and exploring possibilities for novel future therapeutics against PD and Lewy body dementia. We are one of several groups in Uppsala focusing on protein aggregation and age-related amyloid diseases. The local scientific environment thus pro-

vides a unique opportunity for collaborative efforts to increase the knowledge on mechanisms underlying amyloid disorders, especially within the Berzelii Centre for Neurodiagnostics and in SciLifeLab. Compared to other dementia research teams in Sweden our focus on molecular mechanisms in the pathogenesis of AD has been very successful. We have a clear scientific strategy and a good research structure. The preclinical and clinical activities have been successfully integrated in Uppsala, which enables a more efficient translational research process.

Publications 2013-2015

2015

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Books

148. Läkemedelsboken 2014. Läkemedelsverket 2013. Mårild S, Hänni A och Zethelius B are authors of one chapter.
149. Fagius J, Nyholm D (Eds.) Neurologi, bok med eLabb. Liber 2013. Ingelsson M and Fagius J are authors of chapter "Syn-punkter på åldrandets neurologi".

Health Economics

Research Group Leader Sophie Langenskiöld, senior lecture

The research group Health Economics started in 2013. A focus has been to understand and influence the prospects within health care, and to achieve better health for the public and cost-effective care for the community. The group aspires to use knowledge of the use of observational data for causal inference, to contribute to the increasing interest in the effectiveness and cost-effectiveness of primarily drugs, but also other interventions in clinical practice.

Members of the Group during 2015

So far, Sophie Langenskiöld has been alone in this group. At the moment, however, we are recruiting a PhD student with medical and economic expertise.

Research Fundings

We are especially proud to acknowledge that the Dental and Pharmaceutical Benefits Agency has provided financial support for one of our projects. They do not normally fund research, but in this case, they provide financial support in compensation for assuring crucial knowledge for their future business. Also, we have joint projects with the Centre for Research Ethics & Bioethics, which now fund part of my salary and which will also fund one PhD student.

Publications

Langenskiöld S. 2015. *Evidensbaserad vård även för de allra äldsta, tack!* *Svensk Geriatrik*, 1:16-20.

Viberg J, Segerdahl P, **Langenskiöld S**, Hansson MG. 2015. *Freedom of Choice about Incidental Findings can frustrate participants' true preferences*. *Bioethics*, 30(3):203-209.

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Michaëlsson K, Wolk A, **Langenskiöld S**, Basu S, Warensjö Lemming E *et al.* (2014). *Milk intake and risk of mortality and fractures in women and men: cohort studies*. *BMJ (Clinical Research Edition)* 349: g6015-.

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Main Research Project

In Sweden and the other Nordic countries, we have built unique registries covering either the entire population, or specific populations suffering from different diseases. Despite this achievement, the registries are sorely underused, and there is a real risk of missing a huge opportunity to offer better care for our population. The yet-unrealized benefits of these registries, we are confident, would justify the time invested in preparing them for broader purposes. The main reason why the registries are underused is the current lack of suitable methods for evaluations in clinical practice based on registry data.

This project intends to develop these methods and to illustrate these through a proof-of-concept study. The toolbox of new methods we produce can then be directed to improve other forms of evaluation in clinical practice. In this way, we will make a broader contribution to improved healthcare, given that some randomized clinical trials, unfortunately, only poorly generalize to clinical practice. There are sub-populations of patients who are especially poorly represented in clinical trials, such as older, female, and multi-morbid patients, and those who require study in clinical practice in order to assure safe, effective, and cost-effective care.

Centre for Research Ethics & Bioethics and Health Economics have initiated collaboration in order to stimulate inter-disciplinary research in ethics and health economics. The two disciplines complement each other in many ways as the economists try to understand the best ways to allocate scarce resources and the allocations in themselves have ethical implications. So far, we have initiated two projects together. One project involves the way cardi-

ovascular and pulmonell risks should be communicated for the patients' best understanding of the risks themselves and their implications on health. Another project investigate how the population want all data of themselves in different registries, medical records *etc* to be handled to assure their privacy at the same time as their data is used to improve care in *e.g.*, research. Both projects involve both qualitative and quantative research.

Health Economic Forum at Uppsala University

The *Health Economic Forum at Uppsala University (HEFUU)* is intended as an interdisciplinary venue for researchers interested in health economics coming both from economics and the medical faculty. Sophie Langenskiöld has been one of the co-coordinators of HEFUU, and is now affiliated to the forum. HEFUU is involved in the organizing and planning of HEFUU's activities. The HEFUU has hosted monthly seminars in health economic research at Uppsala University, courses, and conferences. During the last year, HEFUU has organized or are organizing several activities which will strengthen its role as a platform for health economic research at Uppsala University.

Apart from the monthly Friday seminars, HEFUU has been host for education-, workshop-, and conference- activities. We are also organizing workshops where different researchers will present their research group and some of their research. Our belief is that this day will not only teach us about what relevant research is conducted at Uppsala University, but also help us to better understand the different skills that we have and the different interest that we share, an understanding which could be channeled into joint research projects in the future. And finally, we have hosted for the 36th Nordic Health Economists' Study Group Meeting in August.

Education

In the fall, Sophie Langenskiöld organized a course in Health Economics at advance level which is an introduction to health economics for public health practitioners. It is intended for those who work with and make decisions about issues related to public health. The overall purpose of the course is to provide knowledge about how theories, methods, and findings from the field of health economics can be used to achieve the goals of public health given our scarce resources. What is public health, and how it should be measured? These questions are obviously not easy to address but nonetheless, important. Their answers allow us to follow up our public health objectives in practice. We discuss the health economists' definitions of health and its measuring. We learn to use health economic models for predicting the im-

pact of different public health initiatives ex-ante. Which existing public health program should we prioritize? You can of course evaluate the public health program from different perspective, and we will train us in judging public health interventions from an economic point of view. The course was popular and only 20 out of the 50 who applied for the course was admitted. All 16 students who began the course fulfilled it, and they were to a high extent satisfied with the course. The different elements of the course were rated between 3.7 and 4.6 and the most rated impressions of the course: interesting (92%), stimulating (67%), applied (58%), useful (50%), and engaging (50%).

Health Services Research

Research Group Leader Ulrika Winblad, PhD, Associate Professor

Health Services Research (HSR) adopts three contrasting but interconnected perspectives; at care provision - organisational - and system level. The Uppsala group is engaged in research at all three levels with focus on governance and implementation, intra-organisational control, inter-organisational relations and patient relations. More specifically, current study objectives include development of exploratory models for differences in public and private care, identification of barriers for implementation of New Public Management reforms as well as identification of facilitators for high quality and patient safety care. The group is multidisciplinary and the researchers have different professional backgrounds such as medicine, psychology, nursing and political science.

Members of the group during 2015

Ulrika Winblad	PhD, Associate Professor, Research Group Leader
Malin Masterton	PhD, Research Group Leader (Jan–June 2015)
Caroline Andersson	PhD student
Carina Ahlstedt	RN, MA
Åsa Muntlin Athlin	RN, PhD
Cecilia Bernsten	RPh, PhD, Associate professor
Ingeborg Björkman	RPh, PhD
Madeleine Boll	RPT, Licentiate, PhD student
Linn Boström	Research assistant
Gunilla Brattberg	MD, PhD, Associate professor
Tobias Dahlström	PhD
Ann Catrine Eldh	RN, PhD, Associate professor
Mio Fredriksson	PhD
Christina Halford	MD, PhD
Marianne Hanning	PhD
Finn Hjelmblink	MD, PhD

Inger K Holmström	RN, professor
David Isaksson	Phd student
Karin Josefsson	Research assistant
Elenor Kaminsky	RN, PhD
Dorte Kjeldmand	MD, PhD
Niklas Källberg	PhD
Jan Larsson	MD, PhD, Associate professor
Anna Mankell	Research assistant
Linda Moberg	PhD student
Fredrik Olsson	Research assistant
Urban Rosenqvist	MD, Professor emeritus
Marta Röing	DDS, PhD
Margareta Sanner	PsyD, PhD, associate professor
Björn Smedby	MD, Professor emeritus
Kristina Star	RN, PhD
Ragnar Stolt	MD, PhD student
Alexander Tegelberg	RN, PhD Student
Anikó Vég	PhD
Sofie Vengberg	Research assistant
Heléne von Granitz	PhD student

Publications 2015 – 2013

2015

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2. **Eldh AC., Fredriksson M., Vengberg S., Halford C., Wallin L., Dahlström T., & Winblad U.** Depicting the interplay between organisational tiers in the use of a national quality registry to develop quality of care in Sweden. *BMC Health Services Research* 2015; 15:519.
3. Nordlöf H., **Winblad U.**, Wiitawaara B., & Westerling R. (2015). Safety culture and reasons for risk-taking at a large steel-manufacturing company: Investigating the worker perspective. *Safety Science*, Vol. 73, 126-135
4. Törmä J., **Winblad U.**, Saletti A., & Cederholm, T. (2015). Strategies to implement community guidelines on nutrition and their long-term clini-

- cal effects in nursing home residents JNHA . *The Journal of Nutrition, Health & Aging*, Vol. 19, nr 1, pp 70-76. doi: 10.1007/s12603-014-0522-4.
5. **Wisell K., Winblad U., & Källemark Sporrang S.** (2015) Reregulation of the Swedish pharmacy sector – Changed rationales over time. *Health Policy*. Vol. 119, no 5, p. 648-653
 6. Brantnell, A., Baraldi, E., van Achterberg, T., **Winblad U.** (2015) Research funders' roles and perceived responsibilities in relation to the implementation of clinical research results : a multiple case study of Swedish research funders. *Implement Sci. Implementation Science*; 2015;1–8.
 7. Blomqvist, P., **Mankell, A., Winblad, U.** (2015). ”Varför så få ideella aktörer inom äldreomsorgen?” pp 165-195. I: Anders Bäckström (red.) *Välfärdsinsatser på religiös grund Skellefteå*: Artos & Norma Bokförlag.
 8. **Winblad U., Blomqvist B., Boström L.,** Patientcentrering i Sverige – aktuella initiativ. Rapport. Stockholm: Forum för Health Policy, 2015-02-11.
 9. **Winblad U., Mankell A., & Olsson F.** Privatisering av välfärdstjänster: hur garanteras kvalitet i vård och omsorg?, *Statsvetenskaplig tidskrift* 117(1) 35–58.
 10. **Winblad U., Mankell A., Olsson F.** (2015). “Vårdval inom specialistsjukvården – vilka krav ställer landstingen på vårdgivarna?” Rapport. Sveriges kommuner och landsting.
 11. **Masterton, M., Boström, L. & Winblad, U.** Patientcentrerade vårdmöten – förutsättningar och begränsningar i svensk hälso- och sjukvård. Forum för Health Policy i samarbete med LIF - de forskande läkemedelsföretagen, 2015
 12. Carlsson L., Lännerström L., Wallman T., & **Holmström I. K.** (2015). General practitioners' perceptions of working with the certification of sickness absences following changes in the Swedish social security system: a qualitative focus-group study. *BMC family practice*, 16(1), 1.
 13. Lindh M., **Holmström I. K.,** Perseus K. I., & Windahl J. (2015). Enhancing adherence to infection control in Swedish community care: Factors of importance. *Nursing & health sciences*.
 14. Ewertsson M., Allvin R., **Holmström I. K.,** & Blomberg K. (2015). Walking the bridge: Nursing students' learning in clinical skill laboratories. *Nurse education in practice*, 15(4), 277-283.
 15. Ewertsson M., Gustafsson M., Blomberg K., **Holmström I. K.,** & Allvin R. (2015). Use of technical skills and medical devices among new regis-

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External Reviews 2015 – 2013

- Ulrika Winblad: The Research Council of Norway, reviewer research applications 2015
- Ulrika Winblad: Member of the Scientific Advisory Board of the Center for Healthy Ageing (CEHA), University of Copenhagen, (2014-2015)
- Ulrika Winblad: Member reference group, Expertgruppen för studier i offentlig ekonomin (ESO) (2013-2014)
- Ulrika Winblad: Member European expertgrupp, Healthy Living and Active Ageing (2013-2014)
- Ulrika: Winblad: Vice Chair, expert group, Uppsala University, Healthy Living and Active Ageing, (2013-2014)
- Ulrika Winblad: External reviewer of Fellow Positions, Riksbankens Jubileumsfond, (2014)
- Åsa Muntlin Athlin: International Emergency Nursing 2014-2015
- Åsa Muntlin Athlin: Chairperson and member of the scientific committee for the International conference on evidence based practice in nursing, Smt. Radhikabai Meghe Memorial College of Nursing, Sawangi (Meghe), Wardha, Maharashtra, India. (2014)
- Ingeborg Björkman: Participated as panel judge for RSAP's Annual Best Paper Award for 2014 (Research in Social and Administrative Pharmacy)

- Ingeborg Björkman: External reviewer of research application for ZonMw - The Netherlands Organisation for Health Research and Development. (2013)

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Research projects 2015

Implementing legally secured governance of individual rights: Does the exercise of discretion in the decision-making process of granting assistance allowance for personal assistance pay regard to the intentions for good living conditions according to the LSS Act?

- Participants: Heléne von Granitz, Karin Sonnander, Ieva Reine, Ulrika Winblad

The Swedish disability policy express the vision of a community based on diversity, designed to allow people with disability of all ages to participate fully in society with equal opportunities. The ambition of the policy is strongest outlined in the LSS legislation, concerning Support and Service for Persons with Certain Functional Impairments (1993:387). The LSS aims to guarantee good living conditions for the users, by stringent requirements to meet individual rights. The act covers a wide range of user groups with regard to age, disability and severity of needs and has been described as the prime political tool to strengthen citizenship of disabled people. There is however a lack of knowledge about the extent to which personal assistance by attendance allowance meets the LSS values of good living conditions and if the support given provides conditions for participation on equal terms for various groups of users. The LSS Act, with a high ambition of executing

rights, lacks clarity and quality criteria on what the implementation should comprise. The exercise of discretion in the decision-making process of granting assistance allowance for personal assistance is known to be difficult with several principal agents responsible for the implementation. The thesis intends to highlight two perspectives. First, to study the outcome of personal assistance, from the perspective of the user and find out if the support received has resulted in more equal opportunities for the eligible persons in achieving good living conditions. Second, to study the implementation of the reform by studying to what extent the intentions of the LSS act are met by the decision of the personal administrator at the Social Insurance Agency (SSIA). The SSIA are responsible for carrying out the investigation and their decision is a prerequisite for access to assistance allowance. Overall, the thesis aims to provide a generally improved knowledge of the conditions for the government control to implement social reforms and specifically the control of the assistance allowance.

Contracting and monitorability in choice systems – what requirements do municipalities and county councils stipulate when contracting out services?

- Participants: Fredrik Olsson, Anna Mankell, Ulrika Winblad

The legal Act of 2009 regarding choice of welfare services (lagen om valfrihet, LOV) has been adopted by both municipalities and counties. The intent of the reform was to enable for Swedish municipalities and county counties to contract external health service providers, and thereby give patients and users of services the opportunity to choose between different providers. When contracting out services, the municipalities and counties are still responsible for the outcomes of the services, and thereby have an inherent need for monitoring the performance of the contractors.

The aim of this study is to give a description of how the municipalities and county counties manage to balance contractual requirements, with the notion of innovation and trust in their relation with the contractors. To conduct the study, contracts from both the elder care and specialised health care were analyzed. In addition, a questionnaire survey was conducted, focusing on methods of monitoring and quality assessment, and it was addressed to all directors in the elder care administrations in Sweden.

The results show that the majority of the contractual requirements concern the processes of the services, rather than structural aspects or quality outcomes. In some cases the monitorability of the services can be questioned due to how the contracts were formulated. The survey of elder care showed relatively low frequencies of monitoring, especially in domiciliary care. In summary, the studies show problems both in the formulation of contracts and in the monitoring of the services.

The role of information in choice of provider systems

- Participants: Caroline Andersson, Ulrika Winblad, Magnus Fredriksson

During the last decades patient choice of provider has become an inherent component in many health care systems. In Sweden provider choice was introduced through national legislation in 2010 (SFS 2009:140 Lag om ändring i hälso- och sjukvårdslagen 1982:763). The choice model allows patients to choose freely between both private and publicly run primary health care providers. Reimbursement follows the patients' choice. Choice of provider is expected to stimulate efficiency, quality and better responsiveness through the threat of exit. An underlying assumption is that providers will have strong incentives to improve their quality if they risk losing resources by not being chosen. A condition often stressed as a vital component in a functioning system of provider choice is access to information about the providers. If patients are unable to monitor the range and quality of services, providers may try to reduce their costs by lowering quality. As a consequence, providers with poor quality might remain on the market, leading to a weakened exit mechanism in the provider choice models.

The central aim of this project is to explore the theoretical assumption that well-informed choices of provider will drive quality in health care. In particular, it focuses on if and how patients make use of information when choosing providers. Both governments and private stakeholders have developed comparative information on services and quality-of-care, but some studies imply that patients rarely make use of such information in the actual choice situation. Instead they often rely on informal information sharing, such as reputation or recommendations from friends or family, but which may not give accurate and clinically relevant information about provider's quality.

The project on provider choice information will be based on four different articles. The first study is initiated and explores what factors that can explain patients' information search behavior in choice of provider and if there are groups of patients that are more active users of information than others. The second study will analyze what kind of information patients turn to, if and when they search for information in the choice of provider. The third study will investigate what kind of information patients have access to and whether it can be used to make an informed choice of health care provider. The fourth article will problematize policy designers' views on patients' role in provider choice systems and to what extent they believe that patients can monitor and drive quality development in health care through active choices. The project is run in collaboration with Magnus Fredriksson, Department of Journalism, Media and Communication, University of Gothenburg.

Facilitators and barriers for quality improvement - a process study of the National quality registers in Sweden

- Participants: Ulrika Winblad, Mio Fredriksson, Tobias Dahlström, Ann Catrine Eldh, Sofie Vengberg, Christina Halford, Lars Wallin

In 2011 the Swedish Association of Local Authorities and Regions (Sveriges kommuner och landsting) and the state agreed on a five-year investment in the development of national quality registers. This initiative followed a review that showed that Sweden can take a leading position in the development of a more efficient and equitable health care based on the use of national quality registers. What obstacles and / or opportunities are there to bring about such a development? This question is investigated in a national research project carried out by three research groups (in Uppsala, Stockholm and Jönköping). The national research project is commissioned by the Swedish Association of Local Authorities. During 2013, the work of the Uppsala research group consisted of a case study in four county councils (and nine hospitals). This was followed by a national web survey to clinical stakeholders in all hospitals using three selected quality registers. The project is run in collaboration with Lars Wallin, Dalarna University.

Assessing and developing gender competence in telephone nursing

- Participants: Elenor Kaminsky, Inger K. Holmström

Sweden's apparently largest healthcare provider, Swedish Healthcare Direct receives about 5.5 million yearly calls, answered by 1500 telephone nurses. The service is considered first line health care for the population. It is, however, a gendered service in that most telephone nurses are female as is a large amount of callers, in particular regarding paediatric health calls and calls for elderly parents. Female telephone nurses have been found to find it easier to talk to women and when parents call for their children, fathers received a recommendation for referral to a higher extent than mothers, who instead received self-care advice. Gender refers to the social constructions of femininity and masculinity and has become an increasingly observed aspect of health inequalities. Intersectionality holds that gender interacts with other markers of difference, such as age, ethnicity, sexuality, social class and (dis)ability. According to the Swedish legislation, healthcare should be distributed on equal terms for all citizens. Contrary to this, earlier studies reveal that inequalities exist within SHD, which emphasises the importance of raising the awareness of inequality and intersectionality among telephone nurses working at SHD. The aim of the project is to develop an instrument that can investigate and contribute to gender competence in telephone nursing and to test an educational intervention for telephone nurses. The project also aims to explore awareness of inequity in healthcare and the intersection between

different structures of power among the population and student nurses. Lastly, the project aims to investigate if and how an educational intervention can improve awareness of equity in healthcare among telephone nurses.

Reviewing telephone nursing in Sweden

- Participants: Elenor Kaminsky, Marta Röing, Inger Knutsson Holmström

Telephone nursing services are expanding globally. In UK, callers get to talk to ‘call handlers’ with a few weeks of health education. National telephone health services such as Swedish Healthcare Direct, employing RNs only, have however been pointed out as ‘right systems’ in maintaining patient safety. The telephone nursing work is nevertheless highly complex, with assessments made solely on verbal communication with callers. People from poorer socioeconomic groups or with communication difficulties are reported less likely to use telephone nursing services. Stakeholder perspectives, *e.g.* callers’, telephone nurses’ and managers’ and what characterises calls in such systems are valuable issues. Findings could be applicable in available similar services internationally, *e.g.* in the UK, the Netherlands, Canada and the US. The aim of the project is to provide a comprehensive understanding of telephone nursing as reflected in research on Swedish national telephone nursing.

Reviewing telephone nursing in Sweden

- Participant: Elenor Kaminsky

Working place environment and managerial culture have unquestionable strong effect on employees’ health and wellbeing. Their impact on patient care results is however sparsely researched. Healthcare delivered by prosperous telephone nurses may possibly save time and money, and lead to fewer malpractice claims. Interventions with health promoting approaches, preferably theory driven, are suggested for a more health promoting working life. The aim of the project is to deductively frame a health promoting working place for telephone nurses. Such a working place could further be empirically tested and evaluated in a quasi-experimental intervention compared to care as usual, regarding for example telephone nurses’ scored health, monitored calls, caller satisfaction, *etc.*

Patients with acute abdominal pain – from the emergency department to the surgical ward: what makes a difference to achieve patient participation, high quality nursing care and safe care transitions?

- Participant: Åsa Muntlin Athlin

This pilot project is part of a multidisciplinary research program (SMAAPP research program) in collaboration between researchers and clinicians in Australia and in Sweden. The aim of the pilot study is to further explore patient experiences across the acute care delivery chain and to test methodological procedures.

SMAAPP research program (Seamless management of patients seeking care for acute abdominal pain - a person-centred approach)

- Participant: Åsa Muntlin Athlin

The overall aim is to use multiple sources of evidence of effective management of patients with acute abdominal pain to develop, implement and test a person-centred intervention to achieve safe high quality care across the acute care delivery chain. The goal is to develop best practice guidelines to be used by the inter-disciplinary teams in the emergency departments and the surgical wards.

Predicting admission requirement likelihood in Australia and Sweden (PARLAAS): an individual prospective approach

- Participant: Åsa Muntlin Athlin

The number of patient visits to emergency departments (EDs) is increasing and about 22-38% of the patients presenting to an ED require hospital admission. ED crowding is a potential threat to patient safety and quality of care. Using predictors of hospital admission may improve the patient flow in the ED and speed up the admission process. The aims of this study are to determine important predictors of hospital admission for children and adults and to determine a hospital admission risk score for patients presenting to the ED that are site and population (child/adult) specific. In addition, a tool for predicting hospital admission will be developed and tested.

How can public authorities monitor private social service providers?

- Participants: Ulrika Winblad, Linda Moberg, Paula Blomqvist

The entrance of private actors into the welfare sector represents a significant development in Swedish politics and creates new demands on steering on part public authorities. Previous research has demonstrated that, in order for societies to reap the benefits of privatization, public authorities must carefully supervise the performance of private actors. In the absence of such supervision, or monitoring, there is a significant risk that quality will be undermined, rather than improved and there will be an unwanted selection of the most profitable users (the brightest pupils, the healthiest patients, *etc*). The reason is the strong economic incentives created by the competition for public contracts, particularly if providers are (like in the Swedish case) primarily for-profit firms. In the project we investigate with the help of a distinct analytical model, how Swedish public authorities supervise private service providers in the social area today and whether it can be said that there exist sufficient political and legal preconditions for effective monitoring. Research methods used include document analysis, interviews and a web-based survey to Swedish municipalities and county councils. The areas studied are health care, primary education, child care, elder care and substance abuse treatment. The project is run in collaboration with the Department of Government (Paula Blomqvist) and Department of Business Studies (Caroline Waks and Maria Blomgren), Uppsala University.

How does the design of the reimbursement systems affect the behavior of primary care providers?

- Participants: David Isaksson, Ulrika Winblad, Paula Blomqvist

A new reform regarding free choice of primary health care provider was introduced in Sweden during 2010. The intent of the reform was to make it possible for patients to visit the health care provider of their choice. The national government has, however, given each county council the responsibility to design their own reimbursement system which means that there exist 21 different systems today. The systems vary in many aspects such as the degree of capitation reimbursement (number of listed patient) compared to the reimbursement based on performance. The design of the reimbursement system is the foundation for the competition in the primary care. Via the reimbursement system each county councils creates financial incentives and thus steer the providers in desired direction. The aim of the project is to examine how the different designs of the reimbursement systems affect how private health care providers operate.

To conduct the study, data regarding the different reimbursement levels, is collected from each county council and a classification of each system is made. In a second stage data regarding number of GP visits, nurse visits, number of new establishments will be collected from each county council. Finally we will use statistical analysis to analyze how the design of the reim-

bursament system affects how the providers behave. The project is run in collaboration with the Department of Government (Paula Blomqvist), Uppsala University.

Market-oriented governance in a universal welfare model – implications for the state, citizens and accountability

- Participants: Linda Moberg, Ulrika Winblad, Paula Blomqvist

During the last decades, many mature welfare states has implemented various marketization reforms, best known under the headline of New Public Management, in their social service sectors to increase service quality and efficiency. The research question for this project is what implications increased marketization has for the governance of publicly funded social services. In particular, it focuses on how, and by whom, service quality should be secured when the Swedish welfare state increase its reliance on market-oriented governance.

The Swedish welfare state, as emerged in the post war era, is characterized by a publicly funded social service sector and based on the concept of universalism. To create broad legitimacy of this welfare system, the state set out to offer all citizens access to high-quality services. This implied that the social services was organized as virtually public monopolies of standardized services, later criticized for offering very little choice for service users. As a response to this critique, the reliance on market-based governance has increased, enabling private facilities to provide social services in exchange for public reimbursement. Particularly, user choice of provider combined with provider competition has been implemented in various social services. This implies that the model for service delivery has undergone extensive changes, affecting the government's ability to steer these sectors. The state, however, still has a legislated responsibility to ensure high and equal quality for all citizens. In this project we therefore address questions regarding what implication increased marketization has for the state's ability to steer and monitor service providers. We also study how the state's new monitoring tools affect the professional groups working in the social service sector. In addition, choice of provider give service users more individuated power as consumers; however, it also implies that there is a risk of making poor choices. Thus, this project also aims to analyze what implication choice of provider have for the users and under what conditions they can make a well informed choice of provider.

The research questions in this project will be addressed through four different articles. The first of these studies has (in the spring of 2015) been accepted for publication in the *Journal of European Social Policy*. In this paper we test if social service users have the preconditions to act as rational consumers by investigating what kind of information they have access to at

the point of choosing service provider. We also study whether the information contain relevant quality indicators and are designed in such a way that it can be used to make a qualitative and informed choice of provider. Another two studies have also been initiated. In the second study we analyze if the implementation of choice in the Nordic welfare states has altered the Nordic model for social service delivery and if it pose a challenge to the idea of universalism. This study is submitted and currently under review for the Journal of Social Policy. The third paper is a comparative study, focusing on how the state audits eldercare and childcare providers. The question addressed in this paper is what implications the audit-process has for the occupational groups working in these sectors, and whether it can be claimed to affect their professional autonomy. This project is run in collaboration with the Department of Government (Paula Blomqvist), Uppsala University.

Drugs and patient behavior – the influence of organizational and professional actors

- Participant: Cecilia Bernsten

Drugs do not work if people do not take them has been a mantra of those researchers investigating how patients comply with directions given by a prescriber. Throughout the years compliance has been replaced by notions such as adherence and coherence, moving the act of compliance from blind obedience to a state of agreement between the professional health care worker and the patient.

The aim of this research was to investigate, describe and analyze patients' and pharmacy customers' drug use behavior and the factors influencing this behavior. Randomized clinical trials with interventions as well as mapping of behavior have been used to study the different phenomena in question. Quantitative as well as qualitative data collection and analyze methods have been used.

Developing gender competence in Swedish telenursing

- Participants: Inger Knutsson Holmström, Marta Röing, Elenor Kaminsky

The overall aim of this project is to use theories of gender and intersectionality in order to investigate how factors such as gender, ethnicity, class and age can play a role in telenursing in Sweden. The aim is to develop an instrument that can investigate and contribute to gender competence in telenursing and to test an educational intervention for telenurses.

Telenursing is considered as first line health care but it is a gendered service in that most telenurses are female and the majority of calls for children and elderly parents are made by women. Gender refers to the social con-

structions of femininity and masculinity and has become an increasingly observed aspect of health inequalities. But there is still a lack of studies on if and how gender can impact the encounter between telenurses and callers and how other social factors interact with each other. Intersectionality holds that gender interacts with other markers of difference, such as "race"/ethnicity, sexuality, social class and (dis)ability.

We analyzed 800 authentic calls to Swedish healthcare Direct from an intersectional perspective, and with in-depth analysis of 20 calls using Critical Discourse Analysis. The results indicate that health behavior is part of "doing gender" since the most common caller was a woman proficient in Swedish, and the least likely caller was a man that was not proficient in Swedish. Calling a telenurse seems to be in line with ideal femininity, where seeking help and taking care of others' health are central aspects. The calls are dominated by task-focused utterances (*e.g.* giving medical information) and closed-ended medical questions are common. Three types of ideological work are found in the calls: gatekeeping, hegemonic masculinity and traditional medicine ideology. These three types of ideological works were part of the dominating discourse in telenursing echoing macro-aspects of society. However, a counter discourse was also found where open questions, questions about the social, information giving and challenging hegemonic masculinity were defining ingredients. An instrument to measure awareness of intersectional aspects has been developed and tested, and we have also made an intervention to raise telenurses awareness of such aspects. The results can also have direct application in nursing education and probably be used in other areas of healthcare and health care education.

Teamwork in an emergency department

- Participant: Åsa Muntlin Athlin

Increasing waiting times and long lead-times in emergency departments are well-known problems, which could influence efficiency, patient safety and patient satisfaction in a negative way. The healthcare needs to use the limited resources in a more effective way. Working in multidisciplinary teams could improve care processes in the healthcare. The overall aim was to investigate how implementation of team work in an emergency department can effect efficiency, quality of care, patient safety and patient satisfaction and work environment. In addition, the implementation process will be further studied. A longitudinal non-randomized intervention study design with three follow ups was used. The intervention was teamwork in the specialty of medicine in an emergency department. Patient questionnaires, staff questionnaires (diaries), patient health records and observations have been used for data collection.

PUP – Pressure Ulcer Prevention

- Participant: Åsa Muntlin Athlin

Despite guidelines for pressure ulcer prevention, clinical reports indicating that pressure ulcer is still common in the healthcare. Research has shown that the pressure ulcer prevalence is higher in Swedish hospitals, compared to other hospitals in Europe and in USA. In 2010, a group of researchers from county councils and universities in Uppsala, Värmland, Dalarna and Gävleborg started a collaboration project with pressure ulcer prevention as the topic. One of the research projects is a randomized clinical trial, where the aim is to study the effect of a pressure reducing heel protection and health economic related effects. This study follows the care chain; from pre-hospital care to discharge from the hospital. Another research project is about describing and comparing Swedish nurses' and nursing students' knowledge and attitudes to pressure ulcer prevention.

Fundamentals of care

- Participant: Åsa Muntlin Athlin

This is an ongoing research collaboration project with an international and multidisciplinary group of clinicians, researchers and scholars from Australia, UK and Sweden. According to healthcare reforms around the world, reports are emphasizing that fundamental aspects of care are being neglected in acute hospital settings. The overall aim with the Fundamentals of Care project is to investigate how fundamental aspects of care are delivered to patients within health systems. Examples of ongoing subprojects are: exploring stroke patients' experiences of fundamentals of care and cancer patients' experiences of fundamentals of care.

Teamwork in emergency care: Using behaviour analysis to understand how changes in practice can be achieved and sustained

- Participant: Åsa Muntlin Athlin

Multi-professional teamwork is a promising method to improve patient outcomes and patient safety in health care. Introduction of teamwork always includes some type of behaviour change, however, this behaviour change has been proven to be a major challenge when implementing teamwork. Thus, understanding how and why behaviour change interventions influence behaviour is emphasized as a prioritized area in implementation research. Sustainability has also been highlighted as one of the most challenging aspects of implementation. The overall aim with the research project is to deepen our understanding of what works when implementing teamwork in a complex context such as the emergency department and how to sustain changes.

A synthesis of phenomenographic studies on patients' ways of experiencing illness

- Participants: Marta Röing, Margareta Sanner

The focus of interest in this study is patients' experiences of illness, or aspects of their illness. *Phenomenography*, originally developed within an educational framework in Sweden, is a research approach which studies the variations in ways that people understand or experience phenomena in the world around them. It is based on the notion that phenomena or aspects of reality in the world can be understood or experienced in a limited number of ways.

Given this potential, we explore research literature as to the application of phenomenography as a qualitative research method in the study of patients' experiences of illness and ask the following questions: What can the uniqueness of a phenomenographic approach to data add to knowledge of patient illnesses? How effective is phenomenography as a tool in patient education and patient empowerment?

Selection criteria for articles applicable for a possible review were that they focused on patient' experiences of illness (or aspects of their illness) and really used a phenomenographic approach to data collection and analysis. These articles will be read in-depth and a meta-synthesis will eventually be performed, using the meta-ethnographic method of synthesis. In this work we will also make a critical review of how the method of phenomenography is applied in the various studies.

Non-prescription drugs and self-medication among adolescents in Sweden

- Participants: Ingeborg Björkman, Marta Röing, Inger Knutsson Holmström

Consumers in Sweden were given greater access to OTC drugs in 2009 after the reregulation of the pharmacy market, which allowed for the establishment of private pharmacies and sale of specific over-the-counter (OTC) drugs in retail stores and gas stations.

Increased access to OTC drugs can give Swedish teenagers new opportunities for self-care. However, the ability to buy OTC drugs outside pharmacies gives little opportunity for the traditional expert surveillance of pharmacists, thus increasing the possibility of careless or inappropriate use of OTC drugs. This study explores and describes Swedish teenagers' views on OTC drugs, with special regard to analgesic drugs, and asks the following questions: How and where to Swedish teenagers acquire their knowledge and attitudes regarding OTC drugs? What perceptions do they have about the use of OTC drugs? This study has a descriptive design with a qualitative ap-

proach. Data was collected in 2011 with 10 focus group discussions with high school students aged 16 to 19 years from different parts of Sweden. The group discussions revealed teenagers' attitudes and knowledge gaps regarding OTC drugs, and the significant influence of parents and peers on their OTC drug use. This study gives insight into how vulnerable some Swedish teenagers can be as new consumers of OTC drugs and underscores their need for more guidance and information about OTC drugs and their use.

Experiences and participation in sick-listing

- Participant: Inger Knutsson Holmström

This project is run in collaboration with participants in the research group for Family Medicine (Thorne Wallman, Linda Lännerström, Lars Carlsson). The project aims at studying both general practitioners views of sick-listing, and experiences and participation in the process of being on long-term sick-leave from the patients view. Sixteen patients on long-term sick-leave have been interviewed about their experiences and about participation in the process. This data-collection was carried out during 2011 and data analysis conducted during 2012 with a phenomenological analysis of the lived experience of being on long-term sick-leave. The findings revealed that the participants' experience of being long-term sicklisted was losing independence. They had to stop working and start to rely on the state for support. Most of the participants experienced their present life as a constant, uncertain pending meanwhile being questioned by authorities and society. They all were exposed to the rules of the social insurance but the rules and the encounters with professionals affected them differently. A few were treated well and went through changes that in the end led to a better life. Many were not treated well which caused impaired confidence in themselves and in authorities. During 2014 a survey about knowledge and attitudes to sick-listing among nurses in primary healthcare has been conducted, and an educational intervention to improve their competence in sick-listing issues for this group.

Patient-centred consultations: preconditions and limitations in the Swedish health care system

- Participants: Malin Masterton, Linn Boström, Ulrika Winblad

The movement to increase patient involvement in their own health care started in the USA some decades ago and is mostly referred to as *patient-centred care*. The most recent indication of Swedish efforts to increase patient involvement in the health care is the passing of a new Patient Law (2014:821) in 2014, which came into force in January 2015. The new law did not, however, make any changes to duty-based legislation of the Swedish health care system. This means that the health care system has a duty to provide care for

a patient, but the patient does not have any enforceable rights vis-à-vis the Swedish health care. The first aim of this work was to investigate the pre-conditions and limitations of the Swedish health care system to incorporate a high level of patient-centred care in the medical consultation. The second aim was to investigate the internationally published literature on the main challenges to achieving patient-centred medical consultation. The work was commissioned by Forum for Health Policy and a report of the study has been published in 2015. The main conclusion is that there is a need for a more unified understanding of what a patient-centred consultation should mean in a Swedish context, in order to facilitate further implementation work. There is also a need to acknowledge potential clashes between a patient-centred consultation and the current health care system in order to look at possible adjustments.

Making decisions in healthcare: policy and preferences in Sweden and England

- Participants: Mio Fredriksson

The main purpose of this research project is to investigate citizens' and patients' opportunities for taking part in decision-making in healthcare, as well as citizens' and patients' preferences with regard to this matter. The distinction between involving patients in decisions about their own treatment and care, on the one hand, and involving the public in strategic decisions about the development, planning and provision of health services on the other, is essential in the proposed research project. Patient involvement generally seeks to improve individual health outcomes and satisfaction, whereas public involvement seeks to address societal values, determine priorities *etc.*

Participation opportunities for patients and citizens in the two countries are compared through a structured analysis of recent so called PPI policies (patient and public involvement). Preferences for participation in individual as well as collective decisions are compared through surveys in both countries. Ultimately, the research project has policy implications for how to organize participation in healthcare in order to enhance the healthcare system's legitimacy and to reach objectives of public health. The project combines perspectives of political science and public health.

Lifestyle and rehabilitation in long term illness

Research Group Leader Professor Karin Nordin

The group *Lifestyle and rehabilitation in long term illness* was formed during 2015. Various projects are ongoing and planned within the group and most projects are cross-disciplinary randomized controlled intervention studies focusing on lifestyle (*e.g.* physical exercise, stress management, nutrition) in cancer patients. The aim is to find evidence-based interventions for changing life styles factors to decrease the burden for the patients and care givers during and after cancer treatments, cost-effective rehabilitation programs and more person-centered health care.

The most prominent project within the group is Phys-Can. This project will evaluate the efficacy and cost-effectiveness of individually tailored high and low intensity physical training, with or without behavioural medicine support strategies (BM). Main outcome is Cancer Related Fatigue (CRF) and secondary outcomes are Quality of Life (QoL), mood disturbance, adherence to the cancer treatment, adverse effects, disease outcome and return to daily living after completed treatment. We will also describe changes in inflammatory markers and cytokines related to physical training and gene expressions following training to investigate whether these serve as mediators for the effects of physical training on CRF and QoL. In addition, we aim to improve cost-effectiveness of rehabilitation programs. It is a controlled multi-centre study including 600 newly diagnosed breast, colorectal and prostate cancer patients during adjuvant therapy at three different centres in Sweden; Uppsala, Lund and Linköping.

Members of the group during 2015

Arving Cecilia, RN, PhD, senior lecture
Carlsson Maria, RN, PhD, associate professor, senior lecturer
Nordin Karin, PhD, professor
Demmelmaier Ingrid, RPT, PhD
Igelström Helena, RPT, PhD
Mazzoni Ann-Sophie, RPT
Månsson Ann, RPT

Associated researchers

Lampic Claudia, associate professor
Berntsen Sveinung, professor
Johansson Birgitta, associate professor
Ingvoldstad Charlotta, PhD
Höyer Lund Marie, PhD
Rissanen Ritva, PhD

PhD students

Hellerstedt-Börjesson Susanne
Isaksson Stina
Matsson Susanne
Henriksson Anna
Jacobsson Larsson Birgitta

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• The Swedish Cancer Society	2 400 000
• Nordic Cancer Union	500 000
• Swedish Research Council	1 960 000
• Onkologklinikens forskningsfond	250 000
• Selanders stiftelse	150 000
• Aktiv mot kreft (Norway) (2012-2016)	3 400 000

International collaboration

- Netherlands Cancer Institute, and EMGO Institute for Health and Care Research, Department of Public and Occupational Health
- VU University Medical Centre, Amsterdam, Department of Medical Psychology, Academic Medical Center, University of Amsterdam
- Alpe d'HuZes Cancer Rehabilitation (A-CaRe): <http://www.a-care.org/english/>
- Predicting OptimaL cAncer RehabilItation and Supportive care (POLARIS) www.polaris-study.org
- University in Bergen Norway, and the Haukeland university hospitals
- University in Agder, Kristiansand, Norway
- Norwegian School of Sport Sciences in Oslo (NIH)
- Centre of Inflammation and Metabolism (CIM), Department of Infectious Diseases, Rigshospitalet,
- University of Copenhagen, Denmark
- University of Leeds, UK

Oxidative Stress and Inflammation

Research Group Leader Samar Basu, M.Sc., PhD,
Professor

The research group Oxidative Stress and Inflammation was a separate unit in the Department until the beginning of 2015 but there is still some activity during the group leader's process of retirement.

Research Group Leader Samar Basu is a Chaire d'Excellence Professor of Biochemistry and Medical Inflammation at the Université d'Auvergne, Faculte de Pharmacie, Clermont-Ferrand, France.

The main research area of this group is related to role of eicosanoids in oxidative stress and clinical inflammation specifically in various diseases and pathophysiological state.

The research group is dedicated to research on inflammation in physiology and in disease state. Additionally, the role of oxidative stress that reflects an increased level of free radicals that are implicated both in ageing and in several inflammatory diseases is also a major research area. Lipid peroxidation products catalysed by free radicals and cyclooxygenases have shown to be of importance in many inflammatory and oxidative stress-related diseases. Bioactive prostaglandin formation by cyclooxygenases from arachidonic acid and their contribution in inflammation is well described by our group in the past years in addition to the role of free radicals-mediated product isoprostanes in physiology and a range of diseases.

The research group have developed crucial assays through raising specific antibodies against isoprostanes indicating oxidative injury and prostaglandin $F_{2\alpha}$ indicating inflammatory response, and is also involved in development of assays on anti-inflammatory resolvins. In addition, we have also established immunohistochemical methods using specific antibodies to study organ damage following an acute or chronic inflammation and oxidative stress. These novel eicosanoids are implicated in healthy individuals and also in development of different human diseases.

Collectively, the research group is devoted to experimental, clinical, epidemiological studies and also development of methodology specifically on eicosanoids. The research group has still many national and international collaborative projects within the research vicinity.

Research projects

Impact of systemic inflammation, oxidative stress and adipokines in breast cancer

- Collaborators: Samar Basu, Alicja Wolk, Anders Larsson, Marie-Paule Vasson

The project is performed in collaboration with Karolinska Institute, Clinical Chemistry, Uppsala University, Sweden and Universite d'Auvergne, Clermont-Ferrand, France.

Association of specific systemic tumor markers in breast cancer

- Collaborators: Samar Basu, Anders Larsson, Marie-Paule Vasson, Alicja Wolk

The project is performed in collaboration with Karolinska Institute, Clinical Biochemistry, Uppsala University, Sweden and Universite d'Auvergne, Clermont-Ferrand, France.

Effects of fish oil in functional foods, capsules or fish on the blood lipids and markers of oxidative stress in mice and humans (Smartfish)

- Collaborators: Samar Basu, Rune Blomhoff and Liver Frøyland

The project is performed in collaboration with Oslo Medical Faculty and Bergen University and is financed by The Norwegian Research Council.

Oxidative stress, inflammation during normal pregnancy, parturition and under normal menstrual cycle

- Collaborators: Maria Palm, Ove Axelsson, and Samar Basu

The project is performed in collaboration with the Department of Women's Health and Clinical Chemistry, Uppsala University.

Prenatal food and multiple micronutrient supplementation and effects on child body composition, metabolic markers and mortality; mechanisms of early programming

- Collaborators: Lars-Åke Persson, Eva-Charlotte Ekström, Sham Arifeen, Rubanna Ruqib, Samar Basu

The research is financed by The Swedish Research Council.

AQUAMAX: The sustainable aquafeeds to maximise the health benefits of farmed fish for consumers

- Collaborators: Samar Basu, Philip Calder

The project is performed in collaboration with Southampton, Granada, Bergen, China and is financed by the European Union (6th Framework).

Multi-laboratory study on biomarkers of oxidative stress (BOSS-study)

- Collaborators: Maria Kadiiska with international colleagues, Ron Mason, Samar Basu

The project is performed in collaboration with NIEHS, National Institute of Health (NIH), USA and other institutions from several countries and is financed by NIEHS (NIH).

Birth weight and inflammation in later life, a follow-up study of 70-80 years in a Swedish population

- Collaborators: Johanna Helmersson, Liisa Byberg, Samar Basu

The project is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital and Department of Surgical Sciences, Uppsala University.

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Sociomedical Epidemiology

Research Group Leader: Professor Ragnar Westerling

The main objective of the research is to analyse factors that influence health and the effectiveness of medical and health interventions in different population groups. The main fields of the research programme are to evaluate the quality and equity in medical care and health system interventions for vulnerable groups.

There is a broad range of factors, including organizational factors and factors related to the target group, which may influence the effectiveness of implemented interventions. We study a broad range of potentially important mechanisms. Our studies on the effectiveness of interventions extend the assessments from the clinical trial situation to understand the influences on the outcome of implemented interventions in ordinary practice. For instance, we have studied the diffusion of medical innovations, the quality of care and access to interventions in different population groups.

In several studies, we have analysed the avoidable mortality, *i.e.* mortality from diseases that are possible to prevent or treat. We compared the Swedish results with results from six other European countries and for several conditions the trend was more favourable in Sweden. For several conditions, mainly in the field of cardiovascular and cancer diseases, we found that preventive strategies were implemented earlier in Sweden and that this was followed by a favourable shift in mortality trends.

We have analysed the access to evidence-based medications for heart failure among all patients treated at hospital in Sweden during a five year period combining data from several medical and social registers in Sweden. We found that only about half of the patients had the recommended treatment. Furthermore, this lack was more common among females, elderly and persons without work. Presently we are analyzing the effect on mortality of the equity in access to evidence-based treatment for heart failure.

Preventive treatment with statins is shown to significantly reduce the absolute risk of coronary heart disease; yet long-term compliance is poor. We have studied the expectations and factors that might affect expectations on statin treatment among patients. Recently, we have also analysed the association between the patient's locus of control and the beliefs about statin medications as well as factors influencing self-rated health in the treatment group. A new method to describe the preventive effects of statin treatment

for patients have been developed by one of the members of the group, and this method is now tested in a randomized study.

The effectiveness of medical care and health interventions may vary between different population groups. In our research, we focus on the health of potentially vulnerable groups in different phases of life and in different social settings. We have for, instance, studied access to medical care and the effectiveness of health interventions among migrants, unemployed groups and adolescents, as well as gender differences. We have also analysed factors that influence the process and outcome of interventions. These factors include health-related behaviours, health literacy and the social capital of target groups.

We are performing evaluations of health system interventions for immigrants, and for persons on long-term sick leave and for school children. This includes studying the impact of international health advisors and other health promotion programs on health and health care utilization among immigrants to Sweden. The health advisors are working with information to immigrants about health related factors and medical care in Sweden. We have also developed an health information package, which have been used and evaluated as part of an intervention project for marginalized female immigrants. We are also analysing the views and expectations of health examinations for asylum seekers in Sweden. We also study the impact of the health examinations on the sexual and reproductive health as well as factors influencing the health care utilization in this field among Thai female immigrants, who are not covered by the health examination system.

Members of the group during 2015

Ragnar Westerling, Professor

Per Lytsy, MD, PhD, Senior lecturer

Achraf Daryani, PhD, Researcher

Annika Åhs, PhD, Researcher

Marcus Westin, MD, PhD

Lars-Age Johansson, PhD

Afsaneh Roshanai, PhD

Kjerstin Larsson, PhD

Stefan Kunkel, PhD

Ulrika Paulsson, Doctoral student

Peter Berg, MD, Doctoral Student

Susanne Sundell Lecerof, Doctoral student, collaboration with Lunds and Malmö University

Anna Ohlsson, MD, Doctoral student

Hasse Nordlöf, Doctoral student, Collaboration with University of Gävle

Josefin Wångdahl, MPh, Doctoral student

Eva Åkerman, MPh, Project coordinator
Erik Berglund, MPh, Doctoral student
Johanna Lagerkvist, MD, Clinical assistant
Elham Mohamaddi, MD, Research assistant
Maissa Al Adhami, MPh, Research assistant

Publications 2013-2015

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Dissertations 2015

Hasse Nordlöf	2015
Maria Grandahl (as co-tutor)	2015

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Health examinations for asylum seekers: (partnership with the Swedish Institute for Communicable Disease Control, the Migration Board/Public Health Agency in Sweden, the National Board of Health and Welfare, the Swedish organization of local authorities, Umeå University and regions and the counties(regions) of Stockholm, Östergötland, Skåne and Norrbotten): 30 000 000 SEK; 2 772 888 SEK managed at our department year 2012-2014 European refugee fund.

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Health, Establishment and work. Macksa Samordningsförbund. 619 000 SEK, 2013-2014.

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A qualitative study of migrants experiences and perceptions of health examinations for asylum seekers. Olle Engkvist fund. 130 000 SEK. 2014.

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Milsa – a supportive platform for migration and health. (Partnership with The County Administrative Board of Malmö and the Institute for studies of migration, diversity and welfare, Malmö University). European Migration Fund 2015. 248 860 SEK.

Intervention study among Thai women in Stockholm county. (Partnership with Lafa – Unit for Sexuality and Health at the Stockholm County Council). 2015. Public Health Agency of Sweden 2015. 193 050 SEK.

How is mortality from heart failure influenced by inequity in evidence-based drug treatment? Forte 990 000 SEK 2016-2017.

ALF-grant. Academic hospital: 241 000 SEK 2013, 1 038 000 SEK 2014; 707 000 SEK 2015.