Department of Public Health and Caring Sciences

Annual Report 2016

Avsändare/Fastställd av Johan Hallqvist 2017-05-31
Introduction

The Department of Public Health and Caring Sciences employs 200 persons, of which there are 11 professors and 34 senior lecturers. The yearly economic turnover is approximately 160 million SEK including ALF.

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 multidisciplinary 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.

The department is in a phase of renewal. During 2016 two professors, in Geriatrics and Caring Sciences, retired. A new professor in Geriatrics was installed in the spring 2016. The next professor in Caring Sciences is recruited and will take up work during 2017. During 2016 the former chair in Social Medicine left his job and instead two new professors in Social Medicine were recruited and started to work during the second half of the year. The former leader for the research group Oxidative Stress and Inflammation also retired at the end of 2016. During 2017 the professor in Prevention Research will retire and during 2018 and 2019 another four professors will reach the age of 67. The research group Clinical Psychology in Healthcare hosting the strategic research program U-CARE moved at the end of 2016 to the department of Women’s and Children’s Health and were replaced by two new research groups lead by the professors in Social Medicine. The department will also have a new head and a new deputy head in 2017.

Education

The Department of Public Health and Caring Sciences is funded for about 820 full time students, which represented 2630 students registered at the department in 2016 (47 million SEK). About 940 registered students were educated in the Nursing programs, about 1090 in the Medicine program, about 65 in the Master program in Public Health and about 510 in separate courses. Six students were registered in contract education. The number of our students studying abroad has increased every year. In 2016 about 72 of them studied abroad during 1-12 weeks, while 14 foreign students visited our department during 4-12 weeks. Three of our teachers taught abroad during 1-4 weeks.

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 2016 there were 325 peer-reviewed scientific publications from researchers affiliated to the department. The yearly average during the last ten years is 250 and there is an increasing trend during later years. In the beginning of the year 2016, 71 doctoral students were in education and during the year 8 of them have past their theses and 13 new applicants have been admitted to studies at the doctoral level. Of the 76 doctoral students at the end of the year 44 were employed by the university and 32 had other employers. Eight dissertations is a somewhat lower number than the yearly average (12) during the last decade.
The research activities during 2016 were 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 Sociomedical Epidemiology. Two new research groups were organised during 2016, the Social Medicine group with Child Health And Parenting (CHAP); and the Public Health Science group.

Caring Sciences
Research in Caring Sciences is conducted at micro, meso and macro levels. The research questions include multidisciplinary teamwork, person centred care, safe and evidence based care, and the implementation in complex health care organisations. Our research ranges from reproductive health to palliative care and includes transcultural aspects. Studies are conducted both nationally and internationally.

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.

Centre for Research Ethics & Bioethics (CRB)
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.

Clinical Nutrition and Metabolism
The CNM research group works along two major lines:
1) Preventive nutrition and metabolism related to fatty acids and insulin-glucose interactions with public health, cardiovascular prevention, diabetes and obesity. Metabolic intervention trials are performed for elucidating effects on insulin sensitivity, body composition and cardio-vascular risk factors. Accordingly, local and national cohorts are utilized as well as large international cohorts in
extensive collaborations to analyse fatty acid relationships to body composition, metabolic syndrome, insulin sensitivity and CVD risks. Associate professor Ulf Riserus is deputy head of the CNM research group and leading the preventive nutrition and fatty acid and insulin-glucose research pathway. Ulf Riserus is board member of the Department of Public Health and Caring Sciences. CNM is by tradition a world leader on fatty acid metabolism and its role in health and disease, dating back to former professor and head Bengt Vessby, who is still active in the group. This tradition is now continued by associate professor Ulf Riserus and his research team, including senior researchers Matti Marklund, Fredrik Rosqvist and David Iggman.

2) Clinical disease- and age-related nutrition with a focus on catabolism, undernutrition and sarcopenia. Various cohorts are used to describe development of sarcopenia, i.e. loss of muscle mass and function, in older populations. Intervention trials are performed to elucidate exercise and nutrition effects for prevention and treatment of sarcopenia, and experimental studies are performed to understand genetic and biologic mechanisms. Professor Tommy Cederholm is head of the CNM research group and also responsible for the disease- and age-related nutrition pathway. Tommy Cederholm is linked to the Department of Geriatrics (MD, Senior consultant) at the hospital and thus also linked to the ALF financial system. During the last 10-12 years Professor Tommy Cederholm has developed a world-leading research line focused on 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. Another significant research line is omega-3 fatty acid treatment of Alzheimer’s disease in collaboration with Karolinska Institutet.

Moreover, CNM performs research a) on food intake and dietary patterns relation to various health outcomes mainly in elderly people from various population cohorts, led by associate professor Per Sjögren, b) related to obesity in adult populations (post-bariatric surgery effects) as well as in children (body composition and energy metabolism), led by researcher Ulf Holmbäck; and c) on effects of tailored training programs in post-stroke patients, led by researcher Birgit Vahlberg.

CNM has two laboratories, one that analyzes FA profiles in various tissues by gas-chromatography technique, and one that estimates body composition and energy metabolism by air-displacement, bioelectrical impedance and indirect calorimetry.

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, therapeutic assignments, 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 Caring Sciences, 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
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. 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. 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 in studies of living conditions, lifestyles, mental well-being, personal assistance, aided communication and parenthood. There are two 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 living conditions and self-perceived health

**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 different themes:

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

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.

**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. In addition, new methods for molecular imaging, *i.e.* positron emission tomography (PET), are being developed. The group applies a broad repertoire of experimental techniques, *e.g.* molecular biology, biochemistry, histology and behavioural analyses in the research. Clinical and epidemiological studies of dementia and successful ageing are also performed.

**Health Economics**

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. However, during the last year, the group has mainly focused on a research project which study the population preferences.
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 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.

Lifestyle and Rehabilitation in Long Term Illness
The research group Lifestyle and rehabilitation in long term illness was established 2015. Most projects in this group are intervention studies focusing on lifestyle (e.g. physical exercise, stress management, nutrition) in patients with cancer. The aim is to develop and evaluate effective health behavior change interventions, person-centered care and cost-effective rehabilitation programs to decrease the burden for patients and healthcare during and after cancer treatment.

Oxidative Stress and Inflammation
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 in 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.

Public Health Science
The public health research group was initiated at Uppsala University in midOctober 2016. The research originates from successful research applications based mainly on ecological life-course epidemiological analyses of the Northern Swedish Cohort. One research strand is a major research programme about mental health in adolescence and the paths ahead - an ecological life course approach to mental health development into adulthood. Another programme is gender theoretical development of how sex/gender and health are interwoven in a Northern European context. The research is performed in international and interdisciplinary collaboration.
Social Medicine (CHAP)
The group is interdisciplinary and focuses on societal support to children and their families. Projects range from prevention through early intervention to attending to the needs of vulnerable populations, such as asylum-seekers. Our special area of interest is parenting support, including both universal child health and early education services and parenting programmes. We specifically deal with effectiveness studies as well as implementation and improvement research, translating research results into practice. We also develop methods to interview preschool children reliably. All trials we conduct include a health economic evaluation of the intervention as well as qualitative studies with different stakeholders, including users.

Sociomedical Epidemiology
The main objective of the research is to analyse factors that influence health, health related social factors and the effectiveness of medical and health interventions in different population groups.

Uppsala May 18, 2017

Johan Hallqvist
Head of Department
List of Contents

Introduction .................................................................................................................. 2
Education ....................................................................................................................... 2
Research ....................................................................................................................... 2
List of Contents ............................................................................................................ 8
Organization ............................................................................................................... 11
  Address List ............................................................................................................... 13
Centres ......................................................................................................................... 17
  Centre for Disability Research (CDR) ................................................................. 17
  Centre for Research Ethics and Bioethics (CRB) ............................................... 17
Education .................................................................................................................... 18
  First-cycle courses and study programs .............................................................. 18
  Second-cycle courses and study programs ........................................................... 19
  Third-cycle course and study program ................................................................. 20
Dissertations 2016 ...................................................................................................... 22
Half time controls 2016 ............................................................................................. 22
Scientific Reports ........................................................................................................ 23
  Caring Sciences ....................................................................................................... 23
    Members of the group during 2016 .................................................................... 24
    Publications 2014-2016 ...................................................................................... 26
    Dissertations 2016 ............................................................................................... 35
    Agencies that support the work/Funding (SEK) ................................................... 35
  Centre for Disability Research (CDR) ................................................................. 37
    The Board of the Centre for Disability Research ............................................. 37
    Agencies supporting CDR work/Funding (SEK) ............................................... 37
  Centre for Research Ethics & Bioethics (CRB) ...................................................... 40
    Members of the group during 2016 ................................................................. 42
    Publications 2014-2016 ...................................................................................... 43
    Agencies that support the work/Funding (SEK) ................................................... 53
    Research projects ................................................................................................. 55
    Project descriptions .............................................................................................. 56
  Clinical Nutrition and Metabolism (CNM) ................................................................. 83
    Members of the group 2016 ............................................................................. 85
    Publications 2014-2016 ...................................................................................... 86
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agencies that support the work/Funding (SEK)</td>
<td>96</td>
</tr>
<tr>
<td>Future promising research at CNM</td>
<td>97</td>
</tr>
<tr>
<td>Clinical Psychology in Healthcare</td>
<td>98</td>
</tr>
<tr>
<td>Members of the group 2016</td>
<td>98</td>
</tr>
<tr>
<td>Publications during 2014-2016</td>
<td>102</td>
</tr>
<tr>
<td>Dissertations 2016</td>
<td>110</td>
</tr>
<tr>
<td>Agencies that support the work/Funding (SEK)</td>
<td>111</td>
</tr>
<tr>
<td>Research projects 2016</td>
<td>112</td>
</tr>
<tr>
<td>Disability and Habilitation</td>
<td>119</td>
</tr>
<tr>
<td>Members of the group during 2016</td>
<td>119</td>
</tr>
<tr>
<td>Publications 2014-2016</td>
<td>120</td>
</tr>
<tr>
<td>Dissertation 2016</td>
<td>124</td>
</tr>
<tr>
<td>Research Projects</td>
<td>126</td>
</tr>
<tr>
<td>Family Medicine and Preventive Medicine</td>
<td>131</td>
</tr>
<tr>
<td>Members of the group during 2016</td>
<td>131</td>
</tr>
<tr>
<td>Publications 2014-2016</td>
<td>132</td>
</tr>
<tr>
<td>Dissertation 2016</td>
<td>151</td>
</tr>
<tr>
<td>Agencies that support our work/Funding 2016 (SEK)</td>
<td>151</td>
</tr>
<tr>
<td>Education</td>
<td>152</td>
</tr>
<tr>
<td>Research projects</td>
<td>155</td>
</tr>
<tr>
<td>Geriatrics</td>
<td>174</td>
</tr>
<tr>
<td>Members of the group during 2016</td>
<td>174</td>
</tr>
<tr>
<td>Publications 2014-2016</td>
<td>175</td>
</tr>
<tr>
<td>Agencies that support the work/Funding (SEK/year)</td>
<td>185</td>
</tr>
<tr>
<td>Research projects</td>
<td>186</td>
</tr>
<tr>
<td>Health Economics</td>
<td>190</td>
</tr>
<tr>
<td>Members of the Group during 2015</td>
<td>190</td>
</tr>
<tr>
<td>Publications 2014-2016</td>
<td>190</td>
</tr>
<tr>
<td>Research Fundings</td>
<td>190</td>
</tr>
<tr>
<td>Main Research Project</td>
<td>190</td>
</tr>
<tr>
<td>Health Services Research</td>
<td>193</td>
</tr>
<tr>
<td>Members of the group during 2016</td>
<td>193</td>
</tr>
<tr>
<td>Publications 2014-2016</td>
<td>194</td>
</tr>
<tr>
<td>Agencies that support the work/Funding (SEK)</td>
<td>198</td>
</tr>
<tr>
<td>Research projects</td>
<td>200</td>
</tr>
<tr>
<td>Lifestyle and Rehabilitation in Long Term Illness</td>
<td>208</td>
</tr>
<tr>
<td>Members of the group during 2016</td>
<td>208</td>
</tr>
<tr>
<td>Publications 2014-2016</td>
<td>209</td>
</tr>
<tr>
<td>Dissertation 2016</td>
<td>210</td>
</tr>
</tbody>
</table>
Organization

**Head of Department**
Professor Johan Hallqvist

**Deputy Head of Department**
Professor Karin Sonnander

**Department Board**
Carina Ahlstedt, Teacher and Researcher Representative
Mats G Hansson, Teacher and Researcher Representative
Anna T Högglund, Teacher and Researcher Representative
Ulrika Winblad, Teacher and Researcher Representative
Henrik Edlund, Technical and Administrative Representative
Jennifer Viberg Johansson, Graduate Student Representative
Adam Bergman, Student Representative
Lena Hedlund, Teacher and Researcher Representative, Deputy
Per Lytsy, Teacher and Researcher Representative, Deputy
Karin Nordin, Teacher and Researcher Representative, Deputy
Ulf Riserus, Teacher and Researcher Representative, Deputy
Maria Peippo, Technical and Administrative Representative, Deputy
Malin Ander, Graduate Student Representative, Deputy
Catarina Olsson, Protocol

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Margaretha Eriksson (until 160531 then replaced by Ulrika Winblad)
Barbro Wadensten

**Directors of Undergraduate Studies**
Carina Ahlstedt, Head
Karin Björkegren, Head (until 160901 then replaced by Anna Sarkadi)
Berit Thoudal
Cilla Arving (until 161231 then replaced by Christine Leo Swenne)
Päivi Adolfsson

**Director of Clinical Issues**
Lars Lannfelt (until 30 June 2016)

**Professors and Research Groups Leaders**
Bengt Arnetz (until 30 June 2016)
Tommy Cederholm
Louise von Essen
Lena Gunningberg
Johan Hallqvist
Anne Hammarström (since 17 October 2016)
Mats G Hansson
Martin Ingelsson
Sophie Langenskiöld
Lars Lannfelt (until 30 June 2016)
Per Kristiansson
Karin Nordin
Anna Sarkadi (since 1 August 2016)
Karin Sonnander
Tanja Tydén (until 30 September 2016)
Ragnar Westerling
Ulrika Winblad

**Adj Professors, Guest Professors and adj Senior Lecturers**
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Hans Basun
Lena Nordgren
Lena Ring
Thorne Wallman

**Senior Professor**
Lars Lannfelt (since 1 July 2016)

**Professor Emeriti**
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Urban Rosenqvist
Björn Smedby
Kurt Svärdsudd
Tanja Tydén (Since 1 October 2016)
Bengt Vessby (Adj professor emeritus)
Claes-Göran Westrin
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<table>
<thead>
<tr>
<th>Last Name</th>
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<tbody>
<tr>
<td>Martinsson Carl Magnus</td>
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<td>Törmä Johanna</td>
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<td>Wallert John</td>
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<td>Wallman Thorne</td>
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<td>Veldwijk Jorien</td>
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<td>Vengberg Sofie</td>
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<td>Westerling Ragnar</td>
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<td>Wickström Östervall Linne</td>
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<tr>
<td>Paulsson Do Ulrica</td>
<td>Wikman Anna</td>
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<td>Peippo Maria</td>
<td>Winblad Spångberg Ulrika</td>
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<td>Winrow Johanna</td>
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<td>Persson Emil</td>
<td>Volgsten Helena</td>
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<td>Perssson Emma</td>
<td>von Berens Åsa</td>
</tr>
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<td>Pettersson Mona</td>
<td>von Essen Louise</td>
</tr>
<tr>
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<td>Wångdahl Josefin</td>
</tr>
<tr>
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<td>Stern Jenny</td>
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</table>
Associated Researchers

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Andersson Sven-Olof  Johansson Gunnar
André Malin  Johansson Linus
Annerbäck Eva-Maria  Kallings Lena
Arakelian Ereouni  Kaminsky Elenor
Arnetz Bengt  Karlström Brita
Arnetz Judith  Keld Vaegter
Ax Erika  Kirsebom Marie
Becker Wulf  Koochek Afsaneh
Berglund Britta  Källberg Niklas
Bernsten Cecilia  Lampic Claudia
Björkegren Karin  Larsson Jan
Björkman Ingeborg  Larsson Kjerstin
Björn Catrine  Lindahl Norberg Annika
Bojner Horwitz Eva  Lindberg Magnus
Burell Gunilla  Lisspers Karin
Carlsson Marianne  Löfander Monica
Cederblad Maria  Lövgren Ekmeheag Björn
Cedervall Ylva  Makenzius Marlene
Dahlström Tobias  Mamhidir Anna-Greta
Edlund Birgitta  Muntlin Athlin Åsa
Ekstrand Maria  Märtensson Gunilla
Eldh Ann Catrine  Nerpin Elisabet
Engström Maria  Nilsson Annika
Engström Sevek  Nordgren Lena
Eriksson Margaretha  Nordløf Hasse
Ernesäter Annica  Olai Lena
Falkenborn Margareta  Persson Fine de Licht Karl
Forsberg Joanna  Peterson Magnus
Glad Johan  Reine Ieva
Godskesen Tove  Rhode Nils
Gottvall Maria  Rissanen Ritva
Gulliksson Mats  Rytter Elisabeth
Gustavsson Catharina  Röing Marta
Halford Christina  Rönnemaa Elina
Hallström Björn  Sahlin Charlotte
Hanning Marianne  Salles Arleen
Held Claes  Sanner Margareta
Hofsten Anna  Schwan Åke
Holmström Knutsson Inger  Silén Marit
Hovén Emma  Skytt Bernice
Häggbström Elisabeth  Star Kristina
Hänni Arvo  Stållhammar Jan
Ingvoldstad Charlotta  Stållberg Björn
Inthorn Julia  Svalastog Anna Lydia
Isaksson Stina  Swartling Malin
Janeslätt Gunnel  Sving Eva
Jansson Stefan  Svärdsudd Kurt
Johansson Hans-Erik  Terner Annika

Tiblom Ehersson Ylva
Torstensson Thomas
Vaegther Keld
Wahlström Rolf
Wallander Marie-Ann
Wallman Thorne
Vég Aniko
Vessby Bengt
Wiholm Clair
Wijk Katarina
von Celsing Anna-Sophia
Zethelius Björn
Åberg Anna Cristina
Åhsberg Elizabeth
Ålander Ture
Tiblom Ehersson Ylva
Torstensson Thomas
Vaegther Keld
Wahlström Rolf
Wallander Marie-Ann
Wallman Thorne
Vég Aniko
Vessby Bengt
Wiholm Clair
Wijk Katarina
von Celsing Anna-Sophia
Zethelius Björn
Doctoral Students

Alfonsson Sven
Almandoz-Gil Leire
Ander Malin
Andersén Åsa
Drevin Jennifer
Fang Xiaotian
Farisco Michele
Grandahl Maria
Gustafsson Gabriel
Henriksson Anna
Karlsson Mikael
Ljungman Lisa
Matar Amal
Mattsson Susanne
Nikitidou Elisabeth
Norlund Fredrika
Paulsson Do Ulrica
Rosqvist Fredrik
Sallin Karl
Stern Jenny
Söllvander Sofia
Tegler Helena
Toft Teolinda
Törmä Johanna
Wallert John
Viberg Johansson Jennifer
von Berens Åsa
Centres

During 2016 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 (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.

Centre for Research Ethics and Bioethics (CRB)

**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. 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 clinical 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 Epignenetics 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.
Education

The Department of Public Health and Caring Sciences is funded for about 820 full time students, which represented 2630 students registered at the department in 2016 (47.2 million SKr).

About 940 registered students were educated in the Nursing programmes, about 1090 in the Medicine programme, about 65 in the Master programme in Public Health and about 510 in separate courses.

Six students were registered in contract education and 71 doctoral students were registered in the department.

First-cycle courses and study programs

The Medicine Programme

The medicine program at IFV covers 74.4 FTE (8.6 million SKr)

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

IFV course responsibility:

| Semester 1-4: | Introduction course | 3 credit points |
| | Professional Skills and Communication 1 | 2.5 credit points |
| | Professional Skills and Communication 2 | 2.5 credit points |
| | Professional Skills and Communication 3 | 2.5 credit points |
| | Professional Skills and Communication 4 | 2.5 credit points |
| Semester 4-11: | Leadership training | 4 credit points |
| Semester 5: | Geriatrics |
| Semester 1-11: | Medical Ethics and Medical Law | 3 credit points |
| Semester 11: | Family Medicine | 6.5 credit points |

Tutor education - supervising students at health care centres.

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

The Nursing Program

The Nursing Program at IFV covers 115 FTE 2016 (27.7 million SKr).

The first five semesters of the new Nursing Program ran in 2015-2016 and has students in both Uppsala and on Campus Gotland.

| Semester 1: | Nursing Methods I | 10 credit points |
| Semester 2: | Nursing Methods II | 18 credit points |
| Semester 3: | Ill Health and Promotion of Health I | 20 credit points |
| Semester 4: | Ill Health and Promotion of Health II | 17.5 credit points |
Semester 5:  
- Electable course 7.5 credit points 
- Clinical Placement 7.5 credit points 
- Degree Project in the Nursing Programme 15 credit points

Semester 6:  
- Nursing and Medical Science in Geriatrics and Elderly Care 10.5 credit points 
- Scientific Methodology and Thesis in caring science 19.5 credit points

Separate courses at the first-cycle level
The following courses are offered as separate courses at the first-cycle level:

Contract education
Research Ethics for Medicine and the Life Sciences, 4 credit points.
The course is open to researchers, doctoral students and professionals from Universities, Research Institutes, Government agencies, NGO's and companies. It runs over ten weeks and covers nine themes. It is an online course, but designed to be interactive. Participants share what they have learned with colleagues at their home institutions and the training will develop participants’ ability to identify and work on ethical aspects in their research. The course provides the basic tools to identify and assess central ethical aspects and offer updated and research-based information. It also provides a resource bank of instructions, forms, guidelines and principles.

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.
Semester 1:  
- Nursing Care in Children and Adolescents with Common and Specific Conditions. 
- Nursing Care and Public Health in Children and Adolescents at Child Health Centres and Schools. 
- Theory and Methodology in Caring Sciences

Semester 2:  
- 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.

Semester 2-3:  
- Degree Project with Focus on Primary Health Care.

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:

Master in Public Health
The program covers 120 credit points, two years of full-time studies.
The focus of the program is 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. The aim of the program is to increase knowledge, understanding and skills in public health and public health work. The students will be prepared to do further research and practical strategic public health initiatives.

Semester 1: Public Health, advanced level 15 credit points
Behavioural Medicine with Applications to Lifestyle-Related Health Problems 7.5 credit points
Equity in Health 7.5 credit point
Semester 2: Research Designs, Methods and Statistics in Public Health 15 credit points
Community Interventions 7.5 credit points
The Organisation and Management of Swedish Health Care 7.5 credit points
Semester 3: Health Promoting Management 7.5 credit points
Diet, Nutrition and Public Health 7.5 credit points
Public Health Ethics 7.5 credit points
Semester 4: Thesis in Public Health 30 credit points

Third-cycle course and study program

Doctoral courses and study programme
In the beginning of the year 2016, 71 doctoral students were in education and during the year 8 of them have past their theses and 13 new applicants have been admitted to studies at the doctoral level. To give new doctoral students a good introduction to their doctoral studies and to the department the directors of doctoral studies in IFV set up a two days introduction.
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 credit points, 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 credit points, given two times a year). Family Medicine and Preventive Medicine participated in “Medical Epidemiology” (1.5 credit points, given once a year). The research group Clinical psychology in healthcare is responsible for the course “Care, Self Care and Psychological Treatment through the internet and Mobile Media” (7.5 credit points, 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 credit points, given six times a year).

**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 (Norlys for the Scandinavian and Baltic countries and Danosfi for the Nordic countries), and Linnaeus-Palme and Minor Field Study for low-income countries such as Tanzania, Uganda, Thailand, and Vietnam. The students also have the opportunity to do clinical practice/internship in the United Kingdom and in non-European countries such as South Africa, Tanzania, Uganda, Thailand and Vietnam.

The number of our students studying abroad has increased every year. In 2016 about 72 of them studied abroad during 1-12 weeks, while 14 foreign students visited our department during 4-12 weeks. Three of our teachers taught abroad during 1-4 weeks; one visited Tallinn Health Care College, Estonia, for teaching in an intensive course supported by Nordplus (Norlys network), one visited Åland University, Finland, for teaching in an intensive course supported by Nordplus (Danosfi network), and one visited Kasetsart University, Thailand, for teaching nursing programme supported by Erasmus Mundus Expert IV. One teacher from Makerere University, Uganda, taught in our department during 3 weeks as a part of the Linnaeus-Palme Exchange Programme. Three teachers from Mahidol University, Thailand, gave a Thai-Swedish seminar on “Reproductive Health and Health Care System” during one week supported by the Swedish Foundation for International Cooperation in Research and Higher Education. 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 2016
(Registered at the Department of Public Health and Caring Sciences)

Sven Alfonsson, Treatment Adherence in Internet-Based CBT: The Effects of Presentation, Support and Motivation.

Catrine Björn, Attractive Work: Nurses’ work in operating departments, and factors that make it attractive.


Lisa Ljungman, Parents of Children with Cancer: Psychological Long-Term Consequences and Development of a Psychological Treatment for Parents of Survivors.

Maria Randmaa, Communication and Patient Safety: Transfer of information between healthcare personnel in anaesthetic clinics.

Fredrik Rosqvist, Dietary Fatty Acids, Body Composition and Ectopic Fat: Results from Overfeeding Studies in Humans.

Lisa Söderström, Nutritional Screening of Older Adults: Risk Factors for and Consequences of Malnutrition.

Anna-Sophia von Celsing, Early risk assessment of long-term sick leave among patients in primary health care: risk factors, assessment tools, multidisciplinary intervention, and patients’ views on sick leave conclusion.

Half time controls 2016

Malin Ander, Cancer during Adolescence: Psychological Consequences and Development of Psychological Treatments.

Tommy Carlsson, To Grasp the Unexpected: Information Following a Prenatal Diagnosis of Congenital Heart Defect in the Fetus.


Helena Wandin, Aided communication intervention in Rett syndrome- current practice and a new approach to assessment.
Caring Sciences

**Research group leader professor Tanja Tydén and professor Lena Gunningberg**

Research in Caring Sciences is conducted at micro, meso and macro levels. The research questions include multidisciplinary teamwork, person centred care, safe and evidence based care, and the implementation in complex health care organisations. Our research ranges from reproductive health to palliative care and includes transcultural aspects. Studies are conducted both nationally and internationally. Between 2014 and 2016, Theo van Achterberg, professor of quality of care at KU Leuven, Belgium, has been a visiting professor in our group. He has visited us 2-3 times per year, giving lectures, inspiring and discussing our research, as well as leading joint grant writing.

All members in Caring Sciences 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.

**Quality of care and patient safety**

One research program, *Pressure Ulcer Prevention*, has investigated different aspects of prevention during a 15-years period, using intervention studies, epidemiological studies and qualitative studies. The overall aim is to reduce the prevalence 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 prevalence and incidence of pressure ulcers in a geriatric hospital ward. Experiences from the multidisciplinary team were also gathered through qualitative interviews. A reduction of the prevalence of pressure ulcers from 38.6% (2015) to 15.4% (2016) was found. In a PhD-project, we are now continuing to study patients’ experiences of using the pressure mapping system in order to increase patient involvement in preventive care. Furthermore, in healthcare today, with high staff and patient turnover, it is problematic to reach a long-lasting effect of successful research findings. Therefore, a three-years follow up of an implementation study (evidence based pressure ulcer prevention) was conducted in 2016 to investigate sustainability. Preliminary findings reveal that pressure ulcer prevention activities remained at the same increased level after three years.

Another research program is *infection control* including hospital-acquired infections following coronary artery bypass graft procedures. An electronic system for reminders and encouragement to good hand hygiene practice is under development. Focus groups were conducted in 2016 to study health care professionals experiences of the system, as well as potential barriers.

*PHASE-20* is a rating scale, developed in our research group, which is used to identify symptoms that may be related to medication in older people. PHASE-20 is recommended by the Swedish National Board of Health and Welfare (2010) and is currently used in all counties in Sweden. In 2016, we published the development of PHASE-Proxy, a scale for proxy use in assessing older people with severe cognitive impairment. PHASE-20 and PHASE-Proxy are most commonly used in nursing homes. We are now planning an implementation study at health care centres. To develop a similar scale for use in psychiatric care is also in pipeline.

*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. In 2017, structured bedside nursing shift handovers will be implemented in the university hospital to increase patient participation. We are planning a clustered RCT to evaluate the effect from different perspectives. 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.

The work environment for nurses affects patient safety. Therefore, a qualitative interview study is ongoing to identify factors for registered nurses’ intention to stay/intention to leave their position at surgical and medical wards, as well as nursing homes. 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.

**Reproductive health**

The aim of a research program in reproductive health is to prevent infertility and HPV-related cancer. The background is that parental age when having a first child in Sweden has increased by five years the past four decades. 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?

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? Could boys also be included in the vaccination programme? An ongoing RCT-study in School Health investigates the outcome of an intervention on HPV vaccination status and about primary prevention of HPV.

We have a PhD-project in collaboration with Faculty of Public Health, Kasetsart University, and Sakon Nakhon Public Health Office, Thailand. The title is “Transition to parenthood and depressive symptoms: A longitudinal study of Thai women from early late pregnancy to after childbirth”. Improved mental health of women in Thailand is closely linked to the third Sustainable Development Goal to promote good health. The outcome will be (i) to increase knowledge of mental health promotion among primary healthcare providers at primary health care units, (ii) to develop guidelines for assessment of perinatal depression, and (iii) to develop and in a pilot study implement an intervention aimed at preventing such depression at Antenatal Care Clinics.

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

**Members of the group during 2016**

**Senior Lecturer**
- Aarts Clara, RN, PhD, associate professor
- Bäckström Josefin, RN, PhD
- Eriksson Leif, RN, PhD
- Gunningberg Lena, RN, PhD, professor
- Hedström Mariann, RN, PhD, associate professor
- Karlsson Ann-Christin, RN, PhD
- Leo Swenne Christine, RN, PhD, associate professor
- Lundberg Pranee, RN, PhD, associate professor
- Nordgren Lena, RN, PhD, associate professor (adjunct)
- Pöder Ulrika, RN, PhD, associate professor
- Svanberg Ann-Carin, RN, PhD
- Tydén Tanja, RNM, PhD, professor, (Chair until Sept 2016)
Lecturers full time or part time 2016
Fagerström Johansson Jenny
Frejd Karin
Godman Nathalie
Hedlund Lena
Hovstådus Eva
Hultin Lisa
Jobs Elisabeth
Kjellberg Sören
Lantz Christine
Lugnet Kerstin
Lundin Birgit
Norinder Camilla
Normark Lena
Staaf Anita
Stenlund David
Thoudal Berit
Thörnqvist Eva

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Carlsson Marianne
Edlund Birgitta
Ekstrand Maria
Engström Maria
Häggström Elisabeth
Lindberg Magnus
Mamhidir Anna-Greta
Nilsson Annika
Silén Marit
Skyytt Bernice
Sving Eva
Tiblom Ehersson Ylva
Westerberg Jacobsson Josefin
Åhsberg Elisabeth

PhD students
Catrine Björn
Petronella Bjurling- Sjöberg
Tommy Carlsson (until Summer 2016)
Jennifer Drevin
Heidi Hagerman
Maria Hedman
Lisa Hultin
Kati Knudsen
Ylva Pålsson
Maria Randmaa
Charlotte Roos
Publications 2014-2016

2014


2016


### Dissertations 2016

**Catrine Björn**, Attractive Work: Nurses’ work in operating departments, and factors that make it attractive. PhD, Medical sciences. **Uppsala University, 2016.**

**Kati Knudsen**, Airway management in anaesthesia care: professional and patient perspectives. PhD, Medical sciences. **Uppsala University, 2016.**

**Maria Randmaa**, Communication and patient safety: transfer of information between healthcare personnel in anaesthetic clinics. PhD, Medical sciences. **Uppsala University, 2016.**

### Agencies that support the work/Funding (SEK)

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<thead>
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<th>Agency</th>
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<td>ALF-medel</td>
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<td>Frimurarstiftelsen</td>
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<td>Högskolan i Gävle, rektors forskningsmedel</td>
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<tr>
<td>Medel för vårdvetenskaplig forskning för juniora forskare</td>
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### International collaboration

- Aga Khan University, School of Nursing and Midwifery, Dar es Salaam, Tanzania
- Associate Editor for Journal of Renal Care
- European Academy of Caring Science (EACS), Core member
- Faculty of Health Education, Stord/Haugesund University College, Norway
- Faculty of Public Health, Kasetsart University, Chalermprakiat Sakonnakhorn Province Campus, and Sakonnakhorn Ministry Health Office, Sakonnakhorn Province, Thailand: PhD research project on women’s mental health in Thailand
• 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
• Hanoi University of Public Health
• International collaboration with the Nordic countries (Nordplus network: Norlys), European countries (Erasmus), and Uganda (Linnaeus-Palme), and with African countries, especially Tanzania, and with Vietnam and Thailand
• Member of Editorial Board of Investigación y Educación en Enfermería
• Member of the Editorial board for the Clinical Nursing Studies
• National Centre of Research Excellence in Nursing, School of Nursing and Midwifery, Griffith University, Australia.
• Nursing Department, Medicine and Health College, Lishui University, China
• Nursing Practice and Education, Stanford Health Care, California, USA
• Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand: Research project on diabetes self-care management
• Randers Hospital/University of Aarhus & Via College Silkeborg, Denmark
• Research Institute for Child Health, Hanoi
• Reproductive Health Center, Cao Bang province
• Schmidt L. MD, Ass. Professor, Dept. of Public Health, University of Copenhagen, Denmark
• STINT project, collaboration with University of Mahidol, Thailand
• The PrePreg-Network
• Trustee of the European Pressure Ulcer Advisory Panel
• Uongbi General Hospital, Uongbi

National commissions
• Board member in The Swedish Society of Nursing
• Chair of Association for Nurses specialists in Ear, Nose and Throat care; [Free translation from Swedish: Specialistföreningen för öron-, näs- och halssjukköterskor, FÖNH]
• Expert group, Patient safety, Swedish Association of Local Authorities and Regions
• Member of Pool of External Experts, Medicine and Care, The Swedish Council for Higher Education, Swedish International Cooperation Agency (SIDA)
• Member of the Research Board, Swedish Cancer Society
• Member of the Scientific Board in The Swedish operating room nurses association (SEORNA) [In Swedish: Riksföreningen för operationssjukvård]
• Scientific advisor, Swedish Society of Nursing

Invited speakers 2016
• ”Att stärka den vakna patientens välbefinnande under operation i regional anestesi” The Swedish Association of Nurse Anesthetists and Critical Care Nurses, Kalmar, Sweden
• Pressure ulcer prevention. Universidad Internacional Menéndez Pelayo Hospital Universitario Son Espases, Mallorca, Spain
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.

The Board of the Centre for Disability Research

Professor Karin Sonnander, (Disciplinary Domain of Medicine and Pharmacy) chairperson
PhD Faculty of Medicine, Karin Hellström (Disciplinary Domain of Medicine and Pharmacy)
PhD Stefan Johansson (Disciplinary Domain of Science and Technology) (from 2016-07-01)
Associate Professor Cecilia Persson (Disciplinary Domain of Science and Technology), (from 2016-07-01)
Professor Rafael Lindqvist (Disciplinary Domain of Humanities and Social Science).(until 2016-06-30)
Professor Don Kulick (Disciplinary Domain of Humanities and Social Science) (from 2016-07-01)
Associate Professor Lotta Lerwall (Disciplinary Domain of Humanities and Social Science)
PhD student Marie Sépulchre
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 (SEK)

Funding has been received for 2016 for the newsletter Forskning om funktionshinder pågår (Current Disability Research). The financiers are:

Norrbacka-Eugenia Foundation 166 000
Sunnerdahl Handicap Fund Foundation 166 000
Sävstaholm Foundation 100 000

Research collaboration

An important aim this year has been to draw attention to the potential of the research for implementation of the UN Convention on the Rights of Persons with Disabilities. This became the theme of the conference on disability, which took place on 28 September and was arranged in cooperation with the Uppsala Regional Council.

The programme included presentations on how it is to work on a daily basis under the Convention, on the role of the disability movement before and after the Convention, and eleven brief presentations of current PhD projects in Sweden that in various ways relate to the UN Convention on the Rights of Persons with Disabilities.
The importance of interaction between research and practice in order to meet the UN Convention’s targets was also highlighted during the conference. A longer presentation dealt with the development of creative projects for the participation of special schools, which is based on cooperation between researchers at Uppsala University (from the Disciplinary Domain of Science and Technology, the Disciplinary Domain of Humanities and Social Sciences and the Disciplinary Domain of Medicine and Pharmacy) and teachers at a special school in the Municipality of Uppsala.

In connection with the conference ‘Forskning pågår om funktionshinder’ (‘Current Research on Disability’), CDR arranged a national network meeting (29 September) and a doctoral student/senior researcher seminar (29-30 September). Holding these events consecutively meant that doctoral students who took part in the seminar could also present their dissertation projects on 28 September. It also allowed researchers who participated in the network meeting to also attend the conference ‘Current Research on Disability’. Both the national network meeting and the doctoral student/senior researcher seminar discussed the research ethics dilemma within the framework of the different lectures.

Combining different activities in this way gives rise to new possible arenas for encounters:
- between doctoral students and researchers from different regions working in different subject areas
- between practice and research
- for presentations and discussions

During the year CDR continued functioning as the coordinator for the Swedish Network of Disability Researchers. Work was also carried out during the year in preparation for Sweden’s arrangement of a Nordic conference on disability research in 2017. 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.

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.

Swedish network on Disability research

CDR is responsible for the national network, for which Karin Jöreskog serves as coordinator. E-mail communication and updates to the addresses in the e-mail list are handled from the CDR office. There are currently 460 addresses in the list. CDR also manages the network’s website (www.snhf.se), which involves such tasks as ongoing administration and updates.
Homepage

The CDR homepage (www.cff.uu.se) presents information about the Centre, board members, lecture and course programmes, etc. The newsletter Forskning 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 2016 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)

Four editions of the newsletter Forskning 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 2016 of 4500, of which 1900 were for the digital-format publication.

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](https://bmreric.org/) ELSI common service and run ELSI services for the Swedish counterpart, [BBMRI.se](https://bmrise.org/) (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](https://ethicsblog.bmrise.org/). 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 neuroethics/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 cannot 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 to use certain medical treatments, preventive interventions or technology. Therefore, 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.

Preference research
In recent years, we have started using methods for preference elicitation in several empirical research projects (see risk research above). We are also coordinating a large public-private partnership under the Innovative Medicines Initiative (IMI) that will provide recommendations on when and how patient preferences can and should inform decision-making in the life cycle of medical products.

Several ongoing PhD projects are looking at peoples preferences in areas ranging from genetic risk information, antibiotics resistance to cardiovascular risk information and communication.

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.

Members of the group during 2016
CRB is a multi-disciplinary group. Here, senior and junior researchers from ethics, philosophy, law, economy, medicine, nursing, physiotherapy, social pharmacy, genetics, neuroscience and other fields come together.

Management
• Mats G. Hansson, Director, Professor of Biomedical Ethics
• Josepine Fernow, Co-ordinator
• Carl Steinbeisser, Project co-ordinator

Researchers & Teaching staff
• Stefan Eriksson, Associate Professor of Research Ethics Senior Lecturer in research ethics
• Kathinka Evers, Professor of Philosophy
• Elisabeth Furberg, PhD Philosophy Deputy Senior Lecturer in Medical Ethics
• Manuel Guerrero Antequera, PhD Sociology, Guest Researcher
• Sara Holm, PhD Physiotherapy, Researcher
• Heidi C. Howard, PhD Neuro Genetics, Senior Researcher
• Anna T. Höglund, Associate Professor of Ethics
  Senior Lecturer in Nursing Ethics and Gender Studies
• Ulrik Kihlbom, Associate Professor of Medical Ethics, Senior Lecturer in Medical Ethics
• Moa Kindström Dahlin, LLD, Researcher
• Anna-Sara Lind, Associate professor of Public Law
• Deborah Mascalzoni, PhD Bioethics, Senior Researcher
• Jessica Nilhén Fahlgquist, PhD Philosophy, Deputy Senior Lecturer in Medical Ethics
• Emil Persson, PhD Economics, Researcher
• Karl Persson de Fine Licht, PhD Philosophy
• Jane Reichel, Professor of Administrative Law
• Lena Ring, Adjunct Professor in Quality of Life Research in Health Care
• Arleen Salles, PhD Philosophy, Senior Researcher
• Pär Segerdahl, Associate Professor of Theoretical Philosophy
• Santa Slokenberga, LLD, Researcher
• Linnea Wickström Östervall, PhD Economics, Researcher
• Jorien Veldwijk, PhD Risk Economics, Researcher

PhD students
• Mirko Ancillotti, MA
• Michele Farisco, Associate Professor of Moral Philosophy
• Åsa Grauman, MSc, Research assistant
• Sofia Lavén, MD
• Amal Matar, MD
• Mona Pettersson, RN
• Arvid Puranen, MD
• Karl Sallin, MD
• Karin Schölin Bywall, MSc, Research assistant
• Jennifer Viberg Johansson, BsC, MA

Associated
• Tove Godskesen, RN, PhD Medical Science
• Julia Inthorn, PhD Philosophy
• Joanna Stjernschantz Forsberg, PhD Medical Science
• Anna-Lydia Svalastog, Professor of Social Work

Publications 2014-2016
A characteristic feature of our interdisciplinarity 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.

2014


2015


2016


Agencies that support the work/Funding (SEK)

Basic funding and agencies that support research

CRB is an inter-faculty centre with basic funding from all disciplinary domains (Medicine and Pharmacy: 1,813,000; Science and Technology: 350,000; Humanities and Social Sciences: 309,000 SEK). We also receive 1,500,000 in centre funding. Our mandatory courses for PhD Students are funded by the disciplinary domains (Medicine and Pharmacy: 210,000; Science and Technology: 390,000 SEK). We also have a connection to the Uppsala County Council, who pays 50 % of Mats G. Hansson’s salary (814,000 SEK). One of our PhD Students (Sofia Lavén) is funded entirely by the County Council (salary not part of our budget).

The basic funding amounts to 5,386,000 SEK (31 % of our total budget). The external funding amounts to 17,342,000 SEK, with the European Union being the largest funding agency (59 %).

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<thead>
<tr>
<th>EUROPEAN UNION</th>
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<tbody>
<tr>
<td>Innovative Medicines Initiative</td>
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<tr>
<td>PREFER (Innovative Medicines Initiative)</td>
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<td>BTCure (Innovative Medicines Initiative)</td>
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<td>RD-connect (Horizon 2020)</td>
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### Swedish Research Council (VR)

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<tr>
<td>CODEX - Rules and Guidelines for Research</td>
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<tr>
<td>Health inequality: advancing measurement, explanation, and policy process</td>
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<tr>
<td><strong>TOTAL VR FUNDING</strong></td>
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### The Swedish Foundation for Humanities and Social Sciences (RJ)

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<td>Mind the Risk</td>
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### The Swedish Heart and Lung Foundation

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<td>Self-perceived risk for cardiovascular diseases and preferences for risk information</td>
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### The Swedish Childhood Cancer Foundation

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<td>PretendPlay</td>
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### AFA Insurance

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<tr>
<td>Ethical competence in health care management</td>
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### The Swedish Agency for Health and Care Services Analysis (Vårdanalys)

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<th>Project</th>
<th>Funding</th>
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<tr>
<td>Informational privacy in health care and research</td>
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<td><strong>TOTAL EXTERNAL FUNDING</strong></td>
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<td><strong>TOTAL BASIC FUNDING</strong></td>
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Research projects

Ongoing research

In 2016, we launched a five year Innovative Medicines Initiative funded public-private partnership PREFER with 33 partners from academia, health technology assessment, patient organisations and the pharmaceutical industry. 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).

- BBMRI.se: Biboanking and molecular resource infrastructure of Sweden
- BBMRI-ERIC: Biboanking and BioMolecular resources research infrastructure
- BBMRI-LPC. Large prospective cohorts
- Be The Cure: (BT Cure) for Rheumatoid Arthritis
- B3Africa: Bridging Biobanking and Biomedical Research across Europe and Africa
- CHIP ME (Citizen health through public private initiatives)
- Euro-TEAM: Towards Early diagnosis and biomarker validation in Arthritis Management
- Health inequality: advancing measurement, explanation, and policy process
- Human Brain Project
- Human embryonic stem cell treatment of diabetes
- Mind the Risk: Managing genetic risk information
- Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER)
- Pretend play
- Publication ethics
- Quality of life assessments in clinical practice
- RD-Connect
- Research regulation
- Self-management of hypertension (Developing and evaluating an interactive mobile phone system to support self-management of hypertension)

PhD projects

The PhD students at CRB have come from a variety of backgrounds: Medicine, nursing, public health, 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.

- Cardiovascular risk communication in primary care
- The neuroscience of disorders of consciousness: from laboratory to clinic
- DNR decisions within oncology and hematology care. Clinical and ethical perspectives
- Ethical and public health considerations of conventional and peptide-based antibiotics
- Ethical issues in preconception genetic screening
- How should incidental findings in biobank research and genome sequencing studies be handled?
- Self-perceived risk for cardiovascular diseases and preferences for risk information
- The value of patient preferences in drug development for rheumatoid arthritis
- What is it like to be unconscious? Perspectives from Philosophy and Neuroscience with special regards to Resignation Syndrome
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 public as well as for groups of patients with prolonged illness:

- 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 cannot 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 strive to produce knowledge that can benefit patients

CRB’s role in BBMRIse - 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 experts cover national laws. 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
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, LLD 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 organisations.

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 Johansson, 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 Mascalzoni, PhD Bioethics, Senior researcher
Jennifer Viberg Johansson, PhD student

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 Universitet, and International Agency for Research on Cancer, International Live Stock Research Institute, Medizinische Universitat Graz and the Institute of Human Virology Nigeria.

CRB’s Role in B3Africa: Work package 1, led by Jane Reichel, and 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 Mascalzoni, 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 Mascalzoni**, 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:
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).

**Human embryonic stem cell treatment of diabetes**

*This project is a collaboration between CRB, the Faculty of Law and the Department of Immunology, Genetics and Pathology at Uppsala University. The project is funded by the Swedish Research Council and runs between 2017-2019.*

**Background:** Type 1 diabetes is treated with daily insulin injections or with insulin pump. An alternative treatment is to transplant new insulin-producing cells derived from human embryonic stem cells. Transplanted devices detect blood sugar levels and regulate the secretion of insulin.

Making such a treatment available for patients presupposes commercialization. This project investigates the ethical and legal framework for commercializing human embryonic stem cell treatment of diabetes. We will study issues of embryo donation, informed consent and patentability, but also philosophical questions about how to view embryos, stem cells, and products derived from human embryonic stem cells.

**Aim:** The project aim is to provide ethical and legal analysis and guidance concerning development of commercial beta-cell replacement products for type 1 diabetes, using cells derived from human embryonic stem cells.

**Participants:**

- **Mats G. Hansson**, Professor of Biomedical Ethics
- **Olle Korsgren**, Professor of Transplantation Immunology
- **Anna-Sara Lind**, Associate Professor of Public Law
- **Bengt Domeij**, Professor of Private Law
- **Jessica Nihlén Fahlquist**, Deputy Senior Lecturer in Medical Ethics
- **Pär Segerdahl**, Associate Professor of Philosophy
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.

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**, Professor of Biomedical Ethics
- **Heidi Carmen Howard**, PhD, Senior Researcher
- **Ulrik Kihlbom**, Senior lecturer & Associate professor in medical ethics
- **Sofia Lavén**, MD, PhD student
- **Jessica Nihlén Fahlquist**, Deputy Senior lecturer
- **Jennifer Viberg Johansson**, BSc, MA
Other partners:
- 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
- Sophiahemmet University College
- Karolinska Institutet

Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER)

PREFER is a five year, public-private research initiative under the Innovative Medicines Initiative. The project is coordinated by Uppsala University (Mats G. Hansson).

PREFER will establish recommendations to support development of guidelines for industry, Regulatory Authorities and HTA bodies on how and when to include patient perspectives on benefits and risks of medicinal products.

Over the next five years, PREFER will run patient preference studies in both academic and industry settings. The experience will provide a better understanding of what will be a recommended best-practice approach to patient-preference studies. PREFER will also show how patient preference studies can give valuable information to support decision making for regulators and HTA bodies.

CRB people in PREFER:
Mats G. Hansson, Professor of Biomedical Ethics
Jorien Veldwijk, PhD, Researcher
Ulrik Kihlbom, Associate Professor of Medical Ethics
Elisabeth Furberg, PhD, Researcher
Karin Schölin-Bywall, MSc, PhD Student
Josepine Fernow, BA, Coordinator

PREFER has 33 partners. The consortium is co-ordinated by Uppsala University, and managed together with Novartis that acts as project leader.

Academic institutions
- Uppsala University (Co-ordinator)
- Erasmus MC - University Medical Centre (EMC)
- Erasmus University Rotterdam
- European Institute of Oncology
- National Cancer Research Center G Paolo II, Bari
- University Medical Centre Utrecht
- University of Birmingham
- University of Erlangen
- University of Leuven
- University of Newcastle upon Tyne

Patient organisations
- European Cancer Patients Coalition (ECPC)
- European Patient Forum (EPF)
- International Alliance of Patients’ Organizations (IAPO)
- Muscular Dystrophy UK (MDUK)
Pretend play

This is a continuation of a pilot project funded by The Swedish Childhood Cancer Foundation (Barn cancerfonden).

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 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
**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

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**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:**
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.

Hanns Lochmüller at Newcastle University coordinates RD-Connect. Mats Hansson leads the ELSI work package 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 organisations 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 for other disease areas and for the development of personalised medicine.

Contact at CRB:

Mats G. Hansson, Professor of Biomedical Ethics
Deborah Mascalzoni, PhD Bioethics, Researcher
Jennifer Viberg Johansson, BSc, MA, PhD Student
Research regulation

Difficulties in regulation are an interesting study object, not only for researchers, but also for legislators, professional organisations and society. 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. In addition, 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

*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

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**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 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 everyday 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 form 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

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.

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

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 organisations, 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:
• **Anal Matter**, MD, MSc

Supervisors:
• **Anna T. Höglund**, Associate Professor of Ethics
• **Mats G. Hansson**, Professor of Biomedical 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 incidental 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.

PhD Student:
• **Jennifer Viberg Johansson**, BSc, MA

Supervisors:
• **Mats G. Hansson**, Professor of Biomedical Ethics
• **Pär Segerdahl**, Associate Professor of Philosophy
• **Sophie Langensköld**, Senior Researcher, Department of Public Health and Caring Sciences, Uppsala University

**Self-perceived risk for cardiovascular diseases and preferences for risk information**

*The PhD project is funded by the Swedish Heart and Lung Fondation’s SCAPIS project.*

To be successful in preventing and treating chronic diseases it is necessary to mobilize the individual. Understanding personal risk can be a good place to start that process. However, individuals can have difficulties in understanding their personal risk and risk information can provoke negative emotions in the individual.

This PhD project will investigate different perspectives of risk perception regarding heart disease using a multimethod approach that includes empirical methods such as survey, focus groups interviewing and discrete choice experiments. It also includes a theoretical study discussing ethical perspectives on cardiovascular risk perception and risk information using critical argumentation.

The target group will be individuals participating in the Swedish Cardiopulmonary BioImage Study (SCAPIS) http://scapis.se/om-scapis/. These participants are men and woman between 50-64 years of age randomly selected from the Swedish population. In SCAPIS, the participants go through thorough health examinations that among other things include new imaging technologies. After their participation, all participants receive a report that consists results from some of the examinations.

**Background:** Cardiovascular diseases, or CVD, has sometimes been described as abstract concepts: They are caused by multiple factors. They also develop over long periods. To be effective in
preventing chronic diseases, practice shared decision-making, or in preference studies, it is important to understand personal risk.

Diseases of heart and vessels, (for example heart attack, heart failure and stroke), are the number one cause of death globally and are to great extent caused by factors people are able to influence and modify themselves. Mortality rates for heart disease between socioeconomic groups. This means that prevention is of great importance for achieving health equality.

PhD student:
- Åsa Grauman, MA

Supervisors
- Mats G. Hansson, Professor of Biomedical Ethics
- Jorien Veldwijk, PhD Risk Economics
- Stefan James, MD, Professor of Cardiology, Department of Medical Sciences, Uppsala University & Uppsala Clinical Research Center

The value of patient preferences in drug development for rheumatoid arthritis

This PhD project is part of the public-private partnership The Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) funded by the Innovative Medicines Initiative (IMI).

The primary reason of all drugs is to benefit the patients. To be licensed, benefits must be shown to be greater than the risks. The evaluation of this balance relies on regulatory process.

This PhD project will look at how rheumatoid arthritis patient preferences can provide added value in regulatory decision making in the drug development process.

The project is entitled "The value of patient preferences in drug development for rheumatoid arthritis". It is part of PREFER, a public-private partnership funded by the Innovative Medicines Initiative.

Background
Drugs are designed to benefit patients. To get a drug approved, regulators assess the drug with regard to effectiveness, quality and safety. There is an increasing demand to include patient’s preferences in this regulatory process. However, there is still a need for knowledge on how and to what extent patient preferences can be used and add value to the regulatory process.

The project focus on patients with Rheumatoid Arthritis (RA). These patients suffer from a chronic inflammatory disease characterized by tenderness, swelling and joint damage. This can led to disability and premature death. There are different treatment options with different risks and benefits. Which is one of the reasons RA patients make an interesting case for preference studies. If patients received treatment in line with their preferences, they will most likely be more satisfied and compliant in taking their medication.

About the PREFER project: PREFER looks at how and when it is best to perform and include patient-preference in decision making during the drug life cycle. We include patient stakeholders at every level of the project. The result will be recommendations to support development of guidelines for industry, Regulatory Authorities and HTA bodies.

PhD student:
- Karin Schölin Bywall, MA, PhD student

Supervisors
- Ulrik Kihlbom, Associate Professor of Medical Ethics, Senior Lecturer
- Jorien Veldwijk, PhD Risk Economics
• Mats G Hansson, Professor of Biomedical Ethics

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, philosophically challenging issues remain, especially with respect to accounting for the first-person perspective or the \textit{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, concerning 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.

\textbf{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 \textit{understanding} and \textit{explanation} in scientific theories in particular in the setting of contemporary neuroscience
- Explore the problem of \textit{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

\textit{PhD Student:}
- Karl Sallin, MD

\textit{Supervisors:}
- Kathinka Evers, Professor of Philosophy
- Predrag Petrovic, Psychiatrist, Associate Professor, Karolinska Institutet

\textit{Mentor:}
- Hugo Lagercrantz, Senior Professor, Karolinska Institutet
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 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 a 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.
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.

Patient preferences in drug development

Since October 2016, we are coordinating a five-year public-private partnership with 33 partners form Europe and the US. Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) has 33 partners from European academic institutions, patient organisations and one health technology assessment body (HTA), working together with partners from European and US pharmaceutical companies. Within the project, we also have stakeholder advisory groups for US and European regulatory authorities, European and Canadian HTA bodies, and European patient organisations. The consortium is co-ordinated by Uppsala University, and managed together with Novartis that acts as project leader.

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. Students participate in seminars where they discuss clinical and ethical dilemmas. Examination is in form of written assignments and mandatory seminars.

**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 neuro-degenerative 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 elective part of the master programme in public health and open to student’s advanced level students. The course 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.

Medicine and Pharmacy
This course deals with the norms of science and ethical norms in theory and practice, scientific publication, fraud in scientific research, 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 (2 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 elective courses for the faculty. From 2016, PhD students in psychology is offered a course. 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.

The course was offered in 2015 and 2016. The fee was 1.125 Euros. We offered two training scholarships for students from low and middle income countries. We continue work to see if we can find collaborating partners to make this kind of training available also in the future.

**Conferences and workshops**

During 2016, we organised a workshop on ethically sustainable partnership between industry and public funded research initiatives using rare diseases as a case study. The workshop was held in Uppsala on November 7-8 2016. It was arranged by CRB together with RD-connect and the CHIP ME Cost-Action network. The workshop had 40 registered participants, mostly from European countries.

**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).

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. We run two WordPress blogs on separate subdomains, www.ethicsblog.crb.uu.se and www.etikbloggen.crb.uu.se. The CRB website was completely re-designed and re-structured in 2015 and a new website was launched in February 2016.

Comparing traffic on the website between 2016 and previous years is misleading as we also changed from AWSTATS to Google Analytics when the new website was launched. For this reason, the statistics below are reported for the period 1 March 2016-28 February 2017. This also means a decrease in traffic as we removed some pages and were unable setting redirects from all old pages to the new website.

During this period, the CRB website had 12,276 users, 17,813 sessions and a total of 45,989 page views (an average of 2.58 pages per session). The bounce rate as 55.63 % and we had 31.4 % returning visitors.

**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 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.

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)

The Ethics Blog had 5,925 users in 2016, with 9,017 page views. The most popular post was where to publish and not to publish in bioethics, listing predatory journals in this field (3,115 page views) followed by a post on the Volkswagen scandal (287) and one on resignation syndrome in refugee children (137).

Etikbloggen (Swedish)

In 2016, Etikbloggen had 5,272 users, with 8,012 page views. Most of the users came from different search engines, followed by Facebook and the CRB website. The most viewed post was entitled “About the fear of genetically modified organisms” (Om rädslan för genmodifierade organismer) with 1,300 views (compared to other popular posts with around 200 views each).

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. In the wake of the Macchiarini scandal at Karolinska Institutet, Mats G. Hansson wrote criticized, the current ethics review legislation in the Dagens Medicin journal (En ny etikprövningslag behövs). Ulrik Kihlbom and Stefan Eriksson signed two debate articles in the Svenska Dagbladet newspaper (Ansvar för läggas även på forskningsledaren & Efter skandalen: “Gråzoner ett sätt att blanda bort korten”).

In his role as an expert on research ethics, Stefan Eriksson was interviewed in ERGO (Uppsala University’s student union magazine). In connection with Santa Slokenberga’s PhD thesis defense, she and Jane Reichel participated in Swedish Public Service radio’s programme 1 show “Vetandets värld” on genetics and gene ethics.

Media coverage

We have not done many press-activities in 2016. A global and a Swedish press release was sent in October to mark the launch of the PREFER project. This was covered by MedicalXpress, SciFeeds,
and ETHealthworld.com, Mats Hansson was interviewed by Pan European Networks (20-Oct-16) and Horizon 2020 Projects.

**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 four issues.

**Issue 1, 2016**

In this issue, Jane Reichel gave her view on how the EU-US Privacy Shield will ensure safe harbours for data transfer in the future. We also reported 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.

We also wrote about challenges to informed consent posed by rare disease research and how RD-Connect researchers proposes to meet them. Finally, on behalf of the CHIPme COST Action network, we invited readers to a workshop on genetic data in public research databases in Bolzano in spring 2016.

**Issue 2, 2016**

In this issue, Anna-Sara Lind gave an update on what the results of the negotiations for a general data protection regulation in the European Union. We also wrote about two papers: One that compares the risks associated with handling personal data in research to the benefits in terms of patient safety if individuals can be identified. The second suggesting that it is not (yet) feasible for European research to give feedback of individual results. One reason is the lack of legal frameworks, guidelines and resources to support the feedback process. We also wrote about the BBMRI-ERIC call for ELSI experts and find out how to choose good bioethics journals.

**Issue 3, 2016**

In this issue, Moa Kindström Dahlin described what BBMRI-ERIC’s new federated Helpdesk for ELSI-issues can offer. Anna-Sara Lind gave her view on the consequences for Sweden. We also announced that the guidelines for informed consent in collaborative rare disease research have received the IRDiRC Recognized Resources label and invited readers to the public-private partnerships workshop in Uppsala the coming November.

**Issue 4, 2016**

In this issue of Biobank Perspectives, we wrote about the legal aspects of direct-to-consumer genetic testing. Santa Slokenberga described her doctoral dissertation in law from Uppsala University and how the Council of Europe and the EU interact with each other and the legal systems in the member states. We followed up from the previous issue where Anna-Sara Lind reported on the General Data Protection Regulation in a Swedish perspective, and gave readers more information about the Swedish Research Data Inquiry. We also announced that a group of researchers from the University of Oxford, University of Iceland, University of Oslo and CRB at Uppsala University received a Nordforsk grant to find solutions for governance of the ‘health cyberspace’ that is emerging from assembling and using existing data for new purposes.
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 primarily 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.

Like the CRB website, the statistics for CODEX are not comparable to that of previous years. The site was moved to a new server that does not support Awstats, which means the total number of users/visitors in 2016 cannot be calculated. However, the trend is that the number of visitors has increased also this year. The weekly record from previous years was exceeded 7 times during 2016 (compared to once in 2015). This trend became very clear towards the end of the year. In 2015. The record for weekly visitor rate in 2015 was 4,435. In 2016, this was the week of 5-11 December when the site had 4,672 visits.
Clinical Nutrition and Metabolism (CNM)

Research Group Leader Professor Tommy Cederholm
The CNM research group works along two major lines:

1) Preventive nutrition and metabolism related to fatty acids and insulin-glucose interactions with public health, cardiovascular prevention, diabetes and obesity. Metabolic intervention trials are performed for elucidating effects on insulin sensitivity, body composition and cardiovascular risk factors. Accordingly, local and national cohorts are utilized as well as large international cohorts in extensive collaborations to analyse fatty acid relationships to body composition, metabolic syndrome, insulin sensitivity and CVD risks. Associate professor Ulf Riserus is deputy head of the CNM research group and leading the preventive nutrition and fatty acid and insulin-glucose research pathway. Ulf Riserus is board member of the Department of Public Health and Caring Sciences. CNM is by tradition a world leader on fatty acid metabolism and its role in health and disease, dating back to former professor and head Bengt Vessby, who is still active in the group. This tradition is now continued by associate professor Ulf Riserus and his research team, including senior researchers Matti Marklund, Fredrik Rosqvist and David Iggman.

2) Clinical disease- and age-related nutrition with a focus on catabolism, undernutrition and sarcopenia. Various cohorts are used to describe development of sarcopenia, i.e. loss of muscle mass and function, in older populations. Intervention trials are performed to elucidate exercise and nutrition effects for prevention and treatment of sarcopenia, and experimental studies are performed to understand genetic and biologic mechanisms. Professor Tommy Cederholm is head of the CNM research group and also responsible for the disease- and age-related nutrition pathway. Tommy Cederholm is linked to the Department of Geriatrics (MD, Senior consultant) at the hospital and thus also linked to the ALF financial system. During the last 10-12 years Professor Tommy Cederholm has developed a world-leading research line focused on 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. Another significant research line is omega-3 fatty acid treatment of Alzheimer’s disease in collaboration with Karolinska Institutet.

Moreover, CNM performs research a) on food intake and dietary patterns relation to various health outcomes mainly in elderly people from various population cohorts, led by associate professor Per Sjögren, b) related to obesity in adult populations (post-bariatric surgery effects) as well as in children (body composition and energy metabolism), led by researcher Ulf Holmbäck; and c) on effects of tailored training programs in post-stroke patients, led by researcher Birgit Vahlberg.

CNM has two laboratories, one that analyzes FA profiles in various tissues by gas-chromatography technique, and one that estimates body composition and energy metabolism by air-displacement, bioelectrical impedance and indirect calorimetry.

Research vision and strategies for CNM:
The CNM vision is to produce high-quality research that will
• increase the general understanding of the crucial role for nutrition in public health, ageing and clinical health care.
• influence and be part of recommendations and guidelines for the improvement of public health and clinical medicine on a global level.

The CNM strategy is to facilitate the fulfilment of our maximal potential by
• further developing global as well as national and local collaborations
• making successful grant applications, and by
• recruiting top researchers and promising PhD students.
**Plans for the future promising research at CNM**

- Fatty acid effects on gene expression, insulin sensitivity, inflammation, endothelial cell function and body composition, including lean body mass and fat distribution (ectopic fat accumulation)
- Nutritional impact on metabolomics
- Cardiometabolic, transcriptomic and epigenetic effects of a healthy Nordic diet
- Evaluation of sagittal abdominal diameter as a valuable anthropometric risk marker
- Understanding sarcopenia from clinical, epidemiological, nutritional and molecular perspectives, and its treatment
- Dietary patterns and potential effects on development of sarcopenia and frailty
- The potentially beneficial effects of combining protein supplementation with exercise and resistance training on function in various older populations, with respect of muscle cell morphology, myofibrillar gene expression patterns
- Implementation techniques of nutritional routines and development of assessment tools for meals in elderly care
- Omega-3 fatty acid effects on epigenetic markers, mononuclear blood cell gene expression and effects on inflammation resolution
- Potential Vitamin D relations with health outcomes like cognition and sarcopenia in old adults
- Individualized treatment of child obesity

In 5-10 years CNM is envisioned as a national knowledge hub for the development and production of top international research in the fields of fatty acid metabolism, glucose-insulin interactions, food pattern effects on longevity, sarcopenia and independent aging, and catabolic mechanisms for ageing and disease with a focus on undernutrition and sarcopenia.

**Leadership and academic culture**

The KOF17 internet leadership evaluation gave CNM a score of 80/100 (to compare with 68/100 overall at the department (IFV)). Open doors and transparency are key words for the leadership strategy at CNM. A good academic culture is a mainstay for high scientific throughput. In the KOF17 evaluation gave CNM a score Organization of 86/100, compared to 76/100 for IFV on a whole. Working climate scored 76/100 at CNM compared 73/100 on the whole.

To keep the academic culture at a high level CNM regularly organizes journal clubs (once a month) and internal monthly research seminars. Informal discussions at coffee breaks are also crucial for the academic culture. We encourage the collaborators to be present at the office in order to contribute to the academic atmosphere. Every 6th week a CNM-leadership meeting is organized for all researchers, incl. PhD students, teachers and staff at CNM (presently 17 are on the list, 7-10 usually shows up). For example, at the meeting everyone gives a 1-3 minute report on their latest achievements. Moreover, we do general research courses for example on fatty acid metabolism.

CNM considers working place atmosphere, IT-support, economy administrative support and statistical support as the crucial infrastructure measures to assure high quality and renewal. For IT-support CNM prioritizes excellence and we collaborate with a private support company (XITE) since about 15 years. From XITE we receive instant high-quality support upon telephone or e-mail contact.

**Recruitment strategies**

CNM is continuously looking for motivated, talented and well-educated persons who can enter our group either as a master student, PhD, or postdoc in many different ways, e.g. through internet, conferences/meetings, but especially when teaching and directly meeting students during lectures at under- and graduate programs. CNM is receiving a large number of national and international
requests from students that are always considered and reviewed. Sometimes when the review is positive and the CV is adequate we give them a chance to show their motivation and skills, and perform and do research as long as there is time and finance available.

Members of the group 2016

<table>
<thead>
<tr>
<th>Employment at CNM</th>
<th>Major funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tommy Cederholm Professor, Head</td>
<td>100%</td>
</tr>
<tr>
<td>Ulf Riserus Docent, Deputy</td>
<td>100%</td>
</tr>
<tr>
<td>Per Sjögren Docent</td>
<td>100%</td>
</tr>
<tr>
<td>Ulf Holmberg Researcher</td>
<td>5-10%</td>
</tr>
<tr>
<td>Anja Saletti Teacher</td>
<td>50%</td>
</tr>
<tr>
<td>Matti Marklund Postdoc</td>
<td>100%</td>
</tr>
<tr>
<td>Fredrik Rosqvist Postdoc</td>
<td>100%</td>
</tr>
<tr>
<td>Johanna Tömör PhD student</td>
<td>100%</td>
</tr>
<tr>
<td>Åsa von Berens PhD student</td>
<td>80%</td>
</tr>
<tr>
<td>Sigvard Sobestiansky PhD student</td>
<td>50%</td>
</tr>
<tr>
<td>Elisabeth Skoglund PhD student</td>
<td>50%</td>
</tr>
<tr>
<td>Zayed Alsharari PhD student</td>
<td>100%</td>
</tr>
<tr>
<td>Mikael Karlsson PhD student</td>
<td>50%</td>
</tr>
<tr>
<td>Lillemor Källström BMA</td>
<td>50%</td>
</tr>
<tr>
<td>Siv Tengblad BMA</td>
<td>100%</td>
</tr>
<tr>
<td>Mia Berglund FOGass</td>
<td>100%</td>
</tr>
<tr>
<td>Roger Olsson Teacher</td>
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</tr>
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</table>

Associated to CNM

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<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Birgit Vahlberg Postdoc</td>
<td>Neuroscience, UU/AS</td>
<td></td>
</tr>
<tr>
<td>Erika Ax Postdoc</td>
<td>FORMAS</td>
<td></td>
</tr>
<tr>
<td>Bengt Vessby Prof em</td>
<td></td>
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<tr>
<td>Brita Karlström Prof em</td>
<td></td>
<td></td>
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<tr>
<td>Wulf Becker Prof em</td>
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<tr>
<td>Viola Adamsson Postdoc</td>
<td></td>
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</tr>
<tr>
<td>Annika Smedman Postdoc</td>
<td>Svensk Mjölk</td>
<td></td>
</tr>
<tr>
<td>Elisabet Rytter Postdoc</td>
<td>Livsmedelsindustrin Li</td>
<td></td>
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<tr>
<td>Afsaneh Koochek Postdoc</td>
<td>Nestle</td>
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<tr>
<td>Erika Olsson Researcher</td>
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</table>

Collaborations, national and international outreach

CNM has close collaboration with several prominent groups to ensure a scientific network with access to the best methodology and equipment needed for our research. Within Uppsala University CNM collaborates via the ICTUS network with a focus on the Uppsala Longitudinal Study on Adult Men (ULSAM). Nationally, CNM collaborates with research groups at Karolinska Institutet, Lund University and Gothenburg University.

Deputy head Ulf Riserus is co-PI of a national strategic research area (SFO) called EXODIAB (Excellence of Diabetes Research in Sweden), as well as the deputy chair of a Nordic Centre of excellence in Systems Biology in Dietary interventions in and cohort studies (SYSDIET), and also the president of the Diabetes and Nutrition Study Group (DNSG), a European study group of the European Association for the Study of Diabetes (EASD). Furthermore we have close collaboration with Oxford University, Tufts and Harvard in Boston (the FORCE consortium in fatty acid research)
as well as with University of Eastern Finland (SYSDIET). Since 2013 CNM has in collaboration with the University of Tabuk, Saudi Arabia a registered PhD student working in Uppsala.

Head Professor Tommy Cederholm has a wide international network with collaboration with stakeholders in the field of undernutrition, sarcopenia and frailty. The VIVE2 Study is performed in close collaboration with Tufts University, Boston. Tommy Cederholm is the co-supervisor of one PhD student in Stellenbosch, South Africa, and also co-supervisor for one PhD-student at The Amsterdam University.

Tommy Cederholm was up to 2016 for four years the treasurer of the European Society for Clinical Nutrition and Metabolism (ESPEN). He is one (representing ESPEN) of two facilitators of a global process aiming at creating a global consensus on diagnostic criteria for malnutrition. Ass professor Per Sjögren recently supervised a master student from India.

Much of the research data coming out of CNM activities are of high public interest. The researchers at CNM are encouraged to communicate with journalists. The media visibility of the research produced by CNM is high. Recently, Tommy Cederholm was the editor of a national medical textbook on food and health; i.e. “Mat och hälsa – en klinisk handbook” (“Food and health – a clinical handbook”) (Studentlitteratur 2015) with many (6 out of 25) of the contributing authors coming from CNM.

CNM has contributed to produce a popular cook-book on Healthy Nordic Diet (Forma AB 2014) that had a wide national spread, and was 2015 awarded as the best cook book in the world on regional foods at Gourmand Cook Book Award Ceremony in Paris, France.

Tommy Cederholm/CNM is contributing to public seminars on nutritional issues arranged by the National Committee of Nutrition and Food Science at the Royal Swedish Academy of Science. As a fellow of the Royal Swedish Academy of Forestry and Agriculture, Tommy Cederholm/CNM contributes to the dissemination of nutrition knowledge through outreach seminars organized 2-3 times per semester.

Several of the researchers at CNM (e.g. ass prof Per Sjögren) are active in The Network in Epidemiology and Nutrition (NEON) that is a Swedish national network for scientists and practitioners with an interest in nutritional epidemiology.

**Publications 2014-2016**

**Publications/bibliometry**

The CNM research group has co-authored more than 400 papers in peer-reveiwed journals during 2007-2016, i.e. an average of >40 papers per year, with an increasing trend over the last years.

With an annual turnover at CNM of <800.000 Euros (~7.000.000 SEK) the average cost of a scientific publication could be estimated (10x750.000/400) at 18,500 Euros/paper (180.000 SEK), i.e. highly cost-effective.

The average journal impact factor is estimated at 3-4; i.e. a vast majority of our research is published in the top journals of our fields (epidemiology, diabetes, metabolism, nutrition, geriatrics).

Ten PhD theses and one Licentiate thesis has been produced by CNM since 2007. Five theses are expected to be finalized within the next four years. Ulf Riserus and Tommy Cederholm have been co-supervisors for several PhD students outside CNM over the last 10 years.

Deputy group leader Ulf Riserus has according to Web of Science (WoS) 193 papers, >4600 citations and h-index of 37; whereas group leader Tommy Cederholm has (WoS) 218 papers, >8600 citations and h-index of 45. Corresponding figures from SCOPUS are for Ulf Riserus: 160 documents, 6520 citations and h-index 41, and for Tommy Cederholm: 230 documents, 11370 citations and h-index 50.
Up-coming senior researchers currently active at CNM, i.e. Per Sjögren, Ulf Holmbäck, Matti Marklund, Fredrik Rosqvist, Birgit Vahlberg and Afsan Koochek have together >2500 citations and h-indices ranging from 2 to 18.

**2014**


**2015**


60. Petrus P, Rosqvist F, Edholm D, Mejhert N, Arner P, Dahlman I, Rydén I, Sundbom M, Riséru U. *Saturated fatty acids in human visceral adipose tissue are associated with*


2016


115. Tylner S, Cederholm T, Faxén-Irving G. Effects on weight, blood lipids, serum fatty acid profile and coagulation by an energy dense formula to older care residents – a randomized controlled cross over trial. *J Am Med Dir Assoc* 2016;17(3):275.e5-11


Agencies that support the work/Funding (SEK)

Funding

The annual turnover at CNM that is administered by IFV is around 7 million SEK. Below, the income structure is briefly described:

A. University: 1) Clinical Nutrition and Metabolism has one of five chairs/full professorships at the department. CNM receives about 500,000 SEK of what the university provides IFV for the chair position (the rest is shared between the heads of the other research groups).

2) “Keyed funds” that are allocated in relation to scientific production is the other source of university funding. Since CNM receives money from the County Council funding system (ALF) CNM allocation is subdued to 27% of the “keyed” activity-related money, usually corresponding to about 200,000 SEK/year.

3) Teaching: Many/most of the researchers at CNM are involved in graduate education at the university; Nurses, physicians and physiotherapists programs are some. Altogether these activities generate salaries of around 3-400,000 SEK.

B. Laboratory services: The two laboratories run by CNM (focusing fatty acid analyses, and energy metabolism and body composition measurements) serve many external research groups and are also performing analyses for clinical use. Depending on the level of collaboration we invoice those that use our facilities and altogether we have revenues equivalent to 1-1.200,000 SEK.

C. County Council - ALF: CNM shares ALF connection with the Geriatric Research group. The combined “ALF-group” generates activity related research funding from the County Council. For research, after rent and teaching expenses are excluded, 5-6 million SEK is divided among the researchers at CNM and Geriatrics. The recent years CNM has received around 1 million SEK annually, i.e. ~20% of the total allocated sum from the City Council.

D. Public Research Council Funding: E.g. Swedish Research Council (VR), FORTE and FORMAS.

a. For the Preventive nutrition and metabolism related research led by ass professor Ulf Riserus the vast majority is from public funding from the research councils. CNM has also received
relevant funding from Swedish Diabetes Association and Heart and Lung foundation, and EXODIAB (see below). Funding also comes from AstraZeneca which supports clinical and exploratory research projects in collaboration with SciLifeLab: Ulf Riserus is the PI of one project and in the steering committee of the whole AstraSciLifeLab-project. The strategy is to apply from research councils and foundations, but we also plan to apply from other funding bodies such as EU calls “Food 2030” and “obesity Horizon 2020”, NIH and other international funding bodies, mostly together with other international research groups.

b. The Clinical disease and age-related nutrition research led by professor Tommy Cederholm regularly receives funding from The Swedish Research Council (VR). CNM also collaborates with many of the larger medical nutrition companies, like Nutricia and Nestle. CNM has recently received quite substantial unconditional research funding for two major research initiatives, i.e. PROVIDE and VIVE2. One of our PhD students is fully funded from his mother university in Saudi Arabia.

**External funding CNM 2016:**

<table>
<thead>
<tr>
<th>Funding Source</th>
<th>Amount</th>
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<tbody>
<tr>
<td>The Swedish Research Council (VR)</td>
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<tr>
<td>FAS/FORTE (Ulf R)</td>
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<tr>
<td>EXODIAB strategic research grant</td>
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<tr>
<td>Dr P Håkansson’s foundation</td>
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<td>Regional Research Council</td>
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<td>National Food Agency</td>
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<td>Sirela Sweden AB</td>
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<tr>
<td>Arla Foods AB</td>
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<tr>
<td>University of Tabuk, Saudi Arabia</td>
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<tr>
<td>Throne Holst Foundation</td>
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<tr>
<td>Thureus</td>
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<td>Swe Nutr Foundation</td>
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<tr>
<td>Astra Zeneca (UR)</td>
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</tbody>
</table>

**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 pattern effects on development of cognitive impairment and prostate cancer
- 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, endothelial cell function and body fat distribution (ectopic fat accumulation)
- Impact of structural membranes for health effects by milk products
- Nutritional impact on metabolomics
- Cardiometabolic, transcriptomic and epigenetic effects of a healthy Nordic diet
- Evaluation of sagittal abdominal diameter as a valuable anthropometric risk marker
- Individualized treatment of child obesity
Clinical Psychology in Healthcare

Research Group Leader professor Louise von Essen

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, therapeutic assignments, 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 Caring Sciences, Economics, Implementation Sciences, Information Systems, and Psychology. The group consists of many young and talented scientists and is highly interactive with the surrounding society.

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 Caring Sciences, Economics, Implementation Sciences, Information Systems, and Psychology.

Members of the group 2016

Members of group

<table>
<thead>
<tr>
<th>Name</th>
<th>Academic title/s</th>
<th>Department/University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Louise von Essen</td>
<td>Professor, Research Group Leader, Program director for U-CARE</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Lena Ring</td>
<td>Associate professor, PhD</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Maria Andér Gottvall</td>
<td>PhD, Registered Nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Red Cross University College</td>
</tr>
<tr>
<td>Erebouni Arakelian</td>
<td>PhD, Registered Nurse</td>
<td>Department of Public Health and Caring Sciences and Department of Surgical Sciences, Uppsala University</td>
</tr>
<tr>
<td>Martin Cernvall</td>
<td>PhD, MSc in Psychology, Licensed Psychologist. Postdoc researcher.</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Helena Grönqvist</td>
<td>PhD, MSc in Cognitive Sciences. Research coordinator for U-CARE</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Claes Held</td>
<td>Associate professor, PhD, MD</td>
<td>Uppsala Clinical Research Centre, Uppsala University</td>
</tr>
<tr>
<td>Emma Hovén</td>
<td>PhD, MSc in Behavioral Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Karolinska Institutet</td>
</tr>
<tr>
<td>Name</td>
<td>Position and Qualifications</td>
<td>Department and Institution</td>
</tr>
<tr>
<td>-------------------------------</td>
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<td>------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Birgitta Johansson</td>
<td>Associate professor, PhD, Registered Nurse</td>
<td>Department of Public Health and Caring Sciences and Department of Immunology, Genetics, and Pathology, Uppsala University</td>
</tr>
<tr>
<td>Annika Lindahl Norberg</td>
<td>Associate professor, PhD, MSc in Psychology, Licensed Psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Karolinska Institut</td>
</tr>
<tr>
<td>Elisabet Mattsson</td>
<td>Associate professor, PhD, Registered Nurse, Registered Midwife</td>
<td>Department of Public Health and Caring Sciences and Department of Women’s and Children’s Health, Uppsala University and Akademiska Sjukhuset Uppsala</td>
</tr>
<tr>
<td>Gunilla Mårtensson</td>
<td>Associate professor, PhD, Registered Nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Erik Olsson</td>
<td>Associate professor, PhD, MSc in Psychology, Licensed Psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Jonas Sjöström</td>
<td>PhD, MSc in Information Systems</td>
<td>Department of Public Health and Caring Sciences and Department of Informatics and Media, Campus Gotland, Uppsala University</td>
</tr>
<tr>
<td>Anna Wikman</td>
<td>Associate professor, PhD, MSc in Health Psychology, MSc in Research Methods in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Sven Alfonsson</td>
<td>PhD, MSc in Psychology, Licensed Psychologist. (Examination 2016)</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Malin Ander</td>
<td>MSc in Psychology, Licensed Psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Anders Brantnell</td>
<td>MSc in Political Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Tommy Carlsson</td>
<td>Registered Nurse, Registered Critical Care Nurse, Registered Midwife, MSc in Caring Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Mudassir Imran Mustafa</td>
<td>MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Laura Kukkola</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Lisa Ljungman</td>
<td>MSc in Psychology, Licensed Psychologist. (Examination 2016)</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Ruth Lochan</td>
<td>MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Susanne Mattsson</td>
<td>Registered Nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Hafijur Mohammad Rahman</td>
<td>MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Anna Norén</td>
<td>MSc in Economics</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Fredrika Norlund</td>
<td>MSc in Psychology, Licensed Psychologist, Licensed Psychotherapist. Director for U-CARE Healthcare</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Teolinda Toft</td>
<td>BSc in Social Work</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>John Wallert</td>
<td>MSc in Psychology, Licensed Psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Emma Wallin</td>
<td>MSc in Psychology, Licensed Psychologist</td>
<td>Department of Psychology, Uppsala University</td>
</tr>
<tr>
<td>Name</td>
<td>Academic title/s</td>
<td>Department/University</td>
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</tr>
<tr>
<td>Mattias Öhman</td>
<td>MSc in Economics. (Examination 2016)</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Fabian Holmberg</td>
<td>BSc in Computer Sciences</td>
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</tr>
<tr>
<td>Ian Horne</td>
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</tr>
<tr>
<td>Ylva Hägg Sylvén</td>
<td>MSc in Technology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Mattia Tomasoni</td>
<td>MSc in Computer Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Kim Einhorn</td>
<td>BSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Marina Forslund</td>
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</tr>
<tr>
<td>Malin Fridlund</td>
<td>BSc in Public Health Sciences</td>
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</tr>
<tr>
<td>Kata Bordas</td>
<td>MSc in Business and Management</td>
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</tr>
<tr>
<td>Helene Börjesson</td>
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<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
</tbody>
</table>

**External partners**

<table>
<thead>
<tr>
<th>Name</th>
<th>Academic title/s</th>
<th>Department/University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theo van Achterberg</td>
<td>Professor, PhD, MSc in Health Sciences, Registered Nurse</td>
<td>Department of Public Health and Primary Care, KU Leuven, Leuven, Belgium</td>
</tr>
<tr>
<td>Enrico Baraldi</td>
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</tr>
<tr>
<td>Gunilla Burell</td>
<td>Associate professor, PhD</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Per Carlbring</td>
<td>Professor, PhD, Licensed Psychologist</td>
<td>Department of Psychology, Stockholm University</td>
</tr>
<tr>
<td>Maria Carlsson</td>
<td>Associate professor, PhD, Registered Nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>JoAnne Dahl</td>
<td>Professor, PhD, Licensed Psychologist, Licensed Psychotherapist</td>
<td>Department of Psychology, Uppsala University</td>
</tr>
<tr>
<td>Matz Dahlberg</td>
<td>Professor, PhD, MSc in Economics</td>
<td>Department of Economics and Institute for Housing and Urban Research, Uppsala University</td>
</tr>
<tr>
<td>Jenny Eriksson Lundström</td>
<td>PhD, MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Paul Farrand</td>
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<tr>
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<td>Name</td>
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<tr>
<td>Erik Grönlund</td>
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<tr>
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<tr>
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<tr>
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<tr>
<td>Thecla Kohi</td>
<td>Associate professor, PhD, Registered Nurse</td>
<td>Muhimbili University of Health and Allied Sciences, School of Nursing, Dar es Salaam, Tanzania</td>
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<tr>
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<tr>
<td>Brjánn Ljótsson</td>
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<td>Department of Clinical Neuroscience, Karolinska Institutet</td>
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<td>Gustaf Ljungman</td>
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<tr>
<td>Christine Rubertsson</td>
<td>Associate professor, PhD, Registered Nurse, Registered Midwife</td>
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<tr>
<td>Robbert Sanderman</td>
<td>Professor, PhD, MSc in Psychology, Licensed Psychologist</td>
<td>Faculty of Behavioural and Social Sciences and Faculty of Medical Science, University of Groningen, Groningen, the Netherlands</td>
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<tr>
<td>Agneta Skoog Svanberg</td>
<td>Professor, PhD, Registered Nurse, Registered Midwife</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
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<tr>
<td>Joanne Woodford</td>
<td>Research Fellow, PhD, BSc in Psychology</td>
<td>College of Life and Environmental Sciences, University of Exeter, Exeter, UK</td>
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<tr>
<td>Anna Cristina Åberg</td>
<td>Associate professor, PhD, Licensed Physiotherapist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and School of Health and Social Studies, Dalarna University</td>
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<tr>
<td>Pär Ågerfalk</td>
<td>Professor, PhD, MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
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<td>Anna Hauffman</td>
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<td>Department of Radiology, Oncology and Radiation Science, Uppsala University</td>
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<td>Tove Kamsvåg Magnusson</td>
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<tr>
<td>Jenny Thorsell</td>
<td>MSc in Psychology, Licensed Psychologist</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
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</table>
Cathrine Bonnedahl  |  Registered Nurse  |  Department of Immunology, Genetics, and Pathology, Uppsala University
---|---|---
Golden Masika  |  Registered Nurse, MSc in Nursing Sciences  |  Muhimbili University of Health and Allied Sciences, School of Nursing, Dar es Salaam, Tanzania
Madeleine Olsson  |  Registered Nurse  |  Department of Immunology, Genetics, and Pathology, Uppsala University
Susanne Sjöberg  |  Registered Nurse  |  Department of Immunology, Genetics, and Pathology, Uppsala University

**Publications during 2014-2016**

**2014**


**Peer-reviewed conference papers**


Parents of Children Previously Treated for Cancer. 16th World Congress of the International Psycho-Oncology Society (IPOS). Lisbon, Portugal.


2015


Peer-reviewed conference papers


2016


Peer-reviewed conference papers


Dissertations 2016

Main supervisor: Associate professor Timo Hursti, Department of Psychology, Uppsala University.
Co-supervisors: Associate professor Erik Olsson, Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University and PhD Jonas Sjöström, Department of Informatics and Media, Uppsala University.

Main supervisor: Professor Louise von Essen, Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University. Co-supervisors: Professor Ata Ghaderi, Department of Clinical Neuroscience, Karolinska Institutet and Associate professor Brjánn Ljótsson, Department of Clinical Neuroscience, Karolinska Institutet.

Main supervisor: Professor Matz Dahlberg, Department of Economics, Uppsala University and Institute for Housing and Urban Research, Uppsala University. Co-supervisors: Professor Louise von Essen, Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University and Associate professor Erik Grönvist, Department of Economics and Institute for Evaluation of Labour Market and Education Policy.

Half time controls 2016

Main supervisor: Professor Louise von Essen, Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University. Co-supervisors: Associate professor Annika Lindahl Norberg, Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University, Associate professor Gustaf Ljungman, Department of Women’s and Children’s Health, Uppsala University, and Associate professor Brjánn Ljótsson, Department of Clinical Neuroscience, Karolinska Institutet.

Main supervisor: Professor Pär Ågerfalk, Department of Informatics and Media, Uppsala University. Co-supervisors: Professor Louise von Essen, Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University and PhD Jonas Sjöström, Department of Informatics and Media, Uppsala University.

Tommy Carlsson. (2016). To Grasp the Unexpected: Information Following a Prenatal Diagnosis of Congenital Heart Defect in the Fetus.
Main supervisor: Associate professor Elisabet Mattsson, Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University and Associate professor Gunnar Bergman, Department of Women’s and Children’s Health, Karolinska Institutet and Associate professor Barbro Wadensten, Department of Public Health and Caring Sciences, Uppsala University.
Agencies that support the work/Funding (SEK)

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<tr>
<th>Funding organization</th>
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<th>PI</th>
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<td>VR/Strategic Research Grant for U-CARE</td>
<td>10 000 000</td>
<td>Vice chancellor Uppsala University/Louise von Essen</td>
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<td>In-kind support (approximately) from the departments of: Economics; Engineering Sciences; Immunology, Genetics, and Pathology; Informatics and Media; and Psychology, Uppsala University</td>
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<td>The Swedish Research Council</td>
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<td>Uppsala University for project in collaboration with researchers at Campus Gotland</td>
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<td>The Swedish Childhood Cancer Foundation</td>
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<td>Svenska Läkaresällskapet</td>
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<td>Hjärtebarnsförbundet</td>
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<td>UU Innovation</td>
<td>136 000</td>
<td>Sven Alfonsson</td>
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<td>Funds under 100 000</td>
<td>140 000</td>
<td>Laura Kukkola (85 000) Anna Wikman (45 000) Malin Ander (11 000)</td>
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During 2016 our main activities have been

- We have provided researchers and PhD students with stimulating career opportunities
- Three PhD students have passed their PhD examinations
- Three PhD students have passed their half-time controls
- We have recruited one Adjunct professor
- We have recruited one PhD student
- 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 conducted the phase I feasibility study Puzzle.

We have involved patients and members of the public in our activities.

We have held the sixth meeting with the U-CARE Scientific Advisory Board and all U-CARE members.

We have consolidated and initiated national and international collaborations.

We have held three research seminar series.

We have participated at national and international conferences.

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 and e-Health.

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.

We have planned and performed the Health Innovation Summer School in collaboration with Halmstad University.

Research projects 2016

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 stepped care 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 stepped care psychosocial intervention for adults diagnosed with cancer.

METHODS: The clinical efficacy and cost-effectiveness is evaluated with a randomized, controlled design. Two hundred forty-five adults with prostate-, breast- or colorectal cancer and self-reported anxiety or depression symptoms are included and randomized to immediate access to the intervention or a control condition. Inclusion was completed in December 2016. Participants answer questions about e.g. anxiety, depression, posttraumatic stress, quality of life, posttraumatic growth, and costs at 6 times during the 24 months follow-up.

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 from start: Professor Louise von Essen, since 2016 Associate professor Birgitta Johansson. 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: Associate professor 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 was completed in December 2016. 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: To grasp the unexpected: Information following a prenatal diagnosis of congenital heart defect in the fetus

OVERALL AIM: To explore experiences and needs of information following a prenatal diagnosis of congenital heart defect, and to assess the quality of publicly available information websites about
congenital heart defects.

METHODS: The project used qualitative and quantitative methods to explore experiences of counseling with fetal cardiologists, informational needs, and web-based information. Qualitative data was collected through interviews and focus groups with females and males faced with a prenatal diagnosis. Quantitative data was collected through systematic assessments of English and Swedish websites about congenital heart defects.

FUNDING: The project started 2012 and is funded by the Regional Research Foundation Uppsala/Orebro, Uppsala County Council, and the Swedish Children’s Heart Association. Principal investigator: Associate Professor Elisabet Mattsson

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: PhD Sven Alfonsson.

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: The psychological status of surgically treated oesophageal cancer patients

OVERALL AIM: To identify factors related to the experience of oesophageal cancer surgery that affect patients’ emotional well-being and psychosocial recovery in the short- and long-term. Specifically to find ways to improve the well-being of oesophageal cancer patients by identifying risk factors for poor recovery.

METHODS: Studies within the programme are based on national cohort studies, registry data and qualitative interviews and international cohort data. Key outcomes are psychological distress as measured by self-report or psychiatric diagnoses or prescribed drugs registered in Swedish national health registries.
FUNDING: The research programme started 2013 and is funded by the Swedish Cancer Society, the Swedish Medical Association, and the Karolinska Institute. Principal investigator: Associate professor Anna Wikman.

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 Neiman’s 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 Conscription 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: Associate professor 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: Associate professor Claes Held and Associate professor Erik Olsson

Title: SibsCan: Development, testing, and evaluation of an internet based psychosocial intervention for adolescent and young adult siblings of young people 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, analyzed 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 in 2014 and is funded by a strategic research grant to U-CARE, the Swedish Childhood Cancer Foundation, and the Kempe-Carlgren 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 program’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.
Title: Identifying needs for psychological support for cancer-related suffering following successful treatment of gynaecological cancer during young adulthood

OVERALL AIM: To explore the situation among women diagnosed with gynaecological cancer during young adulthood regarding cancer-related distress and the need for psychological support after end of successful treatment. The study will provide the foundation for subsequent development, testing and evaluation of internet-delivered psychological self-help for women following gynaecological cancer.

METHODS: Women diagnosed with gynaecological cancer during young adulthood were identified via the Swedish national quality registry of gynaecological cancer and invited to complete a web-based (or paper-based) questionnaire addressing cancer-related distress and perceived needs for support following end of treatment.

FUNDING: The project started 2016 and is funded by a strategic research grant to U-CARE. Principal investigator: Associate professor Anna Wikman

Title: Increased understanding of distress among parent dyads and development of a support intervention

OVERALL AIM: To increase knowledge about behavioral processes related to distress among parents of children on cancer treatment and to develop an accessible supportive intervention for parent dyads with the purpose to alleviate and prevent distress.

METHODS: In an observational study, ecological momentary assessment (EMA) is used to investigate whether experiential avoidance is related to the development of symptoms of posttraumatic stress (PTSS) and depression among parent dyads of children on cancer treatment, and if so, it is tested whether this relationship is moderated by partner support, contextual, and/or dispositional factors. EMA implies that participants report repeatedly on their experience in real-time and in their natural environment.

A low-intensity supportive intervention that can be accessed via mobile devices will be developed in collaboration with parents with lived experience and tested in a feasibility study.

FUNDING: The project started 2016 and is funded by the Swedish Childhood Cancer Foundation. Principal investigator: PhD Martin Cernvall.


OVERALL AIM: To investigate the risk of psychiatric morbidity in the short- and long-term among survivors of cancer diagnosed during adolescence. Specifically to determine whether adolescent cancer increases the likelihood of psychiatric morbidity (defined as psychiatric in-patient care, psychiatric out-patient care and prescribed psychotropic medications) following the cancer diagnosis, while accounting for variations in socioeconomic variables.

METHODS: Registry-based study including all individuals born in Sweden from 1980-1993 with a primary cancer diagnosis when aged 13-18 years. Data on psychiatric morbidity over time is obtained from the Patient registry and the Prescribed drug registry.

FUNDING: The project was initiated during 2017 and is funded by the Swedish Childhood Cancer Foundation. Principal investigator: Associate professor Anna Wikman.
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. 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 in studies of living conditions, lifestyles, mental well-being, personal assistance, aided communication and parenthood.

There are two 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 living conditions and self-perceived health

**Members of the group during 2016**

Päivi Adolfsson, PhD, associated researcher
Johan Glad, BA, PhD Faculty of Medicine, associated researcher
Gunnel Janeslätt, 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 Terner, Med Lic, Faculty of Medicine, associated researcher
Öie Umb-Carlsson, PhD Faculty of Medicine, senior researcher
Helena Wandin, BA, PhD student

**External partners**

Ulla Beijer, PhD Faculty of Medicine, Department of Women´s and Children´s Health, Karolinska Institute, Stockholm
Pia Ek, PhD Faculty of Medicine, professor emerita, Department of Medical Biochemistry and Microbiology, Uppsala University
Hans G. Eriksson, statistician, Research and Development in Sörmland, Eskilstuna
Heléne Wernöe von Granitz, PhD student, Health Service Research, Department of Public Health and Caring Sciences, Uppsala 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
Edward Palmer, PhD, adjunct professor, Department of Economics, Uppsala Centre for Labour Studies, Uppsala University
Kristina Persson, PhD Faculty of Medicine, Pediatrics, Department of Women’s and Children’s Health, Uppsala 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
Emme-Li Vingare, PhD student, Department of Social Work, Linnaeus University, Växjö/Kalmar

Publications 2014-2016

2014


2015


2016


Literature reviews


Conference oral presentations and poster presentations

8. 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.


**Dissertation 2016**

*Helena Wandin*. Aided communication intervention in Rett syndrome- current practice and a new approach to assessment. (Halftime review).

**Agenies that support the work/Funding (SEK)**

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<th>Agency</th>
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<td>Vinnova</td>
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**Related tasks (members)**

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

- Promotion from senior lecturer to professor, Göteborg University 2016 (Karin Sonnander, expert)
- During 2016 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) and Journal of Applied Research in Intellectual Disabilities (Öie Umb-Carlsson).

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 a national user survey in the disability field (Öie Umb-Carlsson)

Undergraduate teaching 2016 (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 Adolfsson 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, lectures and essay examination (Karin Sonnander) and essay tutorials, lectures and examination (Öie Umb-Carlsson).

Freestanding courses

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

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

Communication partners of children with severe cerebral palsy and intellectual disability prescribed with high technology speech generating devise.

Participants: Helena Tegler, Monica Blom Johansson, Mia Pless and Karin Sonnander

This project focuses on communication with high technology speech generating devices between speaking communication partners and children with severe cerebral palsy and intellectual disability. The aim of the first study is to examine speech and language pathologists’ practises and perceptions of high technology speech generating device intervention targeting communication partners (i.e. caregivers, teachers and assistants). The second study has two aims. First, to examine communication partners’ practice and perceptions of communication with high technology SGD. Second, to examine in which contexts and for what reasons children use their SGDs. Study number three and four are intervention studies, which aim to evaluate high technology speech generating device intervention targeting communication partners.

Aided communication between persons with Rett syndrome and their interaction partners

Participants: Helena Wandin, Per Lindberg, Karin Sonnander

Individuals with Rett syndrome have significant motor and communicative disabilities and it is difficult to assess their cognitive abilities. To express communication is therefore difficult for them and their non-linguistic communication is problematic to interpret for their communication partners. The aim of the project 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.

Development of clinical guidelines for the management of communication in individuals with Rett syndrome

Participants: Leopold MG Curfs, Gillian Townend, Theresa Bartolotto, Helena Wandin, Anna Urbanowicz

A severe disruption in communication skills is one of the characteristic features of Rett syndrome and has a fundamental impact on quality of life for both individuals Rett syndrome and for their families. The literature on best practices in communication assessment and intervention in Rett syndrome is limited. There is a need to develop guidelines which ensure consistent and evidence based information regarding the management of communication is provided to families internationally. The creation of such guidelines would help to empower families by giving them the opportunity to share them, and to work together with educators and therapists to assist in the design of best-practice intervention programmes. The guidelines will be developed through a Delphi process.
Barriers and facilitators in interaction between children with profound multiple disabilities and children without disabilities

Participants: Nina Klang, Jenny Wilder, Helena Wandin

Interaction with peers is important for development and wellbeing. To have a friend with a disability may influence acceptance of diversity and persons with disabilities in general. Interaction between children with and without disabilities seldom occurs. Children with disabilities do not participate in interaction and play to the same extent as children without disabilities. The aim of this study is to study barriers and facilitators in interaction between children with profound disabilities and children with typical development. The research questions are a) what patterns of peer directed behaviours can be seen in interaction? b) what are the characteristics of situations in which interaction occurs? c) what do children with typical development view as facilitators in interaction with peers with profound multiple disabilities?

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, Helena Lindstedt

The aim is, by using semi-structured interviews, to 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 Kählín, 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.

The significance of received targeted support for living conditions and self-perceived health

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, Hélène 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 is based on national
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

**Implementing legally secured governance of individual rights: Does the
exercise of discretion in the decision-making process of granting
assistance allowance for personal assistance fulfil the intentions of the
LSS Act?**

**Participants: Heléne Wernöe 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 Act, concerning Support and Service for
Persons with Certain Functional Impairments (1993:387). The LSS Act aims to guarantee good
living conditions for the users, by stringent requirements to meet individual rights and covers a wide
range of user groups with regard to age, disability and severity of needs. The Act frames an
ambitious reform of fulfilling disability rights and has been described as the prime political tool to
strengthen citizenship of persons with disability in Sweden. There is however a lack of knowledge
about the extent to which personal assistance meets the intentions set out in the LSS Act, i.e., if the
support given promotes participation in society on equal terms or contributes to health and wellbeing
of the user. Further on, the exercise of discretion in the decision-making process of granting
assistance allowance for personal assistance is known to be difficult. This seems to be partly due to
inadequate administrative guidelines, which has raised issues of legal security. The project thus
derives from these two perspectives; to examine if the support received corresponds to the intentions
set out in the LSS Act and secondly to what extent the intentions of the LSS Act are met in the
decision-making process in granting assistance allowance for personal assistance. Overall, the
project aims to provide improved knowledge of the conditions for the government to implement
social reforms and to fulfil disability rights.

**Changes in living conditions of people with intellectual disability: a follow
up after 15 years**

**Participant: Óie Umb-Carlsson**

One aim of the Swedish disability policy is to promote equality in living conditions for people with
disabilities and people without disabilities. National statistics illustrate annual changes in the
population´s living conditions but do not allow the disclosure of people with intellectual disabilities.
Special studies are therefore necessary.

A study in 2001 described living conditions of people with intellectual disabilities born 1959-1974 in
Uppsala County as compared to the general population in the same age group. The comparison
showed that people with intellectual disabilities had worse living conditions compared to that of the
general population.

The aim of this project is to conduct a 15-year follow up of living conditions of people with
intellectual disabilities and compare with those of corresponding age groups in the general
population. Another aim is to explore experience of living conditions of people with intellectual
disabilities and to compare with general populations´ perception of their living conditions.

The study group consists of 110 people who participated in the Uppsala study in 2001. Information
on the living conditions of people with intellectual disabilities will be obtained by relative and staff
questionnaire reports and interviews with people with intellectual disabilities. A study specific
questionnaire is developed based on the questionnaire used in the 2001 study. The questionnaire
includes six domains: housing, employment and daily activities, finances, recreation and culture, family and social relations, and personal safety. For the interviews, people with intellectual disabilities will prepare an interview guide. Thereby the guide will be based on the perspective of those in question regarding what counts as important and relevant to focus. It also increases the possibility that many people understand the issues and are able to provide answers.

National welfare statistics will be used to collect data on the general population. In addition to a comparison between people with intellectual disabilities and the general population information concerning the living conditions of people with intellectual disabilities will be analyzed across gender, age and disabilities. This project reveals similarities and differences that are important to identify in a diversity perspective. This is of particular importance because people with intellectual disabilities should have the opportunity to live like others and be included in the community.

**Nutritional support for people with intellectual disabilities**

**Participants:** Päivi Adolfsson, Öie Umb-Carlsson, Pia Ek

The purpose of the project is to investigate how dieticians work with and provide nutritional support to people with intellectual disabilities and to develop an instrument for the diet-related health to be used in community residences for persons with intellectual disabilities.

**Promoting a healthy lifestyle for adults with intellectual disabilities**

**Participant:** Öie Umb-Carlsson

One aim of the Swedish public health policy is to promote societal preconditions for good health on equal terms for the entire population. A large part of health problems are among people with disabilities. Several health problems are related to disability but in many cases affected by lifestyle such as unhealthy eating habits and sedentary leisure.

It is essential that both staff providing support in housing and people with disabilities have knowledge about diet and other health issues as well as the fitness activities available.

The aim of this study is to evaluate how a health promotion intervention influences staff knowledge and way of working, as well as health literacy and lifestyle of the people living in a group home. The health promotion is inspired by the programme “Health promotion in community residences for people with intellectual disabilities” developed in Stockholm county and consists of four competence-enhancing parts: (1) a course for day staff in the group home, (2) appointment of a health ambassador among the staff, (3) a course for people with intellectual disabilities living in the group home, and (4) fitness activities for people with intellectual disabilities living in the group home. The intervention will be conducted during one year (spring 2016-spring 2017).

The study sample comprises day staff (n=6) and people with intellectual disabilities (n=5) in a group home in Sörmland county.

Quantitative data on changes in fitness activities, diet and other health related issues (e.g. weight and blood pressure) will be obtained by study specific measures. In addition, two focus groups will be created, with staff and people living in the group home respectively, in order to evaluate the experiences of participating in the project.

The project will contribute to the scarce knowledge of health promotion interventions for people with intellectual disabilities and may be used in the development of health promotion environments in group homes.
Men and women with intellectual disabilities and quality of life

Participants: Öie Umb-Carlsson, Päivi Adolfsson

Quality of Life (QoL) has become an important outcome in evaluations of services and support for people with intellectual disabilities. Models and measures are typically based on the perspectives of professionals and researchers and are thus developed at a distance from those in question. Including people with intellectual disabilities as active parts in the research process and taking the starting point in their views may broaden our understanding of QoL and help us find adequate criteria for assessing QoL.

The Uppsala QoL (UQoL) model describes QoL from the perspective of people with intellectual disabilities through individual interviews. UQoL is build-up of a general essence (well-being) and five hierarchically ordered themes (adult social status, control of life, personal safety, social belonging and self-chosen solitude).

This project aims to examine the UQoL model regarding its inherent component parts and explore the interrelatedness and boundaries between the building component parts. A qualitative research approach was chosen. Four focus groups (n=30) were created with people with mild and moderate intellectual disabilities in different life stages and situations. Each group discussed and reflected on the prerequisites for QoL in various life domains.

The study will contribute to the understanding of the concept QoL from the perspective of people with intellectual disabilities. Thus, the point of departure of the UQoL model is the users’ perspective rather than user perspective as perceived by professionals and researchers.
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 chronic obstructive pulmonary disease (COPD)
- communication skills
- diabetes and cardiovascular disease
- organizational factors, work stress and performance
- pain and musculo-skeletal disorders
- prevention
- reproductive health
- social insurance medicine
- symptom reporting and utilisation of pharmaceuticals
- vitamin D deficiency

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.

Members of the group during 2016

Kerstin Ahlqvist, physiotherapist, PhD student
Abdul Alim, PhD student
Åsa Andersén, RN, PhD student
Malin André, MD, PhD, associate professor, associate researcher Specialized in Family Medicine, Research in infections, priority setting and decision making.
Sven-Olof Andersson, MD, PhD, associate researcher
Ingrid Anderzén, PhD, associate professor
Eva-Maria Annerbäck, PhD, psychotherapist, trained Social worker/reg, associate researcher
Bengt Arnetz, MD, PhD, Professor
Judith Arnetz, PhD, associate professor
Annika Bardel, MD, PhD, adjunct senior lecture
Britta Berglund, PhD, associate researcher
Regina Bendrik, physiotherapist, PhD student
Elisabeth Krefting Bjelland, PT, PhD, associate researcher
Anne Björk, MD, PhD student
Karin Björkegren, MD, PhD, senior lecturer
Eva Bojner Horwitz, PhD, RPT, Reg. DMT, associate researcher
Kristina Bröms, MD, PhD, associate researcher
Gunilla Burell, PhD, associate researcher
Stephen Butler, MD, FRCP(C), associate researcher
Lars Carlsson, MD, PhD student
Jan Cederholm, MD, associate professor, associate researcher
Maria Cederblad, MD, PhD, associate researcher
Christoffer Cederland, adjunct teacher
Florim Delijaj, MD, PhD student
Lars Englund, MD, PhD, associate researcher
Sevek Engström, DD, MPH, PhD, associate researcher
Margaretha Eriksson, PhD, associate researcher
Christina Grape Viding, RN, PhD student
Mats Gulliksson, MD, PhD, associate researcher
Catharina Gustavsson, RPT, PhD, associate researcher
Johan Hallqvist, PhD, MD, BSc, professor in prevention research, senior physician at the Academic hospital, and head of the Department of Public Health.
Björn Hallström, MD, PhD, associate researcher
Johanna Haraldsson, MD, PhD student
Charlotta Hellström, PhD, associate researcher
Linus Johnsson, MD, PhD, associate researcher
Lena Kallings, PhD, associate researcher
Paul Kallikoski, MD, PhD student
Bo Karlsson, MD, PhD student
Per Kristiansson, MD, PhD, associate professor
Anne Lindgren, physiotherapist, PhD student
Karin Lisspers, MD, PhD, associate researcher
Linda Lännerström, RN, PhD student
Monica Löfvander, MD, PhD, associate professor, associate researcher
Mats Martinell, MD, PhD student
Annika Nolin, Master of Arts, research assistant
Lena Nordgren, PhD, associate researcher
Lena Olai, RN, PhD, associate researcher
Magnus Peterson, MD, PhD, associate researcher
Ronnie Pingel, PhD, statistician
Rathi Ramji, research assistant
Nils Rohde, MD, associate researcher
Angela Schlager, physiotherapist
Åke Schwan, MD, PhD, associate researcher
Jan Ståhlhammar, MD, associate professor
Björn Ställberg, MD, PhD, associate researcher
Elisabet Sundgren, RN, PhD student
Kurt Svärdssudd, MD, professor emeritus, associate researcher
Malin Swartling, MD, PhD, associate researcher
Eva Thorell, MD, PhD, associate researcher
Thomas Torstensson, RPT, PhD, associate researcher
Keld Vaeger, MD, PhD, associate researcher
Anna-Sophia von Celsing, MD, PhD, associate researcher
Rolf Wahlström, MD, PhD, associate researcher
Mari-Ann Wallander, PhD, associate professor, associate researcher
Thorne Wallman, MD, PhD, adjunct senior lecturer
Clairy Wiholm, PhD, associate researcher
Katarina Wijk, PhD, associate researcher

Publications 2014-2016

2014


49. Lange K, Berglund B. Osäker munhälsa med sällsynta diagnoser. Tandläkartidningen 2014.


2015


124. Lennartsson AK, Bojner Horwitz E, Theorell T, Ullén F. Creative artistic achievement (in writing, music, dance, theatre and visual arts) is associated with emotional competence. *J Psychosom Res* 2015;ISSN 0022-3999, E-ISSN 1879-1360.


129. Nordgren L, Söderlund A. Associations between socio-demographic factors, encounters with healthcare professionals and perceived ability to return to work in people sick-listed due to heart failure in Sweden: a cross-sectional study. *Disabil Rehabil* [Epub 2015 Apr 2].


131. Nordgren L, Söderlund A. Being on sick leave due to heart failure: Encounters with social insurance officers and associations with socio-demographic factors and self-estimated ability to return to work. *Eur J Cardiovasc Nurs* [Epub 2015 Feb 3].


149. Sundh J, Ställberg B, Lisspers K, Kämpe M, Janson C, Montgomery S. Comparison of the COPD Assessment Test (CAT) and the Clinical COPD Questionnaire (CCQ) in a Clinical Population. COPD [Epub 2015 Sep 14].


2016


**Abstract/poster/oral presentations from congresses and not referee reviewed papers/book chapters**

- Åsa Andersén – [Slutrapport - ENTER: Ett samverkansprojekt med huvudsyfte att underlätta för unga med aktivitetsersättning att komma ut i arbetslivet eller studier. 2016]
- Ingrid Anderzén – together with Lindberg P. [Anderzén I, Lindberg P. Predictors of wellbeing at work. 4th wellbeing conference Amsterdam 2016]

• Annika Bardel, Mari-Ann Wallander and Kurt Svärdsudd – [Factors associated with adherence to drug therapy. The world book of family medicine (Carl Steytaerts (red)). Narodna in univerziteta, Ljubljana, 2015:100-102]


• Karin Björkegren – [AMEE, an International Association for Medical Education 5/9-9/9 2015 i Glasgow]


• Stephen Butler – together with Miclescu A and Karlsten R. [Miclescu A, Butler S, Karlsten R. The changing face of the acute pain. 8th World Congress of Institute of Pain New York 20Th-23 Th May , 2016]


- Paul Kalliokoski – [20th Wonca Europe Conference 2015 Istanbul. Distriktsläkaren 2016; ISSN 0283-9830 (Print) 2001-810X(Online), nr 1]


Björkegren K, Nyberg F, Svärdsudd K. Neuropeptide Y levels are reduced after cognitive behavioural therapy (CBT) in women with fibromyalgia (FMS). International Congress of Behavioral Medicine. 2014;P569


- Per Kristiansson – [Anatomical landmarks of the intra-pelvic sidewall as sources of pain in women with pregnancy-related chronic pelvic pain. XXI FIGO World Congress of Gynecology and Obstetrics, 4-9 October, 2015, Vancouver, Canada]

- Per Kristiansson – [Betydelsen av anatomiska strukturer i lilla bäckenet för diagnostik av kroniska bäckensmärtor och behandling med lokal steroidinjektion. Tvärfackligt seminarium Oslo April 2014]


• Lena Nordgren – [Nordgren L, Söderlund A. Impact of encounters with healthcare professionals on perceived ability to return to work in people on sick leave due to heart failure. European Journal of Cardiovascular Nursing 2016; ISSN 1474-5151, E-ISSN 1873-1953, Vol. 15, S48-S49]


förrändring av hälsostatus vid KOL i en sjuårsuppföljning? (Abstract Svenska Lungkongressen 2015)]


**Dissertation 2016**


**Agencies that support our work/Funding 2016 (SEK)**

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**Education**

**Medical Programme**

Karin Björkegren – director of under-graduate studies  
Annika Bardel – responsible for training of student tutors  
Karin Björkegren – responsible for “Professionell utveckling” in semesters 1 and 2  
Per Kristiansson – responsible for “Professionell utveckling” in semesters 1, 2 and 11  
Gunilla Burell – in seminars 2 and 3  
Bo Karlsson – responsible for seminars 3 and 4  
Karin Björkegren – in semester 4  
Per Kristiansson – in semester 4  
Annika Bardel – in semester 4  
Mats Gulliksson – in semester 4  
Åke Schwan – in semester 4  
Jan Stålhammar – in semester 4  
Per Kristiansson – responsible for supervision and examination of ”Självständigt arbete”, sem. 10  
Bo Karlsson – responsible for semester 11  
Karin Björkegren – in semester 11  
Gunilla Burell – “Motivational interviewing” semester 11  
Karin Lisspers – in semester 11  
Mats Martinell – in semester 11  
Magnus Peterson – in semester 11  
Åke Schwan - in semester 11  
Björn Ställberg – in semester 11  
Thorne Wallman and Anna-Sophia von Celsing – responsible for social insurance medicine sem.11

**Masterprogramme in Public Health**

Ingrid Anderzén – responsible for the course Health Promoting Leadership  
Gunilla Burell – “Hälsofrämjande ledarskap”

**Doctoral course**

Johan Hallqvist – Medical epidemiology for PhD students

**External lectures or courses**

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  
Per Kristiansson – lecture in SFOG-course Endometriosis  
Björn Ställberg and Karin Lisspers – 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 Pinzel – 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 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.

• 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 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 Ställberg – an international cost-effectiveness study in COPD.
• Karin Lisspers and Björn Ställberg – International Primary Care Respiratory Group (IPCRG) - international collaboration aimed at highlighting unanswered questions on the management of respiratory diseases of importance in primary care.

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.
• Karin Lisspers, Björn Ställberg, 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 Ställberg – Research collaboration with the Center for Family and Community Medicine (CEFAM), at the Karolinska Institute
• Björn Ställberg – member of the steering committee in an asthma clinical trial
• Björn Ställberg 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 Jakobsårdarna, Borlänge
• Centre for clinical research, CKF in County of Västmanland
• Medical faculty in University of Örebro

Invited speakers
• Karin Lisspers – at an asthma symposium at the Congress of the Swedish Medical Society
• Monica Löfvander – Migration and Health. At Asyl och Integrationshälso, 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 Ställberg 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 Ställberg is chair of the asthma and COPD national program group at the Swedish Association of Local Authorities and Regions (SKL)
Research projects

**Asthma, 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. An eight report regarding asthma control has been published during 2014 and a ninth about a comparison between an assessment scale and a quality of life questionnaire for COPD patients has been published. 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).

**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. Lisspers and Ställberg are the leads of two new research projects within UNLOCK, one about asthma and one about COPD and co-morbidities.

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 and a second submitted.

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.

**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.

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

**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 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.

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 fist author and one about swallowing dysfunction in patients with stable COPD with Margareta Gonzalez Lind as first author. Two abstracts have also been submitted to the ERS congress in 2016 and several manuscripts are under preparation.

Karin Lisspers, Björn Ställberg 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-Olov Andersson, Malin Swarting, Malin André, 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 started during 2015 and 2016, has been to
train supervisors at primary health care centers communication and supervision skills. Which improve the communication skills among the medical students.

We have seen the videos recorded by the students during their last semester, when all the students have been trained by their supervisors for 2 weeks at a primary health care center. The students are told to make a video and show the encounter they prefer. Each semester we have 85 students training their communication skills with their GP. We could not evaluate all the videos due to lack of written permissions from either the patients or the medical students.

The videos we have had access to, are now evaluated by 4-5 GPs from the participants above, now with help of the translated Calgary-Cambridge Guide, to Swedish. During 2017 we are planning to evaluate this year’s videos and evaluate the statistic results.

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 Svärdssudd

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.

A fourth report has been published during 2015 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.

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.

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 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. 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.

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.

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.

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. 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.

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.

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.

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.

**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. The study was elaborated by Jan Cederholm in cooperation with Björn Zethelius, Geriatrics/Department of Public Health and Caring Sciences.

**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. ANDiU collaborate with ANDIS (L. Groop, Lund University) and ESTRID (S. Carlsson, J Löfvenberg, 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.

**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.

**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. Researchers are involved in the structure and scientifically evaluating the effect. The project started in autumn 2015.
Organizational Factors, Work Stress and Performance

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.

Pain and musculo-skeletal disorders

Epicondyllosis

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). 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.

Biomarkers and Diagnostic Imaging of Physiological Processes Associated with Tendon Healing and Tendinopathy

Participants: Abdul Alim, Paul W Ackerman, Pernilla Eliasson, Per Kristiansson, Per Aspenberg, Gunnar Pejler, Magnus Peterson.

This project is aiming to investigate the molecular pathophysiology underlying healing and chronic pain mechanism in tendon tissue after rupture, in human as well as in rat model. Furthermore, to verify biomarkers, which are upregulated in tendon healing of humans and rats that could be used as targets for PET tracer development.

To achieve this goal, we have performed tissue collection and preparation of tissue slices from the rat Achilles tendon (intact and rupture). From this study, we have already generated a small manuscript data, which is mainly focusing on mast cells quantification and co-localization of target biomarkers (e.g. mast cell tryptase vs. glutamate receptor, NMDAR1). The manuscript is ready to submit.

In parallel, we have worked for the verification of target antibodies (e.g. NMDAR1, PGP 9.5, mast cell tryptase and CGRP) by immunofluorescence and then used for labelling with 125I and in an autoradiography analysis. Some antibodies (e.g. NMDAR1, Mast cell tryptase, PGP 9.5) have already been optimized with 125I labelling, at the pre-clinical PET center, and confirmed that the used antibodies are working fine by checking their radioactivity and purity after labelling.
Cognitive behavioral therapy in fibromyalgia
Participants: Bo Karlsson, Karin Björkkegren, Per Kristiansson, Gunilla Burell, Fred Nyberg Kurt Svärdssudd

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 Neuropeptid Y. One paper is published 2015 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.

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 and published in 2016.

Cultural Activities and Health
Participants: Christina 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. This project is generating one PhD thesis (Christina Grape Viding).

Social epidemiology: the role of life course and social context
Participant: 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.

**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.

**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 Krefting Bjelland, Johanna Haraldsson, Per Kristiansson, Anne Lindgren, Annika Nolin, 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 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 Rutger 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.


**Uppsala Pelvic Pain Study (UPPS)**

**Participants:** Kerstin Ahlqvist, Angela Schlager, Åsa Wiberg, Annika Holten, RoseMarie Casselbrant, Ingrid Djurback, Mansour Alemi, Christina Olsson, Lena Nilsson-Wikmar, 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 process.

The study is a population-based cohort study of, at the moment, 300 women with baseline assessment before gestational week 12 and additional assessments at gestational week 36 and 6 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 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 and 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 result 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. 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, 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. So far, about 30 women have been included in the study that includes a 4 weeks treatment session with either active or sham treatment with follow-up immediately and 6 months after end of treatment. 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.

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: Katja Ångerud, Santosh Boddeti, Hans-Peter Söndergaard, Eva-Maria Annerbäck, 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.

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: Lars Carlsson, Catharina Gustavsson, Johan Hallqvist, Linda Lännerström, Inger Knutsson Holmström, Thorne Wallman.

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. Generated one paper in 2013. 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 and two in manuscript 2016. The project is generating one PhD thesis (Lars Carlsson). Financial support has been provided by Centre for Clinical Research Dalarna, Dalarna County Council and Uppsala University.

Determinants for return to work among sickness certified patients in general practice
Participants: Anna-Sophia von Celsing, Kurt Svärdsudd, Karin Björkegren, Margaretha Eriksson, Thorne Wallman.

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. 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 in 2013 and 2014 and two in manuscripts. The project was generating one PhD thesis in 2016 (Anna-Sophia von Celsing). Financial support has been provided by Centre for Clinical Research Sörmland, Sörmland County Council and Uppsala University.

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 2013, and one accepted during 2016. The project is generating one PhD thesis (Linda Lännerström). Financial support has been provided by Centre for Clinical Research Sörmland, Sörmland County Council and Uppsala University.

**MEDiTUNA – Vocational rehabilitation: how does it affect health and quality of life?**
**Participants:** Linda Lännerström, Thorne Wallman.

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 and Baseline and 6 months follow-ups are finished. Six months, one year and two year follow-ups were finished in 2015. MEDiTUNA data was analyzed in 2016 and will generate two papers in 2017.

**Absenteeism and Return to Work**
**Main responsibility:** Ingrid Anderzén

Participants from the group: Ingrid Anderzén, Åsa Andersén, 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.

**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. The project will also generate at least three articles in two PhD thesis (Åsa Andersén and Lars Carlsson).

**DIRIGO 1 and 2 – “I control”**

*Participants in the research team: Ingrid Anderzén, Åsa Andersén and Kjerstin Larsson.*

*Externals 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).


**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).
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 is submitted to a peer reviewed journal. We found that women reported higher prevalence than men for 24 of 30 symptoms. We also found four patterns increasing, decreasing, stable and biphasic prevalence after multivariate analyses. The symptoms in the various pattern groups differed among men and women. Symptoms related to strain were prominent among symptoms decreasing with age. Moreover, there were secular trends. Across all symptoms reporting prevalence increased over time in men as well as in women.

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.

In 2016 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 2016.

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 and another publication is waiting for acceptance.

Vitamin D

Vitamin D status, physical performance and birth outcome in pregnant women

Participants: Paul Kalliokoski and Monica Löfvander

Deficient levels of vitamin D negatively affect muscle contractility, endurance and increases bone turnover thus contributing to body-ache and reduced functional ability. Veiled fertile women seem to be risk group for having low vitamin D levels.

In springtime 2010 we conducted a cross-sectional study in Borlänge including target-and reference groups of pregnant women (Somalia, n=52; Sweden, n=71). The main aim was to explore vitamin D status, bone turnover and physical performance in their hands and upper legs before and after treatment.
The first paper presented that 90% of the Somali and 10% of Swedish women were deficient of vitamin D. 1/3 of the Somali women had un-measurable levels, and high bone-turnover parameters (s-PTH and s-ALP). Practically all of the Somali women had very weak hands and a poor upper leg performance (i.e. squatting) was common. PK has also reported results of the first paper as a poster at an international congress for family doctors at Wonca 2015, Istanbul.

A subsequent treatment study included the 71 women with vitamin D ≤ 50 nmol/L. Intervention included lifestyle advice and supplements of vitamin D3 and calcium for 10 months. It resulted in a second paper published in 2016.

A third study on vitamin D, prolonged labor and delivery outcome in the cohort of 123 women is finished. The manuscript will be completed at the end of 2017.

The project is generating one PhD thesis (Paul Kalliokoski). A half-time doctoral seminar is to be held in 2017.

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.

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. The project is generating one PhD thesis in 2017 (Anne Björk).
Geriatrics

Research Group Leader Professor Martin Ingelsson

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. In addition, new methods for molecular imaging, i.e. positron emission tomography (PET), are being developed. The group applies a broad repertoire of experimental techniques, e.g. molecular biology, biochemistry, histology and behavioural analyses in the research. Clinical and epidemiological studies of dementia and successful ageing are also performed.

Members of the group during 2016

Professors
Martin Ingelsson (chair)
Lars Lannfelt (senior professor)
Hans Basun (adjunct)

University lecturer
Lena Kilander (associate professor 2010)

Associate Professors
Joakim Bergström (associate professor 2013)
Stina Syvänen (associate professor 2013)
Anna Erlandsson (associate professor 2013)
Björn Zethelius (adjunct, associate professor 2006)
Anna Cristina Åberg (adjunct, associate professor 2010)

Researchers
Dag Sehlin
Vilmantas Giedraitis
Veronica Lindström
Sara Ekmark-Lewén
Greta Hultqvist
Bernice Wiberg
Malin Degerman-Gunnarsson
Ylva Cedervall
Gustaf Boström (adjunct)
Bodil Weidun (adjunct)

Postdocs and research assistants
Astrid Gumucio
Sahar Roshanbin

PhD students
Gabriel Gustafsson
Kristin Franzon
Xiaotian Fang
Leire Almandoz-Gil
Elisabeth Nikitidou
Jinar Rostami
Emma Persson
Publications 2014-2016

2014


2015


2016


### Books


### Agencies that support the work/Funding (SEK/year)

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<td>Vetenskapsrådet</td>
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### International collaborations

Harvard Medical School, NIH, University of Goettingen, University of Kuopio, 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, University of Copenhagen

### 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 consortia
The research group has been a member of the Berzelii Technology Centre for Neurodiagnostics, the Swedish Brain Power network, the U4 network (together with the Universities of Göttingen, Ghent and Groningen) and the HEAT-NET (Harvard European Alumni Training NETwork).

Engagement in the external society
- Membership of The Regional Ethics Review Board (REPN) in Uppsala (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)
- Associate Editor of Frontiers in Neuroscience (Martin Ingelsson)
- Member of the Scientific Committee of the Swedish Parkinson Foundation (Parkinsonfonden) (Martin Ingelsson).
- Member of the Scientific Committee of the Swedish Brain Foundnation (Hjärnfonden) (Lars Lannfelt)

Research projects

The role of astrocytes in Alzheimer’s disease and Parkinson’s disease
(Anna Erlandsson, PhD)
Knowledge about the cellular mechanisms behind the spreading of Alzheimer’s disease (AD) and Parkinson’s disease (PD) in the brain is still very limited. Decades of research have focused on neuronal abnormalities in AD/PD 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 AD/PD progression and to investigate the astrocytes therapeutic potential. Our results demonstrate that astrocytes engulf large amounts of aggregated amyloid-beta (Aβ) and alpha-synuclein (αSYN) that are stored, rather than degraded, by the cells. The accumulation of the protein aggregates by the astrocytes results in lysosomal defects, mitochondrial impairment, exosome-induced apoptosis of neurons and spreading via tunneling nanotubes. To further elucidate the role of astrocytes in AD/PD, we use primary cultures of astrocytes and neurons as well as brain tissue from AD patients and transgenic mice. Moreover, we examine the possibility to increase the astrocytes’ degradation of the ingested proteins by antibody treatment. In order to prevent the onset of AD/PD, or at least limit the neurodegeneration, a better understanding of the cellular and molecular mechanisms of the disease is highly desirable. Astrocytes have great impact on the brain environment and we believe that they may constitute a potent treatment target.

Generation of bispecific antibodies for efficient treatment of Aβ and α-synuclein brain pathology
(Dag Sehlin, PhD, Stina Syvänen, PhD, Greta Hultqvist, PhD)
Intra-brain aggregation of Aβ and α-synuclein is characteristic for Alzheimer’s disease and Parkinson’s disease, respectively. Efforts are today devoted towards removal of these protein species using antibodies as therapeutics. Antibodies are, however, large molecules that distribute slowly and to a low extent to the brain. The research aim of this project is to generate bispecific antibodies...
targeting both the transferrin receptor (TfR) expressed at the blood-brain barrier and Aβ/α-synuclein. The TfR acts as a shuttle from the blood into the brain for the bispecific antibody. Using this strategy we have increased the brain distribution of a number of Aβ and α-synuclein antibodies up to 100-fold. Ongoing and planned immunotherapy studies will reveal if such bispecific antibodies can increase treatment efficacy compared to traditional antibodies.

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 includes 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 several new 124I-labelled imaging agents based on antibody mAb158 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 mAb158 sufficiently. This has enabled us to use the mAb158 based bispecific antibodies as PET radioligands to generate PET images of Aβ protofibrils in the living mouse brain. The focus of our present research is to further improve the brain distribution and pharmacokinetics of the bispecific antibodies 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

(Martin Ingelsson, MD/PhD and Joakim Bergström, PhD)

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

(Martin Ingelsson, MD/PhD 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. Most notably, we have discovered a new mutation in the 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 (Aβ). Deletions like this have never been described in Alzheimer’s disease. We are now investigating aggregation properties and biochemical features of the mutated proteins. Furthermore, we have generated a transgenic mouse strain carrying the “Uppsala mutation” and will now use this mouse model for in vivo studies of the pathological changes caused by this mutation. 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 we are using our collection of DNA samples from sporadic Alzheimer’s disease patients and healthy controls.

Clinical and epidemiological research
(Lena Kilander, MD/PhD Björn Zethelius, MD/PhD Malin Degerman Gunnarsson, MD/PhD Ylva Cedervall, PhD, Anna Cristina Åberg, PhD)

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 (n=40). 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 study (2-11 years) of this cohort, high CSF total-tau predicted institutionalization and conversion to moderate dementia (Degerman Gunnarsson -16), 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 reflects 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 et al., J Neuroimaging. 2015)

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 Aβ 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 independent aging, defined as maintained cognitive and ADL functioning (Franzon et al. 2015). Independent ageing is assessed both at age approximately 87 and 92 years and the predictors are preferably modifiable lifestyle risk factors. 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 Cristina Åberg and Ylva Cedervall are studying new methods for clinical motor function assessment, as well as a potential association between motor and cognitive functions and subjective health aspects, such as life satisfaction and fear of falling. This area includes assessment of postural control, dual-tasking and interventions for fall prevention. The research is mainly directed towards older people with frail health and a need for rehabilitation due to
multiple diseases/functional limitations, and those with specific neurodegenerative diagnoses, such as 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.

Since April 2015 the Stroke Unit at Akademiska Hospital takes part in a national stroke study named EFFECTS. It is an academic initiated, investigated led multicentre, parallel group, randomised, placebo-controlled trial of fluoxetine for stroke recovery. We are testing the following hypothesis: Does administration of fluoxetine after an acute stroke improves the patient’s functional outcome? So far 700 patients have been included at 35 centers and the aim is 1500. At our center 37 patients are included so far.

Finally, we investigate risk factors for subarachnoidal haemorrhage (SAH) using an adequately powered novel nationwide cohort consortium. We have obtained individual participant data of 949,683 persons (330,334 women) from 21 population-based cohorts collected during more than 50 years and geographically covering entire Sweden. Outcomes have been obtained from the Swedish Hospital Discharge and Causes of Death Registries. The first obtained data shows that the incidence rate increased exponentially with higher age. The risk of SAH was nearly 50% higher in women than in men and substantial gender differences in risk factors exist. There was also a markedly stronger effect of smoking in women than in men. Additional statistical analyses are ongoing.

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 provides 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.
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 is alone in this group.

Publications 2014-2016

2014

2015

2016

Research Fundings

During the year, I have had a joint project with the Centre for Research Ethics & Bioethics, and as I needed to be more operational that originally anticipated, the Center has funded part of my salary.

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 main reason why the registries are underused is the current lack of suitable methods for evaluations in clinical practice based on registry data.

One project intends to develop these methods and to illustrate these by evaluation the new oral anticoagulants against the older warfarin. 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.

Another project tend to use a natural experiment in order to understand the clinical consequences of the contamination of public water by fluorinated chemicals. The consequences for humans are still unknown. As PFAS is a group of chemicals that are persistent in the environment, bioaccumulate in wild life and humans, and are shown to be toxic in laboratory tests and for animals, we will live with a large potential harm of human health for a long time. It is, therefore, important that the potential impact on humans from this exposure is assessed. In this project, we evaluate and value the health consequences for humans over the life-cycle.

And finally, a project in collaboration with Centre for Research Ethics & Bioethics, Health Economics is investigating 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. The project involves both qualitative and quantative research. It is this project which has been the focus during the past year as previously mentioned.

**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. HEFUU has, for example, been host for education-, and workshop activities. We have organized a two-day education in Causal inferences by Professor Kosuke Imai, Princeton University in may 2016. Also, we have organized two different workshops with altogether 10 researchers at Uppsala University who has presented their research group and some of their research. Our belief is that these days 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.

**Education**

In the year, Sophie Langenskiöld has improved the previously held course in Health Economics at advance level. It 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 discuss what aspects we should take into consideration in comparing programs from a health
economic perspective, and which programs to 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 appreciated the last time it was given, and will be held again in fall 2017.

Other

The group is also very proud to have nominated Donald B Rubin (Dept. of Statistics, Harvard University) for an honorary doctorate in recognition of his seminal contributions to statistical methods. Rubin will be of great help to optimize our use of Sweden’s unique registries for causal inferences, taking either the frequentist or the Bayesian perspective, and for handling data complexities such as differences across groups (propensity-score), missing data (EM-algorithm), truncated and censored data (principal stratification).
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 2016

*=associated members in the research group

Ulrika Winblad PhD, Associate Professor, Research Group Leader
Carina Ahlstedt RN, PhD student
Cecilia Bernsten* RPh, PhD, Associate professor
Annica Björkman* MD, PhD
Ingeborg Björkman* RPh, PhD
Tobias Dahlström* PhD
Ann Catrine Eldh* RN, PhD, Associate professor
Mio Fredriksson PhD
Christina Halford* MD, PhD
Anna Hallberg Research assistant
Marianne Hanning* PhD
Caroline Hoffstedt PhD student
Inger K Holmström* RN, professor
David Isaksson PhD student
Karin Josefsson Research assistant
Elenor Kaminsky* RN, PhD
Marie Kirsebom* PhD
Dorte Kjeldmand* MD, PhD
Linn Kullberg PhD student
Niklas Källberg* PhD
Jan Larsson* MD, PhD, Associate professor
Ylva Lindberg Research assistant
Anna Mankell* PhD student
Linda Moberg PhD student
Åsa Muntlin Athlin* RN, PhD
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
Alexander Tegelberg RN, PhD Student
Publications 2014-2016

2014


2015


2016


**Agencies that support the work/Funding (SEK)**

<table>
<thead>
<tr>
<th>Agency</th>
<th>Amount (SEK)</th>
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<tbody>
<tr>
<td>Uppsala University Hospital, Strategic investments (Åsa Muntlin Athlin)</td>
<td>360 000</td>
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<tr>
<td>Uppsala University Hospital (Åsa Muntlin Athlin)</td>
<td>1 479 000</td>
</tr>
<tr>
<td>Disciplinary Domain of Medicine and Pharmacy (Områdesnämnden, Mio Fredriksson)</td>
<td>270 000</td>
</tr>
<tr>
<td>Healthdox, NORFACE, ERA-NET (Ulrika Winblad)</td>
<td>100 000</td>
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</tbody>
</table>
Swedish Council for Working Life and Social Research (Forte) (Ulrika Winblad) 2 130 000
The Swedish Research Council (Mio Fredriksson) 525 000
Uppsala County Council (Ulrika Winblad) 390 000
Total: 5 254 000

**External Reviews 2014-2016**


Inger K Holmström: The Swedish Research Council (Vetenskapsrådet), Medicine & Health.

Åsa Muntlin Athlin: Convenor to lead the consultation response of Uppsala University regarding the Swedish Board of Health and Welfare’s proposal for regulations and general advice on healthcare providers’ systematic patient safety work.

Åsa Muntlin Athlin: Editorial Advisor, International Emergency Nursing, 2016-


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)

Ulrika Winblad: Member of the Scientific Advisory Board of the Center for Healthy Ageing (CEHA), University of Copenhagen, (2014-2016)


Ulrika Winblad: The Research Council of Norway, reviewer research applications 2015

Ulrika Winblad: Member of the Electorate committee, FORTE 2015-

Ulrika Winblad: Member reference group, Expertgruppen för studier i offentlig ekonomin (ESO) (2013-2014)

Ulrika Winblad: Member European expert grupp, Healthy Living and Active Ageing (2013-2014)

Ulrika: Winblad: Vice Chair, expert group, Uppsala University, Healthy Living and Active Ageing, (2013-2014)


Ingeborg Björkman: Participated as panel judge for RSAP’s Annual Best Paper Award for 2014 (Research in Social and Administrative Pharmacy)

**Awards 2014-2016**


Linda Moberg. Thuns travelling stipend (Uppsala University) for research at Stanford University, USA. (2014-2015)

Elenor Kaminsky. Best Poster award at the Nordic Conference in Nursing Research, Odense, Danmark. (2014)

Research projects

An ethnographic approach to understand what affects nurses’ daily work motivation
Participants: Carina Ahlstedt, Inger K Holmström, Åsa Muntlin Athlin
A prerequisite for continued high quality care is that employees are motivated in their daily work. Today there is a problem with shortage of nurses in health care and when media writes about nurses, it is predominantly about the work problems that exist. The overall aim of this project is to describe RNs professional role, actions and work motivation in an acute care context from a positive organizational research perspective with an ethnographic approach.

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.

Priority setting and resource allocation in local health systems: putting retrenchment policy into action in Dalarna county council
Participants: Mio Fredriksson, Ulrika Winblad, Inga-Britt Gustafsson, Lars Wallin
A process of ‘restructuring’ of the health service in Dalarna county council started in 2015, sparked by many years of repetitive budget deficits. Until 2019, 700 million SEK needs to be cut to achieve ‘a balanced budget’. The restructuring process – which may be described in terms of a retrenchment policy – includes many aspects: e.g. the concentration of services to more urban areas, efficiency improvements, closures, changed staffing policies and the introduction of new methods for making continuous priorities at the clinics. In this project we study how large-scale priorities and cutbacks are decided and implemented in a complex organization with many types of professionals (politicians, administrators, health professionals) with different jurisdictions. In particular, we are interested in how decision-makers at different levels within Dalarna county council work to create internal legitimacy (within the organization) and external legitimacy (in relation to citizens and patients) for the unpopular decision to make extensive savings. The project has two parts. Firstly, the decision-making processes leading to a number of ‘restructuring plans’ are analyzed. Important questions are how initial horizontal priorities were identified and justified, how the decision-making process was structured and who were involved, and how interest groups such as unions and patient associations were involved. Secondly, the processes of implementing the plans are studied. We focus on what types of decisions have been implemented and what types have not. What can explain why certain decisions were not possible to put into action? How are the clinics working to implement the national model for open priority-setting, which was one solution to sustainable finances that was introduced in one of the restructuring plans? Overall, the project interconnects the discourses on
Making decisions in healthcare: policy and preferences in Sweden and England

Participant: 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.

Implementing legally secured governance of individual rights: Does the exercise of discretion in the decision-making process of granting assistance allowance for personal assistance fulfill the intentions of the LSS Act?

Participants: Heléne W 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 Act, concerning Support and Service for Persons with Certain Functional Impairments (1993:387). The LSS Act aims to guarantee good living conditions for the users, by stringent requirements to meet individual rights and covers a wide range of user groups with regard to age, disability and severity of needs. The Act frames an ambitious reform of fulfilling disability rights and has been described as the prime political tool to strengthen citizenship of persons with disability in Sweden. There is however a lack of knowledge about the extent to which personal assistance meets the intentions set out in the LSS Act, i.e., if the support given promotes participation in society on equal terms or contributes to health and wellbeing of the user. Further on, the exercise of discretion in the decision-making process of granting assistance allowance for personal assistance is known to be difficult. This seems to be partly due to inadequate administrative guidelines, which has raised issues of legal security. The project thus derives from these two perspectives; to examine if the support received corresponds to the intentions set out in the LSS Act, and secondly to what extent the intentions of the LSS Act are met in the decision-making process in granting assistance allowance for personal assistance. Overall, the project aims to provide improved knowledge of the conditions for the government to implement social reforms and to fulfill disability rights.

The role of information in choice of provider systems

Participants: Caroline Hoffstedt, 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 and 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.

**Developing gender competence in Swedish telenursing**

**Participants: Inger K Holmström, 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 telephone nursing in Sweden. The aim 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. Telephone nursing is considered as first line health care but it is a gendered service in that most telephone nurses are female and the majority of calls for children and elderly parents are made by women. Gender refers to the social constructions 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 telephone nurses 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 analysed 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 behaviour 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. The calls are dominated by task-focused utterances (e.g. giving medical information) and close-ended medical questions are common. Three types of ideological work are found in the calls: gatekeeping, hegemonic masculinity and traditional medicine ideology. 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, both in a public population and among students. We have also made an intervention to raise telephone nurses’ awareness of intersectional aspects, based on lectures, case-discussions, reading and reflection-on-action. The participating nurses were positive in general to the intervention, but we found limited changes in their intersectional awareness. The results, published during 2016 can also have direct application in nursing education and probably be used in other areas of healthcare and health care education.

**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, Kurt Svärdssudd). The project aims at studying both general practitioners’ and primary healthcare nurses’ views of sick-listing, and experiences and participation in the process of being on long-term sick-leave from the patients view. The findings revealed that patients’ 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. A survey about knowledge and attitudes to sick-listing among nurses in primary healthcare has been conducted, showing a great need for learning more within this field. Therefore, an educational intervention to improve their competence in sick-listing issues has been conducted, including pre-post measurements of knowledge and attitudes, as well as a process-evaluation. A manuscript about the intervention is under preparation.

**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, and to discuss these findings in relation to the international literature on TN.

**Health promoting working place in the context of telephone nursing**

**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.

**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 analyse how the design of the reimbursement system affects how the providers behave. The project is run in collaboration with the Department of Government (Paula Blomqvist), Uppsala University.

**Marketization in Swedish eldercare – implications for users, professionals, and the state**

**Participants: Linda Moberg, Ulrika Winblad, Paula Blomqvist**

During the last decades, Swedish policy makers have implemented various marketization reforms into the public welfare sector in order to make it more cost-efficient and to improve its quality. The aim of this project is to study what implications this marketization trend has had for the organization of Swedish eldercare. In particular, the research question addresses how marketization reforms such as privatized provision, increased competition and user choice has transformed the relationship between the service users, the professionals, and the state.

The research questions in this project will be addressed through four different articles. The first two of these studies has (during 2016) been published in the Journal of European Social Policy and in the Journal of Social Policy. In the first 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. In the second study Moberg analyses if the implementation of choice in the Nordic welfare states has altered the Nordic model for social service delivery in such a way that it poses a challenge to the idea of universalism. The third paper is a comparative study, focusing on how the state audits eldercare and childcare providers. The aim of this study is to explore how enhanced audit creates conditions for professional development in these two areas of social care. In particular we ask whether the new audit professes support or undermine professionalizations of the occupations working in Swedish childcare and eldercare. This study is submitted to Social Policy and Administration and after the initial review process we have been given the opportunity to revise and resubmit the manuscript. In the fourth paper, Moberg study how the Swedish policy makers who crafted the Swedish choice reform in eldercare reasoned with regard to the tension between user choice and citizens equal right to quality care. To answer this question the study, which is based on the method of qualitative text analysis, addresses three dimensions (i) what role did the choice
reform assign to the choice reform assign to the users and how did the policy makers view their ability to make informed choices? (ii) How did the policy makers view the role of the public authorities and what tools were they given to ensure citizens’ equal access to good quality eldercare? (iii) Did the policies entail a new form of social citizenship for the elderly in Sweden? This project is run in collaboration with the Department of Government (Paula Blomqvist), Uppsala University.

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, who are all members of the International Learning Collaborative (ILC). According to healthcare reforms around the world, reports are emphasizing that fundamental aspects of care are being neglected in acute hospital settings. The ILC works to transform the way we deliver care in high tech environments and to elevate the standard of fundamentals of care around the world.

SMAAPP research program (Seamless management of patients seeking care for acute abdominal pain - a person-centred approach)
Participants: Åsa Muntlin Athlin, Alexander Tegelberg

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.

Symptoms on display: Securing equality and person-centred care by innovative usage of e-health technology for patient-reported acute pain
Participant: Åsa Muntlin Athlin

The expectations of equality and justness in healthcare are growing, but to meet these expectations new methods and care processes need to be developed and implemented. This project focuses on equality and pain management at an ED, as a reaction to the evidence showing that healthcare still today is unequal as women, elderly, and people who do not speak the language or are born in the country of care, or of another ethnic background, often receive poorer care. The overall aim of the project is to improve and secure equal pain management through person-centred care by innovative usage of e-health technology (Symptoms system) for patient-reported acute pain in the ED. Research team members represents research, clinic and industry.

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.
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.

Managers’ perspective of the care of patients with acute abdominal pain and how they describe they affect care.

Participants: Alexander Tegelberg and Åsa Muntlin Athlin

Care in prehospital, emergency care and the acute care hospital settings are not just about life-saving medical-technical interventions. For a successful outcome of the hospital stay, patients also need safe and high quality fundamental care. Managers’ perspective on how care should be designed or operated is an unexplored field. Studies indicate that lack of clarity concerning the manager role, authority and responsibility may have negative consequences, not only for the working conditions of managers, physicians, and other healthcare professionals, but also for the quality of care. The aim of the study is to describe the managers’ perspective of the care of patients with acute abdominal pain and describe how the managers affect the care.

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.
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 2011-16, the Swedish Association of Local Authorities and Regions (Sveriges kommuner och landsting) and the state agreed on an investment in the development of national quality registers, NQRs. This was initiated by, among other things, a review indicating that Sweden can take a lead in the development of a more efficient and equitable health care based on a use of national quality registers. However, little was known as to what are the barriers and/or facilitators for this? Three research groups (in Uppsala, Stockholm and Jönköping) were assigned to investigate the conditions for health care improvements by means of the quality registers, and the impact of the national investment. Commissioned by the Swedish Association of Local Authorities, the work of the Uppsala research group consisted of a case study in four regions (nine hospitals) in terms of a recognised NQR on stroke, followed by a national web survey to clinical stakeholders in all hospitals using three unique NQRs. The project is run in collaboration with Lars Wallin, Dalarna University.
Lifestyle and Rehabilitation in Long Term Illness

Research group leader Professor Karin Nordin

The research group *Lifestyle and rehabilitation in long term illness* was established 2015. Most projects in this group are intervention studies focusing on lifestyle (e.g. physical exercise, stress management, nutrition) in patients with cancer. The aim is to develop and evaluate effective health behavior change interventions, person-centered care and cost-effective rehabilitation programs to decrease the burden for patients and healthcare during and after cancer treatment.

The most prominent project within the group is Physical Training in Cancer (Phys-Can). This project will evaluate the efficacy and cost-effectiveness of individually tailored high and low intensity physical exercise, with or without use of behaviour change techniques (BCTs) to facilitate exercise. Main outcome is cancer-related fatigue (CRF) and secondary outcomes are quality of life (QoL), mood disturbance, adherence to the adjuvant cancer treatment, adverse events, 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 exercise to investigate whether these serve as mediators for the effects of physical exercise on CRF and QoL. In addition, we aim to improve cost-effectiveness of rehabilitation programs. Phys-Can is a controlled multi-centre study including 600 newly diagnosed patients with breast, prostate or colorectal cancer during adjuvant therapy at three different sites in Sweden; Uppsala, Lund and Linköping.

Members of the group during 2016

<table>
<thead>
<tr>
<th>Name</th>
<th>Academic title</th>
<th>Professional title</th>
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<tbody>
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<tr>
<td>Johanna Zetterlund</td>
<td>MSci</td>
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Associated members

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<tr>
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<tr>
<td>Sveinung Berntsen</td>
<td>Professor</td>
<td>Exercise physiologist</td>
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<tr>
<td>Birgitta Johansson</td>
<td>Associate professor</td>
<td>Nurse</td>
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<tr>
<td>Claudia Lampic</td>
<td>Associate professor</td>
<td>Psychologist</td>
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<tr>
<td>Charlotta Ingvoldstad</td>
<td>PhD</td>
<td>Genetic counselor</td>
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<tr>
<td>Marie Höyder Lund</td>
<td>PhD</td>
<td>Nurse</td>
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<tr>
<td>Ritva Rissanen</td>
<td>PhD</td>
<td>Behavioral science</td>
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Publications 2014-2016

2014


2015


2016


**Dissertation 2016**

**Birgitta Jacobsson Larsson.** Quality of Life, Coping and need for Support during the ALS disease trajectory.
Agencies that support the research work/Funding (SEK)

- The Swedish Cancer Society 2 400 000
- Swedish Research Council 1 960 000
- Onkologklinikens forskningsfond 250 000
- Selanders stiftelse 250 000

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
- Predicting Optimal Cancer Rehabilitation and Supportive care (POLARIS) [www.polaris-study.org](http://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 Professor Samar Basu, M.Sc., PhD.

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 Clermont Auvergne, Faculté 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 in a range of diseases.

The research group have developed crucial assays through raising specific antibodies against isoprostanes indicating oxidative injury and prostaglandin F\textsubscript{2α} 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.

Members of the group during 2012

Samar Basu
Johanna Helmersson
Lillemor Källström
Elisabet Rytter

External

Maria Palm
Emma Lindström
Adriana Miclescu
Publications 2014-2016

2014


2015


2016


Research projects

Impact of systemic inflammation, oxidative stress and adipokines in breast cancer
Participants: Samar Basu, Alicja Wolk, Anders Larsson and Marie-Paule Vasson
The project deals with systemic inflammatory biomarkers such as CRP, prostaglandins and isoprostanes and chemokines such as adipokines in Swedish Mammography Cohort. This study is performed in collaboration with Karolinska Institute, Clinical Chemistry, Uppsala University, Sweden and Université Clermont 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)
Participants: Samar Basu, Rune Blomhoff and Liver Frøyland
The project deals on the effect of fish oil in functional foods on markers of oxidative stress and inflammation in mice and Norwegian subjects. The study is performed in collaboration with Oslo Medical Faculty and Bergen University and is financed by The Norwegian Research Council.

Oxidative stress and inflammation during parturition
Participants: Maria Palm, Ove Axelsson, and Samar Basu
The project deals with the role of oxidative stress and inflammation in normal parturition. This study is performed in collaboration with the Department of Women's Health and Clinical Chemistry, Uppsala University.

AQUAMAX: The sustainable aquafeeds to maximise the health benefits of farmed fish for consumers
Participants: Samar Basu and Philip Calder
The project deals with health benefits of farmed fish in terms of oxidative stress and inflammation in English and Chinese subjects. This study 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)
Participants: Maria Kadiiska with international colleaues, Ron Mason and Samar Basu
The project deals with comparison of different biomarkers of oxidative stress in various experimental model of oxidative stress. This study 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
Participants: Johanna Helmersson, Liisa Byberg and Samar Basu
The project deals with birth weight in ULSAM cohort men and inflammatory response biomarker, prostaglandins at age 77 to investigate the clinical outcome. This study is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital and Department of Surgical Sciences, Uppsala University.
Public Health Science

Research Group Leader Anne Hammarström, Professor
The public health research group was initiated at Uppsala University in mid-October 2016. The research originates from successful research applications based mainly on ecological life-course epidemiological analyses of the Northern Swedish Cohort. One research strand is a major research programme about mental health in adolescence and the paths ahead - an ecological life course approach to mental health development into adulthood. Another programme is gender theoretical development of how sex/gender and health are interwoven in a Northern European context. The research is performed in international and interdisciplinary collaboration.

Members of the group during 2016-2017

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<th>Name</th>
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<td>Annica Åhs</td>
<td>Researcher</td>
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<tr>
<td>Christopher Bean</td>
<td>Post-doc</td>
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<tr>
<td>Noora Berg</td>
<td>Post-doc</td>
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<td>Pekka Virtanen</td>
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<tr>
<td>Marianna Virtanen</td>
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<td>Lotta Harju</td>
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<tr>
<td>Ellen Annandale</td>
<td>Professor</td>
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<tr>
<td>Maria Wiklund</td>
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<tr>
<td>Christina Ahlgren</td>
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Publications 2014-2016

2014


217

2015


2016


45. Harryson L, Áléc L, Hammarström A. "I have surly passed a limit, it is simply too much": women's and men's experiences of stress and wellbeing when living within a process of


Agencies that support the work/Funding 2016 (SEK)
FORMAS – Anne Hammarström  30 000 000
The Swedish Research Council  8 000 000
FORTE  3 000 000
Västerbotten county council Cutting edge  2 600 000
Total  43 600 000

Research projects

Mental health in adolescence and the paths ahead. An ecological life course approach to mental health development into adulthood
The overall objective is to analyse the importance of mental health in adolescence for well-being and health status in adulthood. Through theoretical development the programme will combine life-course epidemiology, the ecology of human development and individual level theories (agency within structures) to identify determinants on various ecological settings for mental health trajectories over the life course. Our prospective school leaver cohort, followed regularly from age 16 with exceptionally high retention rate (>94% at age 43) (n=1010), will be extended to a 32 year follow-up with new questionnaires, biomedical measurements, diagnostic interviews and register data (in order to analyse all ecological levels). Uniquely, regular interviews have been performed from age 16 with a risk group for poor mental health. New individual interviews will be conducted with that group and with a strategic selection of participants in each life course trajectory for mental health. Thus, the programme will extend an outstanding established field study by adopting an innovative combination of theoretical development and applying a mixture of advances in quantitative and qualitative methods. The interdisciplinary research group has extensive experience in communicating with stakeholders. By increasing knowledge about health promoting and deteriorating determinants of mental health over the life course, the programme will with high precision target special vulnerable groups.

Unemployment and scarring – a life-course analyses of the health consequences of youth unemployment in adult age in boom compared to recession
In spite of the deep recession of the 1990ies, there is a lack of research about the long-term health consequences of unemployment (the so called scars of unemployment). The aim of the study is to analyse, from a life-course perspective, the importance of unemployment in young ages for the health status in adulthood and to analyse possible mechanisms.

The research questions are:
1. What does unemployment in young age mean for the health status in adulthood?
2. What is the importance of trade in young ages (for those in unemployment, work and studies) for the health status in adult age?

The design is two cohorts of all school leavers in a middle-sized town in Northern Sweden. One of the cohorts left compulsory school in 1981 (n=1010) and entered the labour market during boom. The other cohort (n=686) left compulsory school in 1989 and entered the labour market during the worst recession in Sweden in the early 1990ies.

The project also contains a qualitative part in which everyone who became early unemployed directly after compulsory school in the older cohort (n=30) have been followed with personal interviews about their health experiences of unemployment and of other labour market positions.
How are sex, gender and health interwoven? Theoretical development in a Northern European context

While most feminist researchers today agree about the need to analyse both sex and gender there is a dearth of research on how sex and gender are interwoven.

The purpose of this project is to develop theories of how sex/gender and health are interwoven in a Northern European context.

The research questions are: 1. How can we move beyond a dichotomous view of the concepts of sex and gender? 2. How are sex/gender interwoven with health focusing on e.g. gender constructions, gender relations, life conditions, bodily experiences, stress and biological markers. 3. Is the interweaving of sex/gender with health related to intersectional power dimensions related to age, class, ethnicity and sexuality?

Our theoretical points of departure are an interesting combination of social constructivism and materialist feminism. Theory building will be undertaken in a double theorizing process carried out through two different but parallel approaches: analyses of theoretical texts (step 1) and theoretical development through empirical analyses of diverse samples (step 2). These two processes will deliver partial knowledge which will be concurrently linked together and finally integrated at key junctures of theorisation. Our project can make important contributions to both the feminist literature as well as to the field of health.
Research area: Child health and parenting (CHAP)

Head of research group: Anna Sarkadi, M.D., PhD, Professor

The group is interdisciplinary and focuses on societal support to children and their families. Projects range from prevention through early intervention to attending to the needs of vulnerable populations, such as asylum-seekers. Our special area of interest is parenting support, including both universal child health and early education services and parenting programmes. We specifically deal with effectiveness studies as well as implementation and improvement research, translating research results into practice. We also develop methods to interview preschool children reliably. All trials we conduct include a health economic evaluation of the intervention as well as qualitative studies with different stakeholders, including users.

Members of the group during 2016

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<tr>
<th>Name</th>
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<tbody>
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<td>Pär Bokström</td>
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<tr>
<td>Anton Dahlberg</td>
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<td>Inna Feldman</td>
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<tr>
<td>Elisabet Fält</td>
<td>RN, PhD student</td>
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<tr>
<td>Karin Fängström</td>
<td>Clinical Psychologist, PhD student</td>
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<tr>
<td>Kirsten Holmberg</td>
<td>Associate professor, associated member</td>
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<td>Laleh Nayeb</td>
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Publications 2014-2016

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**Dissertations 2016**

Maria Cederblad, Filipa Sampaio

**Agencies that support the work/Funding (SEK)**

<table>
<thead>
<tr>
<th>Year</th>
<th>Program/Network</th>
<th>Description</th>
<th>Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>HFS-network</td>
<td>“Hälsokalkylator” (2012-2016)</td>
<td>1 500 000</td>
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<tr>
<td>2016</td>
<td>Skandia. Health economic evaluation of prevention of mental health problems in children</td>
<td>1 300 000</td>
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<tr>
<td>2015</td>
<td>ALF</td>
<td>1 236 500</td>
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<tr>
<td>2015</td>
<td>Allmänna Barnhuset. A validation study of the computer software In My Shoes.</td>
<td>350 000</td>
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<tr>
<td>2015</td>
<td>Skandia. Health economic evaluation of prevention of mental health problems in children</td>
<td>800 000</td>
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<tr>
<td>2015</td>
<td>Gillberg Foundation.</td>
<td>200 000</td>
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**Child Health Centres service development**

Sweden is in the international forefront both in terms of children’s rights and the equity of welfare services. For almost three decades there was no apparent need to change service delivery within the child health services. However, society structures as well as macroeconomic and political circumstances imply a need to develop more effective and equitable services. PhD students Laleh Nayeb and Kine Johansen (Anna Sarkadi co-supervises) work directly on improving the evidence-base of child health services through developing better methods for screening bilingual children (at 30 months) and motor developmental problems, respectively. Our largest project, the Parents and
**Childreni Focus trial (see below) involves a new method of information transfer between the preschools and child health centres, using the Strengths and Difficulties questionnaire. Elisabet Fält is a PhD student in the project, looking at how parents, nurses, and preschool teachers perceive the information transfer, how it is implemented and with what clinical effects, and how parent and teacher scores correlate.**

**Effects, costs, and cost-effectiveness of preventive interventions**

Research has shown that there is a strong association between parental behaviour and developmental outcomes in children. Previous studies have shown that when parents are taught strategies that are more consistent, warm, authoritative, moderate and firm in the context of parenting programs, children’s rates of problematic behaviours decrease. Several research projects in our group therefore concern parenting programs. Raziye Salari is looking at factors that influence parents’ motivation to participate in parenting programs and how that might be influenced. We received major funding for a project on long-term effects of parenting programs as preventive interventions, where Helena Fabian is project leader and researcher. The study is a cluster-randomised controlled trial with three arms: two intervention arms and a comparison condition. The aim of the project is to determine what mix of parenting support interventions will lead to best outcomes on children’s mental health on the population level. The intervention is Triple P (Positive Parenting Program) and the two intervention types are universal and universal plus selected intervention, where the latter is more intense and involves identification of vulnerable groups/individuals. To evaluate the intervention, all children 3, 4 and 5 years of age are sent a questionnaire before their annual visit to the CHC. Results from these questionnaires are also used to describe the physical and mental health of this population of children. Antónia Tökés is research assistant in the project, responsible for the sorting and scanning of more than 6000 questionnaires yearly. Anton Dahlberg is also PhD student in the project, looking at the effects of the parenting program Triple P on population outcomes as well as effects on those participating in the intervention.

In parenting program research the extent of health economic evaluations is limited, nationally as well as internationally. An important focus of our group is therefore to conduct such analyses. Inna Feldman leads this research and Filipa Sampaio and research assistant Camilla Nygren are involved in this quite ground-breaking effort to model long-term effects of early interventions and thus provide decision-makers tools to base investment decisions on. Filipa Sampaio completed her dissertation in 2016 and currently works as a postdoc in the group. Richard Ssegonja, health economist and MD is a PhD student looking at adolescent depression and its costs and consequences.

**The voices of young children**

Preschool children’s capacity to communicate their experiences in unaided face-to-face interviews is limited. Two PhD students in the group, Karin Fängström and Pär Bokström are therefore working on validating a computer-assisted interview called In My Shoes, for use with preschool children. They have conducted 54 interviews with preschool children after their visit at the child health clinic (which was video-recorded). PhD student Anton Dahlberg, also a psychologist, assists them with important work rating the interviews to ensure that there is an objective observer, not involved in the project that rates accuracy of children’s accounts in relation to a video-recorded child health visit. Karin Fängström finished her half-time in 2015 and showed that In My Shoes is feasible with preschool children and that it is as efficient as a standard verbal interview in terms of accuracy and completeness. In 2016 we published an article showing that In My Shoes is not inferior to the standard interview method routinely used by the police and is in fact more accurate in identifying people involved in the situation the child is interviewed about (using the video recordings).
Service development for unaccompanied refugee minors with symptoms of PTSD

In 2015, a total of 35,369 unaccompanied refugee minors (URMs) sought asylum in Sweden. Unaccompanied refugee minors (URMs) are a particularly vulnerable group. In a previous study of 208 URM, we found that 76% screened positive for PTSD on the Children’s Revised Impact of Event Scale: CRIES-8. To address this magnitude of mental health problems with potential later consequences, an indicated prevention program, Teaching Recovery Techniques, was translated to Swedish and piloted in a number of different settings in Uppsala County, Sweden. The pilot study included seven sites (health centre, NGO, school, 3 municipality group homes, and university) running a total of 10 groups.

Baseline measures are available for 67 participants: 85% reported moderate or severe depression and 42% suicidal ideation or plans. Preliminary results indicate that depression scores decreased significantly, whereas PTSD scores remained stable. More than half (60%) of participants reported negative life events during the study. In qualitative interviews, the participants reported feeling more in control of their own body and reactions and to cope better with crises. The “carers” appreciated the program contents but acknowledged the difficulties in supporting the participants in their home practices. Overall, results indicate that Teaching Recovery Techniques is a promising indicated preventive intervention for URM with PTSD symptoms. The TrT program can be delivered by staff without previous therapeutic experience in the Swedish context. This successful pilot study needs to be followed up with a controlled design and moderation. Anna Sarkadi and Raziye Salari are responsible for the project, financed by the National Public Health Agency and Skandia ideas for Life.

For our work CHAP received the Children's Rights Prize 2016 awarded by the Children's Ombudsman in Uppsala County.
Sociomedical Epidemiology

Research Group Leader Professor Ragnar Westerling

The main objective of the research is to analyse factors that influence health, health related social factors and the effectiveness of medical and health interventions in different population groups.

There is a broad range of factors, including organisational 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.

The effectiveness of medical care and health interventions may vary between different population groups. In our research, we focus on the health and 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 behaviors, health literacy and the social capital of target groups.

We study both the equity of medical care and the effectiveness of health interventions performed in collaboration with other social bodies, such as municipalities, schools and employment offices. In these studies we focus on the interaction between health and social integration, for instance for migrants and persons on sick leave or otherwise outside the labor force. We are also involved in the planning, designing, testing and evaluation of new health interventions. Several studies have been performed in cooperation with different organisations, such as county councils, municipalities and national authorities.

We use data from a wide range of sources, including registers, questionnaires and interviews, and combine both quantitative and qualitative methods. We apply modern epidemiological techniques and are involved in the quality development of data and methods. We have contributed to the methodological development of cross-cultural research, by data collection in other languages and cultural contexts. Several of our studies have been conducted with international collaboration.

The research group Sociomedical epidemiology consists of about 20 members who have a range of professional backgrounds: medical specialists in social medicine, individuals with Master’s degrees in Public Health, psychologists and nurses, as well as graduates in Behavioral Sciences, Economy, Sociology and Nutrition. We also have staff members with a variety of cultural and linguistic background. About half of the group have PhDs and half are doctoral students or research assistants. We also cooperate with other groups within the department and with other university departments.

Effectiveness and equity in medical care

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 favorable 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 favorable shift in mortality trends.

Se 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. 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 has been tested in a randomized study showing favourable results.

**Development and evaluation of health systems for vulnerable groups**

We are performing evaluations of health system interventions for immigrants, 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. In present projects the health communication is
integrated into the civic orientation included in the establishment services for refugees. There is also
an ongoing project in which the civic orientation has been broadened to several arenas in the society,
in order to promote social capital, health literacy and self-efficacy among the migrants. We are
responsible for the evaluation of these projects.

We have also developed a health information package, which has 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.

We are also performing migration studies, where data from the original country of migrants are
compared to data for the corresponding migrant group in Sweden, as well as with Swedish born
populations. These studies focus on the impact of the migration from one health care system, in the
country of origin, such as Turkey and Iran, to the Swedish health care system.

We are also involved in several collaborative projects assessing the efficacy of various innovative
return-to-work strategies for persons on long-term sick-leave. 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.

**Members of the group during 2016**

Ragnar Westerling, Professor
Per Lytsy, MD, Associate professor. Senior lecturer
Ingrid Anderzén, Associate professor
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.
Hasse Nordlöf, PhD
Publications 2014-2016

2014


2015


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Dermatology and Venereology, Uppsala University Hospital, Department of Public Health and Caring Sciences, Uppsala University, Department of Neurology, Care Sciences and Society, Karolinska Institutet 2016. (In process in Nurs Health Sci)


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**Agencies that support the work/Funding (SEK)**

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; 2 772 888 managed at our department year 2012-2014 European refugee fund.

Athena (partnership with the municipality, county and employment office of Uppsala):4 389 146 (2 056 000 managed at our department) year 2012-2014. European Social Fund.

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Social insurance agency, 200 000.

Working life agency, 118 000.