Department of Public Health and Caring Sciences

Annual Report 2013
Introduction

The Department of Public Health and Caring Sciences employs 170 persons, of which there are 12 professors 19 senior lecturers. The yearly economic turnover is approximately 140 million SEK.

The Department of Public Health and Caring Sciences has extensive responsibilities in the teaching of nursing students, medical students, master of public health students and graduate students. The research questions addressed within the department of Public Health and Caring sciences covers a broad spectrum of issues ranging from contemporary hot public health issues on the political agenda to pertinent issues of molecular biology related to important public health problems. They take advantage from a truly multi-disciplinary collaboration, and involve cooperation with other departments of the university and other universities in Sweden and around the world. The Department is also the host of three Centres; the Centre for Disability Research, the Centre for Research Ethics and Bioethics, and the Uppsala University Psychosocial Care Program (U-CARE).

Education

There were about 3350 students registered at the department in 2013, in terms of funding corresponding to about 532 full time students. About 740 registered students were educated in the Nursing programme, 1100 in the Medicine programme, 50 in the Master-programme in Public Health and about 680 in separate courses. Through well-established collaboration with several universities abroad and different exchange programmes nursing students and teachers were able to get international experience. Contract education conducted by the Department additionally hosted approximately 760 registered students.

Research

The Department of Public Health and Caring Sciences is commissioned by the Disciplinary Domain of Medicine and Pharmacy at Uppsala University to perform scientific research in Caring sciences, Diet, nutrition and metabolism, Family medicine and clinical epidemiology, Geriatric research, Preventive research, and Social medicine. During 2013 there were 251 peer-reviewed scientific publications from researchers affiliated to the department, slightly more than the yearly average of 220 during the last ten years.
There were 12 dissertations, close to the yearly average during the last decade, and two students passed their licentiate examination. During 2013 98 registered doctoral students worked on their theses at the department.

The research activities are organized in eleven research groups; Caring Sciences, Research Ethics and Bioethics, Clinical Nutrition and Metabolism, Disability and Habilitation, Family Medicine and Preventive Medicine, Geriatrics, Health Economy, Health Services Research, Oxidative Stress and Inflammation, Psychosocial Oncology and Supportive Care, and Sociomedical Epidemiology.

Caring Sciences
The research has a multidisciplinary and multiprofessional perspective including preventive, supportive, caring, and rehabilitation actions. The focus is on clinically relevant problems in the health care sector. There are three research themes; 1) reproductive health, 2) cancer rehabilitation, 3) quality of care and patient safety.

Centre for Research Ethics and Bioethics
The Centre for Research Ethics & Bioethics (CRB) looks at ethical, legal and social aspects of medicine and biology (bioethics), ethical problems that arise within clinical settings in association with diagnosis, treatment and the organisation and delivery of health care (clinical ethics), and the application of ethical principles and values to different scientific topics (research ethics). The research topics cover a wide range of ethical questions related to biobanks and registry research, ethical review, informed consent, medical treatment of patients, nursing, explanations of human consciousness, quality of life, end of life care and more. The methods in use range from analytical philosophical methods to empirical studies using both qualitative and quantitative methods.

Clinical Nutrition and Metabolism
Metabolic and dietary interaction during health and disease is the research focus. Within this overall focus there are two major research pathways, i.e. 1) clinical disease- and age-related nutrition, which includes understanding of catabolic processes, consequences and treatment related to undernutrition, cachexia and sarcopenia in hospital, elderly care and community settings, and 2) preventive nutrition and metabolism, including nutritional epidemiology, obesity and metabolic intervention trials for elucidating effects on insulin sensitivity and cardio-vascular risk factors, and 3) food intake and dietary patterns in relation to various health outcomes.
Disability and Habilitation
Research activities focus disability as a function of the interplay between a person’s health condition and his or her physical, social and societal environment. There are three main research tracks: 1) the development and test of assessment methods, interventions and documentation in services for people with disabilities, 2) the significance of received targeted support for self-perceived health, and 3) participatory research in which the facilitating and restraining aspects of the environment as well as the participation and perspectives of persons with disabilities, professionals and significant others are highlighted.

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 ten different themes: 1) Social insurance medicine, 2) Pain and musculo-skeletal disorders, 3) Asthma, allergy and COPD, 4) Utilisation of pharmaceuticals, 5) Cardiovascular disease and diabetes, 6) Reproductive health, 7) Communications skills, 8) Prevention, 9) Organizational factors, work stress and performance, and 10) Social medicine.

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. The group applies a broad repertoire of experimental techniques, e.g. molecular biology, biochemistry, histology and behavioural analyses in our research.

Health Economics
The Health Economics was started during 2013 as a part of Health Economic Forum of Uppsala University (HEFUU), a collaboration between different Departments at the university.

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 in-
clude development of exploratory models for differences in public and private care, identification of barriers for implementation of patient choice reforms as well as identification of facilitators for high quality and patient safety care, especially within telecare. The group is multidisciplinary and the researchers have different professional backgrounds such as medicine, psychology, nursing and political science.

Oxidative Stress and Inflammation
The key research areas are inflammation in physiology and in disease state, specifically with bioactive eicosanoids. Additionally, oxidative stress that reflects increased levels of free radicals that are implicated both in ageing and in several inflammatory diseases is also a major research area.

Psychosocial Oncology and Supportive Care and U-CARE
The research activities mainly concern cross-disciplinary basic and applied research within the area of psychological treatment and psychosocial support for patients and significant others experiencing psychological distress in connection to a somatic disease. Knowledge from Economics, Information Systems, and Psychology are used to reach the research goals. The main research projects concern investigations of: psychological and economic effects of childhood cancer for those struck by the disease, their parents and siblings; the clinical efficacy and cost-effectiveness of self-help programs consisting of cognitive behavioral therapy via the internet or face-to-face to persons struck by various diseases such as cancer or myocardial infarction. In order to raise the quality of the research the public and the patients are involved in all the research activities.

Sociomedical Epidemiology
The primary objective of the research is to analyze mechanisms behind social differences in health and health care and to develop and evaluate health system interventions in order to increase equity in health. The main fields of the research programme are quality and equity in medical care and health system interventions for vulnerable groups like unemployed, lone parents and immigrants. Methodological aspects of avoidable mortality are also an important research interest.

Uppsala April 30, 2014

Johan Hallqvist
Head of Department
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Centres

During 2013 the Department of Public Health and Caring Sciences was the host of three Centres: the Centre for Disability Research, the Centre for Research Ethics and Bioethics, and the Uppsala University Psychosocial Care Program (U-CARE).

Centre for Disability Research (CDR)
(www.cff.uu.se)
Director: Karin Jöreskog
The Centre for Disability Research was established in 1988 to coordinate in disability issues in various subject areas at the faculties at Uppsala University and to interact with society in issues related to disability research. The aim is to disseminate information about research and to stimulate long term acquisition of knowledge about issues involving disability by enhancing the flow of information among teachers, researchers, and doctoral students as well as interested parties outside the University (p 51).

Centre for Research Ethics and Bioethics (CRB)
(www.crb.uu.se)
Director: Mats G Hansson
The Centre for Research Ethics & Bioethics (CRB) is an interfaculty centre that was established in 2008. The researchers at the Centre for Research Ethics & Bioethics at Uppsala University have been active for several years investigating ethical, philosophical and legal aspects of biomedical research and clinical practice within the format of multi-disciplinary research projects. We publish the results of our research in international peer-reviewed scientific journals and in books. Roughly our research covers three main areas: research ethics, clinical ethics and bioethics. Our research topics originate in close collaboration with clinicians, and through ongoing communication and international collaboration with highly qualified researchers and scientists (p 55).
Uppsala University Psychosocial Care Program (U-CARE)
www.u-care.uu.se

Director: Louise von Essen

U-CARE is one of the government’s strategic research programmes at Uppsala University. U-CARE is integrated in the research group Psychosocial oncology and supportive care, that is internationally strong in basic and applied psychosocial care research. The overarching goal of our group and the U-CARE Programme 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. The research is interdisciplinary, using knowledge mainly from the academic disciplines of Caring Sciences, Economics, Information Systems, and Psychology. (p 244)
Education

The Department of Public Health and Caring Sciences is funded for about 532 full time students (GLIS 140407), which represented 3350 students registered at the department in 2013. About 740 registered students were educated in the Nursing programmes, about 1100 in the Medicine programme, about 50 in the Master programme in Public Health and about 680 in separate courses (Uppdok 140331).

About 760 students were registered in contract education and about 90 doctoral students were registered in the department (Uppdok 140331).

First-cycle courses and study programs

Courses in the Medicine Programme

Medical education in Uppsala means early patient contact.

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

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

Semester 1: Introduction course, 3 credit points
Semester 1: Professional Skills and Communication 1, 2.5 credit points
Semester 2: Professional Skills and Communication 2, 2.5 credit points
Semester 3: Professional Skills and Communication 3, 2.5 credit points
Semester 4: Professional Skills and Communication 4, 2.5 credit points
Semester 4-11: Leadership training, 4 credit points
Semester 5: Geriatrics.

This course covers gerontology, Alzheimer’s disease and other neuro-degenerative dementia disorders, various aspects on frail elderly patients with multiple co-morbidities and poly-pharmacy, falls, delirium and other geriatric syndromes, orthogeriatrics, stroke rehabilitation and palliative care, during a total of three weeks.
Semester 1-11: *Medical Ethics and Medical Law*, 3 credit points
The course extends over the entire program. The different elements are related to the other courses that students take during the current period. Each session includes either a half or a full day. The course involves close collaboration with various clinical specialties, including group exercises based on actual patient cases that are either presented by the participating teacher/doctor or generated by the students themselves. Group discussions are integrated with lectures. The course is examined with an individual moral case deliberation. A web-based ethics toolkit is under development.

Semester 11: *Family Medicine*, 6.5 credit points.
Theoretical education is mixed with seminars for two weeks and the students have practical training in managing patients by themselves in a health care centre for another two weeks. The students ranked *Family Medicine* as number 1 in their evaluation of all courses.

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

Courses in the Nursing Programme
The Nursing Programme covers 180 credit points – the research group *Caring Sciences* is responsible for 91.5 of the credit points (Nursing Methods I and II, Nursing and Medical Science in Internal Medicine, Nursing and Medical Science in Surgery and Acute Medicine, Nursing and Medical Science in Public Health Practice and Primary Health Care, Nursing and Medical Science in Geriatrics and Elderly Care, Scientific Methodology and Thesis in caring science).

Radiography Nursing programme Courses
The Radiography nursing programme has 180 credit points – the research group *Caring Sciences* is responsible for 37.5 of the credit points (Medicine, Geriatrics, Paediatrics and Obstetrics; Surgery, Emergency Care and Pharmacology, Nursing Care in Surgery and Medicine, Work Placed Education Surgical Care).

Separate courses at the first-cycle level
The following courses are offered as separate courses at the first-cycle level: Culture and Health, Trends in Global Health, Motivational Interviewing in Health Promotion, Impairment and Disability, Nursing Care Planning and Quality Improvement, Bachelor's essay in caring sciences, Health Politics and Health Economics, Introduction to Theory of Science with Focus on

Contract education

The course *Understanding and Providing Leadership Based on the National Basic Value System for the Elderly*, 7.5 credits, is given as a contract education in cooperation between the Department of Public Health and Caring Sciences and the Division for Contract Education at Uppsala University, on behalf of the Swedish National Board of Health and Welfare. The course is given to leaders in the elderly care sector in Sweden. The course consists of 4 modules: The national basic value system, Ethics & humanism, Communication and Improvement management. The students are given the tools needed to implement and maintain the National Basic Value system for elderly in their daily work.

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

The course *Motivational Interviewing in Occupational Rehabilitation*, 7.5 credits is given as a contract education in cooperation between the Department of Public Health and Caring Sciences and the Division for Contract Education. One course was offered to the County Council of Västmanland in collaboration with the Government Agency for Employment and the Swedish Social Insurance Agency. This course was also offered to the Swedish Social Insurance Agency in the region of Stockholm South in collaboration with the Government Agency for Employment within the context of Project Dirigo, financed by EFS.
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 – the research group Caring Sciences is responsible for Pharmacology related to Diseases and the Extended Role of the District nurse, Nursing Care and Public Health in Adults and Elderly in Primary Health Care, Nursing Care and Public Health in Children and Adolescents at Child Health Centres and Schools, Nursing Care in Children and Adolescents with Common and Specific Conditions, Advanced Studies in Primary Health Care Nursing.

Postgraduate Diploma in Specialist Nursing with focus on care of elderly
Postgraduate Diploma in Specialist Nursing with focus on care of elderly, 60 credit points – the research group Caring Sciences is responsible for all the courses (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: The research group Caring Sciences is responsible for Courses; Psychosocial Cancer Care I and II, Palliative Care I and II.

Separate courses
The following courses are offered as separate courses at the second-cycle level: Research Designs, Methods and Statistics in Public Health, Public Health Ethics, Theories in Caring Sciences, The Organization and Management of Swedish Health Care, Health Promoting Management, Diet Nutrition and Public Health, Equity in Health, Clinical Nutrition and Energy Balance, Psychosocial Cancer Care, Palliative Care, Challenges in Global Health, Community Interventions, Neuroethics, Behavioural medicine with applications to lifestyle related health problems, Dementia and Nursing Care - Basic Course for Nurses, Genetic Counselling, Gerontology and Nursing Focused on Healthy Ageing.
Master in Public Health
Two years of full-time studies, 120 credit points, started in year 2007.

The modules are: Public Health (advanced level, 15 credit points), Research Designs, Methods and Statistics in Public Health (advanced level, 15 credit points), Behavioural medicine with applications to lifestyle related health problems (7.5 credit points), Community Interventions (7.5 credit points), Organisation and Management of Swedish Health Care (7.5 credit points), Equity in Health (7.5 credit points), Diet, Nutrition and Public Health (7.5 credit points), Public Health Ethics (7.5 credit points), Health Promoting Management (7.5 credit points), Thesis (advanced level, 30 credit points).

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

Third-cycle course and study program

Doctoral courses and study programme
In the beginning of the year 2013, 83 doctoral students were in education and during the year 12 of them have past their theses and 15 new applicants have been admitted to studies at the doctoral level.

Different research groups at the department are taking part in the training courses in the theory components of the doctoral education. In the obligatory courses at the Faculty of Medicine, members from Centre for Research Ethics & Bioethics are involved in “The introduction to scientific research” (7.5 ECTS, given three times a year). The Centre for Research Ethics & Bioethics is also responsible for the course “Research Ethics and Philosophy of Science” (1.5 ECT, given two times a year). Family Medicine and Preventive Medicine participated in “Medical epidemiology” (1.5 ECT, given once a year). The research group Research in Psychosocial Oncology and Supportive Care is co-organizer for the course “Health economics and cancer prevention” (1.5 ECT, given once a year).

Uppsala University Psychosocial Care Programme (U-CARE) research school was launched in 2012. The students admitted are anchored at four different Departments: Public Health and Caring Sciences, Psychology, Informatics and Media, and Economics. The postgraduate course given includes 15 credits divided into two modules. The second module “Psychosocial care in the interactive society” (7.5 ECTS) has been given in 2013.
The Centre for Research Ethics & Bioethics is also responsible for doctoral courses given at other faculties at Uppsala University: “Research Ethics for Science and Technology” (2 ECTS, given three times a year), “Research Ethics for Natural Science” (1 ECT, given three times a year), and “Research Ethics for Social Science” (4 ECTS, given once a year).

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

Education project

Two new web-based basic level courses were further developed in the fields of public health and scientific theory. Also, an overview of the total set of basic level web-based courses in Public Health started, and a new structure and content were developed for one of these.

International activity

We have well-established collaboration with different 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 Life Long Learning Programme for European countries, Nordplus (Norlys for the Scandinavian and Baltic countries, and Danosfi for the Nordic countries), and Linnaeus-Palme and Mini Field Study for developing countries such as Vietnam, Tanzania, Thailand and Uganda. The students also have the opportunity to do clinical practice/internship in other countries outside of Europe such as South Africa. In 2013 about 30 of our students studied abroad during 1-12 weeks, while 11 foreign students visited our department during 4-12 weeks. In the same year two of our teachers taught abroad during 1-3 weeks, while two foreign teachers taught in our department during 5 weeks. The exchange programmes give students and teachers knowledge, experiences and international contacts which are highly valuable for their personal development and careers as well as for their universities.
Dissertations 2013
(Registered at the Department of Public Health and Caring Sciences)

- Atry, Ashkan. Transforming the Doping Culture: Whose responsibility, what responsibility?
- Degerman Gunnarsson, Malin. Biomarkers as Monitors of Drug Effect, Diagnostic Tools and Predictors of Deterioration Rate in Alzheimer’s Disease.
- Fagerqvist, Therese. Studies of α-synuclein Oligomers-with Relevance to Lewy Body Disorders.
- Kaminsky, Elenor. Telephone Nursing: Stakeholder views and understandings from a paediatric and a gender perspective.
- Kuhlau, Frida. Responsible Conduct in Dual Use Research: Towards an Ethic of Deliberation in the Life Sciences.
- Nerpin, Elisabet. The Kidney in Different Stages of the Cardiovascular Continuum.
- Star, Kristina. Safety of Medication in Paediatrics.
- Thorell, Eva. Physical Fitness and Pregnancy.
- Vægter, Keld. Promoting Rational Drug Prescribing in General Practice.

Licentiate 2013

- Margareta Widarsson. Transition to parenthood: Perceived needs of support during pregnancy and parental stress 18 month after childbirth.
Caring Sciences

Research group leader professor Tanja Tydén, chair

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

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

In 2011-2013, we had following three research themes:

- Reproductive health
- Cancer rehabilitation
- Quality of care and patient safety

Research is a process and we are in a phase of developing our research into new themes. Within the group reproductive health the aim is to contribute to the prevention of sexually transmitted infections (STI) and cancer related to Human papillomavirus (HPV) with focus on the vaccine against HPV and to find evidence-based interventions to improve behaviour towards the use of STI preventive measures. Moreover we are investigating health and lifestyle prior to conception, during and after pregnancy among women, their partners and their new-borns. Another ongoing project evaluates the effect of The Reproductive Life Plan (RLP) on knowledge, attitudes and behaviour related to reproductive health and lifestyle prior to conception.

Various projects are ongoing and planned within the group cancer rehabilitation; cross-disciplinary randomized controlled intervention studies focusing on lifestyle (e.g. physical exercise, stress management, nutrition) in cancer patients. The aim is to find evidence-based interventions for changing life style factors to decrease the burden for the patients and care givers dur-
ing and after cancer treatments, cost-effective rehabilitation programs and more person-centered health care.

The aim within the group of *quality of care and patient safety* is to reduce the incidence of patients with hospital-acquired pressure ulcers. One project will investigate if it is feasible for registered nurses, assistant nurses, and student nurses to reposition the patients in bed, using the “Continuous Bedside Pressure Mapping System”, so interface pressure is consistent with PU prevention. Another project will investigate terminal ulcers in patients in late palliative phases, *i.e.* prevalence, classification and relationship to imminent death.

**Members of the group during 2013**

Aarts, Clara, RN, PhD
Arving Cecilia, RN, PhD, researcher
Carlsson Maria, RN, PhD, associate professor, senior lecturer
Carlsson Marianne, PhD in psychology, professor
Edlund Birgitta, RN, PhD, associate professor, senior lecturer
Gunningberg Lena, RN, PhD, professor
Hedström Mariann, RN, PhD, senior lecturer
Ingvoldstad Charlotte, PhD
Leo Swenne Christine, RN, PhD, senior lecturer
Lundberg Pranee, RNM, PhD, associate professor, senior lecturer
Nordin Karin, licensed psychologist, professor 50% at Uppsala University and 50% chair of genetic counseling, University of Bergen
Pöder Ulrika, RN, PhD, senior lecturer
Svanberg Annacarin, RN, PhD
Tydén Tanja, RNM, PhD, professor, chair
Wadensten Barbro, RN, PhD, associate professor, senior lecture

**Lecturers fulltime or part time**

Ahlstedt, Carina
Eriksson-Öhman, Solweig
Holm, Marta
Hovstadius, Eva
Kjellberg, Sören
Lundin, Birgit
Norinder, Camilla
Rosvall, Paula
Schmidt, Meta
Staaf, Anita
Svanberg, Annacarin
Thoudal, Berit

32
Thörnqvist, Eva
Lugnet, Kerstin
Marnell, Harriet.
Normark, Lena
Pettersson, Mona

Associated researchers
Berglund, Gunilla
Ekstrand, Maria
Engström, Maria
Häggström, Elisabeth
Kristofferzon, Marja-Leena
Kullberg, Kerstin
Lindberg, Magnus
Maria Lindberg
Lindqvist, Ragny
Ljunggren, Birgitta
Lunner, Katarina
Mamhidir, Anna-Greta
Nilsson, Annika
Oscarsson, Marie
Roshanai, Afsaneh
Röndahl, Gerd
Skytt, Bernice
Stenhammar, Christina

Ongoing PhD students
Gottvall, Maria
Höyer, Marie
Nordin, Jenny
Björn, Catrine
Isaksson, Stina
Rissanen, Ritva
Östlund, Ann-Sofi
Sving, Eva
Kirsebom, Marie
Hagermann, Heidi
Knudsen, Kati
Randmaa, Maria
Widarsson, Margareta
Kerstis, Birgitta
Stern, Jenny
Grandahl, Maria
Hellerstedt-Börjesson, Susanne
Publications 2011-2013

2011


2. Ekstrand, M., Tydén, T., & Larsson M. (2011). Exposing oneself and one’s partner to sexual risktaking as perceived by young Swedish men who requested a Chlamydia test. The European Journal of Contraception and Reproductive Health Care, 16(2), 100-107.


2012


2013


137. Winters, M., Lindberg, M., & Sol B. (2013). Validation of a Dutch self-efficacy scale for adherence to fluid allowance among patients on


**Dissertations 2013**

- Kerstin Birgitta. Expectant parents needs of support and early parenthood, Licentiate examination.

**Awards 2013**

- Jenny Stern, received the “Young Scientists Award” at The first global conference on contraception, reproductive and sexual health, May 22-25, 2013, Copenhagen, Denmark.
- Lena Gunningberg, received the Uppsala County ”Landstingets forskningspris”, 2013, Uppsala, Sweden.

**Agencies that support the research work/Funding**

<table>
<thead>
<tr>
<th>Agency</th>
<th>Funding (SEK)</th>
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<td>Uppsala County Council</td>
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<td>InDevelop</td>
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<td>Medical Faculty Uppsala University</td>
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<td>The Swedish Cancer Society</td>
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<td>The Swedish Breast Cancer Association (BRO)</td>
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<td>Nordic Cancer Union</td>
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<tr>
<td>“Acrtive Against cancer” (Norway)</td>
<td>3 700 000</td>
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<tr>
<td>Regional Research Council Uppsala/Örebro</td>
<td>400 000</td>
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</tbody>
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International collaboration

- The PrePreg-Network
- 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 (POLA-RIS) www.polaris-study.org
- Trustee of the European Pressure Ulcer Advisory Panel (board member)
- Member of European Academy of Caring Science
- European Academy of Caring Science (EACS), Core member.
- International Co-coordinator for Nordic countries (Nordplus network: Norlys), European countries (Erasmus), and Linnaeus-Palme (Vietnam), Department of Public Health and Caring Sciences, Uppsala University
- Guest Lecturer, Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand.
- Guest Researcher, Department of Nursing, Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy, Ho Chi Minh City, Vietnam.
- Guest Researcher, School of Economics, Sukhothai Thammathirat Open University, Thailand
- Guest Lecturer, Makerere University, College of Health Sciences, Kampala, Uganda
- Guest Lecturer, Muhimbili School of Nursing, Dar es Salaam, Tanzania
- Member of the Editorial board for the Journal: Nursing Research and Education
- Guest Researcher, Early rehabilitation of cancer patients at the Department of Oncology and Medical physics, Haukeland University hospital, Bergen, Norway.

National commissions

Expert group – Pressure Ulcer/Patient Safety – The Swedish Association of Local Authorities and Regions.
Advisor to Vice Chancellor concerning gender equality.
Fellow of Royal Academy of Science in Uppsala.
Member of the research board, Swedish cancer society.
Co-member of the board of director, Swedish cancer society.
Member of the Council of the Center for Clinical Research, Dalarna County Council.
Member of the Board for Stiftelsen InDevelops u-landsfond.
Member of the Scientific Board of Investigación y Educación en Enfermería Research and Education in Nursing - (ISSN_p: 0120-5307, ISSN_e:2216-0280).

Invited speaker 2011-2013

- University of Basel and University hospital, Basel, and University hospital, Zurich, Switzerland, 2011.
- EPUAP 14th Annual European Pressure Ulcer Meeting, Oporto. Portugal, 2011.
- Key note. Trykksårskonferansen, Norske Sykepleierforbundet Oslo, Norway, 2011.
- Forskning pågår om äldre och åldrande Uppsala universitet, Regionförbundet Uppsala län, Uppsala, 2011.
- Skejby University Hospital, Aarhus, Denmark April 2011.
- The 1st International Clinical Nursing Research Congress, Izmir, Turkey, 30 May-2 June, 2012.
- The Danish Council of Ethics, Ministry of Health, Copenhagen 2013
- School nurses Conference 2013, Borås.
The Centre for Disability Research (CDR) was established in 1988 to coordinate disability issues in scientific fields represented at the faculties at Uppsala University and to interact with the wider community on issues relating to disability research. The Centre is placed at the Faculty of Medicine and administratively associated with the Department of Public Health and Caring Sciences.

During 2013 the CDR has coordinated of the Swedish Network for Disability Research network. In the autumn Umeå University hosted a network meeting and in the spring Malmö University hosted a network meeting. Scientists from all over Sweden participated in the meetings, where important matters were discussed regarding the future of the network.

Within the framework of regular operations, eight lectures were arranged for the purpose of disseminating information about current research in the disability field at Uppsala University.

Four issues of the newsletter *Forskning om funktionshinder pågår* (Current Disability Research) have been published. The newsletter presents Swedish research on disabilities. A reader survey has been conducted. On the whole, the newsletter - both the printed and the digital version - gets good reviews.

The CDR administers *Uppsala nätverket* (the Uppsala Network), which is an e-mail network for individuals with either a personal or a professional interest in research on disabilities. CDR sends out current information. Information reaching the CDR is forwarded to the ca. 450 recipients.

The CDR homepage (www.cff.uu.se) presents information about activities at CDR, its 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 Board of the Centre for Disability Research

Professor Karin Sonnander, (Disciplinary domain of medicine and pharmacy) chairperson.
PhD Faculty of Medicine, Åsa Myrelid (Disciplinary domain of medicine and pharmacy) (until 2013-06-30).
PhD Faculty of Medicine, Monica Blom-Johansson (Disciplinary domain of medicine and pharmacy) (from 2013-07-01).
Professor Håkan Lanshammar (Disciplinary domain of science and technology), vice chairperson (until 2013-06-30).
PhD Faculty of Technology, Kjartan Halvorsen, (Disciplinary domain of science and technology) (from 2013-07-01).
Professor Anders Rydberg (Disciplinary domain of science and technology).
Professor Margareta Sandström (Disciplinary domain of humanities and social science) (until 2013-06-30).
Professor Rafael Lindqvist (Disciplinary domain of humanities and social science).
PhD Faculty of Technology, Kjartan Halvorsen, (Disciplinary domain of science and technology) (from 2013-07-01).
Professor Anders Rydberg (Disciplinary domain of science and technology).
Professor Margareta Sandström (Disciplinary domain of humanities and social science) (until 2013-06-30).
Professor Rafael Lindqvist (Disciplinary domain of humanities and social science).
PhD Faculty of Humanities and social Sciences, Lotta Lerwall (Disciplinary domain of humanities and social science) (from 2013-07-01).
PhD student Johan Gladh (until 2013-06-30).
PhD student Gunilla Sandberg (until 2013-06-30).
Former Senior lecturer, Sonja Calais van Stokkom (The swedish disability federation).
Director Research and Development, Mia Pless (Uppsala county council).
Managing Director, Marie Palmgren (Municipalities in Uppsala county).

Agencies supporting CDR work/Funding

Funding has been received for 2013 for the newsletter Forskning om funktionshinder pågår (Current Disability Research). The financiers are:

- Norrbacka-Eugenia Foundation SEK 133 000
- Sunnerdahl Handicap Fund Foundation SEK 133 000
- Sävstaholm Foundation SEK 74 000
- Council for Working Life and Social Research (FAS) SEK 250 000

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

- Council for Working Life and Social Research (FAS) SEK 250 000

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. 450 recipients. Recipients
include researchers, representatives of care and social caring operations, personnel, relatives of individuals with disabilities, civil servants in county, municipal, or state administration, and other interested parties.

Homepage
The CDR homepage (www.cff.uu.se) presents information about the Centre, board members, lecture and course programmes, etc. The newsletter 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 2013 eight lectures were arranged, and we have seen an increase in the number of people in the audience.

The newsletter Forskning om funktionshinder pågår
(Current Disability Research)
The launching of the newsletter was a way of meeting an expressed need from the Swedish disability organisations, who asked for easily accessible written information on current disability research. The newsletter is published by the CDR, Uppsala University. However, the content is not limited to research activities from Uppsala University but includes disability research from all over Sweden. As of a few years ago, the introduction of every article is written in easy-to-read Swedish. Every issue is available as a PDF document, to be found on the website of the Centre for Disability Research, Uppsala University. Those interested in a particular topic or looking for a special article can search all published issues on the website, using keywords (in Swedish). The current number of recipients is 4370, 3100 of whom subscribe to a printed version and 1270 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. A reader survey has been conducted. On the whole, the newsletter - both the printed and the digital version - gets good reviews. The answers to the survey also show that the newsletter is 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

Evaluation of ethical issues has to be made in a systematic and informed manner, based on sound research and scholarship.

The researchers at the Centre for Research Ethics & Bioethics at Uppsala University have been active for several years investigating ethical, philosophical and legal aspects of biomedical research and clinical practice within the format of multi-disciplinary research projects.

We publish the results of our research in international peer-reviewed scientific journals and in books. Roughly our research covers three main areas: clinical ethics, research ethics, and bioethics.

Our research topics originate in close collaboration with clinicians, and through ongoing communication and international collaboration with highly qualified researchers and scientists.

Clinical Ethics

Ethical problems arise within clinical settings in association with diagnosis, treatment and the organisation and delivery of health care.

Our research in clinical ethics includes end of life treatment and palliative care in paediatric oncology, questions related to ‘do not resuscitate orders’ (DNR), assessment of cardiovascular risk in primary health care settings and communication of genetic risk information. Other projects have studied gender issues in association with telenursing moral distress in clinical settings and issues on prioritization within health care.

A couple of projects have studied issues on ethical competence in health care management and examined if ethical rounds are good instruments for improving the ethical climate at psychiatric outpatient care. The research in clinical ethics are 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. Issues in family ethics and relational autonomy are objects of study and collaboration within the “Family ethics” network.
Research Ethics

Ethical issues arise on several levels in association with research. There are questions related to the interpretation of legal frameworks, the recruitment of research subjects, the research process and the dissemination of research results.

Biomedical research using biobanks and registries have been and are objects for many studies related to questions about informed consent, privacy and how to handle incidental findings in association with such research. Other projects concern the recruitment of patients for clinical trials and the participation of patients in research.

Many studies are carried out within international consortia and funded by the European Commission. CRB is responsible for ethical and legal issues within the Swedish infrastructure for biobank based research, BBMRI.se. The research in research ethics provides updated knowledge for courses in research ethics and training of graduate students.

New developments in biomedical research raise new ethical issues and calls for rethinking of old concepts and theories of human life.

Bioethics

One of the greatest challenges of modern science is understanding the human brain. Uppsala University’s Centre for Research Ethics & Bioethics (CRB) is part of the European Commission flagship initiative to simulate the human brain and will look at the social, ethical and philosophical implications of The Human Brain Project. Currently, two connected PhD projects are running, one looking at disorders of consciousness, another focusing on what is it like to be unconscious.

Other issues relate to the possibility of how the scientific community in a responsible way should manage collaboration across geographical and cultural borders, while protecting the rights and interests of native people.

Recent PhD projects have looked into the possibility of dual use of biological research, human enhancement through doping, and issues concerning how dead persons should be respected.

In the past, we have also studied animal ethics and the linguistic and moral capacities of our fellow primates.

The research in bioethics provides updated knowledge for courses in neuroethics, bioethics and public health ethics.
Members of the group during 2013
(In alphabetical order)

Mirko Ancillotti, MA, Intern
Mirko Ancillotti started a one year internship with CRB in September 2013. He holds a degree of Master of Arts in Philosophy from the University of Pisa in 2012. His Master thesis regarded John Harris’ influence on contemporary bioethical debate on cloning and enhancement.

Ashkan Atry, MA, PhD student
Ashkan Atry started his PhD studies in April 2008. He holds a degree of Master of Arts in Theoretical Philosophy from Uppsala University (2008). His main area of interest is bioethics (questions about doping and fairness in sports), value theory, ethics, philosophy of action, epistemology and philosophy of culture. Ashkan Atry defended his PhD thesis in 2013.

Stefan Eriksson, ThD, Associate Professor of Research Ethics, Senior lecturer
Stefan Eriksson is a senior lecturer in research ethics at the Centre for Research Ethics & Bioethics and has conducted research on issues such as informed consent and autonomy, biobank ethics, and the function and impact of research ethics codes. He is the editor of CODEX - a web resource run by the Swedish Research Council. He received his doctoral degree on a dissertation regarding Wittgenstein's influence on philosophy of religion (1999). In January 2010 Stefan was appointed Associate Professor of Research Ethics.

Kathinka Evers, PhD, Associate Professor of Philosophy, Senior researcher
Kathinka Evers is a senior researcher at the Centre for Research Ethics & Bioethics. Her main research focus is neuroethics and the neural basis of consciousness and she teaches an advanced level course in neuroethics. Kathinka Evers’ research also includes biobank ethics and she is part of the BBMRI.se network. She conducted her doctoral studies in philosophy at Balliol College, University of Oxford, at the Research School of Social Sciences, Australian National University, Canberra, and at Lund University, Sweden, where she received her doctoral degree in 1991. She has been a research fellow at Balliol College, University of Oxford (1994); at the Department of Philosophy and Human Rights Centre, University of Essex, Colchester (1996-97); invited professor at the University of Tasmania, Hobart (1999), at École Normale Supérieure, Paris (2002), and at Collège de France, Paris (2006-07). For six years (1997-2002) she was the Executive Director for the Standing Committee on Responsibility and Ethics in Science (SCRES) of the International Council for Science (ICSU). She is also divi-
sion leader for ethical and societal implications of the EU-flagship Human Brain Project.

Michele Farisco, MA, PhD, PhD student
Michele Farisco holds a degree in Philosophy from University of Naples "L'Orientale" in 2003, a PhD in "Ethics and Anthropology. History and Foundation" from University of Lecce in 2008 and a Master degree in Biolaw from the University of Rome "Lumsa" in 2009. He spent time on an exchange grant from the European Neuroscience and Society Network within the European Science Foundation joining the Coma Science Group of the University of Liège (Belgium). He is the head of the "Science and society" research unit of Biogem Genetic Research Centre in Ariano Irpino (Italy). He is the author of three books and several articles about posthuman philosophy and philosophical, ethical and legal implications of genetics and neuroscience.

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

Josepine Fernow, BA, Co-ordinator
Josepine Fernow is the centre co-ordinator and communications officer. She is also the editor of the centre website and electronic newsletter and arranges our conferences. Her background is undergraduate studies in Cultural Anthropology and Sociology at Uppsala University. She was on maternity leave from April 2013-February 2014.

Joanna Forsberg, MD, PhD
Joanna Forsberg defended her PhD thesis on biobank research (individual rights and public benefit) on October 6, 2012. She started her PhD studies in bioethics in 2007. She holds a degree in Medicine from Uppsala University (1998) and a license to practice (2002). Her main area of interest is the relationship between rights and duties of individuals and society in healthcare and medical research, in particular in biobank based research and public health ethics. Joanna left CRB in 2013 to do a residency in Social Medicine at the Karolinska University Hospital.

Tove Godskesen, RN, PhD student
Tove Godskesen started her PhD studies in October 2010 after advanced level studies in both Caring Sciences and Public Health. She is a registered nurse (2006) and has worked at the Akademiska sjukhuset (Uppsala University Hospital) hematology clinic.
Maria Gottvall, RN, PhD student
Maria Gottvall started her PhD studies in December 2008. She is a registered nurse (2008). Her main area of interest is sexual and reproductive health. Maria defended her PhD thesis in February 2014.

Mats G. Hansson, BS, ThM, ThD, Professor of Biomedical Ethics, Director
Mats G. Hansson is the director of the Centre for Research Ethics & Bioethics and has conducted extensive research in biomedical ethics as principal investigator in several multi-disciplinary research projects dealing with issues ranging from ethical, social and legal aspects of the implementation of genetic diagnosis in clinical practice and the use of human tissue materials in research, to clinical and medical ethics. He holds an undergraduate degree in biology (1974) and a doctoral degree of theology (1991). Mats G. Hansson is Professor of Biomedical Ethics, funded by Uppsala University and the Uppsala County Council together. He also works as a clinical consultant at Akademiska sjukhuset (Uppsala University Hospital).

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

Yusuke Inoue, MPH, PhD, Guest researcher from the Department of Public Policy, Institute of Medical Science, University of Tokyo (IMSUT)
Yusuke Inoue joined CRB in October, 2012. His research interest deals with regulatory bioethics in biomedical research, especially concerning human tissue research and banking. He is also interested in the publication ethics of medical journals. Yusuke Inoue holds an undergraduate degree in Socio-Behavioral Science (2001), a master of Public Health (2003), and a doctoral degree in Public Health (2010) from Kyoto University, Japan. He has experience from several ethics advisory activities on large cohort studies and brain biobanking, including BioBank Japan, the Japan Environment and Children's Study, and the Japanese Society for Hygiene.
Li Jalmsell, MD, PhD student
Li Jalmsell started her PhD studies in Bioethics in 2008. She holds a degree in Medicine from Karolinska Institutet (2005) and a license to practice (2007). She also works as a medical doctor at the oncology unit in Visby, Gotland. Her main area of interest is the palliative care of dying children and how to improve it. Before joining the Centre for Research Ethics & Bioethics she worked with these issues at Karolinska Institutet.

Linus Johnsson, MD, PhD

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

Sofia Kälvemark Sporrong, PhD, Associated researcher
Sofia Kälvemark Sporrong received her PhD from Uppsala University in 2007. Her research deals with ethical competence and moral distress in health care, including pharmacies. Currently her research focuses on pharmacy practice and policy, and the pharmacy professions. Her background is undergraduate studies in social sciences.

Frida Kuhlau, PhD
Frida Kuhlau defended her thesis on dual use and responsible life science research in March 2013. She started her PhD studies in bioethics in 2007. She holds a degree in Political Science and was previously working in a project on chemical and biological warfare at the Stockholm International
Peace Research Institute (SIPRI) (2001-2007). Her main area of interest is how means and methods in bioethics can be used to prevent proliferation of biological weapons.

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

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

Deborah Mascalzoni, PhD Bioethics, Researcher
Deborah Mascalzoni joined CRB in April 2013. She adds to our competence on biobank and registry research and will work mainly with the 7th Framework programme RD-Connect. Deborah Mascalzoni worked on ELSI Issues related especially to the population based CHRIS project at the Center of Biomedicine, European Academy (EURAC). She completed her undergraduate studies in Philosophy (2005) and holds a PhD in Bioethics from the Faculty of Law at Bologna University (2005). She has also been teaching ethics at the 'Claudiana' University of Roma in Bolzano. She is a member of the Ethical board of South Tyrol and the local health system ethical board of Bolzano as well as the Telethon Advisory Board. She is involved in the WIKI platform of BBMRI.IT, a member of the BRIF project and a member of the ethical group of the International Genetic Epidemiological Society (IGES). Her main research interests are genetics and new technologies, informed consent, patient communication, privacy & data sharing and the role of stakeholders in medicine.

Malin Masterton, PhD, Postdoc
Malin Masterton's main area of interest is bioethics, and in particular ethical aspects connected to molecular biology. Her background is undergraduate studies in biology (molecular biology) at the University of Edinburgh (2002), followed by courses in practical philosophy at Uppsala University, and PhD studies in bioethics. Malin Masterton defended her thesis "Duties to Past Persons: Moral Standing and Posthumous Interests of Old Human Re- mains" in 2010. She started her post-doc at CRB looking at disaster victim identification and the role of the dead body. Before that, she looked at public
opinion of science and animal testing within the framework of the COMBINE consortium.

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

In her PhD project Amal Matar will study ethical issues concerning preconception genetic screening, as it raises general concerns of genetic testing and counseling, and the handling of information and risk assessments. It also raises questions surrounding the decision-making process and consent procedures, and concerns about screening programs. A central question to the project is how preconception genetic screening accentuates and influences our familial responsibilities. Her PhD project will be pursued in cooperation with The Ethics of Family in Health and Social Care Research Consortium.

Jessica Nihlen Fahlquist, PhD, Senior lecturer in Medical Ethics
Jessica Nihlen Fahlquist is a senior lecturer at the Centre for Research Ethics and Bioethics. She also works as a postdoctoral researcher at the Philosophy Section at Delft University of Technology in the Netherlands. Jessica's research focuses on applied ethics, and she has a particular interest in notions of moral responsibility. She has published articles in public health ethics, risk ethics, the ethics of technology and environmental ethics. Jessica received her PhD in Philosophy at the Division of Philosophy at the Royal Institute of Technology in Stockholm in 2008.

Karin Nordin, Professor of Caring Sciences
Karin Nordin is a licenced psychologist and Professor of Caring Sciences at the Department of Public Health and Caring Sciences. Her research at CRB focuses on genetic counselling and risk information. This research is also conducted in close collaboration with the University of Bergen, Norway.

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

Jane Reichel, Associate Professor of Administrative Law
Jane Reichel joined CRB in September 2011 to work with the legal aspects of research conducted on human tissue samples within the BBMRI.se net-
work. Jane Reichel is senior lecturer at the Department of Law at Uppsala University and is tied part-time to CRB.

**Lena Ring, Associated Researcher, Associate Professor of Pharmaceutical Outcomes Research**

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

**Karl Sallin, MD, PhD Student**

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

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

**Pär Segerdahl, PhD, Associate Professor of Philosophy, Senior researcher**

Pär Segerdahl investigates notions of nature and animal in animal ethics, animal welfare and various eco-philosophies, as well as in contemporary culture more generally. He holds a PhD in theoretical philosophy from Uppsala University (1993). He was a guest researcher at the Centre for Gender Research at Uppsala University from 2007-2009. Pär Segerdahl became associate professor of theoretical philosophy at Åbo Akademi Univeristy in 1998 and Uppsala University in 2001. He currently develops new ideas for
research on absolutism and relativism in the notion of morality. Pär Segerdahl is also involved in research communication for the BBMRI.se (Biobanking and Biomolecular Resources Research Infrastructure Sweden) and editor of the ethics blog and etikbloggen.

Pär Segerdahl is a member of Nordic Network for Philosophical Anthropology and The Nordic Wittgenstein Society.

Marit Silén, PhD, Postdoc
Marit Silén joined CRB in December 2011 to work on a project aimed at improving the ethical climate for staff in psychiatric outpatient care. She received her PhD in nursing from Jönköping University in 2011 and is also a registered nurse (2005).

Anna Lydia Svalastog, PhD, Associate Professor of Religious Studies, Associated researcher
Anna Lydia Svalastog has worked primarily on questions about cultural heritage and religion. She has conducted extensive studies on how images structure personal life and wrote her PhD thesis on reproduction and heterosexuality. Post doc projects have analysed how medical ethics structures risk handling procedures for plant science, and how research history and national politics have structured academic teaching and academic theories about Sámi people’s history and culture. Anna Lydia Svalastog holds a doctoral degree in Theology, History of Religion from Uppsala University (1998), and became Associate Professor in religious studies at Umeå University (2005). Anna Lydia Svalastog is currently looking at bioethical concerns regarding native people, and at the relation between public debate, cultural history and myths, and public opinion. She is a member of the research network Bio-objects and their boundaries, governing matters at the intersection of society, politics and science, and UppSam. She co-ordinates the research network Culture Health and Bioethics and the ad hoc group Riekkis.

Jennifer Viberg, BSc, MSc, PhD Student
Jennifer Viberg joined CRB in October 2011 where she is involved in the IMI-funded BTCure project on Rheumatoid Arthritis. She is a licensed Prosthetist and Orthotist. Before joining CRB she was a teacher at the Orthopeadics Engineering Programme (prosthetics and orthotics) at Jönköping University, School of Health Science.

Publications 2011-2013
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.

**Publications 2011-2013**


2. Atry A, Hansson MG, Kihlbom U, Cheating is the name of the game: Conventional cheating arguments fail to articulate moral responses to doping, Physical Culture and Sport. Studies and Research(ISSN 2081-2221)(EISSN 1899-4849).


Dissertations 2013


Agencies that support the work/Funding

In 2013 we signed contacts for several research grants for new projects. The largest was for 35 900 000 SEK from the Swedish Foundation for Humanities and Social Sciences (Riksbankens Jubileumsfond) for the international research collaboration “Mind the Risk”. We also received 2 265 525 SEK for our part in the EU Flagship Human Brain Project. The Swedish Cancer Society funds a project on follow up and treatment using computer based quality of life instruments (500 000 SEK). Selanders foundation also decided to support the PhD project on DNR decisions with 40 000 SEK.

Support from other organizations

Several staff have their salary covered by other organizations. The director Mats G. Hansson is covered 50 % by the Uppsala County Council.

Two persons are paid by other employers but work here. Sofia Lavén is a PhD student 30 % covered by her employer, the Uppsala County Council. Lena Ring is an adjunct professor 20 % covered by the Swedish Medical Products Agency.

The external funding we used in 2013:

<table>
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<tr>
<th>FUNDING AGENCY</th>
<th>PROJECT</th>
<th>AMOUNT (SEK)</th>
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<td>European Commission, FP 7</td>
<td>Euro-TEAM</td>
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<td>BBMRI-LPC</td>
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<td>The Swedish Agency for Health and Care Services Analysis</td>
<td>Repoer on integrity</td>
<td>180 000</td>
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<tr>
<td></td>
<td>Do Not Resuscitate (DNR) orders in oncology</td>
<td>40 000</td>
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<td>Selanders stiftelse</td>
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Research projects 2013

Autonomy and trust in biobank research (PhD project)

Collaborators:
- Linus Johnsson, MD, PhD student
- Mats G. Hansson, Professor of biomedical ethics, supervisor
- Gert Helgesson, Associate professor, Department of Learning, Information, Management and Ethics (LIME), Karolinska Institutet, supervisor
- Stefan Eriksson, Associate professor of research ethics, supervisor

People are often willing to participate in biobank research in spite of concerns raised in media about potential risks to personal integrity. Moreover, information about the research is often disregarded by participants. This suggests a connection between autonomy and trust; however, neither the nature of this connection nor the relative importance of these concepts is clear. In this project, these questions will be investigated. Factual inclination to participate in biobank research will be determined and contrasted with estimations made through contemporary attitude surveys. The concepts of autonomy and trust will be analyzed, their role in informed consent procedures elucidated, and their ethical value discussed.


Funding: AutoCure, BT-Cure, BBMRI.se.

At the intersection of curative and palliative treatment in paediatric oncology (PhD project)

Collaborators:
- Li Jalmsell, MD, PhD student
- Mats G. Hansson, Professor of biomedical ethics, supervisor
- Britt-Marie Frost, Department of Paediatric Oncology, Uppsala University Hospital (Akademiska sjukhuset), supervisor

Today there is no clear picture about how children in terminal care and their families perceive the meaning and importance of palliative care in the Nordic countries. How patients and their families see the distinction between curative and palliative treatment has primarily been a focus for retrospective interviews with parents and there is a lack of knowledge in particular regarding the clinical and moral significance of hope.
The degree of activity for patients in the terminal phase of care varies, but there is only anecdotal evidence available. We need to understand how different paediatric oncology departments manage the intersection of curative and palliative treatment and how children and their relatives perceive the different activities offered to them.

This project will:

- examine to what extent there is a distinctive focus on palliative treatment in departments of paediatric oncology in Denmark, Finland, Norway and Sweden.
- examine how children in terminal care and their families perceive the meaning and importance of palliative care.
- give an account of the clinical and moral significance of hope in paediatric oncology.

The project is designed with an integration of three different methodologies. It has a descriptive, a qualitative and a philosophical/theological component. Li Jalmsell will have her halftime thesis seminar in May 2013.

Funding: The Swedish Childhood Cancer Foundation (Barncancerfonden).

**BBMRI.se - Biobanking and Molecular Resource Infrastructure of Sweden: Ethical and legal aspects (WP7)**

Collaborators:
- Mats G. Hansson, Professor of Biomedical Ethics (WP leader)
- Kathinka Evers, Associate Professor, Senior Researcher
- Joanna Stjernschantz Forsberg, MD, PhD Student
- Anna-Sara Lind, Associate professor of Public Law
- Jane Reichel, Associate Professor of Administrative Law
- Pär Segerdahl, Associate Professor of Philosophy

BBMRI.se is a national effort for efficient and automated collection of biological material.

WP7 works with pressing ethical and legal questions rising from biobank related research. There are a number of ethical and legal aspects of research conducted on human tissue samples that need to be addressed in a professional and constructive manner. The proposed new act on biobanks, existing laws on personal data and public access to information and secrecy, exert an influence on what can and can’t be done with biobanks and data. A major obstacle for researchers is that laws in part overlap, but provide slightly different answers to some questions and fail to address certain aspects of research activities. This poses major challenges for the scientific community in their strife to produce knowledge that can benefit patients.

To meet these challenges, WP7 was expanded in the autumn 2011 to examine the legal aspects. Some questions have also been raised in the media on the ethics of biobank research, especially in connection to the large popu-
lation studies. WP7 will examine these questions and also provide answers to frequently asked questions (FAQ). WP7, together with the other work packages, plans to host a national biobank fair in Uppsala, Hands on biobanks.

Within the framework of BBMRI.se WP7 will:

- Assist the management of BBMRI.se and researchers with qualified legal and ethical advise and training.
- Be a knowledge centre for ethical management of biobank related research.
- Contribute to a constructive weighing of ethical interests in the field of biobanking.
- Constitute a competitive and attractive node for international cooperation on ethical and legal aspects of biobank research.
- Contribute to an initiated discussion on biobank related issues in society.
- Investigate how biobank research that protects integrity can be conducted.
- Investigate how biobanks can collaborate with national quality registries in an efficient and legal manner.
- Investigate the legal requirements for updating collections of samples thorough single mass-withdrawals from health-data registries.
- Investigate the legal prerequisites for using databases and biobanks for future unspecified purposes.
- Investigate the legal requirements for supplementing quality registries within the health care sector with blood and tissue samples.

Funding: The Swedish Research Council (Vetenskapsrådet).

**BTCure (Be The Cure)**

Collaborators:

- Mats G. Hansson, Professor of Biomedical Ethics
- Kathinka Evers, Associate professor of Philosophy
- Joanna Forsberg, PhD, Researcher
- Jennifer Viberg, PhD student

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. BTCure 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.

- **BTCure (Be The Cure)** focuses on Rheumatoid arthritis (RA) and RA-like diseases.
- BTCure has 33 partners. It is co-ordinated by professor Lars Klareskog, Karolinska Institutet and Professor Tom Huizinga, Leiden University Medical Centre.
- CRB 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.
- BTCure has received funding from the IMI call on Inflammation – Translational Research and Adaptive Immunity. Funding: IMI (Innovative Medicines Initiative).

DNR decisions within oncology and hematology care. Clinical and ethical perspectives (PhD project)

Collaborators:

- Mona Pettersson, RN, PhD student
- Anna Höglund, Associate Professor, supervisor
- Mariann Hedström, Senior Lecturer, Department of Public Health and Caring Sciences, supervisor
- Gunnar Birgegård, Professor, Department of Medical Sciences

The aim of this project is to investigate attitudes to and perceptions of ‘Do Not Resuscitate’ (DNR) orders among staff in oncology and hematology 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.

Within oncology and hematology 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 project consists of four studies:

1. In an interview study, using qualitative methodology, oncology and hematology nurses will be asked about their experiences and perceptions of DNR decisions.
2. In a similar qualitative study, physicians working within oncology and hematology 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 hematology 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.

Funding: The Swedish Cancer Society (Cancerfonden), Selanders stiftelse.

Dual use and responsible life science research – A bioethical approach (PhD project)
Collaborators:
- Frida Kuhlau, MA, PhD student
- Anna T. Höglund, Associate professor of ethics, supervisor
- Stefan Eriksson, Associate professor of research ethics, supervisor
- Kathinka Evers, Associate professor of philosophy, supervisor

This project will examine the responsibility of biomedical researchers in circumventing proliferation of biological material, technology and knowledge to actors with malicious intents. Much of the biomedical research conducted today is of ‘dual-use’ nature, which means that it can have both peaceful (civil) and military applications. The current perception of a bio-terrorist threat (due to recent terrorist events) and the subsequent security countermeasures, demands the scientific community to take responsibility and assist in protecting biological material and knowledge of concern. Central questions include; if biomedical researchers have a responsibility to minimize the risk of proliferation and, if so, what does that responsibility entail, what is the response to proposed obligations among life science researchers, and how is security consciousness to be implemented in life science research?

Frida Kuhlau defended her thesis “Responsible Conduct in Dual Use Research: Towards an Ethic of Deliberation in the Life Sciences” in March 2013.

Funding: Uppsala University.

Controlling chronic inflammatory diseases with combined efforts (COMBINE)
Collaborators:
- Mats G. Hansson, Professor of Biomedical Ethics
- Sofia Kälvemark, PhD, Researcher
- Malin Masterton, PhD, Researcher
• Tobias Renberg, PhD, Researcher

The COMBINE consortium aims to investigate how patients perceive research on chronic inflammation by creating a network of scientists, clinicians, patients and industrial representatives, which together can use unique Swedish advantages to improve understanding of why inflammatory diseases develop, what are the most essential goals for patients to achieve, and to develop and implement novel prevention and therapy for these diseases. The operational strategy is to create infrastructure and programs where systematic capture of data takes place in routine healthcare and is utilised in research, and where the same infrastructure is used to feed information from research back to healthcare.

The consortium consists of clinicians/scientists, biomedical scientists, epidemiologists, care scientists, bioethicists, members of patient organisation, and representatives from industry. The steering committee has been chosen to both represent all medical faculties/universities in Sweden and to have a track record of building functional national research networks. We suggest the formation of a new structure for a public private partnership between academia, care and industry in translational research, clinical trials and longitudinal patient studies where unique resources in Swedish health care and epidemiology are utilised. We also suggest a new structure for international collaboration utilising the same Swedish resources where investments from international partners can supplement investments from the Foundations and other national agencies.

The aims will be approached within 13 work packages (WP), each with distinct goals and budgets. The Centre for Research Ethics & Bioethics participates with Work Package 13: Ethics.


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

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
• Lena Ring, Associate Professor of Pharmaceutical Outcomes Research

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-centered, 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. CRB's 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.

Funding: The Swedish government's strategic investment in health and care research and 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.

Funding: The Swedish government's strategic investment in health and care research and the University of Gothenburg.

Efficacy and costs-effectiveness of physical training and behavioral medicine strategies in reducing fatigue, improving well-
being and disease outcome in cancer patients – a randomized intervention study with long term follow-up

Collaborators:
- Karin Nordin, Professor of Caring Sciences (PI)
- Lena Ring, Associate Professor of Pharmaceutical Outcomes Research
- Birgitta Johansson, PhD, senior lecturer, Department of Radiology, Oncology and Radiation Science, Uppsala University
- Cecilia Arving, PhD, Department of Public Health and Caring Sciences, Uppsala University

This project will evaluate the efficacy and cost-effectiveness of individually tailored high and low intensity physical training, with or without behavioural medicine support strategies (BM).

Recent relevant reviews have shown evidence for positive effects of physical training during and after cancer treatments but they emphasized the lack of well-designed randomized controlled intervention studies with large sample sizes.

The project will look at:
- Cancer Related Fatigue (CRF)
- Quality of Life (QoL)
- Mood disturbance
- Adherence to the cancer treatment
- Adverse effects
- Disease outcome
- Return to a daily life after completed treatment

We will also describe changes in inflammatory markers and cytokines related to physical training and gene expressions following training to investigate whether these serve as mediators for the effects of physical training on CRF and QoL.

This project is a collaboration between researchers from Uppsala University, Lund University and Linköping University in Sweden and the University of Bergen in Norway. It is a controlled multi-centre study looking at newly diagnosed breast, colorectal and prostate cancer patients during adjuvant therapy at three different centres in Sweden; Uppsala, Lund and Linköping.

Researchers at CRB are responsible for parts of a work package that deals with outcomes.

Funding: The Swedish Cancer Society (Cancerfonden).

Ethical aspects of biobank research – Individual rights vs. the public good? (PhD project)

Collaborators:
- Joanna Forsberg, MD, PhD
- Mats Hansson, Professor of biomedical ethics, supervisor
- Stefan Eriksson, Associate professor of research ethics, supervisor
In this project bioethical methods and theories are used to analyze the tenability and implications of viewing biobank based medical research from a public health perspective. Consequences of adopting such a view on biobank research are investigated, for instance regarding the issues of obtaining informed consent and returning individual results to participants. Putative rights and duties of individuals and society in the context of healthcare and medical research are explored. This research project is undertaken from an applied ethics perspective, and its focus is therefore on the practical consequences and policy implications of different philosophical positions, rather than on their theoretical underpinnings.


Funding: AutoCure, BBMRI.se, CCPRB and Pfizer.

EURO-TEAM
Collaborators:
- Mats G. Hansson, Professor of Biomedical Ethics (WP-leader)

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.

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.

Funding: EU, 7th Framework Programme.

Factors associated with participation in phase 1 and phase 3 oncology trials (PhD project)

Collaborators:
• Tove Godskesen, RN, PhD student
• Ulrik Kihlbom, supervisor
• Karin Nordin, Professor, Department of Public Health and Caring Sciences, supervisor
• Peter Nygren, Professor, Department of Radiology, Oncology and Radiation Science, supervisor

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

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

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

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

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

Funding: The Swedish Cancer Society (Cancerfonden).

Gender aspects in telenursing
Collaborators:
- Elenor Kaminsky, Senior researcher, Health Services Research
- Anna T. Höglund, Associate Professor of Ethics
- Marianne Carlsson, Professor of Caring Sciences, supervisor
- Inger Knutsson Holmström, Professor, Mälardalens Högskola

This project will use theories on gender and intersectionality to investigate the role of factors such as gender, age and ethnicity in Swedish telenursing. An instrument that can investigate gender competence in telenursing and evaluate the effect of an educational intervention with focus on gender competence for telenurses will also be developed.

This research will:
- Investigate gender differences in the communication and outcome of telenursing consultations (measured in GP appointments, self-care advice or referrals to other care providers) and explore these differences through the use of theories on gender and intersectionality.
- Develop a tool that can measure gender competence in health care practice in general and telenursing in particular.
- Test an educational intervention for telenurses, with focus on gender, age and intersectionality.

Funding: The Swedish Research Council (Vetenskapsrådet).

How do patients prioritize in situations of limited resources?
Collaborators:
- Mats G. Hansson, Professor of Biomedical Ethics
- Lilianne Eninger, Associate Professor, Senior Researcher, Department of Psychology, Uppsala University
- Li Tsai, MD, Associate Professor, Orthopaedic Surgery, Karolinska University Hospital, Huddinge
Leif Ryd, MD, Professor of Orthopaedic Surgery, Karolinska University Hospital, Huddinge.
Håkan Magnusson, MD, Orthopaedic Surgery, Karolinska University Hospital, Huddinge

This is a collaboration with researchers in orthopaedic surgery at the Karolinska University Hospital.

In times of limited resources within the health care sector, a pertinent issue for both health care administrators and politicians is that of making priorities between patients in need of treatment. An interesting aspect is that neither the public, nor the patients themselves, have been involved in discussion on prioritizations. This research project aims to investigate how patients would make priorities among other patients on a waiting-list for major joint (hip- or knee) replacement, when resources are strained and it isn’t possible to provide treatment for all patients. A spectrum of motivations guiding patient priorities will be identified and documented. The prioritizations made by an orthopaedic patient group will be compared to priorities suggested by orthopaedic surgeons, general practitioners, and a representative sample of the general population.

Thirty patients on the waiting list for major joint replacement at the Karolinska University Hospital in Huddinge were invited to participate in the first phase of the study, and experienced orthopaedic surgeons assessed these patients’ relative priority for surgery using a validated clinical scoring instrument. Patients were also asked to complete questionnaires including psychosocial aspects of their health, such as quality of life. From these assessments, 10 patient vignettes, including clinical as well as psychosocial aspects, have been constructed and included in a questionnaire. In the second phase of the study, this questionnaire will be sent to a new group of orthopaedic patients on the waiting list at the Karolinska University Hospital, to a representative sample of the public, and to orthopaedic surgeons and general practitioners.

Funding: The Vardal Foundation For Health Care Sciences and Allergy Research (Vårdalstiftelsen) and the Uppsala County Council (Landstinget i Uppsala län).

Improving the ethical climate in psychiatry outpatient clinics

Collaborators:
Marit Silén, PhD, Post doc
Kristina Haglund, Senior lecturer, Department of Neuroscience, Uppsala University & Uppsala University Hospital
Mats G. Hansson, Professor of Biomedical Ethics
Mia Ramklint, MD PhD, clinical lecturer, Department of Neuroscience, Uppsala University
Children, adolescents and adults come to psychiatric outpatient clinics to be assessed, diagnosed and treated. Their symptoms and diagnosis range depression, anxiety disorders, bipolar disorders, eating disorders to obsessive compulsive disorders and post-traumatic stress disorder.

At these clinics they meet a number of professions: physicians, nurses, social workers, psychologists and physiotherapists. Sometimes, difficult decisions have to be made regarding referral to inpatient care or restraint. For the staff, these decisions raise a number of ethical questions. These questions range from how to balance the wish to do good with the respect for the patient’s autonomy to priorities between different kinds of need. Ethical questions to be solved while handling balancing a high workload and demanding patients.

The staff at outpatient psychiatric clinics needs to be prepared to handle these kinds of ethical challenges. Previously, the ethics rounds method has been used in order to try to strengthen healthcare staff’s ability to handle ethically difficult situations. It has been shown to increase mutual understanding and decrease professional hierarchies. This could have consequences for the way in which ethical problems are handled. Besides legal and other regulations and the healthcare ethical principles, the relationships at the specific workplace have an impact on how ethical problems are handled. Business ethics research has used the concept of ethical climate in order to describe how ethical problems are handled, and what relationships and practices that either hinder or facilitate a positive ethical climate.

In the present project we will investigate whether ethics rounds can improve the ethical climate in psychiatry outpatient clinics. The project will have a quasi-experimental design, using both control and intervention groups measured before and after the intervention.

Funding: AFA Insurance (AFA Försäkring).

Mind the Risk
Collaborators:
- Mats Hansson, Professor of Biomedical ethics and director of the Centre for Research Ethics & Bioethics at Uppsala University. Principal Investigator.
- Ulrik Kihlbom, PhD, Senior Lecturer in Medical Ethics, CRB
- Sofia Lavén, MD, PhD student, CRB
- Silke Schicktanz, Professor of Philosophy, Dept. of Medical Ethics and History of Medicine, George-August University of Göttingen.
- Julia Inthorn, PhD in philosophy, Senior Researcher, Dept. of Medical Ethics and History of Medicine, George-August University of Göttingen and Associated Researcher at CRB
- Sabine Wöhlke, PhD student Dept. of Medical Ethics and History of Medicine, George-August University of Göttingen
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.

Modern technology also gives us increasing possibilities to diagnose and predict disease using DNA-analysis of tissue, cell-lines and blood samples. This makes individualized treatment and prevention of disease easier, but it also raises questions and concerns when it comes to evaluating and dealing with genetic risk information, both as a professional health care giver and as a patient.

For six years The Centre for Research Ethics & Bioethics will be coordinating an international interdisciplinary research project with the ultimate
goal to support health care, patients and policy makers when it comes evaluation and handling genetic risk information.

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

The scientific structure of the international research collaboration includes philosophy, psychology, medicine, health economics and will also include empirical studies of risk research.

The project is a research initiative. Among other things, the research group is planning an interactive, web based game, SimGene, that will be a tool for assimilating and understanding risk information.

Funding: The Swedish Foundation for Humanities and Social Sciences (Riksbankens Jubileumsfond).

Phys-Can
Collaborators:
- Karin Nordin, Professor of Caring Sciences
- Lena Ring, Adjunct professor Quality of Life
- Birgitta Johansson, PhD, senior lecturer, Department of Radiology, Oncology and Radiation Science, Uppsala University
- Cecilia Arving, PhD, Department of Public Health and Caring Sciences, Uppsala University

Efficacy and costs-effectiveness of physical training and behavioral medicine strategies in reducing fatigue, improving well-being and disease outcome in cancer patients – a randomized intervention study with long term follow-up

Recent relevant reviews have shown evidence for positive effects of physical training during and after cancer treatments but they emphasized the lack of well-designed randomized controlled intervention studies with large sample sizes.

This project is a collaboration between researchers from Uppsala University, Lund University and Linköping University in Sweden and the University of Bergen in Norway.

It is a controlled multi-centre study looking at newly diagnosed breast, colorectal and prostate cancer patients during adjuvant therapy at three different centres in Sweden; Uppsala, Lund and Linköping.

This project will evaluate the efficacy and cost-effectiveness of individually tailored high and low intensity physical training, with or without behavioural medicine support strategies (BM).

Researchers at CRB are involved in WP 3:
- WP1: Patient recruitment/clinical implementation. This work package involves collaboration with patient representatives.
• WP2: Interventions/methods. This work package is divided into three parts: Physical training, behavioural medicine and statistics.
• WP3: Outcomes Physical training/cytokines. This work package looks at both fatigue and quality of life.

Funding: The Swedish Cancer Society (Cancerfonden).

Prevention of doping through increased understanding of the sense of fairness in sport (PhD project)

Collaborators:
• Ashkan Atry, MA, PhD student
• Mats G. Hansson, Professor of biomedical ethics, supervisor
• Ulrik Kihlbom, PhD, supervisor

This PhD project studies if, and in what sense doping is incompatible with fairness in sport and whether notions of fairness and fair play may function as a foundation upon which arguments opposing doping in sport can based on in a constructive manner.

Doping sometimes is perceived as an admissible method used in order to render the sport fairer by levelling an otherwise unfair dispersal of natural talents in sport. In this view, those with less talent are given a possibility to compensate by means of doping and this will make sport fairer. However, the term fairness seems to have different meanings in the arguments concerning doping in general and gene-doping in particular.

This project constitutes an attempt to achieve an “inside-out” perspective in regard to ethical and philosophical questions concerning performance enhancement in sport. This entails that by understanding sport as a form of social activity, and by placing this activity within the broader social context, this project aims at addressing ethical and philosophical issues by considering, as a starting point, qualities that are inherent to sport.

Ashkan Atry will defend his thesis in October 2013.

Funding: The Swedish National Centre for Research in Sports (Centrum för idrottsforskning) and the Swedish School of Sport and Health Sciences (Gymnastik och idrottskolan).

RD-Connect

Collaborators:
• Mats G. Hansson, Professor of Biomedical Ethics, (WP leader)

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.

A separate work package will address ethical, legal and social issues (ELSI) with the following objectives:

- 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.
- Engage with relevant stakeholders, e.g. patient organizations and patient groups, clinical and research networks, legislators and policymakers, pharma industry.
- Develop a proposal for an expedient regulatory framework for linking of medical and personal data related to RD on a European and global level.

Funding: EU, 7th Framework Programme.

Research biobanks and custodianship

Collaborators:

- Yusuke Inoue, Guest researcher from the Department of Public Policy, Institute of Medical Science, University of Tokyo (IMSUT)

This project looks at biobank custodians: who can control and manage a sustainable use of these resources and how they manage it. A previous study on biobank laws in Nordic countries found that there are contrasting understandings of “custodianship”.

What should the relationship between researchers and biobanks look like? The recent trend towards a broader consent gives each sample a wider potential for use. This means that each sample has a lot of potential users, and can be used in several ways. However, given the limited and depleteable nature of the samples, their use needs to be carefully controlled. We also have to take the future needs of researchers into account when we decide what to do with samples today.

This project is an empirical study of:

- How to set a standard for allocation of samples: Priority setting vs equality of access - the conflict between open access (equality) and the sustainability of biobanks.
- Incentives for the researchers who originally collects samples: The collector's incentive vs the neutrality of access/decision making.

The methods used are document analysis on legal and ethical discussions on biobank custodianships along with interviews with experts with biobank custodians, researchers (as users) and opinion leaders.

Funding: the Japanese Society for the Promotion of Science and the Royal Swedish Academy of Sciences (Kungliga vetenskapsakademin).
SIMSAM-INFRA

Collaborators:
- Magnus Stenbeck, project manager, Department of Clinical Neuroscience, Insurance medicine, Karolinska Institutet
- Anna Holmström, Unit of Epidemiology and Global Health, Umeå University
- Joanna Forsberg, PhD
- Peter Somogyi, Department of Medical Epidemiology and Biostatistics (MEB), Karolinska Institutet

SIMSAM is short for "Swedish Initiative for Research on Microdata in the Social And Medical Sciences", an initiative supported by the Swedish Research Council via its Committee for Research Infrastructure. By giving priority to interdisciplinary, innovative register-based research, SIMSAM will contribute to better public health and increased knowledge of social issues, for instance which factors in childhood that result in increased risk for obesity or cancer later in life. The initiative is also intended to promote improved and expanded use of registers in research and to increase the knowledge of how registry research is organized in Sweden and internationally. Six research nodes and one graduate school have been granted funding for five years from December 2008 until November 2013.

This is an infrastructure project for population registers in epidemiology and in the social sciences funded by the Swedish Research Council. The project priorities are to A) develop the information from SIMSAM to the research community and provide descriptions of the SIMSAM research data bases, data management work performed on the register data, contact persons, availability, and other additional information related to these. The project will also B) develop a website for register data containing overarching information in Swedish and English on available register data from the central and regional/local authorities (including social, demographic, health care, biobank data sources). CRB is involved in C) the analysis of the ethical foundation on which current legislation is based, in order to propose rules and applications more appropriate for research. Finally, SIMSAM-INFRA will D) review security solutions, ethical principles and ongoing reforms in the area of personal data for research, and propose legally acceptable security solutions for distributed (federated and other) data systems involving person identified data.

Funding: The Swedish Research Council.

Vaccine against HPV – Ethical and social aspects: Survey, exploration and intervention (PhD project)

Collaborators:
- Maria Gottvall, RN, PhD student
- Tanja Tydén, Professor of caring sciences, supervisor
Cervical cancer is caused by the human papillomavirus (HPV). Today, there are more than 100 different variants of HPV; of these, HPV types 16 and 18 are the most common oncogene virus types, which cause approximately 70% of all cases of cervical cancer. This cancer affects about 450 women annually in Sweden. HPV is even related to vaginal and anal cancer and to known cancers in the vulva, penis and pharynx.

Recently, two very effective vaccines against HPV have been registered. The National Board of Health and Welfare has recommended that the new vaccine should be included in the general vaccination program for children and youths in Sweden. The vaccine is very expensive and the recommendation was preceded by an intense debate on its cost effectiveness. The new HPV vaccine raises many questions from both ethical and gender perspectives, e.g., how youths and their parents should be informed; what effects the vaccine would have on youngster’s sexual habits; and how boys might be informed on HPV as the vaccine will only be given to girls.

The purposes of this project are:

- To survey youth’s knowledge on sexually transmitted infections and their consequences, together with their views on the use of condoms, with special focus upon HPV and the new vaccine against it.
- Through an explorative interview study, using focus group method, examine how midwives and school nurses view their task of informing youths and their parents on the vaccine against HPV.
- With these results as a base, carry out a targeted intervention, with the aim of increasing youth’s knowledge of STIs in general and of HPV in particular.
- To present constructive suggestions of clinical guidance for midwives and school nurses concerning the social and ethical aspects of the new HPV vaccine.

Funding: The Swedish Cancer Society (Cancerfonden).

Quality of life assessments in clinical practice

Collaborators:

- Hanna Fagerlind, PhD, Department of Pharmacy, Uppsala University
- Bengt Glimelius, Professor, Department of Radiology, Oncology and Radiation Science, Uppsala University
- Mathilde Hedlund-Lindberg, PhD, Department of Neurobiology, Care Sciences and Society (NVS), Karolinska Institutet
- Åsa Kettis, Associate Professor, Planning division, Uppsala University
- Lena Ring, Associate Professor of Pharmaceutical Outcomes Research
This project started in 2005 and is funded by The Swedish Cancer Society. The main aim is to evaluate the effectiveness of Quality of Life (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 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.

Funding: The Swedish Cancer Society.

International Collaborations

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

Mind the Risk
A multidisciplinary research collaboration on how to manage and handle genetic risk information, generated by information technology.

Biobank and Registry Ethics
CRB participates in several European networks and EU-funded projects on the ethical aspects of biobanking: the EU Network of Excellence CCPRB (Cancer control using population based registries and biobanks) that ended recently; AutoCure - Curing autoimmune rheumatic diseases, an EU funded research project within the sixth framework programme; BBMRI.se (Biobanking and Molecular Resource Infrastructure of Sweden) funded by the Swedish Research Council; and the IMI (Innovative Medicines Initiative) funded BTCure, focusing on Rheumatoid Arthritis (RA) and RA-like diseases; BBMRI-LPC is an EU 7th Framework project focusing on Large prospective cohort (LPC) studies; BiobankCloud is an EU 7th Framework project aiming to build the first open and viable platform-as-a-service (PaaS) for storage and analysis of digitized genomic data; Euro-TEAM is an EU 7th Framework project aiming towards early diagnosis and biomarker validation in arthritis management; and RD-connect, an EU 7th framework programme that aims to build an integrated platform connecting registries, biobanks and clinical bioinformatics for rare disease research.

Culture, Health and Bioethics
Together with researchers from universities and museums in Australia, Norway, Sweden and the United Kingdom, CRB has formed a multi-disciplinary network on health, culture and bioethics. The network is funded by Riksbankens Jubileumsfond (Bank of Sweden Tercentenary Foundation).

Family Ethics
CRB collaborates with ECEC, CBmE and PEALS on family ethics health and social care with funding from Riksbankens Jubileumsfond for the initiation of this international multi-centre research collaboration.

Neuroethics
CRB has extensive collaborations on Neuroethics with Collège de France and the Pasteur Institute in Paris. We also collaborate with the Centro de Investigaciones Filosóficas (CIF) and the Institute of Cognitive Neurology (INECO) in Buenos Aires. We are also part of the EU-flagship Human Brain Project.

Undergraduate Teaching
At the Faculty of Medicine, ethics has for several years been part of the curriculum for nurses and doctors. Within the nurse's programme, ethics courses totalling 7,5 credits are distributed over the three years of the programme. For medical doctors, medical ethics and medical law is part of the profes-
sional training curriculum that runs through the programme from the first to the eleventh semester.

In the midwifes programme we are responsible for 4,5 credits. We also teach within the specialist nurses programmes and other educational programmes at Uppsala University.

Advanced level courses

We offer an advanced level course in ethics and public health (7,5 credits) that can be taken both as a single subject course and as an electable part of the master programme in public health. The course is offered in Swedish. Our web based advanced level course in neuroethics (7,5 credits) has increased in popularity and was offered again in Spring 2012.

We teach ethics at the Uppsala Graduate School for Biomedical Research (UGSBR), in a curriculum offered also to students at the master programmes in infection biology and biomedicine.

Postgraduate Teaching

- Science and Technology: A course in research ethics (2 credits) is compulsory for PhD students admitted after July 1, 2008. Preciously, this course was divided into two separate courses (Research ethics A [1 credit] and Research ethics B [1 credit]. The B-course now runs parallel to allow those students who have taken the A course to meet the requirements. The courses are open to all postgraduate students at the faculty.
- Medicine and Pharmacy: Research ethics and philosophy of science (1,5 credit) is compulsory for PhD students. The course can be taken separately, or as part of a 7,5 credits integrated course called Introduction to scientific research.
- Social Sciences: the electable 4 credits course tailored for the social sciences was not offered in 2013 but will be in 2013.

Conferences and symposia

In 2012 we were responsible for arranging the BBMRI.se user conference “HandsOn: Biobanks” on September 20-21. The conference was organized by BBMRI.se together with BBMRI.fi and Biobank Norway. We were also involved in arranging the pre-conference “International Biobanking Summit: Future directions” on September 19. The pre-conference was organized by P3G, ISBER, BioSHaRE.eu, ENGAGE, BBMRI.se and ESBB.
Both meetings attracted around 400 participants from 27 different countries. The HandsOn-concept was interactive. Apart from plenary lectures, seminars and poster presentations, we organized “idea labs” and other kinds of interactive workshops. We also had an interactive exhibition as part of the conference programme. This exhibition called “The Route” allowed participants to follow the sample through the research process and discuss the value of research.

The concept was very successful and BBMRI-NL asked to bring it to the Netherlands in 2013. The next meeting will be held in the Hague on November 21-22.

Public outreach

The CRB website, www.crb.uu.se had around 28 282 unique visitors in 2013, (compared to 26 495 in 2012), on average visiting our website 1,59 times (45 220 visits). Most visits were from Sweden, followed by Germany, Italy, the Netherlands, Norway, China, France, United Kingdom, Poland and India (with 500 page views or more).

CRB has several e-mail lists, together making up around 2 500 subscribers. We use our lists to distribute information about conferences, seminars and to distribute our electronic newsletter and conference information.

Our higher seminar is open and invitations are distributed to a list where subscribers include people who have registered for more information, plus the practical philosophy group at the Department of Philosophy, and the ethics group at the Department of Theology at Uppsala University, ethics lecturers at the Swedish University of Agricultural Sciences and the ethics group at the Department of Learning, Information, Management and Ethics at Karolinska Institutet. We also collaborate with the seminar on medical law at the Department of law, whose LLD students are also on this list.

CRB’s staff are also 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.

Social media: The Ethics Blog and Etikbloggen

After the KoF research evaluation, CRB started an ethics blog to meet the panel’s suggestion that CRB could become more visible. Pär Segerdahl, Associate Professor of Theoretical Philosophy, was recruited as editor.

The blog is funded by BBMRI.se. It is published in two versions, in Swedish (www.etikbloggen.crb.uu.se) and in English (www.ethicsblog.crb.uu.se). 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 blog has 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 discuss questions of current interest”
- “We find new aspects”
- “We like challenging questions”
- “We have a clinical perspective”
- “In dialogue with the public”

The blog serves to update readers about bioethically relevant news. It participates in ethical debates. It explains bioethical research. It comments on recent publications and current events. It spreads information about CRB research and explains our ideas. It communicates with researchers, practitioners, politicians, and the general public. Finally, the blog tries to vitalize the ethical debate by identifying questions and perspectives that are novel, challenging and scientifically well-grounded.

In 2012, the Swedish “Etikbloggen” had 10,357 visits, with an average 28 visits per day. Most of the visitors were of course from Sweden, but the blog also had substantial numbers of visits from Finland and Norway. The English version, the “Ethics blog” have a little less visits. In 2013, the blog was visited 6,675 times, with an average of 18 visits per day. Most of the visitors were from Sweden, closely followed by the United States and Canada. The rest of the visitors were mainly from the United Kingdom, Finland, Germany, India, the Phillipines, Italy, Australia, the Netherlands and France with 100 visits or more.
Clinical Nutrition and Metabolism

Research Group Leader Professor Tommy Cederholm

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

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

Members of the group 2013

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<th>Member</th>
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<td>Tommy Cederholm</td>
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<td>Brita Karlström</td>
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<td>Dietitian</td>
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<td>Bengt Vessby</td>
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<td>Ulf Risérus</td>
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<td>Per Sjögren</td>
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<td>Ulf Holmbäck</td>
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<td>Anja Saletti</td>
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<td>Afsaneh Koochek</td>
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<td>Viola Adamsson</td>
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<td>David Iggman</td>
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<td>Johanna Törmä</td>
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Partly affiliated or associated to CNM

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<td>Wulf Becker</td>
<td>Associate professor</td>
<td>Chief nutritionist</td>
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<td>Stefan Branth</td>
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<td>Annika Smedman</td>
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<td>Torbjörn Åkerfeldt</td>
<td>PhD student</td>
<td>MD</td>
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**2013**


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

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- The Swedish Research Council (VR): 500 000
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- Medicinska Fakultetsmedel/KOF: 200 000
- Zetterlings stiftelse: 240 000
- Regionala Forskningsrådet Uppsala-Örebro: 225 000
- University of Tabuk, The Kingdom of Saudi Arabia: 500 000
- Uppsala County Council – ALF: 975 000
- Stockholm County Council – ALF (The OmegAD Trial): 400 000
- Uppsala Municipality: 750 000
- Uppsala Municipality: 560 000
- Nestec: 3 000 000
- Arla/Semper/Svensk Mjölk/Skånemejerier: 380 000
- Throne Holst: 72 000
Research projects

On-going projects

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

Clinical trials concern understanding of sarcopenic mechanisms during disease and senescence, as well as potential effects of designed amino acid solutions and vitamin D either alone or in combination with physical exercise, to sarcopenic old adults.

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

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

Special emphasis is laid on studying pre-defined dietary patterns and their relation to health outcomes, like cancer, cognition and sarcopenia, but also to identify underlying dietary patterns in the Swedish population.

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

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

Future promising research at CNM

- Understanding sarcopenia from clinical, epidemiological and molecular perspectives, and its treatment.
- Implementation techniques of nutritional routines and development of assessment tools for meals in elderly care.
- Dietary patterns and potential effects on development of cognitive impairment and 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 composition, including lean body mass and 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.
• Potential Vitamin D relations with health outcomes like cognition and sarcopenia in old adults.
• Individualized treatment of child obesity.
Disability and Habilitation

Research Group Leader Professor Karin Sonnander

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

- Development and test of assessment methods, interventions and documentation in services for people with disabilities.
- The significance of received targeted support for self-perceived health.
- Participatory research in which the facilitating and restraining aspects of the environment as well as the participation and perspectives of persons with disabilities, professionals and significant others are highlighted.

Members and external partners of the group during 2013

Members

Päivi Adolfsson, PhD, Centre for Disability Research, Uppsala University
Monica Blom Johansson, PhD Faculty of Medicine
Gunilla Eriksson, PhD Faculty of Medicine, associated researcher
Johan Glad, BA, PhD student
Carina Gustafsson, PhD Faculty of Medicine, associated researcher
Gerth Hedov, PhD Faculty of Medicine, associated researcher
Gunnel Janeslått, PhD Faculty of Medicine, associated researcher
Kjerstin Larsson, PhD Faculty of Medicine, associated researcher
Helene Lidström, PhD Faculty of Medicine, associated researcher
Helena Lindstedt, PhD Faculty of Medicine, senior researcher
Mia Pless, PhD Faculty of Medicine, associated researcher
Ieva Reine, PhD Faculty of Medicine, associated researcher
Karin Sonnander, PhD, professor
Annika Terner, BA, PhD student
Õie Umb-Carlsson, PhD Faculty of Medicine, senior researcher
Helena Wandin, BA, PhD student

External partners
- Ann-Britt Ivarsson, PhD Faculty of Medicine, associate professor, School of Health and Medical Sciences, Örebro University.
- Ulla Jergeby, PhD, National Board of Health and Welfare, Stockholm.
- Niklas Källberg, PhD, Stockholm School of Economics, and Helseplan consulting Group.
- Per Lindberg, PhD, professor, Department of Psychology, Uppsala University.
- Liselotte Norling Hermansson, PhD Faculty of Medicine, Clinical Research Centre, Örebro University Hospital, Örebro.
- Edward Palmer, PhD, adjunct professor, Department of Economics, Uppsala Center for Labor Studies, Uppsala University.
- Ingvor Pettersson, PhD Faculty of Medicine, senior lecturer, School of Health and Medical Sciences, Örebro University.
- Birgitta Rosberg, registered occupational therapist, Uppsala University Hospital.
- 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.
- Anna Cristina Åberg, PhD Faculty of Medicine, associate professor, Geriatrics, Department of Public Health and Caring Sciences.

Publications 2011-2013


perspective of individuals with aphasia. *International Journal of Language and Communication Disorders, 47* (2), 144-55.


Conference oral presentations and poster presentations


8. **Larsson, K.** (2012). Disease prevention – tobacco and alcohol – in Uppsala County. U-fold Conference (Forum for research on addiction to medical products and illegal drugs), Uppsala (Oral presentation).


Dissertations 2013


Agencies that support the work/Funding (in SEK)

Swedish Council for Working Life and Social Research (FAS) 1 230 000
Regional Research Council in Uppsala-Örebro Region 350 000
The Sävstaholm Foundation 430 000
Södermalm District Council, Stockholm City/
The National Board of Health and Welfare 100 000
The Swedish Institute of Assistive Technology (SIAT) 450 000
Medical Faculty (Uppsala University) 125 000
Uppsala County Council 142 000
The Norrbacka Eugenia Foundation 100 000
Jämtlands County Council 300 000
The National Board of Health and Welfare 540 000
Uppsala County Council 1 230 000
Related tasks (members)

- Chairperson, member of the board, Centre for Disability Research, Uppsala University (Karin Sonnander).
- Member of the board, Centre for Disability Research, Uppsala University (Johan Glad).
- Member of the board of the Sävstaholm Foundation, Stockholm (Karin Sonnander).
- Chairperson, member of the board of the Carola and Erik Tengström Foundation, Uppsala (Karin Sonnander).
- National editor Scandinavian Journal on Disability Research (Karin Sonnander).
- Reviewer of grant applications, The Swedish Association of Occupational Therapists (FSA) (Helena Lindstedt).
- Academic teacher trainer, Uppsala University (Öie Umb-Carlsson).

Examinations and evaluations (members)

During 2013 assignments as external expert senior lectureship, Stockholm University, promotion to full professor, Göteborg University, expert review grant proposal, Forte and peer reviews Disability & Rehabilitation (Karin Sonnander).


Third stream activities (members)

Associated member of the management group, Centre for Disability, Uppsala County Council (Karin Sonnander).

Associated member of the committee for Research and Development, Uppsala Regional Council (Karin Sonnander).

Editor National Newsletter on Disability Research (Forskning om funktionshinder pågår), published by Centre for Disability Research, Uppsala University (Karin Sonnander).

Reference group at Public Health Agency of Sweden regarding the Government's strategy for the implementation of disability policy 2011-2016 (Öie Umb-Carlsson).

Single lectures for professionals arranged by MISA (Methods for Individual support in work/activity) and for people with intellectual disabilities arranged by FUB The Swedish National Association for Persons with Intellectual Disability (Öie Umb-Carlsson).
Open lecture arranged by Center for Disability Research, Uppsala University (Œie Umb-Carlsson).

Evaluation of the project “Individual goal setting and evaluation of persons with mental disability”. Södermalm district council, Stockholm (Helena Lindstedt).

Teaching and supervision of Goal Attainment Scaling for staff in the Södermalm district council, Stockholm (Helena Lindstedt).

Teaching 2013 (members)

Nursing Program
Scientific Method 4.5 Higher Education Credits (Monica Blom Johansson lectures and group work on Statistical Package for the Social Sciences (SPSS). Nursing and Nursing methods 15 Higher Education Credits (Œie Umb-Carlsson lectures on Discrimination Act and Act concerning support and service for persons with certain functional impairments, seminar on Treatment and Disability and essay tutorials).

Caring Science Freestanding courses
Essay Course 15 Higher Education Credits (essay examination) (Helena Lindstedt).

Single lectures and examinations (Œie Umb-Carlsson) and essay examination (Karin Sonnander).

Master Program in Public Health
Essay tutorials and essay examination (Karin Sonnander) and lectures and examination (Œie Umb-Carlsson).

Freestanding courses
Course coordinator including lectures and seminars (Œie Umb-Carlsson) and examination (Karin Sonnander) for the course Impairment and Disability-Introductory Course 7.5 Higher Education Credits. The course is freestanding and elective within the Medical Program, the Nursing Program and the Physiotherapy Program.

Joint course coordination and examination (Œie Umb-Carlsson) for the commissioned course Understanding and Providing Leadership Based on the National Basic Value System for the Elderly, 7.5 Higher Education Credits.

Speech-Language Pathology Programme (Department of Neuroscience)
Head of Speech-Language Pathology Programme, Director of studies, and Course coordinator, lectures, group work and tutorials (master’s thesis) on introductory and advanced levels (Monica Blom Johansson).
Extra mural teaching
Single lectures Karolinska Institutet (Helena Lindstedt).

Research Projects

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

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

Aided communication between persons with Rett syndrome and their interaction partners
Participants: Helena Wandin, Per Lindberg, Karin Sonnander.
The aim is to increase the knowledge of aided communication intervention targeting people with Rett syndrome. The different studies aim at 1) examining Swedish speech and language pathologists’ experiences of communication intervention, especially aided communication intervention provided to persons with Rett syndrome 2) developing and evaluating instruments that measure different communicative aspects in interaction between individuals with Rett syndrome and a close communication partner 3) evaluating an aided communication intervention targeting the social network of persons with Rett syndrome. Caregivers take an active part in designing, performing and evaluating the intervention for each individual.
People with mental health disorder, implementing individual treatment goals and long-term follow-up in psychiatric rehabilitation

Participants: Helena Lindstedt, Marianne Carlsson, Ann-Britt Ivarsson.

The aim is to implement and evaluate a treatment concept with individualized measurable methodology and structured long-term follow-up (Goal Attainment Scaling, GAS) for people with mental health disorders. Patients (n=20) report subjective occupational performance, daily occupation satisfaction and quality of life. Occupational therapists (n=5) report work satisfaction.

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 develop and evaluate activities and strategies supporting continuous quality improvement.

Returning to work after stroke


The purpose of the project is to develop an evidence-based client-centred intervention programme addressing return to work after stroke and evaluate the effect of and the experiences of participating in the intervention programme.

The HOME Inventory, Home Observation for Measurement of the Environment – A Swedish Adaptation

Participants: Johan Glad, Carina Gustafsson, Ulla Jergeby, Karin Sonnander.

Environmental characteristics have a direct impinge on children’s development. Thus, when investigating children’s needs and parents’ capacity in a developmental context, it is meaningful and important to look into the child’s immediate environment. The Home Observation for Measurement of the Environment (HOME) Inventory is one of the earliest and most widely used methods to address different aspects of the home environment that have a direct impact on the child. The aim of this thesis is to assess the relevance of the HOME Inventory and to develop a reliable and valid Swedish version. Psychometric properties and issues pertinent to administration and implementation in a Swedish context will be established based on a national sample (n=150).
The electronic health record system: professional use and patient safety
Participants: Annika Terner, Helena Lindstedt, Mia Pless, Karin Sonnander.

The use of electronic health records (EHRs) for documentation in health care has increased greatly during the first decade of the 21st century. The EHR serves as an important tool for documentation and exchange of health care information as well as a source of information for patients according to the Swedish Patient Data Act. The quality of health care and patient safety is expected to improve by providing complete and unambiguous information that is easily accessible by means of searchable predefined headings. The aim of this thesis is to investigate inter-professional use and patient safety by studying a multi-professional EHR system in a Swedish county council. Research questions concern characteristics of existing pre-defined headings in the EHR system, to what extent they are applied across eight different health professions as well as shared by these professional groups and what aspects of health, health care and legislation headings reflect.

Prevalence of International Classification of Functioning, Disability and Health (ICF) components in a tertiary Swedish Pain Clinic
Participants: Kjerstin Larsson, Ruth Kusec Fredriksson, Carl Molander.

The aim is to examine what and how frequently ICF components occur in psychosocial assessments of chronic pain patients made by medical social worker documented in medical files in a tertiary pain clinic setting. A clinical data-mining was performed from psychosocial assessments made by 12 medical social workers. A total of 66 patients gave their informed consent to a search of ICF components in their medical files. A data retrieval form including the ICF components Activity, Participation and Environmental factors was used for the data collection. Data is analyzed by categorization of ICF components and descriptive statistics.

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

Environmental help or hindrance?

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

Stroke patients' experiences and opinions of care and rehabilitation
Participants: Kjerstin Larsson, Öie Umb-Carlsson.
The aim of this project is to enhance the knowledge about how stroke patients’ experience and value hospital care, information about stroke and stroke related subjects, and rehabilitation assessed three months after a stroke event. Data is collected from patients’ comments in follow up questionnaires from the National Qualitative Register of care and rehabilitation (RiksStroke) and analyzed by qualitative thematic analysis.

Importance of personal assistance financed by the Swedish social insurance for meeting national health objectives for men and women with serious functional impairment
The aim of this project is to analyze the significance of the state assistance benefit for the well being and health of people with state personal assistance. A direct relationship is drawn to the public health objectives and the project is conducted with a gender perspective. The study will be based on cohorts from 2010 to 2014 and contains a large number of analysis variables, such as demographic and health variables, including health-related selection, participation and empowerment, labor market participation and economic factors. Identification of the mechanisms that explain the relationship between personal assistance and self-perceived health is central to the analysis.

Men and women with intellectual disabilities and quality of life
Participants: Öie Umb-Carlsson, Kjerstin Larsson.
The aim is to uncover the essence of the phenomenon quality of life from the perspective of women and men with intellectual disabilities. Women and men with mild and moderate intellectual disability are interviewed concerning their lived experiences of quality of life (n=21).

Long-term rehabilitation for children and adolescents after acquired brain injury
Participants: Helene Lidström, Anette Höglund, Gunnar Ahlsten,
The aim of the study is to investigate the incidence and prevalence of acquired brain injury in children aged 2-16 years treated ≥ 1 day of care at Children's Hospital, University Hospital, Uppsala, and describe their functioning, activities and participation at discharge. In addition, the aim is to investigate the children's participation in everyday activities, as well as the children and families’ need of support, assistive technology and or adaptations, 1-4 years after discharge.

3. Participatory research

People with intellectual disabilities as participants in the research process
Participant: Öie Umb-Carlsson.

The aim of the project is to gain experience and further knowledge in involving people with intellectual disabilities in the research process. People with intellectual disabilities are involved in validation of a quality of life model, in identifying issues of importance in a quality of life scale and in production of the research report.
Family Medicine and Preventive Medicine

Research group leader associate professor Per Kristiansson, chair

General Practice is the core of the health care system with a broad spectrum of health problems to be cared for by professionals of several disciplines. This is an opportunity and a challenge for both education and research.

The unit of Family Medicine and Preventive Medicine continuous to play an appreciated and awarded role in teaching medical students about general practice and preventive care. The academic staff works with a large and dedicated group of clinical teachers all around Uppsala County to deliver our medical curriculum. Apart from education on undergraduate level the academic staff is engaged in education on master and doctoral level.

Our research in Family Medicine emanates from the multidisciplinary perspective of primary health care and conducted by the large group of researchers throughout the Uppsala-Örebro region. Our present research profile includes 6 major program areas: social insurance medicine, asthma and COPD, drug utilization, diabetes and cardiovascular disease, pain and reproductive health.

Our research within Preventive Medicine addresses mechanisms of social inequities in health, theories of the life course approach in current epidemiology, pertinent empirical topics like the combined effect of early life and later life risk factors on health and morbidity and risk factors triggering the onset of health problems, and the feasibility and efficiency of interventions.

A common theme for the stress research is enhancing the scientific understanding of risk- and resiliency factors, including bio-psycho-social mechanisms, of relevance for sustained and equitable occupational and social health and wellbeing. Research includes effective use of health care resources, and its implications for major health care stakeholders, including patients, staff, and third-party payers.

Members of the group during 2013:

Research supervisors:

Mansour Alemi  Associate researcher, PhD
Dan Andersson  Associate researcher, MD, PhD
Ingrid Anderzén  Researcher, PhD
Malin André  Associate researcher, MD, PhD
Eva-Maria Annerbäck  Associate researcher, MD, PhD
Bengt Arnetz  Professor, MD, PhD
Judith Arnetz  Associate professor, PhD
Annika Bardel  Associate lecturer, MD, PhD
Britta Berglund  Associate researcher, PhD
Karol Björkegren  Lecturer, MD, PhD
Stefan Blomberg  Postdoc, MD, PhD
Johan Bogefeldt  Associate researcher, MD, PhD
Kristina Bröms  Associate researcher, MD, PhD
Gunilla Burell  Senior researcher, Psychologist, PhD
Stephen Butler  Associate researcher, MD
Jan Cederholm  Associate professor, MD, PhD
Lars Englund  Associate researcher, MD, PhD
Sevek Engström  Associate researcher, PhD, dentist
Margaretha Eriksson  Researcher, PhD
Marie Grunnesjö  Postdoc, PhD
Mats Gulliksson  Associate researcher, MD, PhD
Catharina Gustavsson  Associate researcher, PhD
Christina Halford  Associate researcher, MD, PhD
David Hallman  Postdoc, PhD
Johan Hallqvist  Professor, MD, PhD
Björn Hallström  Associate researcher, MD, PhD
Anna Hofsten  Associate researcher, MD, licentiate
Sara Holmberg  Postdoc, MD, PhD
Gunnar Johansson  Adjunct professor, MD, PhD
Linus Johnsson  Associate researcher, MD, PhD
Lena Källings  Associate researcher, PhD
Per Kristiansson  Associate professor, MD, PhD
Karim Lisspers  Associate researcher, MD, PhD
Monica Löfvander  Associate professor, MD, PhD
Lena Nordgren  Associate researcher, PhD
Gunilla Norrmén  Postdoc, MD, PhD
Lena Olai  Associate researcher, PhD
Magnus Peterson  Associate researcher, MD, PhD
Rathi Ramji  Research assistant, MPh
Nils Rodhe  Associate researcher, MD, PhD
Åke Schwan  Postdoc, MD, PhD
Carina Seidel  Associate researcher, MD, PhD
Jan Ståhlhammar  Associate researcher, MD, PhD
Björn Ställberg  Associate researcher, MD, PhD
Kurt Svärdssudd  Professor emeritus, MD, PhD
Malin Swartling  Postdoc, MD, PhD
Eva Thorell  Associate researcher, MD, PhD
Keld Vaegter, Associate researcher, MD, PhD
Petra Vogt, Associate researcher, MD, PhD
Rolf Wahlström, Associate researcher, MD, PhD
Mari-Anne Wallander, Associate professor, Epidemiologist, PhD
Thorne Wallman, Associate lecturer, MD, PhD
Clairy Wiholm, Associate researcher, PhD
Ture Ålander, Associate researcher, MD, PhD

Doctorial students:
Åsa Andersén, PhD student, Master in Public Health
Regina Bendrik, PhD student, Physiotherapist
Anne Björk, PhD student, MD
Charlotte Björkenstam, PhD student, BSc
Emma Björkenstam, PhD student, BSc
Anders Carlberg, PhD student, Psychotherapist
Lars Carlsson, PhD student, MD
Anna-Sofia von Celsing, PhD student, MD
Frida Fröberg, PhD student, BSc
Grape Viding Tina, PhD Student, RN
Johanna Haraldsson, PhD Student, MD
Stefan Jansson, PhD student, MD
Bo Karlsson, PhD student, MD
Kyriaki Kosidou, PhD student, MD
Sofia Lavén, PhD student, MD
Anne Lindgren, PhD student, Physiotherapist
Lena Lundholm, PhD student, BSc
Linda Lännerström, PhD student, RN
Mats Martinell, PhD student, MD
Elisabet Sundgren, PhD student, RN
Jenny Söderberg, PhD student, RN
Thomas Torstensson, PhD student, Physiotherapist

External:
Joel Ager, PhD, Professor
James Blessman, MD
Kerstin Ekberg, Professor, Psychologist, Department of Medical and Health Sciences, Linköping University
Anna Finnes, psychologist, Uppsala University Hospital
Lars Frimanson, PhD, lecturer, Department of Business Studies, Uppsala University
Hikmet Jamil, Professor, Wayne State University
Thomas Karlsson, PhD student, Centre for Musculoskeletal Research, University of Gävle,
Niels Kuster, PhD, Professor, ITIS Foundation, Switzerland
Kjerstin Larsson, PhD, Disability and Habilitation, Dept of Public Health and Caring Sciences
Phil Levy, MD
Anna Liljestam Hurtigh, Research assistant, Master in Education
Per Lindberg, lecturer, Associate Professor, Centre for Musculoskeletal Research, University of Gävle,
Mark Luborsky, PhD, Professor
Mark Lumley, PhD, Professor, Wayne State University
Eugene Lyskov, PhD, Associate Professor, College of Gävle
Per Lytsy, MD, PhD, Sociomedical epidemiology, Dept of Public Health and Caring Sciences
Johan Lökk, MD, PhD, Associate Professor, Karolinska Institutet
Wasim Maziak, PhD
Maria Nilsson, PhD, Associate Professor
Carina Pettersson, Physiotherapist
Nnamdi Pole, Associate Professor, Smith College
Karin Przyklen, PhD, Professor
Douglas Ruden, Associate Professor, Wayne State University
Weisong Shi, PhD, Professor, Wayne State University
Christian Ståhl, PhD, Department of Medical and Health Sciences, Linköping University
Mark Upfal, MD, MPH, Assistant Professor
Eva Vingård, MD, Professor
Ludmila Zhdanova, PhD, Assistant Professor

Publications 2011-2013:

1) Articles from former Family Medicine and Clinical Epidemiology
2) Articles from former Preventive Medicine
3) Articles from former Social Medicine

2013


15. 1) Butler S. The IMMPACT factor or IMMPACT strikes again! **Pain** 2013;154(11): 2243-44.


34. 2) Hultin H, Hallqvist J, Alexanderson K, Johansson G, Lindholm C, Lundberg I, Möller J. Lack of adjustment latitude at work as a trig-

35. 2) Ivert T, Brorsson B. Similar survival 15 years after coronary artery surgery irrespective of left main stem stenosis. *Scand Cardiovasc J* 2013;47(1);42-49.


38. 3) Jamil HJ, Rajan AK, Grzybowski M Fakhouri M, Arnetz B. Obesity and overweight in ethnic minorities of the Detroit Metropolitan area of Michigan. *J Community Health* 2014;39(2):301-09 [Published online: 29 August 2013].


Peterson M, Breivik H. Even a “simple” pain condition such as “Tennis Elbow” is not only a somatic experience: body and mind are inseparable entities. *Scand J Pain* 2013;4(3):153-54.


Shirazi M, Lonka K, Parikh SV, Ristner G, Alaeddini F, Sadeghi M, Wahlström R. A tailored educational intervention improves doctor's


2012


87. 1) Ekström N, Miftaraj M, Svensson AM, Sundell Andersson K, Cederholm J, Zethelius B, Gudbjörnsdottir S, Eliasson B. Glucose-lowering treatment and clinical results in 163 121 patients with type


106. 1) Jonsdottir IH, Halford C, Eek F. Mental health and salivary cortisol. The role of saliva cortisol measurement in health and disease (red


196. Sandelowsky H, Ställberg B, Nager A, Hasselstrom J. High prevalence of undiagnosed chronic obstructive pulmonary disease in


**Dissertations 2013:**

Agencies that support our work / Funding 2013 (SEK)

Uppsala County Council (ALF) 2,820,000
Uppsala and the surrounding County Councils 4,250,000
The Swedish Social Insurance Agency 200,000
The Swedish Research Council 2,920,000
European Social Fund 2,000,000
AFA 130,000
REHSAM 2,700,000
ArbetsRehab -- Organization for Financial Coordination Uppsala County 500,000
The Royal Foundation of Sweden (Kungafonden) 460,000
The Swedish Research Council (Impact of Religion Program, Program Leader, The Swedish Council for Working Life and Social Research) 700,000

Education

Medical Programme - Professional Development

Annika Bardel, responsible for training of student tutors.
Karin Björkegren, responsible for terms 1 and 2 and director of undergraduate studies.
Bo Karlsson, responsible for terms 3, 4 and 11.
Beside the above mentioned many other members from Family Medicine and Preventive Medicine are taking part on different educational levels:

Research projects

Social Insurance Medicine

Ingrid Anderzén, Lars Englund, Johan Hallqvist, Kurt Svärdsudd, and Thorne Wallman.

Regional social insurance research group in the Uppsala-Örebro region (RUFS)
RUFS is the Swedish acronym for the regional social insurance research group in the Uppsala Örebro Region in Sweden. This research group consists of senior researchers and PhD students from the primary health care county councils of Dalarna, Sörmland, Västmanland, Örebro and Uppsala, Uppsala and Örebro universities and one pharmacist, PhD, from Umeå University. It was established in May 2010. Members are participating in one national social insurance research group, SPID, with four annual meetings and the international research group EUMASS.

The natural history of disability pension – risk factors, track record and health consequences

A consortium including the research group for cardiovascular epidemiology at the Sahlgrenska Academy, Gothenburg, the Swedish Social Insurance Agency and our unit of Family Medicine and Preventive Medicine was created to perform a project aiming at analysing the course of events leading to disability pension (track record), to find factors which, in addition to the underlying disease, affect the course of events, and to determine the consequences in terms of health situation, quality of life, continued health care utilisation and survival as compared with the corresponding general population.

The study population was created using data from five ongoing population studies with approximately 7,000 men and women who have been followed since 1980-1993 and onwards. The database has generated one PhD thesis in 2008 (Thorne Wallman) and four articles during 2011-2013: two published [94, 95] and two in manuscript.

(For number in brackets – see “Publications 2011-2013” on page 131-151)

Determinants for return to work among sickness certified patients in general practice

This work is based on a project carried out during eight months in 2004 at a Primary Health Care Centre in Eskilstuna, Sweden. The overall purpose was early rehabilitation of sick-listed individuals, considered to be at risk of long-term sickness absence, in cooperation with the Swedish Social Insurance Agency, jobseekers agency and the county council for social support, in order to regain work ability. The early prediction of patients at risk of long-term sickness absence is essential for identification of individuals in need of rehabilitation measures. The aim of this study was to analyse possible determinants of return to work and their relative impact. All 943 patients aged 18 to 63 years, sickness certified at this Primary Health Care Centre from January until 31 August 2004, were followed up for three years. Baseline information on age, sex, sick leave diagnosis, extent of sick leave, employment status, and sickness absence during the year before baseline was ob-
tained, as was information on all compensated days of sick leave, disability pension and death during follow-up. The two most influential variables on return to work was sick leave because of psychiatric disease and sick leave track record [135]. This study was presented in an oral presentation and a poster at The 2nd Nordic Conference in work-related rehabilitation, in Grenå, Denmark in September 2012 [von Celsing AS, Björkegren K, Eriksson HG, Eriksson M, Svärdssudd K, Wallman T. Early prediction of patients at risk for long term sickness absence]. We have also analysed whether the most important determinants for return to work used in a risk assessment tool (nomogram). The results were compared to a categorisation, performed by a team of experienced rehabilitation professionals, considering six risk factors for long-term sickness absence from the sickness certificate, The team categorised all sick-listed individuals into two groups, group 1 (n=447) at high risk, and group 2 (n=496) with less risk for long-term sickness absence.

Furthermore, the effects of the rehabilitation intervention in cooperation with primary health care, the Swedish Social Insurance Agency, Jobseekers Agency and the County Council for Social support, will be studied. Do sick listed individuals regain work ability after an intervention to a greater extent than those who did not receive any intervention at all? The project has so far generated one published article [135], and one under final review “Predicting return to work among sickness certified patients in general practice: Properties of two assessment tools”. The project is generating one PhD thesis (Anna-Sophia von Celsing).

Experiences of sick-listing – Nurses’ and patients’ participation in the sick-listing process

The objective of this project is to describe experiences of sick-listing from a nurse and a patient perspective. In study I fourteen nurses working with telephone advisory services in primary health care centres in Sweden were interviewed in groups. In the group interviews the nurses’ experiences of managing sick-listing issues were explored. The nurses experienced stress and difficulties related to being gatekeepers and related to the act of balancing different demands from patients, co-workers and the organisation. The project was presented by a poster at The 2nd Nordic conference on work-oriented rehabilitation, in Grenå, Denmark in September 2012 [Lännerström L, Wallman T, Söderbäck M. Nurses’ experiences of managing sick-listing issues in telephone advisory Services] and has generated one published article [113]. Sixteen people on long-term sick-leave were interviewed individually in study II. Findings revealed that the participants’ experienced that their life-worlds were radically changed when they became sick-listed. They described losing their independence in the process of stepping out of working society, attending the mandatory steps in the rehabilitation chain and having numerous encounters with professionals. The most conspicuous find-
nings were the fact that stopping working brought with it so many changes, the participants’ feelings of powerlessness in the process, and their experiences of offensive treatment by and/or encounters with professionals. This part of the study has generated one published article [45]. The project is generating one PhD thesis (Linda Lännerström).

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Factors in health care and patients affecting the risk of long-term sick leave

“RUMPVALS” – is an acronym for “Randomized study of early multidisciplinary assessment in a primary care centre to prevent long-term sick leave” in Swedish. Patients who visited doctors for psychiatric or musculoskeletal problems and were sick-listed were invited to participate in the study. After randomization half of the participants were assessed by a physiotherapist, psychotherapist and occupational therapist. The other half received “regular care”, which did not include such early assessments. Our hypothesis was that such assessments would result in faster and more adequate rehabilitation leading to faster recover and less need of sick leave. In this trial the intervention group was sick-listed longer. This project was presented by a poster at The 2nd Nordic Conference in work-related rehabilitation, Grenå Denmark, in September 2012 [Carlsson L, Englund L, Hallqvist J, Wallman T. Early multidisciplinary assessment resulted in longer periods of sick-leave: a randomized controlled trial in a primary health care center] and at The 6th European Public Health Conference (EUPHA) in Brussels 2013. One article is published [16].

In another project GP’s experiences of working with sick leave after the changes in the Swedish social security system was analyzed. A descriptive qualitative inductive focus group discussion approach was chosen. Assigning sick leave was still perceived by Swedish GPs as a burdensome task. However, the system changes in recent years, in the Swedish social security system, have facilitated this work. Cooperation with other professionals regarding the sick leave cases is perceived positively by Swedish GPs. One article is submitted for publication. The project is generating one PhD thesis (Lars Carlsson).

Research area - Absenteeism and Return to Work

In collaboration with the Swedish Social Insurance Administration, the Swedish Public Employment Service, and the Psychiatric Division at 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 indi-
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.

VITALIS – An RTC study to support women on long term sick leave to return to working life through ACT or Team evaluation

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 have been completed during 2013. Approximately 400 women on long term sick leave due to pain, stress, depression and/or anxiety symptoms, identified by the National Insurance Agency in Uppsala County 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 one year follow-up data collection is completed and the two year data collection is ongoing. The evaluation of the project is receiving financial support from REHSAM (forskning om arbetsrehabilitering).

The project has been presented by posters at The 2nd Nordic Conference in work-related rehabilitation in Grenå Danmark in September 2012 [Anderzén I, Lytsy P, Finnes A. Vitalis – back to life and back to work] the Work, Stress and Health Conference in Los Angeles, USA in May 2013 [Anderzén I, Lytsy P, Finnes A. Vitalis – back to life and back to work] and also at The 11th Stress research conference – New Frontiers in Swedish Stress Research - what is underway? in Gothenburg in May 2013 [Andersén Å, Larsson K, Lytsy P, Anderzén I. Self-efficacy in women on long term sick leave – the Vitalis project]. The project has so far generated one submitted article [Lytsy P, Larsson K, Anderzén I. Health in women on long term sick leave due to
pain or mental illness]. The project will also generate two articles in a PhD thesis (Åsa Andersén).

Participants in the project are Ingrid Anderzén, Åsa Andersén, Anna Liljestam Hurtigh, and Per Lytsy.

**DIRIGO 1 and 2 – “I control”**

Dirigo 1 and 2 are two ongoing projects funded by The European Social Fund (ESF) and is 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 goal is that about 1800 individuals will participate in the project. 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 evaluate 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 [137].

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 will be completed in 2014 and final reports are presented in September 2014. The projects end up with a conference the 5 of May 2014 in Stockholm.

Participants in the research team are Ingrid Anderzén, Åsa Andersén, Kjerstin Larsson. Externals are Kerstin Ekberg, Christian Ståhl, and Eva V-ingård.

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**UMiA**

The project “UMiA” is founded by the European Social Fund (ESF) and is operated by The Social Insurance Office in Stockholm. The aims of the project are 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 will be completed in 2014. During 2012 and 2013 three work reports have been completed and presented for the employees in the project. The project UMiA will generate two articles in a PhD thesis (Åsa Andersén).

Participants in the evaluation process are Ingrid Anderzén, Åsa Andersén and Kjerstin Larsson.

Pain and musculo-skeletal disorders
Participants: Karin Björkegren, Stefan Blomberg, Johan Bogefeldt, Marie Grunnesjö, Per Kristiansson, Magnus Peterson, Kurt Svärdsudd, and Mari-Ann Wallander.

Epicondylosis
Tennis elbow (epicondylitis) is a common pain condition that heals spontaneously within three months in 90% of cases. In the remaining 10% the condition becomes “chronic” or persistent and the diagnosis changed to epicondylosis. This project has three main parts:

2. A randomized controlled trial of different types of graded exercise as treatment for this condition.
3. An experimental study investigate the pathophysiology of the condition by imaging methods.

The first part was fulfilled in a postal questionnaire study involving general practitioners and physiotherapists, which showed that a large number of methods were used, some of which were not tested for efficacy, and even some that had been shown to be ineffective.

The second part was fulfilled in a double randomised controlled clinical trial in which the effect of exercise versus wait-and-see was first tested, and then the effect of two treatment methods (eccentric and concentric exercise) were compared. The study involved more than 200 patients in a multicentre setting in Uppsala and Linköping. A publication on exercise versus wait-and-see has been published [190]. A manuscript on eccentric versus concentric exercise is under review [Peterson M, Butler S, Eriksson M, Svärdsudd K: A randomised controlled trial of eccentric versus concentric exercise in chronic tennis elbow (lateral epicondylosis)].

The third part was fulfilled by positron emission tomography (PET) of physiological processes associated with pain in the peripheral painful tissue of the healthy compared to the affected elbow. The PET scan data have been analysed in cooperation with the Uppsala PET-centre and a manuscript has been published [48]. The project has generated one PhD thesis in 2011 [Magnus Peterson. Chronic tennis elbow: aspects on pathogenesis and
Cognitive behavioral therapy in fibromyalgia

The main purpose in this project was to assess the effects of cognitive behavioural therapy (CBT) given to fibromyalgia patients 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 have been collected through questionnaires and blood samples. The project has been performed in collaboration with the section for biological research on drug dependence at Uppsala University. The project has been presented by a poster at The International Congress of Behavioral Medicine in Budapest 2012 [Karlsson B, Anderberg UM, Burell G, Nyberg F, Svärdsudd K. Substance P (SP) levels are reduced after distress management with cognitive behavioural therapy (CBT) in women with the fibromyalgia syndrome (FMS): A randomised controlled clinical study]. An abstract submission has been sent to The International Congress of Behavioral Medicine in Groningen 2014 [Karlsson B, et al Neuropeptide Y levels are reduced after cognitive behavioural therapy (CBT) in women with fibromyalgia]. An article has been submitted and a halv-time seminar was given in 2013. The project is generating one PhD thesis (Bo Karlsson).

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Asthma, allergy and COPD

Participants: Kristina Bröms, Gunnar Johansson, Karin Lisspers, Björn Ställberg and Kurt Svärdsudd.

A national study of the health of children at allergy avoidance and conventional day care centres in Sweden

The main purpose is to assess whether special allergy avoidance day care centres improves the situation for allergic children. All such existing day care centres in the country were identified and ordinary day care centres in the vicinity were chosen as controls. All received a postal questionnaire regarding the physical environment of the school. Considerably less allergo-
generic environments at the allergy avoidance centres than in the control centres has been shown.

A postal questionnaire was sent to parents of 8,700 children at the day-care centres. It has been shown that population density, as a proxy for degree of urbanisation, has effects on age and sex-specific prevalence of asthma in Swedish preschool children. One report focused on the prevalence and co-occurrence of asthma and allergic manifestations [14]. In a third publication the asthma incidence and its determinants was estimated [80]. The project has generated one PhD thesis in 2010 (Kristina Bröms).

The Praxis-study asthma/COPD

The aim of the Praxis-study is to compare asthma and COPD guidelines with the actual care. A postal survey in 2005 was answered by 1,210 randomly selected patients with asthma and 1,113 with COPD from 56 randomly selected primary health care centres and outpatient clinics at 14 hospitals in the Uppsala-Örebro health care region. The records of these patients have also been examined. 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 [197]. A fourth report about sex-related differences in asthma has been published [43] and was a part of Karin Lisspers’ dissertation 2008. A fifth report regarding dyspnoea, obstruction, smoking and exacerbations (DOSE index) and mortality has been published [128]. A sixth report about quality of life in COPD (CCQ) and mortality has been published [127] and a seventh about exacerbations in COPD has been published [60]. An eight report of asthma control has been submitted. A follow-up investigation has been started in 2012 with new longitudinal data from the cohort of asthma and COPD patients from 2005.

The PRAXIS-project has generated one PhD thesis 2013 (Josefin Sundh, Department of Respiratory Medicine, Örebro University Hospital), and is 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. A predoctoral student, Anna Källander, has started to work with the asthma part of the PRAXIS-study in 2012.

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

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International research collaboration in asthma and COPD in primary care

Karin Lisspers and Björn Ställberg are involved in 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 [119]. 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 submitted [Kruis A, Ställberg B, Jones R, Tsiligianni I, Lisspers K, Molen T, Kocks JW, Chavannes N. Real-life COPD patients compared to large COPD study populations: an UNLOCK external validity study]. Lisspers and Ställberg are the leads of two new research projects within UNLOCK, one about asthma and one about COPD.

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 publication has been published from this research collaboration [196].

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 [68].

Clinical trials

Björn Ställberg was a member in the steering committee for a study about treatment of rhino-sinuites, the SOSAR-study [124]. Karin Lisspers was a member of the steering committee for a study regarding screening for COPD, the DETECT-study [133].

The NO-KOL study

This study was performed at one single centre, Nyby health care centre. 40 patients with chronic obstructive pulmonary disease (COPD) were random-
ized 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 [Malinovschi A, Johansson G, Venge P, Hedström H, Alving K. 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
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 [65].

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

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. By extraction of data from 80 primary health care centres data were obtained 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 Pre-
scription Register. Data on social-economic status has also be collected from Statistics Sweden (SCB). The merging of data has been performed by the National Board of Health and Welfare. The software program Pygargus Customized eXtraction Program (CXP) was used to extract patient data from the electronic patient records of the participating primary care centres for all patients with a diagnosis of COPD (ICD 10: J44) and/or prescription of drugs in the ATC class R03 (pharmaceuticals for obstructive lung diseases). The social security number of identified patients was immediately replaced with a study ID-number for further anonymous processing of data. No identification of patients is possible once the database is finalized. Collected data are being processed.

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. Three papers has been published [39, 42, 59] from the PATHOS study and a forth manuscript is submitted.

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

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.

**How can COPD patients with risk for exacerbations be identified? A prospective cross-sectional study in primary and secondary care**

A new prospective study in collaboration with the research Centre in Gävle and the Department of Medical Sciences: Respiratory Medicine & Allergology, Uppsala University has started during 2013.

Karin Lisspers, Björn Ställberg and Kristina Bröms are members of the steering committee. The aim of the study is to find clinical tools for identifying patients with risk for COPD exacerbations.

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**Utilisation of pharmaceuticals**

Participants: Annika Bardel, Keld Vaegter, Kurt Svärdsudd, and Mari-Ann Wallander.
Womens utilisation of pharmaceuticals
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. We presented the results in four reports during 2000-2009 and it has generated one PhD thesis in 2007 (Annika Bardel). In the last report we studied the reported symptom prevalence across age and use of pharmaceuticals.

Symptom reporting has also been tested in the consort dataset including more than 17,000 observations in men and women 25-99 years old. In 2012 have two articles been published where among all self-rated health has been is focus [94, 95].

The relationship between 30 symptoms reported by men and women have also been examined. The results were presented at Sörmland county R&D 2011, 2012 and 2013. We now intend to examine the relationship between symptom reporting among men and women and their sick-listing, disability pension, survival and use of hospital care.

The project is being led by Mari-Ann Wallander and Annika Bardel and is receiving financial support by Sörmland county R&D and Uppsala University.

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Rational drug prescribing
This project is based on the registration of prescribed pharmaceuticals in the county of Storstrøm in southern Denmark. Ninety-four practices for general practitioners were involved. The aim was to study factors leading to rational drug prescribing. In the first report, prescription data from the 94 practices (DDD/1,000 listed patients for 13 drug groups) were extracted from the database and published in 2010. Every six months for seven years a letter was then sent to each practice, asking about the level of prescriptions, and how they thought it compared with all the other practices.

In the second part of the project, a trained general practitioner made two visits, one year apart, to each practice. The GPs in the practice were asked to indicate their level of prescriptions, and to estimate how they thought that level compared with the levels of all the other practices. The results of the first visit were somewhat better than chance, while on the second occasion they had improved significantly. A report has been submitted for publication [136].

In the third part of the project the 94 practices were randomized to two groups: an intervention group and a control group, to investigate the prescription of antibiotics (ATC group J). The groups were then switched for the next intervention, to investigate the prescription of non steroid anti inflammatory drugs (NSAID) (ATC group M01). The same general practitioner as above visited the 94 practices once a year and discussed the use of anti-
biotics in half of the practices and the use of NSAIDs in the other half. The effects of these visits in terms of prescriptions were followed by examining register data. Two papers are in preprint [“Effect of outreach visits on the prescribing of non-steroid anti-inflammatory drugs in general practice: A randomised controlled trial in southern Denmark” and “Reducing the prescribing of antibiotics in general practices through outreach visits: a randomised controlled trial in southern Denmark”]. The project has generated one PhD thesis in 2013 [Keld Vaegter. Promoting Rational Drug Prescribing in General Practice. Medical Science. Uppsala University].

Pharmacoepidemiology

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.

We have longstanding research collaboration with Dr Luis A García Rodríguez and colleagues at Centro Español de Investigación Farmacoepidemiológica-CEIFE (Spanish Centre for Pharmacoepidemiologic Research) which has resulted in numerous publications on the natural history of diseases including respiratory diseases such as COPD and pneumonia, diabetes, gastroesophageal reflux disease and irritable bowel disorder, rheumatoid arthritis cardiovascular diseases like atrial fibrillation, MI, chest pain and also studies investigating the safety and utilization of a new statin, rosuvastatin.

In the study of the natural history of gastroesophageal reflux disease, research has also been done and published in collaboration with a research group in Bologna, Italy and researchers from several Chinese Universities.

In recent years, we have also had research collaboration with Professor John Dent, Adelaide, Professor Roger Jones, London, Professor Christos Lionis, Kreta, Professor Ken Rothman, Boston, Professor Hershel Jick, Boston, Professor Susan Jick, Boston, Professor Alexander Walker, Boston and Professor David Price, Aberdeen.

The research collaboration with especially Centro Español de Investigación Farmacoepidemiológica (CEIFE) has continued in three major areas namely: an epidemiological project on meningioma in the UK, an epidemiological project in haemorrhagic stroke and a third project investigating on the use of prescription contraceptive methods in the UK general population.

Methods and results of these projects have been published in peer reviewed journals during the above mentioned period.

Further research has been conducted in collaboration with the Boston Collaborative Drug Surveillance Program with among others Professor Susan Jick investigating on the risk of mortality in patients with multiple sclerosis in comparison with the general population. Results from this project are due for publication in 2014.
One further project has been finalized during 2013 dealing with the risk for acute liver injury in patients treated with antimicrobials. The study has been conducted in collaboration with researchers from the US and Spain and publications of the results are due in 2014.

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Cardiovascular disease and diabetes
Dan Andersson, Bengt Arnetz, Judy Arnetz, Jan Cederholm, Sevek Engström, Mats Gulliksson, Johan Hallqvist, Gunnar Johansson, Lena Kallings, Lena Olai, Jan Stålhammar and Kurt Svärdsudd.

Determinants for the survival of diabetes patients
This project is based on the 776 diabetes patients followed and treated at Laxå primary health care centre since 1972 and 3,880 referents from the general population matched to the 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 [40].

A fourth report has been submitted studying if screening of diabetes compared with clinical detection is advantageous in terms of reduced mortality and cardiovascular disease incidence [Jansson S, Andersson DKG, Svärdsudd K. Mortality and cardiovascular outcomes in patients detected by screening or clinically diagnosed type 2 diabetes: a 30-year follow-up study of 740 incident patients with type 2 diabetes].

The project is being led by Dan Andersson and Stefan Jansson, is generating one PhD thesis in January 2014 (Stefan Jansson) and is receiving financial support 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, in cooperation with Björn Zethelius (Geriatrics), forming the Uppsala branch of the Working Group of the NDR.

More than 40 articles have been published 2002–2014, as presented at www.ndr.nu – 2011–2013 [17, 19, 20, 21, 22, 64, 69, 84, 85, 86, 87, 89, 105, 141, 152, 154, 163, 188, 189, 202].

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 [17] and in reviews (Diabetes Care, Eur J Cardiovasc Medicine) [188].

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, which is in accordance with recent guidelines from the European Societies of Hypertension and Cardiology and the American Diabetes Association, and the NDR-study was presented by ESC/ESH as one of two evidence-based references for this treatment goal [84].

Specific statistical graphical technique was applied to illustrate in detail the variation of CVD risk across the BP distribution [84, 85]. Half of the patients in the NDR register still have a systolic BP ≥140 mmHg [188, 189]. 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 [22, 154]. Recent guidelines from American Heart Association underline no evidence-base for low 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 [163]. 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, and both risk models have shown good validation when applied to large samples of patients with diabetes overall in Sweden [152, 202]. 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 [89].

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 [69].

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 [141]. Albuminuria more than renal impairment was strongly related to risk of CVD and mortality during 5 years of follow-up [64].

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 [20, 86, 87]. Another long-term study on aspirin in patients with type 2 diabetes and no previous CVD showed no decrease in risks of CVD or mortality with aspirin use, not even in patients with high predicted risk of CVD [21].

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 [105].

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All New Diabetics in Uppsala – ANDiU

ANDiU is a forth-going study of patients with newly diagnosed diabetes residing in Uppsala County. The patients are classified into 9 diabetic subgroups based on age, fasting c-peptide and titer of glutamate decarboxylase antibodies (GAD ab). Single Nucleotide Polymorphism (SNP) associated with diabetes and anti-diabetic drugs are analysed.
The aim is to explore the impact of these SNP on clinical manifestations and treatment outcome. Our vision is to provide an individualised diabetes care by using genetic information in clinical practice.

ANDiU is part of the EXODIAB collaboration between Lund and Uppsala University and is funded by grant from the Swedish Research Council.

Principle investigator is Per-Ola Carlsson, Department of Medical Cell Biology, Uppsala University and project leader is Mats Martinell.

A retrospective epidemiological study to investigate outcome and mortality with glucose lowering drug treatment in primary care - ROSE

This is a retrospective epidemiological study of patients with diabetes mellitus and an investigation of the outcome and mortality associated with glucose lowering treatment 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. By extraction of data from 80 primary health care centres data were obtained on approximately 80,000 patients. In addition, data regarding morbidity and mortality were collected from the Hospital Discharge Register (Slutenvårdsregistret) and the Cause of Death Register and information on prescribed drugs were collected from the Prescription Register. Data on social-economic status were also collected from Statistics Sweden (SCB).

The merging of data has been performed by the National Board of Health and Welfare. The software program Pygargus Customized eXtraction Program (CXP) was used to extract the patient data from the electronic patient records of the participating primary care centres for all patients with a diagnosis of diabetes mellitus (ICD-10: I10). The social security numbers of identified patients was immediately replaced with a study ID-number for further processing of data. It will not be possible to identify patients once the database is finalized. Data are now collected.

The project is being led by Gunnar Johansson and is receiving financial support from AstraZeneca. The data management will be performed by Pygargus and the Family Medicine and Preventive Medicine section.

Data has been presented at international diabetes congresses and four reports have been published [12, 51, 62, 70].

Cardiovascular events during primary treatment of hypertension – REAL-LIFE

This study compared the effects of antihypertensive treatment with candesartan or losartan on cardiovascular disease (CVD) using Swedish registers (merged data from existing electronic patient records, and electronic hospital discharge and cause of death registers). Patients without previous CVD who were prescribed candesartan (n=7,329) or losartan (n=6,771) for hyperten-
sion during 1999-2007 at 72 Swedish primary care centers were followed up for 9 years. Adjusted risk reduction in all CVD was 14% with candesartan compared with losartan treatment irrespective of sex, age, previous antihypertensive treatment, baseline blood pressure, and presence diabetes. Patients treated with losartan had more outpatient contacts (+15.6%), laboratory tests (+13.8%) and more hospitalizations (13.8%) compared with the candesartan group. Two papers have so far been published [170, 195].

The project is a co-operation between Family Medicine and Preventive Medicine section (Jan Stålhammar), Oslo university and AstraZeneca and is receiving financial support from AstraZeneca. The data management was performed by Pygargus and the Family Medicine and Preventive Medicine section.

Effects of angiotensin converting enzyme inhibitors vs candesartan in reducing cardiovascular events in primary treatment of hypertension – ARB-ACE study

The study is retrospective study on the effect of ACEs vs candesartan on cardiovascular events and on health economic effects in a “real life” setting in Sweden. The study procedure is the same as described in the ROSE project. The project has been transformed to a doctorial thesis project for Pål Hasvold, Oslo, with professor Sverre Kjeldsen as principal supervisor. The estimated number of patients is 16,000. Jan Stålhammar is associated supervisor.

The project is receiving financial support from AstraZeneca. The data management will be performed jointly by Oslo University and the Family Medicine and Preventive Medicine section.

Retrospective Analysis of Heart Failure Patients in Sweden – RAHFS

Primary objective: identify and describe the population of heart failure patients (proportion of patients with diastolic, systolic, acute and chronic conditions) and to determine outcomes of various types of heart failure patients (CV-related hospitalizations, mortality and resource utilization)

This is a retrospective epidemiological study to map out patients with heart failure and describe heart failure in a real-life primary care setting from 1995 to 2006. Data was extracted anonymously from electronic patient journals obtained through the primary care setting. In addition, data regarding morbidity and mortality information on prescribed drugs was collected from the Prescription Register. The merging of data was performed by the National Board of Health and Welfare. To be able to differentiate the types of heart failure, the data was linked to a local register kept by the Department of Physiology, Uppsala University Hospital. Finally, resource utilization data
regarding specific care for heart failure related procedures data was collected from Riks-Svikt (TBD).

During a period of 18 months data was collected from 31 primary care centers in Uppsala County. A total of 252 heart failure patients had a left ventricular ejection fraction <40 % and were categorized as having HF-REF. More than half of the patients had >1 CV heart failure –related hospitalization. All-cause mortality was high: 15.9% died within 1 year after the index date. The mean annual cost per patient was EUR 7610 (72,613 SEK) [125].

The study was a co-operation between Dept of Public Health and Caring Sciences, Dept of Cardiology, Uppsala University and Pygargus AB. Sponsor: Novartis Pharmaceuticals Corporation.

Principal investigator is Jan Stålhammar and investigator is Gerhard Wikström.

Screening for diabetes and hypertension in the Dental Care Service

The dental care is the only clinical area where patients on a large scale come for check-ups without having symptoms. This project deals with the possibility of using the dental health care as a screening function for high blood pressure and diabetes. The purpose is to evaluate to what extent new diabetes or hypertension cases, not known previously to health care personnel, can be detected. Three dental care clinics in Gävleborg County, measured blood pressure and blood sugar in patients attending the dental service, approximately 1,600 patients. All patients who had blood pressure or blood sugar concentration above preset levels were referred to the primary health care centre for follow-up. Data from these units regarding the referred persons covering the three years preceding and following the screening occasion, in total more than 30,000 appointments, were obtained to find out whether the referred person was already known or, and if those referred came for follow-up and, if so, they received a hypertension or diabetes diagnosis. A published paper based on a pilot study showed a strong relationship between high blood pressure and the prevalence of deep gingival pockets. In a second report the efficacy of blood pressure screening in dental care and primary care follow-up was analysed, showing that the blood pressure screening was very efficient [157]. In the third report the diabetes screening showed the need for inclusions criteria, as age and BMI, for efficient finding those at risk [24]. The forth project is calculating the direct cost for this type of screening organisation [25]. The project has generated one PhD thesis in 2012 [Sevek Engström. Dental health care cooperating with primary health care as a resource in early case finding of patients with diabetes or hypertension. Medical sciences. Uppsala University].

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Damaged brain and susceptible life
The project is a one-year follow up of all 390 stroke patients discharged from Falun Hospital during a specified period of time and who, before admission, were living in their own homes. At discharge, the staff was asked to indicate their view of the patient’s prognosis. The patients were followed with an interview at home immediately after discharge, and again after 3 and 12 months. On the same occasions a close relative responded to a matching questionnaire. Furthermore, all health care utilization at hospital, primary health care, municipal social service support and the caring efforts of close relatives have been recorded. The project has generated four papers [117] one PhD thesis in 2010 (Lena Olai).

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Reproductive health
Physical activity and pregnancy
Participants: Eva Thorell, Laura Goldsmith, Gerson Weiss, Kurt Svärdsudd, 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 [132] 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, Lena Nilsson-Wikmar, 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 senso-
ry innervation and indicate allodynia and central sensitization. This suggests that pain mapping can be used to evaluate and confirm the pain experience and contribute to diagnosis. The project has generated four papers [67] and is generating one PhD thesis in February 2014 (Thomas Torstensson).

**Borlänge Uppsala Pelvic Pain Study (BUPPS)**

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

The focus of this prospective cohort study is the patho-physiologic process explaining how apparently healthy and well-trained young women within a few months of pregnancy can become severely disabled by pregnancy induced low back and pelvic pain that may persist for several years after delivery. We hypothesize that a functionally disturbed remodelling and repair of ligaments of the lowest back will be involved in the development of disabling pregnancy-induced low back pain persistent years after childbirth.

The study is a population-based cohort study of 1000 women with baseline assessment before gestational week 12 and additional assessments at gestational week 36 and 6-9 months after childbirth. Individual patient data are collected by means of web-based questionnaires, clinical examination and blood tests. General joint mobility and skin extensibility, as a measure of fragile connective tissue, will be measured thoroughly as well as the outcome measures reported low back pain location and back pain provocation tests.

The studies are going to start in 2014. The project is planned to generate several PhD theses and has financial support from Regionala Forskningsrådet in the Uppsala-Örebro region, Uppsala County Council and Uppsala University.

**Imaging of the back and pelvis in diagnosis of chronic pelvic pain**

Collaboration project together with Gunnar Åström, Cecilia Wassberg, professors Niels Egund and Anne-Grethe Jurik, Aarhus, Denmark.

There is a great need of an imaging method to diagnose chronic pelvic pain induced in pregnancy. In the present study of 500 women with back pain recruited from a back rehabilitation clinic and matched controls will use magnetic resonance tomography (MRT) to investigate the importance of changes in the vicinity of the anterior part of the sacro-iliac joints and reported pain in the back and pelvis. Initial MRT investigation has been conducted 2011 and a follow-up will be performed three years later. The project has financial support from the Uppsala County Council.
Pelvic pain during pregnancy and hormonal contraceptive use
Participants: Elisabeth Bjelland, Per Kristiansson, Hilde Nordeng, Siri Vangen, Malin Eberhard-Gran.

The project was the results of collaboration with researchers involved in the Norwegian Mother and Child Cohort. The study results suggest an exogenous hormonal influence on the development of pregnancy induced pelvic pain as the reported use of progestine hormonal contraceptive was associated with a higher degree of pregnancy induced pelvic pain induced in pregnancy. An additional study will evaluate the effect of hormonal contraceptive use and pelvic pain persisting after childbirth. This latter work will be part of Elisabeth Bjelland’s post-doc stay at the unit of Family Medicine and Preventive Medicine during autumn 2014.

Laser therapy of pregnancy induced back and pelvic pain persistent after childbirth
Participants: Anne Lindgren, Thomas Torstensson, Sahruh Turkmen, 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. Application for ethical approval has been submitted. This is collaboration between physiotherapists, gynecologist, general practitioner and laser manufacturer. The project is part of a PhD project.

Joint mobility and pregnancy induced back pain
Participants: Anne Lindgren, Per Kristiansson.

Finger joint laxity as a reflection of constitutional weakness of connective tissue and number of previous pregnancies were associated with the development of back pain induced in pregnancy and persisting after childbirth. These factors may provide a foundation for development of targeted prevention strategies which have to be confirmed in future research including measurement of general joint laxity. The project is part of a PhD project and has financial support from Västernorrland County Council and Uppsala University.

Sexual and reproductive health among young men
Participants: Johanna Haraldsson, Lena Nordgren, Ylva Tindberg, Per Kristiansson.

The overall aim of the study is to investigate present conditions and room of improvement for sexual and reproductive health within the primary health
care. The study will analyze possible differences of time for yourself under confidentiality with a physician by sex, describe the notion of sexual and reproductive health among young men and among staff of primary health care and assess sexual and reproductive health among young men in Sweden. The study is generating one PhD thesis and is receiving financial support from the Primary Health Care of Sörmland County Council and Uppsala University.

**Adverse childhood experiences**
Participants: Jennifer Drevin, Jenny Stern, Anna-Maria Annerbäck, Magnus Peterson, Tanja Tydén, Margareta Larsson, 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. 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 will be elucidated. Financial support is received from Uppsala County Council.

**Pregnancy planning**
Participants: Jenny Stern, Margareta Larsson, Per Kristiansson, Tanja Tydén, Andreas Rosenblad, Anna Berglund, Clara Aarts.

Many women have insufficient knowledge of reproduction including health-promoting lifestyle prior to conception and, highly educated women in particular, postpone childbearing until ages when their fertile capacity has started to decrease. With a randomized controlled design the Reproductive Life Plan-based information in contraceptive counselling increased women’s knowledge both of reproduction and of folic acid intake prior to pregnancy; affected the women’s RLP; and was appreciated by the women.

**Communication skills**
Participants: Annika Bardel, Åsa Lööv, Karin Björkegren, Bo Karlsson, Per Kristianssson.

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

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.

Triggers of the onset of disease and other health problems

Johan Hallqvist

The case-crossover methodology was developed at Harvard in the beginning of the 1990-ies and it opened up a new field of research; the study of risk factors with short induction periods, that is, triggers of disease. In the ongoing projects all conducted in collaboration with research groups at Karolinska Institutet we aim to identify triggers of acute health events, and to quantify their effects.

In the first four case-crossover projects we are applying the design to data bases extracted from Swedish National registers. In studies of Side-effects of drugs, the first aim is to identify harmful side-effects of pharmaceutical drug use and the second aim is to potentially develop a system for surveillance. We use a record linkage between the new drug prescription register (exposures and sometimes also outcomes) and the hospital discharge register (outcomes).

Another study concerns Psychiatric care as acute deterrent or trigger of suicide, in which the inherent self-control in the design makes it possible to study the quality of the psychiatric evaluation of suicide risk in consulta-
tions. The study is based on record linkage between inpatient, outpatient and cause-of-death registers.

In a third study we examine Non-cardiac surgery as trigger of myocardial infarction. It is based on record linkage between hospital registers and myocardial infarction incidence registers. The trigger effect is well known and RCT’s testing beta blockers as prophylaxis has been undertaken but our aim is to quantify the absolute and relative risks with different types of surgical procedures.

We also examine Acute life events (like death of close relative) as triggers of acute diseases like myocardial infarction and stroke, in a study based on record linkage between the multigenerational register and the hospital and the cause of death registers.

TUFS (Swedish acronym for triggers of sickness absence) was a part of a thesis work and aimed at identifying non-medical triggers interacting with reduced work ability due to illness. It was based on extensive data collection from more than 1000 spells of sickness absence at six work places. TOFA (Triggers of falling) is based on data collected from old men and women with hip fractures.

Finally Psychoactive substances as triggers of violence is a study based on data collection from individuals in custody in Stockholm because of criminal activities including violence (The Stockholm Social Medicine Custody Project).

[10, 34, 102, 104, 112, 171, 176]

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Social epidemiology: the role of life course and social context
Johan Hallqvist

We have earlier shown that there are inherent difficulties in the task of disentangling time-related exposure constructs like accumulation, critical period and mobility in life course epidemiology. At present we pursue further in-depth analyses of specific hypotheses related to these theoretically based mechanisms in collaboration with researchers at Karolinska Institutet. We also have a general interest in methodological issues related to the study of mechanisms behind inequalities in health and we have for example shown the importance of distinguishing between differential exposure and differential susceptibility when analyzing for example the effects of exposure to job strain.

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 65000 participants. In associated projects we use the SHEEP database and the Uppsala Birth Cohort to investigate the combined effects of fetal growth impairment, cognitive development, social trajectories and adult obesity on cardiovascular disease.

In *Pain in the body and the soul* the aim is to identify life course factors that influence psychological well-being, psychological ill-health, depression and musculoskeletal pain. This project is based at Karolinska Institutet and makes use of the new Stockholm Public Health Cohort (SPHC) and national register data bases.

*Life course risk factors and socioeconomic differences in the risk of mental illness* concerns risk factors like adverse marital trajectories, school failures, and criminal careers. The project is also base at Karolinska Institutet and concerns register studies on the total population of Sweden.

The other aspect concerns the social environment and macro-determinants of disease. In carefully designed studies we have contributed with further empirical evidence to the yet unresolved questions on if and how social context in terms of socioeconomic deprivation or low social capital on the aggregate level impinge on the etiology of specific individual diseases.

An ongoing study at Karolinska Institutet concerns *Social context in Swedish municipalities and juvenile delinquency*. The question is whether contextual characteristics like socioeconomic deprivation or lack of social integration influence crime rates among adolescents when individual characteristics are controlled for. Family based designs and multi-level analyses will be employed on register data of all Swedes.

In another study the effect of *contextual and individual social capital on psychological distress and self-rated health* is analyzed in the Stockholm County using neighborhoods as the contextual level.

[11, 13, 27, 44, 49, 53, 54, 78, 90, 92, 96, 97, 109, 111, 121, 126, 139, 140, 149, 150, 180, 185, 187, 192, 193]

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**Obesity care**

Jenny Söderberg, Gunilla Mårtensson, Per Kristiansson, Marianne Carlsson. The aim of this study is to affect physical activity and unhealthy eating habits among people with overweight and obesity by using the National Guidelines for Methods of Preventing Disease of the National Board of Health and Welfare (Socialstyrelsen). The data collection has started and the project will generate one PhD thesis. The study is funded by University of Gävle.

**Physical activity on prescription**

Participants: Lena Kallings, 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 and one to two PhD students are planned to be recruited to the project. 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 and an application for ethical approvement is submitted. The start of data collection is expected to early autumn 2014.

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 [121].

There has been a positive trend in the total number of FaR prescribed in Sweden since 2007, with a yearly increase of 30-67 %. Though, only 49,000 FaR were prescribed in 2010, with large variations between different county councils and regions [107]. Consequently there is a need for improved implementation of FaR.

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Physical activity on prescription (PAP) to patients with osteoarthritis
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. Nearly all patients are included and have been tested at baseline, and several have been followed up. The study is financially supported by Gävleborg county council and Uppsala-Örebro regional research council. The project is being led by Margareta Emtner, Lena Kallings and Kristina Bröms.

Physical activity in treatment of depression
One clinical study with physical activity in treatment of depression and validation of different methods for evaluate physical capacity in this patients is now analyzed and in manuscript. The study is financially supported by Uppsala county council and Uppsala-Örebro regional research council. The project is being led by Margareta Emtner and Lena Kallings.
Lessons from implementation of the method physical activity on prescription (PaP) to patients in primary health care in the Uppsala-Örebro region

This project is planned to investigate factors in patients, in prescribers of PaP and in the organisation, both in the health care center and in the county council that could explain the effect on physical activity of the prescription of PaP. The study is a collaboration project between researchers in the county councils in Dalarna, Gävleborg, Sörmland, Uppsala, Värmland and Västmanland. This study has received financial support from Uppsala-Örebro regional research council and Gävleborg county council. An application for ethical approval is in progress. The project is being led by Lena Kallings, Kristina Bröms and Catharina Gustavsson.

Organizational Factors, Work Stress and Performance
Participants: Ingrid Anderzén, Lars Frimanson, Per Lindberg and Thomas Karlsson.

There is a clear association between psychosocial factors in the organization, stress, and performance. We develop and evaluate workplace intervention programs and look at the effects on employee health, biological stress markers, and organizational productivity. In an interdisciplinary research program we combine two fields of knowledge; social medicine and Management control systems (MCS). The purpose is to examine and explain how MCS design affects psychosocial factors in the organization, stress, and performance. This is important because MCS are used for planning and evaluation in organizations. MCS can thus be expected to influence the psychosocial factors in organization that are associated with negative stress reactions, work-related health, and performance outcomes.

Management control systems and stress: interdisciplinary field experiments
Participants: Ingrid Anderzén, Lars Frimanson.

Management control systems (MCS) in organizations have become more complex. They measure performance on more objects, with new and more measurements, they provide information more frequent and quicker, and they are used at lower levels in organizations. But we do not know how these complex MCS influence the human body. Do they improve health, well-being and performance in organizations? Or do they make people develop insomnia, stress and other unhealthy outcomes that are economically and socially costly? This interdisciplinary research program combines two fields of knowledge; social medicine and MCS. The purpose is to examine and explain how MCS design affects psychosocial factors in the organization,
stress, and performance. This is important because MCS are used for planning and evaluation in organizations. MCS can thus be expected to influence the psychosocial factors in organization that are associated with negative stress reactions, work-related health, and performance outcomes. Data collection was finished during year 2012 and the analyses are ongoing. A poster was presented at The 11th Stress research conference “New Frontiers in Swedish Stress Research - what is underway?” in Gothenburg, Sweden, 11-12 May 2012 [Frimanson L, Anderzén I. The impact of formal performance evaluation frequency on psychosocial and biological employee energy markers: An organizational experiment]. One article is submitted [Frimanson L, Anderzén I. The impact of formal performance evaluation on psychosocial and biological energy mobilization in employees: a randomized intervention study].

This project is running in collaboration with Department of Business Studies, Uppsala University, and receiving financial support from Riksbankens Jubileumsfond.

GodA - Good working environment and healthy workplaces. Test of a model linking the work environment, employee well-being and corporate development

Participants: Ingrid Anderzén, Per Lindberg and Thomas Karlsson.

"Promoting factors” at work are supposed to promote both the individual’s physical and mental health and the company's competitiveness and profitability, thus providing "healthy workplaces". Which factors act health promoting, as well as how an organization can work to promote the health of the employees while ensuring a commercially sound business, is still in its infancy. The GodA-study aims to test whether a development project organized by the so-called PATH-model (Grawitch et al., 2006) results in increased employee well-being and concurrent organizational improvements.

In 2012, a pre-study in form of focus groups and individual interviews in three medium sized enterprises was undertaken. The interviews sought to examine what employees and managers considered to characterize a "good" work environment and what gives them wellbeing at work. The results from the interviews and known health and safety parameters have constituted the basis for a questionnaire with which employees of the three companies are followed for 2 years. Parallel, data concerning the companies’ key indicators and internal developments are collected. One of the companies’ designs its work with their internal development according to the PATH-model. At the two-year follow-up the results from the “PATH-company” concerning the well-being of both employees and the company will be compared with the results from the other two companies designing their internal development after their own choice. This study aims to increase knowledge about how to achieve sustainable health and wellbeing of both the individual and the com-
pany parallel. Such conditions can be assumed to save suffering for the individual and reduced costs for the company and society.

This project is running in collaboration with Centre for Musculoskeletal Research, University of Gävle and receiving financial support from AFA.

Social medicine
Participants: Bengt Arnetz, Judith Arnetz, Christina Halford, David Hallman, Rathi Ramji, Clairy Wiholm.
A common theme for this group’s research is enhancing the scientific understanding of risk- and resiliency factors, including bio-psycho-social mechanisms, of relevance for sustained and equitable occupational and social safety, health, and wellbeing. Research includes effective use of health care and institutional resources, and its implications for major health care stakeholders, including patients, staff, and third-party payers.

Bio-psycho-social mechanisms contributing to health disparities, resource utilizations and Healthy organizations
Research in this area looks at the relationship between socioeconomic and psychosocial factors, biological disease pathways, e.g., biomarkers and epigenetics, and public health, including somatic and mental health and sick leave behaviour. We are especially interested in furthering the understanding of determinants of sustained health. A NIH funded project focuses on post-displacement/migration contextual and individual factors related to occupational and social integration of refugees. The project aims at comparing policy, cost-effectiveness, and public health outcomes among Iraqi refugees forcibly displaced to Sweden and the United States, respectively.

In the domain of tobacco health risks, we have also initiated studies concerning the role of water pipe (hookah) smoking as a possible gateway drug, along with cigarettes, alcohol, and marijuana, into heavier drugs and other risky behaviour in Swedish and US adolescents. We completed, and secured funding, for a proposal to the Public Health Agency of Sweden (Folkhälsoomyndigheten), in collaboration with public health researchers at Umeå University, focusing on socioeconomic and ecological determinants of waterpipe (hookah) initiation and use in high school students in Sweden.

In collaboration with The Swedish Social Insurance Administration and the Primary Health Care sector, we evaluated “the Pathway to Work” process. Different research projects are developed and strategies to decrease sick leave, improve the sick leave processes and facilitate people’s return to work are evaluated. 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.
Stress factors and psychophysiological consequences of the modern lifestyle

Some of our projects focus on the impact on health and wellbeing from our technology-driven society. In a project involving researchers at Uppsala University and Wayne State University, we are involved in research assessing the functionality of wireless sensor technologies and mobile phones to assess stress-related mental and cardiovascular responses in real-time. The purpose is to collect detailed and up-to-the-minute information as to how our physiological system, especially the cardiovascular system, is affected by environmental stressors in inner-city people as well as in women in high-pressured leadership roles.

Another important area of research concerns the impact of acute and chronic stress on the health and performance among first responders, including police, fire fighters, EMS, coast guards, and the military. In collaboration with the management and unions of Sweden’s First Responder organizations and Kungafonden, we have identified major high-intensity and low-intensity stressors among First Responders, and strategies used to counteract adverse health and performance effects. We are currently discussing with the Swedish Association of Federal Employers and Employees (Partsrådet) and Kungafonden to secure funding for the third and final phase of this project, which involves developing a state-of-the-art stress assessment and intervention web-based tool.

Modern health care – implications for patients, health care organisations and society

A number of studies aimed at evaluating the implications of current structural and economic changes to patients, employees, health care organizations and society have been carried out. We look at the implications of enhanced patient involvement for staff, patients and hard treatment outcome, including cost, morbidity and mortality. We also study the inter relationship between health care environment and quality of care patient care.

As part of the multi-year, multidisciplinary research program, The Impact of Religion, financed by the Swedish Research Council, Vetenskapsrådet, we are looking at the organizational and individual role of spirituality and existential factors in promoting health and wellbeing among health care staff as well as in patients. We are also interested in how health care personnel utilize patients’ spiritual belief in the diagnostic and treatment processes. In 2013, our first manuscript linking existential organizational culture to attenuated occupational stress was published.

Another area of substantial interest to the Division’s researchers concerns employee and organizational health and safety, with a particular focus on work stress and workplace violence in healthcare settings and implications
for the quality of care. In collaboration with researchers at Wayne State University in Detroit, we are conducting a randomized controlled intervention study funded by the National Institute for Occupational Safety and Health (NIOSH) focused on improving and standardizing the surveillance, risk analysis, and prevention of workplace violence in hospitals.

Self-rated health
Simple global self-ratings of health (SRH) hold predictive validity in relation to functional ability, morbidity, health care utilisation, and mortality, and are therefore extensively used in public health monitoring and research. In this project, associations between stress-theory based psychobiological variables and SRH were investigated in 212 adult healthy women and men. Psychological resource and psychological strain variables were strongly associated with SRH in women and men. Associations between endocrine variables and SRH were observed in men, but not in women. Furthermore, associations between age, year of investigation and SRH, and effects of SRH on risk of sick leave, disability-pension, hospital admission and mortality, were investigated in a population-based sample of 11,880 adult and elderly women and men. Age, year of investigation, and SRH were inversely associated, linearly in women, and non-linearly in men. Furthermore, in women and in men, SRH was inversely associated with number of days on sick leave, disability pension, and with mortality, during the follow-up period. Finally, SRH was inversely associated with first hospital admission rate in men, but not in women. The project has generated four published articles [94, 95] and one PhD thesis in 2010 [Christina Halford Self-rated health with special reference to prevalence, determinants and consequences. Medical science, Uppsala University].

(For number in brackets -- see “Publications 2011-2013” on page 131-151)

Varia
Vitamin D status among immigrated women from countries in the Middle East as compared with Swedish women
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. Preliminary results show a large difference in vitamin D levels with low values in many immigrant women in comparison with the Swedish women. Treatment with vitamin D and calci-
Vitamin D status and the correlation to muscle function in patients with chronic obstructive pulmonary disease (COPD)

Many patients with advanced COPD are affected by their decreased lung function and often have reduced muscular function as well. They consequently often do not go out, and their diet also tends to be low in products containing vitamin D. This study will investigate the vitamin D status and the correlation to muscle function in these patients with COPD. The study is planned to be performed at a primary health care centre by a physician and a dietician. If the patients are shown to have low values, treatment with vitamin D and calcium will be initiated. The paper “Evaluation of sun holiday, diet habits, origin and other factors as determinants of vitamin D status” has been published [9]. Co-authors in the paper have been Per Kristiansson, Karin Björkegren, Annika Bardel, Åsa Andersson and Gunnar Johansson.
Geriatrics

Research Group Leader Professor Lars Lannfelt

The main areas of research are molecular studies of dementia as well as clinical and epidemiological research in these and other age related diseases, such as cardiovascular and renal disorders. Cellular and transgenic models of Alzheimer’s disease, Parkinson’s disease and Lewy body dementia are used to understand mechanisms of abnormal protein aggregation in the brain and to develop new biomarkers and disease-modifying therapies. We are applying a broad repertoire of experimental techniques, e.g. molecular biology, biochemistry, histology and behavioural analyses in our research.

Members of the group during 2013

- Professors – Lars Lannfelt (chair), Hans Basun (adjunct)
- University lecturer – Lena Kilander
- Researchers – Martin Ingelsson, Vilmantas Giedraitis, Anna Erlandsson, Joakim Bergström, Stina Syvänen, Johan Årnlöv, Björn Zethelius, Anna Cristina Åberg, Dag Sehlin
- Postdocs and research assistants – Hedvig Welander, Veronica Lindström, Elisabet Ihse, Bernice Wiberg, Hans-Erik Johansson
- PhD students – Astrid Gumucio, Sofia Söllvander, Therese Fagerqvist, Gabriel Gustafsson, Malin Degerman-Gunnarsson, Ylva Cedervall, Kristin Franzon, Xiaotian Fang, Leire Almandoz-Gil, Elisabeth Nikitidou.
- Other personnel – Linda Cato (BMA), RoseMarie Brundin, Käthe Ström (research nurses).
Publications 2011-2013

2013


57. Ärnlöv J, Larsson TE. The authors reply. *Kidney international* 2013; 84: 621.


2012


75. Fox CS, Matsushita K, Woodward M, Bilo HJ, Chalmers J, Heerspink HJ, Lee BJ, Perkins RM, Rossing P, Sairenchi T, Tonelli M, Vas-


103. Årnlöv J. Cathepsin S as a biomarker: where are we now and what are the future challenges? Biomarkers in medicine 2012; 6: 9-11.

2011


126. Kullberg K, Björklund A, Sidenvall B, Åberg AC. 'I start my day by thinking about what we're going to have for dinner'--a qualitative study on approaches to food-related activities among elderly men with somatic diseases. *Scand J Caring Sci* 2011; 25: 227-34.


**Books**


**Dissertations 2013**

- Malin Degerman Gunnarsson. Biomarkers as monitors of drug effect, diagnostic tools and predictors of deterioration rate in Alzheimer’s disease 2013

Agencies that support the work/Funding

Hjärnfonden, project grants and donators 1 500 000 SEK/year
Berzelii Center for Neurodiagnostics, Uppsala 2 500 000 SEK/year
ALF-medel, Uppsala läns landsting 4 000 000 SEK/year
Fakultetsmedel, Uppsala universitet 2 500 000 SEK/year
Parkinsonfonden 1 000 000 SEK/year
PET-forskning 500 000 SEK/year
Hjärt-kärlfonden 400 000 SEK/year
Wallenberg-stiftelsen 700 000 SEK/year
Alzheimerfonden 1 000 000 SEK/year
Diverse andra fonder 1 800 000 SEK/year

International collaborations

Harvard Medical School, NIH, University of Goettingen, University of Kuopio, University of Ulm, INSERM, Max Planck/Berlin, Swedish National Diabetes Register, DECODE, A European diabetes research collaboration, Århus University, Denmark, professor A Flyvbjerg, Odense University, Denmark, professor J Juul Holst, University of Tuebingen, University of Lisbon, Institut Pasteur de Lille, University of California San Diego, University of California San Francisco, Mental Health Research Institute, Parkville Australia, University of Oxford, University of California San Diego, University of Erlangen.

Guest visits in foreign laboratories

Elisabet Ihse (with Dr E. Masliah, La Jolla, San Diego, USA 2013-14, returning to the unit 2015, financed for three years by VR).

Adjunct professors

Hans Basun, BioArctic Neuroscience, 2005-
Håkan Hall, Uppsala Applied Science Laboratory, GE Healthcare, 2010-11.
Research Consortias

The research group is a member of the Berzelii Technology Centre for Neurodiagnostics, the Swedish Brain Power network and the U4 network (together with the Universities of Göttingen, Ghent and Groningen).

Engagement in the external society


Research projects

Aβ protofibrils in Alzheimer’s disease
(Anna Erlandsson, PhD)

We have previously shown that the antibody mAb158 that specifically binds to Aβ protofibrils promotes clearance of amyloid-beta (Aβ) in a transgenic mouse model of Alzheimer’s disease (AD). The mechanism behind this effect is however not known. Accumulation of Aβ and formation of senile plaques in the AD brain is due to an imbalance between the Aβ production and clearance. Since the majority of the patients with late-onset AD do not have an increased Aβ production, the main cause of this form of the disease might instead be ineffective degradation. Astrocytes are known to control many functions in the brain, but their role in AD is poorly understood.

The aim with the present study is to investigate the role of astrocytes in Aβ clearance by adding Aβ to mixed cell cultures containing astrocytes, neurons and oligodendrocytes. Furthermore we are interested in how the presence of mAb158 affect Aβ clearance. Our results show that astrocytes engulf large amounts of Aβ, compared to oligodendrocytes and neurons, which only ingest very little of the protein. Furthermore, we have found that astrocytes effectively degrade monomeric Aβ, while Aβ protofibrils are accumulated within the astrocytes for long times. Our previous studies show that increased Aβ protofibril levels correlate with impaired spatial learning in a mouse model of AD. To investigate if Aβ protofibril levels could be used as a biomarker for AD we investigate the Aβ protofibril content in brain tissue, CSF and plasma from AD patients. Moreover we isolate exosomes from the cell culture medium of Aβ treated neurons and glia in order to analyze their protein content. The ultimate goal of these studies is to develop a
novel biomarker for early diagnosis of AD and for evaluation of amyloid-directed therapies.

Pathology and amyloid imaging in transgenic Alzheimer’s disease mice

(Stina Syvänen, PhD and Dag Sehlin, PhD)

The over-all purpose of this project is to improve clinical Positron Emission Tomography (PET) imaging in Alzheimer’s disease (AD) such that the technique can be used to monitor disease progression and therapeutic efficacy of intervention with drug candidates. The project include development of new radioligands as well as development of imaging paradigms based on already existing radioligands that target neuroreceptors believed to be involved in the pathogenesis of AD. We have developed a 125I-labelled new imaging agent based on mAb158 by using its F(\(\text{ab}'\))\(_2\) fragment. The advantages with using a F(\(\text{ab}'\))\(_2\) fragment compared to a whole antibody is mainly two-fold; first, the smaller fragment is likely to be distributed across the blood-brain barrier to a higher degree compared to the larger antibody, and second, F(\(\text{ab}'\))\(_2\) fragments have considerably shorter half-life than antibodies. This is beneficial as it reduces the radioactivity in the blood volume of the brain and thereby also reduces contamination of the radioactivity signal in the brain area (that should reflect radioactivity in tissue only) detected in the PET-scanner. The focus of our present research is to further improve the brain distribution of the 125-I labelled F(\(\text{ab}'\))\(_2\) fragment using protein engineering and thus develop a new amyloid PET radioligand for use in the clinic.

Parkinson’s disease

(Assoc. Prof. Martin Ingelsson and Joakim Bergström, PhD)

As aggregation of pathological proteins in the brain is a general feature for neurodegeneration, immunotherapy could have potential also for other disorders than AD. In Parkinson’s disease (PD), \(\alpha\)-synuclein deposits as Lewy bodies and Lewy neurites inside the neurons. As with A\(\beta\) in AD, large soluble oligomeric or protofibrillar forms of \(\alpha\)-synuclein are believed to be particularly neurotoxic in PD and Lewy body dementia. By working with recombinant forms of \(\alpha\)-synuclein oligomers / protofibrils, we are analyzing the formation and effects of such intermediately sized species of \(\alpha\)-synuclein in vitro and on cell models. The most toxic protein forms have been used as antigen to generated conformation-selective monoclonal antibodies. A number of such antibodies have now 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 these antibodies can lower the levels of toxic \(\alpha\) -synuclein oligomers/protofibrils in transgenic mice. Moreover, we seek to adopt the anti-
bodies in assays, such as ELISA; to be able to measure the presence of toxic oligomers / protofibrils as a novel disease biomarker for PD and Lewy body dementia. We are also investigating the underlying mechanisms by which α-synuclein impair key cellular function. A key question is to find out how oligomers can impair cellular degradation systems and how α-synuclein oligomers can perturb cellular function, e.g. by interfering with the endoplasmic reticulum.

Genetics

(Assoc. Prof. Martin Ingelsson and Vilmantas Giedraitis, PhD)
We have access to a large and well characterised collection of sporadic and familial dementia patients. Using high throughput sequencing technology, we are screening for mutations in known and putative disease susceptibility genes in patients with early onset forms of frontotemporal dementia, Alzheimer’s disease and Parkinson’s disease. In collaboration with other research groups, we are searching for new disease susceptibility genes by association analysis.

Clinical and epidemiological research

(Assoc. Profs. Lena Kilander, Björn Zethelius, Johan Ärnlöv, Anna Cristina Åberg)
The close contact between the laboratory and the Geriatric 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 clinically and neuropathologically. This research is based on our own tissue bank with DNA, plasma and serum (approximately 1500 samples), CSF samples (n= approximately 600), and brain tissues. Data on 196 AD patients, followed for 2-9 years since the lumbar puncture, show that high baseline concentrations of total tau and phospho-tau are powerful predictors of negative long-term outcome. Interestingly, high tau and phospho-tau levels were correlated to conversion from mild to moderate dementia, rapid clinical decline, institutionalization and death in advanced dementia (Degerman-Gunnarsson -13). Thus, CSF tau and phospho-tau are not only markers of dementia stage and predictors of conversion from MCI to AD, but also reflect the rate of neurodegeneration and long-term prognosis. Longitudinal studies of dementia patients are carried out in collaboration with the Uppsala PET-center, using the amyloid-binding PIB ligand together with PET FDG and AD CSF-biomarkers.

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 respec-
tive predictive values for development of AD. Further, the role of cerebrovascular risk factors and dietary intake of fat as predictors of AD are examined. Impaired insulin secretion at age 50 has been shown to predict the development of AD at high age. In one substudy, we are assessing mid-life and late-life predictors of healthy aging, defined as maintained cognitive and ADL functioning at age 85 years (Franzon, in manuscript). Measurements focusing on cognition and sarcopenia are currently undertaken on survivors at age 88-93 years, 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.

New powerful predictors for disease outcome are explored. In an epidemiological project lead by Johan Ärnlöv, novel aspects of the interplay between kidney and the cardiovascular system are investigated. Dr Johan Ärnlöv is involved in international collaborations such as the CKD-prognosis Consortium and CystC MR consortium. The project has received funding from Vetenskapsrådet, Marianne and Marcus Wallenberg foundation and the Swedish Heart-Lung Foundation and has so far led to several publications in leading medical journals.

One line of research aims to investigate motor function and physical activity in relation to health among elderly people. Anna Christina Åberg is studying new methods for clinical motor function assessment, as well as a potential association between motor function and subjective health aspects, such as life satisfaction and fear of falling. The research is mainly directed towards elderly with a need for rehabilitation due to multiple diseases/functional limitations, and those with specific neurological or neurodegenerative diagnoses, such as stroke or AD.

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 mecha-
nisms 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 senior lecture Sophie Langenskiöld

The research group Health Economics has just started and Sophie Langenskiöld joined the group 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. In addition, the research group want to shed more light on why health care costs are increasing this knowledge can help us learn how to control these costs. Uppsala University is well positioned to lead in these areas, thanks to its experience with the Swedish registry and the in-house skills it offers in data analysis.

Members of the Group during 2013

The research team has been invited to participate in other research groups, both as a collaborator and an advisor.

Publications


Research profile

Understand and influence the prospects within health care

In our society, there is a rapid demographic change. Fewer babies are born, and more people are living longer; the elderly population is growing. This means that health care costs will keep rising as the elderly consume a relatively large share of the resources utilized.
Is there reason for concern? Not necessarily! There is less reason for concern if the economy grows as fast as costs increase. In this case, at least we would not have to increase the percentage of our economy’s income that we spend on health care. Such an increase would be necessary, however, if health care cost grow faster than our economy does.

Can these costs be controlled? Possibly! If so, we must know more precisely what is driving the cost increase. Hopefully, there are factors other than demographics; if so, the costs could be controlled by new structures and incentives.

In short, Health Economics is evaluating the cause for concern about rising health care costs. We study in-depth the underlying factors, so that we can have better control over costs going forward.

Achieving better health for the public and cost-effective care to the community

Randomized studies evaluate benefits in relation to risks under ideal conditions. For that reason, they offer little information about the relationship in clinical practice, where patients have multiple disorders, are treated with more drugs, and comply less with treatments:

- The elderly have, for example, an increased susceptibility to chronic diseases, which means that they often suffer from multiple diseases and are treated with multiple drugs. Despite these factors increasing their morbidity, mortality and the cost to society, these patients are often excluded from randomized trials.
- Children and pregnant women also are often underrepresented in randomized trials, although both the FDA and EMA have stressed the importance of studying how the benefits relate to the risks in these vulnerable populations.
- Patients also show poorer adherence in clinical practice than in randomized trials. Many believe this is the main reason why it is difficult to generalize the benefits and risks found in randomized trials, to clinical practice.

In Sweden we have a unique opportunity to study these issues. We have 73 national, high-quality registries which, along with prescription files and other non-medical records, give us more information than any other non-Nordic country.

We can therefore study the benefits and risks of our drugs in clinical practice on the entire population receiving drugs on prescription. Countries with less complete records are forced to study non-representative populations.

Moreover, thanks to the rich data sets, we can control for other factors that bias the relationships we want to estimate. “The perfect doctor” e.g., knows the optimal treatment for the patient and unless this selection is controlled for, the effect of the treatment will be overestimated.
This research team wants to help regulatory authorities in Europe, and HTA agencies, to make better decisions when drug approval (via PAES studies) and subsidy decisions are conditioned on benefits and risks in clinical practice.

Our primary goal: to ensure that patients receive only treatments whose benefits exceed their risks, and thus improve patients’ health. Second: we want to ensure that increasingly scarce resources in health care are allocated cost-effectively.

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 is one of the co-coordinators of HEFUU, and involved in the organizing and planning of HEFUU’s activities. During the year, HEFUU had an opening conference with international as well as speakers addressing the potentials of the Swedish registers to address our concerns for the future, e.g. the efficient allocation of resources within healthcare, the socioeconomic gradient in health etc. The conference attracted nearly 90 participants. HEFUU has also organized a two-day course in causal inference last year which was held by the distinguished Professor Donald Rubin, Harvard University, which attracted nearly 120 participants from all over Sweden. In addition, HEFUU has organized monthly seminars in Health Economic Research.

Education

Sophie Langenskiöld is preparing a master course in Health Economics which is scheduled for the spring 2015. During the year, she has mostly contributed to health economic lessons in other courses at the Department of Public Health and Caring Science, Department of Economics, and Karolinska Institutet but also individual lessons at e.g. the Department of Global Health.

Examples of other assignments

Uppsala Health Summit is an international forum for dialogue between leading representatives for healthcare, and this year, the forum will meet around the challenges facing us from a rapidly growing proportion of elderly in the population, “Healthcare for healthy aging”. Sophie Langenskiöld is part of the program committee and contributes to the conference in general. In specific, she will contribute with a workshop which will focus on potential obstacles for providing effective, safe, and cost-effective medical care for the elderly in the future.
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 patient choice reforms as well as identification of facilitators for high quality and patient safety care, especially within telecare. The group is multidisciplinary and the researchers have different professional backgrounds such as medicine, psychology, nursing and political science.

Members of the group during 2013

Ulrika Winblad, PhD, associate professor, research group leader

Caroline Andersson, PhD student
Åsa Muntlin Athlin, RN, PhD
Cecilia Bernsten, Registered pharmacist, PhD, associate professor
Ingeborg Björkman, Registered pharmacist, PhD
Madeleine Boll, Physiotherapist, Licentiate, PhD student
Eva Boström, RN, PhD
Linn Boström, research assistant
Gunilla Brattberg, MD, PhD, associate professor
Tobias Dahlström, PhD
Ann Catrine Eldh, RN, PhD
Helène Eriksson, Administrator
Annica Ernesäter, RN, PhD
Mio Fredriksson, PhD
Finn Hjelmblink, MD, PhD
Inger K Holmström, RN, professor
David Isaksson, MSc, Phd student
Elenor Kaminsky, RN, PhD
Publications 2011–2013


Dissertations 2013
Elenor Kaminsky – Telephone Nursing: Stakeholder views and understandings from a paediatric and a gender perspective.

Agencies that support the work/Funding 2013 (in SEK)

- The Swedish Research Council - Ulrika Winblad: 1 257 000
- AFA Insurance - Inger K Holmström: 908 000
- Swedish Competition Authority (Konkurrensverket) - Ulrika Winblad: 392 000
- Swedish Council for Working Life and Social Research (FAS) - Ulrika Winblad: 800 000
- Swedish Association of Local Authorities and Regions (SKL) - Ulrika Winblad: 750 000
- The Swedish Research Council - Mio Fredriksson: 1 050 000
- Dalarna County Council - Ulrika Winblad: 125 000
- The Swedish Agency for Health and Care Services Analysis - Ulrika Winblad: 26 000
- Norrbacka-Eugeniastiftelsen - Helene Von Granitz: 150 000
- Swedish Research Council f. Health, Working Life and Welfare (Forte) - Åsa Muntlin Athlin: 1 000 000

Total 6 458 000

External Reviews 2011-2013
- Margareta Sanner: External reviewer of research applications, Health and Medical Research Fund, Food and Health Bureau, Government secretariat, Hong Kong (2012).
National and international commitments

- Jan Larsson - Pedagogical advisor at the Västra Götaland Region project “Building a training program tailored for doctors with their basic medical training abroad”.
- Jan Larsson - Lecturer at the Swedish annual course for tutors in anaesthesia.

Awards

- Ulrika Winblad, Received The Commonwealth Fund's Harkness Fellowships in Health Care Policy and Practice for 2014 (2013).
- Åsa Muntlin Athlin: Inaugural Eleanor Harrald post doctoral fellowship, School of Nursing, University of Adelaide, Australia (2012).

Research projects

Parents’ views of calling Swedish Healthcare Direct regarding pediatric health issues

Participants: Elenor Kaminsky, Inger K. Holmström and Marta Röing.

Telenursing is a rapidly expanding service and Swedish Healthcare Direct handles up to 2.4 million pediatric health calls yearly. Mothers make the majority of the calls and reportedly receive self-care advice more than fathers. Parents’ views are important for the development and safe use of telenursing health services. A exploratory and descriptive design is used. Twenty-one qualitative interviews with parents were analysed using content analysis. According to the interviewees, the decision to contact SHD or not is influenced by their degree of worry or trust in the service. Calls are carefully prepared, and who will call is often predetermined and affected by gender. Parents want to be given a chance to speak first in their communication with telenurses. They want to be listened to carefully and to be accorded respect, to have their needs fully explored and to have their concerns relieved. Most parents follow telenurses’ recommendations, a few exclusively. Some primarily trust their own intuition. Learning is frequent, implying the public health potential of calls, not least for foreign-born callers. Exploring parents’ expectations provides insight into parents’ worries, potential to increase parents’ learning and may develop their trust in telenurses’ recommendations. Telenurses’ awareness of gender impact can further develop the telenursing health service in providing safe care on equal terms for a vulner-
able patient group, children. An article from this project was accepted in Clinical Nursing Studies in June 2013.

Reasons for Continuing DNA-identification of Named Victims
Participants: Malin Masterton.
An increasing number of countries in the world, including Sweden, now hold dedicated teams to investigate victims’ identities in case of major disasters. The advancements of DNA technology mean that also in high impact disasters, with high levels of intermingling and fragmentations of victims’ bodies, small body parts can be identified to person. Legally, the work can be stopped as soon as all victims have been officially identified, but in the aftermath of disasters the work is sometimes continued despite high costs, as was the case in the Hercules crash. In March 2012, a Hercules military aircraft crashed into Kebnekaise, killing all five Norwegian personnel on board. The massive impact meant that the bodies were highly fragmented and spread over a most challenging terrain at 2000 meters above sea level. The retrieval of human remains had to be done in two time periods, and the subsequent identification work on the human remains over the set minimum size was extended to include the second recovery phase as well. The aim of this case study was to explore the reason(s) behind the decision for the extended identification, which went beyond the official requirements. The proposed hypothesis is that a lack of alternatives in handling mixed and unidentified human remains ethically lie behind the chosen action. To conduct the study, key stakeholders have been interviewed, relevant documents have been collected and relevant laws studied. The work was done in collaboration with Dr. Kerstin Montelius, PhD, at the Forensic Genetics Laboratory at the National Board of Forensic Medicine. The study is of relevance for revealing norms, expectations and possible alternative actions in the event of disaster victim identification.

Patients with acute abdominal pain – from the emergency department to the surgical ward: what makes a difference to achieve patient participation, high quality nursing care and safe care transitions?
Participant: Åsa Muntlin Athlin.
This pilot project is part of a multidisciplinary research program in collaboration between researchers and clinicians in Australia and in Sweden. The aim of the pilot study is to further explore patient experiences across the acute care delivery chain and to test methodological procedures.
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.

Choice in primary care in Uppsala county council - External review of access, choice, financial resources and quality

(Vårdval i Uppsala län - Extern granskning av tillgänglighet, valfrihet, resurser och kvalitet)

Participants: Mio Fredriksson, Linn Boström, Andreas Karlsson

During the latter half of 2012, the Health Services Research group evaluated the introduction of choice in primary care in Uppsala county council (Vårdval Uppsala län). Mio Fredriksson led the work of the evaluation which was commissioned by Uppsala county council. According to the decision of the county council executive board, the evaluation approached questions about healthcare quality, access, choice, economics and patient satisfaction.

Among other things, the evaluation shows that the access to primary care providers (both phone access and physician access) has improved since 2009 when “choice in primary care” was introduced in the county council. Choice of provider has increased only in the larger urban areas. Most primary care providers are today available in parts of Uppsala where residents have the most resources. The number of visits to a primary care physician or nurse has increased, and so has the costs. Particularly with regard to antibiotic prescribing there are differences between private and public health centers. Patient satisfaction has increased only marginally since “choice in primary care” was introduced.

In the evaluation report, it is concluded that it is difficult to establish the impact of the choice reform in Uppsala county council. During the studied time period the regulatory framework has changed, so also the financial compensation model and reporting methods. Other national reforms such as the Waiting-time guarantee also affect the delivery of primary care in the county councils.
Media coverage and public awareness, knowledge and attitudes to the Swedish waiting-time guarantee

Participant: Mio Fredriksson.

In this project, the focus is media coverage of access-enhancing policies in Sweden. The central question is whether media coverage of access-enhancing policies in Sweden is linked to the public’s level of knowledge of the Swedish waiting-time guarantee and the public’s opinions on how well the time-limits in the Swedish waiting-time guarantee are met. Another more general way to phrase the question is: what role do media play to convey a message from national decision-makers to the population? The project (reported in December 2012) was commissioned by the National Board of Health and Welfare being a part of the authority’s yearly evaluation of the Waiting-time guarantee and the “Queue-billion”. The results of an analysis of the relationship between the regional media coverage of the waiting-time guarantee (WTG) and the queue billion (QB) and the public awareness, knowledge and attitudes show that media coverage in the county councils does not seem to correlate with public awareness or knowledge of the WTG. There is however a strong correlation to the public’s negative as well as positive attitudes. When controlled for actual waiting-times in the county councils, there is still a significant correlation between media coverage and the public’s negative attitudes to how well they perceive the waiting-time guarantee to be met.

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 treat-
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.

Obstacles and opportunities for quality improvement - a process study of the National quality registers in Sweden

In 2011 the Swedish Association of Local Authorities and Regions (Sveriges kommuner och landsting) and the state agreed on a five-year investment in the development of national quality registers. This initiative followed a review that showed that Sweden can take a leading position in the development of a more efficient and equitable health care based on the use of national quality registers. What obstacles and / or opportunities are there to bring about such a development? This question is investigated in a national research project carried out by three research groups (in Uppsala, Stockholm and Jönköping). The national research project is commissioned by the Swedish Association of Local Authorities. During 2013, the work of the Uppsala research group has consisted of a case study in four county councils (and nine hospitals) and an upcoming national web survey to hospitals using three selected quality registers. Members of the project are also Lars Wallin (Dalarna County Council) and Christina Halford (Department of Public Health and Caring Sciences).

How does the design of the reimbursement systems affect the behavior of primary care providers?
Participants: David Isaksson, Ulrika Winblad.

A new reform regarding free choice of primary health care provider was introduced in Sweden during 2010. The intent of the reform was to make it possible for patients to visit the health care provider of their choice. The national government has, however, given each county council the responsibility to design their own reimbursement system which means that there exist 21 different systems today. The systems vary in many aspects such as the degree of capitation reimbursement (number of listed patient) compared to the reimbursement based on performance. The design of the reimbursement system is the foundation for the competition in the primary care. Via the reimbursement system each county councils creates financial incentives and thus steer the providers in desired direction. The aim of the project is to examine how the different designs of the reimbursement systems affect how private health care providers operate.

To conduct the study, data regarding the different reimbursement levels, is collected from each county council and a classification of each system is made. In a second stage data regarding number of GP visits, nurse visits,
number of new establishments will be collected from each county council. Finally we will use statistical analysis to analyze how the design of the reimbursement system affects how the providers behave. The project is run in collaboration with the Department of Government (Paula Blomqvist), Uppsala University.

Choice systems in universal welfare models – implications for state, citizens and accountability
Participants: Linda Moberg, Ulrika Winblad.
During the last decades, social service sectors in many welfare states have undergone a marketization process. The research question for this project is what implications these market-oriented reforms have for the governance of publicly funded social service sectors. In particular, it focuses on how quality-monitoring techniques in the Swedish welfare state change when choice systems are implemented.

The Swedish welfare state, as emerged in the post war era, is characterized by a publicly funded social service sector and based on the concept of universalism and social egalitarianism. The basic idea behind these organizational settings was to create broad legitimacy of the welfare system by offering all citizens high-quality services. This implied that the sector was organized as virtually a public monopoly of standardized services, later criticized for offering very little choice for service users. As a response to this critique, market steering logics have become more dominant. Particularly, user choice of provider combined with provider competition has been implemented in various social services. This implies that the model for service delivery has undergone extensive changes during the last decades, affecting the government’s ability to steer these sectors. However, the state still has a legislated responsibility to ensure high and equal quality for all citizens. In this project we therefore address questions regarding what implication this form of ‘governing the social’ has for the state’s ability to steer and monitor service providers, and whether the introduction of choice systems is consistent with the objective of universalism. Furthermore, choice of provider imply that citizens have to become more active to realize their social welfare rights, but also that they become at least co-responsible for the outcome of their choices. Hence choice systems give users more individuated power as consumers but also involve the risk of making poor choices. Thus, this project also aims to analyze what implication choice of provider have for the concept of social citizenship and under what conditions citizens can make a well informed, quality enhancing choice of provider.

These research questions will be addressed through four different articles. Two of these studies have currently been initiated. In the first paper we test the theoretically grounded assumptions that user choice will enhance service quality since only high quality providers are expected to withstand the com-
petition. However, in order for choice system to have quality enhancing effects users need access to information on the relative quality of these providers and they must exercise their right to choose based on these quality indicators. The study therefore aims to investigate what kind of information social service recipients have access to and whether it can be used to make a qualitative and informed choice of provider. The second study analyzes how the Nordic welfare states have chosen to organize the delivery of social services. Choice has been a political buzzword in these countries during the last decade, implying that the public authorities ability to steer the social service sectors have altered. In this study we therefore analyze how the Nordic countries have increased choice, and whether it is still plausible to talk about a Nordic model of social service delivery.

This project is run in collaboration with the Department of Government (Paula Blomqvist), Uppsala University.

Telenursing in Sweden: what goes wrong and why?
Participants: Annica Ernesäter, Inger Knutsson Holmström, Ulrika Winblad.

During the last years centralization of telenursing services has occurred in Sweden with a national telephone number for the entire country. Within this service computerized decision support (CDSS) are used and two studies have focused on telenurses’ experiences of working with CDSS. The CDSS was perceived as incomplete, lacking information, not fully adapted to telenurses way of working. Yet it was a useful tool, proving security.

SHD is one of Sweden’s largest healthcare providers there are no studies regarding patient safety within this context. A study of 450 incident reports was analyzed with the aim of this to describe errors reported within this context. Data were collected from all county councils that participated in SHD and the most frequent outgoing incident reports (i.e., sent from SHD) regarded Accessibility Problems and the most frequently incoming ones (i.e., sent to SHD) regarded Incorrect Assessment.

During 2010 a study aimed at analyzing communication between telenurses and callers with a clear request for a specific level of care. 30 calls to SHD were analyzed using the Roter Interaction Analysis System (RIAS). Results show a mean call time of 4 minutes and 14 seconds and that telenurses mostly used close-ended questions.

Analysis of all malpractice claims (n=33) regarding SHD showed how male patients (n=19) were in majority and the most common reason for calling were abdominal pain (n=11). Thirteen of the patients died and 12 were admitted to intensive care. Communication failure was the most common reason as identified by the National Board of Health and Welfare. Measures made by the health care provider was discussion in work group (n=13).
Developing gender competence in Swedish telenursing

Participants: Roya Hakimnia, Inger Knutsson Holmström, Marta Röing, Elenor Kaminsky.

The overall aim of this project is to use theories of gender and intersectionality in order to investigate how factors such as gender, ethnicity, class and age can play a role in telenursing in Sweden. The aim is also to develop an instrument that can investigate and contribute to gender competence in telenursing and to test an educational intervention for telenurses.

Telenursing is considered as first line health care. Most telenurses are female. The majority of calls for children and elderly parents are made by women and a study showed that fathers received advice to seek physician twice as often as mothers. 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 telenurses and callers and how other social factors interact with each other.

Intersectionality hold that gender interacts with other markers of difference, such as "race"/ethnicity, sexuality, social class and (dis)ability. The results can also have direct application in nursing education and probably be used in other areas of healthcare and health care education.

We have analyzed 800 authentic calls to Swedish healthcare Direct from an intersectional perspective. The service was not used equally. The most common caller was a woman proficient in Swedish, and the least likely caller was a man that was not proficient in Swedish. Calling a telenurse seems to clash with hegemonic masculinity, while being in line with ideal femininity, where seeking help and taking care of others’ health are central aspects. Health behavior is hence a part of “doing gender”. Furthermore, we made an in-depth analyzis of 20 calls to SHD with Roter Ineractional Analysis System and Critical Discourse Analysis. The calls are dominated by task-focused utterances such as giving medical information. Open medical questions are rare while close ended medical questions are common. Three types of ideological work were found in the calls: gatekeeping, hegemonic masculinity and traditional medicine ideology. These three types of ideological works was part of the dominating discourse in telenursing echoing macro-aspects of society. A counter discourse was however also found where open questions, questions about the social, information giving and challenging hegemonic masculinity were defining ingredients.

Drugs and patient behavior – the influence of organizational andprofessional 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.

Competence as ways of restructuring
Participants: Madeleine Boll, Urban Rosenqvist, Cecilia Bernsten.

The overall aim of my doctoral thesis in process is to describe and explore physiotherapists understanding of and being in their work in contexts at the system level within health care organizations. The thesis comprehends four qualitative studies where totally thirty four physiotherapists has been interviewed. In study I the focus was on understanding of and approaches to work, where seven physiotherapists in primary care were working with health promotion in compulsory schools. Study II was about how twenty one physiotherapists working on organizational and societal levels varied in their understanding of their work. In Study III understanding of work was explored as a transforming process regarding experiences and developed skills on individual level into work on organizational and societal levels. In study IV former made interviews in study I to III were explored concerning ways of sense making in managerial work. The thesis offers possibilities of challenging traditional use of physiotherapy as just treating individuals.

Teamwork in an emergency department
Participant: Åsa Muntlin Athlin.

Increasing waiting times and long lead-times in emergency departments are well-known problems, which could influence efficiency, patient safety and patient satisfaction in a negative way. The healthcare needs to use the limited resources in a more effective way. Working in multidisciplinary teams could improve care processes in the healthcare. The overall aim was to investigate how implementation of team work in an emergency department can effect efficiency, quality of care, patient safety and patient satisfaction and work environment. In addition, the implementation process will be further studied. A longitudinal non-randomized intervention study design with three follow ups was used. The intervention was teamwork in the specialty of medicine in an emergency department. Patient questionnaires, staff questionnaires (dia-
PUP – Pressure Ulcer Prevention
Participant: Åsa Muntlin Athlin.
Despite guidelines for pressure ulcer prevention, clinical reports indicating that pressure ulcer is still common in the healthcare. Research has shown that the pressure ulcer prevalence is higher in Swedish hospitals, compared to other hospitals in Europe and in USA. In 2010, a group of researchers from county councils and universities in Uppsala, Värmland, Dalarna and Gävleborg started a collaboration project with pressure ulcer prevention as the topic. One of the research projects is a randomized clinical trial, where the aim is to study the effect of a pressure reducing heel protection and health economic related effects. This study follows the care chain; from pre-hospital care to discharge from the hospital. Another research project is about describing and comparing Swedish nurses’ and nursing students’ knowledge and attitudes to pressure ulcer prevention.

Fundamentals of care
Participant: Åsa Muntlin Athlin.
This is an ongoing research collaboration project with an international and multidisciplinary group of clinicians, researchers and scholars from Australia, UK and Sweden. According to healthcare reforms around the world, reports are emphasizing that fundamental aspects of care are being neglected in acute hospital settings. The overall aim with the Fundamentals of Care project is to investigate how fundamental aspects of care are delivered to patients within health systems. Examples of ongoing subprojects are: exploring stroke patients’ experiences of fundamentals of care and cancer patients’ experiences of fundamentals of care. Another collaboration project is between the Hampstead Rehabilitation Centre (Australia) and the University of Adelaide in Australia, focusing on improving the fundamentals of care in the sub-acute care. The main purpose with the research project is to evaluate method of introducing change (Knowledge Translation (KT) toolkit) and to evaluate the fundamentals of care framework. An additional project is to investigate clinical rounding and nursing clinical handovers with special attention to fundamental aspects of care.

The Future Shape of the Nursing Workforce: A Synthesis of the Evidence of Factors that Impact on Quality Nursing Care
Participant: Åsa Muntlin Athlin.
An informal group of Australian nurse leaders highlighted the need for looking at the nursing future and identify the evidence around what makes a pos-
tive environment for nursing, in order to influence the direction of health care and nursing’s future. This led to the commissioning of an umbrella review, funded by the Department of Health and Ageing, Australian Government. A total of 79 systematic reviews published between 1995 and 2012 were included in the umbrella review. Recommendations for practice, research, education and policy initiatives were provided.

Teamwork in emergency care: Using behaviour analysis to understand how changes in practice can be achieved and sustained

Participant: Åsa Muntlin Athlin.

Multi-professional teamwork is a promising method to improve patient outcomes and patient safety in health care. Introduction of teamwork always includes some type of behaviour change, however, this behaviour change has been proven to be a major challenge when implementing teamwork. Thus, understanding how and why behaviour change interventions influence behaviour is emphasized as a prioritized area in implementation research. Sustainability has also been highlighted as one of the most challenging aspects of implementation. The overall aim with the research project is to deepen our understanding of what works when implementing teamwork in a complex context such as the emergency department and how to sustain changes.

A synthesis of phenomenographic studies on patients’ ways of experiencing illness

Participants: Marta Röing och Margareta Sanner.

The focus of interest in this study is patients’ experiences of illness, or aspects of their illness.

Phenomenography, originally developed within an educational framework in Sweden, is a research approach which studies the variations in ways that people understand or experience phenomena in the world around them. It is based on the notion that phenomena or aspects of reality in the world can be understood or experienced in a limited number of ways.

Given this potential, we explore research literature as to the application of phenomenography as a qualitative research method in the study of patients’ experiences of illness and ask the following questions: What can the uniqueness of a phenomenographic approach to data add to knowledge of patient illnesses? How effective is phenomenography as a tool in patient education and patient empowerment?

Selection criteria for articles applicable for a possible review were that they focused on patient’ experiences of illness (or aspects of their illness) and really used a phenomenographic approach to data collection and analysis. These articles will be read in-depth and a meta-synthesis will eventually be performed, using the meta-ethnographic method of synthesis. In this work
we will also make a critical review of how the method of phenomenography is applied in the various studies.

Non-prescription drugs and self-medication among adolescents in Sweden
Participants: Ingeborg Björkman, Marta Röing, Pia Bastholm-Rahmner, Inger Knutsson Holmström.
Consumers in Sweden were given greater access to OTC drugs in 2009 after the deregulation of the pharmacy market, which allowed for the establishment of private pharmacies and sale of specific over-the-counter (OTC) drugs in retail stores and gas stations.

Increased access to OTC drugs can give Swedish teenagers new opportunities for self-care. However, the ability to buy OTC drugs outside pharmacies gives little opportunity for the traditional expert surveillance of pharmacists, thus increasing the possibility of careless or inappropriate use of OTC drugs. This study explores and describes Swedish teenagers' views on OTC drugs, with special regard to analgesic drugs, and asks the following questions: How and where to Swedish teenagers acquire their knowledge and attitudes regarding OTC drugs? What perceptions do they have about the use of OTC drugs? This study has a descriptive design with a qualitative approach. Data was collected in 2011 with 10 focus group discussions with high school students aged 16 to 19 years from different parts of Sweden. The group discussions revealed teenagers’ attitudes and knowledge gaps regarding OTC drugs, and the significant influence of parents and peers on their OTC drug use. This study gives insight into how vulnerable some Swedish teenagers can be as new consumers of OTC drugs and underscores their need for more guidance and information about OTC drugs and their use.

Experiences and participation in sick-listing
Participant: Inger Knutsson Holmström.
This project is run in collaboration with participants in the research group for Family Medicine (Thorne Wallman, Linda Lännerström, Lars Carlsson). The project aims at studying both general practitioners views of sick-listing, and experiences and participation in the process of being on long-term sick-leave from the patients view. Sixteen patients on long-term sick-leave have been interviewed about their experiences and about participation in the process. This data-collection was carried out during 2011 and data analysis conducted during 2012 with a phenomenological analysis of the lived experience of being on long-term sick-leave. The findings revealed that the participants’ experience of being long-term sicklisted was losing independence. They had to stop working and start to rely on the state for support. Most of the participants experienced their present life as a constant, uncertain pending meanwhile being questioned by authorities and society. They all were exposed to
the rules of the social insurance but the rules and the encounters with professionals affected them differently. A few were treated well and went through changes that in the end led to a better life. Many were not treated well which caused impaired confidence in themselves and in authorities. The interview-parts about participation in the sick-listing process will be separately analyzed during 2013 with qualitative content analysis.

Parents’ expectations and experiences of calling Swedish Healthcare Direct regarding paediatric health issues
Participants: Elenor Kaminsky, Inger Knutsson Holmström, Marta Röing.
During 2012, 5.2 million calls were made to the Swedish Healthcare Direct. About 50% are paediatric calls made by parent callers. The Study aims at performing a descriptive and exploratory interview study, with a strategic sample of 21 parents who had used the service for their child within the last six months. Seventeen hours of transcribed interview data was analyzed using qualitative content analysis. Conclusions made from the findings are that parents desire an equal relationship with telenurses. Moreover, exploring parents’ expectations will reduce their worry, increase their learning and result in greater trust in telenurses’ recommendations. Telenurses’ awareness of gender impact can further develop the telenursing health service in providing safe care on equal terms for a vulnerable patient group, children.

Goals of telephone nursing work - the managers’ perspectives: A qualitative study on Swedish Healthcare Direct
Participants: Elenor Kaminsky, Inger Knutsson Holmström, Jan Larsson, Mio Fredriksson.
The aim of this project is to explore and describe what Swedish Healthcare Direct (SHD) managers perceive as the primary goals of Telephone Nursing (TN) work and how the managers view health promotion and implementation of equitable healthcare with gender as example at SHD.

SHD receives 6 million calls yearly and aims at increased public sense of security and healthcare efficiency. Little is known about what SHD managers perceive as the primary goals of TN work and how the organisation matches goals of health promotion and equitable healthcare, so important in Swedish healthcare legislation.

All 23 managers employed at SHD has been interviewed and data analysed using deductive directed content analysis.

The findings reveal four themes describing the goals of TN work as recommended by the SHD managers: ‘create feelings of trust’, ‘achieve patient safety’, ‘assess, refer and give advice’, and ‘teach the caller’. Most of the managers stated that health promotion should not be included in the goals, whereas equitable healthcare was viewed as an important issue. Varying suggestions for implementing equitable healthcare were given. The inter-
viewed managers mainly echoed the organisational goals of TN work. The managers’ expressed goal of teaching lacked the caller learning components highlighted by telenurses in previous research. The fact that health promotion was not seen as important indicates a need for SHD to clarify its goals as the organisation is part of the Swedish healthcare system, where health promotion should always permeate work. Time used for health promotion and dialogues in a gender equitable manner at SHD is well invested as it will save time elsewhere in the health care system, thereby facing one of the challenges of European health systems.
Research Group Leader: Samar Basu, M.Sc., PhD., Professor

The research group “Oxidative Stress and Inflammation” was established in January 2009. The main research area is related to role of eicosanoids in oxidative stress and clinical inflammation specifically in various diseases and pathophysiological state.

Research Group Leader Samar Basu is a Professor of Biochemistry and Medical Inflammation at the Universite d’Auvergne, Faculte de Pharmacie, Clermont-Ferrand, France, and he holds a Chaire d’Excellence Professor and Director position.

This research group “Oxidative Stress and Inflammation” is dedicated to research on inflammation in physiology and in disease state. Additionally, the role of oxidative stress that reflects an increased level of free radicals that are implicated both in ageing and in several inflammatory diseases is also a major research area. Lipid peroxidation products catalysed by free radicals and cyclooxygenases have shown to be of importance in many inflammatory and oxidative stress-related diseases. Bioactive prostaglandin formation by cyclooxygenases from arachidonic acid and their contribution in inflammation is well described by our group in the past years in addition to the role of free radicals-mediated product isoprostanes in physiology and a range of diseases. The research group have developed crucial assays through raising specific antibodies against isoprostanes indicating oxidative injury and prostaglandin F$_2\alpha$ indicating inflammatory response, and 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 devoted to experimental, clinical, epidemiological studies and also development of methodology specifically on eicosanoids. The research group has many national and international collaborative projects within the research vicinity.
Members of the research group
Samar Basu
Johanna Helmersson
Elisabet Rytter
Lillemor Kallstrom

External
Maria Palm
Emma Lindström
Adriana Miclescu

Publications 2011-2013


Peer-reviewed review articles in scientific journals

Peer-reviewed review articles in books, conference proceedings, popular science and thesis

Book Chapters

Book Editor

Agencies that support the work/Funding
(>100,000 SEK)
The Swedish Research Council, Sweden
The Norweigian Research Council, Norway
The Conseil Regional d’Auvergne, France

Research projects
Impact of systemic inflammation, oxidative stress and adipokines in breast cancer
Collaborators: Samar Basu, Alicja Wolk, Anders Larsson, Marie-Paule Vasson.
The project is performed in collaboration with Karolinska Institute, Clinical Chemistry, Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.
Association of specific systemic tumor markers in breast cancer
Collaborators: Samar Basu, Anders Larsson, Marie-Paule Vasson, Alicja Wolk.
The project is performed in collaboration with Karolinska Institute, Clinical Biochemistry, Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.

Cellular localisation of COXs, aromatase, adipokines and their receptors in breast cancer specimen
Collaborators: Samar Basu and Marie-Paule Vasson.
The project is performed in collaboration with Universite d’Auvergne, Clermont-Ferrand, France.

Eicosanoids, COXs, ROS and adipokines in experimental mouse model of breast cancer
Collaborators: Samar Basu and Marie-Paule Vasson.
The project is performed in collaboration with Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.

Smartfish - Effects of fish oil in functional foods, capsules or fish on the blood lipids and markers of oxidative stress in mice and humans
Collaborators: Samar Basu, Rune Blomhoff and Liver Frøyland.
Financed by The Norwegian Research Council, Norway.
The project is performed in collaboration with Oslo Medical Faculty and Bergen University, Norway.

Oxidative stress, inflammation during normal pregnancy, parturition and under normal menstrual cycle
Collaborators: Maria Palm, Ove Axelsson, and Samar Basu.
The project is performed in collaboration with the Department of Women's Health and Clinical Chemistry, Uppsala University.

Oxidative stress among pregnant women exposed by iron, arsenic and cadmium
Collaborators: Eva-Charlotte Ekström, Marie Vahter and Samar Basu.
The project is performed in collaboration with the International Maternal and Child Health, Uppsala University, MINIMAT (Bangladesh) and Karolinska institutet and financed by The Swedish Research Council.
Prenatal food and multiple micronutrient supplementation and effects on child body composition, metabolic markers and mortality; mechanisms of early programming
Collaborators: Lars-Åke Persson, Eva-Charlotte Ekström, Sham Arifeen, Rubanna Ruqib, Samar Basu.
Financed by The Swedish Research Council.

Oxidative stress, inflammation among 82-years ULSAM men and cardiovascular risk
Collaborators: Johanna Helmersson, Anders Larsson and Samar Basu.
The project is performed in collaboration with the Clinical Chemistry, Uppsala University.

Oxidative stress and neuroprotection following cardiac arrest by different therapy
Collaborators: Samar Basu and Lars Wiklund.
The project is performed in collaboration with the Department of Surgery and Anaesthesiology, Uppsala University.

Oxidative stress and neuroprotection following cardiac arrest by hypothermia
Collaborators: Samar Basu and Sten Rubertsson.
The project is performed in collaboration with the Department of Surgery and Anaesthesiology, Uppsala University.

Oxidative stress and regional pain syndrome
Collaborators: Samar Basu and Torsten Gordh.
The project is performed in collaboration with the Smart Centrum, Akademiska Hospital, Uppsala University.

Oxidative stress and acute traumatic brain injury
Collaborators: Samar Basu and Lars Hillered.
The project is performed in collaboration with the Department of Neurosurgery, Uppsala University.

Antibody and assay development on resolvins/protectins
Collaborators: Samar Basu, Charles Serhan.
The project is performed in collaboration with Brigham and Women's Hospital, Harvard Medical School, Boston, USA.
Oxidative stress and cataract formation:
The Swedish Mammo-graphy Cohort
Collaborators: Samar Basu, Anders Larsson and Alicja Wolk.
The project is performed in collaboration with Clinical Biochemistry, Uppsala University and Karolinska Institute, Sweden.

AQUAMAX: The sustainable aquafeeds to maximise the health benefits of farmed fish for consumers
Collaborators: Samar Basu, Philip Calder.
The project is performed in collaboration with Southampton, Granada, Bergen, China.

Multi-laboratory study on biomarkers of oxidative stress (BOSS-study)
Collaborators: Maria Kadiiska with international colleagues, Ron Mason, Samar Basu.
The project is performed in collaboration with NIEHS, National Institute of Health (NIH), USA and other institutions from several countries and is financed by NIEHS (NIH).

Birth weight and inflammation in later life, a follow-up study of 70-80 years in a Swedish population
Collaborators: Johanna Helmersson, Liisa Byberg, Samar Basu.
The project is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital, Department of Surgical Sciences, Uppsala University, Sweden.

Complicated pregnancy and inflammation
Collaborators: Samar Basu and Osamu Ishihara.
The project is performed in collaboration with Saitama Medical School, Tokyo, Japan.
Psychosocial Oncology and Supportive Care

Research Group Leader professor Louise von Essen

With the help of the Swedish Government’s funding of the Uppsala University Psychosocial Care Program: U-CARE, Uppsala University has been given the possibility to support our research group that is internationally strong in basic and applied psychosocial care research. The overarching goal of our group’s 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, Information Systems, and Psychology.

Members of and external partners to the group during 2013

Members:

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<th>Name</th>
<th>Task/s in group</th>
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<td>Lisa Ljungman</td>
<td>PhD student</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Ruth Lochan</td>
<td>PhD student</td>
<td>MSc in Information Systems</td>
<td>Department of Public Health and Caring Sciences, and Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Pernilla</td>
<td>PhD student</td>
<td>MSc in Psychology,</td>
<td>Department of</td>
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<table>
<thead>
<tr>
<th>Name</th>
<th>Degree Level</th>
<th>Field of Study</th>
<th>Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jernerén Maathz</td>
<td>PhD student</td>
<td>Psychology, Licensed psychologist</td>
<td>Psychology, Uppsala University</td>
</tr>
<tr>
<td>Susanne Mattsson</td>
<td>PhD student</td>
<td>Registered nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Anna Norén</td>
<td>PhD student</td>
<td>MSc in Economics</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Mudassir Imram Mustafa</td>
<td>PhD student</td>
<td>MSc in Information Systems</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Fredrika Norlund</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist, Licensed psychotherapist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Teolinda Toft</td>
<td>PhD student</td>
<td>BSc in Social Work</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Emma Wallin</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist</td>
<td>Department of Psychology, Uppsala University</td>
</tr>
<tr>
<td>Mattias Ohman</td>
<td>PhD student</td>
<td>MSc in Economics</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Hafijur Mohammad Rahman</td>
<td>PhD student</td>
<td>MSc in Information Systems</td>
<td>Department of Public Health and Caring Sciences, and Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Madeleen Hermelin</td>
<td>Developer</td>
<td>MSc in Information Systems</td>
<td>Department of Public Health and Caring Sciences, and Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Fabian Holmberg</td>
<td>Developer</td>
<td>BSc in Computer science</td>
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</tr>
<tr>
<td>Benjamin Lefoul</td>
<td>Developer</td>
<td>MSc in IT and Communication Technology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Sofia Leijon</td>
<td>Research assistant</td>
<td>Student at the Psychology program, Uppsala University</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Marike Boger</td>
<td>Research assistant</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Name</td>
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<td>Department/University</td>
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<tr>
<td>Marina Forslund</td>
<td>Research assistant</td>
<td>MSc in Nutrition</td>
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</tr>
<tr>
<td>Golden Masika</td>
<td>Research assistant</td>
<td>MSc in Caring Sciences, Registered nurse</td>
<td>University of Dodoma, Dodoma, Tanzania</td>
</tr>
<tr>
<td>Sandra Waara</td>
<td>Psychologist</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
</tbody>
</table>

**External partners:**

<table>
<thead>
<tr>
<th>Name</th>
<th>Task/s</th>
<th>Title/s</th>
<th>Department/University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrico Baraldi</td>
<td>Researcher</td>
<td>Professor, PhD, MSc in Business administration</td>
<td>Department of Engineering Sciences, Uppsala University</td>
</tr>
<tr>
<td>Gunilla Burell</td>
<td>Researcher</td>
<td>PhD, MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Maria Carlsson</td>
<td>Researcher</td>
<td>Associate professor, PhD, Registered nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Matz Dahlberg</td>
<td>Researcher</td>
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</tr>
<tr>
<td>Jenny Eriksson Lundström</td>
<td>Post doc researcher</td>
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</tr>
<tr>
<td>Inna Feldman</td>
<td>Researcher</td>
<td>PhD, MSc in Mathematics</td>
<td>Department of Women's and Children's Health, Uppsala University</td>
</tr>
<tr>
<td>Lena Hedén</td>
<td>Post doc researcher</td>
<td>PhD, Registered nurse</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Fredrik Holländare</td>
<td>Post doc researcher</td>
<td>PhD, Licensed psychologist</td>
<td>Psychiatric research centre, Örebro county council</td>
</tr>
<tr>
<td>Timo Hursti</td>
<td>Researcher</td>
<td>Associate professor, PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Psychology, Uppsala University</td>
</tr>
<tr>
<td>Thecla Kohi</td>
<td>Researcher</td>
<td>Professor, PhD, Registered nurse</td>
<td>Muhimbili University of Health and Allied Sciences, School of Nursing, Dar es Salaam, Tanzania</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Qualifications</td>
<td>Department/Institution</td>
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<tr>
<td>Claudia Lampic</td>
<td>Researcher</td>
<td>Associate professor, PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Neurobiology, Care Sciences and Society, Karolinska Institutet</td>
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<tr>
<td>Brjánn Ljótsson</td>
<td>Post doc researcher</td>
<td>PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Clinical Neuroscience, Karolinska Institutet</td>
</tr>
<tr>
<td>Gustaf Ljungman</td>
<td>Researcher</td>
<td>Associate professor, PhD, MD</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Johan Lyhagen</td>
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<td>Department of Statistics, Uppsala University</td>
</tr>
<tr>
<td>Gunilla Mårtensson</td>
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<td>The Faculty of Health and Occupational Studies, University of Gävle</td>
</tr>
<tr>
<td>Thomas Parling</td>
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<td>PhD, Licensed psychologist</td>
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</tr>
<tr>
<td>Christine Rubertsson</td>
<td>Researcher</td>
<td>Associate professor, PhD, Registered nurse, Registered midwife</td>
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</tr>
<tr>
<td>Robbert Sanderman</td>
<td>Researcher</td>
<td>Professor in Health Psychology, PhD, Licensed psychologist</td>
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</tr>
<tr>
<td>Agneta Skoog Svanberg</td>
<td>Researcher</td>
<td>Associate professor, PhD, Registered nurse, Registered midwife</td>
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</tr>
<tr>
<td>Anna Cristina Aberg</td>
<td>Researcher</td>
<td>Associate professor, PhD, Licensed physiotherapist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
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<tr>
<td>Pär Agerfalk</td>
<td>Researcher</td>
<td>Professor, PhD, MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
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<tr>
<td>Anna Hauffman</td>
<td>PhD student</td>
<td>Registered nurse</td>
<td>Department of Radiology, Oncology and Radiation Science, Uppsala University</td>
</tr>
<tr>
<td>Tove Kamsvåg Magnusson</td>
<td>PhD student</td>
<td>MD</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
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<tr>
<td>Jenny Thorsell</td>
<td>PhD student</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>
Publications 2011-2013 (From the table of members)

2013

Publications


Peer-reviewed conference papers


58. Cernvall, M., Silberleitner, N., & von Essen, L. (2013). Posttraumatic stress symptoms in parental dyads of children diagnosed with can-
59. Cornel, J.H., Tricoci, P., Horton, J., Moliterno, D.J., Wallentin, L.,
Armstrong, P.W., Aylward, P.E., Huang, Z., Lokhnygina, Y., Chen,
E., Leonardi, S., Van de Werf, F., White, H., Held, C., Strony, J., Ma-
haffey, K.W., & Harrington, R.A. (2013). Effects of use of glycopro-
tein IIb/IIIa inhibitors in combination with Vorapaxar, a platelet
thrombin-receptor antagonist, in patients with non–ST-segment eleva-
tion acute coronary syndrome: insights from the TRACER trial.
American College of Cardiology (ACC.13). San Francisco, USA.
Peer-reviewed conference paper.

60. Déry, J., Mahaffey, K.W., Tricoci, P., White, H.D., Podder, M.,
Moliterno, D.J., Harrington, R.A., Chen, E., Strony, J., Van de Werf,
S.V. (2013). Arterial access site and outcomes in patients undergoing
percutaneous coronary intervention with and without Vorapaxar.
American Heart Association, Dallas, USA. Peer-reviewed conference
paper.

61. Filla, R., Olsson, E.M.G., von Schéele, B.H.C., & Ohlsson, K.
(2013). A case study on quantifying the workload of working machine
operators by means of psychophysiological measurements. The 13th
Scandinavian International Conference on Fluid Power. Linköping,
Sweden. Peer-reviewed conference paper.

research including the design of an internet based psychological inter-
vention. New Developments in Public Involvement in Research, Exe-
ter, UK. Peer-reviewed conference paper.

63. Grönqvist, H., Olsson, E., Norlund, F., Wallin, E., Burell, G.,
domized controlled study of the effects of internet-based cognitive be-
havior therapy on depression and anxiety in patients with a previous
myocardial infarction - a clinical trial protocol. Medicine 2.0: Social
Media, Mobile Apps, and Internet/Web. London, UK. Peer-reviewed
conference paper.

64. Halvorsen, S., Atar, D., Yang, H., Granger, C.B., Hanna, M., de Ca-
terina, R., Erol, C., Garcia, D., Held, C., Husted, S., Jansky, P.,
Ruzyllo, W., Hylek, E.M., Lopes, R.D., & Wallentin L. (2013). Effi-
cacy and safety of apixaban compared with warfarin according to age
for stroke prevention in atrial fibrillation. American College of Cardi-
ology (ACC.13). San Francisco, USA. Peer-reviewed conference paper.


Psycho-Oncology. Rotterdam, the Netherlands. Peer-reviewed conference paper.


84. Varenhorst, C., Jensevik, K., Jernberg, T., Sundström, A., Hasvold, P., **Held, C., Lagerqvist, B., & James, S.** (2013). Short duration of dual antiplatelet treatment is associated with increased risk of recurrent ischemic events in a large cohort of patients with acute coronary syndromes. European Society of Cardiology (ESC). Amsterdam, the Netherlands. Peer-reviewed conference paper.


2012

**Publications**


parisons to normative data. European Journal of Cancer Care, 21, 642-649.


**Peer-reviewed conference papers**


137. Thalén-Lindström, A., Glimelius, B., & Johansson, B. (2012). Anxiety and depression in heterogenous oncology patients, a comparison between a clinical assessment session and the Hospital Anxiety and Depression Scale. IPOS 14th World Congress. Brisbane, Australia


2011 Publications


143. Engvall, G. (2011). Cancer during adolescence: coping shortly after diagnosis and psychosocial function during the acute and extended


Peer-reviewed conference papers


Agencies that supported the work/Funding during 2013

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<thead>
<tr>
<th>Agency</th>
<th>Amount</th>
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<td>Strategic Research Grant, U-CARE</td>
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<td>Swedish Research Council</td>
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<td>The Swedish Childhood Cancer Foundation</td>
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<td>The Swedish Cancer Society</td>
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<td>Uppsala County Council, ALF funds</td>
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<td>U-CARE-Portal</td>
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Co-funding from main applicant Higher education institution:

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<tr>
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<tr>
<td>Departments of: Economics, Informatics and Media</td>
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<td>Radiology, Oncology, and Radiation Science</td>
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<tr>
<td>Engineering Sciences and Psychology</td>
<td>2 400 000 SEK</td>
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</table>

During 2013 our main activities have been

- Ten post doc researchers and nineteen PhD students have been provided stimulating career opportunities within U-CARE.
- A PhD student from University of Groningen, University Medical Centre Groningen, the Netherlands and a MSc in psychology from Radboud University, Nijmegen Medical Centre, the Netherlands have visited U-CARE.
- Two system developers have been recruited.
- The feasibility study for the RCT YoungCan has been completed via the U-CARE-portal.
- The pilot study for the RCT AdultCan has been completed via the U-CARE-portal.
- The pilot study for the RCT Heart has started via the U-CARE-portal.
- The pilot study for the RCT JUNO (PI associated researcher) has started via the U-CARE-portal.
- The RCT AdultCan has started via the U-CARE-portal.
- Three associated researchers have been provided access to the U-CARE-portal.
- Major external funding has been attracted for 2014 and onwards by U-CARE and its associated researchers.
- Involvement of members of the public has been implemented in U-CARE research activities.
- For members of the group during 2013: Forty-five original peer-reviewed publications have been accepted/published, thirty-two peer-reviewed contributions have been presented at scientific conferences, and eight other publications have been accepted/published.
• The third meeting with the U-CARE Scientific Advisory Board and all U-CARE members has been held.
• Four seminar series have been arranged.
• Part II of the high-quality research-based, cross-disciplinary PhD course in Psychosocial care in the interactive society has been provided.
• High-quality research-based graduate education in Implementation of complex interventions has been provided in collaboration with scholars at Radboud University, Nijmegen Medical Centre, The Netherlands.
• High-quality research-based, cross-disciplinary education in psychosocial care in the interactive society has been further implemented in the educational programs for nurses and psychologists and in the master program for management, communication, and IT.
• A high-quality research-based, cross-disciplinary PhD course in sustainable citizen-centered health care via information and communications technology has been built up.
• High-quality research-based, cross-disciplinary education in psychosocial care in the interactive society for the educational program for physicians and the master program in public health has been built up.
• U-CARE has been established as a health care provider.
• U-CARE has been re-organized to support theoretical depth as well as cross-disciplinarity in research.
• U-CARE has been re-organized to promote leadership to increase educational and research output and share U-CAREs work on a national and global scale.
• A seminar on public involvement in research has been held during the Almedalen week.

Research projects
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 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 have been collected. Participants answered questions about quality of life, anxiety, and depression. Additionally those struck by cancer answered questions about 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 since then funded by the Swedish Childhood Cancer Foundation and the Swedish Cancer Society.

Occurrence and development of posttraumatic stress among parents of children with cancer

OVERALL AIM: To investigate occurrence of posttraumatic stress, predictors of posttraumatic stress, and health economic consequences among parents of children struck by cancer.

METHODS: The project has a longitudinal design with seven measurements 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, and the child’s medical situation.

FUNDING: The project started 2002 and is since then funded by the Swedish Research Society, the Swedish Childhood Cancer Foundation and the Swedish Cancer Society.

U-CARE: 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.

METHOD: The clinical efficacy is evaluated with a randomized, controlled design. Parents are included and randomized to immediate access to a cognitive behavioral-based intervention or a wait-list control condition with delayed access to the intervention. Fifty-five parents have been included. Inclusion is ongoing. Parents answer 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 Society, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation.

U-CARE: Petra. Development, testing, and evaluation of face-to-face cognitive behavioral therapy for parents of children previously treated for cancer

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

METHOD: The clinical efficacy is evaluated with an uncontrolled, within group design where cognitive behavioral therapy is given to parents of chil-
children previously treated for cancer. Fifteen parents were included. Inclusion has finished. Each parent receives 10-15 sessions of face-to-face individual cognitive behavioral therapy. Parents answer questions about posttraumatic stress, anxiety, experiential avoidance, depression, and quality of life and semi-structured questions about experienced suffering.

FUNDING: The project started 2012 and is funded by the Swedish Research Society, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation.

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 of an online, guided psychological intervention for young people diagnosed with cancer during adolescence.

METHODS: The clinical efficacy is evaluated with a randomized, controlled design. Approximately 150 adolescents and young adults will be included and randomized to immediate access to the intervention or a waitlist control condition with delayed access to the intervention. Participants will 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 from the Swedish Research Society to Uppsala University Psychosocial Care Program: U-CARE, the Swedish Cancer Society, and the Swedish Childhood Cancer Foundation.

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

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

METHODS: The clinical efficacy is evaluated with a randomized, controlled design. Approximately 250 adults with prostate-, breast- or localized colo- or rectal cancer will be included and randomized to immediate access to the intervention or a control condition. Inclusion is ongoing. Participants answer questions about e.g. posttraumatic stress, anxiety, depression, quality of life, posttraumatic growth, and costs.

FUNDING: The project is funded by a strategic research grant to Uppsala University Psychosocial Care Program: U-CARE, the Swedish Cancer Society, and ALF funds.
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 of an online, guided psychological intervention for adults struck by a myocardial infarct.

METHODS: The clinical efficacy is evaluated with a randomized, controlled design. Approximately 500 adults struck with a myocardial infarct will be included and randomized to immediate access to the intervention or a control condition. Participants answer questions about *e.g.* posttraumatic stress, anxiety, depression, quality of life, posttraumatic growth, and costs.

FUNDING: The project is funded by a strategic research grant to Uppsala University Psychosocial Care Program: U-CARE, ALF funds, and Swedish Heart-Lung Foundation.
Sociomedical Epidemiology

Research group leader: Professor Ragnar Westerling

The primary objective of the research is to analyze mechanisms behind social differences in health and health care and to develop and evaluate health system interventions in order to increase equity in health. The main fields of the research programme are quality and equity in medical care and health system interventions for vulnerable groups.

The research of the group is established internationally in the field of quality and equity in health care, and includes international collaboration with several universities. We have contributed to the development of the studies of avoidable mortality, *i.e.* mortality from causes of death amenable to medical intervention, by integrating this concept into the field of quality and equity in health care, by introducing a gender perspective, by developing methods for small-area analyses, by performing comparisons with former Soviet Baltic states and by evaluating studies of avoidable factors preceding death. Furthermore we have contributed to the methodological development of cause of death statistics by introducing validity analyses based on international classification rules (ICD) and by targeting for non-obvious errors in causes of death.

We have published several studies on mechanisms behind social differences in health and equity in health care utilization, including studies of potentially vulnerable groups such as unemployed, lone parents and immigrants. We are also studying the consequences of inequity on for instance the health of children and the prognosis for unemployed to return to employment.

The research field also include studies of the diffusion of innovations and implementation of evidence based medicine as well as evaluation of the implementation of organizational programs, such as waiting time guarantee and quality systems in health care.

We are presently developing a research line on health system interventions for vulnerable groups in which a health system and a health promotion approach is combined. In this research field we are collaborating with several counties, municipalities and other authorities in Sweden as well as other research groups and departments at Uppsala University and outside Uppsala. For instance, we are performing evaluations of health system interventions
for immigrants, and for persons on long-term sick leave and for school children.

The research group is multi-professional including persons with the backgrounds as medical doctors as well as from behavioural, economical and Public Health sciences.

Members of the group during 2013

Ragnar Westerling, Professor
Per Lytsy, MD, PhD. University adjunct
Achraf Daryani, PhD. Researcher
Annika Åhs, PhD, Researcher
Marcus Westin, MD, PhD
Marianne Hanning, PhD
Lars-Age Johansson, PhD
Afsaneh Roshanai, PhD
Stefan Kunkel, PhD.
Ulrika Paulsson, Doctoral student
Peter Berg, M.D. Doctoral Student
Susanne Sundell Lecerof, Doctoral student, collaboration with Lunds and Malmö University
Anna Ohlsson, M.D. Clinical research assistant
Hans Nordlöf, Doctoral student, Collaboration with University of Gävle
Egba Hallberg, MPH
Josefin Wångdahl, MPH, University adjunct
Eva Åkerman, MPH, Project coordinator
Erik Berglund, MPH.
Johannaa Lagerkvist, M.D
Elham Mohamaddi, M.D.
Minoo Mohseni-Nazari, research assistant

Publications 2011-2013


fectiveness of health systems. EU Public Health Program 2007106, August 2011.


27. Flodström E. Unga irakiers syn på sexuell och reproduktiv hälsa och rättigheter. (In Swedish: Young Iraqis view on sexual and reproductive health and rights) SMT 2012;89:140-149.


37. Sundell Lecerof S, Stafström M, Westerling R, Östergren PO. Does social capital protect mental health among migrants in Sweden?. Social medicine and global health, Department of Clinical Sciences Malmö, Lund University and Department of Public Health and Caring Sciences, Uppsala University 2013 (Submitted).

38. Nordlöf H, Wiitavaara B, Winblad U, Wijk K, Westerling R. Safety culture and reasons for risk-taking at a large steel-manufacturing company: Investigating the worker perspective. Centre for Musculoskeletal Research, Department of Occupational and Public Health Sciences, Faculty of Health and Occupational Studies, University of Gävle, Department of Public Health and Caring Sciences, Uppsala University and Faculty of Educational Science, Uppsala University, Uppsala 2013 (Submitted).


47. Wångdahl JM, Mårtensson LI, The communicative and critical health literacy scal (Swedish version) Scandinavian journal of public health (Epub 2013 Aug 27).


Agencies that support the work/Funding 2011-2013

International Health Communicators (partnership with Malmö University, Lund’s University and the region of Skåne and Västra Götaland, the county of Blekinge, the municipalities of Botkyrka, Eskilstuna, Kinda, Malmö, Blekinge institute of technology, Östsam and the National Board of Health and Welfare). 6835 000 SEK, 2009-2011. European refugee fund.


Health information for immigrants. Public health funds, Uppsala county, 300 000 SEK 2009-2010, 298 000 SEK 2010-2011.
Health, Migration and Integration (partnership with Malmö University, Lunds University, the municipalities of Bollebygds, Herrljunga, Marks, Svenljunga, Tranemo, Ulricehamn and the employment office of Borås). European Integration Fund. 3 635 000 SEK 2010-2012.

Health examinations for asylum seekers: (partnership with the Swedish Institute for Communicable Disease Control, the Migration Board, the National Board of Health and Welfare, the Swedish organization of local authorities, Umeå University and regions and the counties(regions) of Stockholm, Östergötland, Skåne and Norrbotten): 30 000 000 SEK

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

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

Academic hospital, Uppsala.

Research projects

Studies of Avoidable mortality and diffusion of innovations

Participants: Ragnar Westerling, Marcus Westin, Anna Ohlsson, Marianne Hanning, Anna Cooray.

According to the concept of studying "avoidable" mortality the health care may prevent mortality from a number of causes of death by means of preventive or therapeutic measures. An agglomeration of deaths from avoidable causes is a warning signal motivating further investigations of avoidable factors preceding death. The method has been used in several studies from different countries and has been applied to Swedish conditions by our research group.

Our research group is one of the partners of a European research initiative aiming at further developing the method. The partners are Johan Mackenbach’s group at the Department of Public Health at Erasmus University in Rotterdam, Martin McKee’s group at London School of Hygiene and Tropical Medicine and Eric Jougla’s group at INSERM in Paris. We also collaborate with researchers in Spain, Germany and Estonia.

In this project a systematic review of the literature has been performed in order to assess the extent to which different causes of death can now, in the light of available evidence, be considered avoidable. The project also include trend analyses as well as analyses of the timing of introduction of innovations, i.e. whether these coincides with measurable declines in deaths from the corresponding causes. Furthermore the potential influence of changes and variations in cause of death classification rules has been assessed and the time trends adjusted for changes in classification. For instance, a linkage in
time was found for preventive innovations in cardiovascular medical care. The findings have been used in a Delphi study involving experts from across Europe, in order to update a set of avoidable mortality-based indicators of the effectiveness of health systems which can be used in surveillance systems. We are presently also performing an in-depth study of equity in treatment of heart failure in Sweden as part of this research field as well as on the impact of incidence changes on mortality trends.

Validity in cause of death statistics and trends
Participants: Lars Age Johansson, Ragnar Westerling.

We have found considerable differences between death certificates and corresponding hospital discharge records. These differences have been further examined in order to find out whether this can be explained by the ICD selection rules. The ACME, a standard software for the selection of underlying cause of death was used to examine the compatibility between the underlying cause of death and the final main conditions. One third of the difference could not be explained by ICD selection rules. Adding hospital discharge data changed the underlying cause in 11 % of the deaths.

We have performed a structured assessment of the causes of death based on 1200 medical acts. The death certificates identified to be problematic by the ACME-test were about twice as often as other death certificates questioned also in this assessment. For these death certificates a change of the choice of cause of death was suggested. Thus, this test should be useful in screening for potential quality problems in the cause of death statistics. These assessments would be useful also since we in a methodological review have found considerable quality problems in studies aiming at evaluating the quality of causes of death statistics. Recently, in-depth analyses of the cause of death statistics for suicide, methadone-related deaths and for prostate cancer has been performed. We are also collaborating with Eric Jouglas’ group at INSERM in Paris in order to analyze validity in cause of death trends and statistics.

Patients and physicians expectations on lipid-lowering drugs
Participants: Per Lytsy, Gunilla Burell, Ebba Hallberg, Erik Berglund, Ragnar Westerling.

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. A total of 909 Swedish statins users were identified and a questionnaire was used to obtain information on the health of the study objects, cardiovascular risk factors, life style and expectations on statin treatment.
On average, statin treated patients believed that 53.6% of statin users would avoid a coronary event as a result of a five-year treatment period. Thus, patients highly over-estimate the general preventive effect of statins. Higher education lowered expectations, but factors commonly used to assess cardiovascular risk, such as age, sex, BMI and previous coronary heart disease, did not affect expectations at all. Patients’ expectations of their own possible treatment benefits were found to be more negative among those with a poor social network and patients not socially active. The health related habits of statin users were compared to non-statin users are analysed showing more concern with meal habits and exercise among statin-users. In a second questionnaire to 600 statin users the expectations were also related to questions about the adherence to the medication. The quantitative studies of the expectations on statin use is presently also combined with an interview study with patients newly prescribed statins. Recently, we have also analysed the association between the patient’s locus of control and the beliefs about statin medications as well as factors influencing self-rated health in the treatment group.

The physicians expectations and attitudes towards statin treatment has also been analysed showing some gender differences in the prescription habits among physicians. This study was performed in collaboration with the pharmaceutical committees in the county of Uppsala and Gävle and supported by the Academic hospital in Uppsala.

Health promoting interventions among immigrants to Sweden

Participants: Achraf Daryani, Josefin Wångdahl, Eva Flodström, Annika Åhs, Afsaneh Roshanai, Ragnar Westerling.

We are evaluating 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 the first part of the project a cross-sectional study of health and health care utilization and experiences of contacts with health advisors among refugees from Iraq has been performed. In another part a longitudinal study has been designed aiming at analysing the effects of contacts with health advisors on the health as well as on the health related knowledge and behaviours of Iraqi migrants to Sweden. Furthermore, focus group interviews have been performed with immigrants from Somalia and Thailand and a questionnaire has been developed based on the results of these interviews, on health related factors in order to get a basis for planning interventions also for these groups. The studies were performed in collaboration with Lund’s University and Malmö University as well as with several municipalities, county councils and other organisations. The project was funded by the European Refuge Fund and Immigrant Fund, respectively.
In a recently started project we are analysing the views and expectations of health examinations for asylum seekers in Sweden. In an explorative phase of the project focus group interviews and interviews with key informants have been performed and a questionnaire has been developed. The focus is on the importance of health literacy for the health examinations and the impact on the sexual and reproductive health. This project is performed in collaboration with the Swedish Institute for Communicable Disease Control, the Migration Board, 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.

Furthermore, a project has started in Uppsala, in which information about health issues and the Swedish health care is developed for study groups among immigrants in Uppsala. A study material has been translated to several immigrant languages and study group leaders have been trained. This project is supported by The Public Health Fund in Uppsala and the project is performed in collaboration with municipality of Uppsala, the county of Uppsala, the County Administrative Board and NBV (The Educational Association of the sobriety movement - a study circle organization). Recently a project has been started in which these study circles is included as part of an intervention for marginalized female immigrants. This project is performed in collaboration with the municipality, county and employment office of Uppsala).

Unhealthy life habits, vulnerability and mental health among school-children

Participants: Ulrika Paulsson, Birgitta Edlund, Marcus Westin, Peter Berg, Ragnar Westerling.

The objective of this project is to study factors that influence health behaviours in general as well as mental health among schoolchildren. We analyse the associations between different health related behaviours, socio-demographic factors and psychosocial vulnerability. Health related behaviours included in the study are alcohol habits, smoking, exercise and food habits. Furthermore, we analyse the influence of health information in school on these different factors.

The study is based on two questionnaires to school children in school classes 7-9. The first is the survey Life and Health conducted by the county of Uppsala. This material includes data from about 10 000 pupils. The second is a questionnaire developed for this project and directed to a strategic sample of schools in Sweden. Structural equation models is used in order to analyse the relation between socio-demographic factors, psychosocial vulnerability factors, health behaviours in general as well as specific health related behaviours. The results show that a general unhealthy behavioural
factor is related to the self-esteem and well-being of the children, factors that differ between gender and socioeconomic position. In another study psychosocial factors were found to have an impact also in the bicycle helmet use of school children. We have also shown that both lone parenthood and low level of social capital influences the children’s mental health negatively. The analyses were based on SDQ (Strengths and Difficulties Questionnaire) measures of the children’s mental health.

Health and health system interventions among non-working populations
Participants: Annika Åhs. Gunilla Burell, Mikael Skärlund, Per Lytsy, Ragnar Westerling.

The last decades there have been considerable changes in the Swedish labour market. During the 1990s the level of unemployment increased considerably and the last years the level of sick leave has been high. In a number of studies we are analysing the risk factors for ill-health among different employment groups. In a recent study we have found that the unemployed experiences depressive mood and indications of potential depression already after a few months of unemployment to a higher extent than employed persons. This depressive pattern occurs irregardless of sociodemographic factors, economic situation and social network factors. However, the unemployed abstained from seeking medical care although when they perceived a need for that more often then the employed did. This was the case also when there were signs of depression or of the so called burnout syndrome. Presently we have analysed the social and health related factors that may predict the chances that the unemployed will be employed one year after the unemployment period started. Economic stress, ill health, and being an immigrant to Sweden predicted a higher risk of being unemployed also one year later. We are also involved in evaluation of an intervention project for persons on long term sick leave at the Academic hospital.

Implementing safety promotion in an industrial working environment

In a doctoral project in collaboration with University of Gävle, the process of change and learning when implementing a safer work environment in an industrial company is explored. The study is performed in a large Swedish steel industry. The project is organized as a case study of the implementation of a Behavioral Based Safety program and the enabling and obstructing factors in the process of change of framework for the safer work environment. The study includes analyses of documents, questionnaires to and interviews
with key persons as well as observations at strategic meetings and of working processes at the industry and focus group interviews with the employed.

Furthermore, a survey on the safety issues was performed among a number of industrial companies.