Department of Public Health and Caring Sciences

Annual Report 2011

Avsändare/Fastställd av Johan Hallqvist 2012-04-30
Introduction

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 2011 the research was carried out in twelve research groups: Caring Sciences, Clinical Nutrition and Metabolism, Disability and Habilitation, Family Medicine and Clinical Epidemiology, Geriatric Research, Health Service Research, Oxidative Stress and Inflammation, Preventive Medicine, Psychosocial Oncology and Supportive Care, Research Ethics and Bioethics, Social Medicine and Sociomedical Epidemiology. Late in the year the three research groups in family medicine, preventive medicine and social medicine joined their forces in a new research group named Family Medicine and Preventive Medicine. The accomplishments of each the now ten research groups at the department are presented in detail in separate chapters in this report. During 2011 the Department of Public Health and Caring Sciences was 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).

The research questions addressed within the department of Public Health and Caring sciences covers a broad spectrum of issues ranging from contemporary hot public health issues on the political agenda to pertinent issues of molecular biology related to important public health problems. They take advantage from a truly multidisciplinary collaboration, and involve cooperation with other departments of the university and other universities in Sweden and around the world.

Research ethics & bioethics

Research is conducted on animal and environmental ethics, autonomy, the ethics of biobanking, dual-use issues related to biosafety and biosecurity, codes and guidelines for research, clinical ethics, enhancement of human performance, genetic information and testing, neuroethics and the philosophy of mind, ethics at the beginning of life, priorities in health care and quality of life issues.

Structure and function of the health services organization

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 focus is on governance and implementation, intra-organizational control, inter-organizational relations and patient relations.

The environment as facilitator and barrier for persons with disabilities

The research questions concern the effectiveness of specialized re/habilitation and community intervention including assistive technology, the participation of people with disabilities and significant others in the re/habilitation process, and staff in service training. Further studies concern the application of assessment instruments of the home environments of children and early child development, using an international standard language and framework for the description health and health-related issues, and an electronic health record system because the professional decision making in healthcare is laden with risk and uncertainty, when assessment is not systematic or a standardized clinical terminology shared by professionals involved is lacking. Studies also focus quality of life from the perspectives of persons with intellectual disabilities and a participatory research approach.
Development of new methodology in psychological treatment and supportive care

The overarching goal of the research is to promote psychosocial health among patients struck by somatic disease and their significant others by developing new treatment technology supporting self help practices that is based on cognitive psychology and distributed via the Internet. The academic disciplines Clinical Psychology, Health Economics, and Information systems collaborate to develop the methodology and to evaluate effects, benefits and costs to the individuals and the society.

Patient safety, organization and new technology in nursing care

The prevalence of pressure ulcers has been developed into a quality indicator on the national level and integrated in the national patient safety program. To better understand optimal pressure ulcer prevention, the research focus on knowledge/attitudes, work load/nurse staffing as well as team-based interventions. In relation to elderly care the research focus on organization and patient safety issues, especially with regard to transitions between care settings, home care and drug utilization. There are also multicentre and multidisciplinary randomized studies of interventions focusing on stress management and physical training to maintain and improve Quality of Life and a functional life during and after treatment for cancer disease. Genetic counseling represents a new challenge in health care due to recent developments in human genetics and ongoing studies concern how to inform prospective parents before prenatal testing, how to communicate risk information and the psychosocial aspects of genetic investigations.

The problems of general practice and family medicine

Primary health care is in the front line of all health care, hence the health care facility patients are expected to consult first. The focus of the research program is on patient-centred questions and the most common diseases and illnesses in the population, using clinical as well as epidemiological techniques. Parallel aspects are found in social insurance medicine when aiming at identifying factors that will help long-listed individuals return to working life, and assessing the efficacy of various innovative return-to-work strategies.

Epidemiological studies of the etiology of major public health problems

Epidemiological methodology and available strong databases are used to study etiologic questions and mechanistic issues related to cardiovascular disease, diabetes, the metabolic syndrome, renal disorders, asthma, allergy, chronic obstructive pulmonary disease, musculo-skeletal disorders, functional limitations, and cognitive dysfunction. New epidemiological techniques are also used to study triggers of the onset of disease and other health problems.

Social etiology, stress and the social aspects of medical problems

The research addresses mechanisms of social inequalities in health, and especially theories in the life course approach in current epidemiology including pertinent empirical topics like the combined effect of early life and later life risk factors on health. Studies also concern potentially vulnerable groups such as unemployed, lone parents and immigrants, and the consequences of inequity on the health of the children of lone parents and the prognosis for unemployed to return to employment. Research based on stress theory aims at 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. The research includes effective use of health care resources, and its implications for major health care stakeholders, including patients, staff, and third-party payers. In studies of avoidable mortality issues of quality and equity in health care are addressed.
Disease prevention and health promotion
Research questions address prevention of life styles related to dieting behaviour among children and adolescents, sexual and reproductive health among adolescents and young adults, and knowledge and attitudes to the new vaccin against HPV. In other projects the feasibility and efficiency of interventions aiming at reducing smoking and increasing physical activity are investigated. A new research line on health system interventions for vulnerable groups in which a health system and a health promotion approach is combined is developed in collaboration with several counties, municipalities and other authorities in Sweden.

Nutrition research for an active and healthy life
The major research foci are to 1) understand and treat catabolic conditions related to ageing and disease, 2) recognize fatty acid metabolism in relation to the metabolic syndrome, insulin resistance, cardio-vascular risk and 3) investigate the roles of dietary patterns for health.

Oxidative Stress and Inflammation
Crucial methods have been developed enabling studies of inflammatory processes in normal physiology and in disease states.

The molecular basis of major geriatric health problems
The main area of research are molecular studies of dementia in which 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 research at the Department of Public Health and Caring Sciences was evaluated in 2011 by panel 21 of the international evaluation program “Quality and Renewal 2011” (KoF 11). In their overall assessment the panel stated that the department had made significant progress since the KoF 07 evaluation. Eleven of the research groups were evaluated and four of them were ranked to be of international top quality (grade A). They were Clinical Nutrition and Metabolism, Geriatric Research, Preventive Medicine, and Research Ethics and Bioethics. Five of the other research groups were assessed as internationally recognized (grade C), one as acceptable (grade D) and one as insufficient (grade E). The average grade for the research groups would then be in between high international standard and internationally recognized standard. The panel considered the department as a whole to have an international recognized standard (grade C). Several actions for future successful development were suggested. Among them were the needs for investments in the departmental infrastructure to establish a methodological core, increased international collaboration and exchange, re-organization to increase synergy within the department, changing the labeling of overlapping research fields, further development of leadership skills and incentive systems, and reducing the teaching load for some senior researchers. In several of these proposed roads ahead the department is on its way as commended by the evaluation panel but the process needs to be strengthened.

During 2011 190 persons held positions at the Department of Public Health and Caring Sciences and 100 researchers employed elsewhere were associated to the department. The department employed 11 professors, 16 senior lectures, and 37 senior researchers. The total economic turnover for 2011 was almost 120 million SEK and approximately two thirds were used for research of which nearly half was received from external fund-holders. The researchers at the department published almost 250 peer-reviewed publications in 2011. There were more than 80 doctoral students and 12 passed their exams during the year. Undergraduate teaching is also an important responsibility for the Department of Public Health and Caring Sciences and approximately one third of the activities in terms of the economy were dedicated to basic education. Nearly 3.000 students corresponding to
almost 600 full-time students were registered at the department, participating in the Nursing
programmes, the Medicine programme, the Master-programme in Public Health or separate courses.
The Department of Public Health and Caring Sciences had a strong out-put in terms of for example
publications in the year 2011 and some research groups were rapidly expanding while others were
consolidating their research plans. Two senior researchers left for positions as professors at other
universities and in a few years some professors will retire. Strategic questions for the forthcoming
period include recruitment of future research leaders and addressing the suggestions put forward by
the Quality and Renewal 2011 panel.

Uppsala April 30, 2012

Johan Hallqvist
Head of Department
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Disability and Habilitation

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Family Medicine and Preventive Medicine

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Dissertations 2011
Agencies that support the work/Funding
Projects

Geriatrics

Members of the group during 2011
Publications 2009-2011
Dissertations 2011
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Projects

Health Services Research

Members of the group during 2011
Publications 2009-2011
Reviews 2009-2011
Agencies that support the work/Funding
Projects

Oxidative Stress and Inflammation

Members of the group during 2011
Publications 2009-2011
Reviews 2010
Agencies that support the work/Funding
Projects

Psychosocial Oncology and Supportive Care

Members of the group during 2011
Publications 2009-2011
Organization

Head of Department
Professor Johan Hallqvist

Deputy Head of Department
Associate Professor Birgitta Edlund

Department Board
Carina Ahlstedt, Teacher and Researcher Representative
Carl-Johan Bergling, Student Representative
Anders Brantnell, Technical and Administrative Representative, Deputy
Tommy Cederholm, Teacher and Researcher Representative Deputy
Martin Cernvall, Graduate Student Representative
Birgitta Edlund, Teacher and Researcher Representative
Margaretha Eriksson, Teacher and Researcher Representative Deputy
Mats G Hansson, Teacher and Researcher Representative Deputy
Anna T Höglund, Teacher and Researcher Representative Deputy
Calle Martinsson, Technical and Administrative Representative
Karin Nordin, Teacher and Researcher Representative Deputy
Catarina Olsson, Protocol
Ritva Rissanen, Graduate Student Representative Deputy
Ulrika Winblad, Teacher and Researcher Representative
Charlotte Traneus, Economist

Professor Emeriti
Urban Rosenqvist
Björn Smedby
Kurt Svärdsudd
Claes-Göran Westrin
Bengt Vessby adj Professor Emeritus

Directors of Graduate Studies
Mats G Hansson, Head
Margaretha Eriksson
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Karin Nordin, MSc in Public Health
Barbro Wadensten

Directors of Undergraduate Studies
Karin Björkegren, Head
Birgitta Edlund, Head
Carina Ahlstedt
Lena Kilander
Sören Kjellberg
Karin Nordin
Ragnar Westerling

Director of Clinical Issues
Lars Lannfelt
Professors and Research Groups Leaders
Bengt Arnetz
Samar Basu
Marianne Carlsson
Tommy Cederholm
Louise von Essen
Johan Hallqvist
Mats G Hansson
Inger Knutsson Holmström (until december 2011)
Lars Lannfelt
Per Kristiansson
Karin Nordin
Karin Sonnander
Tanja Tydén
Ragnar Westerling
Ulrika Winblad

Adj Professors, Guest Professors and adj Senior Lecturers
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Hans Basun
Wulf Becker
Mats Gulliksson
Håkan Hall
Gunnar Johansson
Marianne Omne-Pontén
Mari-Ann Wallander
Thorne Wallman
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Address List

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Gustavsson Catharina
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Hallström Björn
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Hedov Gerth
Helmersson Johanna
Hänni Arvo
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Kjeldmand Dorte
Kristofferzon Marja-Leena
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Kunkel Stefan
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Lindau Maria
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Ljunggren Birgitta
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Rissanen Ritva
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Rönneamaa Elina
Sobestiansky Sigvard
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Stolt Ragnar
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Sundgren Elisabet
Sving Eva
Söderström Lisa
Söllvander Sofia
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von Celsing Anna-Sophia
Östlund Ann-Sofi
Centres
During 2011 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
(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. There is a close collaboration with the research group Disability and Habilitation. (p 87).

Centre for Research Ethics and Bioethics (CRB)
Director: Mats G Hansson
The Centre for Research Ethics & Bioethics is an interfaculty centre. The centre is integrated with the research group Research Ethics and Bioethics. The research profile includes research ethics, bioethics, and medical law. More specifically, research on animal and environmental ethics, autonomy, the ethics of biobanking, dual-use issues related to biosafety and biosecurity, codes and guidelines for research, clinical ethics, enhancement of human performance, genetic information and testing, medical law, neuroethics and the philosophy of mind, ethics at the beginning of life, priorities in health care and quality of life issues. (p 40).

Uppsala University Psychosocial Care Program (U-CARE)
Director: Louise von Essen
The U-CARE program is one of the strategic research fundings from the Swedish Government and was established in 2010. The program is integrated with the research group Psychosocial oncology and Supportive care. The research activities are performed within the areas of paedriatic oncology, adult oncology, and cardiology in close collaboration with clinicians at Uppsala Akademiska Hospital and other Swedish hospitals. U-CARE is a forum for interdisciplinary encounters and networking across the borders between social and medical sciences. (p 179).
Education

The Department of Public Health and Caring Sciences is funded for about 600 full time students, which in themselves represent nearly 3,000 students registered at the department. The students belong to different courses and programmes, 400 were educated within Nursing programmes, 70 within the Medicine programme, 22 within the Master-programme in public health and about 100 in separate courses. About 80 doctoral students were also registered.

First-cycle courses and study programs

Courses within Medicine Programme

Medical education in Uppsala means early patient contact.

Throughout the program the students train patient contact, examination and other clinical skills in primary care, as well as ethical and scientific questions within the course in Professional Skills and Communication, which start as early as the first semester.

The program involves the integration between the biological basis and clinical science but also 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. The course covers gerontology, various aspects on frail elderly patients with multiple co morbidities and polypharmacy, Alzheimer's disease, falls and delirium, orthogeriatrics, stroke rehabilitation and palliative care. The students ranked geriatrics as number 7 out of 25 in their evaluation of the clinical training at the hospital wards.

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 a half day or full day. The course involves close collaboration with various clinical specialties, with 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 the lectures. The course is examined by an individual moral case deliberation. An ethics toolkit on the course web is under development.

Semester 11: Family Medicine, 6.5 credit points

2011, we conducted the new family medicine course for the first time. The students have theoretical education mixed with seminars for two weeks and have practical training in a health care centre by managing patients by themselves. The students ranked the course highest spring semester 2011 and we received “the Optimus award”.

Tutor education: Training doctors for supervision of students at the health care centre, each course lasts for three days.
Courses within Nursing Programme Courses

Nursing Programme has 180 credit points and it is 91.5 credit points at our department. The research group Caring Sciences is responsible for 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

Radiography nursing programme has 180 credit points and it was 37.5 credit points at our department 2011. The research group Caring Sciences is responsible for Courses; Medicine, Geriatrics, Pediatrics and Obstetrics; Surgery, Emergency Care and Pharmacology; Nursing Care in Surgery and Medicine; Work Placed Education Surgical Care.

Separate courses

The following courses are offered as separate courses

Challenges in Global Health, Community Interventions, Culture and Health, Psychosocial Cancer Care, Palliative Care, Clinical Nutrition and Energy Balance, Neuroethics, Motivational Interviewing in Health Promotion, Impairment and Disability, Introductory Course, Nursing Care Planning and Quality Improvement, Advanced Course C.

Public health

Two new web-based basic level courses were 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 was developed for one of these.

Second-cycle courses and study programs

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, 60 credit points and all courses are at our department. The research group Caring Sciences is responsible for 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, 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, Research Designs, Methods and Statistics in Public Health, Advanced Level, Theories in Caring Sciences.

Master in Public Health

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

Modules:
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 program aims to increase knowledge, understanding and skills in public health and public health work. This means that students will be competent both for further research and for practical strategic public health initiatives. An important profiling of the program is a focus on health promotion interventions at community and individual levels, design and evaluation of programs and operations and an ethical approach.

Third-cycle course and study program

Doctoral courses and study program

In the beginning of the year 2011 60 doctoral students were in education and during the year 8 of them have past their theses and 19 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 credit points, given two times a year). The Centre for Research Ethics & Bioethics is also responsible for the course “Research Ethics and Philosophy of Science” (1.5 credit point, given two times a year). Family Medicine and Preventive Medicine takes part in “Medical epidemiology” (1.5 credit point, given once a year). The research group Research in Psychosocial Oncology and Supportive Care is responsible for the course “Quantitative and Qualitative research methods” (7.5 credit points, given once a year). In this course the research groups Health Services Research and Centre for Research Ethics & Bioethics give lectures. The Centre for Research Ethics & Bioethics is also responsible for doctoral courses in “Research Ethics for Natural Science”, “Research Ethics for Science and Technology” and “Research Ethics for Social Science”, 2.5, 2.5 and 4 credit points, respectively.

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 these 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, specific the Faculty of Medicine and our own department. An important item is of the course the new doctoral students meeting with the older doctoral ones.

Education project

A student run open health clinic – a two times one-week pilot project.

Clinical practice and inter-professional education provides students with opportunities to develop their own professional roles and learn about other professions.

In these project five different educational programmes, i.e. medicine (semester 11), nursing (semester 4), physiotherapy, pharmacy and clinical dietetic students participated. The students worked together in mixed pairs to learn about and understand other professions, to develop their own professional roles and learn about health promotion strategies and communication. The students had support from before and after each client visit.
Conclusions were that a student run open health clinic enhances good teamwork and inter-professional learning that in the long run might lead to an increased patient safety and decrease hierarchies within health care practice. Both teachers and students learned from inter-professional working in this student run open health clinic. We hope that this week should be permanent in all programmes from spring 2013, and then also the psychology programme also wants to participate.

Other examples of projects funded by KRUUT are; Clinical examination of professional competence in nursing, at undergraduate and postgraduate levels and Process-oriented supervision of nursing students at Uppsala University: a pilot study.

**International activity**

We have well-established collaboration with universities abroad within several exchange programmes for nursing students on undergraduate level, nursing students on advanced level in different specialties, and teachers. The main programmes are Erasmus Life Long Learning Programme for European countries, Norlys for the Scandinavian and Baltic countries, Danosfi for the Nordic countries, and Linnaeus-Palme and Mini Field Study for developing countries such as Vietnam, Tanzania and Thailand. In 2011 about 18 of our students studied abroad during 2-12 weeks, while 16 foreign students visited our department during 4-12 weeks. In the same year three of our teachers taught abroad during 1-3 weeks, while three foreign teachers taught in our department during 1-5 weeks. The exchange programmes give students and teachers’ knowledge, experiences and international contacts, which are highly valuable for their personal development as well as for their careers.
Dissertations 2011

**Erebouni Arakelian**, Operating Room Efficiency and Postoperative Recovery after Major Abdominal Surgery, (Department of Surgical Sciences)

**Ewa Axelsson**, Patientsäkerhet och kvalitetssäkring i svensk hälso- och sjukvård: En medicinrättslig studie, (Faculty of Law)

**Helena Bjermo**, Dietary Fatty Acids and Inflammation: Observational and Interventional Studies

**Gunn Engvall**, Cancer during Adolescence: Coping Shortly after Diagnosis and Psychosocial Function during the Acute and Extended Phase of Survival

**Marie Grunnesjö**, Low Back Pain: With Special Reference to Manual Therapy, Outcome and its Prognosis

**Catharina Gustavsson**, Self-management of Persistent Neck Pain: A Multi-component Group Intervention in Primary Health Care

**Eva Jangland**, The Patient–Health-professional Interaction in a Hospital Setting, (Department of Surgical Sciences)

**Sara Andréasson Näslund**, Work Environmental Dilemmas in the Operating Room during CRS and HIPEC. Factors Influencing Choice of Protective Equipment against Electrocautery Smoke, (Department of Surgical Sciences)

**Thomas Näström**, Characterization of α-synuclein oligomers: Implications for Lewy Body Disorders

**Paul O'Callaghan**, Heparan Sulfate in the Amyloidosis and Inflammation of Alzheimer's Disease

**Magnus Peterson**, Chronic Tennis Elbow: Aspects on Pathogenesis and Treatment in a Soft Tissue Pain Condition

**Elisabet Rytter**, Effect of Dietary Antioxidants on Oxidative Stress, Inflammation and Metabolic Factors: Studies in Subjects with Overweight and with Type 2 Diabetes

**Johan Sundelöf**, Amyloid β-protein, Cystatin C and Cathepsin B as Biomarkers of Alzheimer's Disease
Scientific Reports

Caring Sciences

Research Group Leader Professor Tanja Tydén
Research in Caring Sciences emanates from a multi-scientific and multi-professional perspective including preventive, supportive, caring, nursing and rehabilitative actions. Our research has a broad focus and we are studying clinically relevant problems in the health care sector. One important field is quality of care and patient safety. Another important field is prevention and rehabilitation of cancer and health and care of elderly. 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. Finally, we are studying sexual and reproductive health with focus on adolescents and young adults. Today focus is especially on following research themes.

Health and care among children, adolescents and young adults
Health and care among elderly
Psychosocial genetics and cancer care
Quality of care and patient safety

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 Specialist Nursing Programs, single subject course and courses within the Master Program in Public Health. Some teachers are also engaged in teaching within other departments at Uppsala University.

Members of the group during 2011
Aarts Clara, RN, PhD, senior lecturer
Arving Cecilia, RN, PhD, research assistant, senior lecturer
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, associate professor, senior lecturer
Hedström Mariann, RN, PhD, senior lecturer
Ingvoldstad Charlotte, PhD
Leo Swenne Christine, RN, PhD, senior lecturer
Lundberg Pranee, RN and midwife, PhD, associate professor, senior lecturer
Nordin Karin, licensed psychologist, professor 50%, at Uppsala University and University of Bergen, 50% chair of genetic counseling
Pöder Ulrika, RN, PhD, senior lecturer
Tydén Tanja, RN, midwife, professor
Wadensten Barbro, RN, PhD, associate professor, senior lecturer
Winblad Ulrika, political scientist, associate professor, research assistant

Lecturers fulltime or part time
Ahlstedt Carina
Bergknut Eva
Eriksson-Öhman Solveig
Hedlund Lena
Holm Marta
Hovstadius Eva
Kjellberg Sören
Lundin Birgit
Norinder Camilla
Normark Lena
Harriet Marnell
Pettersson Mona
Rosvall Paula
Schmidt Meta
Staal Anita
Svanberg Ann Carin
Thoudal Berit

Associated researchers
Ekstrand Maria, RN and midwife, PhD
Engström Maria, RN, associate professor, PhD
Hägström Elisabeth, RN and midwife, associate professor
Kristofferzon Marja-Leena, RN, PhD
Kullberg Kerstin, occupational therapist
Lindberg Magnus, RN, PhD
Lindqvist Ragny, RN, PhD
Ljunggren Birgitta, RN, PhD
Lunner Katarina, PhD
Muntlin Athlin Åsa, RN, PhD
Nilsson Annika, RN, PhD
Oscarsson Marie, RN and midwife, PhD
Skytt Bernice, RN, PhD
Smide Bibbi, RN, PhD
Christina Stenhammar, RN, PhD
Söderback Ingrid, occupational therapist, PhD
Wasteson Elisabet, licensed psychologist, PhD
Westergberg Jacobson Josefin, MSc, PhD
Winterling Jeanette, RN, PhD

Ongoing PhD students
Björn Catrine
Gottvall Maria
Grandahl Maria
Hagerman Heidi
Höyer Marie
Isaksson Stina
Kerstis Birgitta
Kirsebom Marie
Knudsen Kati
Lindberg Maria
Nordin Jenny
Randmaa Maria
Rissanen Ritva
Star Kristina
Sving Eva
Widarsson Margareta
Östlund Ann-Sofi
Publications 2009-2011

Health and Care among Children, Adolescents and Young Adults

2009


2010


10. Engvall G, Skolin I, Mattsson E, Hedström M &von Essen L (2010). Are nurses and physicians able to assess which strategies adolescents recently diagnosed with cancer use to cope with disease- and treatment-related distress? Supportive Care in Cancer Published online Mars 27


2011


**Psychosocial Genetics and Cancer Care 2009**


2010


2011


Quality of Care and Patient Safety 2009


2010


2011


Health and Care among Elderly

2009


2010


130. Kullberg K, Björklund A, Sidenvall B, Åberg AC (2010). ‘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 older men with somatic diseases. Scandinavian Journal of Caring Sciences, Early view (Article on line in advance of print) Article first published online: 26 Jul 2010. DOI: 10.1111/j.1471-6712.2010.00813.x


2011


Övrigt

2009


2010


2011


**Dissertations 2011**

Eva Jangland, “The Patient–Health-professional Interaction in a Hospital Setting”, 2011 (Department of Surgical Sciences)

Erebouni Arakelian, “Operating Room Efficiency and Postoperative Recovery after Major Abdominal Surgery”, 2011 (Department of Surgical Sciences)

Sara Andréasson Näslund,”Work Environmental Dilemmas in the Operating Room during CRS and HIPEC. Factors Influencing Choice of Protective Equipment against Electrocautery Smoke”, 2011 (Department of Surgical Sciences)

**Agencies that support the work/Funding**

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<td>Medical Faculty Uppsala University</td>
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<td>County Council of Uppsala</td>
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</table>
M Sjöströms och A Karlssons stiftelse 125 000 SEK
Prostatacancerförbundet 100 000 SEK

International collaboration
- Adjunct Assistant Professor at School of Nursing, University of California San Francisco
- Trustee of the European Pressure Ulcer Advisory Panel (board member)
- Member of European Academy of Caring Science
- 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

National commissions
- Expert group – Pressure Ulcer/Patient Safety – The Swedish Association of Local Authorities and Regions
- Board of Wound Nurses in Sweden
- Advisor to Vice Chancellor concerning gender equality
- Fellow of Royal Academy of Science in Uppsala
- Assistant Head of the Center for Clinical Research Uppsala University and County Council of Gävleborg
- 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 Pool of External Experts, Medicine and Care, International Programme Office for Education and Training, Swedish International Cooperation Agency (SIDA)
- Member of the Board for Stiftelsen InDevelops u-landsfond

Invited speaker 2009-2011
The International Society of Pharmacovigilance. Reims, France, 2009
EPUAP 13th Annual European Pressure Ulcer Meeting, Birmingham, United Kingdom, 2010.
Tokyo Metropolitan Institute of Gerontology, Tokyo, Japan, 2010.
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.
Läkarstämman 2011, Stockholm.

Opponent for PhD 2009-2010
Karolinska Institutet, Department of Clinical Science, Intervention and Technology, Stockholm.
Laparoscopic cholecystectomy. Patients’ experiences of self-reported symptoms, perception of health and sense of coherence in the short and long term perspective, 2009
Sahlgrenska Akademin, Göteborg. Living with amyotrophic lateral sclerosis-perspective of patients and next of kin, 2010
Sahlgrenska Akademin, Göteborg. Health-related quality of life after stem cell transplantation – The first year, 2010
Research Ethics and Bioethics has become increasingly important for Uppsala University. As a result, the Centre for Research Ethics and Bioethics was established on January 1, 2008. The centre is placed at the Faculty of Medicine and administratively associated to the Department of Public Health and Caring Sciences.

Our research profile includes research ethics, bioethics and medical law. More specifically, we conduct research on animal and environmental ethics, investigate autonomy, the ethics of biobanking, dual-use issues related to biosafety and biosecurity, codes and guidelines for research, clinical ethics, enhancement of human performance, genetic information and testing, neuroethics and the philosophy of mind, ethics at the beginning of life, priorities in health care and quality of life issues.

Research ethics involves the application of ethical principles and values to a variety of scientific research topics. It has both a practical and a theoretical side. It aims to create good research, while at the same time studying what good research is.

Bioethics includes philosophical, theological, legal and social scientific aspects of medicine and biology. It deals with norms and value conflicts in health care and the biosciences. For example, it looks at ethical questions that arise in connection with priorities in health care, informed consent, palliative care, and neurobiological explanations of human consciousness, animal welfare and the use of biotechnology.

Medical law spans a wide range of traditional branches of law and is associated to the Centre through our collaboration with the Department of Law at Uppsala University.

Our work in research ethics has received international recognition. In 2010, the European Science Foundation has conducted a study of how institutions of higher education in different countries proactively approach research ethical issues. Uppsala University was highlighted as a good example and praised for its thorough efforts at preventing research misconduct and promoting sound research practices. Special mention was made of the University’s Centre for Research Ethics & Bioethics, which coordinates activities related to research ethics, bioethics and medical law, pursues associated research and trains students and researchers.

In the 2011 research evaluation at Uppsala University (KoF), CRB’s research was graded world-leading level. After the evaluation, CRB, initiated an internal process to work with the feedback from the international expert panel that looked at the centre’s research. According to the international panel, the centre's publications “range among the top-quality in the field” and they were impressed with the creative research environment.

CRB decided to use this opportunity to start a process to develop the research profile. The panel suggested efforts could be developed into larger, focused research themes, and the Centre started working towards that in September 2011. The panel also encouraged CRB to become more visible, a suggestion that has started a very interesting and creative process. The Ethics Blog is a result of the work done since the evaluation. CRB have also started looking at improving the website structure and content. Furthermore, CRB decided to become more visible in the public debate and strengthen the dissemination of research results and
Members of the group during 2011
(In alphabetical order)

**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.

**Ewa Axelsson, LLM, LLD student**

**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 (2006-7). For six years (1997-2002) she was the Executive Director for the Standing Committee on Responsibility and Ethics in Science (SCRES) of the International Council for Science (ICSU).

**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.

**Joanna Forsberg, MD, PhD student**
Joanna Forsberg 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.

**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.
Roya Hakimnia, MD, PhD student
Roya Hakimnia started her PhD studies in November 2010. She holds a degree in medicine from Karolinska Institutet (2010). Her main area of interest is using intersectional gender theories on medicine and health care. Her PhD project aims to use theories of gender and intersectionality on telenursing and to develop a tool for improving gender competence.

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

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.

Li Jalmell, MD, PhD student
Li Jalmell 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 student
Linus Johnsson started his PhD studies in bioethics in 2006. He also works part-time as a medical doctor at a health care centre in Strängnäs. His main area of interest is the connection between autonomy and trust in biomedical research and health care. He holds a degree in Medicine from Uppsala University (2004) and license to practice (2006).

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 Kálvemark Sporrong, PhD, Associated researcher
Sofia Kálvemark 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, BA, PhD student
Frida Kuhlau 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.

**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 Remains" in 2010. Her current research deals with public opinion of science and animal testing within the framework of the COMBINE consortium.

**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 focusses 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 network. 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 is senior researcher in Outcomes research, focusing 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 Upsala 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.

**Elisabeth Rynning**, LLD, Professor of Medical Law, Senior researcher
Elisabeth Rynning's research interests include the rights of patients and research subjects, especially autonomy and privacy, as well as the use of new technology in health care and biomedical research. She has ample experience from multi-disciplinary European research projects, has been a longstanding member of the Swedish National Council on Medical Ethics and has participated in a number of law commissions in the areas of health care and biomedical research. She holds an LLD in public law (1994).
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 University 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, Research Assistant
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.

Kavot Zillén, LLM, LLD student
Kavot Zillén started her LLD studies in Medical Law in September 2010. She holds a LLM from Uppsala University (2007) and worked as a legal expert at the medical responsibility board (HSAN) for three years (2007-2010). Her main area of interest is human rights and healthcare. Her thesis focuses on which way healthcare professionals' religious beliefs and values have an impact on their obligations to provide good healthcare.
Publications 2009-2011

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.

During this three year period the following monographs have been published:


The complete list for this period is:


70. Svalastog AL, Eriksson S, You can use my name: You don’t have to steal my story – A critique of anonymity in indigenous studies, Developing World Bioethics 2010;10(2):104-110.
Review 2009


Dissertation 2011


Agencies that support the work/Funding

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<td>EU (COMBINE)</td>
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<td>The Swedish School of Sport and Health Sciences (Is FairPlay Compatible with Doping in Sport?)</td>
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<td>AFA Insurance (Improving the ethical climate in psychiatry outpatient clinics)</td>
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<td>The Cancer Foundation (Factors associated with participation in phase 1 and phase 3 oncology trials)</td>
<td>600 000</td>
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<td>The Swedish Research Council (BBMRI.se)</td>
<td>2 059 083</td>
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<td>The Swedish Research Council (CODEX)</td>
<td>700 000</td>
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<tr>
<td>The Swedish Cancer Foundation (Developing clearer definitions and clinical guidelines for Do Not Resuscitate (DNR) orders in oncology care)</td>
<td>300 000</td>
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<td>EU (AutoCure)</td>
<td>159 505</td>
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<tr>
<td>Riksbankens Jubileumsfond (Bank of Sweden Tercentenary Foundation) (Culture Health and Bioethics network)</td>
<td>116 524</td>
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Projects

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

Collaborators: Joanna Forsberg, MD, PhD student, 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

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, Anna T. Höglund, Associate Professor of Ethics, supervisor, Margareta Larsson, Associate Professor, Department of Women’s and Children’s Health, 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).
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.

Funding: The Swedish Childhood Cancer Foundation (Barncancerfonden)

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

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
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)

Developing clearer definitions and clinical guidelines for Do Not Resuscitate (DNR) orders in oncology care (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 Birgergård, Professor, Department of Medical Sciences

The aim of this project is to investigate attitudes to and perceptions of ‘Do Not Resuscitate’ (DNR) orders in oncology care among Swedish oncologists and oncology nurses. Further the experiences of education in DNR and understanding of DNR orders among students in nursing and medical school will be investigated.

Within oncology 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...
arrest neither basic nor advanced CPR is to be performed. DNR situations can lead to severe ethical dilemmas and moral distress among the staff.

Research design:
1. Two interview studies, using qualitative methodology, will be performed with oncology nurses and oncologists concerning their experiences of DNR decisions.
2. Nursing and medical students will be interviewed in a qualitative study concerning their understanding of DNR and their education on this concept.
3. In a study using Delphi-methodology a panel of oncologists and oncology nurses will be asked to assess a suggestion of definition of DNR and guidelines for DNR in oncology care.

The goal is to establish clearer definitions and guidelines with relevance for both oncologists and oncology nurses on DNR orders in oncology care.

Funding: The Swedish Cancer Society (Cancerfonden)

**Gender aspects in telenursing (PhD project)**

**Collaborators:** Roya Hakimnia, MD, PhD student, Anna T. Höglund, Associate Professor, supervisor, Inger Holmström, Associate Professor, supervisor, Marianne Carlsson, Professor of Caring Sciences, supervisor

This project will use theories on gender and intersectionality to investigate the role of factors such as gender 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 for analysis of gender competence including aspects of power and intersectionality.
- Test an educational intervention for telenurses, with focus on gender and intersectionality.

Funding: The Swedish Research Council (Vetenskapsrådet)

**Empower the patient: Hip fracture as outpatient care (R&D Project)**

**Collaborators:** Leif Ryd (Principal Investigator), Karolinska University Hospital, Huddinge, Mats G. Hansson, Professor of Biomedical Ethics, Lilianne Eninger, Associate Professor, Senior Researcher, Department of Psychology, Stockholm University

This is a research and development project funded by the Stockholm County Council that started in 2005. The project is a collaboration between Professor Leif Ryd (Principal Investigator) at the Karolinska University Hospital, Huddinge, and researchers at CRB.

Within the health-care system, patients are often seen as helpless and in need of caretaking by healthcare professionals. This view may many times be disabling for the health-care process, extending rehabilitation, resulting in great costs both to the patient and to the health-care sector. It would clearly be beneficial if the health-care process could be made more efficient, with more expedient care, a shorter rehabilitation process involving more outpatient care and at the same time could be tailored more specifically to the individual patient’s needs and resources. Empowering patients to take charge of their own health and rehabilitation process is an important step in actualizing the overall goal of a more efficient health-care process.

Hip fracture patients constitute a large and resource-consuming group which could benefit from an increasing extent of outpatient care. A research project has been started, aimed at providing a new treatment framework by combining vertebroplasty, as an effective operative technique for hip fractures, with the patients’ personal involvement and control of the rehabilitation process. Addressing and changing the views and attitudes commonly held within the health-care system was
determined to be essential in order for patient empowerment to be feasible. The first phase of the project, which is currently underway, therefore involves an evidence-based program, focused on educating health-care providers in a different way of interacting with patients, highlighting individual patient strengths and resources. After completion of this program, the subsequent phase of the project, involving the development of an individualized treatment and care process, will ensue. This process is designed to be sensitive to the multiplicity of personal values at stake and with self-control of the patient as the fundamental aim. The process starts from the moment of emergency admission of the patient to the clinic and ends when the end point in terms of quality of life during the post-operative rehabilitation phase has been attained.

Funding: Stockholm County Council

**AutoCure - Curing autoimmune rheumatic diseases**

**Collaborators:** Mats G. Hansson, Professor of Biomedical Ethics, Linus Johnsson, MD, PhD student

AutoCure is an EU funded research project within the sixth framework programme. Involved in the project are 26 different partners, of which 6 are industrial partners and 20 are from the academia, from all over Europe. The project duration is 60 months from March 1st 2006 and the total budget is 11 m€.

The objective is to transform knowledge obtained from molecular research particularly within genomics, into a cure in an increasing number of patients suffering from inflammatory rheumatic diseases. Rheumatoid arthritis (RA) is used as a prototype since this disease offers unique opportunities to define and evaluate new therapies. Professor Lars Klareskog at Karolinska Institutet is co-ordinator of AutoCure.

In addition to providing an ethics management structure, the Centre for Research Ethics & Bioethics will actively work through a specific work-package in order to offer possible solutions to urgent problems estimated to arise in association with the research. A doctoral student, Linus Johnsson (MD) works with a project comparing the attitudes to genetic and biobank research as it is revealed in public surveys and in actual decisions made by research subjects. He will examine and analyse the frequency of withdrawals to biobank sampling made by sample providers and elaborate the concept of risk related to this kind of research including a critical examination of what constitutes "dignitary harms". His theoretical framework will be developed through a philosophical analysis of the concepts autonomy and trust.

Funding: European Union

**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 strive 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 population 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 co-operation 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 masswithdrawals 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, Jennifer Viberg, Research Assistant

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)

Ethical dilemmas in telenursing

Collaborators: Anna T. Höglund, Associate Professor of Ethics, Senior Lecturer, Centre for Research Ethics & Bioethics, Inger Holmström, Associate Professor, Department of Public Health and Caring Sciences, Health Services Research

This is a research collaboration between members of the health services research group at the Department of Public Health and Caring Sciences and CRB.
A qualitative interview study revealed that telenurses experience a wide range of ethically troubling situations, covering subjects such as autonomy, integrity and prioritizing. Although several of the identified dilemmas also occur in other areas of nursing it is reasonable to argue that these situations are particularly challenging in telenursing, as the encounter with the patient is faceless and the nurse can not be sure of the callers’ identity.

A similar study has investigated how gender impacts the encounter between the caller and the telenurse. The results revealed several aspects of how gender norms are present in telenursing. Questions of power relations, the picture of the mother/woman as the primary care taker of small children and distrusting men in their parental role were particularly highlighted.

Funding: Uppsala University

Ethical aspects of longitudinal studies involving children

Collaborators: Mats G. Hansson, Professor of biomedical ethics, Stefan Eriksson, Associate Professor of ethics, Johnny Ludvigsson, Professor, Linköping University, Gert Helgesson, Associate professor, Karolinska Institutet, Ulrika Gustafsson Stolt, PhD, Linköping University

The ABIS study (All Babies in South-East Sweden) is a longitudinal predictive screening for type 1 diabetes (T1DM) that has followed a large birth cohort since 1997 (n=17, 055). ABIS I followed children 0-7 years of age. Clinical data have been collected through diary, extensive questionnaires (at birth, 1 year, 2,5-3 years, and 5-6 years), and biological samples (cord- and capillary blood, hair, stool, saliva, urine). ABIS II will follow the same children at ages 9-14. Tied to the ABIS biomedical research is a multi-disciplinary project aiming to analyse and suggest criteria for information, consent, and disclosure issues in Swedish longitudinal medical research involving children. This is a co-operation between the ABIS group and the Centre for Bioethics. A number of publications stemming from this co-operation are under production.

The project is a collaboration between researchers at the Centre for Research Ethics & Bioethics and the ABIS group at the Department of Molecular and Clinical Medicine, Linköping University. More information: http://www.abis-studien.se/

Funding: The Swedish Research Council (Vetenskapsrådet) and the Swedish Council for Working Life and Social Research (FAS). 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).

**International Bilateral Collaborations**

**Centre for Biomedical Ethics (CBmE), National University of Singapore**
The Centre for Biomedical Ethics (CBmE), National University of Singapore constitutes one of the nodes in the network on ethics at the end of life.

**CESAGEN, Cardiff University and Lancaster University**
CRB collaborates with Cardiff University and CESAGEN (at the universities of Cardiff and Lancaster). This collaboration constitutes a joint conference series in medical ethics. The first conference took place in Uppsala 14-16 June 2010 and was entitled “Is Medical Ethics Really in the Best Interest of the Patient?”.

**Expertise Center Ethics of Care at University Medical Center (ECEC), Groningen University**
CRB’s collaboration with ECEC holds joint supervision of PhD students, developing of e-learning in medical ethics and we are learning from each other’s experiences of teaching medical ethics to medical students. Apart from teaching, we are also exchanging knowledge and experience in other fields. Researchers from ECEC will visit CRB to learn how from Swedish experiences of dealing with biobanking.

**Policy, Ethics and Life Sciences Research Centre (PEALS), Newcastle University**
CRB and PEALS are currently working on an agreement to formalise our bilateral collaboration. This includes joint publications and project planning. Several research collaborations are underway, for example regarding the relationship between normative and empirical ethics, end of life care, reproductive ethics and patient perspectives in medical research.

**The Hastings Center, New York**
We have an ongoing exchange with the Hastings Center in New York. Mats G. Hansson of CRB is a Fellow of the Hastings Center and Tom Murray of the Hastings Centre has received a honorary doctorate degree from the Faculty of Medicine at Uppsala University. A Science publication resulted from Mats Hansson’s collaboration with Karen Maschke at Hastings Center. International Network Collaborations

**BioBank Ethics**
CRB has worked extensively on biobank ethics and 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) and the IMI funded BTCure (Be The Cure) focusing on Rheumatoid Arthritis (RA) and RA-like diseases.

**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). The network is divided into five sub groups: 1: Bioethics and native peoples, 2: The ethics in prospecting biological diversity, 3: Native peoples and quality of life, 4: Cultures of knowledge and organisations and 5: Creativity
**End of Life**
CRB collaborates with ECEC, CBmE and PEALS on issues relating to end of life care and decisions. A joint anthology is in planning, edited by Ulrik Kihlbom of CRB and Marian Verkerk of ECEC. This network held a first joint workshop workshop in Singapore in January 2010.

**Family Ethics**
CRB collaborates with ECEC, CBmE and PEALS on family ethics health and social care. A workshop in Groningen was held on 28-29 April 2011 started this collaboration that also includes Hilda Lindeman and James Nelson, philosophers from Michigan State University. CRB has received funding from Riksbankens Jubileumsfond for the initiation of this international multi-centre research collaboration on family ethics, currently working on a white paper. The group held its second meeting in Uppsala on October 6-7 2011 and will hold a third meeting in Michigan in 2012.

**Neuroethics**
Kathinka Evers has extensive collaborations on Neuroethics with Collège de France in Paris, where she is a returning guest lecturer, and the Pasteur Institute in Paris. There are also collaborations with the Centro de Investigaciones Filosóficas (CIF), and the Institute of Cognitive Neurology (INECO) in Buenos Aires. In 2010, CRB launched a web-based course in Neuroethics with lectures by several well known researchers in the neurosciences.

**Research Ethics & Bioethics**
CRB collaborates with the Swedish University of Agricultural Sciences (SLU) and Karolinska Institutet within the framework of the Network for Research Ethics and Bioethics (NRB). This network was formally established on July 1 2007.

**More**

**CODEX - Rules and Guidelines for Research**
CODEX is a website with rules and guidelines for research. The website, www.codex.vr.se, is run in collaboration between CRB and the Swedish Research Council.

**EACME**
CRB is an associate member of the European Association of Centres of Medical Ethics (EACME).

**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 professional 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. An electable evening course on Archaeology and ethics (3 credits) was offered spring term 2011.

**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.

We offered our web based advanced level course in neuroethics (7.5 credits) for the second time. 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 credit integrated course called Introduction to scientific research.
- **Social Sciences:** 4 credit course tailored for the social sciences. This course is electable and was offered in 2011.

**Conferences and symposia**

The Centre for Research Ethics & Bioethics has hosted an annual international multi-disciplinary symposia series on Biomedicine, Ethics and Society. This series ended in 2009 and was replaced by a bi-annual conference hosted by CRB together with CESAGEN at the universities of Cardiff and Lancaster. The first meeting in this series attracted 200 participants, of which over 70 speakers from more than 20 countries. Main sponsor was The Journal of Internal Medicine. In 2011 we were coorganizers of a Nordic Committee on Bioethics conference on biobanking. In 2011 we also started planning for an interactive international biobanking conference in Uppsala hosted by BBMRI.se (where CRB is responsible for a work package on ethics and law).

- **End of Life Decisions: Ethics in clinical practice, research and policy:** XI Annual Swedish Symposium on Biomedicine, Ethics and Society: Seglarhotellet, Sandhamn, 8-9 June 2009
- **Is Medical Ethics Really in the Best Interest of the Patient?** Uppsala Konsert & Kongress, 14-16 June 2010.
  - June 14: Should ideology be allowed to trump patient well-being?
  - June 15: What is the role of informed consent in medical research?
  - June 16 Ethical review boards: are they important ethical safeguards or overburdensome and unnecessary bureaucracy?
- **Nordic Biobank Research: Obstacles and opportunities.** Uppsala Konsert & Kongress, 3-4 May 2011

**Public outreach**

The CRB website, www.crb.uu.se had 22985 unique visitors in 2011, on average visiting our website twice (46005 visits). Most visits were from Sweden, followed by Germany, Norway, Italy, the Netherlands, the United Kingdom, USA, Belgium, Thailand, China and Ireland (with 500 page views or more).

CRB has several e-mail lists, together making up around 2 800 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 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.

CRB staffs 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 wellgrounded.

The blogs have, during their first six months, had 11,000 visits, approximately 60 visits per day. Other blogs have begun to link to us; blogs about ethics, law, philosophy and bioethics. We have also begun to accumulate links in our Blog roll to other blogs that we consider are of interest to our visitors.

Our aim for the future is to attract 150-200 visits per day, which will require more efforts to spread information about new posts via a variety of social media. We will also engage more CRB researchers to appear as guest authors on the blog.

**CRB in Swedish and international media**

The strategy to become more visible also included the Swedish media. In 2011, the Centre director Mats G. Hansson, signed four debate articles about the use of animals in research on Svenska Dagbladet’s opinion pages. The first two (debate and response) article argued that important research is hindered because of increased bureaucracy and unbalanced interpretations of Swedish animal welfare legislation (Nästan alla djurförsök godkänns -2011-11-29 and Ensidig kampanj för djurrätt - Svenska Dagbladet 2011-12-01). The first article was cited in almost all Swedish national and local media. The second two dealt with the decision by the Swedish Data Inspection Board to stop LifeGene (Alltför diffust hänvisa till framtida forskning - Svenska Dagbladet 2011-12-27 and Trångsynt beslut hotar forskningen - Svenska Dagbladet 2011-12-25)

Mats G. Hansson also wrote a debate article in the Journal of the Swedish Medical Society (Läkartidningen) arguing that the current demands for informed consent before a patient can be included in a study puts vulnerable patient groups at risk, by excluding them from the research process, and thereby from the results, which in the end excludes them from receiving the best treatment possible.

Anna T. Höglund signed a debate article on Dagens Nyheter’s debate pages arguing that the health care system needs to ask patients about experiences of intimate partner violence on a regular basis (Vården måste fråga kvinnor om de har utsatts för våld - Dagens Nyheter 2011-05-13).

Malin Masterton also participated in a debate arranged by the National History Museum on human remains in Swedish museums (Het Historia). That debate was televised (Mänskliga kvarlevor – spara eller begrava?), UR Samtiden 2011-11-07) and the issue further covered by television (Etiken om att ställa ut mänskliga kvarlevor - TV4 Nyhetsmorgon direkt från Museum Gustavianum 2011-09-27).
The launch of the ethics blog also received a lot of attention. The press office at Uppsala University issued a press release and it received mention in several media. As did an article by Joanna Stjernschantz Forsberg, Mats G. Hansson and Stefan Eriksson in the British Medical Journal (Biobank Research: who benefits from individual consent?) who issued a press release when the article was published that was covered by Nature News Blog (Time to abandon biobanking consent rules? Nature News Blog 2011-10-04)

**CRB in Swedish and international media (a selection)**

Alltför diffust hänvisa till framtida forskning, Svenska Dagbladet 2011-12-27
Trångsynt beslut hotar forskningen, Svenska Dagbladet 2011-12-25
Ensidig kampanj för djurrätt, Svenska Dagbladet 2011-12-01
Nästan alla djurförsök godkänns, Svenska Dagbladet 2011-11-29
Djurskyddet har gått för långt, Svenska Dagbladet 2011-11-27
Etik i vården ska diskuteras på nätet, IT i vården 2011-11-11
Forskare vid Uppsala universitet startar etikblogg, Dagen 2011-11-09
Ny blogg om forskningsetik, Kemivärlden Biotech.se 2011-11-09
Följ etikernas diskussion på etikbloggen, Uppsala Bio 2011-11-09
Männsliga kvarlevor - spara eller begrava? UR Samtiden 2011-11-07
Biobank Research and Informed Consent, MedIndia 2011-10-07
Oron minskade efter genetisk vägledning, Upsala Nya Tidning 2011-10-02
Etiken om att ställa ut mänskliga kvarlevor, TV4 Nyhetsmorgon direkt från Museum Gustavianum 2011-09-27
Färre operationer ska ställas in, Upsala Nya Tidning 2011-07-04
Vården måste fråga kvinnor om de har utsatts för våld, Dagens Nyheter 2011-05-13
Hinder för forskning innebär ökade risker för patienterna, Läkartidningen 2011-03-01
Övning ger säkerhet i vården, Sydsvenskan 2011-01-24
Clinical Nutrition and Metabolism

Research Group Leader Professor Tommy Cederholm

Metabolic and dietary interaction during health and disease is the research focus at CNM. 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.

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.

Epidemiological studies consider nutritional, metabolic and dietary factors 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 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, liver fat and other cardio-vascular risk factors.

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.

Members of the group during 2011

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<thead>
<tr>
<th>Name</th>
<th>Academic title</th>
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<tr>
<td>Tommy Cederholm</td>
<td>Professor</td>
<td>MD</td>
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<td>Wulf Becker</td>
<td>Adjunct professor</td>
<td>Chief nutritionist</td>
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<tr>
<td>Brita Karlström</td>
<td>Professor</td>
<td>Dietitian</td>
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<tr>
<td>Bengt Vessby</td>
<td>Professor emeritus</td>
<td>MD</td>
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<td>Ulf Risérs</td>
<td>Associate professor</td>
<td>Researcher</td>
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<td>Ulf Holmbäck</td>
<td>Post-doc</td>
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<tr>
<td>Anja Saletti</td>
<td>Post-doc</td>
<td>Dietitian</td>
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<td>Per Sjögren</td>
<td>Post-doc</td>
<td>Researcher</td>
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<td>Viola Adamsson</td>
<td>PhD student</td>
<td>Nutrition manager</td>
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<td>David Iggman</td>
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<td>Roger Olsson</td>
<td>PhD student</td>
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<td>Helena Bjermo</td>
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Elisabet Rytter  PhD student  
Johanna Törmä  PhD student  Dietitian  
Sigvard Sobestiansky  PhD student  MD  
Erika Olsson  Licentiat student  Dietitian  
Erika Ax  PhD student under reg.  
Fredrik Rosqvist  PhD student  
Siv Tengblad  Laboratory technician  
Eva Lena Andersson  Tutor  
Linda Bratteby-Tollerz  Physiotherapist  
Marie Berglund  Research assistant  

Partly affiliated or associated to CNM  
Stefan Branth  Postdoc  MD  
Anders Forslund  Postdoc  MD  
Anders Sjödin  Ass professor  MD  
Annika Smedman  Postdoc  
Torbjörn Akerfeldt  PhD student  MD

Publications 2009-2011


Other articles 2009-2011

1. **Cederholm T.** Sarcopenia, osteoporosis and fractures. Chapter in Sarcopenia, Wiley 2012


4. Raynaud-Simon A, **Cederholm T.** Malnutrition in the elderly: Epidemiology and consequences. Module 36.1 in ESPEN LLL Educational Program www.espen.org/lllprogramme.html


6. **Cederholm T.** Åldrande, mat och näring, i Vetenskapligt underlag till råd om Bra mat i äldreomsorgen, Livsmedelsverkets rapportserie, s. 3-11, nr 3/2011.


Dissertations 2011


**Agencies that support the work/Funding**

- The Swedish Research Council: 900 000
- Hjärt-Lungfonden: 300 000
- Diabetesfonden: 130 000
- FAS: 490 000
- Centrum för klinisk forskning Dalarna: 136 000
- Uppsala County Council – ALF: 1 080 000
- Stockholm County Council – ALF (The OmegAD Trial): 400 000
- Uppsala Municipality (“Stimulansmedel”): 1 700 000
- Danone/Nutricia Research: 500 000

**Future promising research at CNM**

- Understanding sarcopenia from clinical, epidemiological and molecular perspectives, and its treatment.
- Implementation techniques of nutritional routines and development of assessment tools for meals in elderly care
- Dietary pattern effects on development of cognitive impairment and prostate cancer
- Omega-3 fatty acid effects on epigenetic markers, mononuclear blood cell gene expression and effects on inflammation resolution
- Fatty acid effects on gene expression, insulin sensitivity, inflammation, endothelial cell function and body fat distribution (ectopic fat accumulation)
- Nutritional impact on metabolomics
- Cardiometabolic, transcriptomic and epigenetic effects of a healthy Nordic diet
- Evaluation of sagittal abdominal diameter as a valuable anthropometric risk marker
- Individualized treatment of child obesity

**Undergraduate Teaching 2011**

**Biomedical Laboratory Science Program** - Biomedicinsk analytiker (BMA)-programmet.
Energy balance, body composition and nutrition status in the course “Biochemistry”; lectures and seminars, together with the Department of Medical Biochemistry and Microbiology.

**Dietitian Program – Dietistutbildningen**
Fifth semester – Pediatrics, geriatrics and nutritional status (course). Nutritional status in theory, methodological tools and practical applications. Body composition in practice, together with the Department of Food, Nutrition and Dietetics.

**Medical Program – Läkarprogrammet**
First semester – Energy balance and nutrition status; lectures and seminars, together with the Department of Medical Cell Biology
Sixth and seventh semester – Clinical nutrition and public health nutrition: lectures, seminars, case reports and discussion.
"Livsmedelsagronom"-programmet
Energy balance, body composition, substrate metabolism and nutrition status in the course "Human nutrition"; lectures and seminars together with the Department of Food Science, the Swedish University of Agricultural Sciences

Master in Public Health - Master i Folkhälsa
Responsible for the 15 HTPS course "Diet, nutrition and health; lectures, seminars, projects and examination.

Nursing Program – Sjuksköterskeprogrammet
First semester – Energy balance and nutrition status; lectures and seminars, together with the Department of Medical Cell Biology
Third semester: "Nursing for obese patients”; lectures, seminars, and memo
Sixth semester: “Nutrition for elderly”; lectures

Physiotherapy Program – Sjukgymnastprogrammet, together with the Department of Neuroscience, Unit of Physiotherapy.
Second semester – Rehabilitation towards increased physical activity (basic course). Caloric turnover in theory, methodological tools and practical applications.
Fourth semester - Rehabilitation towards increased physical activity (advanced course). Caloric turnover and nutritional status in theory, methodological tools and practical applications.

International collaborations
CNM researchers have on-going collaborations with scientists from Tufts University, from Harvard School of Medicine and from Harvard School of Public Health, Boston, USA regarding research in exercise/nutrition physiology, nutritional epidemiology and n-3 fatty acid biochemistry. We work with University of Alberta, Nursing Science, Canada on issues of importance for elderly care and implementation research, and takes part of nutria-genetic collaborations within The CHARGE Consortium, University of Texas. Together with Cambridge/Oxford Integrative Physiology Consortium for Metabolic Diseases and Centre for Diabetes and Royal Society of Medicine, London we collaborate on the interaction between food and insulin resistance. Fatty acid metabolic collaborations are in progress with University of Cape Town, South Africa and University of Helsinki, Finland. CNM is part of the LIPGENE Study funded in the EU 7th Frame Work Program. In the Systems biology in dietary intervention studies (SYSDIET), Nordic Centre of Excellence in Food, Nutrition and Health (NoCE), a vast Nordic collaboration is performed with University of Eastern Finland, Kuopio, and University of Copenhagen. OPUS is another Nordic collaboration between various Danish and international universities to orchestrate the world’s largest intervention study on the effect of diet and lifestyle on children and adolescents. The Provide Study is a multicenter study with centres in Brussels, Newcastle, Nuernberg and Cologne, performed in collaboration with Danone/Nutricia Research and where CNM is PI centre. In collaboration with University of Parma, Italy, joint efforts are performed with the InChianti Study to evaluate interactions of food and health in elder populations of different origins. Circadian metabolic disturbances and metabolism of sleep disorders are joint objectives with University of Chicago, and University of Ottawa.

International networks/memberships
Gerontonet - European Centre of Excellence in Geriatric Science. European Society for Clinical Nutrition and Metabolism (ESoten): Council membership for chairmen of the national societies (Swespen). ESPEN Special Interest Group - Geriatric nutrition/The SIG GN works on a European level to coordinate research efforts and recommendations for nutrition in the elderly. EFSA – Scientific cooperation & Assistance Directorate within European Food Safety Authority. Diabetes Nutrition Study Group – DNSG is a part of the European Association for the Study of Diabetes (EASD) and comprise of researchers mainly involved in the development of nutritional guidelines
for the treatment of diabetes. Other international networks are EuroFIR – European Food Information Resource, which is an EU 6th Framework Network of Excellence in the area of food composition databases with 47 partners across Europe. Euronut – 15 European institutions with high quality nutrition research collaborating around Diet and ageing, in accordance with EU:s 7th Frame Program. Nordic Nutrition Academy – Nordic Nutrition School for young researchers in nutrition; six three day-seminars over two years. European Working Group on Sarcopenia.

**National collaborations**

CNM have numerous collaborations with researchers at Karolinska Institutet, at the departments of Geriatrics, Endocrinology & Metabolism, Physiology & Pharmacology, Clinical Neuroscience, Nephrology, Molecular Medicine, and Medical Epidemiology and Cardio-Vascular Research to name some. We also collaborate with the Kungsholmen Project, Aging Research Center, KI, the Stockholm Hip Fracture Group which includes Departments of Surgery at Karolinska University Hospital Solna and Huddinge, Stockholm Söder Hospital and Danderyds Hospital. Moreover we work together with University of Agricultural Sciences (SLU), Uppsala, Integrative Biological Medicine, Umeå University (sarcopenia and the KNOTA Project), Health 70 with University of Gothenburg, and Uppsala Community and Uppsala County Council (elderly care), Stress Research Institute, Stockholm University. Lunds University in the SYSDIET project, and Dept of Health and Social Sciences, Högskolan, Dalarna. At Uppsala University CNM collaborates with researchers in the Uppsala Longitudinal Study on Adult Men (ULSAM), Prospective Investigation of Vasculature in Uppsala Seniors (PIVUS), and has co-workers at Dept of Food Science, Dept of Medical Science, Dept of Radiology, Oncology and Radiation Science, Dept of Neuroscience, Department of Food Science, Faculty of Social Sciences, Dept of Surgical Science, Dept of Women and Children’s Health etc. Logistic services and collaboration in many studies, mainly intervention trials, is performed with Good Food Practice (GFP), a private enterprise for clinical nutrition trials.

**National networks and memberships**

Projects

1) Nutrition, ageing and disease
Participants: Tommy Cederholm, Brita Karlström, Anja Saletti, Johanna Törmä, Erika Ohlsson, Per Sjögren, Sigvard Sobestiansky

Sarcopenia in geriatric care – the importance of skeletal muscle in elderly patients (The SIGVARD Study)
Collaborators: Sigvard Sobestiansky, Anna Christina Åberg, Thomas Gustafsson, Andreas Fugman, Tommy Cederholm

Sarcopenia denotes the loss of muscle mass linked to physiological changes during ageing which is enhanced by age-related conditions like chronic disorders, chronic inflammation, insufficient dietary intake an low physical activity, including periods of bed-rest due to illnesses. Sarcopenia is the cause of disability and inability to recover from disease in the old subject. Increased attention has been paid to this condition during the last 10-20 years. In a joint effort with expertise on physiotherapy and muscle metabolism the prevalence of sarcopenia and methods to define and diagnose the condition will be studied in a group of 100 consecutively admitted geriatric patients. Body composition, physical strength, physical function and clinical outcome will be addressed. Progress: During 2010 the major part of collecting the patient material has been achieved

Muscle cell gene expression patterns predictive of sarcopenia in old men and women
Collaborators: Sigvard Sobestiansky, Thomas Gustafsson, Brun Ulfhake, Lars-Erik Thörnell, Karl Michaelsson, Lars Lind, Lena Kilander, Ulf Riserus, Jamie Timmons, Tommy Cederholm

The objective of this project is if there is a specific gene expression pattern that predicts later development of sarcopenia. In the ULSAM study >1000 of the male participants at age 70 agreed to leave a muscle biopsy. From 100 subjects who also did DXA for body composition measurement at 88 years of age muscle biopsies at 70 will be utilized for microarray analysis in order to identify possible predictors through bioinformatic tools in combination with knowledge of body composition data obtained from the DXA scans. To quantify total number and number of activated satellite cells conventional immunohistochemistry will be used and to locate specific mRNA expression in situ hybridization will be used. In order to assess if gene expression patterns found in old men are also valid for older women, 100 female participants in the PIVUS cohort will be asked to leave a muscle biopsy at the age of 80. These specimens are planned to be analysed similar to those of the ULSAM cohort.

Changes in muscle morphology and muscle regenerative capacity in Swedish men from 70 to 90 years of age.
Collaborators: Sigvard Sobestiansky, Thomas Gustafsson, Brun Ulfhake, Lars-Erik Thörnell, Karl Michaelsson, Tommy Cederholm

The objective is to identify mechanisms involved in age-related muscle wasting by comparing molecular and cellular findings in biopsies taken at ages 70 and 88 years in 40 Swedish males. ULSAM cohort members who performed the 88 year follow-up, including DXA scan and had a muscle biopsy taken at the age of 70 will be asked if they are willing to leave a new biopsy at age 90. The material will be analysed according to the content of embryonic myosin (i.e. regeneration), expression of acetyl choline receptor subunits (i.e. denervation) and numbers and activity of satellite
cells, which is the stem cell of muscle regeneration. Moreover, fiber type distribution, muscle fiber area and muscle capillary density will be compared between the biopsies from 70 to 90 years of age. Single nucleotide polymorphisms (SNPs) will be related to muscle phenotypic data.

**Selective Androgen Receptor Modifiers (SARMs) for the treatment of muscle wasting/sarcopenia in free-living older adults**

**Collaborators:** Ulf Holmbäck, Maria Berglund, Torbjörn Åkerfeldt, Roger Olsson, Karl Michaelsson, Tommy Cederholm.

CNM was one of many international centers in a Phase II/III study performed by MSD to evaluate feasibility, safety and effects on muscle strength and functionality in community-dwelling older adults with limited functional impairments by a new Selective Androgen Receptor Modifier (SARM). CNM did a thorough screening of close to 50 subjects and finally was able to include 4 in a 6-month protocol. CNM was the most successful of all participating centers. **Progress:** The data collection was finished during 2009. Data analyses were performed in 2010. SARM gave a significant increase in muscle mass but only a trend-wise improved muscle strength.

**Protein and vitamin enforced supplementation to sarcopenic older adults - The PROVIDE Study**

**Collaborators:** Ulf Holmbäck, Marie Berglund, Sigvard Sobestiansky, Tommy Cederholm

This project aims to evaluate the muscle strengthening effects of a liquid supplementation rich in essential amino acids, vitamin D and vitamin B	extsubscript{s}, to subjects >65 years of age, altogether ~300, with reduced muscle mass and muscle strength. It is a RCT design and the intervention period will be 6 months. It is a multi-center study involving 5 international centers and the study is financed by Danone/Nutricia, the Netherlands and is performed in collaboration with Good Food Practice, Uppsala, who provides logistic support. **Progress:** During late 2010 patient recruitment started and CNM has been able to enroll about one third of its allocated required participants.

**Combined exercise training and dietary intervention by whey protein and vitamin D to sarcopenic old adults – The VIVE2 Study**

**Collaborators:** Tommy Cederholm, Afsaneh Kochek, Anna Cristina Åberg, Margaretha Nydahl, Mai-Lis Hellenius, Roger Fielding

The aim is to test if provision of high-quality protein and vitamin D combined with an exercise program give a stronger anabolic effect than exercise training alone. The study has been planned during 2010 and will be performed as a joint venture between Uppsala University, Karolinska Institutet, Tufts University in Boston, USA and Nestle Nutrition Research, Schweiz. Inclusion criteria is reduced 400 meter walking speed and reduced score in Short Physical Performance Battery (SPPB). All subjects will participate in physiotherapist supervised exercise sessions three times per week for 6 months. The participants will be randomized to receive a newly developed whey protein and vitamin D enriched liquid formula or placebo.

**Implementing nutritional routines into institutionalized elderly care (The MUMS Project)**

**Collaborators:** Anja Saletti, Johanna Törmä, Brita Karlström, Marianne Sellgren, Ulrika Winblad, Marianne Carlsson, Tommy Cederholm.

In year 2006 the Uppsala municipality adopted nutritional guidelines for the elderly. In order to perform and evaluate the implementation process scientifically, the municipality searched cooperation with the University of Uppsala. The project consists of three substudies:
Nutritional, cognitive, functional and vitamin D interactions and relationships with 1-year mortality in elderly care residents

Undernutrition and vitamin D deficiency is common in residents of municipal elderly care and related to reduced physical and cognitive function and mortal outcome. In 172 elderly care residents in Uppsala, the nutritional status by Mini Nutritional Assessment, MNA 0-30 p (20), ADL by Barthel Index (0-20 p) and cognitive function by Short Portable Mental State Questionnaire (SPMSQ 0-10 p), were determined. From 110 residents blood samples were drawn for analyses of nutrition-related biomarkers, including plasma 25-hydroxy(OH) vitamin D, inflammatory/catabolic indicators and insulin-like growth factor-I (indicating anabolism). Population registers will be used for determining mortality rate within one year after base-line examination. Progress: Preliminary results indicate prevailing undernutrition in elderly care residents with functional correlations for nutritional status and prevalent reductions of plasma 25-OH vitamin D concentrations.

Implementing nutritional routines into elderly care

Despite an improved nutritional awareness and several years of educational efforts, malnutrition and insufficient food intake is still common among elderly in community care. The hypothesis of this project is that an action research based implementation program will create an effective model for implementation of nutritional guidelines. Two interventions will be compared during the implementation project, i.e. one model is based on the four principles of action research; plan, act, observe and reflect. Action research involves both researchers and practitioners (managers, nurses and care staff from four nursing homes), and the other is a three-hour educational session. The effects of implementation on staff level are measured by a survey using process (actual care delivered in accordance with the nutritional guidelines) and outcome indicators (nutritional status, mobility, cognitive ability, blood samples and health-related quality of life (EQ-5D). Process indicators will evaluate to what extent the staff screen for malnutrition and carry out nutritional care plans by document analysis. In addition, whether the length of the night fast and the number of meals is in accordance with the guidelines will be measured by dietary assessment. Finally, observations of the mealtimes will be carried out to evaluate the ambience during mealtimes. Progress: The questionnaire survey from baseline is collected and the 221 personal responses from the eight units are analyzed.

Development of a tool for evaluating mealtime’s ambience in elderly care

Improvement of mealtimes in elderly care is one way to increase quality of life and nutritional status. During the MUMS implementation project it became clear that there is a need for a tool to measure ambience at mealtimes. As a template for such tool the Five Aspects Meal Model (FAMM) is used. It is based on restaurant visits and emphasizes “the room”, “the meeting”, “the food and beverages served”, together creating “the ambience” or the atmosphere surrounding the meal. These four aspects are in turn affected by “the management control system”. The tool will be created based on this model. A panel of experts consisting of researchers and practitioners will be asked to give their aspects of the norm of the mealtimes. The tool will be tested in a pilot study. The validity of the items in each aspect will be determinate through factor analyses. Progress: A literature search on mealtime effects has been performed. Out of 69 articles, 60 were reports from special housing, nursing homes and assisted living, and a few in the hospital setting. About half were performed in cognitive intact populations, and it was mainly older people’s perspective that was highlighted.
**CNM as collaborating partner 2011:**

**Omega-3 fatty acid epigenetic effects, effects on gene-expression and on inflammation resolution - The OmegAD Study**


The OmegAD Trial, a collaborative study of 200 patients with Alzheimer's disease (AD) given omega-3 fatty acids, mainly docosahexaenoic acid, in a randomized protocol for 6 and in an open protocol for another 6 months, has partly been able to confirm epidemiological evidence indicating that high intake of fish oils rich in omega-3 fatty acids may slow decline rate of cognitive impairment in patients with Alzheimer’s disease. Effects on cognition, behavior, nutrition, oxidation, inflammation and gene expression are studied. Tommy Cederholm is PI for this study. **Progress:** During 2010 data on fatty acid concentrations in cerebrospinal fluid during the treatment period was analyzed. Micro-array analyses of gene expression effects in blood mononuclear cells were performed. Studies on epigenetic effects of n-3 FA treatment were prepared, and IRB approval was given for the analyses of DHA-metabolites with inflammation resolution properties, e.g. resolvins, protectins and maresins.

**Functionality and quality of life in stroke patients one year after the event**

Collaborators: Birgit Wahlberg Tommy Cederholm, Lena Zetterberg, Karin Hellström, The aim of this study is to describe the functional capacity and psycho-social well-being in 200 stroke patients 65-85 years of age one year after the event. Nutritional status (MNA), body composition (BIA), function (ADL, gait speed, Physical Activity Scale) self-efficacy and coping will be tested. This project is performed in collaboration with the Department of Neuroscience at UU. **Progress:** Data collection was finalized 2010.

**Protein supplementation and bisphosphonates in elderly lean patients with hip fracture**

Collaborators: Tommy Cederholm, Amer Al Ani, Nils Dalen, Paul Ackerman, Lena Flodin, Margareta Hedström.

In the frame work of the Stockholm Hip Fracture Group, a research joint action between the University hospitals in Stockholm, the effects on muscle and skeleton by the combined treatment with protein supplementation and bisphonates are studied. Lean elderly patients with hip fracture are randomized to active treatment or placebo for 6 months. Function, muscle mass and bone mineral density are the main outcome variables. The study is performed in collaboration with Fresenius Kabi. **Progress:** Initial power calculations indicated the need of 120 patients in the study. Currently 70 patients have been recruited.
2) Preventive nutrition and metabolism
Participants: Ulf Risérus, Brita Karlström, Siv Tengblad, Per Sjögren, Bengt Vessby.

Fat and carbohydrates in the diet and the body

Effects of a healthy Nordic diet on cardiovascular risk and the metabolic syndrome
Collaborators: Ulf Risérus, Viola Adamsson, Bengt Vessby, Gunnar Johansson, Tommy Cederholm, Fredrik Rosqvist, David Iggman

In a series of randomized controlled studies, we are currently investigating the role of a “healthy Nordic diet”, i.e. a diet containing foods traditionally used in the Nordic countries, and foods that have documented health effects on metabolic and cardiovascular risk factors,

- CNM, Uppsala is one of 11 academic centres in the consortium “Nordic Centre of Food, Nutrition and Health”, financed by NordForsk. The aim is to conduct a large dietary multi-centre intervention study using systems biology to investigate the genetic and metabolic effects of a Nordic diet in overweight subjects with the metabolic syndrome (SYSDIET project).

- We are also investigating the clinical effects of a Nordic diet in subjects with hypercholesterolemia (NORDIET project), as well as

- investigating the metabolic impact of a Nordic healthy breakfast (NORDBREAK project)

Effects on liver- and abdominal fat accumulation when substituting saturated fat with polyunsaturated fat in the diet – The HEPFAT Study
Collaborators: Ulf Risérus, Håkan Ahlström, Peter Arner, Mats Rudling, Tommy Cederholm, Helena Bjermo, David Iggman

Liver fat accumulation has been suggested to be causal for the development of type 2 diabetes. In a randomized controlled trial, HEPFAT, we aim to investigate if accumulation of hepatic and visceral fat can be reduced in abdominally obese subjects by substituting saturated fat with vegetable oils (n-6 polyunsaturated fat) in an isocaloric diet. Secondary aim is to investigate the effects on adipose tissue gene expression. Other clinical variables such as insulin resistance, blood lipids, oxidative stress and inflammation will also be investigated. Progress: The trial is conducted, the results are being analyzed and manuscript(s) are under preparation. We collaborate closely with the Radiology dept at Uppsala Academic hospital, with Karolinska institutet on gene expression and assessment of mechanisms behind cholesterol lowering effects of unsaturated fatty acids. This study is currently followed up by another controlled study (LIPOGAIN study), where a similar protocol will be used but under hypercaloric conditions aiming at increasing the knowledge behind metabolic consequences of weight gain and the influence of dietary fats.

Clinical measures of abdominal obesity and the link to insulin resistance, metabolic disorders and cardiovascular risk
Collaborators: Ulf Risérus, Helena Bjermo, Johan Ärnlöv

It is known that abdominal, rather than generalized obesity is particularly health hazardous. For example, in many cases, waist girth is a better risk marker than the body mass index (BMI). Abdominal (visceral) fat distribution is closely associated with the metabolic syndrome and is a strong risk factor for type 2 diabetes, stroke and cardiovascular disease. In various populations we have compared different anthropometric measures that could be easily used in the clinic or in diabetes and cardiovascular research. In particular, we have reported in several studies that the "sagittal abdominal diameter", i.e. the "abdominal height" measured with the patient in lying
position on a bench, seem an even better risk marker than waist girth and waist-to-hip ratio. Especially, the abdominal height predicts metabolic disorders related to insulin resistance. In collaboration with prof Mai-Lis Hellénius and prof Ulf de Faire at Karolinska Institute, we are now performing a large study comparing different anthropometric measures with regard to metabolic and cardiovascular risk. The aim is to identify the best anthropometric measure with regard to identifying those individuals at highest risk, and therefore require lifestyle and drug treatment.

**LIPGENE; diet, genomics and the metabolic syndrome: an integrated nutrition, agro-food, social and economic analysis.**

*Collaborators: Ulf Risérus, Brita Karlström, Helena Bjermo, Bengt Vessby and researchers from 25 other universities and colleges across Europe.*

Lipgene is a EU-project within the 6th frame work and the aim is to elucidate in the role of dietary fat in development of the metabolic syndrome. Genetic variability, production technology and consumer acceptance are taken into account. Uppsala University is taking part in a dietary intervention study that includes 8 other European universities and their participants. **Progress:** The intervention is conducted and several manuscripts are recently published or under preparation.

**Fatty acid composition in serum lipid esters and desaturases in health and disease - dietary and genetic aspects.**

*Collaborators: Ulf Risérus, Tommy Cederholm, Fredrik Rosqvist, Eva Warensjö, Tommy Olsson, Julia Goedecke, Marja Mutanen, Björn Sundström, Juan Jesus Carrero, Bengt Vessby.*

It is well known that the fatty acid composition in serum lipids and estimated desaturase activities, as a marker of fat quality, is linked to obesity, insulin resistance, cardiovascular disease and diabetes. Associations between fatty acid composition, estimated desaturase activities and clinical variables, metabolic disease and dietary intakes are studied in several substudies using various cohorts. The aim of our studies is to learn more about the FA-composition and estimated desaturase activities in relation to the metabolic syndrome, to cardio-vascular risk factors such as endothelial markers, as well as a potential role in the development of malignancy. We will also study how the FA composition and estimated desaturase ratios change after a diet rich in either saturated fat or unsaturated fat. In addition, genetic differences (SNPs) in the SCD-gene will be studied in relation to obesity, insulin sensitivity and FA-ratios. The importance of delta-5-desaturase (FADS) will be addressed. Several of these studies will be carried out in the ULSAM- and PIVUS cohorts. We also have several international collaborations with this regard, e.g. in collaboration with University of Capetown and Umeå University we perform detailed phenotype characterization of white and black South African women in order to detect dietary, anthropometric and metabolic differences among these sub-populations, including fatty acid metabolism. Apart from our main focus on obesity-related diseases and cardiometabolic disorders we have also several other projects going concerning other major diseases as well as rare diseases. We believe that fatty acid intakes play a role as well as an altered fatty acid metabolism in multiple diseases. For example, the relation between dietary fat, FA profiles in plasma and desaturase activity in young women from Mozambique will be studied. In collaboration with Umeå University FA-profiles in patients with rheumatic diseases, and in collaboration with researchers at Dept of Nephrology, Karolinska Institutet, similar questions will be addressed in patients with chronic kidney failure. These studies might influence future dietary recommendations since FA composition and desaturase activities are modifiable by diet.
Effects on appetite and cognitive performance of meals with different glycaemic load

Collaborators: Agneta Andersson, Anders Sjödin, Bengt Vessby, Louise Dye and John Blundell

In within-subjects repeated-measures design the effect on appetite, cognitive performance and subjective state during the post-lunch period of composite meals with different carbohydrates sources is investigated. A computerised cognitive test battery is used to evaluate the cognitive performance before and after lunch. Simultaneous appetite and subjective mood is rated and analyses of blood glucose and insulin is performed. An ad libitum meal is finally used to assess effect on food intake later during the day. In these way possible relationships between glucose and insulin levels in blood, cognitive performance and appetite are evaluated. The project is performed in collaboration with the Biopsychology Group, Leeds University, UK and financial supported by VINNOVA.

Progress: Data are collected. Manuscript will be written.

3) Dietary patterns and health effects

Participants: Wulf Becker, Brita Karlström, Bengt Vessby, Annika Smedman, Per Sjögren

Dietary patterns and long-term health. Longitudinal studies in 70 year old men in the ULSAM Cohort

Collaborators: Per Sjögren, Erika Olsson, Erika Ax, Brita Karlström, Tommy Cederholm, Lena Kilander, Karl Michaelsson, Anna Bill Axelson, Hans Garmo, Lars Holmberg, Marcello Maggio, Wulf Becker

Dietary data collected in the ULSAM Study at 70 years of age, around 1100 males, is compiled into dietary patterns; i.e. Mediterranean-like Diet, WHO-recommended Diet and Carbohydrate Restricted (Atkins-like). Detailed dietary habits were available from 7-day dietary records and misreporters of dietary energy intake were identified. We investigate relationships between the adherence to the various dietary patterns and long-term health outcome, e.g. mortality, cardiovascular disease, cognitive function, osteoporosis and cancer. Corresponding studies are planned for the PIVUS cohort.

Dietary pattern and mortality

Aim: To study the impact of the habitual dietary habits on all-cause and cardiovascular mortality over a 12-year follow-up period.

Methods: The study was based on the third follow up of the ULSAM study. Degree of adherence to the various dietary patterns (described above) was related to all-cause and cardiovascular mortality (derived from national registries). Risk relations were calculated with and without dietary misreporters included, and adjusted for potential confounders. Progress: A first paper from this project was published during 2010 in the American Journal of Clinical Nutrition. We found strong protective effects on both cardiovascular and all-cause mortality from increased adherence to a Mediterranean-like diet. Conversely, adherence to a Carbohydrate restricted diet was associated with increased mortality, especially cardiovascular mortality in these men.

Dietary pattern and prostate cancer

Aim: To study the impact of the habitual dietary habits on the risk of prostate cancer over a 16-year follow-up period.

Methods: The study is based on the third follow-up of the ULSAM study. Degree of adherence to the various dietary patterns (described above) will be related to the incidence of prostate cancer, derived
from the National Cancer Registry. Risk relations will be calculated with and without dietary misreporters included, and adjusted for potential confounders. The risk of competing events will be taken into consideration. Exploratory analyses will be performed to investigate the impact of individual nutrients. Progress: Preliminary data are presented. Corresponding studies have been initiated in other population based cohorts, one Swedish (H70, Gothenburg) and one Italian (InChianti, Parma).

**Dietary pattern and risk of cognitive disorders (The DICO Study)**

**Aim:** To study the impact of dietary intake and the risk of incident Alzheimer's disease, all-type dementia and mild cognitive impairment, respectively, in late life.

**Methods:** The study will be based on the third and fifth follow up of the ULSAM study. Data from the dietary survey at age 70 will be used and related to the incidence of Alzheimer's disease, all-type dementia and mild cognitive impairment, respectively. All participants in the first investigation of the ULSAM study were invited to a third follow up for a new investigation at the age of 70 years old. Risk relations will be calculated with and without dietary mis-reporters included, and adjusted for potential confounders such as ApoE-genotype. Progress: Dietary data and risk relations were computed in the beginning of 2010. Due to maternal leave the project will be completed 2011.

**Dietary patterns in relation to nutritional status, body composition, psychological status, health and disease in 82 year old men (ULSAM cohort).**

**Collaborators:** Per Sjögren, Erika Olsson, Brita Karlström, Karl Michaëlsson, Tommy Cederholm

The aim of the study is to evaluate dietary intake and dietary habits in the ULSAM population at the age of 82, i.e. energy and nutrient intake, meal pattern, and frequency of meals/food items. Moreover, to relate dietary intake/dietary habits to nutritional status and body composition (DEXA), risk of malnutrition (MNA), vitamin B12, folate, ADL, psychosocial situation, medical-, psychological and sociological factors, physical activity level, and parameters for health/diseases (coronary heart disease and diabetes). Dietary intake was measured at the fifth follow-up of ULSAM - Uppsala Longitudinal Study of Adult Men, when the participants were 82 years old, using a pre-coded 7-d record book and with a food frequency questionnaire (FFQ).

**An investigation of food intake in relation to environmental toxins in 70-year old men and women in the PIVUS cohort**

**Collaborators:** Per Sjögren, Erika Ax, Tommy Cederholm, Monica Lind, Lars Lind

Cross-sectional relations between food intake and environmental toxins in the body will be investigated. The study will be based on baseline data from the PIVUS cohort, a longitudinal study of 1000 men and women (all 70 years of age) initiated in 2001 and with ongoing re-investigations and follow-ups. Detailed dietary habits are available from 7-day dietary records, including food groups and nutrients. Mis-reporters of reported energy intake will be identified. Quantitative measures of a wide spectrum of environmental toxins, such as PCB, dioxins and phthalates, are available from fasting blood samples of all participants. Associations between dietary patterns, food groups and nutrients and the different toxins will be investigated. Progress: Computation of dietary data was initiated in 2010 and associations to environmental toxins will be carried out in 2011.
Gene-diet-interactions and cardio-metabolic risk (The ULSAM, PIVUS and LIPGENE cohorts)

Collaborators: Per Sjögren, Ulf Riserus, Erik Ingelsson, Lars Lind, Jennifer A Nettleton

Our genetic background interacts with dietary modifications in determining health outcome. In this project we focus on the intake of certain nutrients, how they interact with selected gene variants and the effect on this interaction on intermediate risk factors for type-2 diabetes and cardiovascular disease. These studies are part of a large multinational collaboration (i.e. the CHARGE consortium) including several prospective cohort studies, and coordinated by JA Nettleton (Texas, USA).

Progress: The first paper was published 2010, investigating the impact from the interaction of whole grain intake and selected gene variants on fasting plasma glucose and insulin levels. Similar studies on selected gene variants and their interaction with dietary patterns, coffee, zinc and magnesium, respectively, are in progress.

Effects of increased intake of fruit and vegetables on dietary composition, body weight and metabolic control

Collaborators: Anette Järvi, Brita Karlström, Wulf Becker, Bengt Vessby.

Project description: Sixty-four overweight adult men and women were randomised to either an intervention group that during 4 months received 500 g/d fruit and vegetables or a control group that received general dietary advice. The effects on dietary habits, anthropometry, blood lipids, blood glucose, antioxidant status, etc., were investigated. Progress: Data are collected. A manuscript will be written.

4) Obesity and overweight in children and adults

Participants: Ulf Holmbäck, Tommy Cederholm, Roger Olsson, Linda Bratteby Tollerz, Marie Berglund, Torbjörn Åkerfeldt, Arvo Hänni, Anders Forslund

Weight reducing operations and effects on body composition and endocrine function.

Collaborators: Ulf Holmbäck, Tommy Cederholm, Anders Karlsson, Arvo Hänni, Magnus Sundbom

Morbid obesity is treated with various operative techniques, depending on degree of obesity. Few studies have examined the impact of various operation techniques at weight stabilization. Using a cross-sectional approach, we are studying obese subjects after gastric bypass or duodenal switch and comparing them to weight matched non-operated controls. We are assessing body composition, energy expenditure, psychometric variables, expression of lipogenic genes, appetite regulation, inflammation and markers for fat, protein and muscle turnover. Progress: About half of the subjects have been examined.

Individualized treatment of pediatric obese patients

Collaborators: Ulf Holmbäck, Anders Forslund, Jan Gustafsson, Roger Olsson, Arvo Hänni

In spring 2008 the children’s obesity clinic opened in Uppsala. We have a multi-disciplinary approach with the aim of individualizing the treatment, both in terms of cognitive treatment but also dietary approaches, and by that keep patient satisfaction high and attrition low. Progress: A pilot study has started.
Assessment of nutrition status in pediatric patients

Collaborators: Roger Olsson, Marie Berglund, Linda Bratteby-Tollertz, Anders Forslund, Ulf Holmbäck

In various diseases, such as obesity, cystic fibrosis or neurological conditions such as cerebral pareses, correct assessment of nutrition status is important. Often caloric needs are estimated from equations, and these equations might underestimate energy needs in these patient populations. By using various techniques such as activity monitors, heart rate monitors and activity diaries, together with indirect calorimetry and body composition assessment, we strive to get a more complete picture of these patients nutrition status. These, hopefully, more correct nutrition status figures will aid in the treatment and increase health in these patient populations. Progress: Data from more than 200 children have been collected. Preliminary data have been presented.

The effects of nutrition and physical activity on muscle metabolism and biochemical variables.

Collaborators: Torbjörn Åkerfeldt, Mats Stridsberg, Ulf Holmbäck

In various clinical settings, such as after surgical procedures, patients have to recover from loss of muscle mass and muscle function. Our projects aim to learn more about how to optimize nutrition support for muscle gain, and also to elucidate what changes occur within the muscle as well as on the whole body level. Progress: Data collection and analysis have ended; manuscript under preparation.

Circadian Metabolism - Metabolic, endocrine and mental performance effects of sleep restriction with and without sleep misalignment

Contact person and collaborators: Ulf Holmbäck, Rachel Leproult (University of Chicago), Eve Van Cauter (University of Chicago)

Subjects are tested before and after sleeping 5 h per night, with or without sleep restriction. Among others, the following variables are studied: glucose metabolism, energy intake, mental performance, hormones and cardiovascular function. Progress: Data collection and analysis have ended. One article published and several manuscripts are under final preparation.

Will short sleep in adolescents affect energy expenditure, glucose metabolism and appetite? – The SLOPUS Study

Participants: Ulf Holmbäck, Anders Sjödin & Lars Klingenberg (University of Copenhagen) & Jean-Philippe Chaput (University of Ottawa).

Adolescents will take part in a randomized interventions trial looking at the effects of short sleep on energy expenditure, glucose metabolism and subjective and objective appetite. Progress: All subjects have been run and initial data analysis have begun, Preliminary data have been presented at conferences.
Disability and Habilitation

Research Group Leader Professor Karin Sonnander

Persons with disabilities often experience extensive difficulties in handling everyday life. 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. A joint conceptual perspective is found in the WHO Classification ICF. Contextual Factors as outlined in the ICF in particular serve as a framework for research activities in elucidating environmental aspects as facilitators and barriers for persons with disabilities at present including 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: Disability Services, Systems and Policies, Clinical Assessment Methods and Documentation and The Perspectives of Persons with Disabilities in Theory and Practice in which the facilitating and restraining aspects of the environment as well as the participation and perspectives of persons with disabilities, professionals and significant others are highlighted.

Members of the group during 2011

Monica Blom Johansson, BA, PhD student
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
Kjerstin Larsson, PhD Faculty of Medicine, associated researcher
Helene Lidström, PhD Faculty of Medicine, associated researcher
Helena Lindstedt, PhD Faculty of Medicine, senior researcher
Gunilla M. Olsson, PhD, associated researcher
Mia Pless, PhD Faculty of Medicine, associated researcher
Karin Sonnander, PhD, professor
Annika Terner, BA, PhD student
Öie Umb-Carlsson, PhD Faculty of Medicine, senior researcher

External partners

Päivi Adolfsson, PhD, Centre for Disability Research, Uppsala University
Amanthi Bandusena, PhD, Department of Community Medicine, University of Sri Jayewardenepura, Colombo, Sri Lanka
Marianne Carlsson, PhD, professor, Department of Public Health and Caring Sciences, Uppsala University
Ann-Britt Ivarsson, PhD Faculty of Medicine, associate professor, School of Health and Medical Sciences, Örebro University
Gunnel Janeslätt, PhD Faculty of Medicine, Centre for Clinical Research Falun, Uppsala University
Lennart Jansson, PhD Faculty of Medicine, Department of Neuroscience, psychiatry, Uppsala University
Ulla Jergeby, PhD, National Board of Health and Welfare, Stockholm
Liselotte Norling Hermansson, PhD Faculty of Medicine, Clinical Research Centre, Örebro University Hospital, Örebro
Ingvar Pettersson, PhD Faculty of Medicine, senior lecturer, School of Health and Medical Sciences, Örebro University
Birgitta Rosberg, registered occupational therapist, Uppsala University Hospital
Anna Cristina Åberg, PhD Faculty of Medicine, associate professor, Department of Public Health and Caring Sciences
Per Östberg, PhD Faculty of Medicine, Department of Neuroscience, Speech-Language Pathology, Uppsala University
Publications 2009-2011


23. **Lindstedt, H.** et al. (2011). Environmental help or hindrance? Environmental factors’ impact on the use and utility of electronic planning devices for people with mental disability (Poster presentation ID-dagarna, Uppsala) (In Swedish)


**Review 2010**

Agencies that support the work/Funding

Regional Research Council in Uppsala-Örebro Region 350 000
Swedish International Development Cooperation Agency (SIDA) 200 000
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
Uppsala Regional Council 115 000

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, Uppsala County Council (Helena Lindstedt, Monica Blom Johansson)
Reviewer of grant applications, The Swedish Association of Occupational Therapists (FSA) (Helena Lindstedt)

Examinations and evaluations (members)

During 2011 assignments as expert at evaluations for one position as associate professor and one position as senior lecturer (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)

Undergraduate teaching 2011 (members)

Nursing Program

Scientific Method 4.5 Higher Education Credits (Helena Lindstedt seminars and examinations in basic statistics). Monica Blom Johansson and Johan Glad contributed with lectures and group work on Statistical Package for the Social Sciences (SPSS).
**Caring Science Freestanding courses**
Course coordinator (Helena Lindstedt) for the following courses:

Scientific Methodology II including biostatistics 7.5 Higher Education Credits (including lectures, seminars and examination).

Care Planning and Quality Improvement 7.5 Higher Education Credits

Essay Course 15 Higher Education Credits (including essay tutorials and examination)

Monica Blom Johansson and Johan Glad contributed with lectures and group work on Statistical Package for the Social Sciences (SPSS), single lectures and examinations (Ôie Umb-Carlsson), and essay examination (Karin Sonnander).

**Master Program in Public Health**
Essay tutorials and essay examination (Karin Sonnander) and lectures and examination (Ôie Umb-Carlsson, Monica Blom Johansson).

**Freestanding courses**
Course coordinator including lectures and seminars (Ôie Umb-Carlsson), single lectures (Monica Blom Johansson, Helena Lindstedt) and examination (Karin Sonnander) for the course Impairment and DisabilityIntroductory Course 7.5 Higher Education Credits. The course is free-standing and elective within the Medical Program, the Nursing Program and the Physiotherapy Program.

Joint course coordinator (Ôie 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

Course coordinator (Helena Lindstedt) and examination (Karin Sonnander) for the commissioned course Current Understanding and Treatment of Persons with Neuropsychiatric disorders, 7.5 Higher Education Credits

**Speech-Language Pathology Programme (Department of Neuroscience)**
Lectures, group work and tutorials (master’s thesis) on introductory and advanced levels (Monica Blom Johansson)

**Social Work Programme (Department of Sociology)**
Lectures on advanced level (Johan Glad)

**Extra mural teaching**
Single lectures (Karolinska Institutet) and part-time employment at Mälardalen University (Ôie Umb-Carlsson)
Projects

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, Marianne Carlsson, Per Östberg, Karin Sonnander

The aim of this thesis is to obtain more knowledge about how the person with aphasia, the significant other and the speech-language pathologists perceive the communication situation between the significant other and the person with aphasia.

A second aim is to develop a model of intervention and carry out a trial of intervention for improving the couple’s communication skills.

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 of treatment and structured long-term follow-up (Goal Attainment Scaling, GAS) for people with mental health disorders. Patients (n=80) report subjective occupational performance, daily occupation satisfaction and quality of life. Occupational therapists (n=20) report work satisfaction.

Support in housing- a comparison between people with psychiatric disability and people with intellectual disability
Participants: Öie Umb-Carlsson, Lennart Jansson

The aim is to compare need and provision of support in housing among people with psychiatric disability (n=397) and people with intellectual disability (n=110) based on questionnaire reports.

Cognitive assistive technology and ADHD: an evaluation
Participants: Helena Lindstedt, Öie Umb-Carlsson

The aim is to develop new forms of assistance in daily life settings for people with ADHD (Attention-Deficit/Hyperactivity Disorder). Evaluated project activities concern the effective use of assistive technology at home, at work and in educational settings as well as in terms of target group, professional and proxy experiences (n=19).

Environmental help or hindrance?
Participants: Helena Lindstedt, Gunnel Janeslätt, Päivi Adolfsson, Ingvar Pettersson, Liselotte Norling Hermansson

Cognitive assistive technology (CAT) prescribed to people with mental/neuropsychiatric disabilities are not used as intended. The aim is to clarify the detailed methodology of the prescribing process of CAT. What environmental factors constitute help or hindrance for individual use and perceived utility of CAT for the target group? 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.
Evaluation of individual treatment goals for people with mental disabilities
Participant: Helena Lindstedt
The aim is to evaluate the outcomes of four evidence based methods (Single System Design, Goal Attainment Scaling, Cognitive assistive devices and Motivational Interviewing) implemented in regular practice in a municipality based service setting.

Stroke patients' experiences and opinions of care and rehabilitation.
Participants: Kjerstin Larsson, Karin Sonnander
The aim is to analyze qualitative text, i.e. patients’ comments, in follow up questionnaires from the National Qualitative Register of care and rehabilitation (RiksStroke).

In-service training and implementation of evidence based practice in a multi-professional specialized habilitation setting
Participants: Mia Pless, Karin Sonnander
The aim is to describe and analyze staff’s experiences of barriers and facilitators in evidence based practice following a three-year systematic in-service training program (n=143).

Clinical Assessment and Documentation
Professional decision making in healthcare as well as social welfare services is laden with risk and uncertainty, when assessment is not systematic or a standardized clinical terminology shared by professionals involved is lacking. Present studies concern adaptation and clinical application of assessment instruments of the home environments of children, early child development, an international standard language and framework for the description health and health-related issues (ICF), and multi-professional use of the electronic health record system.

The HOME Inventory, Home Observation for Measurement of the Environment - A Swedish Adaptation
Participants: Johan Glad, Carina Gustafsson, Ulla Jergeby, Karin Sonnander
The aim of this thesis is to assess the relevance of an international published instrument (HOME) for assessing parental ability to satisfy children’s needs 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).

Early identification by parental assessment of children with developmental delay in Colombo, Sri Lanka
Participants: Amanthi Bandusena, Karin Sonnander
The general objective of this study is to estimate the prevalence of children aged eighteen months in the Colombo district with developmental delay, to describe their parents’ perceptions on selected aspects of care giving and facilities currently available for them.

Parents’ use of ICF and ICF-CY when reporting on focus in habilitation services for their children with developmental disabilities
Participants: Mia Pless, Nina Ibragimova, Margareta Adolfsson, Eva Björck-Åkesson, Mats Granlund
The aim is to report on parents' use (n=87) of the International Classification of Functioning, Disability and Health, ICF/ ICF-CY (Children and Youth version) when reporting on what focus
habilitation services have concerning their children with developmental disabilities. The design is descriptive with a questionnaire using the structure and language in ICF model and with questions concerning identification, goal setting and intervention of function and health.

**Prevalence of psychosocial factors in ICF categories in a tertiary Swedish Pain Clinic.**

**Participants:** Kjerstin Larsson, Ruth Kusec Fredriksson, Carl Molander

The aim is to investigate the prevalence of ICF categories in social worker evaluation of chronic pain patients in a Swedish tertiary pain clinic setting.

**The electronic health record system: professional use and patient safety**

**Participants:** Annika Terner, Helena Lindstedt, Karin Sonnander

The aim of this thesis is to investigate health professional documentation, inter-professional use and patient safety by studying a multi-professional EHR system in a Swedish county council. Research questions concern characteristics of applied terms in the EHR system, to what extent they are applied across eight different health professions as well as shared by these professional groups and how health professional users value the shared EHR system. Finally, reported aberrancy incidents before and after the implementation of a shared EHR system will be studied. Reported incidents related to documentation in patient records will be identified and analyzed.

**The Perspectives of Persons with Disabilities in Theory and Practice**

Recent decades have seen a growing emphasis, in a number of contexts, on acknowledging and acting on the views of people with disabilities. This trend was given added weight by the UN Convention on the Rights of Persons with Disabilities, ratified in 2008. Studies focus quality of life from the perspectives of persons with intellectual disabilities and a participatory research approach.

**Men and women with intellectual disabilities and quality of life**

**Participants:** Öie Umb-Carlsson, Helena Lindstedt

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).

**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.

**Other**

**The concept of successful aging from the perspective of elderly men**

**Participants:** Öie Umb-Carlsson, Birgitta Rosberg, Anna Cristina Åberg

The aim is to describe, define and gain insight into the concept of successful aging from the perspective of elderly men. Elderly men born between 1920 and 1924 are interviewed concerning the concept of successful aging, contributory factors of successful aging and their lived experiences of successful aging.
Using motivational interviewing to support the use of safer sex
Participants: Eva Lejelind, Kjerstin Larsson

The aim is to develop new procedures to inform people about condom use and study whether a motivational interviewing approach when informing about condoms and the practice of safer sex would increase condom use among visitors to a clinic for sexually transmitted infections (STI).
Family Medicine and Preventive Medicine

Research Group Leader Per Kristiansson, MD, PhD, Lecturer

Family medicine reflects the fact that primary health care is in the front line of all health care, i.e. it is the health care facility patients are expected to begin by consulting. For this reason family medicine research focuses on the most common diseases and illnesses in the population. In the research programme the focus is on patient-centred research, using clinical as well as epidemiological techniques. We also pay special attention on social insurance medicine to identify factors that will help long-listed individuals return to working life, assessing the efficacy of various innovative return-to-work strategies.

The research within preventive medicine addresses mechanisms of social inequalities 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 in social medicine 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 2011

Research supervisors
Mansour Alemi, Associate researcher, PhD, Faculty of Medicine
Åsa Andersén, Research assistant, RN, Master of Public Health
Dan Andersson, Associate researcher, postdoc, MD, PhD
Ingrid Anderzén, Researcher, PhD
Malin André, Associate researcher, MD, PhD
Bengt Arnetz, Professor, MD, PhD
Judith Arnetz, Associate professor, PhD
Annika Bardel, Associate lecturer, postdoc, MD, PhD
Karin Björkegren, Lecturer, MD, PhD
Stefan Blomberg, Postdoc, MD, PhD
Johan Bogefeldt, Postdoc, MD, PhD
Kristina Bröms, Associate researcher, postdoc, MD, PhD
Gunilla Burell, Senior researcher, Psychologist, PhD
Jan Cederholm, Associate professor, MD, PhD
Dag Elmfeldt, Adjunct professor, emeritus, MD, PhD
Lars Englund, Postdoc, MD, PhD
Margaretha Eriksson, Researcher, postdoc, PhD, Faculty of Medicine
Marie Gronnesjö, Postdoc, PhD, Faculty of Medicine
Mats Gulliksson, Postdoc, MD, PhD
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1) Articles from former Family Medicine and Clinical Epidemiology
2) Articles from former Preventive Medicine
3) Articles from former Social Medicine

2011


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Beside the above mentioned many other members from Family Medicine and Preventive Medicine are taking part on different educational levels: Kristina Bröms, Gunilla Burell, Anders Carlberg, Anna-Sophia von Celsing, Sevek Engström, Margaretha Eriksson, Christina Halford, Johan Hallqvist, Per Kristiansson, Karin Lisspers, Mats Martinell, Magnus Peterson, Åke Schwan, Jan Stålhammar, Björn Ställberg, Kurt Svärdsudd, Thorne Wallman.

Projects

Research area I

Social Insurance Medicine

Participants: Ingrid Anderzén, Lars Englund, Johan Hallqvist, Gunilla Norrmén, Kurt Svärdsudd, Malin Swartling, Rolf Wahlström and Thorne Wallman

Regional social insurance research group in the Uppsala-Örebro region (RUFS) (I:1)

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, and one pharmacist, PhD, from Umeå University. It was established in May 2010 and has every semester at least one full-day meeting at which regional social insurance research is presented and discussed. In spring 2011 all RUFS’s projects were presented and discussed and at the fall meeting a new primary health consultant project was planned. Members are participating in one national social insurance research group, SPID, with four annual meetings. GP's sickness certification in the Nordic countries was presented in a symposium at the 17th Nordic Congress of General practice, Tromsø Norway, in June 2011 [1]. RUFS was during 2011 financed by the Uppsala-Örebro Regional Research Council.

Life and Health Sörmland (I:2)

FmG Sörmland is a local research group in the county of Sörmland, working with the regional study Liv & Hälsa (Life and Health), which contains data on 43,600 women and men 18-84 years of age. One article has been published in 2009 [2] and another has been submitted for publication [3]. During 2011 this project was presented by a poster at the 5th Nordic Social Pharmacy and Health Services Research Conference, Reykjavik, Island [4].

The natural history of disability pension – risk factors, track record and health consequences (I:3)

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. Thorne Wallman, who completed his PhD in 2008 [5], is working with the study, which is financially supported by the Swedish Social Insurance Agency, the Medical Research Council, Sörmland county council, Västra Götaland county council and Uppsala University.

The first report shows that health care utilisation continued to be 3-4 times higher among disability pensioners than among the corresponding general population even 13 years after retirement. The health care diagnoses had no relation to the retirement diagnoses [6]. Retirement thus had no obvious curative effect, as has been claimed previously.

In the second report, survival after disability retirement was presented as compared to the corresponding general population. Male pensioners had a more than threefold and female pensioners an approximately 2.5-fold increased mortality rate, even when the influences of age, education, smoking habits, family structure, reason for retirement and health care diagnoses after retirement (underlying disease) were taken into account. The increased mortality rate is thus non-specific, i.e., not related to the underlying disease and could be attributable to factors relating to the retirement process per se [7].

In a third report, the track record measured as duration of sick-listing periods before retirement was analysed and compared with that of the corresponding general population. The sick leave track record was the most important predictor of the probability of being granted a disability pension in this study, even when the influences of other variables affecting the outcome were taken into account [8].

In the fourth report, the quality of life before and after retirement was analysed. Quality of life has been measured on several occasions and in various points in time in relation to retirement. Time-dependent analysis was used in order to disclose a possible relationship to retirement [9].

To be or not to be sick-listed (I:4)

This project is based on approximately 600 appointments in Örebro primary health care, where sickness certification was a possible option. The physician and the patient each gave their view of what factors were of importance for the outcome, i.e., to be or not to be sick-listed. In the first report, physician-related factors were analysed. A long professional career, part-time work and training in social insurance medicine all increased the probability of the patient being sick-listed [10]. In the second report, patient-related medical factors and functioning were analysed [11]. The strongest predictors for sick-listing were the patient’s and GP’s assessment of the patient’s reduced work capacity, with a striking concordance between physician and patient on this assessment. Patient complaints judged by the physician to be non-somatic increased the probability of the patient being sick-listed. In the third report, the patient’s family, leisure time, and work situation were analysed [12]. Work-related factors, indicating support in work and influence over the work situation reduced the probability of sick-listing, while worrying about becoming ill or injured at work almost doubled the probability of sick-listing. Family and leisure time variables had little impact on the probability of being sick-listed. In the fourth report, attitudes towards statements concerning health and social insurance matters among physicians and patients in relation to the probability of the patient being sick-listed was analysed. GPs and their patients had fairly similar views on the statements. Attitudes expressed by the GPs seem to have a greater impact than patients’ attitudes on the GP’s decision of whether or not to sick-list a patient [13]. The project has generated one PhD thesis (Gunilla Normén 2010) [14].

Early prediction of patients at risk for long-term sickness absence (I:5)

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. A team of experienced rehabilitation professionals, one physiotherapist, one physician and one administrator from the local social insurance agency categorised all sick-listed individuals into two groups considering risk factors for long-term sickness absence. The rehabilitation team used a few variables from the sickness certificate form when categorising all sick-listed individuals into two groups, group 1 (n=447) at risk for long-term sickness absence and group 2 (n=496) without risk factors. Variables at baseline were age, sex, sick leave diagnosis, extent of sick leave percentage, employment status, and periods of sick leave one year before baseline. In this three-year prospective cohort study, data was obtained from the Swedish Social Insurance Agency on all compensated days of sick leave and disability pension from 1 January 2003 until 31 December 2007. The aim of the study is to reveal whether risk of long-term sickness absence can be predicted on the basis of just a few variables from the sickness certificate [15]. This study was presented by a poster at the 17th Nordic Congress of General practice, Tromsø Norway, in June 2011 [16].

We will also evaluate possible effects of the rehabilitation intervention in cooperation with primary health care. 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 is generating one PhD thesis (Anna-Sophia von Celsing).

Experiences of sick-listing – Nurses’ and patients’ participation in the sick-listing process (I:6)

The objective of this project is to describe experiences of sick-listing from a nurse and a patient perspective. In study I 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 in phone calls were explored. The study has resulted in a submitted article describing the nurses’ actions when managing sick-listing issues. The article also describes enabling and obstructing conditions effecting the management. This project was also presented by a poster at the 17th Nordic Congress of General practice, Tromsø Norway, in June 2011 [17].

Patients on long-time sick-leave were interviewed individually in study II. The patient interviews will result in two articles. The first will describe how the patients experiences being sick-listed. The second article will describe how they experience their participation in the sick-listing process. The project is generating one PhD thesis (Linda Lännerström).

Factors among doctors, patients and patients' families affecting the risk of long-term sick leave periods and effects of early multidisciplinary assessment in primary health care (I:7)

“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 saw 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 does 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. One article is under review. In two other projects, factors among doctors and patients’ families affecting sick leave, are studied. The project is generating one PhD thesis (Lars Carlsson).

Physicians’ views of the sick-listing commission (I:8)

This project is being carried out in collaboration between our research group, the rehabilitation section of the Department of Neuroscience, Uppsala University, and the social insurance centre at
the Department of Clinical Neuroscience, Karolinska Institute. It is focused on obtaining information concerning physicians’ views of patients’ wishes to be sick-listed and the physician’s duty to the social insurance system, as a gatekeeper in society. Deep interviews and postal questionnaires were used. Two groups of physicians, general practitioners and orthopaedic surgeons, were approached [18-21]. The project was led by Rolf Wahlström, has generated one PhD thesis (Malin Swartling 2008 [22]) and has received financial supported from the Swedish Social Insurance Agency and Uppsala University.

“NySatsa Haninge” – A project to support individual’s on long term sick leave to return to working life through individual development and guidance (I:9)

The project "NySatsa Haninge” has the overall aim to support individuals to return to working life through individual guidance. Fifty participants on long term sick leave have been given the opportunity to personal development and training through various tools for guidance. The objective has been to facilitate the return to working life, full-time or part-time, school studies, or other working life related activities based on the individual’s conditions, motivation and participation. The project started in July 2008. The follow up after one year shows that 52% of the participants have returned to working life. The study shows that’s long term sick absence due to diffuse and subjective health problems is not a permanent condition even in participants with substantial work absences periods. A cognitive approach to make individuals self participate and develop a rehabilitation plan seems to be an effective method if combined with close interaction with other rehabilitation agents. The results in this study also support the idea that return to work is an important contributor to a better self-perceived and mental health for people who have been outside the labor market for a long time. The project has been evaluated in autumn 2010 and the participants have been are Ingrid Anderzén, Ann-Sophie Hansson, Per Lytsy and Anna Liljestam Hurtigh.

“SAMKLANG”: In Cooperation – Acceptance, motivation and return to work among long-term sick listed (I:10)

The project “SAMKLANG” is founded by The European Social Fund (ESF) and the project is in cooperation with The Swedish Social Insurance Administration, The Swedish Public Employment Service and The Study Promotion Association. The aim of the project is to support individuals to return to working life. Sixty participants on long term sick leave have been treated with Acceptance and commitment therapy (ACT) by a Psychologist during three months. After one year 68% of the participants are ready to return back to work or studies. The project will go on with an interview study with those participants that had return to working life. The aim of this study is to find factors that predict return to work for those individuals that had been on a long term sick leave. Participants in the project are Ingrid Anderzén, Anna Liljestam Hurtigh, Anna Finnes, Annica Åbring and Anna Thunell.

VITALIS – An RTC study to support women on long term sick leave to return to working life through ACT or Team evaluation (I:11)

This project is in collaboration with the Swedish Social Insurance Administration, the Swedish Public Employment Service, and the Primary Health Care sector. Fifty-five percent of people presently sick listed in Uppsala County are diagnosed with psychological problems, such as depression, anxiety and stress related symptoms, and/or chronic pain. The overall aim with this project is 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 will be completed in 2011. Approximately 320 women on long term sick leave due to pain, stress, depression and/or anxiety symptoms, identified by the National Insurance Agency in Uppsala County have been randomized into one out of three conditions: a multimodal team assessment and intervention, a home based internet supported unimodal psychological intervention (Acceptance and
Commitment Therapy) and a treatment as usual (TAU) intervention. The project will evaluate the long term effects of those two different rehabilitation packages: multidisciplinary team assessment/intervention and CBT/ACT home based/internet treatment as compared to TAU, for the population of women who will lose insurance payments within 4 months. All data has been collected and analyses are to be continued. Participants in the project are Ingrid Anderzén, Per Lytsy, Annica Åbring, Anna Finnes, Jenny Thorsell, Linnea Molin, Emma Wallin, Anna Olsson, Carina Wennman and Ragnar Westerling.

Research area II

Musculo-skeletal disorders

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

The Säter and Gotland studies (II:1)

These projects are based on two randomised controlled clinical trials of manual therapy (orthopaedic medicine therapy) versus traditional treatment (traditional physiotherapy and the patient’s own physical activities) with the aim of assessing whether manual therapy affects the pain level, use of analgesic drugs and return to work more than traditional physiotherapy. The two trials had somewhat different designs. In the Säter study the manual therapy was performed by one therapist and primary health care personnel performed the control treatment. In the Gotland study general practitioners trained in manual therapy performed the manual therapy and orthopaedic surgeons the control treatment. In both studies, patients who received manual therapy had a faster return to work and less sick-listing, and used less analgesics [23, 24].

In the Gotland study pain drawings were tested for their clinical value as predictors of pain course [25], the nomenclature used by different categories of physicians for the same pain condition were described [26, 27] and the effect on health-related quality of life [28]. The project has generated three PhD theses (Stefan Blomberg 1993 [23], Johan Bogefeldt 2009 [29] and Marie Grunnesjö 2011 [30]). The projects are receiving financial support from Stockholm stay-active clinic, the province of Gotland, and Uppsala University.

Prevalence and consequences of low back pain (II:2)

This project is based on data from a large number of ongoing population studies in Gothenburg, Eskilstuna, and Uppsala with a total of 14,000 observations and an age range of 25-99 years in both sexes and data collected during the time period 1980-1993. Some of the instruments used in the population studies were identical and will be used in the project. The aims are to analyse the prevalence of low back pain by sex and age, adjusted for a large number of possible other outcome-affecting variables, to analyse possible secular trends (cohort effects) related to increasing or decreasing back pain reporting over time, and to analyse the consequences of low back pain in terms of well-being, sick leave, health care utilisation, disability pension, and survival [31, 32]. The project has generated one PhD thesis (Johan Bogefeldt 2009 [29]) and is being carried out in cooperation with the research group for cardiovascular epidemiology at the Sahlgrenska Academy, Gothenburg, the Swedish Social Insurance Agency, and the National Board of Health and Welfare.

Epicondylosis (II:3)

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 purposes to map treatment methods
currently used in primary health care, to test a new treatment method, and to shed some light on the pathophysiology of the condition.

The first purpose 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 [33]. The second purpose 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 [34]. A manuscript on eccentric versus concentric exercise is in progress [35].

The third part of the project is a study of the pathophysiology of epicondylitis by analysis of tissue biopsies from healthy and affected elbows in cooperation with Kings College, London. The pathophysiology is also being studied with positron emission tomography (PET) of the healthy and the affected elbows in cooperation with Uppsala PET-centre. The PET scan data are analysed and a manuscript has been submitted. The project has generated one PhD thesis (Magnus Peterson [36]) and has received financial support from the Medical Research Council, the Amersham Fund, the General Medicine Fund and Uppsala University.

Cognitive behavioural therapy in fibromyalgia (II:4)

This project, which is being performed in collaboration with the sections of social medicine and caring sciences at our department and the section for biological research on drug dependence at Uppsala University, is a randomised controlled trial of cognitive behavioural therapy (CBT) in fibromyalgia, the purpose of which is to assess the effects of CBT on this condition. Fifty women with a fibromyalgia diagnosis in Northern Uppland 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 data are now being analysed. The project is generating one PhD thesis (Bo Karlsson) and is receiving financial support from Uppsala University.

Pregnancy-induced low back pain (II:5)

Pregnancy-induced low back pain is a common complaint described by women all over the world. The severity of pain varies from mild discomfort to severely debilitating pain. In most women, the back pain disappears soon after delivery, although in several instances disabling back pain persists many years after delivery. Almost 1 of 10 women still experienced disabling daily back pain 2 years after childbirth with high impact on the individual, family, and society. On spite of this, the sources of pain and effective treatment are uncertain.

In a randomized double blind controlled clinical trial the purpose was to evaluate the pain relief effect of locally injected corticosteroid treatment in women with long-lasting sacral low back pain with onset during pregnancy. Thirty-six women were allocated to injection treatment, with slow-release triamcinolone and lidocaine or saline and lidocaine, given at the sacrospinous ligament insertion on the ischiadic spine bilaterally with 4 weeks follow-up time.

The corticosteroid treatment group has significantly reduced pain intensity, number of pain locations, and pain-provoking test results between baseline and follow-up as compared with the saline treatment group [37]. Beside this, the corticosteroid group has significantly improved disability rating index, gait speed and endurance and strength and endurance of trunk muscles [38]. The anatomic region around the sacrospinous ligament insertion on the ischial spine is suggested to be one source of long-lasting sacral low back pain with onset during pregnancy. A half-time review was done in 2011 [39]. The project was appointed as a key note presentation given by the project leader Per Kristiansson at the 7th Interdisciplinary World Congress on Low Back & Pelvic Pain in
Los Angeles 2010 [40], is generating one PhD thesis (Thomas Torstensson) and is receiving financial support by grants from the Västernorrland County Council and Uppsala University.

The VIP study (II:6)
VIP is the Swedish acronym for well-being in the population – a population-based study. This project is a postal questionnaire-based case referent study of 150 women in Uppsala County diagnosed with fibromyalgia (cases) and 750 matched reference individuals from the general population. The purpose of the study is to compare cases and referents regarding psycho-socio-economic status, symptom reporting, and prevalence of functional gastrointestinal problems. This is one the first controlled studies in the world of symptom reporting among fibromyalgia patients that has shown that a considerable proportion of the fibromyalgia patients report not only traditional fibromyalgia symptoms but also high frequencies of other symptoms. A first report has been published [41].

Research area III
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 (III:1)
This project is a national study of the health of preschool children regarding asthma and various allergies, and of their home and school environments. 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 for each such centre two ordinary day care centres in the vicinity were chosen as controls, giving a total of 593 day care centre sections. All these sections received a postal questionnaire regarding the physical environment of the school, cleaning routines, rules regarding personnel and parents smoking and pets at home. A first report showed considerably less allergogenic environments at the allergy avoidance centres than in the control centres [42]. Later a postal questionnaire about the children’s health situation and home environment was sent to the parents of the 8,700 children at the allergy avoidance and control centres. All children who had signs of asthma in the returned questionnaires received a symptom diary to be filled out for two weeks in order to get a better measure of asthma severity than was possible from the questionnaire. In early 2007 a follow-up questionnaire similar to the first one was sent out to the parents.

The first results from the questionnaire are focused on providing reliable age and sex-specific prevalence. There are several earlier studies but they are regional, local or small. We have computed one-year age class prevalence for boys and girls using five diagnostic criteria. Using physician-based criteria there are large regional prevalence differences, whereas physician-neutral criteria show no regional differences. Moreover, in an analysis of geographical asthma prevalence gradients, the strongest geographic/demographic variable was population density, as a proxy for degree of urbanisation [43]. In a third report the “atopic march” hypothesis was tested, i.e., that allergic children develop one atopic manifestation after another. A manuscript has been submitted [44]. A fourth publication is submitted in which the asthma incidence is estimated [45]. The project has generated one PhD thesis (Kristina Bröms 2010 [46]) and is receiving financial support from Vårdalstiftelsen, the Asthma and Allergy Patient Foundation, Uppsala University, and a number of smaller funds.
The AIM study (III:2)

AIM is the Swedish acronym for “Asthma in Mid-Sweden”. In this project asthma management and treatment in adults at primary health care centres in the Uppsala-Örebro health care region was investigated. The purpose was both to assess asthma control and quality of life in patients with asthma and to assess the proportion of centres with special asthma clinics [47].

A random sample of approximately 1,100 patients from the 42 randomly selected centres was drawn and patients were sent a questionnaire regarding their socio-economic background, asthma symptoms, treatment and quality of life. The first report from the AIM study described the organisation of asthma care in primary care [47].

Another report demonstrated that Swedish adolescents with asthma were managed and treated somewhat differently in paediatric and primary care but with equal and, for the most part, satisfactory results [48]. A third report has been published showing a strong association between perceived quality of life and the asthma disease control [49].

A fourth report demonstrated that female sex, age, pollen and pet allergy, not having the asthma prescription filled owing to cost, and daily smoking were all independently associated with asthma severity [50].

A fifth report from the AIM study has demonstrated that having an asthma clinic at a primary health care centre improves asthma patients’ knowledge of the disease, and better asthma control is achieved if the nurse is allocated more time [51].

The project was led by Gunnar Johansson, has generated three PhD theses (Mikael Hasselgren 2006 [52], Karin Lisspers and Björn Ställberg in 2008 [53, 54]) and has received financial support from the county councils of the Uppsala-Örebro Region, and Uppsala University. The study has now been concluded.

Asthma during childhood and adolescence (III:3)

This project is based on a series of measurements in 150 school children in a small municipality. The purpose was to evaluate the course of asthma with onset in childhood. The six year follow-up study demonstrated that many adolescents with current asthma do not achieve asthma control. One reason might be under-treatment with inhaled corticosteroids. This study was part of Björn Ställberg’s dissertation; he is the project leader [55]. The project was supported by Sörmland’s county council.

The Praxis-study asthma/COPD (III:4)

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. Three reports have been published, the first about asthma control, which concluded that in spite of treatment guidelines many patients in Swedish primary care still have insufficient asthma control [56]. The second evaluated how often a diagnosis of COPD was confirmed with spirometry [57]. The third report has evaluated the associations of comorbidity and body mass index with quality of life in COPD [58]. A fourth report about sex-related differences in asthma was part of Karin Lisspers’ dissertation [53]. A fifth report regarding dyspnea, obstruction, smoking and exacerbations (DOSE index) and mortality has been submitted [59]. A follow-up investigation has been started in 2011 with new longitudinal data from the cohort of asthma and COPD patients from 2005. The project is being led by Karin Lisspers, Björn Ställberg and Christer Jansson (Professor at the Department of Medical Sciences: Respiratory Medicine & Allergology, Uppsala University). The project is generating one PhD thesis (Josefin Sund, Department of Respiratory Medicine, Örebro University Hospital), and is receiving financial support from the county councils of the Uppsala-
International research collaboration in asthma and COPD in primary care (III:5)

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 published Research Needs Statement from the International Primary Care Respiratory Group (IPCRG) [60]. A publication about the needs of prioritising respiratory research in primary care has also been published [61]. They are also involved in an international research project comparing the management of COPD in primary care in different countries, the UNLOCK study [62].

The physicians’ actions in the management of COPD (III:6)

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 [63].

Validation study (III:7)

Björn Ställberg, in collaboration with researchers at the Karolinska Institute, has published a validation study of the Clinical COPD Questionnaire (CCQ) in primary care [64].

Clinical trials (III:8)

Björn Ställberg has been involved as coordinator in two clinical trials in asthma and COPD respectively [65, 66].

Björn Ställberg is a member in the steering committee for a study about treatment of rhino-sinuites, the SOSAR-study [67].

Karin Lisspers is a member of the steering committee for a study regarding screening for COPD, the DETECT-study [68].

The NO-KOL study (III:9)

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

The treatment with inhaled mometasone significantly reduced the NO as compared with placebo. The expiratory flows measured with spirometry (FEF75, FEF50 and FEF25) were significantly improved by the steroid treatment as compared with placebo. The baseline value for NO did not predict a positive response in terms of improvements in expiratory flows. Instead, the major reduction in NO after active treatment was related to significant improvements in expiratory flows. A study has been submitted for publication [69]. The project is being led by Gunnar Johansson and Kjell Alving and is receiving financial support from Schering-Plough.
Treatment of asthma in primary health care using exhaled nitric oxide analysis (III:10)

A total of 187 patients with asthma at 17 primary health care centres have been included in a study. The aim is to examine whether use of exhaled nitric oxide (NO) to guide anti-inflammatory treatment can improve asthma-related quality of life in adult patients with allergic asthma. The data have been collected and are being processed. The same study is examining whether there is an association between different circulating cytokines (systemic inflammation), exhaled NO and quality of life. The project is being led by Kjell Alving, Jörgen Syk and Gunnar Johansson and is receiving financial support from Karolinska Institutet.

A retrospective epidemiological study to map outpatients with chronic obstructive pulmonary disease (COPD) and describe COPD health care in real-life primary care during the first ten years of the 21st century – PATHOS (III:11)

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 gas been collected from the Hospital Discharge Register (Slutenvårdsregistret) and the Cause of Death Register and information on prescribed drugs was collected from the Prescription Register. Data on social-economic status has also 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 is receiving financial support from AstraZeneca. The data management will be performed by Pygargus and Uppsala Clinical Research Centre. Abstracts for congresses are in progress.

Research area IV

Utilisations of pharmaceuticals

Participants: Annika Bardel, Kurt Svärdsudd and Mari-Ann Wallander

Women’s utilisation of pharmaceuticals (IV:1)

This project is based on a postal questionnaire sent to a random sample of 4,200 women in the Uppsala-Örebro region, 35-64 years old. The purpose of the project is to study utilisation of pharmaceuticals among women. In a first report the pharmaceutical panorama and the diseases for which the drugs were prescribed was presented [70]. In a second report the use of hormone replacement therapy at menopaus and symptoms reported by users and non-users was presented [71]. In a third report adherence to the prescribed drug and its determinants were presented [72]. Adherence increased with age, if a new appointment was scheduled and if the disease was serious or the drug necessary, while adherence decreased if the respondent had negative feelings about the safety of the drug. A fourth report shows the symptom prevalence across age and use of pharmaceuticals [73]. Symptom reporting has now been tested in the consort dataset (see above under natural history of disability pension) including more than 17,000 observations in men and
women 25-99 years old. We have now examined the relationship between 30 symptoms reported by men and women and have presented this in Sörmland county R&D 2011. We intend to examine the relationship between symptom reporting among men and women and their sick-listing, disability pension, survival and use of hospital health care. The project is being led by Mari-Ann Wallander and Annika Bardel, has generated one PhD thesis (Annika Bardel 2007 [74]), and is receiving financial support by Vårdalstiftelsen, Sörmland county R&D and Uppsala University.

**Rational drug prescribing (IV:2)**

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. 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. One report has been published [75].

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 [76].

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 antibiotics 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. A third manuscript will be forthcoming. The project is generating one PhD thesis (Keld Vaegter), and is receiving financial support from Storstrøms amt, Sörmland county R&D and Uppsala University.

**Pharmacoepidemiology (IV:3)**

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 [77-79], diabetes [80], gastroesophageal reflux disease and irritable bowel disorder [81] [82], rheumatoid arthritis [83] cardiovascular diseases like atrial fibrillation [84], MI [85], chest pain [86] and also studies investigating the safety and utilization of a new statin, rosuvastatin [87, 88].

In the study of the natural history of gastroesophageal reflux disease, research has also been done in collaboration with a research group in Bologna, Italy [89] and researchers from several Chinese Universities [90-93].

In recent years, we have also had research collaboration with Professor John Dent, Adelaide [82, 93], 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.
Research area V

Cardiovascular disease and diabetes

Participants: Dan Andersson, Bengt Arnetz, Judy Arnetz, Jan Cederholm, Mats Gulliksson, Johan Hallqvist, Gunnar Johansson, Lena Kallings, Lena Olai, Jan Ståhlhammar and Kurt Svärdsudd

Determinants for the survival of diabetes patients (V:1)

This project is based on the 760 diabetes patients followed and treated at Laxå primary health care centre since 1972 and approximately 4,000 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 [94] as well as a study of mortality trends in subjects with and without diabetes during 33 years of follow up [95]. A third report will be forthcoming studying the effect of blood pressure, anti-hypertension treatment, fasting blood glucose and diabetes treatment on cardiovascular disease incidence. The project is being led by Dan Andersson and Stefan Jansson, is generating one PhD thesis (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 (V:2)

The Swedish National Diabetes Register (NDR), now including more than 70% 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. About 30 articles have been published in 2002-2011, as presented at www.ndr.nu [96-125]. A summary of the development of risk factor control in type 1 and type 2 diabetes, and in patients with previous coronary heart disease (CHD) in recent years was published in Läkartidningen 2009 [113], including a report on the importance of risk factors for risk of CHD and cardiovascular disease (CVD). In summary, almost half (40-43%) of all cases of CHD and CVD could be prevented, if HbA1c (DCCT) >7.5%, blood pressure >140/90 mmHg, obesity and smoking could all be eliminated at the same time.

It has been shown that HbA1c (DCCT) <7% strongly reduced risk of CVD, with no increased risk at low HbA1c values, even in patients with longer diabetes duration in type 1 [114] and type 2 diabetes [118], and in patients with a history of CVD in type 2 diabetes. It has also been shown that systolic blood pressure (SBP) <140 mmHg strongly reduced risk of CVD, indicating a SBP treatment target well below 140 mmHg where half of the patients in the NDR register still have a SBR >140 mmHg. However, no significant differences in CVD risk were seen between SBP 130-139 mmHg and 110-129 mmHg [116, 119-121]. Normal weight reduced risks of CHD and CVD by 15% and 22%, as compared with overweight or obesity [109], and non-smoking at middle age reduced risks of CHD and CVD by 57% and 38% [109]. A multifactorial approach to risk factor control decreased CVD risk, and combined long-term control of HbA1c <7.5% (median 6.5%) and BP <140/90 mmHg (median 130/80) was shown to reduce risks of CHD and CVD by 31% and 33%, with additive effects of HbA1c and BP on outcomes risks [111]. High pulse pressure >75 mmHg (indirect measure of increased arterial stiffness) has been shown as an independent risk factor for CHD and CVD [112].

Different blood lipids have been analysed for risk of CHD in type 2 diabetes, where the ratio non-HDL/HDL cholesterol was a stronger risk factor than LDL-cholesterol. With attained target value for this lipid ratio, more improved values were found for HDL-cholesterol and triglycerides than
with attained target for LDL-cholesterol [122]. Combined analysis of blood lipids and HbA1c showed additive effects for risk of CVD, where the ratio total-/HDL-cholesterol had a stronger effect, although HbA1c also showed a considerable effect. The combination of the highest quartiles of both these risk factors showed 150% higher CVD risk of CVD, compared to the combination of the lowest quartiles of them. No increased CVD risk (no J-shaped curve) was seen at the lowest levels of HbA1c (DCCT values 5.0-6.4%) or ratio total-/HDL-cholesterol [123].

Long-term tight control of HbA1c [106] and BP were related to low BMI, HbA1c also to non-smoking, and BP also to absence of albuminuria [102]. Long-term development of renal complications (albuminuria and renal impairment) were predicted by elevated HbA1c and systolic BP, and also by elevated BMI and triglycerides [100] [117]. Treatment in the early years of follow-up in newly diagnosed patients with type 2 diabetes has been analysed [124] and studies on the effect of pharmacological treatment on CVD risk for such patients in NDR have begun [126].

A simplified risk model for estimation of 5-year CVD risk has been introduced for clinical use [107]. More elaborated risk models for estimation of 5-year CVD risk in both type 1 and type 2 diabetes have been published and these two risk models are presented at www.ndr.nu and can be useful for diabetes care in daily clinical practice [118, 125].

All data in the NDR from a participating unit are reported back to the unit and also compared with corresponding national NDR-data in order to improve diabetes care. Patients can follow their own data together with a treating doctor or nurse at www.ndr.nu. The patient organization Swedish Diabetes Association strongly supports the NDR.

**Real-life Effectiveness and Care Patterns of Diabetes Management – Recap-DM (V:3)**

Recap-DM includes primary care data of 11,856 patients with type 2 diabetes (T2DM) residing in the county of Uppsala, Sweden, from January 1993 to October 2004. The register was created from electronic medical records by automated data-mining at 26 publically financed primary health care centres. Four additional data sources were used. The Akademiska Hospital provided data on the number of appointments study patients had at individual hospital outpatient clinics. The National Inpatient Register provided data on all hospitalisations in Sweden between 1987 and 2004, with information on diagnoses, surgical procedures and dates of admission and discharge. The Causes of Death Register provided comprehensive data on mortality and underlying cause of death until 2003. Finally, the Swedish Registry for Active Treatment of Uremia (SRAU) provided data on treatment for renal failure between 1988 and 2005, including the date of treatment start and the initial form of treatment. The aim of Recap-DM is to study fiscal cost, managemental praxis, treatment patterns, morbidity and mortality of T2DM in a real-life setting. So far, four publications have evolved from the project [127-130]. The first study described the incidence and prevalence of T2DM [127]. The second and third studies provided an in depth analysis of the resource use and costs of T2DM [128, 129]. In the fourth study the time to insulin treatment and factors associated with insulin prescription are described [130]. The project is being led by Jan Stålhammar, is generating one PhD thesis (Mats Martinell) and is being supported by primary health care in Uppsala and Uppsala University.

Recap-DM is a joint venture between us (Family Medicine and Preventive Medicine), the Karolinska Institute (A. Ringborg, PhD, MD; the project was generating her PhD thesis) and i3 Innovus Sweden (P. Lindgren, PhD, MD). The data extraction and initial data management was financed by Merck Sharpe & Dohme (MSD), Sweden AB.

**Prevalence of lipid abnormalities before and after introduction of lipid modifying therapy among Swedish patients with dyslipidemia – PRIMULA (V:4)**

The objective of this study is to estimate the prevalence of dyslipidemia and attainment of goal/normal lipid levels in patients treated with lipid modifying therapy. It is a longitudinal
A retrospective observational study which covers time periods before and after treatment. Data were collected from 1994-2007 electronic patient records in public primary health care centres in Uppsala county Sweden. Patients were included if they had been treated with lipid modifying therapy and had at least one lipid abnormality indicating dyslipidemia and if complete lipid profile data were available. Threshold levels for lipids were defined as per Swedish guidelines. 5,424 patients were included. Focusing therapy on low-density lipoprotein reduction allows 40% of patients to achieve goal levels and helps reducing triglyceride level during follow-up [131]. Almost 60% of patients experience persistent high-density lipoprotein and/or triglyceride abnormality independent of low-density lipoprotein levels. The project is generating one PhD thesis (Billie Pettersson, Linköping University).

The data extraction and initial data management was financed by Merck Sharpe & Dohme (MSD), Sweden AB. PRIMULA is a joint venture between us (Family Medicine and Preventive Medicine) and the Karolinska Institute.

A retrospective epidemiological study to investigate outcome and mortality with glucose lowering drug treatment in primary care - ROSE (V:5)

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 (Slätenvårdsregistret) 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 publications are under progress.

Cardiovascular events during primary treatment of hypertension – REAL-LIFE (V:6)

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 hypertension 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 [132] irrespective of sex, age, previous antihypertensive treatment, baseline blood pressure, and presence diabetes [133]. The project is being led by Jan Stålhammar and is receiving financial support from AstraZeneca. The data management is 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 (V:7)

The planned study will be a 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 above described in the ROSE project (V:6). The estimated number of patients is 50,000. The project is being led by Jan Stålhammar and is receiving financial support from AstraZeneca. The data management will be performed by Pygargus and the Family Medicine and Preventive Medicine section.

SUPRIM (V:8)

This project deals with secondary prevention after a coronary heart event and is a randomised controlled clinical trial of two prevention concepts: optimised risk factor control and behavioural modification. The study population consists of 362 patients discharged from Uppsala University Hospital to their general practitioners. All patients were randomised to behavioural modification or no modification.

After a baseline examination immediately after discharge, the patients were followed up with new examinations every six months for 30 months, where the risk factor levels were measured. A nutritional examination was also done twice, as has a video interview to measure the effects of the behavioural modification programme, and a large number of psycho-socio-economic variables have been measured by questionnaire. The trial has now been concluded. The first publication described the patients’ psycho-socio-economic status during the first year after a CHD event. It compared almost 1,000 matched referents, matched to cases by age, sex, and place of residence. In this first controlled study, disease and gender status both appeared to be determinants of psychological well-being, with gender status apparently the strongest [134]. In a second report the main results of the randomised trial were presented. During a mean 94 months of follow up, the intervention group had 41% fewer fatal and non-fatal first recurrent CVD (HR 0.59, 95%CI 0.42-0.83, p=0.003), 45% fewer recurrent AMI (HR 0.55, 95%CI 0.36-0.85, p=0.007), and a non-significant 28% lower all cause mortality (HR 0.72, 95%CI 0.40-1.30, p=0.28) than the reference group after adjustment for other outcome affecting variables. In the cognitive behavioural therapy (CBT) group there was a strong dose-response relationship between intervention group attendance and outcome. During the first 2 years of follow up there were no significant group differences in traditional risk factors [135]. The project has generated one PhD thesis (Mats Gulliksson 2009 [136]). This study has received financial support from Swedish Medical Research Council, Vårdal Foundation, the Swedish Council for Working Life and Social Research, the National Board of Health and Welfare, the National Heart and Lung Patient Association, Uppsala county council, Uppsala branch office of the Swedish Social Insurance Agency, and Uppsala University.

Secular trends in recurrent myocardial infarction (V:9)

This project is being performed in collaboration with Centre for Epidemiology (EpC) at the National Board of Health and Welfare and the Cardiovascular Epidemiology Group at Sahlgrenska Academy, Gothenburg. It is based on the National Swedish Myocardial Infarction Register at EpC, which contains all incidents of myocardial infarction (AMI) since the early 1970s, in total 1.2 million incidents. The purpose is to study the risk of recurrent AMI during the years following a first AMI, and how this risk has changed over the years. During the study period, the risk of a new event among survivors of a previous AMI decreased sharply during the first 2 years after the previous event, reached its lowest point after 5 years, and then increased slowly again. The risk of a recurrent AMI during the first year after a previous event was fairly stable over time until the late 1970s and then decreased by 36% in women and 40% in men until the late 1990s, irrespective of age and AMI number, mirroring the incidence decrease over the years for primary events [137]. In a second report the effects of degree of urbanisation on the risk of recurrent acute myocardial infarction were
described. There was considerable geographical variation in recurrent AMI risk, the same for men and women, best explained by residential area population density [138]. The project has generated one PhD thesis (Mats Gulliksson 2009 [136]), and has received financial support from the Swedish Medical Research Council, the Vårdal foundation, the Swedish Council for Working Life and Social Research, the Swedish National Board of Health and Welfare, the Swedish Heart and Lung Association, Uppsala primary health care administration, and Uppsala University.

**Damaged brain and susceptible life (V:10)**

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.

In the first publication the prognostic ability of the staff was analysed. Prognoses were given regarding health development, need of help and living condition. The prognoses were correct (67%) or much better than chance (33%), and were mainly influenced by the patient’s pre- and post-morbid state [139]. The risk of dying or having a new stroke decreased rapidly during the early post-stroke phase. Health care utilization, in hospitals as well as in primary health care, and municipal social service support were all considerably higher after the stroke than before, but the utilization of these services was lower than previously reported [140]. Health problem prevalence according to interview and record scrutiny was modest, peaked early after discharge and then declined [141]. Support from informal caregivers increased significantly after discharge and remained high during the first post-stroke year. The informal caregivers reported considerable strain and burden, with significantly higher levels of anxiety and depression than the stroke patients [142]. The project has generated one PhD thesis (Lena Olai 2010 [143]), and has received financial support from Vårdal foundation, Dalarna county council and Uppsala University.

**Screening for diabetes and hypertension in the Dental Care Service (V:11)**

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 first publication based on a pilot study showed a strong relationship between high blood pressure and the prevalence of deep gingival pockets [144]. 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 [145]. In the third report the diabetes screening showed the need for inclusions criteria, as age and BMI, for efficient finding those at risk [146]. The forth project is calculating the direct cost for this type of screening organisation. The project is generating one PhD thesis (Sevek Engström), and is receiving financial support from Gävleborg county council, Public Dental Service Gävleborg and Uppsala University.
Physical activity in prevention and treatment of disease (V:12)

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 with cardiometabolic risk factors. 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, and has good adherence [147-149]. Data collection from long-term follow ups of an RCT have been collected and will be analyzed, several papers are planned. One paper has been published from the 6-month follow up and, shows that PAP increases physical activity level at moderate intensity, and reduces sedentary time as well as reducing several cardiometabolic risk factors in elderly women and men with low physical activity level, overweight and abdominal obesity [150]. This study is being conducted in collaboration with several researchers at the Karolinska Institute, Uppsala University and Umeå University. The project leader is Lena Kallings. One RCT with patients with osteoarthritis in primary health care started spring 2010 and one PhD student is involved in the project which is financially supported by Gävleborg county council and Uppsala-Örebro regional research council. One clinical study with physical activity in treatment of depression will start in 2011 and one RCT with PAP to patient with depression is planned for 2012. One PhD student is involved in the studies with depression which is financially supported by Uppsala county council and Uppsala-Örebro regional research council. Adaption and testing PAP as a method to promote physical activity in children and adolescents is conducted as a method development, financially supported by Uppsala county council. Lena Kallings is responsible and a RCT is planned to start in 2012. On behalf of a “The Nordic network for physical activity, nutrition and health” an overview of existing approaches in physical activity prescriptions in the Nordic countries has been carried out during 2010 [151], financially supported by the Nordic Council of Ministers. This work has been reported on both Nordic level and international level (HEPA meeting in Czech Republic). As a result a similar work for the whole Europe will be planned in Slovakia Mars 2011.

Pregnancy and physical activity (V:13)

Physical fitness and physical activity before and during pregnancy positively influences the course and outcome of pregnancy with reduced risk of prenatal complications such as excessive weight gain, abnormal glucose tolerance, gestational diabetes and musculoskeletal problems. Moderate prenatal exercise is useful in improving physiological reserves and aerobic fitness without affecting fetal growth. Thus, maintaining light to moderate physical activity is recommended during an uncomplicated pregnancy, whereas higher levels of physical activity may be questioned. Women in general are at increased risk of sedentary and low physical activity lifestyles compared with men. During pregnancy a further decline in women’s physical activity across the trimesters has been documented. Thus, it is important to know whether reductions in physical activity during pregnancy lead to reduced fitness. If so, this could affect pregnancy outcome as well as other chronic health conditions for which lower oxygen uptake or inactivity increases the risk (such as metabolic syndrome, diabetes type II). The influence of full-term pregnancy on maternal health, physical fitness and activity has not been very much studied. Population-based studies have relied on self-reported questionnaires and data from prospective studies of physical measurements are thoroughly performed but from small numbers of selected pregnant women. Data from the general population are scarce. In Sweden, the County Health Care Board offers all pregnant women free maternity health care during the pregnancy at local antenatal clinics. More than 95 % of women make use of this offer, which makes this organization suitable for clinical epidemiological studies. In a prospective study from maternal health care centers, information in early pregnancy and postpartum on oxygen uptake, physical activity and perceived health was retrieved allowing for the study of pregnancy-related changes. In the first study there was shown that pregnancy had a moderate influence on physical fitness and perceived health half a year postpartum despite less regular physical activity during pregnancy. In addition, estimated peak oxygen uptake in early
pregnancy was positively correlated to perceived physical health [152]. In further analyses, relation between physical fitness to pregnancy-related back pain, blood pressure during pregnancy and gestational length will be elucidated [153].

The involved patient: implications for treatment outcome and secondary prevention of myocardial infarction (V:14)

This project studied the implications of patient involvement for length of stay, compliance, treatment outcomes, and the work of physicians and nurses caring for heart attack patients. Initiated in 2004, this project was a multidisciplinary collaborative effort with Uppsala Clinical Research Centre which administers the Swedish national quality registry for cardiovascular disease, RIKS-HIA. Group participants are Judy Arnetz, Anna Höglund, Ulrika Winblad, Bengt Arnetz.

Etiologic and prognostic risk factors in myocardial infarction (V:15)

Based on SHEEP, which is a very large case-control study of myocardial infarction (2246 cases) that also has follow-up data for approx 8 years. The extensive exposure information makes it possible to study a range of new questions.

Research area VI

Stress

Participants: Ingrid Anderzén and Bengt Arnetz

Management control systems and stress: interdisciplinary field experiments (VI:1)

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 is finished during year 2011 and will be analysed during year 2012. Participants in the project are Ingrid Anderzén, Lars Frimanson.

Spiritual and existential moderators of the stress – health relationship (VI:2)

This project concerns the adaptation and development of scales to assess to whether and to what extent existential and spiritual factors modify individuals and organizations response to stress. Furthermore, we will explore whether health care staff utilize patients’s existential and spiritual belief in the diagnostic and treatment processes. This project entails collaboration with Swedish and American researchers and study participants represent both countries as well. This project is part of a large, multi-year Linne’ research grant awarded to Uppsala University under the leadership of Professor Anders Bäckström. Participant from IFV is Bengt Arnetz.
The importance of post-displacement institutional and stressors and resiliency factors and its implications for refugee post-displacement mental health (VI:3)

This is a comparative study of the importance of post-displacement stressors and resiliency factors in Iraqi refugees in the United States versus Sweden. In addition, there are plans to carry out policy and cost-benefit analysis of the two countries refugee integration program. Participant is Bengt Arnetz.

Low impact stress among first responders: implications for Health and Performance (VI:4)

This three-phase collaborative research project focuses on better defining, measuring and managing low-impact, job-derived stressors among first responders (first line employees within the military, coast guard, customs control, and the police). During phase 1, we carried focus groups interviews to define low-impact stressors and its perceived effects on health and performance. In phase 2, we used this knowledge in designing a national survey that was distributed to a large random sample of Swedish first responders. In phase 3, we will make use of results based on advanced modelling from this survey to design a state-of-the-art web-based self-assessment and intervention program. The research is done in close collaboration with Kungafonden (“The Swedish Royal Foundation”), and senior management and unions representing all of Sweden’s major First Responders professions, including the police, defence, coast guard, and customs. Participants are Bengt Arnetz, Sarah Thomsen, Dana Nevedal, Matt Ventimiglia.

Real-time assess of psycho-physiological stress responses (VI:5)

Despite epidemiological research linking psychosocial stress to cardiovascular disease and other stress-related disorders, we still lack convincing evidence about the biological mechanisms linking stress to cardiovascular disease. In a collaborative study between researchers at Uppsala University and Wayne State University, we have developed a prototype of a wireless heart rate sensor and Smartphone system that allows for the immediate transmission of heart rate data to a central server. The central server is programmed to send text messages to the phone when the heart rate deviates from a normal average. Text messages concerns stress and related questions of interest to identify possible reasons for the heart rate response. The pilot study will be critical for the design of a system at will subsequently be used to trace cardiovascular and emotional responses in inner-city inhabitants as well as female managers: a high-risk group for stress-related disorders. Participants are Bengt Arnetz, Clairy Wiholm, Mark Lumley, Weisong Shi.

Research area VII

Triggers of the onset of disease and other health problems

Participant: 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 Insitutet 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
consultations. The study is based on record linkage between inpatient, outpatient and cause-of-death registers. In a third study we examine Surgical procedures as triggers 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 based on data collection from individuals in custody in Stockholm because of criminal activities including violence (The Stockholm Social Medicine Custody Project).

Research area VIII

Social epidemiology: the role of life course and social context

Participant: Johan Hallqvist

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

Feasibility and efficiency of interventions
Participants: Johan Hallqvist, Lennart Fredriksson

As a part of Elisabet Sundgren’s thesis work we are studying to what extent it is possible to help people diagnosed with psychosis to stop smoking through an organized effort including health screening and follow-up procedures with motivational support and advice. The study employs both qualitative and quantitative methodology. We are also involved in studies evaluating the efficiency of repeated brief moments of advice in dental care as a method for helping people to quit smoking.

Research area X

Varia
Participants: Lars Englund, Christina Halford, Gunnar Johansson, Nils Rodhe and Kurt Svärdsudd

Infections in the elderly (X:1)
The purpose of the project is to determine whether or not asymptomatic bacteriuria in elderly should be treated. The project is based on all individuals 80 years old or older in a health care district of Falun. The study population was followed for a few years with repeated assessments, bacterial cultivations and other lab tests. Four reports have been published, showing the prevalence of asymptomatic bacteriuria as measured by means of urine cultures, determinants of asymptomatic bacteriuria, change of bacterial strains indicating that the infections come and go, and the possibility of differ between simple lab tests innocent asymptomatic bacteriurias and those in need of treatment with [154-157]. The project was led by Lars Englund, has generated one PhD thesis (Nils Rodhe 2008 [158]), and the project has received financial support from Dalarna county.

Self-rated health (X:2)
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. Two articles have been published [159, 160], one manuscript has been submitted [161] and one manuscript is forthcoming [162]. The project has generated one PhD thesis (Halford 2010, [163]). The project is being financially supported by the Uppsala University.
Vitamin D status among immigrated women from countries in the Middle East as compared with Swedish women (X:3)

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 will be investigated by a physician and a dietician in terms of different aspects of their vitamin D status and possible associated diseases. They will be 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 calcium is ongoing. The principal investigators are Anne Björk, Åsa Andersson and Gunnar Johansson. The project is receiving financial support by the Uppsala primary health care.

Vitamin D status and the correlation to muscle function in patients with chronic obstructive pulmonary disease (COPD) (X:4)

Many patients with advanced COPD are affected by their decreased lung function and often have reduced muscular function as well. They consequents 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 principal investigators are Anne Björk, Åsa Andersson and Gunnar Johansson. The project is receiving financial support from the Uppsala primary care.

Domestic Violence among Iraqi Immigrant and Refugee Women in Detroit (X:5)

In a joint project between Uppsala University and Wayne State University in Detroit, Michigan, researchers examined the prevalence and health-related outcomes of intimate partner violence among Iraqi immigrant women. Intimate partner violence is difficult to study in any population, due to the sensitive nature of the subject. This two-year project employed novel investigative techniques that enabled women to respond to an anonymous questionnaire in a safe environment. This pilot work, funded by the Skandia ACOW grant to Uppsala University, will serve as the foundation for additional grant applications to conduct similar research among larger samples of immigrant women.

References to the ten research areas:


40. Kristiansson P: Corticosteroid injection treatment to the ischiadic spine reduced pain in women with long-lastig sacral low back pain with onset during pregnancy: a randomized double blind controlled trial. In 7th Interdisciplinary World Congress on Low Back & Pelvic Pain. Los Angeles November 9-12; 2010.


52. Hasselgren M: Epidemiological aspects of asthma in primary care: special references to prevalence, clinical detection and validation. Medical Sciences. Uppsala University; 2005.


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 2011

Professors – Lars Lannfelt (chair), Hans Basun (adjunct)

University lecturer – Lena Kilander

Researchers – Martin Ingelsson, Xiao Zhang, Vilmantas Giedraitis, Frida Ekholm-Pettersson, Joakim Bergström Johan Årnlöf, Björn Zethelius, Anna Cristina Åberg

Postdocs and research assistants – Hedvig Welandar, Veronica Lindström, Dag Sehlin, Thomas Näström, Bernice Wiberg, Hans-Erik Johansson

PhD students – Astrid Gumucio, Sofia Söllvander, Therese Fagerqvist, Malin Degerman-Gunnarsson, Ylva Cedervall, Kristin Franzon

Other personnel – AnneMarie Ljungberg (BMA), RoseMarie Brundin, Gunilla Gertz (research nurses).


Publications 2009-2011


Levels of TCF7L2 and MYC of the Wnt Pathway in Tg-ArcSwe Mice and Alzheimer's Disease Brain. *Int J Alzheimers Dis* 2010; 2011: 936580.


2009


**Books**


**Dissertations 2011**

Johan Sundelöf, Amyloid Beta-Protein, Cystatin C and Cathepsin B as Biomarkers of Alzheimer’s Disease.

Thomas Nässström, Characterization of alpha-synuclein oligomers.

Paul O’Callaghan, Heparan Sulfate in the Amyloidosis and Inflammation of Alzheimer’s Disease.

**Agencies that support the work/Funding**

Vetenskapsrådet (2011-4519; 2010-6745; 2009-4567; 2009-4389; 2006-3464) 3 725 000 SEK/year

Hjärnfonden, project grants + donators 1 500 000 SEK/year

Berzelii Center for Neurodiagnostics, Uppsala 2 500 000 SEK/year

Vinnova – SAMBIO 2 500 000 SEK/year

ALF-medel, Uppsala läns landsting 4 000 000 SEK/year

Fakultetsmedel, Uppsala universitet 2 500 000 SEK/year

Polysaccharide research in Alzheimer’s disease 500 000 SEK/year

Parkinsonfonden 500 000 SEK/year

PET-forskning 1 000 000 SEK/year

Diverse fonder 1 800 000 SEK/year

Hjärt-kärlfonden 400 000 SEK/year

Center for Clinical Research / Falun 500 000 SEK/year

**International collaborations**

**Guest visits in foreign laboratories**

Thomas Nässström (with Dr. Tiago Outiero, Lisbon, Portugal; Febr-May 2010)

**Foreign collaborative partners**

Harvard Medical School, NIH, University of Goettingen, University of Kuopio, University of Ulm, INSERM, Max Planck/Berlin- 7 publications, Swedish National Diabetes Register- 11 publications, DECODE, A European diabetes research collaboration– 9 publications, Århus University, Denmark, professor A Flyvbjerg– 4 publications, Odense University, Denmark, professor J Juul Holst – 2 publications, 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 – manuscripts in progress

**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 and the the Swedish Brain Power network.
Engagement in the external society

Recruitments
Stina Syvänen, PhD, Hedvig Welander, PhD (Karolinska Institutet), Marie Svedberg (Karolinska Institutet), Kristina Magnusson PhD, Veronica Lindström PhD

Projects

**Aβ protofibrils in Alzheimer’s disease**  
(Assoc. Prof. Frida Ekholm Pettersson)

We are testing our hypothesis that large soluble Aβ oligomers, i.e. protofibrils, are neurotoxic to the brain in Alzheimer’s disease (AD). We have developed mAb158 and other Aβ protofibril selective monoclonal antibodies (mAbs). With ELISA based on these mAbs, we have found that increased Aβ protofibril levels correlate with impaired spatial learning in a transgenic mouse model for the disease. At present, we assess brain, CSF, plasma and fibroblasts from AD patients for Aβ protofibril 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.

Moreover, we aim to establish novel immunotherapies for dementia. Immunotherapy is at present a promising strategy for treating AD and has received great attention worldwide. As a direct result of our research, a humanized version of mAb158, BAN2401, has now been brought to clinical trial. A clinical phase I study, launched in the US in August 2010, is carried out by Eisai Pharmaceuticals of Japan after licensing the rights from BioArctic Neuroscience, founded by Prof. Lannfelt. At present all patients have been recruited and no serious side effects have been reported. Apart from having brought BAN2401 to clinical trial, BioArctic Neuroscience is seeking to commercialize other therapeutic and diagnostic tools generated by the academic group at Uppsala University.

We have also started up a new study where we compare the systemic immune cells and mediators of AD patients to age-matched healthy individuals. We aim to investigate if patients with Alzheimer’s disease have a different immune profile, i.e if they respond differently to the Alzheimer related peptide, Aβ. This could help to understand the etiology of Alzheimer’s disease and could thus give ideas on new therapeutic strategies for the disease. Moreover, we plan to study the impact of immune cells on the most promising strategy for treating AD, i.e. immunotherapy. This will hopefully answer if there are certain immune profiles to consider as more favorable to passive immunization. Perhaps we need to consider giving the patients immunosuppressive treatment in combination with the therapeutic antibodies in the future?

**Pathology and amyloid imaging in transgenic Alzheimer’s disease mice**  
(Stina Syvänen, PhD)

For pre-clinical evaluation, we are treating transgenic Alzheimer mice with mAb158 and other Aβ protofibril selective mAbs. For development of novel biomarkers, we have developed a new 125I-labelled antibody-based ligand that detects soluble Aβ protofibrils. The transgenic mice are now examined with micro-PET using this ligand and the general amyloid-ligand 11C-PIB. The ultimate aim of this project is to bring our new biological ligand to the clinic, as a novel PET marker for early diagnosis and for monitoring functional decline in Alzheimer patients.
Parkinson’s disease

(Assoc. Prof. Martin Ingelsson)

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 Aβ 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 α-synuclein oligomers / protofibrils, we are analyzing the formation and effects of such intermediated sized species of α-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 these are currently being evaluated for immunotherapy on both cell and animal models for the actual diseases. Moreover, we seek to adopt the antibodies in assays, such as ELISA; to be able to measure the presence of toxic oligomers / protofibrils as a novel disease biomarker for PD and Lewy body dementia.

Genetics

(Dr. Vilmantas Giedraitis)

We are screening for mutations and copy number changes of established dementia-causing genes and searching for new disease genes with genetic mapping. We have access to a large and well characterised collection of familial dementia patients, diagnosed with various dementia disorders. Association studies searching for susceptibility factors are carried out, mainly in collaboration with other research groups.

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 dementia patients clinically and neuropathologically. This research is based on our own tissue bank with DNA, CSF, plasma, serum, fibroblasts 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, manuscript in preparation). 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 respective predictive values for development of AD. Further, the role of cerebrovascular risk factors and dietary intake of fat as predictors of AD are examined. Impaired insulin secretion at age 50 has been shown to predict the development of AD at high age. In one substudy, we are assessing the correlation between cognitive, radiological, biochemical and neuropathological features of healthy aging, by performing cognitive testing, 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, different pathways that may explain the interplay between kidney damage and the development of cardiovascular disease are explored. Dr Johan Ärnlöv is involved in international collaborations such as the CKD-prognosis Consortium and CKDgen. The project has received funding from Vetenskapsrådet and the Swedish Heart-Lung Foundation and has so far led to several publications in leading journals.

One line of research aims to investigate motor function and physical activity in relation to health among elderly people. Dr 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 on exploring possibilities for novel future therapeutics against PD and Lewy body dementia. We are one of several groups focusing on protein aggregation and age-related amyloid diseases in Uppsala. The local scientific environment thus provides a unique opportunity for collaborative efforts to increase the knowledge on mechanisms underlying amyloid disorders, especially within the Berzelii Centre for Neurodiagnostics and in SciLifeLab. Compared to other dementia research teams in Sweden our focus on molecular mechanisms in the pathogenesis of AD has been very successful. We have a clear scientific strategy and a good research structure. The preclinical and clinical activities have been successfully integrated in Uppsala, which enables a more efficient translational research process.

The most promising research lines in a 5-10 year perspective

In 2009, we started to collaborate with GE Healthcare and Imanet on the development of imaging, targeting soluble Aβ with engineered antibody-fragments. Antibody-based ligands are new in PET imaging. The project was funded by a three-year grant from VINNOVA and two postdoctoral fellows were hired. Within only two years, we have rapidly generated promising in vitro and ex vivo data with a 125I-labelled antibody.
Health Services Research

Research Group Leaders Inger Knutsson Holmström, RN, PhD, Associate Professor and Ulrika Winblad, PhD, Associate Professor

Health Service Research (HSR) adopts three contrasting but interconnected perspectives; at care provision - organisational - and system level. The Uppsala group is engaged in research at all three levels with focus on governance and implementation, intra-organisational control, inter-organisational relations and patient relations. More specifically, current study objectives include development of exploratory models for differences in public and private care, identification of barriers for implementation of 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 2011

Inger Knutsson Holmström, RN, PhD, associate professor, research group leader
Ulrika Winblad, PhD, associate professor, vice group leader
Caroline Andersson, MSc, research assistant
Pia Bastholm Rahmner, PhD
Cecilia Bernsten, Registered pharmacist, PhD, associate professor
Ingeborg Björkman, Registered pharmacist, PhD
Madeleine Boll, Physiotherapist, Licentiate, PhD student
Eva Boström, RN, PhD
Gunilla Brattberg, MD, PhD, associate professor
Helène Eriksson, Administrator
Annica Ernesäter, RN, MSc, PhD student
Mio Fredriksson, MSc, PhD student
Roya Hakimnia, MSc (Medicine), PhD student
Finn Hjelmblink, MD, PhD
Johan Hopfgarten, Medical student, research assistant
David Isaksson, BSc, research assistant
Elenor Kaminsky, RN, BSc, PhD student
Dorte Kjeldmand, MD, PhD
Jan Larsson, MD, PhD
Linda Lännerström, PhD
Linda Moberg, PhD
Åsa Muntlin Athlin, RN, PhD
Martin Rejler, MD, PhD student
Urban Rosenqvist, MD, Professor emeritus
Marta Röing, DDS, PhD
Margareta Sanner, Registered psychologist, PhD, associate professor
Ragnar Stolt, Licentiate, PhD student
Anikó Vég, PhD

Publications 2009-2011

1. Larsson J, Holmström IK. How excellent anaesthetists perform in the operating room – a qualitative study on non-technical skills. Submitted.


5. Röing M, Holmström IK. Involving patients in treatment decisions – a delicate balancing act for Swedish dentists. Submitted


7. Björkman I, Sanner MA. The Swedish swine flu vaccination campaign - why did not all Swedes take the vaccination? Submitted.

8. von Thiele Schwarz U, Hasson H, Muntlin Athlin Å. (2011) Perceived efficiency in the Emergency Department – low throughput rates or having a lot to do? Accepted for Publication in Arbete och Hälsa [Work and Health]


**Reviews 2009-2011**


**Ulrika Winblad**: External reviewer of research applications for the Research Program for Health Services 2011, Research Council of Norway.

**Ulrika Winblad**: External reviewer of research applications, Vårdalstiftelsen, Stockholm, 2011.


**Inger K Holmström**: Expert reviewer in Health Services Research for the Research council of Norway, 2010

**Inger K Holmström**: External reviewer in gender studies for the Swedish research council. 2011

**Agencies that support the work/Funding**

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**National and international commitments**

**Ulrika Winblad**: First opponent (*Föredragande i betygdsnämnd*). Disputation of Camilla Palmhøj Nielsen, 9 Dec 2010, Samfundsvidenskablige Fakultet, Copenhagen’s University.

**Ulrika Winblad**: First opponent (*Første opponent*). Disputation of Trond Tjerbo, 25 May 2009. Medical Faculty, University of Oslo.

**Jan Larsson**: Basel 2011: invited lecturer at a block course for staff and residents based on, New Tools in Anesthesia” at the Department of Anesthesia, University Hospital Basel, Switzerland.
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.

Projects

Privatization of elderly care and its consequences on care quality
Participants: Ragnar Stolt, Ulrika Winblad.

One of the major policy trends in recent decades has been the privatization of social services. Particularly in the elderly care sector with an increase of private providers from 1% in 1990 to 16% in 2010. The on-going privatization of elderly care in Sweden and many other countries has raised important questions regarding the consequences of this policy transformation.

The focus of this national research project is to explain the mechanisms behind privatization as well as the resulting effects on care quality. Almost all nursing homes in Sweden are included in the study. Preliminary results imply that privately managed elderly care has established itself mainly in metropolitan areas dominated by right-wing regimes. Furthermore, our findings indicate that privatization has indeed resulted in substantial quality differences. The number of employees per resident is significantly smaller (-10%) among private regimes. On the other hand the participation (+7%), the proportion of elderly with a reasonable length of nightly fast (+15%), and the number of food alternatives (+26%) are significantly in favour of private contractors. The overall aim with this research project is not only to assess the effects of privatization but also to use these findings to build exploratory models that explain these quality differences and can be used as tools to improve care quality.

Between equity and local autonomy – a governance dilemma in Swedish healthcare
Participants: Mio Fredriksson, Ulrika Winblad

Both national equity in healthcare and the county councils’ local autonomy are important values supported by Swedish law. Politically it is a balancing act; how much freedom should the county councils have and to what extent should healthcare be equal throughout the country? This tension – more specifically the manifestations of the tension in political governance – is the main focus of a dissertation defended in January 2012. Mainly, the results show that the Swedish state is becoming more active in governing and regulating healthcare, and that national equity – or rather national equivalence – is increasingly emphasized, which is interpreted in terms of Swedish healthcare being recentralized. Delivery and financing of healthcare are still the responsibilities of the county councils. Planning and arranging – the setting of the regulatory framework – is however increasingly taken over by the central state. When local autonomy looses ground, it becomes more difficult to tailor healthcare according to local needs and conditions in the county councils, and decisions are taken at greater distance from the citizens. Thus, a future challenge is to maintain or strengthen the procedures for democratic legitimacy through citizen participation at the local level.

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, Uppsala University.

Incorporation of user empowerment in the sector of social care

Participants: Linda Moberg, Ulrika Winblad

The project focuses on how demands for increased user empowerment are incorporated within the sector of social care in the Swedish welfare system. The Swedish welfare model has been characterized by public provision of social services and is based on the concept of universalism, implying that priorities and allocation of public services shall be made on the logic of need. However, it has been argued that the public dominance prohibit recipients to influence how these services are carried out. Reforms to create provider pluralism and to enhance user empowerment have therefore been carried out. However, it can be claimed to be a tension between the objectives for increased user empowerment and the principle of universalism. The project therefore aims to study in what ways political attempts to enhance user empowerment have been expressed within the sector of social care, and in what way the tension between user empowerment and universalism have been managed. The project is run in collaboration with the Department of Government, 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.
Developing gender competence in Swedish telenursing  
Participants: Roya Hakimnia, Inger Knutsson Holmström

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.

Elderly care on contract-basis: How can quality be ensured?  
Participants: Ulrika Winblad, Ragnar Stolt, David Isaksson

This project examines how Swedish municipalities supervise the quality of care services contracted out to private firms. The practice of contracting is fairly new in Swedish elderly care, but currently about 16% of all publicly financed care services for the elderly are carried out by private providers, mostly large, for-profit firms. Even if care services are contracted out, local authorities (municipalities) are still legally obliged to ensure that the services are of high quality. The main question in the project is how they perform this function and what sanctions they use against the private providers if they find the care quality to be low?

The methods used in the project includes analysis of juridical and political documents (contracts, policy statements), interviews with politicians, civil servants and private providers in four selected Swedish municipalities, as well as a web-survey to all municipalities. The project brings knowledge about privatization which is a new mode of governance in Swedish health and social care. The project is run in collaboration with the Department of Government, Uppsala University.

What information do patients and citizens need to make informed choices of health care providers?  
Participants: Ulrika Winblad, Caroline Andersson

In 2008, the Swedish parliament passed a law that made it mandatory for all county councils to introduce choice models in the primary care model. The main purpose of the law was to give patients' and citizens’ greater choice and control over care and treatment within the publicly financed health care system, by allowing them to choose between a number of both public and private health care givers on an open market. A difficulty with choice models is the lack of transparency on the health care market. How can patients value the quality of different care providers on a health care market which is most often characterized by high complexity and product differentiation? What kind of information do patients and citizens need to be able to choose a health care provider within the setting of health care choice models. Also, we investigate what type of information patients might need to be able to choose between different medical treatments. Parts of the assignment is to describe what kind of information patients and citizens have access to at present, to investigate how other countries comparable to Sweden have managed the matter of patient information, and finally to give recommendations on how the information should be developed further in order to support informed choices among citizens and patients.
Teamwork in an emergency department

Participant: Åsa Muntlin Athlin

Increasing waiting times and long lead-times in emergency departments are well-known problems, which could influence efficiency, patient safety and patient satisfaction in a negative way. The healthcare needs to use the limited resources in a more effective way. Working in multidisciplinary teams could improve care processes in the healthcare. The overall aim was to investigate how implementation of team work in an emergency department can effect efficiency, quality of care, patient safety and patient satisfaction and work environment. In addition, the implementation process will be further studied. A longitudinal non-randomized intervention study design with three follow ups was used. The intervention was teamwork in the specialty of medicine in an emergency department. Patient questionnaires, staff questionnaires (diaries), patient health records and observations have been used for data collection.

PUP – Pressure Ulser 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.

The Swedish A(H1N1) vaccination campaign – Why did not all Swedes take the vaccination?

Participants: Margareta Sanner, Ingeborg Björkman

The aim of the study is to explore patterns of motives of people in Sweden that did not take the vaccine against the swine flu A(H1N1), their decision process and their risk analyses. In complex behaviour even the motives are complex; therefore the study uses a qualitative method. The sampling strategy was to maximize variation; 28 individuals with various socio-demographic background has been interviewed. Specific questions asked were: Did the way the campaign was organized influence the decision? Were there practical problems getting access to the vaccination? How was the risk of getting the vaccine compared with the risk of having the influenza perceived? Was the campaign experienced as caring for the people or as groundless alarm? Was the decision not taking the vaccination influenced by distrust of authorities, pharmaceutical manufacturers, and the vaccine quality? What were the attitudes towards other kinds of vaccination?

Drugs and patient behavior – the influence of organizational and professional actors

Participant: Cecilia Bernsten

Drugs do not work if people do not take them has been a mantra of those researchers investigating how patients comply with directions given by a prescriber. Throughout the years compliance has been replaced by notions such as adherence and coherence, moving the act of compliance from blind obedience to a state of agreement between the professional health care worker and the patient.

The aim of this research was to investigate, describe and analyze patients’ and pharmacy customers’ drug use behavior and the factors influencing this behavior.
Randomized clinical trials with interventions as well as mapping of behavior have been used to study the different phenomena in question. Quantitative as well as qualitative data collection and analyze methods have been used.

**Competence as ways of restructuring**

**Participants:** Madeleine Boll, Urban Rosenqvist, Cecilia Bernsten

The overall aim of my doctorial 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 being in career options at the system level. The thesis offers possibilities of challenging traditional use of physiotherapy as just treating individuals.

**Deceased organ donors**

**Participant:** Margareta Sanner

Member of an European project group administered and financed by ELPAT (Ethical, Legal, and Psychological Aspect of Transplantation). In this group of European researchers problems concerning deceased organ donors are being identified. Actual issues are legal boundaries and applications of rules concerning definitions of death and criteria of death which are examined through a questionnaire to intensivists all over Europe.

**GPs and emergency care physicians’ views on their role in drug prescribing**

**Participants:** Inger Knutsson Holmström, Urban Rosenqvist

Using qualitative methods, we have investigated emergency physicians’ expectations of a computerized drug prescribing support system before it was implemented. The expectations were high and the physicians were eager to use it.

However, in a further study we found that the physicians did not use it in practice due to practical problems and lack of integration of systems. In addition, they did not find it as their task to adjust the patients’ drug list. Their focus was on the “here and now” and they only dealt with obvious side effects or well known interactions. In their view, other aspects of drug use should be handled by the patients GPs. When we studied the GP’s view on drug prescribing, they had five different views of it. Only a few had the patients’ entire life situation in focus, and a particular difficulty was the use of drugs to prevent future diseases. Aspects of environmental effects of drugs and economy were also mentioned. Drugs should be prescribed in a safe and effective manner. Decision support systems were not an integrated part of their drug prescribing work. Instead, they leaned on personal experiences and discussion with colleagues. This project was run in collaboration with the Karolinska Institutet.

**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 projects 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 nursing clinical handovers with special attention to fundamental aspects of care.

Non-prescription drugs and self-medication among adolescents in Sweden
Participants: Ingeborg Björkman, Marta Röing, Pia Bastholm-Rahmner, Inger Knutsson Holmström

In July, 2009, the state-owned monopoly on the pharmacy market in Sweden was reregulated, allowing the establishment of private pharmacies, and the sale of specific over-the-counter medicinal products outside pharmacies, for example in grocery stores or in gas stations. In order to evaluate the consequences of the reregulation, a large project was initiated by the Medical Products Agency of Sweden. As part of the project, the overall aim of this study was to explore and analyze Swedish adolescents’ use and attitudes towards non-prescription drugs, with special focus on analgesics. Ten focus group interviews were held with adolescents attending schools in different geographical areas of Sweden. The group interviews focused on the following questions. How do adolescents look upon their own (and other’s) use of non-prescription analgesics? What attitudes do they have about the availability, risks, and effects of analgesics? Are there any differences in how adolescents look upon the different purchasing outlets (example grocery stores, pharmacies, and internet) for buying non-prescription analgesics? The results may lead to an understanding of the consequences of the reregulation of the pharmacy market for adolescents in Sweden. Moreover, the results may be used by the Medical Products Agency, as they may reveal the possible needs for informational and educational efforts among Swedish adolescents, and the public in general.

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. Data analysis will start in 2012 with a phenomenological analysis of the lived experience of being on long-term sick-leave. The interview-parts about participation in the process will thereafter be separately analysed with qualitative content analysis. In addition, general practitioners will be interviewed in focus-groups about their experiences of their work with sick-listing. During 2011 an ethical approval for the study has been given, and data collection is under planning. The focus-group interviews will be conducted in 2012.

Parents’ expectations and experiences of calling Swedish Healthcare Direct about paediatric health issues
Participants: Elenor Kaminsky, Inger Knutsson Holmström

During 2010, four million calls were made to Swedish Healthcare Direct. About 50% of these concerned pediatric health issues. The project is ongoing during 2010-2012. The Study aims at performing a descriptive and exploratory interview study, with a strategic sample of 21 parents who
had called Swedish Healthcare Direct for their child within the last six months. The data collection was ended in March 2011. Seventeen hours of transcribed interview data was analyzed using qualitative content analysis, during spring and fall 2011. The manuscript will be submitted spring 2012.

**Department director’s views on the telenursing work, regarding parental advice**

*Participants: Elenor Kaminsky, Inger Knutsson Holmström*

The project is ongoing during 2011-2013. The Study aims at performing a descriptive and explorative telephone interview study, with the 23 employed department director’s at Swedish healthcare Direct, regarding their views on telenurses’ work and their paediatric advice to parents. The data collection will be performed from March to May 2012 and analysis starts fall 2012.
Oxidative Stress and Inflammation

Research Group Leader Samar Basu, M.Sc., PhD., Professor

The research group “Oxidative Stress and Inflammation” was established in January 2009 and previously was a part of research groups Geriatrics and later Clinical Nutrition and Metabolism. The main research area of this group is “Oxidative stress and Clinical Inflammation”.

Research Group Leader Samar Basu is currently 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 levels 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\textsubscript{3α} 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 group during 2011

Samar Basu
Johanna Helmersson
Lillemor Källström
Elisabet Rytter

(External)
Maria Palm
Emma Lindström
Adriana Miclescu

Publications 2009-2011


Does two portions of salmon per week consumption enhance the antioxidant defense system in pregnant women? Antioxidants & Redox Signaling 2011, 15, 2819-2823.


Reviews 2010


Agencies that support the work/Funding

The Swedish Research Council
The Norweigian Research Council
The Conseil Regional d’Auvergne, France

Projects

AQUAMAX: The sustainable aquafeeds to maximise the health benefits of farmed fish for consumers
Collaborators: Samar Basu, Johanna Helmersson, Philip Calder
Financed by the European Union (6th. Framework). The project is performed in collaboration with Southampton, Granada, Bergen, China

Smartfish
Collaborators: Samar Basu, Rune Blomhoff and Liver Fröyland
Financed by The Norwegian Research Council, Norway. The project is performed in collaboration with Oslo Medical Faculty and Bergen University, Norway
Magnesium intake and diabetes development
Collaborators: Arvo Hänni, Brita Karlström/Bengt Vessby, Johanna Helmersson
Study design: Estimated intake of diet magnesium in relation to the risk of diabetes development in the ULSAM-cohort.

Polymorphisms in the PLA2, COX-2, PG endoperoxide reductase, 15-PGDH, 13-reductase, interleukin-6, CRP, SAA, cystatin C gene and cardiovascular risk
Collaborators: Johanna Helmersson, Anders Larsson, Samar Basu
Study design: The project is performed in collaboration with the section of Molecular Medicine and is financially supported by Wallenberg Consortium North.

Oxidative stress, inflammation and angiogenesis during normal pregnancy, parturition and under normal menstrual cycle
Collaborators: Maria Palm, Ove Axelsson, Anders Larsson and Samar Basu
The project is a 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 a 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 a 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 a 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.

Antibody and assay development on resolvins
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 Mammography Cohort
Collaborators: Samar Basu, Anders Larsson, Alicja Wolk
The project is performed in collaboration with Clinical Biochemistry, Uppsala University and Karolinska Institute, Sweden.

Impact of 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 Biochemistry, Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.

F-isoprostane metabolism and detection of oxidative stress
Collaborators: Denis Calleweart, Samar Basu
The project is performed in collaboration with University of Oakland (MI) and Vanderbilt University, USA.

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).

Vitamin D status and inflammation and oxidative stress in humans
Collaborators: Johanna Helmersson, Samar Basu, Kalle Michaelsson, Anders Larsson, Håkan Melhus
The project is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital, Department of Medical Sciences, Uppsala University and Department of Surgical Sciences, Uppsala University.

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, Ilona Koupil, Anders Larsson, David Leon
The project is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital, Department of Surgical Sciences, Uppsala University, Epidemiology unit,
London School of Hygiene and Tropical Medicine, UK and Centre for Health Equity Studies, Karolinska Institute/Stockholm University, Sweden

**Prostaglandin F$_2$α as a predictor of cardiovascular morbidity and mortality**

Collaborators: Johanna Helmersson, Johan Ärnlöv, Anders Larsson, Samar Basu

The project is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital and Geriatrics, Public Health and Caring Sciences, Uppsala University

**Pentraxin-3 and cardiovascular risk**

Collaborators: Johanna Helmersson, Anders Larsson

The project is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital

**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 Programme: U-CARE, Uppsala University has been given the possibility to support our research group Psychosocial oncology and supportive care, 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 use knowledge from the academic disciplines Clinical Psychology, Economics, and Information systems.

Members of the group during 2011

Members and external partners/associated researchers are listed below in Table 1 and 2 respectively.

Table 1. Members during 2011

<table>
<thead>
<tr>
<th>Name</th>
<th>Academic title</th>
<th>Professional title</th>
<th>Department/University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Louise von Essen</td>
<td>PhD, Professor</td>
<td>Psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Annika Lindahl Norberg</td>
<td>PhD, Associate professor, Researcher</td>
<td>Psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Department of Women’s and Children’s Health, Childhood Cancer Research Unit, Karolinska Institutet</td>
</tr>
<tr>
<td>Elisabet Mattsson</td>
<td>PhD, Researcher</td>
<td>Registered nurse, Registered midwife</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Erik Grönqvist</td>
<td>PhD, Post doc researcher</td>
<td></td>
<td>Department of Economics and Department of Public Health and Caring Sciences, Uppsala University</td>
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<tr>
<td>Emma Hovén</td>
<td>PhD, Researcher</td>
<td></td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Department of Women’s and Children’s Health, Childhood Cancer Research Unit, Karolinska Institutet</td>
</tr>
<tr>
<td>Elly-Ann Lindström</td>
<td>PhD, Post doc researcher</td>
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<td>Department of Public Health and Caring Sciences and Office of Labour Market Police Evaluation, Uppsala University</td>
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<tr>
<td>Erik Olsson</td>
<td>PhD, Post doc researcher</td>
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</tr>
<tr>
<td>Jonas Sjöström</td>
<td>PhD, Post doc researcher</td>
<td>System analyst</td>
<td>Department of Informatics and Media and Department</td>
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<tr>
<td>Sven Alfonsson</td>
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</tr>
<tr>
<td>Martin Cernvall</td>
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</tr>
<tr>
<td>Gunn Engvall</td>
<td>MSc, PhD student until September 2011, Researcher from October 2011</td>
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<td>Department of Public Health and Caring Sciences and Department of Women’s and Children’s Health, 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>Fredrika Norlund</td>
<td>MSc, PhD student</td>
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</tr>
<tr>
<td>Teolinda Toft</td>
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<td>Department of Public Health and Caring Sciences, Uppsala University</td>
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<tr>
<td>Ruth Lochan</td>
<td>MSc, Research assistant until September, PhD student from October</td>
<td>Software engineer</td>
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</tr>
<tr>
<td>Susanne Lorenz</td>
<td>Research assistant</td>
<td>Registered nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
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<tr>
<td>Hafijur Rahman</td>
<td>Research assistant</td>
<td>Software engineer</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
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<tr>
<td>Riyadh Ul-Islam</td>
<td>Research assistant</td>
<td>Software engineer</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Anders Brantnell/member</td>
<td>MSc, Coordinator</td>
<td></td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
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</table>

Table 2. External partners/associated researchers during 2011.
<table>
<thead>
<tr>
<th>Name</th>
<th>Degree, Position</th>
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<tbody>
<tr>
<td>Pär Ågerfalk</td>
<td>PhD, Professor</td>
<td>System analyst</td>
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<td>Claes Held</td>
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<tr>
<td>Inger Holmström</td>
<td>PhD, Associate professor, Researcher</td>
<td>Registered nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Gustaf Ljungman</td>
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<td>MD</td>
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</tr>
<tr>
<td>Lena Wettergren</td>
<td>PhD, Associate professor, Senior lecturer</td>
<td>Registered nurse</td>
<td>Department of Neurobiology, Care Sciences and Society, Division of Nursing, Karolinska Institutet</td>
</tr>
<tr>
<td>Niklas Zethraeus</td>
<td>PhD, Associate professor, Researcher</td>
<td></td>
<td>Stockholm School of Economics</td>
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**Publications 2009-2011**


Dissertation 2011

Agencies that support the work/Funding
The Swedish Research Society 5 750 000 SEK
The Swedish Children’s Cancer Foundation 500 000 SEK
The Swedish Cancer Society 600 000 SEK
Uppsala County Council 550 000 SEK

During 2011 our main activities have been to:

• Construct an internet platform: carebase.se to provide e.g. interactive support and cognitive behavioral therapy. The platform will support, among other things, rule-based unfolding of self-help material for patients, interaction between patients and therapists, interaction within a patient community, and research.

• Construct self-help programs of interactive support and cognitive behavioral therapy to be provided via the platform: carebase.se for adolescents with cancer, U-CARE TeenCan; adults with cancer, U-CARE AdultCan, and adults having had a myocardial infarct: U-CARE Heart.

• Include parents of children newly diagnosed with cancer in an ongoing randomized controlled study investigating the clinical efficacy and cost-effectiveness of cognitive behavioral therapy via internet to reduce traumatic stress.

• Interview participants in the ongoing, longitudinal studies: Cancer during adolescence: psychosocial and health-economic consequences (1999-; 10 years after diagnosis) and Occurrence and development of posttraumatic stress among parents of children with cancer (2002-; 5 years after end of successful treatment).

• Stimulate cross-disciplinary research between researchers from the academic fields: Clinical Psychology, Economics, and Information systems.

• Build up and start undergraduate education in Psychosocial care in the interactive society for the Psychology and Nursing programs at Uppsala University.

• Build up advanced education in Psychosocial care in the interactive society (7.5 hp + 7.5 hp).

• Build up advanced education in Implementation of complex interventions in health care (7.5 hp) in collaboration with researchers at Radboud University, Holland.

• Arrange and hold the first meeting with the Scientific Advisory Board and all U-CARE members in Uppsala 5-6 September 2011.

• Initiate collaboration with researchers at University of Miami, US; University of South Florida, US; Radboud University, Holland, and University of Exeter, UK.

• Establish the ownership of the platform: carebase.se and the self-help programs U-CARE TeenCan, U-CARE AdultCan, and U-CARE Heart.
Projects

Cancer during adolescence. Psychosocial and health economic consequences

OVERALL AIM
To investigate psychosocial and health economic consequences of adolescent cancer; compare the psychosocial and health economic situation of those struck by cancer during adolescence vs. matched controls and investigate whether there are any positive consequences of adolescent cancer.

METHODS
The project has a comparative, longitudinal design with eight measurements from a month to ten years after diagnosis. Sixty-one adolescents have been included. Data from a control group of 300 healthy persons have been collected. All participants answer questions about quality of life, anxiety and depression via telephone. Additionally those struck by cancer answer questions about disease- and treatment-related distress, whether and if so how they cope with distress and whether they experience any negative and positive cancer-related consequences.

FUNDING
The project started 1999 and is since then funded by The Swedish Children’s 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. 250 parents have been included. Parents answer questions about e.g. posttraumatic stress, emotional support and the child’s medical situation via telephone.

FUNDING
The project started 2002 and is since then funded by The Swedish Research Society, The Swedish Children’s Cancer Foundation and The Swedish Cancer Society.

Quality of life and needs of care and support among East Africans with cancer

OVERALL AIM
To investigate quality of life and explore needs of care and support among East Africans struck by cancer.

METHODS
The project has a comparative, explorative design. 100 patients have participated in focus-group interviews and answered questions about quality of life.

FUNDING
The projected started 2006 and has been funded by Indevelop and the Faculty of Medicine, Uppsala University.
U-CARE: Betsy. Treatment of posttraumatic stress among parents of children with cancer with cognitive behavioral therapy over the internet

OVERALL AIM
To investigate the clinical efficacy and cost-effectiveness of a cognitive behavioral self-help program delivered via the internet to parents of children struck by cancer.

METHOD
The study has a randomized, controlled design. 150 parents will be included and randomized to early program, starting 6 weeks after the child’s diagnosis or late program, starting 70 weeks after the child’s diagnosis. Inclusion started 2010. Parents answer questions about e.g. posttraumatic stress, anxiety, depression, quality of life and costs via the internet.

FUNDING
The project started 2008 and is funded by The Swedish Research Society, The Swedish Cancer Society and The Swedish Children’s Cancer Foundation.


OVERALL AIM
To investigate the clinical efficacy and cost-effectiveness of a self-help program consisting of support and cognitive behavioral therapy delivered via the internet to adolescents struck by cancer.

METHOD
The study has a randomized, controlled design. 150 adolescents will be included and randomized to early program, starting 5 weeks after diagnosis or late program, starting 20 months after diagnosis. Adolescents answer questions about e.g. posttraumatic stress, anxiety, depression, quality of life, posttraumatic growth and costs via the internet.

FUNDING
The project is funded by a strategic research grant to Uppsala University Psychosocial Care Programme: U-CARE.


OVERALL AIM
To investigate the clinical efficacy and cost-effectiveness of a self-help program consisting of support and cognitive behavioral therapy delivered via the internet to adults struck by cancer.

METHOD
The study has a randomized, controlled design. 250 adults with prostate-, breast- or localized colorectal cancer will be included and randomized to a self-help program or waiting-list. Participants answer questions about e.g. posttraumatic stress, anxiety, depression, quality of life, posttraumatic growth and costs via the internet.

FUNDING
The project is funded by a strategic research grant to Uppsala University Psychosocial Care Programme: U-CARE.

U-CARE: Heart. A randomized controlled trial of the effect of a self-help program via internet on anxiety and depression among adults after a myocardial infarct

OVERALL AIM
To investigate the clinical efficacy and cost-effectiveness of a self-help program consisting of cognitive behavioral therapy delivered via the internet to adults struck by a myocardial infarct.

METHODS
The study has a randomized, controlled design. 500 adults struck with a myocardial infarct will be included and randomized to a self-help program or waiting-list. Participants answer questions about e.g. posttraumatic stress, anxiety, depression, quality of life, posttraumatic growth and costs via the internet.

FUNDING
The project is funded by a strategic research grant to Uppsala University Psychosocial Care Programme: U-CARE.
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 the children of lone parents and the prognosis for unemployed to return to employment.

The research field also includes 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 2011

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
Stefan Kunkel, PhD.
Ulrika Paulsson, Doctoral student
Peter Berg, M.D., Doctoral student
Mikael Skärlund, Research assistant
Susanne Sundell Leceof, Doctoral student, collaboration with Lunds and Malmö University
Anna Ohlsson, M.D., Clinical research assistant
Hans Nordlöf, Doctoral student, Collaboration with University of Gävle
Ebba Hallberg, MPh student
Publications 2009-2011


13. Lytsy P, Berglund L, Sundström J. A Proposal for an Additional Clinical Trial Outcome Measure Assessing Preventive Effect as Delay of Events. (Submitted)
14. Berg P, Sundelin C, Westerling R. The connection between socioeconomic and psychosocial factors and bicycle helmet use among school children and teenagers. Department of Public Health and Caring Sciences, Social Medicine, Uppsala University (Submitted)


18. Lytsy P. Slutrapport. Utvärdering av samverkan med rehabkoordinatorer och kontaktpersoner i primärvården respektive psykiatrin under 2010. (In Swedish: Final report. Evaluation of collaboration between rehabilitation coordinators and contact persons in primary care and psychiatry, respectively in 2010.). Dnr PUBCARE 2010/1


37. Paulsson U, Edlund B, Westerling R. Associations with the clustering of unhealthy behaviors in Swedish upper primary school pupils. Department of Public Health and Caring Sciences, Social Medicine, Uppsala University 2011 (Submitted).


47. Skärlund M, Åhs A, Westerling R. Health-related and social factors predicting non-reemployment amongst newly unemployed. Department of Public Health and Caring Sciences, Uppsala University 2011.(Submitted)


**Agencies that support the work/Funding**

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, Östsm and the National Board of Health and Welfare). 6 835 000 skr, 2009-2011. European refugee fund.


Health information for immigrants. Public health funds, Uppsala county, 300 000 skr 2009-2010, 298 000 skr 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 skr 2010-2012. Academic hospital, Uppsala.

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 investigation of factors which may increase the possibilities to prevent these causes of 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 Jouglà’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. 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

In our studies 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. Furthermore, in-depth analyses of the cause of death statistics for suicide, methadone-related deaths and for prostate cancer has been performed. We are collaborating with Eric Jouglà's 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 statins 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.

The physicians expectations and attitudes towards statin treatment has also been analysed showing some gender differences in the prescription habits among physicians. This study is performed in collaboration with the pharmaceutical committees in the county of Uppsala and Gävle and supported by the Academic hospital in Uppsala and is included in Per Lytsy’s thesis together with studies of the patient’s expectations.

Health promoting interventions among immigrants to Sweden

Participants: Achraf Daryani, Josefin Wångdahl, Eva Flodström, 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 i. 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 are 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 are performed in collaboration with Lund’s University and Malmö University as well as with several municipalities, county councils and other organisations. The projects are funded by the European Refugee Fund and Immigrant Fund, respectively.

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). A project has been planned together with the municipality of Uppsala in which these study circles will be included as part of an intervention for marginalized female immigrants.
Unhealthy life habits, vulnerability and mental health among schoolchildren

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 in 2007. 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 sociodemographic 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. Presently, the social and health related situation of the families is followed up in a longitudinal study.

Health and health system interventions among non-working populations.

Participants: Annika Åhs, Gunilla Burell, Mikael Skärlund, Ragnar Westerling and research group at Social Medicine department/CEOS, Academic hospital

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 than the employed did. This was the case also when there were signs of depression or of the so called burned out syndrome. Presently we are analysing 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 seems to have predicted a higher risk of being unemployed also one year later.

We are also involved in evaluation of intervention projects for persons on long term sick leave at the Social Medicine department/CEOS at Academic hospital.

Implementing safety promotion in an industrial working environment

Participants: Hans Nordlöf, Birgitta Wiitavaara, Katarina Wijk, Ulrika Winblad, Ragnar Westerling

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.