Department of Public Health and Caring Sciences

Annual Report 2012
Introduction

The Department of Public Health and Caring Sciences employs 170 persons and has a yearly economic turnover of approximately 130 million SEK. The research activities are organized in ten research groups; Caring Sciences, Clinical Nutrition and Metabolism, Disability and Habilitation, Family Medicine and Preventive Medicine, Geriatrics, Health Services Research, Oxidative Stress and Inflammation, Psychosocial Oncology and Supportive Care and U-CARE, Research Ethics and Bioethics, and Sociomedical Epidemiology, with the following research foci:

Caring Sciences

The research has a multidisciplinary and multiprofessional perspective including preventive, supportive, caring, and rehabilitation actions. The focus is on clinically relevant problems in the health care sector. There are four research themes; 1) health and care among children adolescents and young adults, 2) health and care among elderly, 3) psychosocial genetics and cancer care, 4) quality of care and patient safety.

Clinical Nutrition and Metabolism

Metabolic and dietary interaction during health and disease is the research focus. Within this overall focus there are two major research pathways, i.e. 1) clinical disease- and age-related nutrition, which includes understanding of catabolic processes, consequences and treatment related to undernutrition, cachexia and sarcopenia in hospital, elderly care and community settings, and 2) preventive nutrition and metabolism, including nutritional epidemiology, obesity and metabolic intervention trials for elucidating effects on insulin sensitivity and cardio-vascular risk factors.

Disability and Habilitation

Research activities focus disability as a function of the interplay between a person’s health condition and his or her physical, social and societal environment. There are three main research tracks: Disability Services, Systems and Policies, Clinical Assessment Methods and Documentation and The Perspectives of Persons with Disabilities in which the facilitating and restraining aspects of the environment as well as the participation and perspectives of persons with disabilities, professionals and significant others are highlighted.

Family Medicine and Preventive Medicine

*Social Insurance Medicine:* the course of events leading to sick-listing and disability pension to detect predictors for sickness absence and return to work aiming at future guidance to patients and profession.

*Pain:* prevalence, determinants and consequences of pain to deepen the patho-physiologic knowledge to develop adequate diagnostic and treatment strategies.

*Reproductive health:* effects of positive and negative influences in early pregnancy on outcome of pregnancy and childbirth aiming at optimizing the conditions of the fetus.

Develop reproductive health care for young adult men in primary health care.

*Asthma, allergy and COPD:* asthma control and quality of life during different periods of life.

*Pharmacoepidemiology:* natural history of diseases including respiratory and inflammatory diseases.

Stress: biological mechanisms linking stress to cardiovascular disease. How management control systems affect the human body.

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

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

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

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

Research Ethics and Bioethics
The Centre for Research Ethics & Bioethics (CRB) looks at ethical, legal and social aspects of medicine and biology (bioethics) and the application of ethical principles and values to different scientific topics (research ethics). The research topics cover a wide range of ethical questions related to biobanks and registry research, ethical review, informed consent, medical treatment of patients, nursing, explanations of human consciousness, quality of life, end of life care and more. The methods in use range from analytical philosophical methods to empirical studies using both qualitative and quantitative methods.
Sociomedical Epidemiology
The primary objective of the research is to analyze mechanisms behind social differences in health and health care and to develop and evaluate health system interventions in order to increase equity in health. The main fields of the research programme are quality and equity in medical care and health system interventions for vulnerable groups like unemployed, lone parents and immigrants. Methodological aspects of avoidable mortality is also an important research interest.

Education
The Department of Public Health and Caring Sciences has extensive responsibilities in the teaching of nursing students, medical students, master of public health students and graduate students. There were about 3530 students registered at the department in 2012, in terms of funding corresponding to about 525 full time students. About 1350 registered students were educated in the Nursing programme, 1600 in the Medicine programme, 20 in the Master-programme in public health and about 560 in separate courses. Through well-established collaboration with several universities abroad and different exchange programmes nursing students and teachers were able to get international experience.

About 100 doctoral students were also registered during 2012. In contract education about 950 students were registered.

Developments
After a period of planning the department’s organization for under-graduate education was centralised at the end of 2012 under a new leadership. The aim was to further increase quality and efficiency in our education system and to facilitate strategic decisions on new courses and in the recruitment of new teachers in senior positions.

Another strategic development during 2012 was the recruitment of a senior researcher in health economics. The ambition of both the department and the university is to create a strong research group in health economics. To support this process the Health Economic Forum at Uppsala University (HEFUU) is organized as a collaborative effort between the Department of Public Health and Caring sciences, the department of Economics and Uppsala Clinical Research Centre.

Uppsala April 30, 2013

Johan Hallqvist
Head of Department
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Organization

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Professor Karin Sonnander

Department Board
Carina Ahlstedt, Teacher and Researcher Representative
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Margaretha Eriksson, Teacher and Researcher Representative
Mats G Hansson, Teacher and Researcher Representative
Calle Martinsson, Technical and Administrative Representative
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Björn Eriksson, Student Representative
Madeleine Grenä, Student Representative
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Viktor Knaust, Student Representative, Deputy
Tove Näslund, Student Representative, Deputy
Fanny Sundin, Student Representative, Deputy
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Catarina Olsson, Protocol

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Kurt Svärdsudd
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Bengt Vessby adj Professor Emeritus

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Lars Lannfelt  
Per Kristiansson  
Karin Nordin  
Karin Sonnander  
Tanja Tydén  
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Ulrika Winblad  

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Hans Basun  
Mats Gulliksson  
Gunnar Johansson  
Marianne Omne-Pontén  
Thorne Wallman  
Anna Christina Åberg
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Centres

During 2012 the Department of Public Health and Caring Sciences was the host of three Centres; the Centre for Disability Research, the Centre for Research Ethics and Bioethics, and the Uppsala University Psychosocial Care Program (U-CARE).

Centre for Disability Research (CDR)

(www.cff.uu.se)

**Director: Karin Jöreskog**

The Centre for Disability Research was established in 1988 to coordinate in disability issues in various subject areas at the faculties at Uppsala University and to interact with society in issues related to disability research. The aim is to disseminate information about research and to stimulate long term acquisition of knowledge about issues involving disability by enhancing the flow of information among teachers, researchers, and doctoral students as well as interested parties outside the University. (p 41).

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 44).
**Education**

The Department of Public Health and Caring Sciences is funded for about 525 full time students, which in themselves represent about 3530 students registered at the department in 2012 (GLIS130327). The students belong to different courses and programmes, about 1350 registered student were educated within Nursing programmes, 1600 within Medicine programme, 20 within Master-programme in public health and about 560 in separate courses.

In contract education were about 950 students registered. About 100 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, Alzheimer's disease and other neurodegenerative dementia disorders, various aspects on frail elderly patients with multiple co-morbidities and poly-pharmacy, falls, delirium and other geriatric syndromes, orthogeriatrics, stroke rehabilitation and palliative care, during a total of three weeks. The students ranked geriatrics as number 5 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.

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.

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

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

Radiography Nursing programme Courses

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

Separate courses at the first-cycle level

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

Contract education

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

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

The course Motivational Interviewing in Occupational Rehabilitation, 7.5 credits is given as a contract education in cooperation between the Department of Public Health and Caring Sciences and the Division for Contract Education. One course was offered to the County Council of Västmanland in collaboration with the Government Agency for Employment and the Swedish Social Insurance Agency. This course was also offered to the Swedish Social Insurance Agency in the region of Stockholm South in collaboration with the Government Agency for Employment within the context of Project Dirigo, financed by EFS.
Second-cycle courses and study programs

**Postgraduate Diploma in Specialist Nursing with focus on District nurse**, 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 – the research group *Caring Sciences* is responsible for all the courses (Geriatrics, Pharmacology and Gerontological Nursing, Gerontology and Nursing Focused on Healthy Ageing, Dementia and nursing care).

**Postgraduate Diploma in Specialist Nursing with focus on oncology care**, 60 credit points and 30 credit points at our department: The research group *Caring Sciences* is responsible for Courses; Psychosocial Cancer Care I and II, Palliative Care I and II.

**Separate courses**

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

**Master in Public Health**

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

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

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

Third-cycle course and study program

**Doctoral courses and study programme**

In the beginning of the year 2012, 90 doctoral students were in education and during the year 8 of them have past their theses and 17 new applicants have been admitted to studies at the doctoral level.

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

Uppsala University Psychosocial Care Programme (U-CARE) research school has been launched in 2012. The eight students admitted are anchored at four different Departments: Public Health and Caring Sciences, Psychology, Informatics and Media, and Economics. The postgraduate course given, also open to students outside the research schools framework, includes 15 credits divided into two modules. The first module “Psychosocial care in the interactive society” (7.5 ECTS) has been given in autumn 2012.

The Centre for Research Ethics & Bioethics is also responsible for doctoral courses given at other faculties at Uppsala University: “Research Ethics for Natural Science”, “Research Ethics for Science and Technology” and “Research Ethics for Social Science”, 2.5, 2 and 4 ECTS, 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**

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

**International activity**

We have well-established collaboration with different universities abroad within several exchange programmes for nursing students on undergraduate level, nursing students on advanced level in different specialties, and teachers. The main programmes are Erasmus Life Long Learning Programme for European countries, Nordplus (Norlys for the Scandinavian and Baltic countries, and Danosfi for the Nordic countries), and Linnaeus-Palme and Mini Field Study for developing countries such as Vietnam, Tanzania, Thailand and Uganda. In 2012 about 34 of our students studied abroad during 2-12 weeks, while 13 foreign students visited our department during 4-12 weeks. In the same year three of our teachers taught abroad during 1-3 weeks, while two foreign teachers taught in our department during 5 weeks. The exchange programmes give students and teachers knowledge, experiences and international contacts which are highly valuable for their personal development as well as for their careers.
Dissertations 2012
(Registered at the Department of Public Health and Caring Sciences)

Sevek Engström, Dental Health Care Cooperating with Primary Health Care as a Resource in Early Case Finding of Patients with Diabetes or Hypertension

Annica Ernesäter, National Telephone Advice Nursing in Sweden: Patient Safety and Communication

Joanna Stjernschantz Forsberg, Biobank Research: Individual Rights and Public Benefit

Mio Fredriksson, Between Equity and Local Autonomy: A Governance Dilemma in Swedish Healthcare

Monica Blom Johansson, Aphasia and Communication in Everyday Life: Experiences of persons with aphasia, significant others, and speech-language pathologists

Maria Lindberg, Methicillin-resistant Staphylococcus aureus (MRSA) an Unclear and Untoward Issue: Patient-Professional Interactions, Experiences, Attitudes and Responsibility

Elina Rönneamaa, Predictors of Dementia: Insulin, Fatty Acids and Vascular Risk Factors

Licentiate 2012

Birgitta Kerstis, Expectant parents needs of support and early parenthood
Scientific Reports

Caring Sciences

Research group leader professor Tanja Tydén, chair

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

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

In 2010-2012, we had following four research themes; 1) health and care among children adolescents and young adults, 2) health and care among elderly, 3) psychosocial genetics and cancer care, 4) quality of care and patient safety.

Research is a process we are in a phase of developing our research into new themes. Various projects are ongoing and planned within the group cancer care and rehabilitation; cross-disciplinary randomized controlled intervention studies focusing on lifestyle (e.g. physical exercise, stress management, nutrition) in cancer patients. The aim is to find evidence-based interventions for changing life styles factors to decrease the burden for the patients and care givers during and after cancer treatments, cost-effective rehabilitation programs and more person-centered health care.

Within the group reproductive health the aim is to contribute to the prevention of sexually transmitted infections (STI) and cancer related to Human papillomavirus (HPV) with focus on Chlamydia, HPV and the vaccine against HPV. The aim is to examine Chlamydia, oral and genital HPV prevalence and correlate these results to sexual behaviour among adolescents. We aim to find evidence-based interventions to improve behaviour towards the use of STI preventive measures.

Lifestyle in the period prior to conception and during pregnancy is an important determinant of maternal and foetal health. In a longitudinal study we are investigating health, lifestyle and wellbeing prior to conception, during and after pregnancy among women, their partners and their new-borns. Another study evaluates the effect of Reproductive Life Plan (RLP) on knowledge, attitudes and behaviour related to reproductive health and lifestyle prior to conception.

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

Members of the group during 2012

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

**Lecturers fulltime or part time**

Ahlstedt Carina
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
Staaf Anita
Svanberg Ann Carin
Thoudal Berit
Thörnqvist Eva
Associated researchers
Ekstrand Maria, RNM, PhD
Häggström Elisabeth, RN, PhD, associate professor
Kristofferzon Marja-Leena, RN, PhD
Lindberg Magnus, RN, PhD
Lindqvist Ragny, RN, PhD
Nilsson Annika, RN, PhD
Oscarsson Marie, RNM, PhD
Skytt Bernice, RN, PhD
Christina Stenhammar, RN, PhD
Westerberg Jacobson Josefin, PhD

**Ongoing PhD students**

Bjurling sjöberg Petronella
Björn Catrine
Gottvall Maria
Grandahl Maria
Hagerman Heidi
Hedman Maria
Hellerstedt-Börjesson Susanne
Publications 2010-2012

Health and Care among Children, Adolescents and Young Adults

2010


3. 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.


27


2012


Psychosocial Genetics and Cancer Care

2010


2011


2012

70. Høyer, M; Nordin, K; Ahlgren, J; Bergkvist, L; Lambe, M; Johansson, B; Lampic, C. (2012) Change in working time in a population-based cohort of patients with breast cancer. Journal of Clinical Oncology 2012 ; 30.(23) s. 2853-2860

71. Nordin, K; Rissanen, R; Ahlgren, J; Burell, G; Fjällskog, M- L; Börjesson, S; Arving, C. (2012) Design of the study: How can health care help female breast cancer patients reduce their stress symptoms? A randomized intervention study with stepped-care. BMC Cancer ; 12.((167)) s. –

72. Roshanai, AH; Lampic, C; Ingvoldstad, C; Askmalm, MS; Bjorvatn, Cathrine; Rosenquist, R; Nordin, K. What Information Do Cancer Genetic Counselees Prioritize?.Journal of Genetic Counseling 2012 ;Volum 21.(4) s. 510-526


Quality of Care and Patient Safety
2010


2011


2012


Health and Care among Elderly
2010
132. 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

2012

Other

2010


2011


2012


Dissertations 2012
Lindberg Maria, ”Methicillin-resistant Staphylococcus aureus (MRSA) an Unclear and Untoward Issue”, PhD examination.


Awards 2012

Mariann Hedström, main responsible for developing, and coordinating the project connected to PHASE-20, a symptom rating scale for identification of possible drug related symptoms in older people. In 2012, the PHASE-20 project was awarded “the Golden pill”, for the best national initiative for improving the medication use within the Swedish health care.

Magnus Lindberg, received Johanna Diepenveen-Speekenbrinkwetenschapsprijs, given by UniversitairMedisch Centrum Utrecht, The Netherlands (as co-supervisor to MSc Marian Winters) September 2012

Agencies that support the work/Funding
Medical Faculty Uppsala University 1 975 000SEK
Regional Research Council Uppsala/Örebro 300 000 SEK
AFA 2 years 1 797 000 SEK
The Swedish Cancer Foundation 1 250 000 SEK
The National Board of Health and Wellfare 200 000 SEK
Uppsala County Council 200 000 SEK
InDevelop 120 000 SEK
Uppsala County 200 000 SEK
The Swedish Research Council 450 000 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
Guest Lecturer, Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand.

National commissions
Expert group – Pressure Ulcer/Patient Safety – The Swedish Association of Local Authorities and Regions
Member of the Board of European Pressure Ulcer Advisory Panel
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
European Academy of Caring Science (EACS), Core member.
Member of the Scientific Board of Investigación y Educación en Enfermería - Research and Education in Nursing - (ISSN_p: 0120-5307, ISSN_e:2216-0280)

Invited speaker 2010-2012
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.


Skejby University Hospital, Aarhus, Denmark April 2011


The 1st International Nursing Conference, Active Healthy Ageing toward the future, Seoul, Sydkorea, 2012

Trycksårskonferens. Hjælpemiddelinstituttet Kolding, Denmark, Feb 29, 2012

The 1st International Clinical Nursing Research Congress, Izmir, Turkey, 30 May-2 June, 2012


Opponent for PhD 2010-2012

Sahlgrenska Akademin, Göteborg. Living with amyotrophic lateral sclerosis-perspective of patients and next of kin, 2010


Linköpings universitet. Aspects of Health-related Quality of Life. Associations with psychosocial and biological factors, and use as patient reported outcome on routine health care. 2012

Sahlgrenska Akademin, Göteborg. Upplevelse och lindring av fatigue och gastrointestinala symptom – hos patienter som genomgår strålbehandling, 2012
Centre for Disability Research (CDR)

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

In 2012 the CDR arranged a second conference Forskning pågår ("Research Underway") in collaboration with the Uppsala Regional Council. The 2012 theme was “Interaction for Inclusion”. The conference brought together researchers from Uppsala University, practitioners, individuals with own experience of disability, interest groups, artists, etc. Besides lectures on topics representing all disciplinary domains at Uppsala University, there was an art exhibition with exhibitors from Uppsala County and Iran.

During 2012 an application for continued operations in the Swedish Network for Disability Research was submitted to and approved by the Swedish Council for Working Life and Social Research (FAS). The CDR will thereby be able to continue to function as coordinator of this network for the period 2012 – 2014. In the autumn the CDR hosted a network meeting. Thirty scientists from all over Sweden participated in the meeting, where important matters were discussed regarding the future of the network.

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

Four issues of the newsletter Forskning om funktionshinder pågår (Current Disability Research) have been published. The newsletter presents Swedish research on disabilities. Funding for 2013 – 2015 has been applied for and secured.

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

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

The Board of the Centre for Disability Research

Professor Karin Sonnander, (Disciplinary domain of medicine and pharmacy) chairperson
PhD Faculty of Medicine, Åsa Myrelid (Disciplinary domain of medicine and pharmacy)
Professor Håkan Lanshammar (Disciplinary domain of science and technology), vice chairperson
Professor Anders Rydberg (Disciplinary domain of science and technology)
Professor Åke Viberg (Disciplinary domain of humanities and social science) (until 2012-11-30)
Professor Margareta Sandström (Disciplinary domain of humanities and social science)
Professor Rafael Lindqvist (Disciplinary domain of humanities and social science) (from 2012-06-01)
Professor Karin Barron (Disciplinary domain of humanities and social science) (until 2012-06-01)
PhD student Johan Gladh
Agencies supporting CDR work/Funding

Funding has been received for 2012 for the newsletter Forskning om funktionshinder pågår (Current Disability Research). The financiers are:

- Norrbacka-Eugenia Foundation SEK133 000
- Sunnerdahl Handicap Fund Foundation SEK 133 000
- Sävstaholm Foundation SEK 74 000
- Council for Working Life and Social Research (FAS) SEK 250 000

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

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

Conference

In 2012 CDR arranged a second Forskning Pågår (“Research Underway”) conference in collaboration with the Uppsala Regional Council. The 2012 theme was “Interaction for Inclusion”. The conference gathered some one hundred individuals.

Public outreach

The Uppsala Network

The Uppsala Network is an e-mail network for individuals with either a personal or a professional interest in research on disabilities. Information reaching the CDR is forwarded to the network’s ca. 450 recipients. Recipients include researchers, representatives of care and social caring operations, personnel, relatives of individuals with disabilities, civil servants in county, municipal, or state administration, and other interested parties.

Homepage

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

Lectures

Each semester, CDR arranges a number of lectures for the purpose of disseminating information about on-going research and making it available to individuals both at Uppsala University and in the wider community. In 2012 eight lectures were arranged, and we have seen an increase in the number
The media have contacted the CDR about recording some of the lectures (URL Samtiden (Swedish Educational Radio: Our Times) and National Assembly Television in South Korea).

**The newsletter Forskning om funktionshinder pågår (Current Disability Research)**

The launching of the newsletter was a way of meeting an expressed need from the Swedish disability organisations, who asked for easily accessible written information on current disability research. The newsletter is published by the CDR, Uppsala University. However, the content is not limited to research activities from Uppsala University but includes disability research from all over Sweden. As of a few years ago, the introduction of every article is written in easy-to-read Swedish. Every issue is available as a PDF document, to be found on the website of the Centre for Disability Research, Uppsala University. Those interested in a particular topic or looking for a special article can search all published issues on the website, using keywords (in Swedish). The current number of recipients is 3,900 (September 2012), 3150 of whom subscribe to a printed version and 750 subscribe to a PDF document distributed by e-mail. Many subscribers are workplaces, so there is reason to believe that the newsletter is made available to and is read by multiple individuals. The audience is varied and includes, besides a significant number of disability researchers, national, regional and local governmental agencies, universities and university colleges, libraries, schools, non-governmental organisations, workplaces and individual employees in local government organisations, persons with a personal interest in the field, national newspapers and media, etc. Most recipients are Swedish, although there are also subscribers in the Scandinavian countries.
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.

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. This work continued in 2012. In the evaluation, the KoF-panel encouraged the centre to become more visible. This led to the launch of the Ethics Blog, focusing on the international bioethics debate, and its Swedish sister Etikbloggen, which also focuses on debates in Swedish media. Our website also received a facelift and work to improve the structure is ongoing.

Members of the group during 2012
(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
Ewa Axelsson started her LLD studies in Medical Law in March 2004. Her thesis focuses on quality assurance in Swedish health care, responsibility and regulation. She holds a LLM from Uppsala University (2002). She defended her dissertation entitled "Patientsäkerhet och kvalitetssäkring i svensk hälso- och sjukvård" on December 9 2011.

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). She is also division leader for ethical and societal implications of the EU-flagship Human Brain Project.

**Josepine Fernow**, BA, Co-ordinator
Josepine Fernow is the centre co-ordinator and communications officer. She is also the editor of the centre website and electronic newsletter and arranges our conferences. Her background is undergraduate studies in Cultural Anthropology and Sociology at Uppsala University.

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

**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.

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

Yusuke Inoue joined CRB in October, 2012. His research interest deals with regulatory bioethics in
biomedical research, especially concerning human tissue research and banking. He is also interested
in the publication ethics of medical journals. Yusuke Inoue holds an undergraduate degree in Socio-
Behavioral Science (2001), a master of Public Health (2003), and a doctoral degree in Public Health
(2010) from Kyoto University, Japan. He has experience from several ethics advisory activities on
large cohort studies and brain biobanking, including BioBank Japan, the Japan Environment and
Children's Study, and the Japanese Society for Hygiene.

**Li Jalmsell**, MD, PhD student

Li Jalmsell started her PhD studies in Bioethics in 2008. She holds a degree in Medicine from
Karolinska Institutet (2005) and a license to practice (2007) She also works as a medical doctor at
the oncology unit in Visby, Gotland. Her main area of interest is the palliative care of dying children
and how to improve it. Before joining the Centre for Research Ethics & Bioethics she worked with
these issues at Karolinska Institutet.

**Linus Johnsson**, MD, PhD

Linus Johnsson defended his PhD thesis (Trust in Biobank Research) on March 9 2013. He works
part-time as a medical doctor at a health care centre in Strängnäs. He holds a degree in Medicine
from Uppsala University (2004) and license to practice (2006). Starting 2013, Linus Johnsson is also
part of the Family Medicine and Preventive Medicine research group at the Department of Public
Health and Caring Sciences.

**Ulrik Kihlbom**, PhD, Senior lecturer

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

**Sofia Kälvemark Sporrong**, PhD, Associated researcher

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

**Frida Kuhlau**, PhD

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

**Sofia Lavén**, MD, PhD student

Sofia Lavén joined CRB in September 2011 and started her PhD studies in January 2012. She is
specialized in Family Medicine and works at Samariterhemmets Vårdbcentral 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. She started her post-doc at CRB looking at disaster victim identification and the role of the dead body. Before that, she looked at public opinion of science and animal testing within the framework of the COMBINE consortium.

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

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

Jane Reichel, Associate Professor of Administrative Law
Jane Reichel joined CRB in September 2011 to work with the legal aspects of research conducted on human tissue samples within the BBMRI.se network. Jane Reichel is a 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 a 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 Uppsala University. She did her post-doc as a Marie Curie Fellow at the Department of Psychology at Royal College of Surgeons in Ireland (2002-2004). She became Associate Professor of Pharmaceutical Outcomes Research in 2007.

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

Publications 2010-2012
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:


22. Hansson MG, Biobanking Within the European Regulatory Framework: Opportunities and Obstacles, Biopreservation and Biobanking 2011;9(2):165-167
54. Patrick D, Burke LB, Gwaltney C, Kline Leidy N, Martin ML and Ring L, Content validity--establishing and reporting the evidence in newly developed patient-reported outcomes (PRO)


66. 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.


Reviews 2010-2012

Kihlbom, Ulrik, review of Döden är förhandlingsbar by Torbjörn Tännsjö, Tidsskrift för politisk filosofi, 2009;3.
Agencies that support the work/Funding

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<td>Factors associated with participation in phase 1 and phase 3 oncology trials</td>
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<td>Developing clearer definitions and clinical guidelines for DNR orders in oncology care</td>
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<td>Quality of life assessments in clinical practice</td>
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<td>AFA Insurance (AFA försäkring)</td>
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<td>Improving the ethical climate in psychiatry outpatient clinics</td>
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We also received 466 666 SEK as a result of the KoF evaluation.
**Research projects**

**Autonomy and trust in biobank research (PhD project)**

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

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

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

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

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

Today there is no clear picture about how children in terminal care and their families perceive the meaning and importance of palliative care in the Nordic countries. How patients and their families see the distinction between curative and palliative treatment has primarily been a focus for retrospective interviews with parents and there is a lack of knowledge in particular regarding the clinical and moral significance of hope.

The degree of activity for patients in the terminal phase of care varies, but there is only anecdotal evidence available. We need to understand how different paediatric oncology departments manage the intersection of curative and palliative treatment and how children and their relatives perceive the different activities offered to them.

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

The project is designed with an integration of three different methodologies. It has a descriptive, a qualitative and a philosophical/theological component.

Li Jalmsell will have her halftime thesis seminar in May 2013.

**Funding:** The Swedish Childhood Cancer Foundation (Barn cancerfonden)

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

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

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

To meet these challenges, WP7 was expanded in the autumn 2011 to examine the legal aspects. Some questions have also been raised in the media on the ethics of biobank research, especially in connection to the large 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 mass-withdrawals from health-data registries.
- Investigate the legal prerequisites for using databases and biobanks for future unspecified purposes.
- Investigate the legal requirements for supplementing quality registries within the health care sector with blood and tissue samples.

Funding: The Swedish Research Council (Vetenskapsrådet)

BTCure (Be The Cure)

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

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

With these tools at hand, we will be able to use new understanding of aetiology and early pathology of human disease for a program aimed at early and curative treatment of human RA and RA-like diseases.
BTCure (Be The Cure) focuses on Rheumatoid arthritis (RA) and RA-like diseases.

BTCure has 33 partners. It is co-ordinated by professor Lars Klareskog, Karolinska Institutet and Professor Tom Huizinga, Leiden University Medical Centre.

CRB are part of a subproject on ethics in the work package (WP5) on ethical issues and dissemination, led by professor Steffen Gay, University Hospital Zürich. The ethics subproject will address ethical aspects of the project and foster patient participation.

BTCure has received funding from the IMI call on Inflammation – Translational Research and Adaptive Immunity.

**Funding:** IMI (Innovative Medicines Initiative)

**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 Birgegård, 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 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:**

Two interview studies, using qualitative methodology, will be performed with oncology nurses and oncologists concerning their experiences of DNR decisions.

Nursing and medical students will be interviewed in a qualitative study concerning their understanding of DNR and their education on this concept.

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)

**Dual use and responsible life science research – A bioethical approach (PhD project)**

**Collaborators:** Frida Kuhlau, MA, PhD student, Anna T. Höglund, Associate professor of ethics, supervisor, Stefan Eriksson, Associate professor of research ethics, supervisor, Kathinka Evers, Associate professor of philosophy, supervisor

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

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

**Funding:** Uppsala University

### Controlling chronic inflammatory diseases with combined efforts (COMBINE)

**Collaborators:** Mats G. Hansson, Professor of Biomedical Ethics, Sofia Kälvemark, PhD, Researcher, Malin Masterton, PhD, Researcher, Tobias Renberg, PhD, Researcher

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

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

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

**Funding:** COMBINE Consortium (Vinnova, Vårdalstiftelsen, Reumatikerförbundet, Invest in Sweden Agency, KK-stiftelsen, Stiftelsen för strategisk forskning)

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

**Collaborators:** Karin Kjellgren, Professor, University of Gothenburg and Linköping University (Principal Investigator), Ulrika Bengtsson, PhD Student, University of Gothenburg, Inger Hallberg, PhD, Post doc, University of Gothenburg, Åsa Mäkitalo, Professor, University of Gothenburg, Dick Kaperowski, Associate Professor University of Gothenburg, Stefan Höfer, Associate Professor, University of Innsbruck, Lena Ring, Associate Professor of Pharmaceutical Outcomes Research

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

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

**Phase 1:** Exploring patients’ and health care professionals’ experiences of high blood pressure and antihypertensive treatment

**Phase 2:** Design and pilot testing of a mobile phone self-management system

**Phase 3:** Analysis of patient self-reports and patient/professional experiences using the interactive mobile phone self-management system

**Phase 4:** Evaluating patient- nurse/physician consultations using the interactive mobile phone self-management system

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

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

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

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

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

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

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

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

The project will look at:

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

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

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

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

**Funding:** The Swedish Cancer Society (Cancerfonden)

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

**Collaborators:** Joanna Forsberg, MD, PhD, Mats Hansson, Professor of biomedical ethics, supervisor, Stefan Eriksson, Associate professor of research ethics, supervisor

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


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

### 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).
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

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

EURO-TEAM aims towards early diagnosis and biomarker validation in arthritis management. An ideal intervention in a chronic inflammatory disease such as Rheumatoid Arthritis (RA) would be a preventive one. In order to develop preventive strategies and therapies two key developments need to occur: (1) Biomarkers need to be identified that can be used to predict an individual’s risk of developing RA. (2) Modifiable disease mechanisms need to be identified and characterized in the early phases of disease. The key objective of the TEAM consortium is to specifically identify diagnostic biomarkers and disease mechanisms operating during the transition from health to rheumatoid arthritis. The consortium will achieve this by developing a collaborative, integrated programme of work that links researchers with key SMEs involved in biomarker development to produce a “personalized predictive bioprofile” for patients destined to develop RA.

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

- To understand the current perspective of individuals in different pre-RA phases about: (1) RA; (2) the meaning and perception of “risk” and “risk assessment”; (3) the utility of predictive tests in the context of RA; (4) their willingness to undergo predictive tests for RA.
- To develop strategies and tools for communication with and education of individuals in different pre-RA phases about: (1) the different stages of RA and the prognosis of RA; (2) the role of interacting biomarkers in prediction of the development of RA; (3) how lifestyle and behaviour factors affect the risk of developing RA and how these can / should be modulated.
- To assess the impact of these communication and education strategies on an individual’s willingness to undergo predictive tests and their subsequent behaviour.
- To disseminate information from this project to relevant stakeholders.

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

Funding: EU, 7th Framework Programme
Factors associated with participation in phase 1 and phase 3 oncology trials (PhD project)

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

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

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

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

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

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

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

**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)

### How do patients prioritize in situations of limited resources?

**Collaborators:** Mats G. Hansson, Professor of Biomedical Ethics, Lilianne Eninger, Associate Professor, Senior Researcher, Department of Psychology, Uppsala University, Li Tsai, MD, Associate Professor, Orthopaedic Surgery, Karolinska University Hospital, Huddinge, Leif Ryd, MD, Professor of Orthopaedic Surgery, Karolinska University Hospital, Huddinge, Håkan Magnusson, MD, Orthopaedic Surgery, Karolinska University Hospital, Huddinge

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

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

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

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

### Improving the ethical climate in psychiatry outpatient clinics

**Collaborators:** Marit Silén, PhD, Post doc, Kristina Haglund, Senior lecturer, Department of Neuroscience, Uppsala University & Uppsala University Hospital, Mats G. Hansson, Professor of Biomedical Ethics, Mia Ramklint, MD PhD, clinical lecturer, Department of Neuroscience, Uppsala University

Children, adolescents and adults come to psychiatric outpatient clinics to be assessed, diagnosed and treated. Their symptoms and diagnosis range depression, anxiety disorders, bipolar disorders, eating disorders to obsessive compulsive disorders and post-traumatic stress disorder.

At these clinics they meet a number of professions: physicians, nurses, social workers, psychologists and physiotherapists. Sometimes, difficult decisions have to be made regarding referral to inpatient care or restraint. For the staff, these decisions raise a number of ethical questions. These questions range from how to balance the wish to do good with the respect for the patient’s autonomy to priorities between different kinds of need. Ethical questions to be solved while handling balancing a high workload and demanding patients.
The staff at outpatient psychiatric clinics needs to be prepared to handle these kinds of ethical challenges. Previously, the ethics rounds method has been used in order to try to strengthen healthcare staff’s ability to handle ethically difficult situations. It has been shown to increase mutual understanding and decrease professional hierarchies. This could have consequences for the way in which ethical problems are handled: Besides legal and other regulations and the healthcare ethical principles, the relationships at the specific workplace have an impact on how ethical problems are handled. Business ethics research has used the concept of ethical climate in order to describe how ethical problems are handled, and what relationships and practices that either hinder or facilitate a positive ethical climate.

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

**Funding:** AFA Insurance (AFA Försäkring)

**Mind the Risk**

**Collaborators:** Mats Hansson, Professor of Biomedical ethics and director of the Centre for Research Ethics & Bioethics at Uppsala University. Principal Investigator, Silke Schicktanz, Professor of Philosophy, Dept. of Medical Ethics and History of Medicine, George-August University of Göttingen. Julia Inthorn, PhD in philosophy, Senior Researcher, Dept. of Medical Ethics and History of Medicine, George-August University of Göttingen. Candidate for Pro Futura VIII. Gabriella Pravettoni, Professor of Cognitive Psychology, Centre for Interdisciplinary Research and Intervention on Decision (IRIDe), University of Milano, Alessandra Gorini, PhD, Senior Researcher, Centre for Interdisciplinary Research and Intervention on Decision (IRIDe), University of Milano, Claudio Lucchiari, PhD Senior Researcher, Centre for Interdisciplinary Research and Intervention on Decision (IRIDe), University of Milano, Frederic Bouder, PhD, Associate Professor, Department of Technology and Society Studies, Maastricht University, Katherine Payne, Professor of Health Economics, Centre for Health Economics, The University of Manchester, Karim Raza, PhD, MD, Associate Professor, Rheumatology Research Group, College of Medical and Dental Sciences, The University of Birmingham, Rebecca Stack, PhD, Clinical psychologist, Rheumatology Research Group, College of Medical and Dental Sciences, The University of Birmingham, Susanne Georgsson-Ohman, PhD, University Lecturer, Sophiahemnets Högskola, Marit Silén, PhD, Post doc, Centre for Research Ethics & Bioethics at Uppsala University.

The following PhD students will participate in the program based on already funded projects: Sofia Lavén, MD, PhD-student, Centre for Research Ethics & Bioethics at Uppsala University; Jennifer Viberg, PhD-student, Centre for Research Ethics & Bioethics at Uppsala University; Caroline Vass, Centre for Health Economics, The University of Manchester.

The purpose of this initiation grant is to prepare a joint proposal of a European research programme to be prepared during summer/autumn 2012 and finalised at a workshop at Krusenberg in November/December 2012. The research programme has the following aims:

- Assess the ethical, psychological and social implications of the increased focus on risk information within genetic information technology.
- Develop a conceptual framework for genetic risk perception and genetic risk management.
- Assess perceptions of genetic risk in the general public, in patient populations and among health care professionals and policy makers.

**Funding:** Planning grant from Riksbankens Jubileumsfond (Bank of Sweden Tercentenary Foundation)
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 on in a constructive manner.

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

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

Ashkan Atry will defend his thesis in October 2013.

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

RD-Connect

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

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

Despite examples of excellent practice, rare disease (RD) research is still mainly fragmented by data and disease types. Individual efforts have little interoperability and almost no systematic connection between detailed clinical and genetic information, biomaterial availability or research/trial datasets. The project will build on and transform the current state-of-the-art across databases, registries, biobanks, bioinformatics, and ethical considerations to develop a quality-assured and comprehensive integrated hub/platform in which complete clinical profiles are combined with -omics data and sample availability for RD research.

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

Develop best ethical practices for balancing patient-related interests associated with RD research using databases/registries, biobanks and omics databases in global networks of clinicians and researchers.

Engage with relevant stakeholders, e.g. patient organizations and patient groups, clinical and research networks, legislators and policymakers, pharma industry.

Develop a proposal for an expedient regulatory framework for linking of medical and personal data related to RD on a European and global level.

Funding: EU, 7th Framework Programme

Research biobanks and custodianship

Collaborators: Yusuke Inoue, Guest researcher from the Department of Public Policy, Institute of Medical Science, University of Tokyo (IMSUT)
This project looks at biobank custodians: who can control and manage a sustainable use of these resources and how they manage it. A previous study on biobank laws in Nordic countries found that there are contrasting understandings of “custodianship”.

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

This project is an empirical study of:

How to set a standard for allocation of samples: Priority setting vs equality of access - the conflict between open access (equality) and the sustainability of biobanks.

Incentives for the researchers who originally collects samples: The collector's incentive vs the neutrality of access/decision making.

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

**Funding:** the Japanese Society for the Promotion of Science and the Royal Swedish Academy of Sciences (Kungliga vetenskapsakademin)

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**SIMSAM-INFRA**

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

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

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

**Funding:** The Swedish Research Council
Vaccine against HPV – Ethical and social aspects: Survey, exploration and intervention (PhD project)

Collaborators: Maria Gottvall, RN, PhD student, Tanja Tydén, Professor of caring sciences, supervisor, 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).

Quality of life assements in clinical practice

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

This project started in 2005 and is funded by The Swedish Cancer Society. The main aim is to evaluate the effectiveness of QoL instruments as means of individualizing cancer care and treatment. We want to explore differences related to cancer patients QoL and to doctor-patient communication. This project consists of a recently completed psychosocial randomised study focusing on the benefits from regular assessments of Quality of Life (QoL) and Health-related Quality of Life (HRQoL) during patient care in daily oncology practice.

Objectives of special interests are:

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

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

**Funding:** The Swedish Cancer Society

**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
CRB 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. Kathinka Evers from CRB is also one of the division leaders for ethics and society in the EU-flagship Human Brain Project.

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

**Advanced level courses**

We offer an advanced level course in ethics and public health (7,5 credits) that can be taken both as a single subject course and as an electable part of the master programme in public health. The course is offered in Swedish.

Our web based advanced level course in neuroethics (7,5 credits) has increased in popularity and was offered again in Spring 2012.

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

**Postgraduate Teaching**

**Science and Technology:** A course in research ethics (2 credits) is compulsory for PhD students admitted after July 1, 2008. Preciously, this course was divided into two separate courses (Research ethics A [1 credit] and Research ethics B [1 credit]. The B-course now runs parallel to allow those students who have taken the A course to meet the requirements. The courses are open to all postgraduate students at the faculty.

**Medicine and Pharmacy:** Research ethics and philosophy of science (1,5 credit) is compulsory for PhD students. The course can be taken separately, or as part of a 7,5 credit integrated course called Introduction to scientific research.

**Social Sciences:** the electable 4 credit course tailored for the social sciences was not offered in 2013 but will be in 2013.

**Conferences and symposia**

In 2012 we were responsible for arranging the BBMRI.se user conference “HandsOn: Biobanks” on September 20-21. The conference was organized by BBMRI.se together with BBMRI.fi and Biobank Norway. We were also involved in arranging the pre-conference “International Biobanking Summit: Future directions” on September 19. The pre-conference was organized by P3G, ISBER, BioSHaRE.eu, ENGAGE, BBMRI.se and ESBB.

Both meetings attracted around 400 participants from 27 different countries. The HandsOn-concept was interactive. Apart from plenary lectures, seminars and poster presentations, we organized “idea labs” and other kinds of interactive workshops. We also had an interactive exhibition as part of the conference programme. This exhibition called “The Route” allowed participants to follow the sample through the research process and discuss the value of research.

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

In 2010, *Is Medial Ethics Really in the Best Interest of the Patient?* was held in Uppsala on 14-16 June. This meeting was arranged by CRB together with CESAGEN at the Universities of Cardiff and Lancaster. The conferences attracted 200 participants from more than 20 countries. Main sponsor was The Journal of Internal Medicine. The conference had different themes each day: 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 over-burdensome and unnecessary bureaucracy?

In 2009 we co-organized the Nordic Committee on Bioethics conference Nordic Biobank Research: Obstacles and opportunities in Uppsala on 3-4 May 2011

Public outreach
Due to the commitment to HandsOn: Biobanks, the rest of our public outreach work suffered slightly. Our newsletter was put on hold to be resumed in 2013. Instead, our lists were used to promote the HandsOn: Biobanks conference and to recruit researchers.

The CRB website, www.crb.uu.se had around 26495 unique visitors in 2012, (compared to 22985 in 2011), on average visiting our website 1,65 times (43814 visits). Most visits were from Sweden, followed by Germany, Norway, the Netherlands, Italy, the United Kingdom, USA and (with 500 page views or more).

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

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

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

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

The blog is funded by BBMRI.se. It is published in two versions, in Swedish (www.etikbloggen.crb.uu.se) and in English (www.ethicsblog.crb.uu.se). The Swedish blog comments current debate and often links to opinion pages in the daily papers, while the English version is more aimed at the scientific community and debates in the field of bioethics.

The blog has a variety of functions. These functions are reflected in the brief self-reflective remarks that end each blog post, such as:
“We think about bioethics”
“Following the news”
“We follow debates”
“We discuss questions of current interest”
“We find new aspects”
“We like challenging questions”
“We have a clinical perspective”
“In dialogue with the public”
The blog serves to update readers about bioethically relevant news. It participates in ethical debates. It explains bioethical research. It comments on recent publications and current events. It spreads information about CRB research and explains our ideas. It communicates with researchers, practitioners, politicians, and the general public. Finally, the blog tries to vitalize the ethical debate by identifying questions and perspectives that are novel, challenging and scientifically well-grounded.

In 2012, the Swedish “Etikbloggen” had 9,289 visits, with an average 25 visits per day. Most of the visitors were of course from Sweden, but the blog also had substantial numbers of visits from Finland and Norway. The English version, the “Ethics blog” have a little less visits. In 2012, the blog was visited 6,208 times, with an average of 17 visits per day. Most of the visitors were from Sweden, closely followed by the United States. The rest of the visitors were mainly from France, the United Kingdom, Germany, Canada and Finland. Together, the blogs were visited 15,497 times last year.

We also tried using Facebook to promote the HandsOn: Biobanks conference as a complement to the conference website. This page has around 70 likes and is now used for the next HandsOn-meeting which will be held in the Hague on November 21-22 2013.

**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 two debate articles dealing 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). This debate ended with a final article in January 2012 with “DI:s beslut måste omprövas (2012-01-04)

CRB in Swedish and international media (a selection)

- **Biobanker fråga för stormöte**
  KI Bladet nummer 6 2012

- **Kathinka Evers: On 'Responsible Neuroethics' and Neuro-rubbish**
  The Neuroethics blog 2012-07-19

- **To the Origins of the Human Mind**
  CCCB - Centre de Cultura Contemporània de Barcelona
  Interview 2012-05-30

- **Utställd**
  Sveriges Radio P1, Tendens 2012-02-01

- **Forskare som tar på sig munkaveln**
  Sveriges Radio P1, 2012-01-31

- **Forskningen och tystnadsplikten**
  Sveriges Radio P1, Vetandets Värld 2012-01-17

- **DI:s beslut måste omprövas**
  Svenska Dagbladet 2012-01-04
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 2012

<table>
<thead>
<tr>
<th>Name</th>
<th>Academic title</th>
<th>Professional title</th>
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<tbody>
<tr>
<td>Tommy Cederholm</td>
<td>Professor</td>
<td>MD</td>
</tr>
<tr>
<td>Brita Karlström</td>
<td>Professor emeritus</td>
<td>Dietitian</td>
</tr>
<tr>
<td>Bengt Vessby</td>
<td>Professor emeritus</td>
<td>MD</td>
</tr>
<tr>
<td>Ulf Risérus</td>
<td>Associate professor</td>
<td>Researcher</td>
</tr>
<tr>
<td>Ulf Holmbäck</td>
<td>Post-doc</td>
<td>Researcher</td>
</tr>
<tr>
<td>Anja Saletti</td>
<td>Post-doc</td>
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<tr>
<td>Per Sjögren</td>
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<tr>
<td>Afsaneh Koochek</td>
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<tr>
<td>Viola Adamsson</td>
<td>PhD student</td>
<td>Nutrition manager</td>
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<tr>
<td>David Iggman</td>
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<td>MD</td>
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<tr>
<td>Elisabet Rytter</td>
<td>PhD student</td>
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<tr>
<td>Johanna Törmå</td>
<td>PhD student</td>
<td>Dietitian</td>
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<td>Name</td>
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<tr>
<td>Sigvard Sobestiansky</td>
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<td>Erika Olsson</td>
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<td>Fredrik Rosqvist</td>
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<tr>
<td>Roger Olsson</td>
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<td>Lecturer/Universitetsadjunkt</td>
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<td>Siv Tengblad</td>
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<td>Laboratory technician</td>
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<tr>
<td>Eva Lena Andersson</td>
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<tr>
<td>Linda Bratteby-Tollerz</td>
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<td>Physiotherapist</td>
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<tr>
<td>Marie Berglund</td>
<td></td>
<td>Research assistant</td>
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<tr>
<td>Love Franzen</td>
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<td>Research assistant</td>
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**Partly affiliated or associated to CNM**

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<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Wulf Becker</td>
<td>Associate professor</td>
<td>Chief nutritionist</td>
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<td>Stefan Branth</td>
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<td>Anders Forslund</td>
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<tr>
<td>Anders Sjödin</td>
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<td>Annika Smedman</td>
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<tr>
<td>Torbjörn Åkerfeldt</td>
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<td>MD</td>
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**Publications 2010-2012**


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**Reviews 2010-2012**


106. Vandewoude MFJ, **Cederholm T, Cruz-Jentoft AJ. Relevant outcomes in intervention trials for sarcopenia. J Amer Ger Soc 2011;59:1566.**


**Other articles 2010-2012**

115. **Adamsson V, Palmdahl K. Nordens Bästa Mat. ICA Förlaget 2012.**


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


121. 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**

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


**Agencies that support the work/Funding**

<table>
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<td>Formas</td>
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<td>Hjärt-Lungfonden</td>
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<td>Zetterlings stiftelse</td>
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<td>Uppsala County Council – ALF</td>
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<td>Stockholm County Council – ALF (The OmegAD Trial)</td>
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<td>Svensk Mjölk</td>
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**Future promising research at CNM**

- Understanding sarcopenia from clinical, epidemiological and molecular perspectives, and its treatment.
- Implementation techniques of nutritional routines and development of assessment tools for meals in elderly care.
- Dietary pattern effects on development of cognitive impairment and prostate cancer.
- Omega-3 fatty acid effects on epigenetic markers, mononuclear blood cell gene expression and effects on inflammation resolution.
- Fatty acid effects on gene expression, insulin sensitivity, inflammation, endothelial cell function and body fat distribution (ectopic fat accumulation).
- Impact of structural membranes for health effects by milk products
- Nutritional impact on metabolomics
- Cardiometabolic, transcriptomic and epigenetic effects of a healthy Nordic diet
- Evaluation of sagittal abdominal diameter as a valuable anthropometric risk marker
- Individualized treatment of child obesity
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 2012

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
Gunnar Janeslått, PhD Faculty of Medicine, associated researcher
Kjerstin Larsson, PhD Faculty of Medicine, associated researcher
Helene Lidström, PhD Faculty of Medicine, associated researcher
Helena Lindstedt, PhD Faculty of Medicine, senior researcher
Gunilla M. Olsson, PhD, associated researcher
Mia Pless, PhD Faculty of Medicine, associated researcher
Ieva Reine, PhD Faculty of Medicine, associated researcher
Karin Sonnander, PhD, professor
Annika Terner, BA, PhD student
Öie Umb-Carlsson, PhD Faculty of Medicine, senior researcher
Helena Wandin, BA, PhD student

External partners

Päivi Adolfsson, PhD, Centre for Disability Research, Uppsala University
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
Ulla Jergeby, PhD, National Board of Health and Welfare, Stockholm
Per Lindberg, PhD, professor, Department of Psychology, Uppsala University
Liselotte Norling Hermansson, PhD Faculty of Medicine, Clinical Research Centre, Örebro University Hospital, Örebro
Edward Palmer, PhD, adjunct professor, Department of Economics, Uppsala Center for Labor Studies, Uppsala University
Ingvar Pettersson, PhD Faculty of Medicine, senior lecturer, School of Health and Medical Sciences, Örebro University
Publications 2010-2012


85


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34. Ekstam, L., Johansson, U, Guidetti, S, Eriksson, G, Tham, K., von Koch, L., Ytterberg, C. Dyads' combined perception of rehabilitation needs one year after stroke: a mixed methods study (Submitted)


Reviews

Conference oral presentations and poster presentations

**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. ID-dagarna, Uppsala (Poster presentation in Swedish)


**Dissertation 2012**

**Blom Johansson, Monica.** Aphasia and Communication in everyday life. Experiences of persons with aphasia, significant others, and speech-language pathologists. Uppsala University 2012

**Agencies that support the work/Funding**

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

**Related tasks (members)**

Chairperson, member of the board, Centre for Disability Research, Uppsala University (Karin Sonnander)
Member of the board, Centre for Disability Research, Uppsala University (Johan Glad)
Member of the board of the Sävstaholm Foundation, Stockholm (Karin Sonnander)
Chairperson, member of the board of the Carola and Erik Tengström Foundation, Uppsala (Karin Sonnander)
National editor Scandinavian Journal on Disability Research (Karin Sonnander)
Reviewer of grant applications, The Swedish Association of Occupational Therapists (FSA) (Helena Lindstedt)
Examinations and evaluations (members)
During 2012 assignments as expert at evaluation for 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 2012 (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). Nursing and Nursing methods 15 Higher Education Credits (Õie Umb-Carlsson lectures on Discrimination Act and Act concerning support and service for persons with certain functional impairments and seminar on Treatment and Disability.

**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 (Õie Umb-Carlsson), and essay examination (Karin Sonnander).

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

Course coordinator including lectures and seminars (Õie Umb-Carlsson), single lectures (Monica Blom Johansson, Helena Lindstedt) and examination (Karin Sonnander) for the course Impairment and Disability-Introductory 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 (Õie Umb-Carlsson) for the commissioned course Understanding and Providing Leadership Based on the National Basic Value System for the Elderly, 7.5 Higher Education Credits

Speech-Language Pathology Programme (Department of Neuroscience)

Course coordinator, 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 (Õie Umb-Carlsson)

**Research projects**

**Disability Services, Systems and Policies**

People with disabilities often experience extensive difficulties in handling everyday life and thus may need and receive lifelong professional service and support. Studies focus 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 of evidence practice in habilitation services.

**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.
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: Helene Lidström, Gunnel Janeslätt, Päivi Adolfsson, Ingvor 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, Öie Umb-Carlsson, 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).

Aided communication between persons with Rett syndrome and their interaction partners
Participants: Helena Wandin, Per Lindberg, Karin Sonnander
The aim is to increase the knowledge of aided communication intervention targeting people with Rett syndrome. The different studies aim at 1) examining Swedish speech and language pathologist's experiences of communication intervention, especially aided communication intervention provided to persons with Rett syndrome 2) examining how interaction partners assess aided communication and if the assessment differ according to relation to the individual with Rett syndrome 3) evaluating an aided communication intervention targeting the social network of persons with Rett syndrome.
Returning to work after stroke

Participants: Gunilla Eriksson, Therese Hallman, Ulla Johansson, Annie Hansen-Falkdal, Birgitta Bernspång, Elin Ekbladh, Birgitta Svensson, Karin Sonnander

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

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

Participants: Ieva Reine, Helène von Granitz, Edward Palmer, Karin Sonnander

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

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, an international standard language and framework for the description of 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).

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 of the 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:** Òie 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:** Òie 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:** Òie 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 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 2012

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**External:**

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Arne Loweden, PhD, Assistant Professor, University of Stockholm
Scott Moffat, PhD, Associate Professor, Wayne State University
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Douglas Ruden, Associate Professor, Wayne State University
Weisong Shi, PhD, Professor, Wayne State University
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Carina Wennman, psychologist
Ulrika Winblad, Associate Professor, Health Services Research, Dept of Public Health and Caring Sciences
Eva Vingård, MD, Professor
Ragnar Westerling, MD, Professor, sociomedical epidemiology, Dep of Public Health and Caring Sciences
Annica Åbrink, occupational therapist, Uppsala University Hospital
Torbjörn Åkerstedt, PhD, Professor, University of Stockholm

Publications 2010-2012
1) Articles from former Family Medicine and Clinical Epidemiology
2) Articles from former Preventive Medicine
3) Articles from former Social Medicine

2012
2. 1) Andre M, Anden A, Borgquist L, Rudebeck CE. GPs' decision-making: perceiving the patient as a person or a disease. BCM Fam Pract 2012;13:38-
5. 1) Arvidsson E, André M, Borgquist L, Andersson D, Carlsson P. Setting priorities in primary health care - on whose conditions?: A questionnaire study. BCM Fam Pract 2012; 13:114-


35. 1) Kiotseridis H, Bjerman L, Pilman E, Ställberg B, Romberg K, Tunsäter A. ALMA, a new tool for the management of asthma patients in clinical practice: development, validation and initial clinical findings. *Prim Care Respir J* 2012;21(2):139-44.


55. 1) Sundh J, Janson C, Lisspers K, Ställberg B, Montgomery S. The Dyspnoea, Obstruction, Smoking, Exacerbation (DOSE) index is predictive of mortality in COPD. *Prim Care Respir J* 2012;21(3):295-301.


2011


2010


151. 1) Holmberg SAC, Thelin AG. Predictors of sick leave owing to neck or low back pain: a 12-year longitudinal cohort study in a rural male population. *Ann Agric Environ Med* 2010;17:251-57.


164. 1) Kallings LV. Fysisk aktivitet på recept i Norden: erfarenheter och rekommendationer *Nordisk netværk for fysisk aktivitet, mat og sundhet* In press.


**Dissertation 2012**

Engström Sevek. *Dental health care cooperating with primary health care as a resource in early case finding of patients with diabetes or hypertension*. Medical sciences. Uppsala University, 2012.

**Agencies that support our work/Funding 2012**

- Uppsala County Council (ALF) 2 240 000
- The Swedish Social Insurance Agency 2 000 000
- The Swedish Research Council 2 920 000
- AFA 130 000
- REHSAM 2 700 000
ArbetsRehab -- Organization for Financial Coordination Uppsala County 2,970,000
The Royal Foundation of Sweden (Kungafonden) 1,400,000
The Swedish Research Council (Impact of Religion Program, Program Leader, The Swedish Council for Working Life and Social Research) 2,100,000
The Municipality of Södertälje 2,100,000

Education

Medical Programme - Professional Development

Annika Bardel, responsible for training of student tutors
Karin Björkegren, responsible for terms 1 and 2 and director of undergraduate studies
Bo Karlsson, responsible for terms 3, 4 and 11

Beside the above mentioned many other members from Family Medicine and Preventive Medicine are taking part on different educational levels:

Kristina Bröms, Gunilla Burell, Anders Carlberg, Anna-Sophia von Celsing, Sevek Engström, Margaretha Eriksson, Christina Halford, Johan Hallqvist, Anna Hofsten, Per Kristiansson, Karin Lisspers, Mats Martinell, Magnus Peterson, Åke Schwan, Jan Stålhammar, Björn Ställberg, Kurt Svärdsudd, Thorne Wallman.

Research projects

Research area I:

Social Insurance Medicine
Participants: Ingrid Anderzén, Lars Englund, Johan Hallqvist, Gunilla Norrmén, Kurt Svärdsudd, 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, Uppsala and Örebro universities 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. Members are participating in one national social insurance research group, SPID, with four annual meetings. The group was represented at the 2nd Nordic Conference in work-related rehabilitation, Grenå, Denmark, September 2012 with three posters: “Early multidisciplinary assessment resulted in longer periods of sick-leave – a randomized controlled trial in a Primary health center” [1], “Nurses’ experiences of managing sick-listing issues in telephone advisory Services” [2], and “Early prediction of patients at risk for long term sickness absence” [3].
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 [4] and another has been submitted for publication during 2012 [5].

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 [6], 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 [7]. 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 [8].

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 [9].

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 [10].

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 [11]. In the second report, patient-related medical factors and functioning were analysed [12]. 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.
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 [14]. The project has generated one PhD thesis (Gunilla Normén 2010) [15].

Determinants for return to work among sickness certified patients in general practice (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. The aim of this study was to analyse possible determinants of return to work and their relative impact. All 943 patients aged 18 to 63 years, sickness certified at this Primary Health Care Centre from January until 31 August 2004, were followed up for three years. Baseline information on age, sex, sick leave diagnosis, extent of sick leave, employment status, and sickness absence during the year before baseline was obtained, as was information on all compensated days of sick leave, disability pension and death during follow-up. The two most influential variables on return to work was sick leave because of psychiatric disease and sick leave track record [16]. The study was presented in an oral presentation and a poster at the 2nd Nordic Conference in work-related rehabilitation, Grenå, Denmark, September 2012 [3].

We will also study whether the most important determinants for return to work may be used in a risk assessment tool (nomogram). The results will be compared to a categorisation, performed by a team of experienced rehabilitation professionals, considering six risk factors for long-term sickness absence from the sickness certificate. The team categorised all sick-listed individuals into two groups, group 1 (n=447) at high risk, and group 2 (n=496) with less risk for long-term sickness absence.

Furthermore, the effects of the rehabilitation intervention in cooperation with primary health care, the Swedish Social Insurance Agency, Jobseekers Agency and the County Council for Social support, will be studied. Do sick listed individuals regain work ability after an intervention to a greater extent than those who did not receive any intervention at all? The project 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 fourteen nurses working with telephone advisory services in primary health care centres in Sweden were interviewed in groups. In the group interviews the nurses’ experiences of managing sick-listing issues were explored. The nurses experienced stress and difficulties related to being gatekeepers and related to the act of balancing different demands from patients, co-workers and the organisation. The project was presented by a poster at The second Nordic conference on work-oriented rehabilitation, in September 2012 in Grenå, Denmark (Abstract) [2] and has generated one published article [17].Sixteen people on long-term sick-leave were interviewed individually in study II. Findings revealed that the participants’ experienced that their life-worlds were radically changed when they became sick-listed. They described losing their independence in the process of stepping out of working society, attending the mandatory steps in the rehabilitation chain and having
numerous encounters with professionals. The most conspicuous findings were the fact that stopping working brought with it so many changes, the participants’ feelings of powerlessness in the process, and their experiences of offensive treatment by and/or encounters with professionals. The article is submitted for publication [18]. The project is generating one PhD thesis (Linda Lännerström).

Factors among doctors, and patients affecting the risk of long-term sick leave periods, and effect 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 did not include such early assessments. Our hypothesis was that such assessments would result in faster and more adequate rehabilitation leading to faster recover and less need of sick leave. One article is under review. This project was also presented by a poster at 2nd Nordic Conference in Occupational Rehabilitation, Gønæ, Denmark, in September 2012 [1] and one submitted article under review [19].

In another project data on GP’s perception of sick leave assignment are being analyzed. Data were gathered through qualitative focus group interviews. The project is generating one PhD thesis (Lars Carlsson).

Absenteism and Return to Work -- Social Medicine (I:8)

In collaboration with the Swedish Social Insurance Administration, the Swedish Public Employment Service, and the Primary Health Care sector, we have projects assessing the efficacy of various innovative return-to-work strategies, including the concept “Pathway Back to Work”. The aims of these projects are focusing on enhancing the pathway back to work and to identify factors that will help long-listed individuals return to the working life.

“SAMKLANG” – In Co-operation – Acceptance, motivation and return to work among long-term sick listed (I:9)

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 study is to find factors that predict return to work for those individuals that had been on a long term sick leave. A Psychologist has treated sixty participants on long term sick leave with Acceptance and commitment therapy (ACT) during three months. After one year 68% of the participants are ready to return back to work or studies. Participants that had return to working life were interviewed and will result in one article. Participants in the project are Ingrid Anderzén, Anna Liljestam Hurtigh, Anna Finnes, and Annica Åbrink.

VITALIS – An RTC study to support women on long term sick leave to return to working life through ACT or Team evaluation (I:10)

This project started as 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 were during 2010 diagnosed with psychological problems, such as depression, anxiety and stress related symptoms, and/or chronic pain. The overall aim with this project was to develop, provide and evaluate accessible rehabilitation programs, for these complexes of problems, to help women on long term sick leave, to return to work. Vitalic started in Spring 2010 and data collection will be completed in 2013. Approximately 400 women on long term sick leave due to pain, stress, depression and/or anxiety symptoms, identified by the National
Insurance Agency in Uppsala County were randomized into one out of three conditions. One as a multimodal team assessment and intervention, one with a home based internet supported unimodal psychological intervention (Acceptance and Commitment Therapy) and one condition as a treatment as usual (TAU) intervention. The project will evaluate the long term effects (after one, and after two years) of those two different rehabilitation packages: multidisciplinary team assessment/intervention and CBT/ACT home based/internet treatment as compared to TAU. The one year follow-up data collection is completed and the two year data collection is on-going. The evaluation of the project is receiving financial support from Rehsam. Participants in the project are Ingrid Anderzén, Åsa Andersén, Anna Finnes, Anna Liljestam Hurtigh, Carina Lundeén, Per Lytsy, Linnea Molin, Eva Toreberg, Ragnar Westerling, and Annica Åbrink.

**DIRIGO – “latin word for I drive” (I:11)**

Dirigo is an ongoing project funded by The European Social Fund (ESF) and is operated by The Social Insurance Office, in co-operation with The Public Employment Service and the municipality, in parts of Stockholm. Participants in the project are sick listed individuals, young individuals with activity compensation from The Social Insurance Office and individuals that receive their compensation through their local municipality. About 1800 individuals will participate in the project. The overall aim with the project is to support and strengthen the individual and its view on their work capacity to return to/come closer to the labour market/employment. Together with the Linköping University we evaluate the project both with quantitative measurements (data from registry and questionnaires) and qualitative measurements during open ended interviews and focus groups with service users and professionals working in the area of vocational rehabilitation. The project started 2012 and will be completed in 2014. Participants in the evaluation process are Ingrid Anderzén, Åsa Andersén Kerstin Ekberg, Kjerstin Larsson, Christian Ståhl, and Eva Vingård.

**UMiA - Youth Mobilization for Working Life (I:12)**

The project "UMiA" is founded by the European Social Fund (ESF) and is operated by The Social Insurance Office in Stockholm. The aim of the project is to develop, and evaluate different methods and interactions in order to support and enhance the ability for young individuals with disabilities to increase their work or study capacity. About 900 individuals, age 19-29 years will participate in the project.

We evaluate the project and the evaluation consists of both quantitative measurements (data from registry and questionnaires) and an on-going evaluation (qualitative) with service users and professionals working in the area of vocational rehabilitation perspective. UMiA started 2013 and will be completed in 2014. Participants in the evaluation process are Ingrid Anderzén, Åsa Andersén Kjerstin Larsson, and Eva Vingård.

**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.

Epicondylitis (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 parts: 1) An epidemiological study of treatment methods in primary health care, 2) A randomized controlled trial of different types of graded exercise as treatment for this condition and 3) an experimental study investigate the pathophysiology of the condition by imaging methods.

The first part was fulfilled in a postal questionnaire study involving general practitioners and physiotherapists, which showed that a large number of methods were used, some of which were not tested for efficacy, and even some that had been shown to be ineffective [33].

The second part was fulfilled in a double randomised controlled clinical trial in which the effect of exercise versus wait-and-see was first tested, and then the effect of two treatment methods (eccentric and concentric exercise) were compared. The study involved more than 200 patients in a multicentre setting in Uppsala and Linköping. A publication on exercise versus wait-and-see has been published [34]. A manuscript on eccentric versus concentric exercise is submitted [35].

The third part was fulfilled by positron emission tomography (PET) of physiological processes associated with pain in the peripheral painful tissue of the healthy compared to the affected elbow. The PET scan data have been analysed in cooperation with the Uppsala PET-centre and a manuscript has been 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.

The PET-project is currently expanded to involve imaging of more and new mechanisms in the peripheral tissue. The research group at Uppsala PET-centre has been expanded and an application for ethical approval is in progress.
Cognitive behavioural therapy in fibromyalgia (II:4)

This project, which is being performed in collaboration with 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 Mid-Sweden were randomised to one of two groups. One group received CBT for one year with the other group as control. After one year the control group also received CBT. A large number of variables have been collected through questionnaires and blood samples. The data has been analysed. The project is generating one PhD thesis (Bo Karlsson) and is supported by grants from the Söderström-Königska Foundation, the Swedish Rheumatism association, the Swedish Social Insurance Agency, Uppsala County Council and Uppsala University. The funding authorities had no influence on the design and performance of the study.

Persistent pregnancy-related low back and pelvic pain (II:5)

Pregnancy-related low back and pelvic 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 within six month after delivery, although in several instances disabling back pain persists many years after delivery. Almost 1 of 10 women still experienced disabling daily low back and pelvic 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 persistent pregnancy-related low back and pelvic pain. 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 ischial 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 persistent pregnancy-related low back and pelvic pain. 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 two PhD theses (Thomas Torstensson and Anne Lindgren) 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. Several 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 published [59]. A sixth report about quality of life in COPD (CCQ) and mortality has been published (Sundh et al) and a seventh about exacerbations in COPD has been submitted (Sundh et al). A follow-up investigation has been started in 2012 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-Örebro Region, Uppsala-Örebro Regional Research Council, the Swedish Heart and Lung Association, the Swedish Asthma and Allergy Association, the Bror Hjerpstedt Foundation, Uppsala, and Uppsala University. A predoctoral student, Anna Ericson, has started to work with the asthma part of the PRAXIS-study in 2012.

**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]. A manuscript about a comparison of COPD patients in large clinical trials and COPD patients attending primary care has been submitted [63].
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 [64].

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 [65].

COPD rehabilitation study (III:8)
Björn Ställberg and Karin Lisspers have members in the steering committee of a national investigation of resources for rehabilitation in COPD. A first paper has been submitted [66].

Clinical trials (III:9)
Björn Ställberg has been involved as coordinator in two clinical trials in asthma and COPD respectively [67, 68].
Björn Ställberg was a member in the steering committee for a study about treatment of rhinosinusitis, the SOSAR-study [69].
Karin Lisspers was a member of the steering committee for a study regarding screening for COPD, the DETECT-study [70].

The NO-KOL study (III:10)
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 [71]. The project is being led by Gunnar Johansson and Kjell Alving and has received financial support from Schering-Plough.

Treatment of asthma in primary health care using exhaled nitric oxide analysis (III:11)
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 has been collected from the Hospital Discharge Register (Slutenvårdsregistret) and the Cause of Death Register and information on prescribed drugs was collected from the Prescription Register. Data on social-economic status has also 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 have been presented and the first article has been accepted for publication in Journal of Internal Medicine: Combination of budesonide/formoterol more effective than fluticasone/salmeterol in preventing exacerbations in chronic obstructive pulmonary disease. The PATHOS study. (Kjell Larsson, Christer Janson, Karin Lisspers, Leif Jørgensen, Georgios Stratelis, Gunilla Telg, Björn Ställberg & Gunnar Johansson). Doi: 10.1111/joim.12067.

**Research area IV:**

**Utilisation 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 [72]. In a second report the use of hormone replacement therapy at menopause and symptoms reported by users and non-users was presented [73]. In a third report adherence to the prescribed drug and its determinants were presented [74]. 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 [75]. 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 and 2012. 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 [76]), and is receiving financial support by 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 [77].

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 [78].

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 [79-81], diabetes [82], gastroesophageal reflux disease and irritable bowel disorder [83][84], reumatoid arthritis [85] cardiovascular diseases like atrial fibrillation [86], MI [87], chest pain [88] and also studies investigating the safety and utilization of a new statin, rosuvastatin [89, 90].

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 [91] and researchers from several Chinese Universities [92-94].

In recent years, we have also had research collaboration with Professor John Dent, Adelaide [84, 95], 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

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

Determinants for the survival of diabetes patients (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 [96] as well as a study of mortality trends in subjects with and without diabetes during 33 years of follow up [97]. 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 [98-127]. 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 [115], 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 [116] and type 2 diabetes [120], and in patients with a history of CVD in type 2 diabetes.

It has also been shown that blood pressure (BP) <140/80 mmHg strongly reduced risk of CVD, indicating a BP treatment target well below 140 mmHg like 130-135/75 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 [118, 121-123, 129]. Specific statistical graphical technique was applied to illustrate in detail the variation of CVD risk across the BP distribution [123, 129]. A BP target 130-135/75 mmHg found in the NDR is in accordance with recent guidelines from the European Societies of Hypertension and Cardiology and the American Diabetes Association.

Normal weight reduced risks of CHD and CVD by 15% and 22%, as compared with overweight or obesity [111], and non-smoking at middle age reduced risks of CHD and CVD by 57% and 38% [111].

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 [113]. High pulse pressure >75 mmHg (indirect measure of increased arterial stiffness) has been shown as an independent risk factor for CHD and CVD [114].

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 [124]. 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 [125].

Long-term tight control of HbA1c [108] and BP were related to low BMI, HbA1c also to non-smoking, and BP also to absence of albuminuria [104]. 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 [102] [119]. Treatment in the early years of follow-up in newly diagnosed patients with type 2 diabetes has been analysed, showing an improvement in estimated CVD risk during the last years among patients in the NDR [126].

Studies of the effect of pharmacological treatment on risk for diabetic complications have been performed in recent years using linking with the Swedish Prescribed Drug Register [128]. Among 51 000 patients with type 2 diabetes followed for 4 years, metformin showed lower risk than insulin for CVD and all-cause mortality and slightly lower risk for all-cause mortality compared with other sulphonylurea. Patients with renal impairment showed no increased risk of CVD, all-cause mortality or acidosis/serious infection. In clinical practice, the benefits of metformin use clearly outbalance the risk of severe side effects [130].

Another study on pharmacological treatment analysed use of aspirin in patients with type 2 diabetes and no previous cardiovascular disease in the NDR. No association was found between aspirin use and risks of CVD or death, also when separating the patients into those with higher or lower predicted CVR risk with use of a risk model. There was a trend towards increased risk of a composite of bleedings associated with aspirin [131].

The association between hyperglycemia and risk for various types of cancer has been analysed in the NDR. A cohort study on 25 000 patients with type 2 diabetes was followed for around 10 years until 2009, with estimation of incidences of and hazard ratios for cancer in groups categorized by HbA1c, lower <58 mmol/mol versus higher >58 mmol/mol, by quartiles of HbA1c, and by HbA1c continuously at Cox regression, adjusting for relevant covariates also with use of a propensity score. There were no associations between HbA1c and risks for all cancers or specific types of cancer in patients with type 2 diabetes [132].

Two risk models for estimation of 5-year CVD risk in type 1 diabetes or type 2 diabetes have been published based on several cardiovascular risk factors and clinical characteristics, and both risk models have shown good validation when applied to patients with diabetes in Sweden. These two risk models are presented at www.ndr.nu and can be useful for diabetes care in daily clinical practice [120, 127]. A simplified risk model for estimation of 5-year CVD risk has also been introduced for clinical use, although less thoroughly validated [109].

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, and the Swedish Association of Local Authorities and Regions funds 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 [133-136]. The first study described the incidence and prevalence of T2DM [133]. The second and third studies provided an in depth analysis of the resource use and costs of T2DM [134, 135]. In the fourth study the time to insulin treatment and factors associated with insulin prescription are described [136]. 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 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 [137]. 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 (Slutenvårdsregistret) and the Cause of Death Register and information on prescribed drugs were collected from the Prescription Register. Data on social-economic status were also 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 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 be 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 [138] irrespective of sex, age, previous antihypertensive treatment, baseline blood pressure, and presence diabetes [139]. 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, all patients were followed up with new examinations every six months for 30 months, where the risk factor levels were measured. A nutritional examination was done twice, as well as a video interview to measure the effects of the behavioural modification programme. 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 [140]. 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. A high attendance rate lowered the risk. During the first 2 years of follow up there were no significant group differences in traditional risk factors [141]. The project has generated one PhD thesis (Mats Gulliksson 2009 [142]). 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 [143]. 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 [144]. The project has generated one PhD thesis (Mats Gulliksson 2009 [142]), 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 [145]. 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 [146]. Health problem prevalence according to interview and record scrutiny was modest, peaked early after discharge and then declined [147]. 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 [148]. The project has generated one PhD thesis (Lena Olai 2010 [149]), 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 [150]. 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 [151]. In the third report the diabetes screening showed the need for inclusions criteria, as age and BMI, for efficient finding those at risk [152]. The forth project is calculating the direct cost for this type of screening organisation. The project has generated one PhD thesis (Sevek Engström 2012 [153]), 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 [154-156]. 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 [157]. 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 [158], 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 exercise 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 [159]. Physical fitness don’t prevent pregnancy-related back pain but fit women experience less pain [160]. Both serum relaxin and absolute VO$_2$ peak, est. was associated to mean diastolic blood pressure levels. Fitness were also associated to gestational length and women with miscarriage has higher absolute VO$_2$ peak, est.

**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 Center which administers the Swedish national quality registry for cardiovascular disease, RIKS-HIA. Participants are Judy Arnetz, Anna Höglund, Ulrika Winblad, Bengt Arnetz.

**Research area VI:**

**Stress**

Participants: Ingrid Anderzén and Bengt Arnetz
Management control systems and stress: interdisciplinary field experiments (VI:1)

In an interdisciplinary research program we combine two fields of knowledge: Medicine and Management control systems (MCS). Management control systems (MCS) in organizations have become more complex. They measure performance on more objects, with new and more measurements, they provide information more frequent and quicker, and they are used at lower levels in organizations. But we do not know how these complex MCS influence the human body. Do they improve health, well-being and performance in organizations? Or do they make people develop insomnia, stress and other unhealthy outcomes that are economically and socially costly? This interdisciplinary research program combines two fields of knowledge; social medicine and MCS. The purpose is to examine and explain how MCS design affects psychosocial factors in the organization, stress, and performance. This is important because MCS are used for planning and evaluation in organizations. MCS can thus be expected to influence the psychosocial factors in organization that are associated with negative stress reactions, work-related health, and performance outcomes. Data collection was finished during year 2012 and the analyses are ongoing. One article is in manuscript. This project is running in collaboration with Department of Business Studies, Uppsala University, receiving financial support from Riksbankens Jubileumsfond. Participants in the project are Ingrid Anderzén, and Lars Frimanson.

GodA - Good working environment and healthy workplace – test of a model linking the work environment, employee well-being and corporate development (VI:2)

"Promoting factors" at work are supposed to promote both the individual's physical and mental health and the company's competitiveness and profitability, thus providing "healthy workplaces". Which factors act health promoting, as well as how an organization can work to promote the health of the employees while ensuring a commercially sound business, is still in its infancy. The GodA-study aims to test whether a development project organized by the so-called PATH-model (Grawitchet al.,2006) results in increased employee well-being and concurrent organizational improvements. In 2012, a pre-study in form of focus groups and individual interviews in three medium sized enterprises was undertaken. The interviews sought to examine what employees and managers considered to characterize a "good" work environment and what gives them wellbeing at work. The results from the interviews and known health and safety parameters have constituted the basis for a questionnaire with which employees of the three companies are followed for 2 years. Parallel, data concerning the companies’ key indicators and internal developments are collected. One of the companies’ designs its work with their internal development according to the PATH-model. At the two-year follow-up the results from the “PATH-company” concerning the well-being of both employees and the company will be compared with the results from the other two companies designing their internal development after their own choice. This study aims to increase knowledge about how to achieve sustainable health and wellbeing of both the individual and the company parallel. Such conditions can be assumed to save suffering for the individual and reduced costs for the company and society. This project is running in collaboration with Centre for Musculoskeletal Research, University of Gävle, receiving financial support from AFA. Participants in the project are Ingrid Anderzén, Per Lindberg and Thomas Karlsson.

Spiritual and existential moderators of the stress – health relationship (VI:3)

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. Participant is Bengt
The importance of post-displacement institutional and stressors and resiliency factors and its implications for refugee post-displacement mental health (VI:4)

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:5)

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 and Matt Ventimiglia.

Real-time assess of psychophysiological stress responses (VI:6)

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 and Weisong Shi.

Research area VII:

Triggers of the onset of disease and other health problems

Johan Hallqvist

The case-crossover methodology was developed at Harvard in the beginning of the 1990-ies and it opened up a new field of research; the study of risk factors with short induction periods, that is, triggers of disease. In the ongoing projects all conducted in collaboration with research groups at Karolinska Institutet we aim to identify triggers of acute health events, and to quantify their effects. In the first four case-crossover projects we are applying the design to data bases extracted from Swedish National registers. In studies of Side-effects of drugs, the first aim is to identify harmful side-effects of pharmaceutical drug use and the second aim is to potentially develop a system for surveillance. We use a record linkage between the new drug prescription register (exposures and sometimes also outcomes) and the hospital discharge register (outcomes). Another study concerns
Psychiatric care as acute deterrent or trigger of suicide, in which the inherent self-control in the design makes it possible to study the quality of the psychiatric evaluation of suicide risk in consultations. The study is based on record linkage between inpatient, outpatient and cause-of-death registers. In a third study we examine Non-cardiac surgery as trigger of myocardial infarction. It is based on record linkage between hospital registers and myocardial infarction incidence registers. The trigger effect is well known and RCT’s testing beta blockers as profylaxis has been undertaken but our aim is to quantify the absolute and relative risks with different types of surgical procedures. We also examine Acute life events (like death of close relative) as triggers of acute diseases like myocardial infarction and stroke, in a study based on record linkage between the multigenerational register and the hospital and the cause of death registers. TUFS (Swedish acronym for triggers of sickness absence) was a part of a thesis work and aimed at identifying non-medical triggers interacting with reduced work ability due to illness. It was based on extensive data collection from more than 1000 spells of sickness absence at six work places. TOFA (Triggers of falling) is based on data collected from old men and women with hip fractures. Finally Psychoactive substances as triggers of violence is a study based on data collection from individuals in custody in Stockholm because of criminal activities including violence (The Stockholm Social Medicine Custody Project).

Research area VIII:

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

We have earlier shown that there are inherent difficulties in the task of disentangling time-related exposure constructs like accumulation, critical period and mobility in life course epidemiology. At present we pursue further in-depth analyses of specific hypotheses related to these theoretically based mechanisms in collaboration with researchers at Karolinska Institutet. We also have a general interest in methodological issues related to the study of mechanisms behind inequalities in health and we have for example shown the importance of distinguishing between differential exposure and differential susceptibility when analyzing for example the effects of exposure to job strain. In Life Time Health: the effect of fetal exposures, social trajectories and social transitions on health and health behavior the aim is to study trajectories and transitions as important features of the life course and to find out how health related parameters are influenced and through which mechanisms. In this project we use the new Stockholm Public Health Cohort (SPHC) with repeated questionnaires and all kinds of register information for approx 65000 participants. In associated projects we use the SHEEP 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. In another study the effect of contextual and individual social capital on psychological distress and self-rated health is analyzed in the Stockholm County using neighborhoods as the contextual level.

**Research area IX:**

**Feasibility and efficiency of interventions**

Johan Hallqvist and 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:**

**Reproductive health**

Per Kristiansson

Reproductive health is a new field of interest that is under development. The overarching questions are reproductive health for women and men in relation to primary health care. The research program will involve about four doctoral students. In this program a unique digital version of pain drawing is developed.

**Research area XI:**

**Varia**

**Self-rated health (XI:1)**

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. Four articles have been published [161, 162, 163, 164], and one manuscript is forthcoming [165]. The project has generated one PhD thesis (Halford 2010, [166]). 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 (XI:2)

Vitamin D in blood has been demonstrated in studies to be low in women from countries located in the southern part of Middle East and some countries in Africa. Immigrant women from countries in the Middle East have been investigated by a physician and a dietician in terms of different aspects of their vitamin D status and possible associated diseases. They were compared with age-matched Swedish women. Preliminary results show a large difference in vitamin D levels with low values in many immigrant women in comparison with the Swedish women. Treatment with vitamin D and 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) (XI:3)

Many patients with advanced COPD are affected by their decreased lung function and often have reduced muscular function as well. They consequently often do not go out, and their diet also tends to be low in products containing vitamin D. This study will investigate the vitamin D status and the correlation to muscle function in these patients with COPD. The study is planned to be performed at a primary health care centre by a physician and a dietician. If the patients are shown to have low values, treatment with vitamin D and calcium will be initiated. The principal investigators are Anne Björk, Åsa Andersson and Gunnar Johansson.

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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 2012

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

Publications 2010-2012

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2010


**Books**


**Dissertation 2012**

**Elina Rönnemaa.** Predictors of Dementia: Insulin, Fatty Acids and Vascular Risk Factors.
**Agencies that support the work/Funding**

Vetenskapsrådet (2012-1593, 2011-4519; 2010-6745; 2009-4567; 2009-4389; 2006-3464) 4 300 000 SEK/year

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

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

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

Fakultetsmedel, Uppsala universitet 2 500 000 SEK/year

Parkinsonfonden 500 000 SEK/year

PET-forskning 500 000 SEK/year

Diverse fonder 1 800 000 SEK/year

Hjärt-kärlfonden 400 000 SEK/year

Wallenberg-stiftelsen 700 000 SEK/year

**International collaborations**

**Guest visits in foreign laboratories**

Thomas Näsström (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, the Swedish Brain Power network and the U4 network (together with the Universities of Göttingen, Ghent and Groningen).

**Engagement in the external society**

Research projects

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

We 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 have recently established cell culture models with primary neurons and astrocytes in order to clarify mechanisms behind initiation and spreading of AD.

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

The over-all purpose of this project is to improve clinical Positron Emission Tomography (PET) imaging in Alzheimer’s disease (AD) such that the technique can be used to monitor disease progression and therapeutic efficacy of intervention with drug candidates. The project will include development of new radioligands as well as development of imaging paradigms based on already existing radioligands that target neuroreceptors believed to be involved in the pathogenesis of AD. We have developed a 125I-labelled new imaging agent based on mAb158 by using its F(ab')2 fragment. The advantages with using a F(ab')2 fragment compared to a whole antibody is mainly two-fold; first, the smaller fragment is likely to be distributed across the blood-brain barrier to a higher degree compared to the larger antibody, and second, F(ab')2 fragments have considerably shorter half-life than antibodies. This is beneficial as it reduces the radioactivity in the blood volume of the brain and thereby also reduces contamination of the radioactivity signal in the brain area (that should reflect radioactivity in tissue only) detected in the PET-scanner. The focus of our present research is to further improve the brain distribution of the 125-I labelled F(ab')2 fragment and thus develop a new amyloid PET radioligand for use in the clinic.

Parkinson’s disease
(Assoc. Prof. Martin Ingelsson and Joakim Bergström, PhD)

As aggregation of pathological proteins in the brain is a general feature for neurodegeneration, immunotherapy could have potential also for other disorders than AD. In Parkinson’s disease (PD), alpha-synuclein deposits as Lewy bodies and Lewy neurites inside the neurons. As with 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 intermediately 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 several of these have been evaluated for immunotherapy on cell and animal models for the actual diseases. Importantly, we have found that intraperitoneal injections with one of these antibodies can lower the levels of toxic alpha-synuclein oligomers/protofibrils in transgenic mice. Moreover, we seek to adopt the 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. We are also investigating the underlying mechanisms by alpha-synuclein impair key
cellular function. A focus is investigating how oligomers impair cellular degradation systems and how alpha-synuclein oligomers present in the endoplasmic reticulum perturb cellular function.

**Genetics**
*(Vilmantas Giedraitis, PhD)*

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 Årnlöv, 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 Årnlöv 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. Anna Christina Åberg is studying new methods for clinical motor function assessment, as well as a potential association between motor function and subjective health aspects, such as life satisfaction and fear of falling. The research is mainly directed towards elderly with a need for rehabilitation due to multiple diseases/functional limitations, and those with specific neurological or neurodegenerative diagnoses, such as stroke or AD.
Ongoing, particularly successful, research

Our translational research efforts have been very successful and we have maintained an international visibility and high quality of publications. Among the expanded and new efforts, we have a particular focus on developing better principles of imaging and diagnostics for AD and exploring possibilities for novel future therapeutics against PD and Lewy body dementia. We are one of several groups in Uppsala focusing on protein aggregation and age-related amyloid diseases. The local scientific environment thus provides a unique opportunity for collaborative efforts to increase the knowledge on mechanisms underlying amyloid disorders, especially within the Berzelii Centre for Neurodiagnostics and in SciLifeLab. Compared to other dementia research teams in Sweden our focus on molecular mechanisms in the pathogenesis of AD has been very successful. We have a clear scientific strategy and a good research structure. The preclinical and clinical activities have been successfully integrated in Uppsala, which enables a more efficient translational research process.
Health Services Research

Research group leader 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 2012

Ulrika Winblad, PhD, associate professor, group leader
Åsa Muntlin Athlin, RN, PhD
Cecilia Bernsten, Registered pharmacist, PhD, associate professor
Ingeborg Björkman, Registered pharmacist, PhD
Madeleine Boll, Physiotherapist, Licentiate, PhD student
Eva Boström, RN, PhD
Linn Boström, research assistant
Gunilla Brattberg, MD, PhD, associate professor
Tobias Dahlström, PhD
Love Edberg, research assistant
Helene Eriksson, Administrator
Annica Ernesäter, RN, MSc, PhD student
Mio Fredriksson, MSc, PhD student
Roya Hakimnia, MSc (Medicine), PhD student
Finn Hjelmblink, MD, PhD
David Isaksson, MSc, Phd Student
Elenor Kaminsky, RN, BSc, PhD student
Dorte Kjeldmand, MD, PhD
Jan Larsson, MD, PhD
Linda Lännerström, PhD student
Anna Mankell, research assistant
Linda Moberg, PhD student
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 2010-2012


12. **Björkman I, Sanner MA.** The Swedish A(H1N1) vaccination campaign - why did not all Swedes take the vaccination? *Health Policy*, 2012 Oct 5. [Epub ahead of print].


**Dissertations 2012**

**Annica Ernesäter**, National Telephone Advice Nursing in Sweden: Patient Safety and Communication

**Mio Fredriksson**, Between Equity and Local Autonomy: A Governance Dilemma in Swedish Healthcare
Agencies that support the work/Funding

The Swedish Research Council (Vetenskapsrådet) Ulrika Winblad 1 257 000 kr
The Swedish Research Council (Vetenskapsrådet) Inger K Holmström 725 000 kr
Swedish Council for Working Life and Social Research (FAS) Ulrika Winblad 800 000 kr
Swedish Competition Authority (Konkurrensverket) Ulrika Winblad 393 000 kr
AFA Insurance Inger K Holmström 866 868 kr
AFA Insurance Åsa Muntlin Athlin 2 404 380 kr
The National Board of Health and Welfare (Socialstyrelsen) Ulrika Winblad 262 950 kr
The Swedish Agency for Health and Care Services Analysis Ulrika Winblad 130 950 kr
Swedish Association of Local Authorities and Regions (SKL) Ulrika Winblad 1 365 850 kr
Uppsala County Council Mio Fredriksson 302 940 kr
Uppsala County Council Åsa Muntlin Athlin 175 000 kr
Medical Products Agency – Sweden (Läkemedelsverket) Inger K Holmström 148 870 kr
Uppsala-Örebro Regional Research Council Åsa Muntlin Athlin 375 000 kr
Uppsala University Åsa Muntlin Athlin 203 000 kr
Department of Health and Ageing, Australian Government Australia Åsa Muntlin Athlin 50 000 AUD

Total 9 410 808 kr
and 50 000 AUD

External Reviews 2010-2012

Ingeborg Björkman: External reviewer of research application for ZonMw - The Netherlands Organisation for Health Research and Development, 2012.

Margareta Sanner: External reviewer of research applications, Health and Medical Research Fund, Food and Health Bureau, Government secretariat, Hong Kong 2012.


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


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

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

Åsa Muntlin Athlin: External reviewer of research applications. Uppsala County Council, Uppsala. 2010

National and international commitments

**Ulrika Winblad:** First opponent (*1:a föredragande i betygdsnämnd*). Disputation of Camilla Palmhøj Nielsen, 9 Dec 2010, Samffundsvidenskablige Fakultet, Copenhagens University.

**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.

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**Research projects**

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

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

**Participants:** Mio Fredriksson, Linn Boström, Love Edberg, Andreas Karlsson, Therese Persson

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

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

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

**Media coverage and public awareness, knowledge and attitudes to the Swedish waiting-time guarantee**

**Participant:** Mio Fredriksson

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

**How can public authorities monitor private social service providers?**

*Participants: Ulrika Winblad, Linda Moberg*

The entrance of private actors into the welfare sector represents a significant development in Swedish politics and creates new demands on steering on part public authorities. Previous research has demonstrated that, in order for societies to reap the benefits of privatization, public authorities must carefully supervise the performance of private actors. In the absence of such supervision, or monitoring, there is a significant risk that quality will be undermined, rather than improved and there will be an unwanted selection of the most profitable users (the brightest pupils, the healthiest patients, etc). The reason is the strong economic incentives created by the competition for public contracts, particularly if providers are (like in the Swedish case) primarily for-profit firms. In the project we investigate with the help of a distinct analytical model, how Swedish public authorities supervise private service providers in the social area today and whether it can be said that there exist sufficient political and legal preconditions for effective monitoring. Research methods used include document analysis, interviews and a web-based survey to Swedish municipalities and county councils. The areas studied are health care, primary education, child care, elder care and substance abuse treatment. The project is run in collaboration with the Department of Government and Department of Business Studies, Uppsala University.

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

*Participants: Ulrika Winblad, Mio Fredriksson, Tobias Dahlström*

In 2011 the Swedish Association of Local Authorities and Regions (Sveriges kommuner och landsting) and the state agreed on a five-year investment in the development of national quality registers. This initiative followed a review that showed that Sweden can take a leading position in the development of a more efficient and equitable health care based on the use of national quality registers. What obstacles and / or opportunities are there to bring about such a development? This question is investigated in a national research project carried out by three research groups (in Uppsala, Stockholm and Jönköping). The national research project is commissioned by the Swedish Association of Local Authorities. During 2012, the work of the Uppsala research group has consisted of project design and preparations for a case study in four county councils (and nine hospitals) and an upcoming national web survey to hospitals using three selected quality registers.

**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.

**Universalism, Choice systems and social citizenship in the Swedish welfare state**

**Participants:** Linda Moberg, Ulrika Winblad

The Swedish welfare state, as emerged in the post war era, is characterized by a publicly funded social service sector and based on the concept of universalism, implying that the service quality should be high and equal to all recipients. In an attempt to achieve this objective the state has traditionally taken on the role as provider of carefully planned and standardized services. However, it has been argued that the public dominance prohibit recipients to influence how these services are carried out and since the 1990’s demands for increased pluralism and user empowerment has been put forward. During the last decades one of the most comprehensive reform trends within the social service sector is the introduction of choice systems. The prime objectives behind these reforms are to make it easier for private providers to establish service facilities with public reimbursement, to enhance user choice and control and to improve the overall service quality. In addition, choice systems are based on the theoretical assumption that when users are given the right to choose and re-choose service providers only high quality providers are expected to withstand the competition.

As choice systems emphasize the values of heterogeneity and provider pluralism, these reforms indicate a shift from the welfare system that was constructed in the post war era. As the introduction of choice system also entails that citizens are given the right to assess what constitute service quality, the traditional means through which these sectors are governed has changed. However, the state still has a legislated responsibility to ensure high and equal quality for all citizens. It is this relation between the states and the individual citizen’s responsibility for service quality that constitute the backdrop for this project, which aims to study whether the introduction of choice systems is consistent with the objective of universalism.

The question will be addressed through four different studies where theoretical assumption underpinning choice systems will be empirically tested. The first study, which has been initiated during 2012, should be understood against the theoretical assumption that when recipients are given the right to choose and re-choose service providers the overall service quality will enhance since only high quality providers are expected to withstand the competition. However, in order for choice system to have quality enhancing effects recipients need access to information on the relative quality of these providers and they must exercise their right to choose based on these quality indicators. The study therefore aims to investigate what kind of information social service recipients have access to and whether it can be used to make a qualitative and informed choice of provider. The 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.

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

**Developing gender competence in Swedish telenursing**

**Participants: Roya Hakimnia, Inger Knutsson Holmström**

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

Telenursing is considered as first line health care. Most telenurses are female. The majority of calls for children and elderly parents are made by women and a study showed that fathers received advice to seek physician twice as often as mothers. Gender refers to the social constructions of femininity and masculinity and has become an increasingly observed aspect of health inequalities. But there is still a lack of studies on if and how gender can impact the encounter between telenurses and callers and how other social factors interact with each other.

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

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

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

Teamwork in an emergency department

Participant: Åsa Muntlin Athlin

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

**PUP – Pressure Ulcer Prevention**

**Participant: Åsa Muntlin Athlin**

Despite guidelines for pressure ulcer prevention, clinical reports indicating that pressure ulcer is still common in the healthcare. Research has shown that the pressure ulcer prevalence is higher in Swedish hospitals, compared to other hospitals in Europe and in USA. In 2010, a group of researchers from county councils and universities in Uppsala, Värmland, Dalarna and Gävleborg started a collaboration project with pressure ulcer prevention as the topic. One of the research projects is a randomized clinical trial, where the aim is to study the effect of a pressure reducing heel protection and health economic related effects. This study follows the care chain; from pre-hospital care to discharge from the hospital. Another research project is about describing and comparing Swedish nurses’ and nursing students’ knowledge and attitudes to pressure ulcer prevention.

**Fundamentals of care**

**Participant: Åsa Muntlin Athlin**

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

**The Future Shape of the Nursing Workforce: A Synthesis of the Evidence of Factors that Impact on Quality Nursing Care**

**Participant: Åsa Muntlin Athlin**

An informal group of Australian nurse leaders highlighted the need for looking at the nursing future and identify the evidence around what makes a positive environment for nursing, in order to influence the direction of health care and nursing’s future. This led to the commissioning of an umbrella review, funded by the Department of Health and Ageing, Australian Government. A total of 79 systematic reviews published between 1995 and 2012 were included in the umbrella review. Recommendations for practice, research, education and policy initiatives were provided.
Teamwork in emergency care: Using behaviour analysis to understand how changes in practice can be achieved and sustained.

Participant: Åsa Muntlin Athlin

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

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

Participants: Marta Röing och Margareta Sanner

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

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

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

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

Non-prescription drugs and self-medication among adolescents in Sweden

Participants: Ingeborg Björkman, Marta Röing, Pia Bastholm-Rahmner, Inger Knutsson Holmström

Consumers in Sweden were given greater access to OTC drugs in 2009 after the reregulation of the pharmacy market, which allowed for the establishment of private pharmacies and sale of specific over-the-counter (OTC) drugs in retail stores and gas stations.

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

Experiences and participation in sick-listing

**Participant: Inger Knutsson Holmström**

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

Parents’ expectations and experiences of calling Swedish Healthcare Direct regarding paediatric health issues

**Participants: Elenor Kaminsky, Inger Knutsson Holmström, Marta Röing.**

During 2012, 5.2 million calls were made to the Swedish Healthcare Direct. About 50% are paediatric calls made by parent callers. The Study aims at performing a descriptive and exploratory interview study, with a strategic sample of 21 parents who had used the service for their child within the last six months. Seventeen hours of transcribed interview data was analyzed using qualitative content analysis. Conclusions made from the findings are that parents desire an equal relationship with telenurses. Moreover, exploring parents’ expectations will reduce their worry, increase their learning and result in greater trust in telenurses’ recommendations. Telenurses’ awareness of gender impact can further develop the telenursing health service in providing safe care on equal terms for a vulnerable patient group, children. The manuscript has been submitted and is under review. The project is ongoing during 2010-2013.

The Swedish Healthcare Direct managers’ views on the telenursing work

**Participants: Elenor Kaminsky, Inger Knutsson Holmström, Jan Larsson, Mio Fredriksson.**

The Swedish Healthcare Direct (SHD) is Sweden’s largest healthcare provider. It aims at increased public sense of security and healthcare efficiency. How this matches legal goals of health promotion and equitable healthcare and what the SHD managers hold as the goals of the telenursing work is unknown. The Study aims at performing a descriptive and explorative interview study with the 23 employed SHD managers regarding their views on the telenursing work. Data was analysed using directed content analysis and the manuscript will be submitted during spring 2013. The preliminary findings show that managers mainly echo the organisational goals of the SHD. The project is ongoing during 2011-2013.
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. The main research area of this group is “Oxidative stress and Clinical Inflammation”.

Research Group Leader Samar Basu is a Professor of Biochemistry and Medical Inflammation at the Universite d’Auvergne, Faculte d’ 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 such as cardiovascular diseases and cancer. The research group have developed crucial assays through raising specific antibodies against isoprostanes indicating oxidative injury and prostaglandin F2 α 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 2012

Samar Basu
Johanna Helmersson
Lillemor Källström
Elisabet Rytter

External

Maria Palm
Emma Lindström
Adriana Miclescu

Publications 2010-2012


Peer-reviewed review articles in scientific journals


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

Book Chapters


Book Editor

Reviews 2010

Dissertations 2012
Maria Palm
Emma Lindström

Agencies that support the work/Funding
The Swedish Research Council
The Norweigian Research Council
The Conseil Regional d’Auvergne, France

Research projects

Smartfish
Collaborators: Samar Basu, Rune Blomhoff and Liver Frøyland
Financed by The Norweigian Research Council, Norway
The project is performed in collaboration with Oslo Medical Faculty and Bergen University, Norway. Financed by Norweigian Research Council.

Impact of inflammation, oxidative stress and adipokines
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. Financed by Conseil d’Auvergne, France
Eicosanoids, COXs, ROS and adipokines in in experimental model of mammary cancer
Collaborators: Collaborators: Samar Basu and Marie-Paule Vasson
The project is performed in collaboration with Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.
Oxidative stress, inflammation and angiogenesis during normal pregnancy, parturition process
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 Department of Women's Health and Clinical Chemistry, Uppsala University.

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 a performed in collaboration with the Department of Surgery and Anaesthesiology, Uppsala University.

Oxidative stress and regional pain syndrome
Collaborators: Samar Basu and Torsten Gordh
The project is a performed in collaboration with the Smart Centrum, Akademiska Hospital, Uppsala University.
Oxidative stress and acute traumatic brain injury  
Collaborators: Samar Basu and Lars Hillered  
The project is a performed in collaboration with the Department of Neurosurgery, Uppsala University.

Antibody and assay development on resolvins  
Collaborators: Samar Basu, Charles Serhan  
The project is a 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 and Alicja Wolk  
The project is performed in collaboration with Clinical Biochemistry, Uppsala University and Karolinska Institute, Sweden. Financed by Conseil Regional d’Auvergne, France.

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

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.

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

Birth weight and inflammation in later life, a follow-up study of 70-80 years in a Swedish population  
Collaborators: Johanna Helmersson, Liisa Byberg, Samar Basu  
The project is performed in collaboration with Clinical Chemistry and Pharmacology, Uppsala University Hospital, Department of Surgical Sciences, Uppsala University, Epidemiology unit, London School of Hygiene and Tropical Medicine, UK and Centre for Health Equity Studies, Karolinska Institute/Stockholm University, Sweden.
Prostaglandin F2α 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.

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

Sleep Apnoea and oxidative stress
Collaborators: Marie Marklund and Samar Basu
The project is performed in collaboration with Umeå Universitet, Sweden.

Conjugated Linoleic acid supplementation and lipid peroxidation
Collaborators: Ronny Kramer, Gerhard Jaheris and Samar Basu
The project is performed in collaboration with University of Jenna, Germany.
Psychosocial Oncology and Supportive Care

Research Group Leader Professor Louise von Essen

With the help of the Swedish Government's funding of the Uppsala University Psychosocial Care Program: U-CARE, Uppsala University has been given the possibility to support our research group 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 mainly use knowledge from Economics, Information systems, and Psychology.

Members of and external partners to the group during 2012

Members of and external partners to the group during 2012 are listed in Table 1 and 2 respectively.

Table 1. Members of the group during 2012.

<table>
<thead>
<tr>
<th>Name</th>
<th>Task/s in group</th>
<th>Title/s</th>
<th>Department/University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Louise von Essen</td>
<td>Research group leader and Program director for U-CARE</td>
<td>Professor, PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Annika Lindahl Norberg</td>
<td>Researcher</td>
<td>Associate Professor, PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Gunn Engvall</td>
<td>Researcher</td>
<td>Senior lecturer, PhD, Registered nurse</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Helena Grönqvist</td>
<td>Post doc researcher and Research coordinator for U-CARE</td>
<td>PhD, MSc in Cognitive Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Erik Grönqvist</td>
<td>Post doc researcher</td>
<td>PhD, MSc in Social Sciences</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Claes Held</td>
<td>Researcher</td>
<td>Associate professor, PhD, MD</td>
<td>Uppsala Clinical Research Centre, Uppsala University</td>
</tr>
<tr>
<td>Emma Hovén</td>
<td>Post doc researcher</td>
<td>PhD, MSc in Behavioral Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Birgitta Johansson</td>
<td>Researcher</td>
<td>Senior lecturer, PhD, Registered nurse</td>
<td>Department of Radiology, Oncology and Radiation Science, Uppsala University</td>
</tr>
<tr>
<td>Elisabet Mattsson</td>
<td>Researcher</td>
<td>PhD, Registered nurse, Registered midwife</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Erik Olsson</td>
<td>Post doc</td>
<td>PhD, MSc in</td>
<td>Department of Public</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Education and Qualification</td>
<td>Institution</td>
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</tr>
<tr>
<td>Jonas Sjöström</td>
<td>Post doc researcher and IT coordinator for U-CARE</td>
<td>PhD, MSc in Information systems</td>
<td>Department of Informatics and Media, and Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Sven Alfonsson</td>
<td>PhD student and Clinical assistant</td>
<td>MSc in Psychology, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Malin Ander</td>
<td>PhD student</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Anders Brantnell</td>
<td>PhD student and Program coordinator for U-CARE</td>
<td>MSc in Political Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Martin Cernvall</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist</td>
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<tr>
<td>Lisa Ljungman</td>
<td>PhD student</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Ruth Lochan</td>
<td>PhD student</td>
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<tr>
<td>Susanne Mattsson</td>
<td>PhD student</td>
<td>Registered nurse</td>
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<tr>
<td>Mudassir Imram Mustafa</td>
<td>PhD student</td>
<td>MSc in Information systems</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Fredrika Norlund</td>
<td>PhD student and Clinical assistant</td>
<td>MSc in Psychology, Licensed psychologist, Licensed psychotherapist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Hafijur Mohammad Rahman</td>
<td>Research assistant</td>
<td>MSc in Information systems</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Name</td>
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<td>Title/s</td>
<td>Department/University</td>
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</tr>
<tr>
<td>Teolinda Toft</td>
<td>PhD student</td>
<td>BSc in Social Work</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>
</tr>
<tr>
<td>Madelen Hermelin</td>
<td>Research assistant</td>
<td>MSc in Information systems</td>
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</tr>
<tr>
<td>Sofia Leijon</td>
<td>Research assistant</td>
<td>Student at the Psychology program</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Ellen Skogseid</td>
<td>Research assistant</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Sandra Waara</td>
<td>Psychologist</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
</tbody>
</table>

Table 2. External partners to the group during 2012.
<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Qualification</th>
<th>Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gustaf Ljungman</td>
<td>Researcher</td>
<td>Associate professor, PhD, MD</td>
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</tr>
<tr>
<td>Christine Rubertsson</td>
<td>Researcher</td>
<td>Associate professor, Senior lecturer, PhD, Registered nurse, Registered midwife</td>
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</tr>
<tr>
<td>Agneta Skoog Svanberg</td>
<td>Researcher</td>
<td>Associate professor, Senior lecturer, PhD, Registered nurse, Registered midwife</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Niklas Zethraeus</td>
<td>Researcher</td>
<td>Associate professor, PhD, MSc in Economics</td>
<td>Stockholm School of Economics</td>
</tr>
<tr>
<td>Jenny Eriksson Lundström</td>
<td>Researcher</td>
<td>PhD, MSc in Information systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Lena Hedén</td>
<td>Researcher</td>
<td>PhD, Registered nurse</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Brjánn Ljótsson</td>
<td>Researcher</td>
<td>PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Clinical Neuroscience, Karolinska Institutet</td>
</tr>
<tr>
<td>Gunilla Mårtensson</td>
<td>Researcher</td>
<td>Senior lecturer, PhD, Registered nurse</td>
<td>University of Gävle</td>
</tr>
<tr>
<td>Anna Hauffman</td>
<td>PhD student</td>
<td>Registered nurse</td>
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<tr>
<td>Tove Kamsvåg Magnusson</td>
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<tr>
<td>Pernilla Jernerén Maathz</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist</td>
<td>Department of Psychology, Uppsala University</td>
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<tr>
<td>Anna Norén</td>
<td>PhD student</td>
<td>MSc in Economics</td>
<td>Department of Economics, Uppsala University</td>
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<td>Jenny Thorsell</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist</td>
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<tr>
<td>Emma Wallin</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist</td>
<td>Department of Psychology, Uppsala University</td>
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<tr>
<td>Mattias Öman</td>
<td>PhD student</td>
<td>MSc in Economics</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Marina Forslund</td>
<td>Research assistant</td>
<td>MSc in Nutrition</td>
<td>Department of Radiology, Oncology and Radiation Science, Uppsala University</td>
</tr>
<tr>
<td>Golden Masika</td>
<td>Research assistant</td>
<td>Registered nurse</td>
<td>University of Dodoma, Dodoma, Tanzania</td>
</tr>
</tbody>
</table>
Publications 2010-2012 (From persons listed in Table 1)

2012


2011

2010

Dissertation 2012
**Half time controls 2012**


**Agencies that support the work/Funding**

- The Swedish Research Society: 10 750 000 SEK
- The Swedish Childhood Cancer Foundation: 500 000 SEK
- The Swedish Cancer Society: 600 000 SEK
- Uppsala County Council: 800 000 SEK
- Hjärtlungfonden: 273 000 SEK

**During 2012 our main activities have been**

Start feasibility/pilot studies via the U-CARE-Portal.

Provide stimulating and challenging career opportunities for young Swedish and international researchers and students.

Start cross-disciplinary research between researchers from the academic fields of Caring Sciences, Economics, Implementation Sciences, Information Systems, and Psychology.

Provide access to the U-CARE-Portal to researchers/research groups at Uppsala University and other Swedish universities.

Consolidate research collaborations with researchers at South Florida, US and Innovation Value Institute, Ireland.

Initiate research collaborations with researchers at Radboud University Nijmegen Medical Centre, the Netherlands and University Medical Centre Groningen, University of Groningen, the Netherlands.

Start the cross-disciplinary, trans-faculty research school Psychosocial Care in the Interactive Society with 8 PhD students partly financed by strategic research funding to U-CARE and partly by the Departments of Economics, Informatics and Media, and Psychology and the Disciplinary Domain of Medicine and Pharmacy, Uppsala University respectively.

Provide part I of the high-quality research-based, cross-disciplinary PhD course in Psychosocial care in the interactive society.

Build up part II of the high-quality research-based, cross-disciplinary PhD course in Psychosocial care in the interactive society.

Build up a high-quality research-based, cross-disciplinary PhD course in Implementation of complex interventions in collaboration with scholars at Radboud University Nijmegen Medical Centre, the Netherlands.

Implement the concepts behind U-CARE research and educational activities in the educational programs for nurses and psychologists and in the Master program for management, communication and IT.

Set up “Lived experience groups” as used by PenCLAHRC in the UK to involve service users in the U-CARE research and educational activities.

Attract major external funding.
Research projects

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

METHODS
The project has a comparative, longitudinal design with eight measurements from one month to ten years after diagnosis. Sixty-one adolescents were included. 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 Childhood Cancer Foundation and the Swedish Cancer Society.

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

METHODS
The project has a longitudinal design with seven measurements from one week after diagnosis to five years after end of treatment. 250 parents were 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 Childhood Cancer Foundation and the Swedish Cancer Society.

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 Childhood Cancer Foundation.
**U-CARE: Petra. Treatment of posttraumatic stress among parents of children diagnosed with cancer with face-to-face cognitive behavioral therapy**

**OVERALL AIM**
To investigate the clinical efficacy of face-to-face cognitive behavioral therapy to parents of children struck by cancer after completion of successful treatment.

**METOD**
The study has an uncontrolled, within group design where cognitive behavioral therapy (CBT) is given to parents of children off cancer treatment. Each parent receives 10-15 sessions of face-to-face individual CBT. Approximately 20 parents will be included. Inclusion started December 2012. Parents answer semi-structured questions about experienced suffering and questions measuring e.g. posttraumatic stress, anxiety, experiential avoidance, depression, and quality of life.

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

**U-CARE: TeenCan. A randomized controlled trial of the effect of a self-help program via internet on anxiety and depression among adolescents with cancer**

**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.

**METHODS**
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 U-CARE-Portal. A pilot study has started.

**FUNDING**
The project is funded by a strategic research grant to Uppsala University Psychosocial Care Program: 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.

**METHODS**
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 U-CARE-Portal.

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

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

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

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

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

Members of the group during 2012

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
Afshaneh Roshanai, PhD
Stefan Kunkel, PhD.
Ulrika Paulsson, Doctoral student
Peter Berg, M.D. Doctoral Student,
Mikael Skärlund, Research assistant
Susanne Sundell Lecerof, Doctoral student, collaboration with Lunds and Malmö University
Anna Ohlsson, M.D. Clinical research assistant.
Publications 2010-2012


3. 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


30. Wångdahl J, Mårtensson L. The Communicative and critical health literacy scale- Swedish version. Department of Public Health and Caring Sciences, Uppsala University and Department of Social Medicine, Gothenburg 2011. (Submitted).


32. Berg P, Sundelin C, Westerling R. The connection between socioeconomic and psycho-social factors and bicycle helmet use among school children and teenagers. Department of Public Health and Caring Sciences, Social Medicine, Uppsala University (Submitted)


38. Roshanai, A H, Nordin K., Berglund G. Factors influencing primary Care physicians’ decision to order prostate-specific antigen (PSA) test for healthy men. [Accepted for publication in Acta Oncologica]


Health communication in home language – does it make any difference? Establishment, development and evaluation) SMT 2012;89:131-139.


47. Westerling R, Westin M, McKee M, Hoffmann R, Plug I, Rey G, Jougla , Lang K, Pärna K, Alfonso JL, Mackenbach, JP. The timing of introduction of pharmaceutical innovations in seven European countries Department of Public Health, Erasmus Medical Center, Rotterdam, London School of Hygiene & Tropical Medicine, London, INSERM, France, Department of Public Health, University of Tartu, Department of Preventive Medicine and Public Health, University of Valencia and Department of Public Health and caring sciences, Uppsala University 2012. (submitted)


52. Sundell Leecrof S, Staffström M, Westerling R, östergren P O. Can social capital protect individuals from the negative effects of post-migration risk factors for poor mental health among Iraqi migrants in Sweden? Social medicine and global health, Department of Clinical Sciences Malmö, Lund University and Social Medicine, Department of Public Health and Caring Sciences, Uppsala University. Social Medicine och Global Health, Lunds University. Research report 2012.

53. Flodström E. Unga irakiers syn på sexuell och reproduktiv hälsa och rättigheter. (In Swedish; Young Iraqis view on sexual and reproductive health and rights) SMT 2012;89: 140-149140-149

Agencies that support the work/Funding
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.

Health examinations for asylum seekers: (partnership with the Swedish Institute for Communicable Disease Control, the Migration Board, the National Board of Health and Welfare, the Swedish organization of local authorities, Umeå University and regions and the counties(regions) of Stockholm, Östergötland, Skåne and Norrbotten):30 000 000 (3 441 000 managed at our department) year 2012-2014 European refugee fund.

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

Academic Hospital, Uppsala.

Research projects

Studies of Avoidable mortality and diffusion of innovations
Participants: Ragnar Westerling, Marcus Westin, Anna Ohlsson, Marianne Hanning, Anna Cooray

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

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

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

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

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

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

**Patients and physicians expectations on lipid-lowering drugs**

*Participants: Per Lytsy, Gunilla Burell, Ebba Hallberg, Erik Berglund, Ragnar Westerling*

Preventive treatment with statins is shown to significantly reduce the absolute risk of coronary heart disease; yet long-term compliance is poor. We have studied the expectations and factors that might affect expectations on statin treatment among patients. A total of 909 Swedish statins users were identified and a questionnaire was used to obtain information on the health of the study objects, cardiovascular risk factors, life style and expectations on statin treatment.

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

The physicians expectations and attitudes towards statin treatment has also been analysed showing some gender differences in the prescription habits among physicians. This study was performed in collaboration with the *pharmaceutical committees in the county of Uppsala and Gästrikland* and supported by the Academic hospital in Uppsala and was 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, Annika Åhs, Afsaneh Roshanai, Ragnar Westerling*

We are evaluating the impact of international health advisors and other health promotion programs on health and health care utilization among immigrants to Sweden. The health advisors are working with information to immigrants about health related factors and medical care in Sweden.

In the first part of the project a cross-sectional study of health and health care utilization among immigrants from Iraq has been performed. In another part a longitudinal study has been designed aiming at analysing the effects of contacts with health advisors on the health as well as on the health related knowledge and behaviours of Iraqi
migrants to Sweden. Furthermore, focus group interviews 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 were performed in collaboration with Lund’s University and Malmö University as well as with several municipalities, county councils and other organisations. The projects was funded by the European Refuge Fund and Immigrant Fund, respectively.

In a recently started project we are analysing the views and expectations of health examinations for asylum seekers in Sweden. In an explorative phase of the project focus group interview and interviews with key informants have been performed and a questionnaire has been developed. This project is performed in collaboration with the Swedish Institute for Communicable Disease Control, the Migration Board, the National Board of Health and Welfare, the Swedish organization of local authorities, Umeå University and regions and the counties(regions) of Stockholm, Östergötland, Skåne and Norrbotten.

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

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

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

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

The study is based on two questionnaires to school children in school classes 7-9. The first is the survey Life and Health conducted by the county of Uppsala. This material includes data from about 10 000 pupils 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.
Health and health system interventions among non-working populations.

Participants: Annika Åhs, Gunilla Burell, Mikael Skärlund, Per Lytsy, Ragnar Westerling.

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

Implementing safety promotion in an industrial working environment

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.