Introduction

The Department of Public Health and Caring Sciences employs 170 persons, of which there are 11 professors and 19 senior lecturers. The yearly economic turnover is approximately 150 million SEK.

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

Education

There were about 3360 students registered at the department in 2014, in terms of funding corresponding to about 627 full time students. About 710 registered students were educated in the Nursing programme, 1130 in the Medicine programme, 50 in the Master-programme in Public Health and about 790 in separate courses. Through well-established collaboration with several universities abroad and different exchange programmes nursing students and teachers were able to get international experience. Contract education conducted by the Department additionally hosted approximately 20 registered students.

Research

The Department of Public Health and Caring Sciences is commissioned by the Disciplinary Domain of Medicine and Pharmacy at Uppsala University to perform scientific research in Caring sciences, Diet, nutrition and metabolism, Family medicine and clinical epidemiology, Geriatric research, Preventive research, and Social medicine. During 2014 there were 310 peer-
reviewed scientific publications from researchers affiliated to the department. The yearly average during the last ten years is 220 but there is an increasing trend during later years. There were 13 dissertations, a somewhat greater number than the yearly average during the last decade, and one student passed her licentiate examination. During 2014 the department had 90 registered doctoral students engaged in thesis projects.

During 2014 one research group changed name from Psychosocial Oncology and Supportive Care to Clinical Psychology in Health Care, one research group disappeared due to retirement (Oxidative Stress and Inflammation), and one new research group called Life Style and Rehabilitation in Long Term Illness was formed by some earlier members of the research group in Caring Sciences. The Department’s administration was also reorganised during 2014, including both economic administration, Human Relations subunit and the course administration, resulting in greater quality, higher efficiency, and a more positive working climate.

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

Caring Sciences
The research has a multidisciplinary and multiprofessional perspective including preventive, supportive, caring, and rehabilitation actions. The focus is on clinically relevant problems in the health care sector. There are two research themes; reproductive health, and quality of care and patient safety. The third theme, cancer rehabilitation, has since late in 2014 established itself as a research group of its own, called Life Style and Rehabilitation in Long Term Illness.

In reproductive health the aim is to enhance preconception health and care among women and men by i) developing, implementing and evaluating a counselling tool, called the Reproductive Life Plan, in clinical health care settings ii) developing, launching and evaluating a preconception information package on the internet, and as a mobile application for the general population to access and use, iii) study ethical and gender issues related to preconception care and iv) develop a health economic model to estimate the long-term cost-effectiveness of preconception care interventions. The group collaborate with the international PrePreg network

Centre for Research Ethics and Bioethics (CRB)
CRB is an interfaculty centre at Uppsala University. The task is to investigate the ethical, philosophical and legal aspects of biomedical research and
Clinical practice in multi-disciplinary research projects that roughly cover three areas: research ethics, clinical ethics and bioethics. The topics originate in close collaboration with clinicians, researchers and scientists, both in Sweden and abroad.

The centre has now been involved in the ethical, social and legal aspects of bio-banking and register research for over a decade and are part of several national and European research networks and infrastructures. In 2014 it became part of the BBMRI-ERIC ELSI common service. They also launched a newsletter to increase the dissemination of the Centre’s research to the international bio-banking community. The newsletter is supported by BBMRI.se and reaches around 4.000 people.

**Clinical Nutrition and Metabolism**

At Clinical Nutrition and Metabolism (CNM) top international and partly world leading research is performed on the role of nutrition for prevention and treatment of non-communicable diseases including cardiovascular disease, type 2 diabetes and other age-related disorders. During 2014 several important grants have been approved (e.g. Swedish Research Council) and a number of news-breaking reports on, for example fatty acid interfaces with fat and muscle distribution, on muscle integrity, i.e. importance of sarcopenia for independence at old age, and dietary pattern influence on risk for dementia, have been published. Researchers at CNM are highly interactive with media and the outside society.

**Clinical Psychology in Health Care**

The research group “Psychosocial Oncology and Supportive Care and U-CARE” has changed its name to “Clinical Psychology in Health Care”. The research group still houses the strategic research program U-CARE. The group’s research is of strategic importance to meet the healthcare challenges ahead and has potentially a high impact on the society and economy as well as Sweden’s competitiveness in a globalized world. They conduct pragmatic e-Health research with clinicians and non-academic organizations as research partners with end-user acceptance and implementation in mind. The research is cross-disciplinary involving Economics, Implementation Sciences, Information Systems, and Psychology.

During 2014 the research group has:

- Established policies to provide the U-CARE software infrastructure and web-based self-help programs open access to be shared with the research community and providers of online psychosocial care and psychological treatment
- Attracted 20 000 000 SEK from the Swedish Research Society, the Swedish Cancer Society, the Swedish Childhood Cancer Foundation, the
Vårdal Foundation, and the Swedish Research Council for Health, Working Life and Welfare for ongoing and future controlled trials investigating the clinical efficacy and cost-effectiveness of web-based self-help programs for a variety of target groups

- Strengthened the link between our research and education at undergraduate, graduate, and post graduate levels at the disciplinary domains of Humanities and Social Sciences, Medicine and Pharmacy, and Science and Technology at Uppsala University

Disability and Habilitation

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

Family Medicine and Preventive Medicine

The research in Family Medicine emanates from the multidisciplinary perspective of primary health care and is conducted by a large group of researchers throughout the Uppsala-Örebro region. The research activities have twelve different themes: 1) social insurance medicine, 2) pain and musculo-skeletal disorders, 3) asthma, allergy and COPD, 4) symptom reporting and utilisation of pharmaceuticals, 5) diabetes and cardiovascular disease, 6) reproductive health, 7) Communications skills, 8) vitamin D deficiency, 10) Prevention, 11) Organizational factors, work stress and performance, and 12) Social medicine.

The research group continues to produce about 70 to 80 scientific articles per year in a wide range of scientific areas. The number of collaborations with Swedish researchers is high and international collaboration is increasing. Much work has been carried out during 2014 to make our vision of an academic primary health care center come true.

Geriatrics

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

Health Economic research group
The Health Economic Research Group was initiated during 2013 as a part of Health Economic Forum of Uppsala University (HEFUU), aiming at increased collaboration between different Departments at the university. The research group has now outlined its first major research project in cooperation with several senior researchers in different departments at Uppsala University, Uppsala Clinical Research Centre (UCR) and Harvard University. The Dental and Pharmaceutical Benefits Agency has also decided to join the project. The group also continues to contribute to the education of the faculty and the students in health economics. Professor van Hout, University of Sheffield, held a much popular two-day course before summer. The group will soon give its first master course in health economics. The first PhD student is about to be recruited in a joint project together with Centre for Research Ethics & Bioethics. Several excellent candidates applied.

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. The group is multidisciplinary and the researchers have different professional backgrounds such as medicine, psychology, nursing and political science.

Life Style and Rehabilitation in chronic disease
A new research group, Lifestyle and rehabilitation in long term illness, including the Phys-Can project have been formed. The project Phys-Can, a multi-center randomized intervention study with Professor Karin Nordin as PI, received comprehensive additional funding during 2014. The project received a strategically funding from the Swedish Cancer society with 12.8 million SEK during 2013-2017. The project received additional 9.8 million SEK from The Swedish Research Council for the period 2014-2018.
Sociomedical Epidemiology

The primary objective of the research is to analyse 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.

Uppsala April 30, 2015

Johan Hallqvist
Head of Department
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Organization

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Professor Johan Hallqvist

Deputy Head of Department
Professor Karin Sonnander

Department Board
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Ulrika Winblad Spångberg, Teacher and Researcher Representative
Mats G Hansson, Teacher and Researcher Representative
Anna Höglund, Teacher and Researcher Representative
Henrik Edlund, Technical and Administrative Representative
Maria Grandahl, Graduate Student Representative
Karin Nordin, Teacher and Researcher Representative, Deputy
Ulf Risérus, Teacher and Researcher Representative, Deputy
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Maria Peippo, Technical and Administrative Representative, Deputy
Åsa Andersén, Graduate Student Representative, Deputy
Catarina Dahlqvist, Protocol

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

Director of Clinical Issues
Lars Lannfelt

Professors and Research Groups Leaders
Bengt Arnetz
Samar Basu
Marianne Carlsson
Tommy Cederholm
Louise von Essen
Lena Gunningberg
Johan Hallqvist
Mats G Hansson
Lars Lannfelt
Per Kristiansson
Karin Nordin
Karin Sonnander
Tanja Tydén
Ragnar Westerling
Ulrika Winblad

Adj Professors, Guest Professors and adj Senior Lecturers
Theo van Achtenberg
Annika Bardel
Hans Basun
Lena Ring
Thorne Wallman
Anna Christina Åberg

Address List

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

Address: The department is situated at three different locations:
  • BMC, Entry A11, Husargatan 3
  • Dag Hammarskjölds väg 14B
  • The Rudbeck Laboratory, Dag Hammarskjölds väg 20

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

Aarts Clara
Adamsson Viola
Adolfsson Päivi
Ahlstedt Carina
Alfonsson Sven
Almadoz-Gil Leire
Ancillotti Mirko

Ander Malin
Andersén Åsa
Anderzén Ingrid
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von Berens Åsa
von Essen Louise
Wångdahl Josefin
Åberg Anna Cristina
Åhs Annika
Åkerman Eva
Ärnlöv Johan

förnamn.efternamn@crb.uu.se
Associated Researchers

Adamsson Viola
Alemi Mansour
Anderberg UllaMaria
André Malin
Annerbäck Eva-Maria
Arakelian Erebouni
Berglund Britta
Bernsten Cecilia
Bjermo Helena
Björkman Ingeorg
Bogefeldt Johan
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Johnsson Linus
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Karlström Britta
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Åberg Anna Cristina
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Ålander Ture
Doctoral Students

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Alfonsson Sven
Almadoz Gil Leire
Alsharari Zayed
Ander Malin
Andersén Åsa
Andersson Caroline
Ax Erika
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Wångdahl Josefin
Åkerman Eva
Östlund Ann-Sofi
Centres

During 2014 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 54).

Centre for Research Ethics and Bioethics (CRB)
(www.crb.uu.se)
Director: Mats G Hansson
The Centre for Research Ethics & Bioethics (CRB) is an interfaculty centre that was established in 2008. The researchers at the Centre for Research Ethics & Bioethics at Uppsala University have been active for several years investigating ethical, philosophical and legal aspects of biomedical research and clinical practice within the format of multi-disciplinary research projects. We publish the results of our research in international peer-reviewed scientific journals and in books. Roughly our research covers three main areas: research ethics, clinical ethics and bioethics. Our research topics originate in close collaboration with clinicians, and through ongoing communication and international collaboration with highly qualified researchers and scientists (p 58).
Uppsala University Psychosocial Care Program (U-CARE)

www.u-care.uu.se

Director: Louise von Essen

U-CARE is one of the government’s strategic research programs at Uppsala University. U-CARE is integrated in the research group Clinical Psychology in Healthcare that is internationally strong in basic and applied psychosocial care research. The overarching goal of our group and the U-CARE Program is to promote psychosocial health among patients struck by somatic disease and their significant others, hopefully at a lower cost to the benefit of individuals and society. The research is interdisciplinary, using knowledge mainly from the academic disciplines of Caring Sciences, Economics, Information Systems, and Psychology (p 258).
Education

The Department of Public Health and Caring Sciences is funded for about 626.5 full time students (GLIS 150226), which represented 3360 students registered at the department in 2014. About 710 registered students were educated in the Nursing programmes, about 1130 in the Medicine programme, about 50 in the Master programme in Public Health and about 790 in separate courses (Uppdok och GLIS 150226).

About 20 students were registered in contract education and about 90 doctoral students were registered in the department (Uppdok 150226).

First-cycle courses and study programs

Courses in the Medicine Programme

Medical education in Uppsala means early patient contact.

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

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

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

Semester 1: Introduction course, 3 credit points
Semester 1: Professional Skills and Communication 1, 2.5 credit points
Semester 2: Professional Skills and Communication 2, 2.5 credit points
Semester 3: Professional Skills and Communication 3, 2.5 credit points
Semester 4: Professional Skills and Communication 4, 2.5 credit points
Semester 4-11: Leadership training, 4 credit points
Semester 5: Geriatrics
This course covers gerontology, Alzheimer's disease and other neurodegenerative dementia disorders, various aspects on frail elderly patients with multiple co-morbidities and poly-pharmacy, falls, delirium and other geriatric syndromes, orthogeriatrics, stroke rehabilitation and palliative care, during a total of three weeks.

Semester 1-11: Medical Ethics and Medical Law, 3 credit points
The course extends over the entire program. The different elements are related to the other courses that students take during the current period. Each session includes either a half or a full day. The course involves close collaboration with various clinical specialties, including group exercises based on actual patient cases that are either presented by the participating teacher/doctor or generated by the students themselves. Group discussions are integrated with lectures. The course is examined with an individual moral case deliberation. A web-based ethics toolkit is under development.

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

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

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

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

Contract education

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

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

Second-cycle courses and study programs

Postgraduate Diploma in Specialist Nursing with focus on District nurse

Postgraduate Diploma in Specialist Nursing with focus on District nurse, 75 credit points – the research group *Caring Sciences* is responsible for Pharmacology related to Diseases and the Extended Role of the District nurse, Nursing Care and Public Health in Adults and Elderly in Primary Health Care, Nursing Care and Public Health in Children and Adolescents at Child Health Centres and Schools, Nursing Care in Children and Adolescents with Common and Specific Conditions, Advanced Studies in Primary Health Care Nursing.
Postgraduate Diploma in Specialist Nursing with focus on care of elderly

Postgraduate Diploma in Specialist Nursing with focus on care of elderly, 60 credit points – the research group Caring Sciences is responsible for all the courses (Geriatrics, Pharmacology and Gerontological Nursing, Gerontology and Nursing Focused on Healthy Ageing, Dementia and nursing care).

Postgraduate Diploma in Specialist Nursing with focus on oncology care

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

Separate courses

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

Master in Public Health

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

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

The aims of the program are to increase knowledge, understanding and skills in public health and public health work. This means that students will be competent both in further research and in practical strategic public health
Third-cycle course and study program

Doctoral courses and study programme

In the beginning of the year 2014, 76 doctoral students were in education and during the year 11 of them have past their theses and 8 new applicants have been admitted to studies at the doctoral level.

Different research groups at the department are taking part in the training courses in the theory components of the doctoral education. In the obligatory courses at the Faculty of Medicine, members from Centre for Research Ethics & Bioethics are involved in “The introduction to scientific research” (7.5 ECTS, given three times a year). The Centre for Research Ethics & Bioethics is also responsible for the course “Research Ethics and Philosophy of Science” (1.5 ECT, given two times a year). Family Medicine and Preventive Medicine participated in “Medical epidemiology” (1.5 ECT, given once a year). The research group Clinical psychology in healthcare is responsible for two courses “Quantitative and qualitative research methods” (7.5 ECT, given once a year) and “Selfcare, care and psychological treatment supported via information communication technology” (7.5 ECT, given once a year).

The Centre for Research Ethics & Bioethics is also responsible for doctoral courses given at other faculties at Uppsala University: “Research Ethics for Science and Technology” (2 ECTS, given four times a year), “Research Ethics for Natural Science” (1 ECT, given two times a year), and “Research Ethics for Social Science” (4 ECTS, given ones a year).

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

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

International activity

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

In 2014 about 44 of our students studied abroad during 4-12 weeks, while 14 foreign students visited our department during 4-12 weeks. Four of our teachers taught abroad during 1-3 weeks, two visited Hull University for a European Academy of Caring Science meeting, and two visited Liverpool University to discuss collaboration and exchange. Four foreign teachers taught in our department during 1-5 weeks, and two came to carry out research during one month with support from Erasmus Mundus. The exchange programmes have given students and teachers knowledge, experiences and international contacts which are highly valuable for their personal development and careers as well as for their universities.
Dissertations 2014
(Registered at the Department of Public Health and Caring Sciences)

- Adamsson, Viola. A healthy Nordic diet and cardiometabolic risk factors: intervention studies with special emphasis on plasma lipoproteins
- Cedervall, Ylva. Physical activity and Alzheimer's disease: measurements, observations and subjective experiences
- Gottvall, Maria. Introduction of school-based HPV vaccination in Sweden: knowledge and attitudes among youth, parents, and staff
- Gumucio-Gatica, Astrid. Therapeutic and functional studies in animal models of Alzheimer's disease
- Höyer Lundh, Marie. Health-related quality of life and return to work following breast cancer
- Jansson, Stefan. A longitudinal study of diabetes mellitus: with special reference to incidence and prevalence, and to determinants of macrovascular complications and mortality
- Jobs, Elisabeth. Cathepsin S as a biomarker of low-grade inflammation, insulin resistance, and cardiometabolic disease risk
- Rissanen, Ritva. Distress, emotional reactivity and fatigue following breast cancer
- Sving, Eva. Pressure ulcer prevention: performance and implementation in hospital settings
- Torstensson, Thomas. Chronic pelvic pain persisting after phildbirth: diagnosis and implications for treatment

Licentiate 2014

- Terner, Annika. Predefined headings in a multi-professional electronic health record: professionals' application, aspects of health and health care and correspondence to legal requirements
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 level 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 2012-2014, we had following three research themes:

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

The reproductive health group investigates different aspects of attitudes to having children in the future among women and men in fertile ages. The main research questions in a longitudinal cohort study are: To what degree do women and men plan pregnancies? Is pregnancy planning associated with demographic factors such as age and education? Is pregnancy planning associated with life style changes and neonatal outcome? We also measure the effects of a new approach of giving contraceptive counseling. The main research questions are: Is it possible to increase knowledge about reproduction and attitudes to plan pregnancies with help of the Reproductive life plan-concept? This is an RCT study among 2000 women attending contraceptive counselling. Prevention of cancer related to Human papilloma virus (HPV) is also studied. An ongoing RCT-study in School Health investigates the outcome of an intervention on HPV vaccination status and use of condom.
Various projects are ongoing and planned within the group cancer rehabilitation; cross-disciplinary randomized controlled intervention studies focusing on lifestyle (e.g. physical exercise, stress management, nutrition) in cancer patients. The aim is to find evidence-based interventions for changing life styles factors to decrease the burden for the patients and care givers during and after cancer treatments, cost-effective rehabilitation programs and more person-centered health care.

The 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 2014

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

Lecturers fulltime or part time

Ahlby Bitte
Ahlstedt Carina
Bäckström Josefin
Cullinane Carli Cheryl
Eriksson Leif
Eriksson-Öhman Solweig
Fagerström Johansson Jenny
Frejd Karin
Godman Nathalie
Hedlund Lena
Hejdenberg Ronsten Barbro
Holm Marta
Hovstadius Eva
Hultin Lisa
Kjellberg Sören
Lugnet Kerstin
Lundin Birgit
Löge Ann
Marnell Harriet
Miller Karin
Norinder Camilla
Normark Lena
Pettersson Mona
Schmidt Meta
Staaf Anita
Stenlund David
Thoudal Berit
Thörnqvist Eva

Associated researchers
Berglund Gunilla
Ekstrand Maria
Engström Maria
Häggström Elisabeth
Kristofferzon Marja-Leena
Kullberg Kerstin
Larsson Bo
Lindberg Magnus
Lindberg Maria
Lindqvist Ragny
Ljunggren Birgitta
Lunner Katarina
Lövgren Ekmehag Björn
Makenzius Marlene
Mamhidir Anna-Greta
Mårtensson Gunilla
Nilsson Annika
Oscarsson Marie
Roshanai Afsaneh
Röndahl Gerd
Skytt Bernice
Stenhammar Christina
Silén Marit
Van Achterberg Matheus
Westerberg Jacobsson Josefin
Tiblom Ebersson Ylva
Åhsberg Elisabeth

Ongoing PhD students
Bjurling-Sjöberg Petronella
Björn Catrine
Carlsson Tommy
Drevin Jennifer
Grandahl Maria
Granström Therese
Hagermann Heidi
Hedman Maria
Hellerstedt-Börjesson Susanne
Isaksson Stina
Kerstis Birgitta
Kirsebom Marie
Knudsen Kati
Pålsson Ylva
Randmaa Maria
Roos Charlotte
Stern Jenny
Söderberg Jenny
Widarsson Margareta
Östlund Ann-Sofi

Publications 2012-2014

2012


13. Hellström-Hyson, E., Mårtensson, G., & Kristofferzon, M-L. (2012). To take responsibility or to be an onlooker. Nursing students’ experi-


2013


45. Wallin, E., Larsson, I-M., Rubertsson, S., & Kristofferzon, M-L. (2013). Relatives’ experiences of everyday life six months after hypo-


2014


let their daughters have the human papillomavirus vaccination. Acta Paediatr, 103, 436-41.


Dissertations 2014
- Maria Andér Gottvall. Introduction of School-Based HPV Vaccination in Sweden: knowledge and attitudes among youth, parents, and staff. PhD, Medical sciences. Uppsala University, 2014
- Marie Höyer Lundh. Health-Related Quality of Life and Return to Work following Breast cancer. PhD, Medical sciences. Uppsala University, 2014
- Ritva Rissanen. Distress, emotional reactivity and Fatigue following Breast cancer. PhD, Medical sciences. Uppsala University, 2014
- Eva Sving. Pressure Ulcer Prevention: Performance and Implementation in Hospital Settings. PhD, Medical sciences. Uppsala University, 2014

Awards 2014
- Jennifer Drevin, “Can Adverse Childhood Experiences affect the development of pain during pregnancy?” at Controversis in Obstetrics and Gynecology, Paris 2014
- Marianne Carlsson. Gustav Adolf Gold Medal (Eighth size) for particularly significant contributions to Uppsala University. 2014

Agencies that support the research work/Funding (SEK)
The Swedish Patient Insurance 60 000
The Swedish Foundation for Inter. Corp. in Research and Higher Educ. 147 999
The Swedish Freemasons Foundation 200 000
Medical Faculty Uppsala University 2 935 000
The Swedish Cancer Society 2 400 000
Bayer Health Care 350 000
Nordic Cancer Union 500 000
Swedish Research Council 1 960 000

International collaboration
- The PrePreg-Network
• Netherlands Cancer Institute, and EMGO Institute for Health and Care Research, Department of Public and Occupational Health
• VU University Medical Centre, Amsterdam, Department of Medical Psychology, Academic Medical Center, University of Amsterdam
• Alpe d’HuZes Cancer Rehabilitation (A-CaRe): http://www.a-care.org/english/
• Predicting OptimaL cAnceR RehabIlitation and Supportive care (POLA-RIS) www.polaris-study.org
• University in Bergen and Kristiansand, Norway, and the respective university hospitals
• Norwegian School of Sport Sciences in Oslo (NIH)
• Centre of Inflammation and Metabolism (CIM), Department of Infectious Diseases, Rigshospitalet,
• University of Copenhagen, Denmark
• University of Leeds, UK
• Trustee of the European Pressure Ulcer Advisory Panel (board member)
• Member of European Academy of Caring Science
• European Academy of Caring Science (EACS), Core member.
• International Co-coordinator for Nordic countries (Nordplus network: Norlys), European countries (Erasmus), and Linnaeus-Palme (Vietnam), Department of Public Health and Caring Sciences, Uppsala University
• International coordinator for African countries especially Uganda and Tanzania
• Member of Scientific Board of Investigación y Educación en Enfermería Research and Education in Nursing.
• Guest professor Theo van Achterberg, professor chair of the Centre for Health Services and Nursing Research and of Quality of Care at KU Leuven, Belgium.
• Guest Lecturer, Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand.
• Guest Researcher, Department of Nursing, Faculty of Nursing and Medical Technology, University of Medicine and Pharmacy, Ho Chi Minh City, Vietnam.
• Guest Researcher, School of Economics, Sukhothai Thammathirat Open University, Thailand
• Guest Lecturer, Makerere University, Colledge of Health Sciences, Kampala, Uganda
• Guest Lecturer, Muhimbili School of nursing, Dar es Salaam, Tanzania
• Member of the Editorial board for the Journal: Nursing Research and Education
• Guest Researcher, Early rehabilitation of cancer patients at the Department of Oncology and Medical physics, Haukeland University hospital, Bergen, Norway
National commissions

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

Invited speaker 2012-2014

- 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
- The Danish Council of Ethics, Ministry of Health, Copenhagen 2013
- School nurses Conference 2013, Borås
The Centre for Disability Research (CDR) was established in 1988 to coordinate disability issues in scientific fields represented at the faculties at Uppsala University and to interact with the wider community on issues relating to disability research. The Centre is placed at the Faculty of Medicine and administratively associated with the Department of Public Health and Caring Sciences.

In 2014 CDR, Uppsala Regional Council and UU Innovation worked together to organise “AIMday Funktionshinder” (“AIMday Disability”) on 27 November 2014. The theme of the event was “How can we help one another overcome obstacles? About disability and living life on disabled people’s own terms.” The work to organise the event went on throughout most of the year and the final meeting brought together some 70 academics and representatives from the wider community, in discussions on 24 topical issues concerning disability. The event was held in premises at Navet, Uppsala Biomedical Centre.

During the year CDR continued functioning as the coordinator for the Swedish network of disability researchers. A network meeting took place in Linköping in April. The network also organised a two-day seminar in November with a programme for contact persons, doctoral students and senior researchers drawn from all over Sweden. The two-day seminar attracted some 60 participants and was held at the Department of Education and Special Education at the University of Gothenburg. The keynote speakers came from Australia and Scotland. A network meeting was held in connection with the seminar.

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

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

More subscriptions have been switched from printed newsletters to digital format (PDF) newsletters and new subscribers were added during the year. The newsletter had a circulation in 2014 of 4400, of which 1400 were for the digital-format publication. In addition to the newsletter, the CDR office sends information to an e-mail network with 800 addresses.
The CDR homepage (www.cff.uu.se) presents information about activities at CDR, its board members, lecture and course programmes, etc. The newsletter Forskning om funktionshinder pågår (Current Disability Research) is available in PDF format. All issues from the start in 1992 are available.

The Board of the Centre for Disability Research

- Professor Karin Sonnander, (Disciplinary domain of medicine and pharmacy) chairperson
- PhD Faculty of Medicine, Karin Hellström (Disciplinary domain of medicine and pharmacy)
- Professor Anders Rydberg (Disciplinary domain of science and technology), vice chairperson
- PhD Faculty of Technology, Kjartan Halvorsen, (Disciplinary domain of science and technology)
- Professor Rafael Lindqvist (Disciplinary domain of humanities and social science)
- PhD Faculty of Humanities and social Sciences, Lotta Lerwall (Disciplinary domain of humanities and social science)
- PhD student Therese Fridström Montoya
- Former Senior lecturer, Sonja Calais van Stokkom (The Swedish disability federation)
- Director Research and Development, Mia Pless (Uppsala county council)
- Managing Director, Marie Palmgren (Municipalities in Uppsala county)

Agencies supporting CDR work/Fund

Funding has been received for 2014 for the newsletter Forskning om funktionshinder pågår (Current Disability Research).

The financiers are:

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

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

- Council for Working Life and Social Research (FAS) SEK 250 00
Research collaboration

During 2014 the Centre for Disability Research (CDR) worked intensively to organise the event “AIMday Funktionshinder” (“AIMday Disability”) in collaboration with Uppsala Regional Council and UU Innovation. The theme of the event was “How can we help one another overcome obstacles? About disabilities and living life on disabled people’s own terms”. CDR took the initiative to bring about the AIMday event focusing on disability, and the office at CDR was a key actor throughout the work.

The purpose of AIMday is to give academic researchers and private sector and civil society organisations the opportunity to make contacts and exchange knowledge. By matching the organisations’ needs for new knowledge with academic expertise, AIMday provides new insights and new perspectives on topical problems and issues. AIMday is based on small group discussions, lasting just one hour, taking their point of departure in questions put by organisations to researchers and experts from a number of different disciplines.

Twenty-four questions were discussed at AIMday on 27 November. Only a few of the questions submitted could not be matched with interested researchers. About 70 people in total attended the event, with approximately as many researchers as participants submitting questions.

An on-the-spot evaluation was carried out as participants were leaving Navet at Uppsala Biomedical Centre on 27 November. It showed that they were very satisfied with the day as a whole and with the discussion groups. Some groups have gone on to collaborate on specific projects, with some also applying for and being allocated pre-study funding.

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 approx. 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 2014 eight lectures were arranged, and we have seen an increase in the number of people in the audience.

The newsletter Forskning om funktionshinder pågår (Current Disability Research)

The launching of the newsletter was a way of meeting an expressed need from the Swedish disability organisations, who asked for easily accessible written information on current disability research. The newsletter is published by the CDR, Uppsala University. However, the content is not limited to research activities from Uppsala University but includes disability research from all over Sweden. As of a few years ago, the introduction of every article is written in easy-to-read Swedish. Every issue is available as a PDF document, to be found on the website of the Centre for Disability Research, Uppsala University. Those interested in a particular topic or looking for a special article can search all published issues on the website, using keywords (in Swedish). The current number of recipients is 4400, 3000 of whom subscribe to a printed version and 1400 subscribe to a PDF document distributed by e-mail. Many subscribers are workplaces, so there is reason to believe that the newsletter is made available to and is read by multiple individuals. The newsletter is also circulated widely. Hence, the newsletter is read by considerably more people than the subscribers. The audience is varied and includes, besides a significant number of disability researchers, national, regional and local governmental agencies, universities and university colleges, libraries, schools, non-governmental organisations, workplaces and individual employees in local government organisations, persons with a personal interest in the field, national newspapers and media, etc. Most recipients are Swedish, although there are also subscribers in the Scandinavian countries.
Centre for Research Ethics & Bioethics (CRB)

Director: Professor Mats G. Hansson

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

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

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

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

Clinical Ethics

We are interested in the ethical issues that arise in clinical settings, in association with diagnosis, treatment and the organization and delivery of health care.

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

PhD projects include end of life treatment and palliative care in paediatric oncology, questions related to ‘do not resuscitate orders’ (DNR), assessment of cardiovascular risk in primary health care settings, communication of genetic risk information and preconception genetic screening and relational autonomy.

Postdoc projects include gender issues in association with telenursing and a pilot study on using pretend play to increase children’s engagement in health care situations is running.
We also look at quality of life issues. Currently two projects are running: One focus on self-management of hypertension and the another on quality of life assessments.

Some of this research is part of a research network on family ethics and social care.

Research Ethics

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

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

Many studies are carried out within international consortia and funded by the European Commission. CRB is responsible for ethical and legal issues within the Swedish infrastructure for biobank based research, BBMRI.se. We are also part of BBMRI-ERIC (where we are responsible for an ELSI-commonservice), RD-Connect, BTCure, Euro-TEAM and BiobankCloud.

The research in research ethics provides updated knowledge for courses in research ethics and mandatory training of graduate students in medicine, pharmacy, science and technology.

Bioethics

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

One of the greatest challenges of modern science is an understanding of the human brain. Uppsala University’s CRB is part of the European Commission flagship initiative to simulate the human brain and will look at the social, ethical and philosophical implications of The Human Brain Project.

Another challenge offered by technology is how genetic risk is communicated. We are running a six year international multi-disciplinary project on how to manage and handle genetic risk information.

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

The research in bioethics provides updated knowledge for courses in neuroethics, bioethics and public health ethics.
Centre staff 2014
(In alphabetical order)

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

Stefan Eriksson, ThD, Associate Professor of Research Ethics, Senior lecturer
Stefan Eriksson, serves as editor of the Swedish Research Council’s website CODEX, and has after invitation and review been appointed “super professor” at Faculty Row.

Stefan is indexed and can be followed at Research Gate and Scopus. He has 80 publications listed, including 3 books, his H-index is 10 and his 32 most prominent articles have been cited over 250 times (as calculated by Scopus in August 2014).

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

Kathinka Evers, PhD, Associate Professor of Philosophy, Senior researcher
Kathinka Evers leads the CRB neuroethics research team. She is a co-director of the EU Flagship Human Brain Project. Her main research focus is neuroethics and the neural basis of consciousness and she teaches an advanced level course in neuroethics. Kathinka Evers’ research also includes biobank ethics and she is part of the BBMRI.se network.

She conducted her doctoral studies in philosophy at Balliol College, University of Oxford, at the Research School of Social Sciences, Australian National University, Canberra, and at Lund University, Sweden, where she received her doctoral degree in 1991. She has been a research fellow at Balliol College, University of Oxford (1994); at the Department of Philosophy and Human Rights Centre, University of Essex, Colchester (1996-97); invited professor at the University of Tasmania, Hobart (1999), at École Normale Supérieure, Paris (2002), and at Collège de France, Paris (2006-07).

For six years (1997-2002) she was the Executive Director for the Standing Committee on Responsibility and Ethics in Science (SCRES) of the In-
ternational Council for Science (ICSU). She is also division leader for ethical and societal implications of the EU-flagship Human Brain Project. Kathinka Evers has recently been appointed Honorary Professor at Universidad Central de Chile.

Michele Farisco, MA, PhD, PhD student
Michele Farisco is part of CRB’s neuroethics research team. He was recently (2015) appointed Associate Professor of Moral Philosophy in Italy. He holds a degree in Philosophy from University of Naples "L'Orientale" in 2003, a PhD in "Ethics and Anthropology: History and Foundation" from University of Lecce in 2008 and a Master degree in Biolaw from the University of Rome "Lumsa" in 2009. He spent time on an exchange grant from the European Neuroscience and Society Network within the European Science Foundation joining the Coma Science Group of the University of Liège (Belgium). He is the head of the "Science and society” research unit of Biogem Genetic Research Centre in Ariano Irpino (Italy). He is the author of three books and several articles about posthuman philosophy and philosophical, ethical and legal implications of genetics and neuroscience.

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

Josepine Fernow, BA, Co-ordinator
Josepine Fernow is our co-ordinator and communications officer. She is also the editor of the centre websites and writes for the Biobank Perspectives newsletter. Her background is undergraduate studies in Cultural Anthropology and Sociology at Uppsala University.

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. Her PhD project deals with participation in phase 1 and phase 3 oncology trials.
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).

Sara Holm, PhD, Researcher

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

Heidi C. Howard, PhD, Senior Researcher

Heidi Carmen Howard joined CRB in April 2014. She adds competence on genetic information to the project Mind the Risk.

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

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

In the autumn of 2013 she spent a semester as assistant professor at the Radboud University Medical Centre (Netherlands). Her main areas of research are the ethical, legal and social aspects of direct-to-consumer genetic testing, public health genomics, genomic medicine, new genomic technologies, participant-centric research initiatives and the translation of genomics from the laboratory to the clinic.
Heidi Carmen Howard is also an invited scholar at the Centre of Genomics and Policy at McGill University (Montréal, Canada) and a member of the Public and Professional Policy Committee of the European Society of Human Genetics.

Anna T. Höglund, ThD, Associate Professor of Ethics, Senior lecturer

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

Li 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.

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 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 Samar-
iterhemmets Vårdcentral in Uppsala. Sofia Lavén holds a degree in Medicine from Uppsala University (2000) and a license to practice (2002).

Anna-Sara Lind, Associate Professor of Public Law, Senior Researcher

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

Deborah Mascalzoni, PhD Bioethics, Researcher

Deborah Mascalzoni joined CRB in April 2013. With her competence on biobank and registry research she is working on the 7th Framework programme RD-Connect.

Deborah Mascalzoni worked on ELSI Issues related especially to the population based CHRIS project at the Center of Biomedicine, European Academy (EURAC). She and holds a PhD in Bioethics from the Faculty of Law at Bologna University. She has also been teaching ethics at the 'Claudiana' University of Roma in Bolzano. She is a member of the Ethical board of South Tyrol and the local health system ethical board of Bolzano as well as the Telethon Advisory Board. She is involved in the WIKI platform of BBMRI.IT, a member of the BRIF project and a member of the ethical group of the International Genetic Epidemiological Society (IGES). Her main research interests are genetics and new technologies, informed consent, patient communication, privacy & data sharing and the role of stakeholders in medicine.

Amal Matar, MD, MSc, PhD Student

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

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

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

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, Professor of Administrative Law
Jane Reichel joined CRB in September 2011 to work with the legal aspects of research conducted on human tissue samples within the BBMRI.se network. Jane Reichel is senior lecturer at the Department of Law at Uppsala University and is tied part-time to CRB. She became Professor of Administrative law in 2014.

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

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

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

Pär Segerdahl, PhD, Associate Professor of Philosophy, Senior researcher
Pär Segerdahl investigates notions of nature and animal in animal ethics, animal welfare and various eco-philosophies, as well as in contemporary culture more generally. He holds a PhD in theoretical philosophy from Uppsala University (1993). He was a guest researcher at the Centre for Gender Research at Uppsala University from 2007-2009. Pär Segerdahl became associate professor of theoretical philosophy at Åbo Akademi Univeristy in 1998 and Uppsala University in 2001. He currently develops new ideas for research on absolutism and relativism in the notion of morality. Pär Segerdahl is also involved in research communication for the BBMRI.se (Biobanking and Biomolecular Resources Research Infrastructure Sweden) and editor of the ethics blog 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). She left CRB in 2014 to work as a lecturer in nursing at the University of Gävle.
Anna Lydia Svalastog, Professor, 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 analyzed 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.

She is professor at Østfold University College in Norway.

Jennifer Viberg, BSc, MSc, PhD Student

Jennifer Viberg's PhD project deals with the ethical issues concerning disclosure of incidental findings to research participants in genetic research. She approaches this question from a philosophical perspective: How does a person’s preference compared to other ethical values? She is also approaching this question from an empirical perspective: How can we investigate and measure people’s preferences in an appropriate way?

Jennifer Viberg holds a degree of Master of Arts in Rehabilitation Science from Mid Sweden University. She also has 5 years of experience as a licensed Prosthetist and Orthotist and 2.5 years as a teacher at the study program in Prosthetics and Orthotics at Jönköping University.

She is also involved in the IMI-funded BTCure project on Rheumatoid Arthritis, Mind the Risk and BBMRI.se.

Publications 2012-2014

A characteristic feature of our interdisciplinarity is that we publish both in scientific journals, often together with researchers from other disciplines, and in monographs. The monograph format is customary in philosophy and humanities and it allows for more in depth analysis of conceptual issues. In fact only publishing in shorter articles would be a little irregular from the perspective of philosophers. Our monographs are often published in established series and always scrutinized in a peer review.
Publications 2012-2014


42. Hamang A, Eide G E, Rokne B, Nordin K, Bjorvatn C, Oyen N. Predictors of Heart-Focused Anxiety in Patients Undergoing Genetic Investigation and Counseling of Long QT Syndrome or Hypertrophic


Dissertation 2014

Gottvall, Maria. Introduction of School-Based HPV Vaccination in Sweden: Knowledge and Attitudes among Youth, Parents, and Staff,
2013, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, doctoral dissertation.

 Agencies that support the work/Funding

In 2014 we signed a contract with the Swedish Agency for Health Care and Service Analysis (Vårdanalys) for 1,500,000 SEK to conduct a project on Integrity.

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

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

With faculty allowances (2,794,887 SEK), KoF allowance (200,000 SEK during 2014), research ethics training for medicine, pharmacy, science and technology (773,792 SEK), external funding (7,233,260 SEK) and some odd sums, our income 2014 totalled 12,399,273 SEK.

Funding 2014

<table>
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<tr>
<th>Funding Agency</th>
<th>Project</th>
<th>Amount (SEK)</th>
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<td>RD-Connect</td>
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<td>Swedish Childhood Cancer Foundation</td>
<td>PedPlay</td>
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Clinical ethics

Quality of life assessments in clinical practice

Funding: The Swedish Cancer Society (Cancerfonden)
Time table: 2012-2014

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

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

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

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

Funding: Primärvården, Landstinget i Uppsala län
Time table: 2012-

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

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

PhD student:
- Sofia Lavén, MD

Supervisors:
- Mats G. Hansson, Professor of Biomedical Ethics
- Karin Björkegren, MD, PhD, Senior lecturer, Family medicine and Preventive medicine, Department of Public Health and Caring Sciences
The aim of this project is to investigate attitudes to and perceptions of ‘Do Not Resuscitate’ (DNR) orders among staff in oncology and hematology care. The need for a certain ethical competence for these decisions will be investigated. Further the experiences of education in DNR and understanding of DNR orders among students in nursing and medical school will be investigated.

Within oncology and hematology care, patients in a terminal phase of cancer sometimes have such a poor prognosis that Coronary Pulmonary Rescue (CPR) is not considered justifiable in case of cardiac arrest. This can lead to a DNR order to be issued by the responsible physician, implying that in case of a cardiac arrest neither basic nor advanced CPR is to be performed. DNR situations can lead to severe ethical dilemmas and moral distress among the staff.

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

PhD Student:
• Mona Pettersson, RN

Supervisors and collaborators:
• Anna T. Höglund, Associate Professor of Ethics
• Mariann Hedström, Senior lecturer, Department of Public Health and Caring Sciences
• Gunnar Birgegård, Professor, Department of Medical Sciences

Gender aspects in telenursing (post doc project)

Time table: 2010-2014
Funding: The Swedish Research Council (Vetenskapsrådet)

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

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

This research is a collaboration with Mälardalens Högskola (Professor Inger Knutsson Holmström), Health Services Research (Senior Researcher Elenor Kaminsky), Caring Sciences (Professor Marianne Carlsson) and CRB (Associate Professor Anna T. Höglund) at the Department of Public Health and Caring Sciences.

Post doc:
Elinor Kaminsky, RN, PhD

Collaborators:
- Anna T. Höglund, Associate Professor of Ethics
- Inger Knutsson Holmström, Professor Mälardalens Högskola
- Marianne Carlsson, Professor, Caring Sciences, Department of Public Health and Caring Sciences

Paediatric Palliative Oncology in a Family Perspective (PhD project)

Funding: The Swedish Childhood Cancer Foundation (Barncancerfonden)

Time table: 2009-2015

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

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

In this project, we will

- Examine to what extent there is a shift in focus on palliative care in the departments if paediatric oncology in Sweden
- Examine which symptoms bereaved parent regard as affecting their dying child the most in the end-of-life period and if there is a relation be-
tween these symptoms and long-term psychological well-being in parents who have lost a child.
• Examine if there is a relation between treatment intensity in the child (in the form of hematopoietic stem cell transplantation) and psychological well-being in bereaved parents.
• Examine how parents and dying children communicate about death.
• Examine how children suffering from cancer view their need for information regarding diagnosis and prognosis and possible treatment-failure.
• Examine how bereaved siblings experience the death of their brother or sister.

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

PhD Student:
• Li Jalmsell, MD
Supervisors:
• Mats G. Hansson, Professor of Biomedical Ethics
• Britt-Marie Frost, Department of Paediatric Oncology, Uppsala University Hospital (Akademiska sjukhuset)
• Jan-Inge Henter, MD, Professor. Childhood Cancer Research Unit, Karolinska University Hospital
• Ulrika Kreicbergs, RN, Professor, Ersta Sköndal University College

Ethical issues in preconception genetic screening (PhD project)

Time table: 2013-2017

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

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

The tests have become more reliable and cost effective, making it possible to consider genetic screening for carrier status in populations. This has led to an ethical debate: On one hand, preconception genetic screening could increase the reproductive choices for individuals or couples and lead to enhanced reproductive autonomy. On the other hand, it is not necessarily so that more choice enhances autonomy. Too much choice can lead to moral distress. The debate has also revolved around the possible medicalization of the reproductive process that preconception genetic screening can lead to.
This project will:
- Explore the ethical issues of preconception genetic testing and screening, taking the family’s and the individual's perspective into account.
- Focus on the interface between health care providers (for example clinical geneticists and gynecologists) and the prospective parents/family.
- Highlight the role and responsibility of family members and health care providers in the decision making process regarding preconception genetic testing and screening.

This project is part of the Ethics of Family in Health and Social Care Research Consortium.

PhD Student:
- Amal Matar, MD, MsC

Supervisors:
- Ulrik Kihlbom, Senior lecturer in Medical Ethics
- Anna T. Höglund, Associate Professor of Ethics
- Marian Verkerk, Professor Ethics of Care, University Medical Center Groningen

Pretend play: children with cancer (Pilot Project)

Funding: The Swedish Childhood Cancer Foundation (Barncancerfonden)

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

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

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

Collaborators:
- Mats G. Hansson, Professor of Biomedical Ethics
- Sara Holm, PhD, Researcher
Developing and evaluating an interactive mobile phone system to support self-management of hypertension

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

Time table 2010-

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.

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

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 treat-
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

Contact and more information: http://www.gpcc.gu.se/english/or http://www.letstudio.gu.se/

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

Research Ethics

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

Funding: The Swedish Research Council (Vetenskapsrådet)

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

Our work package (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 advice and training.
- Be a knowledge centre for ethical management of biobank related research.
- Contribute to a constructive weighing of ethical interests in the field of biobanking.
- Constitute a competitive and attractive node for international cooperation on ethical and legal aspects of biobank research.
- Contribute to an initiated discussion on biobank related issues in society.
- Investigate how biobank research that protects integrity can be conducted.
- Investigate how biobanks can collaborate with national quality registries in an efficient and legal manner.
- Investigate the legal requirements for updating collections of samples through 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.

Collaborators:

- Mats G. Hansson, Professor of Biomedical Ethics
- Kathinka Evers, Professor of Philosophy
- Anna-Sara Lind, Associate Professor of Public Law
- Jane Reichel, Professor of Administrative Law
- Pär Segerdahl, Associate Professor of Philosophy
- Jennifer Viberg, BSc, MSc, PhD Student

RD-Connect (ELSI Work Package)

Funding: EU, 7th Framework Programme
RD-Connect aim to build an integrated platform connecting registries, biobanks and clinical bioinformatics for rare disease research.

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

CRB’s role in RD-connect: 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.

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

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

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

CRB:
- Mats G. Hansson, Professor of Biomedical Ethics
- Deborah Mascalzoni, PhD, Senior Researcher
- Jennifer Viberg, BSc, MSc, PhD Student

BTCure (Be The Cure) (work package)
Funding: IMI (Innovative Medicines Initiative)
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.

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.

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

Collaborators:
- Mats G. Hansson, Professor of Biomedical Ethics
- Kathinka Evers, Professor of Philosophy
- Jennifer Viberg, BSc, MSc, PhD Student

Euro-TEAM (work package)

Funding: EU, 7th Framework Programme

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.

Collaborators:
- Mats G. Hansson, Professor of Biomedical Ethics
- Deborah Mascalzoni, PhD, Senior Researcher

BiboankCloud - Scalable, Secure Storage of Biobank Data (STREP) (work package)

Funding: EU Seventh Framework Programme project
Time table: 2012-2015

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

The BiobankCloud PaaS framework will be designed to run primarily on private cloud platforms. It will be built on open-source projects for big data and provide added features to those projects. The platform will be designed in cooperation with BBMRI.eu.
CRB is part of a work package on Regulatory and ethical requirements for data storage and analysis run by Jan-Eric Litton at Karolinska Institutet. Together, we will provide a framework of legal and ethical regulations that enable the BiobankCloud to operate under controlled conditions. This framework will consider the different levels of legal protection in the EU member states.

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

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

The scale of the storage requirements needed for genomic information is huge – a single human genome requires analysis of three billion base pairs. The analysis requires both a massive parallel computing infrastructure and data-intensive computing tools and services to perform analyses in reasonable time.

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

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

Co-ordinator:
- Dr. Jim Dowling (jdowling@kth.se) KTH – Royal Institute of Technology, Sweden

Collaborators at CRB:
- Mats G. Hansson, Professor of Biomedical Ethics
- Jane Reichel, Professor of Administrative Law

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

Funding: The Swedish Cancer Society (Cancerfonden)
Time table: 2010-2012
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.

PhD Student:
- Tove Godskesen, RN

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

The project group also includes:
- Mats G. Hansson, Professor of Biomedical Ethics
How should incidental findings in biobank research and genome sequencing studies be handled? (PhD project)

Funding: This project has received funding from BT-Cure and BBMRI.se

Time table: 2012-

This project will assess the argument for and against disclosure of incidental findings in biobank and –omic research and suggest how these findings should be handled in practice. Both philosophical analysis of basic concepts and arguments and an empirical study will be conducted. The empirical study intends to answer if research participants want to know about incidental findings, and if so under what conditions do they want to know. The method for that study will be Discrete Choice Experiments, developed for health economy studies, and the primary aim is to capture the individuals’ preferences in complex choice situations.

PhD student:
- Jennifer Viberg, BSc, MSc

Supervisors:
- Mats G. Hansson, Professor of Biomedical Ethics
- Pär Segerdahl, Associate Professor of Philosophy

Publication ethics

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

Collaborator:
- Stefan Eriksson, Associate Professor of Research Ethics, Senior Researcher

Regulation of research

Difficulties in regulation are an interesting study object, not only for researchers, but also for legislators, professional organizations and the society at large. Future developments of regulation should rest on a comprehensive and thoughtful approach to science regulation.

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

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

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

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

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

Collaborator:
- Stefan Eriksson, Associate Professor of Research Ethics, Senior Researcher

Bioethics

The neuroscience of disorders of consciousness: from laboratory to clinics (PhD Project)
Funding: European Union Flagship: The Human Brain Project
Time table: 2013-

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

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

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

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

PhD Student:
- Michele Farisco, Associate Professor of Moral Philosophy

Supervisors:
- Kathinka Evers, Professor of Philosophy, Senior Researcher
- Steven Laureys, MD, PhD, Cyclotron Research Center and Department of Neurology, Sart Tilman Liège University Hospital

Mind the Risk

International network collaboration with scientists and researchers from Uppsala, Göttingen, Manchester, Milano and Stockholm.
Funding: Riksbankens Jubileumsfond (The Swedish Foundation for Humanities and Social Sciences).
Time table: 2014-2020
Biomedical research is constantly finding new ways to detect genetic variation and link the findings to diseases and to the effects of various drug treatments.

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

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

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

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

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

Collaborators at CRB:
- Mats G. Hansson, Professor of Biomedical Ethics
- Terry Flynn, Senior Researcher
- Heidi C. Howard, PhD Neurogenetics, Senior Researcher
- Ulrik Kihlbom, Senior lecturer in Medical Ethics
- Sofia Lavén, MD, PhD Student
- Jessica Nihlén Fahlquist, Senior lecturer in Medical Ethics
- Jennifer Viberg, BSc, MSc, PhD Student

International partners:
- Georg-August-Universität, Göttingen: The Department of Medical Ethics and History of Medicine
- The Interdisciplinary Research Center on Decision Making Processes in Milano
- University of Manchester: The Centre for Health Economics, Institute of Population Health
- University of Birmingham & Sandwell & West Birmingham Hospitals NHS Trust
- University of Maastricht: Department of Technology and Society Studies, Faculty of Arts and Social Sciences
- Karolinska Institutet and Sophiahemmet University College
- deCODE genetics
Synthetic Biology: media portrayal and public understanding


Synthetic biology is a rapidly evolving field that has the potential to change how we live and understand the world. A trend in current technology assessment is the idea that it should include public involvement. This seems particularly true in the case of synthetic biology, given its relatively low language codification and potential to affect public interest.

There is, however, a risk that scientists spin their results in order to further the field. This, coupled with ethicists focussing on speculative ethics and media focussing on drama, can put the public and policy makers at a disadvantage: Reducing their ability to properly assess synthetic biology and its possible applications. Therefore, the way the public is addressed and the way that synthetic biology is presented and perceived are key factors.

This project focuses on synthetic biology outreach and the way it is popularized by scientists.

The aims are:

- To suggest conceptual tools for a sober and grounded understanding of synthetic biology
- To suggest tools for communicating synthetic biology to the public in a way that relates to common moral intuitions about life

Collaborators:
- Mirko Ancillotti, MA, Research Assistant
- Stefan Eriksson, Associate Professor of Research Ethics

The Human Brain Project (sub project on science and society)

Funding: European Community (FET) Flagship Project
Time table: 2013-

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

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

- Future Neuroscience
- Future Medicine and
- Future Computing

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

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

CRB is part of HBP through professor Kathinka Evers who leads the philosophical research within the HBP. She is director of the Subproject 12, "Ethics & Society", and a member of the HBP’s Internal Advisory Board.

Two of our PhD projects are also part of HBP:

- The neuroscience of disorders of consciousness: from laboratory to clinics (PhD Student: Michele Farisco)
- What is it like to be unconscious? Perspectives from Philosophy and Neuroscience with special regards to Resignation Syndrome (PhD Student: Karl Sallin)

Collaborators at CRB:

- Kathinka Evers, Professor of Philosophy, Senior Researcher
- Michele Farisco, Associate Professor of Moral Philosophy, PhD Student
- Omar Gutierrez Arenas, PhD Neuroscience, Postdoc
- Karl Sallin, MD, PhD student

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

Funding: European Union Flagship: The Human Brain Project
Time table: 2013-

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

A clinical condition resembling Pervasive Refusal Syndrome (the Swedish diagnostic term translated into English is Resignation Syndrome (RS)) rose in prevalence in an astounding manner in 2004-5 among asylum-seeking refugee adolescents in Sweden. Clinical symptoms persist for months to years leaving the patients in a seemingly unconscious state characterized by flaccid paralysis and a complete lack of response even to pain. Tube-feeding is necessary and no therapeutic intervention hastening recovery is known. Little is known of the biological background of the condition.
The study of RS is, with regards to its severity, duration and lack of treatment, paramount. Exhibiting altered states of consciousness and being hitherto unexplored from the perspective of neuroscience, these patients also provide an opportunity to study the biology of consciousness. Can such findings, and others from neuroscience, help us understand how consciousness and in particular the first person-perspective can arise in the brain.

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

PhD Student:
- Karl Sallin, MD, PhD student

Supervisors:
- Kathinka Evers, Professor of Philosophy, Senior Researcher
- Predrag Petrovic, Psychiatrist, Associate Professor, Karolinska Institutet

Mentor:
- Hugo Lagercrantz, Senior Professor, Karolinska Institutet

International Collaborations

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

Mind the Risk

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

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

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 funding for this network ended in 2013. Ongoing collaborations are led by Anna-Lydia Svalastog.

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

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

An ongoing PhD project on pre-conception genetic testing is part of this network, co-supervised from the Netherlands.

Neuroethics

The CRB Neuroethics research team is led by Kathinka Evers. The group is part of the European Commission flagship initiative The Human Brain Project (HBP) that will simulate the human brain. A project with that raises many philosophical and ethical questions.

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

Undergraduate Teaching

At the Faculty of Medicine, ethics has for several years been part of the curriculum for nurses and doctors. Within the nurse’s programme, ethics courses 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.

Ethics is also part of the midwife programme and we teach within the specialist nurses programmes and other educational programmes at Uppsala University.

We are currently working together with the Biology Education Centre to integrate structured ethics teaching for students in science and technology.

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.

Online training

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

In 2014 we offered a course pilot to students from Sweden, Italy, Egypt and Singapore. The first open training opportunities are offered during the autumn 2015. The training has its own website: www.ethicstraining.crb.uu.se (launched spring 2015).

Conferences and symposia

In 2014 we planned a multi-disciplinary workshop on epigenetics as the meeting point between nature and nurture that was held in March 2015.
Public outreach

In 2014, www.crb.uu.se had 31 347 unique visitors (between 1200 and 1700 per week) and 51 970 (about 1,65 visits per visitors), 115 249 pages were visited (2.21 pages per visit) and we had 609 127 hits (11.72 hits per visit).

The average visit takes 141 seconds. About 0.9 per cent of our visitors stay for an hour or longer (86.4 leave within 30 seconds, which is one of the reasons why text for web needs to be short, precise and preferably organized in bullet points.)

Obviously there are fewer visits during the summer and on weekends. After the summer, our web traffic increased, going from around 2 500 unique visitors per month to around 3 000 peak in October (3470) and December (3172) (especially after we sent out the blog book Christmas card).

Traffic tends to increase when we send e-mails on our lists. This year we have send information about the epignetics conference (which explains some of the October peak) and the Biobank perspectives newsletter (January, April and September increases in traffic) and also the Blog books as a Christmas greeting. We are restrictive with these lists (2 000 on a "general" list and another 2 000 on a biobank related list) not to tire them.

Our visitors come from Sweden mainly, followed by .com, .net Germany, Italy, unspecific European countries, the Netherlands, Turkey, China, Norway, USA, France, and United Kingdom. Romania, Spain, Finland, Portugal, Poland, USA (edu) and many more, including a few visits from the Faroe Islands, Yemen and São Tomé and Príncipe – a very international outreach.

CRB’s staff members 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 2014, the Swedish blog had 8700 visits, while the English blog had 5400 visits. Both blogs have increased their following, both via e-mail and Wordpress.

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

Popular project report
Marit Silén’s postdoc project on ethical rounds in psychiatric outpatient clinics ended in 2014. We decided to make a very short popular summary and print a folder as a means of returning results to participants.

CRB: media and opinion
Researchers at CRB sometimes participate in the public debate. We also try and interest the press in our research. In 2014, Stefan Eriksson wrote an opinion piece in Curie (2014-10-27, Viktigt rättsfall om forskares användning av studentarbeten). He was also interviewed by them (2014-06-03, Nya sätt att granska forskningen) and by Läkartidningen (2014-09-10, Helsingforsforsdeklarationen 50 år: Ur nazismens grymheter föddes forskningsetiken).

Mats G. Hansson co-authored an opinion piece in Dagens Medicin (2014-06-12, Stora nätverk med patientdata ger chans att höja vården). He was also


Anna T. Höglund was interviewed by Swedish Radio Uppland (P4) about a study of authentic calls to Swedish Health Care Direct (1177) (2014-09-23).

Deborrah Mascalzoni was interviewed for Biobank Sweden (#14, October 2014. Sharing is ethical), about the international charter of principles for sharing biospecimens and data that was published in the European Journal of Human Genetics 2014.

Finally, Tove Godskesen was interviewed by Upsala Nya Tidning (2014-02-09, Cancerpatienter vill hjälpa andra) about her interview study with patients in clinical trials that was published by the European Journal of Cancer Care in February 2014.

Biobank perspectives: Newsletter launch

In 2014 we launched a newsletter on biobank ethics and law. The circulation for the printed version is around 300 copies. We also publish an electronic version (both pdf and html) that is distributed via e-mail to around 4,000 recipients.

We published the first issue in January 2014, one in May and a third issue in September. The newsletter has been very well received and we will continue with 3-4 issues per year.

The newsletter discusses biobank regulation and presents research results to the biobanking community. It is part of our work within BBMRI.se.
Clinical Nutrition and Metabolism

Research Group Leader Professor Tommy Cederholm

Research profile

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

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

Members of the group 2014

<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>
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<tr>
<td>Ulf Risérus, deputy</td>
<td>Associate professor</td>
<td>Researcher</td>
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<tr>
<td>Per Sjögren</td>
<td>Associate professor</td>
<td>Researcher</td>
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<tr>
<td>Brita Karlström</td>
<td>Professor emeritus</td>
<td>Dietitian</td>
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<tr>
<td>Bengt Vessby</td>
<td>Professor emeritus</td>
<td>MD</td>
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<tr>
<td>Ulf Holmstäck</td>
<td>Postdoc</td>
<td>Researcher</td>
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<tr>
<td>Anja Saletti</td>
<td>Postdoc</td>
<td>Dietitian</td>
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<td>Afsaneh Koochek</td>
<td>Postdoc</td>
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<tr>
<td>Matti Marklund</td>
<td>Postdoc</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>
<td>PhD student</td>
<td>MD</td>
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Johanna Törmä PhD student Dietitian
Sigvard Sobestiansky PhD student MD
Erika Olsson Licentiat student Dietitian
Erika Ax PhD student Nutritionist
Fredrik Rosqvist PhD student Nutritionist
Zayed Alsharari PhD student Nutritionist
Mikael Karlsson PhD student Dietitian
Elisabeth Skoglund PhD student MD
Roger Olsson Lecturer/Universitetsadjunkt
Siv Tengblad Laboratory technician
Linda Bratteby-Tollerz Physiotherapist
Marie Berglund Research assistant
Âsa von Berens Research assistant
Maria Saevig Research assistant

Partly affiliated or associated to CNM
Wulf Becker Associate professor Chief nutritionist
Elisabet Rytter Postdoc Nutritionist
Helena Bjermo Postdoc Nutritionist
Stefan Branth Postdoc MD
Anders Forslund Postdoc MD
Anders Sjödin Associate professor MD
Annika Smedman Postdoc
Torbjörn Åkerfeldt PhD student MD

Publications 2012-2014

2014


55. Cederholm T. Fettkvalitet och hjärtsjukdom i omstridd meta-analys. Läkartidningen 2014;111:CW3R.


2013


86. Vahlberg B, Cederholm T, Lindmark B, Zetterberg L, Hellstrom K. Factors related to mobility and physical activity in individuals one to


2012


105. Thornell LE, Gustafsson T, **Cederholm T**, Ulfhake B. Sarcopenia has earned its living (Letter to the Editor). *J Appl Physiol* 2012;113:683-84.


125. Adamsson V, Reumark AC, **Cederholm T**, **Vessby B**, **Riserus U**, Johansson G. What is a healthy Nordic Diet. Foods and nutrients in the


Other articles 2012-2014


Dissertation 2014

Agencies that support the work/Funding (in SEK)
The Swedish Research Council (VR) 1 150 000
The Swedish Research Council (VR) 800 000
FORTE 800 000
FAS/FORENTE 500 000
Medicinska Fakultetsmedel 857 000
Medicinska Fakultetsmedel/KOF 200 000
Regionala Forskningsrådet Uppsala-Örebro 70 000
University of Tabuk, The Kingdom of Saudi Arabia 50 000
EXODIAB strategic research grant 500 000
Uppsala County Council – ALF 1 057 000
Stockholm County Council – ALF (The OmegAD Trial) 400 000
Uppsala Municipality 160 000
Nestec 3 000 000
Throne Holst 72 000
SNF 50 000

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

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

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

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

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

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

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

Future promising research at CNM

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

Research Group Leader Professor Karin Sonnander

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

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

Members of the group during 2014

Päivi Adolfsson, PhD, associated researcher
Gunilla Eriksson, PhD Faculty of Medicine, associated researcher
Johan Glad, BA, PhD Faculty of Medicine, associated researcher
Gunnel Janeslätt, PhD Faculty of Medicine, associated researcher
Helene Lidström, PhD Faculty of Medicine, associated researcher
Helena Lindstedt, PhD Faculty of Medicine, associated researcher
Mia Pless, PhD Faculty of Medicine, associated researcher
Ieva Reine, PhD Faculty of Medicine, associated researcher
Karin Sonnander, PhD, professor
Annika Terner, BA, PhD student
Öie Umb-Carlsson, PhD Faculty of Medicine, senior researcher
Helena Wandin, BA, PhD student

External partners

- Heléne von Granitz, PhD student, Health Service Research, Department of Public Health and Caring Sciences, Uppsala University
- Ann-Britt Ivarsson, PhD Faculty of Medicine, associate professor, School of Health and Medical Sciences, Örebro University
- Niklas Källberg, PhD, Stockholm School of Economics, and Helseplan consulting Group
- Per Lindberg, PhD, professor, Department of Psychology, Uppsala University
- Liselotte Norling Hermansson, PhD Faculty of Medicine, Clinical Research Centre, Örebro University, Hospital, Örebro
- Edward Palmer, PhD, adjunct professor, Department of Economics, Uppsala Center for Labor Studies, Uppsala University
- Ingvor Pettersson, PhD Faculty of Medicine, senior lecturer, School of Health and Medical Sciences, Örebro University
- Barbro Wadensten, PhD Faculty of Medicine, associate professor, Caring Sciences, Department of Public Health and Caring Sciences, Uppsala University
- Ulrika Winblad Spångberg, PhD, associate professor, Health Services Research, Department of Public Health and Caring Sciences, Uppsala University

Publications 2012-14

2012


2013


2014


Literature reviews


Conference oral presentations and poster presentations


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


naire. 16\textsuperscript{th} International Congress of the World Federation of Occupational Therapists (WFOT), Yokohama, Japan (Workshop).


30. Janeslätt, G. (2014). Parents on the outside- a pilot study of a support group for parents with cognitive limitations who have lost the care of their children. 10\textsuperscript{th} Cognitive Symposium, Redondo Beach, California, USA.


Dissertations 2014


Agencies that support the work/Funding (SEK)

Swedish Council for Working Life and Social Research (FAS) 1 230 000
The Sävstaholm Foundation 2 280 000
Uppsala County Council 142 000
The Norrbacka Eugenia Foundation 100 000
The Promobilia Foundation 100 000
Jämtlands County Council 300 000
The National Board of Health and Welfare 216 000
Uppsala County Council 1 230 000
Related tasks (members)

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

Examinations and evaluations (members)

During 2014 assignments as member of examining committee at public defense of doctoral theses at University of Gothenburg and Uppsala University, expert review Swedish Social Insurance and peer reviews Disability & Rehabilitation (Karin Sonnander).

Third stream activities (members)

- Associated member of the management group, Centre for Disability, Uppsala County Council (Karin Sonnander)
- Associated member of the committee for Research and Development, Uppsala Regional Council (Karin Sonnander)
- Editor National Newsletter on Disability Research (*Forskning om funktionshinder pågår*), published by Centre for Disability Research, Uppsala University (Karin Sonnander)
- Reference group at Public Health Agency of Sweden regarding the Government's strategy for the implementation of disability policy 2011-2016 (Œie Umb-Carlsson)
- Single lectures arranged by municipalities for professionals, politicians and people with intellectual disabilities arranged by FUB The Swedish National Association for Persons with Intellectual Disability (Œie Umb-Carlsson)
- Open lecture arranged by Center for Disability Research, Uppsala University (Œie Umb-Carlsson)
Undergraduate teaching 2014 (members)

Nursing Program
Nursing and Nursing methods 15 Higher Education Credits (Œie Umb-Carlsson lectures on Discrimination Act and Act concerning support and service for persons with certain functional impairments, seminar on Treatment and Disability and essay tutorials).

Caring Science Freestanding courses
Single lectures and examinations (Œie Umb-Carlsson) and essay examination (Karin Sonnander).

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

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

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

Projects

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

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

- Participants: Monica Blom Johansson, Karin Sonnander

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

Aided communication between persons with Rett syndrome and their interaction partners

- Participants: Helena Wandin, Per Lindberg, Karin Sonnander

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

Reports on implementation of evidence-based practice

- Participants: Mia Pless, Karin Sonnander

The overall aim is to report on implementation of evidence-based practice in multi-professional rehabilitation and habilitation services. A specific aim is to develop and evaluate activities and strategies supporting continuous quality improvement.

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-centred intervention programme addressing return to work after stroke and evaluate the effect of and the experiences of participating in the intervention programme.
The HOME Inventory, Home Observation for Measurement of the Environment – A Swedish Adaptation

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

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

The electronic health record system: professional use and patient safety

- Participants: Annika Terner, Helena Lindstedt, Mia Pless, Karin Sonnander

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

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

- Participants: Päivi Adolfsson, Karin Jöreskog, Gunnel Janeslätt

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

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

*Environmental help or hindrance?*
- Participants: Helene Lidström, Gunnel Janeslätt, Päivi Adolfsson, Ingvor Pettersson, Liselotte Norling Hermansson, Helena Lindstedt

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

*Importance of personal assistance financed by the Swedish social insurance for meeting national health objectives for men and women with serious functional impairment*
- Participants: Ieva Reine, Heléne von Granitz, Edward Palmer, Karin Sonnander

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

*Men and women with intellectual disabilities and quality of life*
- Participants: Õie Umb-Carlsson, Päivi Adolfsson

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

*People with intellectual disabilities as participants in the research process*

- Participant: Öie Umb-Carlsson

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

Research group leader associate professor Per Kristiansson, chair

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

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

Our research in Family Medicine emanates from the multidisciplinary perspective of primary health care and is conducted by the large group of researchers throughout the Uppsala-Örebro region. Our present research profile includes 9 program areas: social insurance medicine, pain and musculo-skeletal disorders, asthma, allergy and COPD, symptom reporting and pharmacoepidemiology, diabetes and cardiovascular disease, reproductive health, GP’s quality in work and communication skills, vitamin D deficiency.

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

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

Members of the group during 2014
Mansour Alemi Associate researcher, PhD
Åsa Andersén  
PhD student, Master in Public Health

Dan Andersson  
Associate researcher, MD, PhD

Sven-Olof Andersson  
Associate researcher, MD, PhD

Ingrid Anserén  
Researcher, PhD

Malin André  
Associate researcher, MD, PhD

Eva-Maria Annerbäck  
Associate researcher, MD, PhD

Bengt Arnetz  
Professor, MD, PhD

Judith Arnetz  
Associate professor, PhD

Annika Bardel  
Associate lecturer, MD, PhD

Regina Bendrik  
PhD student, Physiotherapist

Britta Berglund  
Associate researcher, PhD

Anne Björk  
PhD student, MD

Karin Björkergren  
Lecturer, MD, PhD

Stefan Blomberg  
Post doc, MD, PhD

Johan Bogefeldt  
Associate researcher, MD, PhD

Eva Bojner Horwitz  
Associate researcher, PhD

Kristina Bröms  
Associate researcher, MD, PhD

Gunilla Burell  
Senior researcher, Psychologist, PhD

Stephen Butler  
Associate researcher, MD

Lars Carlsson  
PhD student, MD

Jan Cederholm  
Associate professor, MD, PhD

Lars Englund  
Associate researcher, MD, PhD

Sevek Engström  
Associate researcher, PhD, dentist

Margaretha Eriksson  
Researcher, PhD

Frida Fröberg  
PhD student, BSc

Christina Grape Viding  
PhD student, RN

Marie Grunnesjö  
Post doc, PhD

Mats Gulliksson  
Associate researcher, MD, PhD

Catharina Gustavsson  
Associate researcher, PhD

Christina Halford  
Associate researcher, MD, PhD

David Hallman  
Post doc, PhD

Johan Hallqvist  
Professor, MD, PhD

Björn Hallström  
Associate researcher, MD, PhD

Johanna Haraldsson  
PhD student, MD

Charlotte Hellström  
PhD student, MD

Anna Hofsten  
Associate researcher, MD, licentiate

Stefan Jansson  
Associate researcher, MD, PhD

Gunnar Johansson  
Adjunct professor, MD, PhD

Linus Johnsson  
Associate researcher, MD, PhD

Lena Kallings  
Associate researcher, PhD

Paul Kalliokoski  
PhD student, MD

Bo Karlsson  
PhD student, MD

Elisabeth Krefting Bjelland  
Associate researcher, Physiotherapist, PhD

Per Kristiansson  
Associate professor, MD, PhD

Sofia Lavén  
PhD student, MD
Anna Liljestam Hurtigh  Research assistant, Master of Publication
Anne Lindgren  PhD student, Physiotherapist
Karin Lisspers  Associate researcher, MD, PhD
Lena Lundholm  PhD student, BSc
Linda Lännerström  PhD student, RN
Monica Löfvander  Associate professor, MD, PhD
Mats Martinell  PhD student, MD
Annika Nolin  Research assistant, Master of Arts
Lena Nordgren  Associate researcher, PhD
Gunilla Norrmén  Post doc, MD, PhD
Lena Olai  Associate researcher, PhD
Magnus Peterson  Associate researcher, MD, PhD
Rathi Ramji  Research assistant, MPh
Nils Rodhe  Associate researcher, MD, PhD
Åke Schwan  Post doc, MD, PhD
Carina Seidel  Associate professor, MD, PhD
Jan Stålhammar  Associate professor, MD, PhD
Björn Stållberg  Associate researcher, MD, PhD
Elisabet Sundgren  PhD student, RN
Kurt Svårdssudd  Professor emeritus, MD, PhD
Malin Swartling  Post doc, MD, PhD
Jenny Söderberg  PhD student, RN
Eva Thorell  Associate researcher, MD, PhD
Thomas Torstensson  Associate researcher, Physiotherapist, PhD
Keld Vaegter  Associate researcher, MD, PhD
Petra Vogt  Associate researcher, MD, PhD
Anna-Sophia von Celsing  PhD student, MD
Rolf Wahlström  Associate researcher, MD, PhD
Mari-Ann Wallander  Associate professor, Epidemiologist, PhD
Thorne Wallman  Associate lecturer, MD, PhD
Clairy Wiholm  Associate researcher, PhD
Ture Ålander  Associate researcher, MD, PhD

Publications 2012-2014

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

2014

1. 2) Abel KM, Heuvelman HP, Jörgensen L, Magnusson C, Wicks S, Susser E, Hallqvist J, Dalman C. Severe bereavement stress during


13. 2) Bohman T, Alfredsson L, Jensen I, Hallqvist J, Vingård E, Skillgate E. Does a healthy lifestyle behaviour influence the prognosis of low


18. 2) Carrasquilla GD, Berglund A, Gigante B, Landgren BM, de Faire U, Hallqvist J, Leander K. Does menopausal hormone therapy reduce myocardial infarction risk if initiated early after menopause?: a population-based case-control study. *Menopause* 2014;Dec 8 [Epub ahead of print].


27. 1) Frank C, Takman C, Nordgren L. Social insurance administrative officers’ perceptions of their assignment and problematic issues in their work with heart failure clients in the sick-leave and rehabilitation process. *Nordic Social Work Research* 2014.


64. 3) Lumley MA, Shi W, Wiholm C, Slatcher RB, Sandmark H, Wang S, Hytter A, Arnetz BB. The relationship of chronic and momentary...


2013


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


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

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


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


142. 1) Meland E, Englund L, Waller G. Perspectives from the Nordic risk group: Existential and religious dimensions in medical practice. 18th Nordic Congress of General Practice, Tampere, Finland. 2013.


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


2012


207. 1) Kiotseridis H, Bjermer 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.


210. 2) Lundholm L, Haggård U, Möller J, Hallqvist J, Thiblin I. The triggering effect of alcohol and illicit drugs on violent crime in a remand


Dissertations 2014


Agencies that support our work / Funding 2014 (SEK)

<table>
<thead>
<tr>
<th>Agency</th>
<th>Amount (SEK)</th>
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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: Kerstin Ahlqvist, Sven-Olof Andersson, Johan Bogefeldt, 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, Thorne Wallman.

Research projects

Social Insurance Medicine
- Participants from the group: Åsa Andersén, Ingrid Anderzén, Lars Carlsson, Lars Englund, Johan Hallqvist, Anna Liljestam Hurtigh, Linda Lännerström, Kurt Svärdsudd, Anna-Sophia von Celsing, Thorne Wallman

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

MEDiTUNA – Vocational rehabilitation: how does it affect health and quality of life?
MEDiTUNA, including 100 women and men, is a project that studies how persons with psychiatric disability are affected by an individual placement and support intervention. Outcome measures are health, quality of life, drug consumption and sick-listing. The project started in 2013. Baseline and 6 months follow-ups are finished. One year and two year follow-ups are planned.
Determinants for return to work among sickness certified patients in general practice

The aim of this study was to analyse possible determinants of return to work and their relative impact. 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 [232]. This study was presented in an oral presentation and a poster at The 2nd Nordic Conference in work-related rehabilitation, in Grenå, Denmark in September 2012 [Early prediction of patients at risk for long term sickness absence].

We have also analysed whether the most important determinants for return to work used in a risk assessment tool (nomogram). The results were compared to a categorisation, performed by a team of experienced rehabilitation professionals, considering six risk factors for long-term sickness absence from the sickness certificate. Furthermore, the effects of the rehabilitation intervention in cooperation with primary health care, the Swedish Social Insurance Agency, Employment Agency and the County Council for Social support, will be studied. Do sick listed individuals regain work ability after an intervention to a greater extent than those who did not receive any intervention at all?

The project has so far generated two published articles [232, 86] and one in manuscript (von Celsing AS, Svärdsudd K, Wallman T. Reversed effect of a vocational rehabilitation programme on return to work among sick-listed primary health care patients: A population-based matched case-control study). The project is generating one PhD thesis (Anna-Sophia von Celsing).

Sick leave in primary health care – Nurses’ work and sick-listed persons’ experiences

The objective of this project is to describe nurses’ work with sick leave in primary health care and also long-term sick-listed persons’ experiences of being on sick leave.

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 organization [211].
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 [140].

In two ongoing studies nurses’ work with sick leave in primary health care is described and an intervention in insurance medicine is performed. The project is generating one PhD thesis (Linda Lännerström).

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

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

Patients who visited doctors for psychiatric or musculoskeletal problems and were sick-listed were invited to participate in the study. After randomization half of the participants were assessed by a physiotherapist, psychotherapist and occupational therapist. The other half received “regular care”, which did not include such early assessments. Our hypothesis was that such assessments would result in faster and more adequate rehabilitation leading to faster recover and less need of sick leave. In this trial the intervention group was sick-listed longer [105] This project has also been presented by one poster at two conferences (Carlsson L, Englund L, Hallqvist J, Wallman T. Early multidisciplinary assessment resulted in longer periods of sick-leave: a randomized controlled trial in a primary health care center. At The 2nd Nordic Conference in work-related rehabilitation, Grenå Denmark, September 2012 and at The 20th Congress of The European Union of Medicine in Assurance and Social Security (EUMASS) in Stockholm 2014).

In another project GP´s experiences of working with sick leave after the changes in the Swedish social security system was analyzed. A descriptive qualitative inductive focus group discussion approach was chosen. Assigning sick leave was still perceived by Swedish GPs as a burdensome task. However, the system changes in recent years, in the Swedish social security system, have facilitated this work. Cooperation with other professionals regarding the sick leave cases is perceived positively by Swedish GPs. One manuscript is submitted (Carlsson L, Lännerström L, Wallman T, Holmström IK. General practitioners' perceptions of working with the certification of sickness absences following changes in the Swedish social security system: a qualitative focus-group study). The project is generating one PhD thesis (Lars Carlsson).
Research area - Absenteeism and Return to Work

In collaboration with the Swedish Social Insurance Administration, the Swedish Public Employment Service, and the Psychiatric Division at Akademiska hospital in Uppsala we have projects assessing the efficacy of various innovative return-to-work strategies, including the concept “Pathway Back to Work”. The aims of these projects are focusing on enhancing the pathway back to work and to identify factors that will help long-listed individuals return to the working life. We have developed and evaluated strategies to decrease sick leave and to improve the return-to-work processes. The Pathway to Work focuses on assisting people on sick leave to become more independent and to earn a living by targeting some of their health-related barriers and by providing financial support. The program has achieved national recognition as an innovative and cost-effective means to decrease sick-leave and facilitate return-to-work for people with long-term stress-related absenteeism.

The Welfare Academy – a public investment for the development of welfare

Participants connected to Uppsala University are Ingrid Anderzén and Johan Hallqvist

The Swedish Social Insurance Agency (SSIA) has taken an initiative to form a welfare academy, which is a co-operative undertaking between the SSIA, other governmental agencies at the local, regional and national level, the business and research communities, Community and non-profit organizations. The purpose of the academy is to improve the support for people who have difficulty find their places in the labor market. The academy shall also organize funding for research and implementation in this area. The challenges of a developing society require co-operation in all avenues of a developing society.

The purposes of the academy are:
- Develop and promote innovations within the welfare society
- Promote implementation and utilization of evidence based methods and procedures
- Contribute to the overall development of the Swedish welfare system

The main task is to bring together researchers and practitioners, establish co-operation in developing research-based methods for decision making that can improve the support systems for people who have difficulty to find their places in the labor market and to provide knowledge-based and practical support in implementation.

The groups prioritized by the academy are recent immigrants, people with functional impairments, and prevention of work-related illness.

The formal start of the Welfare Academy is January 2016.
VITALIS – An RTC study to support women on long term sick leave to return to working life through ACT or Team evaluation
Participants in the project are Ingrid Anderzén, Åsa Andersén, Anna Liljestam Hurtigh, and Per Lytsy

This project started as collaboration with the Swedish Social Insurance Administration, the Swedish Public Employment Service, and the Health Care sector. Fifty-five percent of people presently sick listed in Uppsala County were during 2010 diagnosed with psychological problems, such as depression, anxiety and stress related symptoms, and/or chronic pain. The overall aim with this project was to develop, provide and evaluate accessible rehabilitation programs, for these complexes of problems, to help women on long term sick leave, to return to work.

Vitalis started in Spring 2010 and data collection have been completed during 2013. Approximately 400 women on long term sick leave due to pain, stress, depression and/or anxiety symptoms, identified by the National Insurance Agency in Uppsala County were randomized into one out of three conditions. One as a multimodal team assessment and intervention, one with a home based internet supported unimodal psychological intervention (Acceptance and Commitment Therapy) and one condition as a treatment as usual (TAU) intervention. The project will evaluate the long term effects (after one and after two years) of those two different rehabilitation packages: multidisciplinary team assessment/intervention and CBT/ACT home based/internet treatment as compared to TAU. The follow-up data collection is completed. The evaluation of the project received financial support from REHSAM (forskning om arbetsrehabilitering).

The project has been presented by three posters at The 2nd Nordic Conference in work-related rehabilitation in Grenå Danmark in September 2012 (Anderzén I, Lytsy P, Finnes A. Vitalis – back to life and back to work) the Work, Stress and Health Conference in Los Angeles, USA in May 2013 (Anderzén I, Lytsy P, Finnes A. Vitalis – back to life and back to work) and also at The 11th Stress research conference – New Frontiers in Swedish Stress Research - what is underway? in Gothenburg in May 2013 (Andersén Å, Larsson K, Lytsy P, Anderzén I. Self-efficacy in women on long term sick leave – the Vitalis project).

A final report has been published 2014 [61] and one article has been accepted for publication (Lytsy P, Larsson K, Anderzén I. Health in women on long term sick leave due to pain or mental illness, Int J Rehabil Res).

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

(For number in brackets -- see “Publications 2012-2014” on page 141-164)
DIRIGO 1 and 2 – “I control”
Participants in the research team are Ingrid Anderzén, Åsa Andersén and Kjerstin Larsson. Externals are Kerstin Ekberg, Christian Ståhl and Eva Vingård

Dirigo 1 and Dirigo 2 are two projects funded by The European Social Fund (ESF) and was operated by The Social Insurance Office, in co-operation with The Public Employment Service and the municipality, in parts of Stockholm.

In Dirigo 1 participants are employees and the aim is to create a base of competence for workers on the welfare arena, enabling them to meet and support the citizen in his/her own process.

Participants in the Dirigo 2 project are sick listed individuals, young individuals with activity compensation from The Social Insurance Office and individuals that receive their compensation through their local municipality.

The overall aims with the two projects are to support and strengthen the individual and its view on their work capacity to return to/come closer to the labor market/employment.

Together with the University of Linköping we have evaluated the projects both with quantitative measurements (data from registry and questionnaires) and qualitative methods during open ended interviews and focus-groups with service users and professionals working in the area of vocational rehabilitation.

During the evaluation process the research team have completed six work reports that have been presented for the employees in the both projects. The projects started 2012 and were completed in 2014 and final reports were presented in September 2014. The projects ended up with a conference the 5 of May 2014 in Stockholm.

The project Dirigo 2 will generate one article in a PhD thesis (Åsa Andersén).

UMiA
Participants in the evaluation process have been Ingrid Anderzén, Åsa Andersén and Kjerstin Larsson

The project UMiA was founded by the European Social Fund (ESF) and is operated by The Social Insurance Office in Stockholm. The aims of the project were to develop, and evaluate different methods and interactions in order to support and enhance the ability for young individuals with disabilities to increase their work or study capacity. About 400 individuals, age 19-29 years will participate in the project.

The evaluation consists of both quantitative measurements (data from registry and questionnaires) and an on-going evaluation (qualitative) with service users and professionals working in the area of vocational rehabilitation perspective. UMiA started 2013 and completed in 2014. During 2012 and
2013 three work reports have been completed and presented for the employees in the project.

The project has been orally presented at The EUMAS Conference in Stockholm in September 2014 (Anderzén I, Larsson K, Andersén Å, Ståhl C. The importance of health care competence in vocational rehabilitation). A final report has been published [56].

The project UMiA will generate one article in a PhD thesis (Åsa Andersén).

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

Pain and musculo-skeletal disorders

- Participants: Karin Björkegren, Bo Karlsson, Per Kristiansson, Magnus Peterson, Kurt Svärdsudd

Epicondylosis

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

- An epidemiological study of treatment methods in primary health care
- A randomized controlled trial of different types of graded exercise as treatment for this condition
- An experimental study investigate the pathophysiology of the condition by imaging methods

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

The second part was fulfilled in a two-part randomised controlled clinical trial. In the first part, the effect of exercise versus wait-and-see was evaluated. In the second part 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. Both a publication on exercise versus wait-and-see and a publication on eccentric versus concentric exercise have been published [74].

The third part was fulfilled by positron emission tomography (PET) of physiological processes associated with pain in the peripheral painful tissue of the affected as compared to the healthy elbow in subjects with unilateral tennis elbow. The results from the PET scan of peripheral tissue (elbows)
have been analysed in cooperation with the Uppsala PET-centre and a manuscript has been published [145].

The project has generated one PhD thesis [Magnus Peterson. *Chronic tennis elbow: aspects on pathogenesis and treatment in a soft tissue pain condition*. Medical sciences. Uppsala University].

In cooperation with Harvard Medical School, the central nervous system has been analysed in relation to the findings in the peripheral tissue. A manuscript has been submitted during 2014. (Clas Linnman C, Catana C, Svärdsudd K, Appel L, Engler H, Långström B, Sörensen J, Furmark T, Fredriksson M, Borsook D, Peterson M. Decreased CNS neurokinin 1 receptor availability in chronic tennis elbow. Submitted).

The PET-project is currently expanded in cooperation between Karolinska and Uppsala University to involve animal studies of other pain-related mechanisms in the peripheral tissue.

In cooperation with the Swedish Agricultural University (SLU) animal studies are conducted on animal models of pain in mast cell deficient mice.

During 2014 two chapters on musculoskeletal pain were published in a clinically oriented textbook [73,40].

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

**Cognitive behavioral therapy in fibromyalgia**

The main purpose in this project was to assess the effects of cognitive behavioural therapy (CBT) given to fibromyalgia patients by a randomised controlled study design. Fifty women with a fibromyalgia diagnosis in Mid-Sweden were randomised to one of two groups. One group received CBT for one year with the other group as control. After one year the control group also received CBT. A large number of variables have been collected through questionnaires and blood samples. The project has been performed in collaboration with the section for biological research on drug dependence at Uppsala University.

The project has been presented by a poster at The International Congress of Behavioral Medicine in Budapest 2012 (Karlsson B, Anderberg UM, Burell G, Nyberg F, Svärdsudd K. Substance P levels are reduced after distress management with cognitive behavioural therapy in women with the fibromyalgia syndrome: A randomised controlled clinical study). Another poster has been presented at the The International Congress of Behavioral Medicine in Groningen 2014 (Karlsson B, Anderberg UM, Burell G, Kristiansson P, Björkegren K, Nyberg F, Svärdsudd K. Neuropeptide Y is reduced after cognitive behavioural therapy in women with fibromyalgia: A randomised clinical trial).

An article has been submitted and a half-time seminar was given in 2013. The project is generating one PhD thesis (Bo Karlsson).
A national study of the health of children at allergy avoidance and conventional day care centres in Sweden

A postal questionnaire was sent to parents of 8,700 children that went to Swedish special allergy avoidance day care centres and ordinary day-care centres in the vicinity as controls. Five years later a follow-up questionnaire was sent to the parents. One report focused on the prevalence and co-occurrence of asthma and allergic manifestations [103]. In another publication the asthma incidence and its determinants was estimated [179]. The project has generated one PhD thesis (Kristina Bröms).

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

The PRAXIS-study asthma/COPD

The aim of the PRAXIS-study is to compare asthma and COPD guidelines with the actual care. A postal survey in 2005 was answered by 1,210 randomly selected patients with asthma and 1,113 with COPD from 56 randomly selected primary health care centres and outpatient clinics at 14 hospitals in the Uppsala-Örebro health care region. The records of these patients have also been examined. Several reports have been published.

In the first about asthma control it was concluded that in spite of treatment guidelines many patients in Swedish primary care still have insufficient asthma control. The second evaluated how often a diagnosis of COPD was confirmed with spirometry. The third report has evaluated the associations of comorbidity and body mass index with quality of life in COPD. A fourth report about sex-related differences in asthma has been published [137] and was a part of Karin Lisspers’ dissertation. A fifth report regarding dyspnoea, obstruction, smoking and exacerbations (DOSE index) and mortality has been published [225]. A sixth report about quality of life in COPD (CCQ) and mortality has been published [224] and a seventh about exacerbations in COPD has been published [157]. An eight report regarding asthma control has been published during 2014 [54] and a ninth about a comparison between an assessment scale and a quality of life questionnaire for COPD patients has been accepted.

A follow-up investigation has been started in 2012 with new longitudinal data from the cohort of asthma and COPD patients from 2005 and in 2014 a new random selection of both asthma and COPD-patients started.

The PRAXIS-project has generated one PhD thesis 2013 (Josefin Sundh, Department of Respiratory Medicine, Örebro University Hospital), and is
receiving financial support from the county councils of the Uppsala-Örebro Region, Uppsala-Örebro Regional Research Council, the Swedish Heart and Lung Association, the Swedish Asthma and Allergy Association, the Bror Hjerpstedt Foundation, Uppsala, and Uppsala University.

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

International research collaboration in asthma and COPD in primary care

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

A publication about the needs of prioritising respiratory research in primary care has also been published [217]. They are also involved in an international research project comparing the management of COPD and asthma in primary care in different countries and promoting research collaboration, the UNLOCK study, published in 2010.

A manuscript about a comparison of COPD patients in large clinical trials and COPD patients attending primary care has been published [53]. Lisspers and Ställberg are the leads of two new research projects within UNLOCK, one about asthma and one about COPD.

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

The physicians’ actions in the management of COPD

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

The project is generating one PhD thesis (Hanna Sandelowsky, Karolinska Institutet, Stockholm). One publication has been published in from this research collaboration and the second is submitted.

COPD rehabilitation study

Björn Ställberg and Karin Lisspers are members in the steering committee of a national investigation of resources for rehabilitation in COPD. A first paper has been published [166].
Clinical trials

Björn Ställberg was a member in the steering committee for a study about treatment of rhino-sinuites, the SOSAR-study [222].

Karin Lisspers was a member of the steering committee for a study regarding screening for COPD, the DETECT-study [230].

The NO-KOL study

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

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

Results have been presented at the European Respiratory Society (ERS) Annual Congress 2013 (Malinovschi A, Johansson G, Venge P, Hedström H, Alving K. Exhaled NO but not eosinophilic inflammation is reduced by inhaled corticosteroid treatment in COPD).

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

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

A total of 187 patients with asthma at 17 primary health care centres have been included in a study. The aim is to examine whether use of exhaled nitric oxide (NO) to guide anti-inflammatory treatment can improve asthma-related quality of life in adult patients with allergic asthma. The data have been collected and are being processed. The same study is examining whether there is an association between different circulating cytokines (systemic inflammation), exhaled NO and quality of life [162].

The project is being led by Kjell Alving, Jörgen Syk and Gunnar Johansson and is receiving financial support from Karolinska Institutet.
A retrospective epidemiological study to map outpatients with chronic obstructive pulmonary disease (COPD) and describe COPD health care in real-life primary care during the first ten years of the 21st century – PATHOS

This is a retrospective epidemiological study to map outpatients with COPD and describe COPD health care in real-life primary care during the first ten years of the 21st century. Data has been extracted anonymously from electronic patient records in primary care. By extraction of data from 80 primary health care centres data were obtained on approximately 25,000 patients. In addition, data regarding morbidity and mortality has been collected from the Hospital Discharge Register (Slutenvårdsregistret) and the Cause of Death Register and information on prescribed drugs was collected from the Prescription Register. Data on social-economic status has also been collected from Statistics Sweden (SCB). The merging of data has been performed by the National Board of Health and Welfare.

The software program Pygargus Customized eXtraction Program (CXP) was used to extract patient data from the electronic patient records of the participating primary care centres for all patients with a diagnosis of COPD (ICD 10: J44) and/or prescription of drugs in the ATC class R03 (pharmaceuticals for obstructive lung diseases). The social security number of identified patients was immediately replaced with a study ID-number for further anonymous processing of data. No identification of patients is possible once the database is finalized. Collected data are being processed.

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

The PATHOS study is receiving financial support from AstraZeneca. The data management has been performed by Pygargus and Uppsala Clinical Research Centre. Four papers have been published [131, 136, 80, 60] from the PATHOS study and additional manuscripts are under preparation.

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

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

A new randomised controlled trial studying the effects on dyspnoea symptoms of a rehabilitation programme on patients with COPD and heart failure has started. This study is carried out in collaboration with Regional Research centres in Karlstad and Örebro. Karin Lisspers and Björn Ställberg are members of the steering committee.
How can COPD patients with risk for exacerbations be identified? A prospective cross-sectional study in primary and secondary care

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

The aim of the study is to find clinical tools for identifying patients with risk for COPD exacerbations. This is a regional study aiming to include 600 COPD patients in the counties of Uppsala, Gävleborg and Dalarna. Recruitment started in May 2014 and patients will be studied during two years with three visits including examination and questionnaires. Participants will be divided into a study-group that has had exacerbations during the last year and a control group that has not had exacerbations during the last year and the study period. Karin Lisspers, Björn Ställberg and Kristina Bröms are members of the steering committee.

Symptom reporting and utilisation of pharmaceuticals

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

Womens utilisation of pharmaceuticals and Symptom reporting among men and women in Sweden

The purpose of this project was initially to study utilisation of pharmaceuticals among women based on a postal questionnaire sent to 4,200 women in the Uppsala-Örebro region. We presented the results in four reports and one PhD thesis (Annika Bardel) has been generated. In the last report we studied the reported symptom prevalence across age and use of pharmaceuticals.

Symptom reporting across age has also been tested in the consort dataset including more than 17,000 observations in men and women 25-99 years old. Parts of these results were presented at Sörmland county R&D 2011-2013, and a publication intended for a peer reviewed journal is close to finalization.

We now intend to move on with further analyses of the consort dataset to examine the relationship between symptom reporting among men and women and their sick-listing, disability pension, survival and use of hospital care.

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

On the request from WONCA an essay entitled “Factors associated with adherence to drug therapy” has been authored by Annika Bardel, Mari-Ann Wallander and Kurt Svärdsudd in 2014. The text has been reviewed and accepted and is due for publication in 2015.
Pharmacoepidemiology

The area of pharmacoepidemiology is a fairly new branch of epidemiology and is methodologically still in its development phase. Research in this area requires access to high quality health care databases and collaboration with various academic groups in Europe and the US.

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

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

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

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

Methods and results of these projects have been published in peer reviewed journals during the last decade.

Further research has been conducted in collaboration with the Boston Collaborative Drug Surveillance Program with among others Professor Susan Jick investigating on the risk of mortality in patients with multiple sclerosis in comparison with the general population. Results from this project are due for publication in 2014.

Another project has been finalized during 2013 dealing with the risk for acute liver injury in patients treated with antimicrobials. This study has been conducted in collaboration with researchers from the US and Spain and publications of the results are due in 2014.

In 2014 the research collaboration with Centro Español de Investigación Farmacoepidemiológica (CEIFE) has continued especially in the project on the use of prescription contraceptive methods in the UK general population. The collaboration has resulted in three peer reviewed publications during 2014 [19, 20, 21].
The project evaluating the risk for acute liver injury in patients treated with antimicrobials conducted with researchers from the US and Spain has been finalized and has resulted in two publications in 2014 [51, 15].

The collaboration with the Boston Collaborative Drug Surveillance Program with among others Professor Susan Jick investigating the risk of mortality in patients with multiple sclerosis has resulted in one publication in Neurology during 2014 [45] and yet another publication is waiting for acceptance.

A study investigating the initial use of a new thrombine inhibitor in Germany has been published during 2014. The study was conducted in collaboration with researchers from Bremen University [46].

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

Diabetes and cardiovascular disease

- Participants: Dan Andersson, Jan Cederholm, Sevek Engström, Johan Hallqvist, Gunnar Johansson, Lena Olai, Jan Stålhammar, Kurt Svärdsudd

Determinants for the survival of diabetes patients

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

A first report dealing with diabetes incidence and prevalence during 30 years of follow up has been published as well as a study of mortality trends in subjects with and without diabetes during 33 years of follow up. In a third report was shown the effect of blood pressure, anti-hypertension treatment, fasting blood glucose and diabetes treatment on cardiovascular disease incidence [44].

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

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

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

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

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

More than 50 articles have been published 2002-2014, as presented at www.ndr.nu – 2012-2014 [31, 48, 106, 108, 109, 110, 111, 161, 167, 183, 184, 185, 186, 187, 188, 204]. Summaries of the risk factor control and associations with diabetic complications, coronary heart disease (CHD), cardiovascular diseases (CVD), mortality, or risk of cancer, in type 1 diabetes or type 2 diabetes, have been published in Lakartidningen 2009 and 2013 [106] and in reviews (Diabetes Care, Eur J Cardiovasc Medicine).

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

Other observational long-term studies showed that blood pressure (BP) <140/80 mmHg strongly reduced risk of CVD, with no significant risk differences between SBP 130-139 and 110-129 mmHg, indicating a BP treatment target 130-135/75 mmHg, is in accordance with recent guidelines from the European Societies of Hypertension and Cardiology and the American Diabetes Association. The NDR-study was presented by ESC/ESH as one of two evidence-based references for this treatment goal [183]. Specific statistical graphical technique was applied to illustrate in detail the variation of CVD risk across the BP distribution [183, 184]. Half of the patients in the NDR register still have a systolic BP ≥140 mmHg [31].

Concerning blood lipids, observational NDR-studies have shown that the ratio non-HDL/HDL cholesterol was a stronger risk factor for CHD than LDL-cholesterol. Specific statistical graphical technique demonstrated that LDL had a markedly attenuated and flattened risk effect below 2.5 mmol/l,
while the risk effect was progressively decreased at lowest lipid ratio values, also showing improved HDL-cholesterol and triglycerides values with lower lipid ratio [111]. Recent guidelines from American Heart Association underline that there is no evidence-base for increased risk effect at lowest LDL targets.

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

Two risk models for estimation of 5-year CVD risk in type 1 diabetes or type 2 diabetes have been published based on observational NDR-studies using multiple cardiovascular risk factors and clinical characteristics as risk predictors; the risk models have shown good validation when applied to large samples of patients with diabetes overall in Sweden. Both risk models are presented at www.ndr.nu, and can be useful for diabetes care in daily clinical practice. A study of newly diagnosed patients with type 2 diabetes showed that the estimated CVD risk has been improved during the last years [188].

A long-term observational study of patients with type 2 diabetes showed considerably increased risks for CVD and mortality with low physical activity (never or 1-2 times 30 min activities per week) compared to higher activity. Inactivity both at baseline and during the 5-year study period showed highest risks, 70% higher CVD risk and 100% higher risk of all-cause mortality [167].

Long-term development of renal complications (albuminuria and renal impairment) was predicted by higher HbA1c and systolic BP, and also by higher BMI and triglycerides. Albuminuria more than renal impairment was strongly related to risk of CVD and mortality during 5 years of follow-up [161].

An observational NDR-study of pharmacological treatment on risk for diabetic complications in type 2 diabetes, using linking with the Swedish Prescribed Drug Register, showed that metformin had lower risk than insulin for CVD and all-cause mortality, and slightly lower risk than sulphonylurea for all-cause mortality. Patients on metformin with mild-moderate renal impairment (GFR 45-60) showed no increased risk of CVD, all-cause mortality or acidosis/severe infection [109, 185,186]. Another long-term study on aspirin in patients with type 2 diabetes and no previous CVD showed no decrease in risks of CVD or mortality with aspirin use, not even in patients with high predicted risk of CVD [110].
A large observational study on 25,000 patients with type 2 diabetes, followed for 10 years until 2009, showed no association between higher HbA1c values and risk for all cancer or specific types of cancer [204]. However, another observational NDR-study showed a strong association between elevated BMI / obesity and increased risk for all cancer as well as increased risks for gastrointestinal, colorectal and postmenopausal breast cancer [48].

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

All New Diabetics in Uppsala – ANDiU

ANDiU is a study on patients with newly diagnosed diabetes residing in Uppsala County. Our aim is to explore the genetics underlying diabetes, facilitate individualized diabetes care and to build a platform for diabetes research. Since launch in maj 2012 ANDiU have contributed to 6 publications [17, 26, 78, 62, 39, 63]. ANDiU collaborate with ANDIS (L. Groop, M. Dorkhan, Lund University) and ESTRID (S. Carlsson, J Löfvenborg, R Hjort, Karolinska Institute).

Principle investigator is Per-Ola Carlsson, Department of Medical Cell Biology, Uppsala University and project leader is Mats Martinell. Other associated researchers are Johan Hallqvist, Jan Stålhammar and Daniel Espes, Uppsala University.

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

This is a retrospective epidemiological study of patients with diabetes mellitus and an investigation of the outcome and mortality associated with glucose lowering treatment in real-life primary care during the first ten years of the 21st century. Data has been extracted anonymously from electronic patient records in primary care. By extraction of data from 80 primary health care centres data were obtained on approximately 80,000 patients. In addition, data regarding morbidity and mortality were collected from the Hospital Discharge Register (Slutenvårdsregistret) and the Cause of Death Register and information on prescribed drugs were collected from the Prescription Register. Data on social-economic status were also collected from Statistics Sweden (SCB).

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

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

Data has been presented at international diabetes congresses and four reports have been published [100, 148, 159, 168].

Screening for diabetes and hypertension in the Dental Care Service

The dental care is the only clinical area where patients on a large scale come for check-ups without having symptoms. This project deals with the possibility of using the dental health care as a screening function for high blood pressure and diabetes.

The purpose is to evaluate to what extent new diabetes or hypertension cases, not known previously to health care personnel, can be detected. Three dental care clinics in Gävleborg County, measured blood pressure and blood sugar in patients attending the dental service, approximately 1,600 patients.

All patients who had blood pressure or blood sugar concentration above preset levels were referred to the primary health care centre for follow-up. Data from these units regarding the referred persons covering the three years preceding and following the screening occasion, in total more than 30,000 appointments, were obtained to find out whether the referred person was already known or, and if those referred came for follow-up and, if so, they received a hypertension or diabetes diagnosis.

A published paper based on a pilot study showed a strong relationship between high blood pressure and the prevalence of deep gingival pockets. In a second report the efficacy of blood pressure screening in dental care and primary care follow-up was analysed, showing that the blood pressure screening was very efficient. In the third report the diabetes screening showed the need for inclusions criteria, as age and BMI, for efficient finding those at risk [114]. The forth project is calculating the direct cost for this type of screening organisation [115].

The project has generated one PhD thesis in 2012 (Sevek Engström. Dental health care cooperating with primary health care as a resource in early case finding of patients with diabetes or hypertension. Medical sciences. Uppsala University).

(For number in brackets -- see “Publications 2012-2014” on page 141-164)
Reproductive health

- Participants: Kerstin Ahlvist, Anna-Maria Annerbäck, Mansour Alemi, Stephen Butler, Elisabeth Krefting Bjelland, Johanna Haraldsson, Per Kristiansson, Anne Lindgren, Lena Nordgren, Magnus Peterson, Eva Thorell, Thomas Torstensson

Physical activity and pregnancy

Participants: Eva Thorell, Laura Goldsmith, Gerson Weiss, Kurt Svärdsudd, Per Kristiansson

The aim of this project was to assess physical fitness in pregnancy and to evaluate its effect on perceived health, back pain, blood pressure and duration of pregnancy. Also, to evaluate the effect of serum relaxin levels on blood pressure and duration of gestation. Perceived health, diastolic blood pressure and duration of gestation were positively affected by physical fitness while no effect was shown on the incidence of back pain. The effect of physical fitness on duration of gestation and diastolic blood pressure might have clinical implications as well as the increased serum relaxin levels on miscarriages.

The project has generated four papers [229] and one PhD thesis in 2013 (Eva Thorell. Physical fitness and pregnancy. Medical sciences, Uppsala University) and has received support from New Jersey Medical School of Rutger University, Örebro County Council and Uppsala University.

Chronic pelvic pain induced in pregnancy

Participants: Thomas Torstensson, Anne Lindgren, Magnus Peterson, Stephen Butler, Lena Nilsson-Wikmar, Per Kristiansson

This study was aimed to explore the pain mechanisms and the origin of the pain and to evaluate a short-term relief treatment in women suffering from chronic pelvic pain induced in pregnancy.

Reports of randomized controlled trials of corticosteroid treatment to the ischial spine of the pelvis decreased pain intensity and increased function are published and infer a source of pain in the pelvis. Referred pain patterns provoked on intra-pelvic landmarks were consistent with sclerotomal sensory innervation and indicate allodynia and central sensitization. This suggests that pain mapping can be used to evaluate and confirm the pain experience and contribute to diagnosis.

The project has generated four papers [165] and has generated one PhD thesis in 2014 (Thomas Torstensson. Chronic pelvic pain persisting after childbirth: diagnosis and implications for treatment. PhD, Medical sciences. Uppsala University).
Borlänge Uppsala Pelvic Pain Study (BUPPS)

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

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

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

The studies started in 2014. One PhD student is so far involved in the project and has financial support from Regionala Forskningsrådet in the Uppsala-Örebro region, Uppsala County Council and Uppsala University.

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

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

There is a great need of an imaging method to diagnose chronic pelvic pain induced in pregnancy. In the present study 500 women with back pain recruited from a back rehabilitation clinic and matched controls without pain as well as 50 men with high load of their pelvis with matched controls without such high load, will use magnetic resonance tomography (MRT) to investigate the importance of changes in the vicinity of the anterior part of the sacro-iliac joints. Initial MRT investigation has been conducted 2011 and a follow-up has started. The project has financial support from the Uppsala County Council.

(For number in brackets -- see “Publications 2012-2014” on page 141-164)
Pelvic pain during pregnancy and hormonal contraceptive use
Participants: Elisabeth Bjelland, Per Kristiansson, Hilde Nordeng, Siri Vangen, Malin Eberhard-Gran

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

Pelvic pain after childbirth: a longitudinal population study
Participants: Elisabeth Bjelland, Katrine Owe, Ronnie Pingel, Per Kristiansson, Siri Vangen, Malin Eberhard-Gran

The project was the results of collaboration with researchers involved in the Norwegian Mother and Child Cohort. The study showed that among women with no pelvic pain during pregnancy the occurrence of pelvic pain postpartum was lowest after planned cesarean deliveries and highest after operative vaginal deliveries. Likewise, women with planned cesarean deliveries reported lower pelvic pain severity scores after childbirth than women with unassisted vaginal deliveries. This latter work was a part of Elisabeth Bjelland’s post doc stay at the unit of Family Medicine and Preventive Medicine during autumn 2014.

Laser therapy of pregnancy induced back and pelvic pain persistent after childbirth
Participants: Anne Lindgren, Thomas Torstensson, Sahruh Turkmen, Elisabeth Bjelland, Jan Magnus Bjordal, Andy Wood, Bryan Pryor, Per Kristiansson

The aim of the study is to evaluate the short and long term effect of low level laser therapy in women with pregnancy-induced chronic pelvic pain regarding functioning and pain relief in a prospective triple-blinded randomized controlled trial. The laser treatment will be applied to the sacral back by a standard laser head and to the internal pelvis by a transvaginal probe. The study is approved by the regional ethics committee and the recruitment of participants has started. This is collaboration between physiotherapists, gynecologist, general practitioner and laser manufacturer.
One PhD-student is involved in the project which has financial support from Uppsala and Västernorrland County Councils.

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

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

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

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

Adverse childhood experiences  
Participants: Jennifer Drevin, Jenny Stern, Anna-Maria Annerbäck, Magnus Peterson, Tanja Tydén, Margareta Larsson, Per Kristiansson

Adverse Childhood Experiences is a concept where a wide range of traumatic events during the first 18 years in life are assessed. Adverse Childhood Experiences is believed to impair a person’s social, emotional and cognitive functions and is associated with increased risk of health problem, disease and premature death. Information of the impact of Adverse Childhood Experiences on pregnant women’s health is scarce. With use of the large “Pre-pregnancy planning” data set different aspects of outcomes during pregnancy will be elucidated. Financial support is received from Uppsala County Council. An abstract presented at the 26th World Congress on Controversies in Obstetrics, Gynecology and Infertility, Paris 4-7 December 2014 was awarded the best submitted abstract.
Pregnancy planning
Participants: Jenny Stern, Margareta Larsson, Per Kristiansson, Tanja Tydén
Andreas Rosenblad, Anna Berglund, Clara Aarts

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

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

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

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

GPs’ perceptions of quality in family practice: A Grounded
Theory study

- Participants: Linus Johnsson and Lena Nordgren

Quality in family medicine is a contentious concept with clinical, ethical and
political connotations. The GP works in a crossfire of discourses, of which
those of biomedicine, technical problem-solving and standardisation tend to
dominate over those of holism, reflective practice and particularity.

The aim of this project is to develop a theory of quality consisting of an
elucidation of the concept of quality from the perspective of the GP as well
as an empirical account of how GPs work towards quality. More specifically,
we ask:

- How is quality in family medicine conceptualised and experienced by
  GPs?
- What is the main concern for GPs as they work toward quality?
- What elements characterise GPs’ efforts to work toward quality?
• What are the basic social processes that can resolve the main concern?
Data is generated through unstructured in-depth interviews with GPs and observations of their interactions with patients, co-workers and other parties. We employ Grounded Theory methodology, carrying out data generation, analysis and theory generation in parallel and iteratively.

The study population consists of doctors practicing in primary care in Sweden. Participants are recruited through various GP networks. Doctors holding a specialist degree in family medicine or currently undergoing specialist training are eligible for inclusion.

We begin with purposive sampling, selecting participants that are most likely to generate thick and rich descriptions of their experiences. Later, we switch to strategic sampling, spelling out central concepts in full detail and filling in gaps in the emerging theory. The familiarity of LJ with family medicine contributes to theoretical sensitivity. The experience of LN with qualitative research will be essential to empirical robustness, and her relative unfamiliarity with family medicine will help reduce investigator bias.

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

Vitamin D deficiency
• Participants: Åsa Andersson, Anne Björk, Gunnar Johansson, Paul Kalliokoski, Monica Löfvander

Vitamin D deficiency among pregnant Swedish women and Somali immigrant women and new mothers
• Participants: Paul Kalliokoski and Monica Löfvander

Vitamin D deficiency leads to myopathy, weak bones, body-ache, negative fetal development and reduced capability of daily work. In a pilot study early 2009 Paul Kalliokoski, specialist in general practice found vitamin D deficiency (90%) in Somali younger women in the town of Borlänge. He contacted Centre for Clinical Research Dalarna and since then continues his research with his main tutor, specialist in general practice, assistant professor Monica Löfvander. They conducted a cross-sectional study including 123 pregnant and recent mothers from Somalia (n=52) and Swedish women (n=71) living in Borlänge spring 2010 with an overall aim to explore vitamin D status, bone turnover, strength and upper leg performance.

Their first paper is published with main conclusion that 90% of the Somali women and 10% of Swedish women had a vitamin D deficiency. 1/3 of the Somali women had unmeasurable levels and had very weak hands and poor upper leg performance as well as high serum levels of parathyroid hormone and alkaline phosfatase indicating high bone-turnover and risk of osteomalacia. Seventy-one with insufficient or deficient levels of vitamin D was in-
cluded in a subsequent treatment study with lifestyle advice and supplements of vitamin D3 and calcium during 10 months [134].

The Project is generating one PhD thesis (Paul Kalliokoski).

Vitamin D status among immigrated women from countries in the Middle East as compared with Swedish women

Vitamin D in blood has been demonstrated in studies to be low in women from countries located in the southern part of Middle East and some countries in Africa. Immigrant women from countries in the Middle East have been investigated by a physician and a dietician in terms of different aspects of their vitamin D status and possible associated diseases. They were compared with age-matched Swedish women. Preliminary results show a large difference in vitamin D levels with low values in many immigrant women in comparison with the Swedish women. Two papers have been published [89, 97]. Principal investigators have been Anne Björk, Åsa Andersson and Gunnar Johansson.

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

Prevention
The experience of health and lifestyle habits among persons with schizophrenia

- Participants: Elisabet Sundgren, Lennart Fredriksson, Johan Hallqvist

People with schizophrenia have a high comorbidity for somatic diseases like cardiovascular diseases, metabolic syndrome, cancer and diabetes type-2 and have a higher prevalence of smoking than the general population.

As a part of Elisabet Sundgren’s thesis work we are studying the experience of health and lifestyle among persons with schizophrenia. The first study was qualitative there we were studying how current smokers with schizophrenia experience health and lifestyle habits and how they experience smoking in relation to health. The second study will be a quantitative evaluation of an intervention to see what types of interventions persons with schizophrenia or other types of psychosis need to be able to change unhealthy habits.

The thesis will further include one qualitative and one quantitative study on the topic of health and lifestyle changes among persons with schizophrenia.

Cultural Activities and Health

- Participants: Tina Grape Viding, Eva Bojner Horowitz, Johan Hallqvist
Cultural activities like singing, dancing, painting, acting, visiting theatres and museums, may promote health through various physiological mechanisms. In this project the physiological effects of singing will be studied. An intervention program called “Kulturpaletten” has been developed and its effects will be examined in randomized studies with first women having burnout symptoms and secondly with patients who have had surgery for colo-rectal cancer. An article has been submitted during 2014 (Grape Viding C, Osika W, Theorell T, Kowalski J, Hallqvist J, Bojner Horwitz J. “The Culture palette”- a randomized intervention study for women with burnout symptoms in Sweden. BJMP 2015, in press).

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) [98, 126, 201, 203, 210].

(For number in brackets -- see “Publications 2012-2014” on page 141-164)

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.

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

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.

Problem gambling among young women and men in Sweden

- Participant: Johan Hallqvist

Gambling among young people is a significant public health concern. While an understanding of the aetiology of gambling problems is crucial for prevention, there is limited knowledge about the onset of and the risk factors for problem gambling among youth. This project aims to estimate the incidence of a first episode of problem gambling and to examine some potential risk factors for problem gambling among Swedish young women and men. The focus is on psychosocial factors associated with youth problem gambling (such as social support, alcohol use, school achievement, maltreatment, and affective disorders). Three of the planned four studies in this project are based on Swelogs data (the longitudinal cohort and a case control study nested in the multipurpose cohort at the National Public Health Agency collected for monitoring and analysing problem gambling in the Swedish population), and one study uses data from the cross-sectional Swedish National Public Health Survey. One of these have been submitted during 2014 (Fröberg F, Modin B, Rosendahl IK, Tengström A, Hallqvist J. The Association Between Compulsory School Achievement and Problem Gambling Among Swedish Young People. J Adolesc Health 2015; Feb 6. pii: S1054-139X(14)00819-2. doi: 10.1016/j.jadohealth.2014.12.007. [29, 118]
Obesity care

- Participants: Jenny Söderberg, Gunilla Mårtensson, Per Kristiansson, Marianne Carlsson

The aim of this study is to affect physical activity and unhealthy eating habits, in a randomized controlled study, among people with overweight and obesity by using the Swedish National Guidelines for Methods of Preventing Disease of the National Board of Health and Welfare (Socialstyrelsen).

In addition, attitudes among primary health care staff and their reported activities regarding then National Guidelines will be described in a quantitative and a qualitative study. The data collection has started and the project will generate one PhD thesis. The study is funded by University of Gävle.

Organizational Factors, Work Stress and Performance

- Participants: Ingrid Anderzén, Lars Frimanson, Per Lindberg, Thomas Karlsson, Susanne Gustafsson and Annica Strömberg

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

Management control systems and stress: interdisciplinary field experiments

- Participants: Ingrid Anderzén, Lars Frimanson

Management control systems (MCS) in organizations have become more complex. They measure performance on more objects, with new and more measurements, they provide information more frequent and quicker, and they are used at lower levels in organizations. But we do not know how these complex MCS influence the human body. Do they improve health, well-being and performance in organizations? Or do they make people develop insomnia, stress and other unhealthy outcomes that are economically and socially costly?

This interdisciplinary research program combines two fields of knowledge; social medicine and MCS. The purpose is to examine and explain how MCS design affects psychosocial factors in the organization,
stress, and performance. This is important because MCS are used for planning and evaluation in organizations. MCS can thus be expected to influence the psychosocial factors in organization that are associated with negative stress reactions, work-related health, and performance outcomes.

Data collection was finished during year 2012 and the analyses are ongoing. A poster was presented at The 11th Stress research conference “New Frontiers in Swedish Stress Research - what is underway?” in Gothenburg, Sweden, 11-12 May 2012 (Frimanson L, Anderzén I. The impact of formal performance evaluation frequency on psychosocial and biological employee energy markers: An organizational experiment) and also at Nordisk workshop i ekonomi- och verksamhetsstyrning in Gothenburg, January 2014 (Frimanson L, Anderzén I The impact of formal performance evaluation on psychosocial and neurobiological energy: A randomized intervention study).

This project ended up in 2014 and was a collaboration with Department of Business Studies, Uppsala University, and receiving financial support from Riksbankens Jubileumsfond.

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

- Participants: Ingrid Anderzén, Per Lindberg, Thomas Karlsson, Annica Strömberg and Susanne Gustafsson

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

In 2012, a pre-study in form of focus groups and individual interviews in three medium sized enterprises was undertaken. The interviews sought to examine what employees and managers considered to characterize a "good" work environment and what gives them wellbeing at work. The results from the interviews and known health and safety parameters have constituted the basis for a questionnaire with which employees of the three companies are followed for 2 years. Parallel, data concerning the companies’ key indicators and internal developments are collected. One of the companies’ designs its work with their internal development according to the PATH-model.

At the two-year follow-up the results from the “PATH-company” concerning the well-being of both employees and the company will be compared
with the results from the other two companies designing their internal development after their own choice.

This study aims to increase knowledge about how to achieve sustainable health and wellbeing of both the individual and the company parallel. Such conditions can be assumed to save suffering for the individual and reduced costs for the company and society. The project was presented in a symposium at The Conference Well-being at Work in Copenhagen 25-28 May 2014 (Lindberg P, Karlsson T, Anderzén I, Strömberg A, Gustafsson S. The birth, rise and success (or fall?) of an intervention project: GodA – a project set up to test a model of the prerequisites for a healthy workplace).

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

Social medicine
- Participants: Bengt Arnetz, Judith Arnetz, David Hallman, Clairy Wiholm
- Collaborators: Professors Hikmet Jamil, Catherine Jen, Rathi Ramji, Melissa Runge-Morris Mark Lumley (Wayne State University)

The leaders of this research team, Professors Bengt B. and Judy E. Arnetz, are based in the United States, holding fully-tenured Professorships at Wayne State University School of Medicin, Detroit, Michigan. However, the group has a number of ongoing collaborative research projects involving the U.S. and Sweden. A common theme for this group’s research is enhancing the scientific understanding of risk- and resiliency factors, including bio-psycho-social mechanisms, of relevance for sustained and equitable occupational and social safety, health, and wellbeing. Research includes effective use of health care and institutional resources, and its implications for major health care stakeholders, including patients, staff, and third-party payers.

Bio-psycho-social mechanisms contributing to health disparities, resource utilizations and Healthy organizations

Research in this area looks at the relationship between socioeconomic and psychosocial factors, biological disease pathways, e.g., biomarkers and epigenetics, and public health, including somatic and mental health and sick leave behaviour. We are especially interested in furthering the understanding of determinants of sustained health. A NIH funded project focuses on post-displacement/migration contextual and individual factors related to occupational and social integration of refugees. The project aims at comparing policy, cost-effectiveness, and public health outcomes among Iraqi refugees forcibly displaced to Sweden and the United States, respectively.
In the domain of tobacco health risks, we have also initiated a National Swedish Public Health Agency (Folkhälsomyndigheten) funded study, in collaboration with University of Umeå, focusing on the role of water pipe (hookah) smoking as a possible gateway drug, along with cigarettes, alcohol, and marijuana, into heavier drugs and other risky behaviour in Swedish and US adolescents.

In collaboration with The Swedish Social Insurance Administration and the Primary Health Care sector, we evaluated “the Pathway to Work” process. Different research projects are developed and strategies to decrease sick leave, improve the sick leave processes and facilitate people’s return to work are evaluated. The Pathway to Work focuses on assisting people on sick leave to become more independent and to earn a living by targeting some of their health-related barriers and by providing financial support.

Stress factors and psychophysiological consequences of the modern lifestyle

Some of our projects focus on the impact on health and wellbeing from our technology-driven society. In a project involving researchers at Uppsala University and Wayne State University, we published a study in Psychosomatic Medicine using wireless heart rate sensors to determine stress in female managers in everyday working life. The study allowed us to develop smartphone-based means to collect detailed and up-to-the-minute information as to how our physiological system, especially the cardiovascular system, is affected by environmental stressors.

Another important area of research concerns the impact of acute and chronic stress on the health and performance among first responders, including police, fire fighters, EMS, coast guards, and the military. In collaboration with the management and unions of Sweden’s First Responder organizations and Kungafonden, we have identified major high-intensity and low-intensity stressors among First Responders, and strategies used to counteract adverse health and performance effects.

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

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

As part of the multi-year, multidisciplinary research program, The Impact of Religion, financed by the Swedish Research Council, Vetenskapsrådet,
we are looking at the organizational and individual role of spirituality and existential factors in promoting health and wellbeing among health care staff as well as in patients.

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

Center for Urban Responses to Environmental Stressors (CURES)

In 2014, we secured funding from the National institute of Environmental Health Sciences for a P30 Center to study the health effects from complex chemical and non-chemical environmental exposures in urban environments with special reference to vulnerable and underserved population. The goal is to initiate collaboration also with non-US-based environmental health researchers, including Sweden, in order to enhance mechanistic understanding of environmental health effects from complex urban exposures, both chemical, e.g. air pollution, and non-chemical, e.g., violence and socioeconomic strain.

Varia

- Participants: Kurt Svärdsudd, Keld Vaegter

Rational drug prescribing

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

In the second part of the project, a trained general practitioner made two visits, one year apart, to each practice. The GPs in the practice were asked to indicate their level of prescriptions, and to estimate how they thought that level compared with the levels of all the other practices. The results of the first visit were somewhat better than chance, while on the second occasion
they had improved significantly. A report has been submitted for publication [233].
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.

The project has generated one PhD thesis in 2013 (Keld Vaegter. Promoting rational drug prescribing in general practice. Medical Sciences. Uppsala University).

(For number in brackets -- see “Publications 2012-2014” on page 141-164)
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 2014

Professors – Lars Lannfelt (chair), Hans Basun (adjunct)
University lecturer – Lena Kilander
Researchers – Martin Ingelsson, Vilmantas Giedraitis, Anna Erlandsson, Joakim Bergström, Stina Syvänen, Björn Zethelius, Anna Cristina Åberg, Dag Sehlin
Postdocs and research assistants – Veronica Lindström, Bernice Wiberg, Hans-Erik Johansson, Greta Hultqvist, Malin Degerman-Gunnarsson, Ylva Cedervall, Sara Ekmark-Lewén, Malin Olsén
PhD students – Astrid Gumucio, Sofia Söllvander, Therese Fagerqvist, Gabriel Gustafsson, Kristin Franzon, Xiaotian Fang, Leire Almandoz-Gil, Elisabeth Nikitidou.
Other personnel – Linda Cato (research engineer), RoseMarie Brundin, Kätte Ström (research nurses).
Dissertations 2014


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

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<tr>
<th>Agency</th>
<th>Funding (SEK)</th>
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<tr>
<td>The Swedish Research Council</td>
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<tr>
<td>The Swedish Brain Foundation (project grants + donators)</td>
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<td>Berzelii Center for Neurodiagnostics, Uppsala</td>
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<td>Uppsala County Council (ALF)</td>
<td>4 000 000</td>
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<td>Fakultetsmedel, Uppsala universitet</td>
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<tr>
<td>The Swedish Parkinson Foundation</td>
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<td>Marianne &amp; Marcus Wallenberg Foundation</td>
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<td>The Alzheimer Foundation</td>
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<td>Various foundations</td>
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International collaborations

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

Guest visits in foreign laboratories

Elisabet Ihse (with Dr E. Masliah, La Jolla, San Diego, USA 2013-14, returning to the unit 2015, financed for three years by The Swedish Research Council.)
Adjunct professors
Employee of BioArctic Neuroscience, Hans Basun, 2005-

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

Engagement in the external society
Swedish association of local authorities and regions, Stockholm. Prevent falls and fall injuries in health care (national campaign for patient safety). Stockholm, 2008 and 2011 (Anna Cristina Åberg), Membership of The Regional Ethics Review Board (REPN) in Uppsala (Lena Kilander, Björn Zethelius, Anna Cristina Åberg). Membership of the Quality assurance group (Q) at the Medical Products Agency since February 2010 (Björn Zethelius). Member of the steering committee for National Swedish Dementia Registry (Lena Kilander).

Projects
Aβ protofibrils in Alzheimer’s disease
(Anna Erlandsson, PhD)
Knowledge about the cellular mechanisms behind initiation and spreading of Alzheimer’s disease (AD) is still very limited. Decades of research have focused on neuronal abnormalities in AD pathology, but recently more attention has been given to the glial cells.

The aim with this project is to clarify the involvement of astrocytes, the most numerous cell type in the brain, in AD initiation and progression and to investigate the astrocytes therapeutic potential.

Our results demonstrate that astrocytes engulf large amounts of aggregated amyloid-beta (Aβ), Aβ protofibrils, that are stored, rather than degraded by the cells. Interestingly, the accumulation of Aβ protofibrils by the astrocytes results in lysosomal defects and exosome-induced apoptosis of neurons.

To further elucidate the role of astrocytes in AD, we use primary cultures of astrocytes and neurons and analyze brain tissue from AD patients and transgenic mice. Moreover, we examine the possibility to increase the astro-
cytes degradation of Aβ by antibody treatment. We believe that the Aβ accumu-
cumulation by astrocytes is especially important in late onset AD, since this form of the disease depends on defects in Aβ degradation rather than Aβ production.

Our previous studies show that increased Aβ protofibril levels in CSF correlate with impaired spatial learning in a mouse model of AD. To investigate if Aβ protofibril levels could be used as a biomarker for AD we investigate the Aβ protofibril content in brain tissue, CSF and plasma from AD patients. Moreover we isolate exosomes from the cell culture medium of Aβ treated neurons and glia in order to analyze their protein content.

The goal of these studies is to develop a novel biomarker for early diagnosis of AD and for evaluation of amyloid-directed therapies.

Pathology and amyloid imaging in transgenic Alzheimer’s disease mice
(Stina Syvänen, PhD, Dag Sehlin, PhD, Greta Hultqvist, PhD)
The over-all purpose of this project is to improve clinical Positron Emission Tomography (PET) imaging in Alzheimer’s disease (AD) such that the technique can be used to monitor disease progression and therapeutic efficacy of intervention with drug candidates.

The project include development of new radioligands as well as development of imaging paradigms based on already existing radioligands that target neuroreceptors believed to be involved in the pathogenesis of AD. We have 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 the considerably shorter half-life of fragments compared to 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. We have recently obtained PET images of soluble Aβ protofibrils in AD mice.

The focus of our present research is to further improve the brain distribution of the 125I-labelled F(ab’)_2 fragment using protein engineering and thus develop a new amyloid PET radioligand for use in the clinic. This is the first time ever, to our knowledge, that an antibody has been used as at PET-ligand for a CNS disorder.

Parkinson’s disease and Lewy Body Dementia
(Assoc. Prof. Martin Ingelsson and Joakim Bergström, PhD)
The protein α-synuclein deposits as Lewy bodies and Lewy neurites inside the neurons of patients with Parkinson’s disease and Lewy body dementia.
Large soluble oligomeric or protofibrillar forms of α-synuclein are believed to be particularly neurotoxic for the affected brain. By working with recombinant forms of α-synuclein oligomers / protofibrils, we are analyzing the formation and effects of such species in vitro and on cell models.

In particular, we are investigating how these species can impair key cellular functions and how they can spread from cell to cell and thereby cause the disease to propagate inside the brain. Moreover, we want to find out how these α-synuclein species can impair cellular degradation and perturb cellular function. We have purified toxic α-synuclein oligomers and used these as antigen to generate monoclonal antibodies. A number of highly selective antibodies have been developed and several of these have been evaluated for immunotherapy on cell and animal models for the actual diseases.

Importantly, we have found that intraperitoneal injections with one of them can lower the levels of α-synuclein oligomers/protofibrils in transgenic mice and also prolong survival in the same animals. Moreover, we seek to adopt the antibodies in assays, such as ELISA; to be able to measure the presence of toxic oligomers / protofibrils as a novel disease biomarker for the actual disorders.

**Genetics**
(Assoc. Prof. Martin Ingelsson and Vilmantas Giedraitis, PhD)

We have access to a large and well characterised collection of sporadic and familial dementia patients. Using high throughput sequencing technology, we are screening for mutations in known and putative disease susceptibility genes in patients with early onset forms of frontotemporal dementia, Alzheimer’s disease and Parkinson’s disease.

In collaboration with other research groups, we are searching for new disease susceptibility genes by association analysis.

**Clinical and epidemiological research**
(Assoc. Profs. Lena Kilander, Björn Zethelius, Malin Degerman Gunnarsson, Ylva Cedervall, Anna Cristina Åberg)

The close contact between the laboratory and the Geriatric Clinic at Uppsala University Hospital facilitates access to appropriate clinical samples. The clinical research unit is currently categorizing patients with various dementia disorders and mild cognitive impairment clinically and neuropathologically. This research is based on our own tissue bank with DNA, plasma and serum (approximately 1500 samples), CSF samples (n= approximately 600), and brain tissues. We previously showed that high concentrations of total tau and phospho-tau were correlated to rapid cognitive decline and death in advanced dementia, (Degerman Gunnarsson -13). In an extended follow-up (2-
11 years) of this cohort, high CSF total-tau predicted institutionalization and conversion to moderate dementia (Degerman Gunnarsson, In manuscript), as well as rapid deterioration in cognition and dementia-related death. Thus, CSF tau is not only markers of dementia stage and predictors of conversion from MCI to AD, but also reflect the rate of neurodegeneration and long-term prognosis, which has not been shown previously. These findings may be valuable in selecting patients to tau immunotherapy trials. Longitudinal studies of dementia patients are carried out in collaboration with the Uppsala PET-centre, using the amyloid-binding PIB ligand together with PET FDG and AD CSF-biomarkers.

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 cerebro-vascular risk factors and dietary intake of fat as predictors of AD are examined. Impaired insulin secretion at age 50 has been shown to predict the development of AD at high age. In one substudy, we are assessing mid-life and late-life predictors of healthy aging, defined as maintained cognitive and ADL functioning at age 85 years (Franzon, in manuscript). Measurements focusing on cognition and sarcopenia have been undertaken during 2014 on survivors at age approximately 90 years (n=145), with CT-scans of the brain, CSF analyses and post-mortem evaluation on a fraction of the ULSAM subjects. Finally, another population based cohort of AD patients and healthy controls have been collected, in which we perform replication studies of genes that have shown association to AD within ULSAM.

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

Research on data in the national diabetes register (NDR) linked to several national registries is performed by Dr Björn Zethelius within the Scientific Working Party at the NDR. Project on Cardiovascular risk has recently developed an online tool for estimated 5-year absolute and modifiable risk for CVDs, providing potential for improvements in multifactorial treatment among primary care patients. It is now (2014) a tool in recommendations from the Swedish Medical Products Agency (Läkemedelsverket) on pharmacological treatment in diabetes and hyperlipidemia. Further, he has lead the largest-ever observational study of physical activity among patients with type 2 diabetes and found that both women and men can substantially reduce
the risk of cardiovascular disease and premature death by exercising regularly. He is also involved in ULSAM-research and international collaborations such as DECODE and DETECT consortia. The work has so far led to several publications in leading medical journals, see reference list.

Ongoing, particularly successful research

Our translational research efforts have been very successful and we have maintained an international visibility and high quality of publications.

Among the expanded and new efforts, we have a particular focus on developing better principles of imaging and diagnostics for AD and exploring possibilities for novel future therapeutics against PD and Lewy body dementia. We are one of several groups in Uppsala focusing on protein aggregation and age-related amyloid diseases. The local scientific environment thus 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.

Publications 2012-2014

2014


2013


2012


128. Huang X, Sjögren P, Cederholm T, Ärnlöv J, Lindholm B, Risérus U, Carrero JJ. Serum and adipose tissue fatty acid composition as bi-


Books

152. Läkemedelsboken 2014. Läkemedelsverket 2013. Mårild S, Hänni A och Zethelius B are authors of one chapter.


Research group leader senior lecture Sophie Langenskiöld

The research group Health Economics started in 2013. A focus has been to understand and influence the prospects within health care, and to achieve better health for the public and cost-effective care for the community. The group aspires to use knowledge of the use of observational data for causal inference, to contribute to the increasing interest in the effectiveness and cost-effectiveness of primarily drugs, but also other interventions in clinical practice.

Members of the Group during 2014

So far, Sophie Langenskiöld has been alone in this group. At the moment, however, we are recruiting a PhD student with medical and/or economic expertise.

Research Fundings

Centre for Research Ethics & Bioethics and Health Economics have initiated collaboration in order to stimulate inter-disciplinary research in ethics and health economics. The two disciplines complement each other in many ways as the economists try to understand the best ways to allocate scare resources and the allocations in theirselves have ethical implications. This collaboration is now formalized as we have received fundings for our first common project. This project involves the way cardiovascular and pulmonell risks should be communicated for the patients’ best understanding of the risks themselves and their implications on health. The project involves both qualitative and quantative research.
Main Research Project

In Sweden and the other Nordic countries, we have built unique registries covering either the entire population, or specific populations suffering from different diseases. Despite this achievement, the registries are sorely underused, and there is a real risk of missing a huge opportunity to offer better care for our population. The yet-unrealized benefits of these registries, we are confident, would justify the time invested in preparing them for broader purposes. The main reason why the registries are underused is the current lack of suitable methods for evaluations in clinical practice based on registry data.

This project, involving five studies altogether, intends not only to develop these methods, but to demonstrate these through evaluation of a relatively new treatment in clinical practice: the new oral anti-coagulants (NOAC), i.e. apixaban, dabigatran or rivaroxaban versus warfarin. This evaluation is an important one, as the sample of patients in randomized clinical trials are generally younger and healthier than the population in clinical practice, and the practice of warfarin monitoring is less developed abroad than in Sweden.

The toolbox of new methods we produce can then be directed to improve other forms of evaluation in clinical practice. In this way, we will make a broader contribution to improved healthcare, given that some randomized clinical trials, unfortunately, only poorly generalize to clinical practice. There are sub-populations of patients who are especially poorly represented in clinical trials, such as older, female, and multi-morbid patients, and those
who require study in clinical practice in order to assure safe, effective, and cost-effective care.

Health Economic Forum at Uppsala University

The Health Economic Forum at Uppsala University (HEFUU) is intended as an interdisciplinary venue for researchers interested in health economics coming both from economics and the medical faculty. Sophie Langenskiöld is one of the co-coordinators of HEFUU, and involved in the organizing and planning of HEFUU’s activities. The HEFUU hosts monthly seminars in health economic research at Uppsala University, courses, and conferences. During the last year, HEFUU has organized or are organizing several activities which will strengthen its role as a platform for health economic research at Uppsala University.

Apart from the monthly Friday seminars, HEFUU has been host for education-, workshop-, and conference- activities. Last spring, we organized a two-day course in health economics. Professor Ben van Hout, University of Sheffield, taught nearly 70 participants how to conduct health economic evaluations.

We are also organizing a workshop where four researchers will present their research group and some of their research. Our belief is that this day will not only teach us about what relevant research is conducted at Uppsala University, but also help us to better understand the different skills that we have and the different interest that we share, an understanding which could be channeled into joint research projects in the future.

And finally, we are host for the 36th Nordic Health Economists’ Study Group Meeting in August.

Education

Sophie Langenskiöld is preparing a master course in Health Economics which is an introduction to health economics for public health practitioners. It is intended for those who work with and make decisions about issues related to public health. The overall purpose of the course is to provide knowledge about how theories, methods, and findings from the field of health economics can be used to achieve the goals of public health given our scarce resources. What is public health, and how it should be measured? These questions are obviously not easy to address but nonetheless, important. Their answers allow us to follow up our public health objectives in practice. We discuss the health economists’ definitions of health and its measuring. How may a certain health program impact health behavior and ultimately health? We learn to use health economic models for predicting the
impact of different public health initiatives ex-ante. Which existing public health program should we prioritize? You can of course evaluate the public health program from different perspective, and we will train us in judging public health interventions from an economic point of view. We discuss different approaches and their ethical implications.

Examples of other assignments

Uppsala Health Summit is an international forum for dialogue between leading representatives for healthcare, and last year, the forum met around the challenges facing us from a rapidly growing proportion of elderly in the population, “Healthcare for healthy aging”. Sophie Langenskiöld was part of the program committee and contributes to the conference in general. She organized a workshop on the importance of providing the right incentives for developing drugs for the growing elderly population and of making sure that the elderly’s innate conditions are accounted for in the documentation and evaluation of medical treatments. This workshop resulted in an interview of Sophie Langenskiöld by Peter Carlish, Scrip Intelligence. Also, Sophie Langenskiöld was offered to write in Svensk Geriatrik as a consequence of this workshop.
Health Services Research

Research group leader Ulrika Winblad, PhD, Associate Professor

Health Services Research (HSR) adopts three contrasting but interconnected perspectives; at care provision - organisational - and system level. The Uppsala group is engaged in research at all three levels with focus on governance and implementation, intra-organisational control, inter-organisational relations and patient relations. More specifically, current study objectives include development of exploratory models for differences in public and private care, identification of barriers for implementation of New Public Management reforms as well as identification of facilitators for high quality and patient safety care, 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 2014
Ulrika Winblad, PhD, Associate Professor, Research Group Leader
Malin Masterton, PhD, Acting Research Group Leader

Caroline Andersson, PhD student
Åsa Muntlin Athlin, RN, PhD
Cecilia Bernsten, Registered pharmacist, PhD, associate professor
Ingeborg Björkman, Registered pharmacist, PhD
Madeleine Boll, Physiotherapist, Licentiate, PhD student
Linn Boström, research assistant
Gunilla Brattberg, MD, PhD, associate professor
Tobias Dahlström, PhD
Ann Catrine Eldh, RN, PhD
Helène Eriksson, Administrator
Annica Ernesäter, RN, PhD
Mio Fredriksson, PhD
Roya Hakinnia, PhD student
Christina Halford, MD, PhD
Marianne Hanning, PhD
Finn Hjelmblink, MD, PhD
Inger K Holmström, RN, professor
David Isaksson, MSc, Phd student
Elenor Kaminsky, RN, PhD
Andreas Karlsson, research assistant
Dorte Kjeldmand, MD, PhD
Niklas Källberg, PhD
Jan Larsson, MD, PhD, associate professor
Linda Lännerström, PhD student
Anna Mankell, research assistant
Linda Moberg, PhD student
Fredrik Olsson, research assistant
Urban Rosenqvist, MD, Professor emeritus
Marta Röing, DDS, PhD
Margareta Sanner, Registered psychologist, PhD, associate professor
Björn Smedby, Professor emeritus
Kristina Star, RN, PhD
Ragnar Stolt, MD, PhD student
Anikó Vég, PhD
Sofie Vengberg, research assistant
Heléne von Granitz, PhD student

Publications 2014 – 2012

2014


2013


2012

54. von Thiele Schwarz U, Hasson H, **Muntlin Athlin Å.** (2012). Perceived efficiency in the emergency department: low throughput rates or having a lot to do?. Arbete och Hälsa.


Agencies that support the work/Funding 2014 (in SEK)

- The Swedish Research Council - Ulrika Winblad 1 257 000
- Swedish Council for Working Life and Social Research (FAS) – Ulrika Winblad 800 000
- Medical Faculty Uppsala University (Vårdforskningsmedel) – Ulrika Winblad 200 000
- The National Board of Health and Welfare (Socialstyrelsen) – Fredrik Olsson 106 667
- Forum för Health Policy – Ulrika Winblad 160 000
- Vinnova – Ulrika Winblad 200 000
- Swedish Research Council f. Health, Working Life and Welfare (Forte) – Ulrika Winblad 900 000
- Dalarna County Council – Ulrika Winblad 125 000
- The Swedish Research Council – Mio Fredriksson 1 050 000
- Swedish Competition Authority (Konkurrensverket) – Ulrika Winblad 784 654

Total 5 583 321
External Reviews 2014 – 2012

- Åsa Muntlin Athlin: Chairperson and member of the scientific committee for the International conference on evidence based practice in nursing, Smt. Radhikabai Meghe Memorial College of Nursing, Sawangi (Meghe), Wardha, Maharashtra, India. (2014)
- Ulrika Winblad: Member of the Scientific Advisory Board of the Center for Healthy Ageing (CEHA), University of Copenhagen, (2014)
- Ulrika Winblad: Member reference group, Expertgruppen för studier i offentlig ekonomin (ESO) (2013-2014)
- Ulrika Winblad: Member European expertgrupp, Healthy Living and Active Ageing (2013-2014)
- Ulrika Winblad: Vice Chair, expert group, Uppsala University, Healthy Living and Active Ageing, (2013-2014)
- External reviewer of Fellow Positions, Riksbankens Jubileumsfond, (2014)
- Ingeborg Björkman: External reviewer of research application for ZonMw - The Netherlands Organisation for Health Research and Development. (2013, 2012)
- Margareta Sanner: External reviewer of research applications for the Health and Medical Research Fund, Food and Health Bureau, Government secretariat, Hong Kong. (2012)

Invited Speaker 2014 – 2012

- Åsa Muntlin Athlin: Invited leader of the seminar “Undertaking systematic literature reviews, part 1 and 2”, Forum Nurse Program and Nurse Specialist Program. (2014)
- Jan Larsson: Invited speaker at the European Anaesthesiology congress, Stockholm. (2014)
- Jan Larsson: Invited speaker at the National Meeting of Pediatric Simulation, Falun, Sweden. (2014)
• Jan Larsson: Invited speaker Anaesthesia department Rikshospitalet Oslo, Norway. (2014)
• Ulrika Winblad: Invited speaker, Center for Gerontology and Healthcare Research, Brown University School of Public Health, USA. (2014)
• Ulrika Winblad: Invited speaker at three seminars in Almedalen. (2014)
• Ulrika Winblad: Invited speaker at Swedish Association of Local Authorities and Regions. (2014)
• Ulrika Winblad: Invited speaker the Finnish Embassy. (2014)
• Åsa Muntlin Athlin: Invited speaker at the National meeting Ortopaedic, Uppsala. (2013)
• Åsa Muntlin Athlin: Invited speaker at the National meeting Surgery, Uppsala. (2013)
• Jan Larsson: Key note speaker at the 7th International meeting on Behavioural Science Applied to Surgery and Acute Care Settings, Karolinska Institute, Stockholm. (2013)
• Ulrika Winblad: Invited speaker Swedish Association of Local Authorities and Regions. (2013)
• Ulrika Winblad: Invited speaker Almedalen. (2013)
• Mio Fredriksson: Invited speaker at the Swedish Congress on Family Medicine and General Practice. (2013)
• Mio Fredriksson: Invited speaker at the Green Party’s county council representatives group meeting in Uppsala. (2013)
• Mio Fredriksson: Invited speaker at Healthcare Leadership Academy (Sjukvårdens ledarskapsakademi). (2013)
• Jan Larsson - Pedagogical advisor at the Västra Götaland Region project “Building a training program tailored for doctors with their basic medical training abroad”. (2012)
• Mio Fredriksson: Invited speaker at the development program for new and young administrators in healthcare (NYS), Swedish Association of Local Authorities and Regions (SKL). (2012)
• Mio Fredriksson: Invited speaker at the Nordic Administrative Association’s general meeting, Finland. (2012)
• Mio Fredriksson: Invited speaker at Dagens Medicins Strategidag. (2012)
Awards 2014 – 2012

- Elenor Kaminsky. Best Poster award (5.000 kr) at the Nordic Conference in Nursing Research, Odense, Danmark. (2014)
- Linda Moberg. Thuns travelling stipend (Uppsala University) for attending Stanford University, USA. (2014)
- Ulrika Winblad. The Commonwealth Fund's Harkness Fellowships in Health Care Policy and Practice (2014)
- Åsa Muntlin Athlin. Inaugural Eleanor Harrald post doctoral fellowship, School of Nursing, University of Adelaide, Australia (2012)

Research projects 2014

Implementing legally secured governance of individual rights: Does the exercise of discretion in the decision-making process of granting assistance allowance for personal assistance pay regard to the intentions for good living conditions according to the LSS Act?

- Participants: Heléne von Granitz, Ulrika Winblad

The Swedish disability policy express the vision of a community based on diversity, designed to allow people with disability of all ages to participate fully in society with equal opportunities. The ambition of the policy is strongest outlined in the LSS legislation, concerning Support and Service for Persons with Certain Functional Impairments (1993:387). The LSS aims to guarantee good living conditions for the users, by stringent requirements to meet individual rights. The act covers a wide range of user groups with regard to age, disability and severity of needs and has been described as the prime political tool to strengthen citizenship of disabled people. There is however a lack of knowledge about the extent to which personal assistance by attendance allowance meets the LSS values of good living conditions and if the support given provides conditions for participation on equal terms for various groups of users. The LSS Act, with a high ambition of executing rights, lacks clarity and quality criteria on what the implementation should comprise. The exercise of discretion in the decision-making process of granting assistance allowance for personal assistance is known to be difficult with several principal agents responsible for the implementation. The thesis intends to highlight two perspectives. First, to study the outcome of personal assistance, from the perspective of the user and find out if the support re-
ceived has resulted in more equal opportunities for the eligible persons in achieving good living conditions. Second, to study the implementation of the reform by studying to what extent the intentions of the LSS act are met by the decision of the personal administrator at the Social Insurance Agency (SSIA). The SSIA are responsible for carrying out the investigation and their decision is a prerequisite for access to assistance allowance. Overall, the thesis aims to provide a generally improved knowledge of the conditions for the government control to implement social reforms and specifically the control of the assistance allowance.

Contracting and monitorability in choice systems – what requirements do municipalities and county councils stipulate when contracting out services?

- Participants: Fredrik Olsson, Anna Mankell, Ulrika Winblad

The legal Act of 2009 regarding choice of welfare services (lagen om valfrihet, LOV) has been adopted by both municipalities and counties. The intent of the reform was to enable for Swedish municipalities and county counties to contract external health service providers, and thereby give patients and users of services the opportunity to choose between different providers. When contracting out services, the municipalities and counties are still responsible for the outcomes of the services, and thereby have an inherent need for monitoring the performance of the contractors.

The aim of this study is to give a description of how the municipalities and county counties manage to balance contractual requirements, with the notion of innovation and trust in their relation with the contractors. To conduct the study, contracts from both the elder care and specialised health care were analyzed. In addition, a questionnaire survey was conducted, focusing on methods of monitoring and quality assessment, and it was addressed to all directors in the elder care administrations in Sweden.

The results show that the majority of the contractual requirements concern the processes of the services, rather than structural aspects or quality outcomes. In some cases the monitorability of the services can be questioned due to how the contracts were formulated. The survey of elder care showed relatively low frequencies of monitoring, especially in domiciliary care. In summary, the studies show problems both in the formulation of contracts and in the monitoring of the services. A report will be published in 2015.

The role of information in choice of provider systems

- Participants: Caroline Andersson, Ulrika Winblad

During the last decades patient choice of provider has become an inherent component in many health care systems. In Sweden provider choice was
introduced through national legislation in 2010 (SFS 2009:140 Lag om ändring i hälso- och sjukvårdslagen 1982:763). The choice model allows patients to choose freely between both private and publicly run primary health care providers. Reimbursement follows the patients’ choice. Choice of provider is expected to stimulate efficiency, quality and better responsiveness through the threat of exit. An underlying assumption is that providers will have strong incentives to improve their quality if they risk losing resources by not being chosen. A condition often stressed as a vital component in a functioning system of provider choice is access to information about the providers. If patients are unable to monitor the range and quality of services, providers may try to reduce their costs by lowering quality. As a consequence, providers with poor quality might remain on the market, leading to a weakened exit mechanism in the provider choice models.

The central aim of this project is to explore the theoretical assumption that well-informed choices of provider will drive quality in health care. In particular, it focuses on if and how patients make use of information when choosing providers. Both governments and private stakeholders have developed comparative information on services and quality-of-care, but some studies imply that patients rarely make use of such information in the actual choice situation. Instead they often rely on informal information sharing, such as reputation or recommendations from friends or family, but which may not give accurate and clinically relevant information about provider’s quality.

The project on provider choice information will be based on four different articles. The first study is initiated and explores what factors that can explain patients’ information search behavior in choice of provider and if there are groups of patients that are more active users of information than others. The second study will analyze what kind of information patients turn to, if and when they search for information in the choice of provider. The third study will investigate what kind of information patients have access to and whether it can be used to make an informed choice of health care provider. The fourth article will problematize policy designers’ views on patients’ role in provider choice systems and to what extent they believe that patients can monitor and drive quality development in health care through active choices.

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

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

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

Patients with acute abdominal pain – from the emergency department to the surgical ward: what makes a difference to achieve patient participation, high quality nursing care and safe care transitions?

- Participant: Åsa Muntlin Athlin

This pilot project is part of a multidisciplinary research program (SMAAPP research program) in collaboration between researchers and clinicians in Australia and in Sweden. The aim of the pilot study is to further explore patient experiences across the acute care delivery chain and to test methodological procedures.

Reasons for Continuing DNA-identification of Named Victims

- Participants: Malin Masterton

An increasing number of countries in the world, including Sweden, now hold dedicated teams to investigate victims’ identities in case of major disasters. The advancements of DNA technology mean that also in high impact disasters, with high levels of intermingling and fragmentations of victims’ bodies, small body parts can be identified to person. Legally the work can be stopped as soon as all victims have been officially identified, but in the aftermath of disasters the work is sometimes continued despite high costs. In March 2012, a Hercules military aircraft crashed into Kebnekaise, killing all five Norwegian personnel on board and causing a high level of fragmentation of the victims’ bodies. The retrieval of human remains had to be done in
two time periods, and the subsequent identification work on the human remains over the set minimum size was extended to include the second recovery phase as well. The aim of this case study was to explore the reason(s) behind the decision for the extended identification. To conduct the study, key stakeholders have been interviewed, relevant documents have been collected and relevant laws studied. The work was done in collaboration with Dr. Kerstin Montelius, PhD, at the Forensic Genetics Laboratory at the National Board of Forensic Medicine. The study is of relevance for revealing norms and ethical justifications in disaster victim identification work.

SMAAPP research program (Seamless management of patients seeking care for acute abdominal pain - a person-centred approach)

• Participant: Åsa Muntlin Athlin

The overall aim is to use multiple sources of evidence of effective management of patients with acute abdominal pain to develop, implement and test a person-centred intervention to achieve safe high quality care across the acute care delivery chain. The goal is to develop best practice guidelines to be used by the inter-disciplinary teams in the emergency departments and the surgical wards.

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.

Predicting admission requirement likelihood in Australia and Sweden (PARLAAS): an individual prospective approach

- Participant: Åsa Muntlin Athlin

The number of patient visits to emergency departments (EDs) is increasing and about 22-38% of the patients presenting to an ED require hospital admission. ED crowding is a potential threat to patient safety and quality of care. Using predictors of hospital admission may improve the patient flow in the ED and speed up the admission process. The aims of this study are to determine important predictors of hospital admission for children and adults and to determine a hospital admission risk score for patients presenting to the ED that are site and population (child/adult) specific. In addition, a tool for predicting hospital admission will be developed and tested.

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

- Participants: Ulrika Winblad, Mio Fredriksson, Tobias Dahlström, Ann Catrine Eldh, Sofie Vengberg, Christina Halford

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

How can public authorities monitor private social service providers?

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

How does the design of the reimbursement systems affect the behavior of primary care providers?

- Participants: David Isaksson, Ulrika Winblad

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

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

Choice systems in universal welfare models – implications for the state, citizens and accountability

- Participants: Linda Moberg, Ulrika Winblad

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

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

These research questions will be addressed through four different articles. The first of these studies has been submitted (and in the spring of 2015 accepted) to the Journal of European Social Policy. Another two studies have been initiated. In the submitted paper we test if social service users can act as rational consumers by investigating what kind of information they have ac-
cess to at the point of choosing service provider. We also study whether the information contain relevant quality indicators and are designed in such a way that it can be used to make a qualitative and informed choice of provider. The second study analyzes if the implementation of choice in the Nordic welfare states has altered the Nordic model for social service delivery and if it pose a challenge to the idea of universalism. The third study focus on the ability of the state to monitor the social service sector when the provision is privatized. This project is run in collaboration with the Department of Government (Paula Blomqvist), Uppsala University.

Drugs and patient behavior – the influence of organizational and professional actors
- Participant: Cecilia Bernsten

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

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

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) re-
garded Accessibility Problems and the most frequently incoming ones (*i.e.*, sent to SHD) regarded Incorrect Assessment.

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

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

Developing gender competence in Swedish telenursing

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

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

Telenursing is considered as first line health care but it is a gendered service in that most telenurses are female and the majority of calls for children and elderly parents are made by women. Gender refers to the social 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 holds that gender interacts with other markers of difference, such as ”race”/ethnicity, sexuality, social class and (dis)ability.

We analyzed 800 authentic calls to Swedish healthcare Direct from an intersectional perspective, and with in-depth analysis of 20 calls using Critical Discourse Analysis. The results indicate that health behavior is part of “doing gender” since the most common caller was a woman proficient in Swedish, and the least likely caller was a man that was not proficient in Swedish. Calling a telenurse seems to be in line with ideal femininity, where seeking help and taking care of others’ health are central aspects. The calls are dominated by task-focused utterances (*e.g.* giving medical information) and close-ended medical questions are common. Three types of ideological work are found in the calls: gatekeeping, hegemonic masculinity and traditional medicine ideology. These three types of ideological works were part of the domi-
nating discourse in telenursing echoing macro-aspects of society. However, a counter discourse was also found where open questions, questions about the social, information giving and challenging hegemonic masculinity were defining ingredients. An instrument to measure awareness of intersectional aspects has been developed and tested, and we have also made an intervention to raise telenurses awareness of such aspects. The results can also have direct application in nursing education and probably be used in other areas of healthcare and health care education.

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.

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

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

Increased access to OTC drugs can give Swedish teenagers new opportunities for self-care. However, the ability to buy OTC drugs outside pharmacies gives little opportunity for the traditional expert surveillance of pharmacists, thus increasing the possibility of careless or inappropriate use of OTC drugs. This study explores and describes Swedish teenagers’ views on OTC drugs, with special regard to analgesic drugs, and asks the following ques-
tions: 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. During 2014 a survey about knowledge and attitudes to sick-listing among nurses in primary healthcare has been conducted, and an educational intervention to improve their competence in sick-listing issues for this group. The intervention will be evaluated during 2015.

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

- Participants: Elenor Kaminsky, Inger Knutsson Holmström, Marta Rööting

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

Goals of telephone nursing work - the managers’ perspectives: A qualitative study on Swedish Healthcare Direct

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

The aim of this project is to explore and describe what Swedish Healthcare Direct (SHD) managers perceive as the primary goals of Telephone Nursing (TN) work and how the managers view health promotion and implementation of equitable healthcare with gender as example at SHD.

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

All 23 managers employed at SHD were interviewed and data analysed using deductive directed content analysis. The findings reveal four themes describing the goals of TN work as recommended by the SHD managers: ‘create feelings of trust’, ‘achieve patient safety’, ‘assess, refer and give advice’, and ‘teach the caller’. Most of the managers stated that health promotion should not be included in the goals, whereas equitable healthcare was viewed as an important issue. Varying suggestions for implementing equitable healthcare were given. The interviewed managers mainly echoed the organisational goals of TN work. The managers’ expressed goal of teaching lacked the caller learning components highlighted by telenurses in previous research. The fact that health promotion was not seen as important indicates a need for SHD to clarify its goals as the organisation is part of the Swedish healthcare system, where health promotion should always permeate work. Time used for health promotion and dialogues in a gender equitable manner at SHD is well invested as it will save time elsewhere in the health care system, thereby facing one of the challenges of European health systems.
Patient-centred consultations: preconditions and limitations in the Swedish health care system
• Participants: Malin Masterton, Linn Boström, Ulrika Winblad

The movement to increase patient involvement in their own health care started in the USA some decades ago and is mostly referred to as patient-centred care. The most recent indication of Swedish efforts to increase patient involvement in the health care is the passing of a new Patient Law (2014:821) in 2014, which came into force in January 2015. The new law did not, however, make any changes to duty-based legislation of the Swedish health care system. This means that the health care system has a duty to provide care for a patient, but the patient does not have any enforceable rights vis-à-vis the Swedish health care. The first aim of this work was to investigate the preconditions and limitations of the Swedish health care system to incorporate a high level of patient-centred care in the medical consultation. The second aim was to investigate the internationally published literature on the main challenges to achieving patient-centred medical consultation. The work was commissioned by Forum for Health Policy and a report of the study is to be published in 2015. The main conclusion is that there is a need for a more unified understanding of what a patient-centred consultation should mean in a Swedish context, in order to facilitate further implementation work. There is also a need to acknowledge potential clashes between a patient-centred consultation and the current health care system in order to look at possible adjustments.

Making decisions in healthcare: policy and preferences in Sweden and England
• Participants: Mio Fredriksson

The main purpose of this research project is to investigate citizens’ and patients’ opportunities for taking part in decision-making in healthcare, as well as citizens’ and patients’ preferences with regard to this matter. The distinction between involving patients in decisions about their own treatment and care, on the one hand, and involving the public in strategic decisions about the development, planning and provision of health services on the other, is essential in the proposed research project. Patient involvement generally seeks to improve individual health outcomes and satisfaction, whereas public involvement seeks to address societal values, determine priorities etc.

Participation opportunities for patients and citizens in the two countries are compared through a structured analysis of recent so called PPI policies (patient and public involvement). Preferences for participation in individual as well as collective decisions are compared through surveys in both countries. Ultimately, the research project has policy implications for how to
organize participation in healthcare in order to enhance the healthcare system’s legitimacy and to reach objectives of public health. The project combines perspectives of political science and public health.
Oxidative Stress and Inflammation

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

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

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

The research group is dedicated to research on inflammation in physiology and in disease state. Additionally, the role of oxidative stress that reflects an increased level of free radicals that are implicated both in ageing and in several inflammatory diseases is also a major research area. Lipid peroxidation products catalysed by free radicals and cyclooxygenases have shown to be of importance in many inflammatory and oxidative stress-related diseases. Bioactive prostaglandin formation by cyclooxygenases from arachidonic acid and their contribution in inflammation is well described by our group in the past years in addition to the role of free radicals-mediated product isoprostanes in physiology and a range of diseases.

The research group have developed crucial assays through raising specific antibodies against isoprostanes indicating oxidative injury and prostaglandin F2α indicating inflammatory response, and is also involved in development of assays on anti-inflammatory resolvins. In addition, we have also established immunohistochemical methods using specific antibodies to study organ damage following an acute or chronic inflammation and oxidative stress. These novel eicosanoids are implicated in healthy individuals and also in development of different human diseases.

Collectively, the research group is devoted to experimental, clinical, epidemiological studies and also development of methodology specifically on eicosanoids. The research group has many national and international collaborative projects within the research vicinity.
The major projects include:

Impact of systemic inflammation, oxidative stress and adipokines in breast cancer

- Collaborators: Samar Basu, Alicja Wolk, Anders Larsson, Marie-Paule Vasson
The project is performed in collaboration with Karolinska Institute, Clinical Chemistry, Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.

Association of specific systemic tumor markers in breast cancer

- Collaborators: Samar Basu, Anders Larsson, Marie-Paule Vasson, Alicja Wolk
The project is performed in collaboration with Karolinska Institute, Clinical Biochemistry, Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.

Cellular localisation of COXs, aromatase, adipokines and their receptors in breast cancer specimen

- Collaborators: Samar Basu and Marie-Paule Vasson
The project is performed in collaboration with Universite d’Auvergne, Clermont-Ferrand, France.

Eicosanoids, COXs, ROS and adipokines in experimental mouse model of breast cancer

- Collaborators: Samar Basu and Marie-Paule Vasson
The project is performed in collaboration with Uppsala University, Sweden and Universite d’Auvergne, Clermont-Ferrand, France.

Effects of fish oil in functional foods, capsules or fish on the blood lipids and markers of oxidative stress in mice and humans (Smartfish)

- Collaborators: Samar Basu, Rune Blomhoff and Liver Frøyland
Financed by The Norwegian Research Council, Norway
The project is performed in collaboration with Oslo Medical Faculty and Bergen University, Norway.
Oxidative stress, inflammation during normal pregnancy, parturition and under normal menstrual cycle

- Collaborators: Maria Palm, Ove Axelsson, and Samar Basu
  The project is performed in collaboration with the Department of Women's Health and Clinical Chemistry, Uppsala University.

Prenatal food and multiple micronutrient supplementation and effects on child body composition, metabolic markers and mortality; mechanisms of early programming

- Collaborators: Lars-Åke Persson, Eva-Charlotte Ekström, Sham Arifeen, Rubanna Ruqib, Samar Basu
  Financed by The Swedish Research Council.

Oxidative stress and neuroprotection following cardiac arrest by hypothermia

- Collaborators: Samar Basu and Sten Rubertsson
  The project is performed in collaboration with the Department of Surgery and Anaesthesiology, Uppsala University.

Oxidative stress and regional pain syndrome

- Collaborators: Samar Basu and Torsten Gordh
  The project is performed in collaboration with the Smart Centrum, Akademiska Hospital, Uppsala University.

Antibody and assay development on resolvins/protectins

- Collaborators: Samar Basu, Charles Serhan
  The project is performed in collaboration with Brigham and Women's Hospital, Harvard Medical School, Boston, USA.

AQUAMAX: The sustainable aquafeeds to maximise the health benefits of farmed fish for consumers

- Collaborators: Samar Basu, Philip Calder
  Financed by the European Union (6th Framework).
  The project is performed in collaboration with Southampton, Granada, Bergen, China.
Multi-laboratory study on biomarkers of oxidative stress (BOSS-study)
• Collaborators: Maria Kadiiska with international colleagues, Ron Mason, Samar Basu
The project is performed in collaboration with NIEHS, National Institute of Health (NIH), USA and other institutions from several countries and is financed by NIEHS (NIH).

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

Research Group Leader professor Louise von Essen

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

Members of group and external partners 2014

<table>
<thead>
<tr>
<th>Name</th>
<th>Task/s in group</th>
<th>Academic title/s</th>
<th>Department/University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Louise von Essen</td>
<td>Research group leader, 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>Claes Held</td>
<td>Researcher</td>
<td>Associate professor, PhD, MD</td>
<td>Uppsala Clinical Research Centre, Uppsala University</td>
</tr>
<tr>
<td>Birgitta Johansson</td>
<td>Researcher</td>
<td>Associate Professor, PhD, Registered nurse</td>
<td>Department of Immunology, Genetics, and Pathology, Uppsala University</td>
</tr>
<tr>
<td>Annika Lindahl Norberg</td>
<td>Researcher, Director for U-CARE Healthcare</td>
<td>Associate Professor, PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Karolinska Institutet</td>
</tr>
<tr>
<td>Martin Cernvall</td>
<td>Researcher</td>
<td>PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
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<tr>
<td>Maria Gottvall</td>
<td>Researcher</td>
<td>PhD, Registered nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Red Cross University College</td>
</tr>
<tr>
<td>Helena Grönqvist</td>
<td>Researcher, 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>Emma Hovén</td>
<td>Post doc researcher, Program coordinator for U-CARE</td>
<td>PhD, MSc in Behavioral Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Karolinska Institutet</td>
</tr>
<tr>
<td>Elisabet Mattsson</td>
<td>Researcher</td>
<td>PhD, Registered nurse, Registered midwife</td>
<td>Department of Public Health and Caring Sciences, Uppsala University and Akademiska Sjukhuset Uppsala</td>
</tr>
<tr>
<td>Erik Olsson</td>
<td>Researcher</td>
<td>PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Jonas Sjöström</td>
<td>Researcher, IT coordinator for U-CARE</td>
<td>PhD, MSc in Information Systems</td>
<td>Department of Public Health and Caring Sciences and Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Sven Alfonsson</td>
<td>PhD student</td>
<td>PhD, 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</td>
<td>MSc in Political Sciences</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Lisa Ljungman</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Ruth Lochan</td>
<td>PhD student</td>
<td>MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</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>
</tr>
<tr>
<td>Susanne Mattsson</td>
<td>PhD student</td>
<td>Registered nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Anna Norén</td>
<td>PhD student</td>
<td>MSc in Economics</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Mudassir Imram Mustafa</td>
<td>PhD student</td>
<td>MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Fredrika Norlund</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist, Licensed psychologist</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Hafijur Mohammad Rahman</td>
<td>PhD student and Developer</td>
<td>MSc in Information Systems</td>
<td>Department of Public Health and Caring Sciences, and Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Teolinda Toft</td>
<td>PhD student</td>
<td>BSc in Social Work</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Emma Wallin</td>
<td>PhD student</td>
<td>MSc in Psychology, Licensed psychologist</td>
<td>Department of Psychology, Uppsala University</td>
</tr>
<tr>
<td>Mattias Öhman</td>
<td>PhD student</td>
<td>MSc in Economics</td>
<td>Department of Economics, Uppsala University</td>
</tr>
<tr>
<td>Fabian Holmberg</td>
<td>Developer</td>
<td>BSc in Computer science</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Ian Horne</td>
<td>Developer</td>
<td>MSc in Applied Technology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Benjamin Lefoul</td>
<td>Developer</td>
<td>MSc in IT and Communication Technology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Mattia Tomasoni</td>
<td>Developer</td>
<td>MSc in Computer Science</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Name</td>
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<tr>
<td>Marike Boger</td>
<td>Research assistant</td>
<td>MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Marina Forslund</td>
<td>Research assistant</td>
<td>MSc in Nutrition</td>
<td>Department of Immunology, Genetics, and Pathology, Uppsala University</td>
</tr>
<tr>
<td>Anneli Hagström</td>
<td>Research assistant</td>
<td>MSc in Business and Management</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>
<tr>
<td>Kata Bordas</td>
<td>Project Administrator</td>
<td>MSc in Business and Management</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
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**External partners**

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<th>Task/s</th>
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<th>Department/University</th>
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<tbody>
<tr>
<td>Enrico Baraldi</td>
<td>Researcher</td>
<td>Professor, PhD, MSc in Business Administration</td>
<td>Department of Engineering Sciences, Uppsala University</td>
</tr>
<tr>
<td>Per Carlbring</td>
<td>Researcher</td>
<td>Professor, PhD, Licensed psychologist</td>
<td>Department of Psychology, Stockholm University</td>
</tr>
<tr>
<td>Matz Dahlberg</td>
<td>Researcher</td>
<td>Professor, PhD, MSc in Economics</td>
<td>Department of Economics and Institute for Housing and Urban Research, Uppsala University</td>
</tr>
<tr>
<td>Robbert Sanderman</td>
<td>Researcher</td>
<td>Professor in Health Psychology, PhD, Licensed psychologist</td>
<td>Faculty of Behavioural and Social Sciences and Faculty of Medical Science, University of Groningen, The Netherlands</td>
</tr>
<tr>
<td>Pär Ågerfalk</td>
<td>Researcher</td>
<td>Professor, PhD, MSc in Information Systems</td>
<td>Department of Informatics and Media, Uppsala University</td>
</tr>
<tr>
<td>Gunilla Burell</td>
<td>Researcher</td>
<td>Associate professor, PhD, MSc in Psychology</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
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<tr>
<td>Maria Carlsson</td>
<td>Researcher</td>
<td>Associate professor, PhD, Registered nurse</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Timo Hursti</td>
<td>Researcher</td>
<td>Associate professor, PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Psychology, Uppsala University</td>
</tr>
<tr>
<td>Thecla Kohi</td>
<td>Researcher</td>
<td>Associate professor, PhD, Registered nurse</td>
<td>Muhimbili University of Health and Allied Sciences, School of Nursing, Dar es Salaam, Tanzania</td>
</tr>
<tr>
<td>Per Kristiansson</td>
<td>Researcher</td>
<td>Associate professor, PhD, MD</td>
<td>Department of Public Health and Caring Sciences, Uppsala University</td>
</tr>
<tr>
<td>Brjánn Ljótsson</td>
<td>Researcher</td>
<td>Associate professor, PhD, MSc in Psychology, Licensed psychologist</td>
<td>Department of Clinical Neuroscience, Karolinska Institutet</td>
</tr>
<tr>
<td>Gustaf Ljungman</td>
<td>Researcher</td>
<td>Associate professor, PhD, MD</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Christine Rubertsson</td>
<td>Researcher</td>
<td>Associate professor, PhD, Registered nurse, Registered midwife</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Agneta Skoog Svanberg</td>
<td>Researcher</td>
<td>Associate professor, PhD, Registered nurse, Registered midwife</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Anna Cristina Åberg</td>
<td>Researcher</td>
<td>Associate professor, PhD, Licensed physiotherapist</td>
<td>School of Health and Social studies, Dalarna University</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>Inna Feldman</td>
<td>Researcher</td>
<td>PhD, MSc in Mathematics</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
</tr>
<tr>
<td>Erik Grönqvist</td>
<td>Researcher</td>
<td>PhD, MSc in Social Sciences</td>
<td>Department of Economics and Institute for Housing and Urban Research, Uppsala University</td>
</tr>
<tr>
<td>Lena Hedén</td>
<td>Post doc</td>
<td>PhD, Registered</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
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<tr>
<td>Fredrik Holländare</td>
<td>Researcher</td>
<td>Psychiatric research centre, Örebro County Council</td>
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<tr>
<td>Gunilla Mårtensonsson</td>
<td>Researcher</td>
<td>The Faculty of Health and Occupational Studies, University of Gävle</td>
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<tr>
<td>Anna Hauffman</td>
<td>PhD student</td>
<td>Department of Radiology, Oncology and Radiation Science, Uppsala University</td>
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<tr>
<td>Tove Kamsvåg Magnusson</td>
<td>PhD student</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
<td></td>
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<tr>
<td>Vicky Lehmann</td>
<td>PhD student</td>
<td>University of Groningen, The Netherlands</td>
<td></td>
</tr>
<tr>
<td>Jenny Thorsell</td>
<td>PhD student</td>
<td>Department of Women’s and Children’s Health, Uppsala University</td>
<td></td>
</tr>
<tr>
<td>Golden Masika</td>
<td>Research assistant</td>
<td>University of Dodoma, Dodoma, Tanzania</td>
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Publications from members of group 2012-2014

2014

Publications


4. Andersen, K., Mariosa, D., Adami, H.O., Held, C., Ingelsson, E., Lagerros, Y.T., Nyrén, O., Ye, W., Bellocco, R., & Sundström, J. (2014). Dose-response relations of total and leisure-time physical ac-


dromes: results from the TRACER Trial. American Heart Journal, 6, 869-877.


nary syndrome patients managed with or without in-hospital invasive procedures - a substudy from the prospective randomized platelet inhibition and patient outcomes (PLATO) trial. Circulation, 129, 293-303. [Epub 2013].


Peer-reviewed conference papers


2013

Publications


Peer-reviewed conference papers


program of psychosocial support and psychological treatment. IPOS 15th World Congress of Psycho-Oncology. Rotterdam, The Netherlands.


vention. New Developments in Public Involvement in Research. Exeter, UK.


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

2012

Publications


164. Skogseid, E. (2012). En tvärsnittsstudie av upplevelsebaserat undvikande, traumatisk stress, livskvalitet och depression hos föräldrar till


Peer-reviewed conference papers


172. Cernvall, M., Ljungman, L., Silberleitner, N., Ljungman, G., & von Essen, L. (2012). Avoidance and hyperarousal mediates the relationship between reexperiencing and hyperarousal in parents of chil-


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


Dissertations 2014


Half time controls 2014

Funding during 2014 - members of group (SEK)

- Strategic Research Grant for U-CARE 10 000 000
- In-kind support from Departments of: Economics; Informatics and Media; Radiology, Oncology, and Radiation Sciences; Engineering Sciences, and Psychology 3 000 000
- Disciplinary Domain of Medicine and Pharmacy 1 700 000
- Swedish Research Council 1 500 000
- The Swedish Cancer Society 1 100 000
- The Swedish Childhood Cancer Foundation 1 000 000
- Uppsala County Council, ALF funds 800 000
- Regional Research Council 500 000
- Incomes for U-CARE-Portal 400 000
- A variety of small funds 400 000

During 2014 our main activities have been

- We have provided ten researchers/post doc researchers and twenty PhD students with stimulating career opportunities
- We have provided a PhD student from University of Groningen, University Medical Centre Groningen, the Netherlands and a MSc in psychology from Radboud University, Nijmegen Medical Centre, the Netherlands, the possibility to spend part of their education in our group.
- We have recruited two system developers
- We have recruited one program administrator
- We have associated three researchers
- We have completed the RCT Betsy – Internet-based cognitive behavioral therapy to parents of children recently diagnosed with cancer
- We have completed the pilot study for the RCT Heart via the U-CARE-portal
- We have completed the pilot study for the RCT AdultCan via the U-CARE-portal
- We have conducted the RCTs: AdultCan; Heart, and AIDA via the U-CARE-portal
- We have provided the infrastructure and support to enable the RCTs: JUNO; U-CARE Gravid, and ISAK and the observational study Uppsala Pelvic Pain Study to be conducted via the U-CARE-portal
- We have attracted major external funding for 2015-2018 for the studies ParentsCan (PI Louise von Essen), Heart (Main applicant Erik Olsson), and AdultCan (Main applicant Birgitta Johansson)
- We have involved patients and members of the public in our research activities
We have held the fourth meeting with the U-CARE Scientific Advisory Board and all U-CARE members
We have consolidated and initiated national and international cooperations
We have held four research seminar series
We have increasingly provided education at the undergraduate and master level at the medical faculty and faculty of social sciences, Uppsala University within the areas of Clinical Psychology in Healthcare, Psychosocial Care in the Interactive Society and Care, Self-Care, and Psychological Treatment via the Internet and Mobile Media
We have provided PhD education within the area of sustainable citizen-centered health care via information and communications technology
We have re-organized U-CARE to promote leadership and increase educational and research output

Research projects
Cancer during adolescence: Psychosocial and health economic consequences
OVERALL AIM: To investigate short- and long-term psychological and economic consequences of adolescent cancer; compare the psychological and economic situation of those struck by cancer during adolescence vs. matched controls and investigate whether there are any positive psychological consequences of adolescent cancer.
METHODS: The project has a comparative, longitudinal design with eight measurements from one month to ten years after diagnosis. Sixty-one adolescents were included. Inclusion has finished. Data from a control group of 300 healthy persons have been collected. Participants answered questions about quality of life, anxiety, and depression. Additionally those struck by cancer answered questions about disease- and treatment-related distress, whether and if so how they coped with distress, and whether they experienced any negative and positive cancer-related consequences.
FUNDING: The project started 1999 and is funded by the Swedish Cancer society and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.

Occurrence and development of posttraumatic stress among parents of children with cancer
OVERALL AIM: To investigate occurrence of posttraumatic stress, predictors of posttraumatic stress, and health economic consequences among parents of children struck by cancer.
METHODS: The project has a longitudinal design with seven measurements from one week after diagnosis to five years after end of treatment. Two hundred fifty parents were included. Inclusion has finished. Participants answered questions about e.g. posttraumatic stress, emotional support, and the child’s medical situation.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

FUNDING: The project started 2012 and is funded by a strategic research grant to Uppsala University Psychosocial Care Program: U-CARE, ALF funds, the Swedish Research Council for Health, Working Life and Welfare, the Vårdal Foundation, FAS, and the Swedish Heart-Lung Foundation. Principal investigator: Professor Louise von Essen. Responsible researcher: As-

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

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

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

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

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

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

METOD: The clinical efficacy is evaluated with an uncontrolled, within group design where cognitive behavioral therapy is given to participants. Inclusion is ongoing. Each participant receives 10-15 sessions of face-to-face individual cognitive behavioral therapy. Participants answer questions about posttraumatic stress, anxiety, experiential avoidance, depression, and quality of life and unstructured interview questions about experienced suffering.

FUNDING: The project started 2014 and is funded by the Swedish Cancer Society and the Swedish Childhood Cancer Foundation. Principal investigator: Professor Louise von Essen.
A Swedish national follow-up study of physical and mental health among young adults born 1990-1992 with extremely low birth weight (<1001 g)

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

METHOD: The participants are survivors in a national cohort of 633 consecutive live-born infants with a birth weight of < 1001 g born April 1990 to March 1992 in Sweden. 372 (59%) survived up to one year. The cohort will be compared to a matched control group born at term with normal birth weight. Participants answer questions online about mental health, transition to adulthood, educational achievement, social competence and behaviour. Long-term metabolic-, and cardio-vascular health and body composition is investigated in a subgroup living close Uppsala University hospital.

FUNDING: The project received funding from Josephine Neimans Fund 2014. Principal investigator: Consultant Neonatologist, PhD Barbro Diederholm, Department of Women’s and Children’s Health, Uppsala University.

Co-applicant from Clinical Psychology in Healthcare: PhD Helena Grönqvist.

SibsCan: Development and testing of an internet based psychosocial intervention for adolescent and young adult (AYA) siblings of young persons struck by cancer

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

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

FUNDING: The project started 2014 and is funded by the Swedish Childhood Cancer Foundation and the Kempe-Carlsgren fund. Principal investigator: Associate professor Annika Lindahl Norberg.
Research group leader: Professor Ragnar Westerling

The primary objective of the Sociomedical Epidemiology research group 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.

In an EU-funded project and research collaboration 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. We found several shifts in mortality trends indicating the influence of the medical innovations on public health.

Furthermore, we have developed a method to analyse indications of quality problems in the causes of death data, which have also been applied in international collaboration. The method is based on the ACME standard software for the selection of underlying cause of death, which was used to examine the compatibility between the underlying cause of death and the final hospital main conditions. Also in an international study, a method to correct for the potential influence of changes and variations in cause of death, classification rules has been developed for time trend analyses.

The research field include studies of the diffusion of innovations and implementation of evidence based medicine. Preventive treatment with statins is shown to significantly reduce the absolute risk of coronary heart disease; yet long-term compliance is poor. We have studied the expectations and factors that might affect expectations on statin treatment among patients. Recently, we have also analysed the association between the patient’s locus
of control and the beliefs about statin medications as well as factors influencing self-rated health in the treatment group. A new method to describe the preventive effects of statin treatment for patients have been developed by one of the members of the group, and this method is now tested in a randomized study.

We have published several studies on mechanisms behind social differences in health and equity in health care utilization. Presently the equity in access to evidence-based treatment for heart failure is analysed, combining data from several medical and social registers in Sweden. We are also studying the consequences of inequity on for instance the prognosis for unemployed to return to employment.

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. We are studying the impact of international health advisors and other health promotion programs on health and health care utilization among immigrants to Sweden. The health advisors are working with information to immigrants about health related factors and medical care in Sweden. We have also developed a health information package, which have been used and evaluated as part of an intervention project for marginalized female immigrants. We are also analysing the views and expectations of health examinations for asylum seekers in Sweden.

The focus is on the importance of health literacy, i.e. to what extent you can understand and use health information, for the perceptions of the health examinations. We also study the impact of the health examinations on the sexual and reproductive health.

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 2014

Ragnar Westerling, Professor
Per Lytsey, MD, PhD, University adjunct
Achraf Daryani, PhD, Researcher
Annika Åhs, PhD, Researcher
Marcus Westin, MD, PhD
Marianne Hanning, PhD
Lars-Age Johansson, PhD

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Publications 2012-2014


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


30. Wångdahl J. Hälsovärnamodell och hälsohälsokommunikation och hälsolitteracitet – av intresse för arbetet med hälsoupplysningsarbetet och asylsökande. (In Swedish: Health communication and health literacy – of interest for the work with


43. Berglund E, Lytsy P Sundström J, Westerling R., Patients more willing to initiate preventive drug therapy when treatment effect is expressed (time-based) as delay of events: A randomized trial of three treatment descriptions. Department of Public health and Caring Sciences and Department of Medical Sciences. Uppsala University. 2014. (Submitted).

44. Grandahl, M, Tydén T, Westerling R, Neveus T, Rosenblad A, Hedin E, Oscarsson M. To consent or decline HPV vaccination: A pilot study I at the start of the national school-based vaccination programme in Sweden. Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Department of Women’s and Children’s Health, Uppsala University, Uppsala, Centre for Clinical Research Västerås, Uppsala University, Västerås, Department of Medical Sciences, Uppsala University, Uppsala, Department of Health and Caring Sciences, Linnaeus University, Kalmar 2014. (Submitted).

45. Lejelind E, Westerling R, Strand A, Larsson K, Strategies and barriers behind condom use during sexual contacts in travels outside Sweden - a qualitative study. Departments of Dermatology and Venereology, Uppsala University Hospital, Department of Public Health and Caring Sciences, Uppsala University, Department of Neurology, Care Sciences and Society, Karolinska Institutet 2014. (Submitted).


Agencies that support the work/Funding 2014 (SEK)

- European refugee Fund 300 000
- European Social Fund 379 000
- Samordningsförbundet - Health, Establishent and work 194 000
  Nacka
- The Swedish Institute for Communicable Disease Control in collaboration with Stockholm County 400 000
- Olle Engkvist Fund 130 000
- ALF-grant. Academic hospital 1 038 000
- Swedish Society of Medicine 100 000