

# Annual Report 2008

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Department of Public Health and Caring  
Sciences

Fastställd av Institutionsstyrelsen 2009-03-23

## Introduction

During 2008 there were eleven research groups at the Department of Public Health and Caring Sciences: Caring Sciences, Clinical Nutrition and Metabolism, Disability research, Family Medicine and Clinical Epidemiology, Geriatric Research, Health Service Research, Preventive Medicine, Psychosocial Oncology and Supportive Care, Research Ethics and Bioethics, and Social Medicine.

In all, 144 persons had positions at the department. There were 11 professors, 2 adj. professors, 4 professors emeriti, 1 adj. professor emeritus, 14 senior lecturers, 2 adj. senior lecturers, 5 assistant professors, 25 researchers, 7 research assistants, 26 teachers, 23 administrators, 5 dieticians, laboratory assistants and technicians, 3 coordinators, and 2 research physicians. Sixty five doctoral students were studying at the department and 19 of those had appointments.

Two hundred and twenty articles were internationally published in scientific journals and 12 of the doctoral students defended successfully their dissertations. The external founding was about 29 million Swedish crowns.

At the undergraduate level, 547 full time students (=HST) were educated at the department. The students belonged to different programs and courses, 342 were educated within the Nursing programs, 77 within the Physician program, 30 within the MSc-program in Public Health and 98 in other short courses.

The research groups are presented below

### **Caring Sciences**

Caring Sciences is a broad concept that includes theory, methods and techniques for the study of problems and intervention for individuals and groups within the health care system. Outcome and relations between different, clinically relevant factors are evaluated, as well as the processes involved. Research in Caring Sciences emanates from a multi scientific and multi professional perspective which includes preventive, supportive, caring and rehabilitative actions. One area of the Caring Sciences emphasizes social and behavioral science, including such theories and methods. An important field of study is the interaction between personnel, patients and their family/significant others. The individual's resources for keeping and regaining optimal health, as well as his/her ability to adjust to change in health status are other important foci for research. Resources within the health care system for support to the individuals and their families are also of great interest, particularly when such resources are lacking and in palliative care. Finally, research concerning health care organizing and education is within the scope of the Caring Sciences.

## **Clinical Nutrition and Metabolism**

The research at Clinical Nutrition and Metabolism (CNM) focuses on dietary intake and metabolism during health and disease. It covers aspects of preventive public health nutrition, clinical disease- and age-related nutrition, child and adult obesity, circadian metabolism and physical activity. Research activities and methodology circle around fatty acid (FA) and carbohydrate metabolism, oxidative stress, inflammation, dietary interventions, dietary assessment, energy metabolism and body composition measurements. CNM runs two laboratories focusing on analyses of FA profiles in various tissues by gas-chromatography and isoprostanes and prostaglandins by unique RIA techniques, as well as measurements of body composition by air-displacement and bioelectrical impedance and energy expenditure. In epidemiological studies nutritional, metabolic and dietary factors, e.g. dietary fatty acid composition and dietary antioxidants, are related to long-term clinical outcomes, e.g. diabetes type 2, metabolic syndrome, cardiovascular disease in middle-aged populations, and functional limitation, cognitive dysfunction, morbidity and mortality in elderly populations.

## **Disability and Habilitation**

Research in disability is interdisciplinary and multi-professional with a fundamental perspective focussing the interface between individuals and environment. A joint conceptual tool is found in WHO's classification ICF (International Classification of Functioning, Disability and Health), that extends beyond the medical perspective in that it includes a societal and environmental perspective. Habilitation, services to persons with disabilities, constitutes planned formal multi-professional interventions provided to individuals with permanent disabilities and their networks in order to promote an optimal level of function and well-being. Current research activities focus studies of living conditions including physical and mental health, gender, everyday perspectives and experiences, quality of life, measurement and evaluation in implementation, prevention and intervention.

## **Family Medicine and Clinical Epidemiology**

Family Medicine is the dominating academic branch in Primary Health Care. Moreover, it is the mother speciality for all other non-surgical physician specialities. The content of Family Medicine is reflecting the fact that primary health care is in the health care front line, i.e. the health care facility that patients are expected to consult in the first place when needed. For this reason Family Medicine research focuses on the most common diseases and illnesses in the population, for instance cardiovascular disease, diabetes, asthma, chronic obstructive lung disease, social insurance medicine (sick-listing and disability retirement), musculo-skeletal disorders, low back pain, tennis elbow, fibromyalgia, pharmaco-epidemiology, and the most common infectious diseases. The researchers also teach in the undergraduate curriculum within the medical and nursing programmes. In the research programme the focus is on patient centred research using clinical as well as epidemiological techniques.

## **Geriatric Research**

The dementia research unit was established in 2001 and the main areas of research are: Molecular studies of dementia, clinical and epidemiological research and clinical and epidemiological research affecting the elderly population.

The researchers are using cellular- and transgenic mice models of Alzheimer's disease to better understand mechanisms of amyloid formation in the brain and to develop disease-modifying therapeutics. The research group is also involved in genetic analysis of dementia in human samples. This entails mutation screening and copy number studies of previously identified disease causing genes, as well as genetic mapping of previously not described genes with effect on dementia.

The clinical research unit is currently categorizing dementia patients clinically and neuropathologically. This research is based on a tissue bank that include DNA, CSF, plasma, serum, fibroblasts and brain tissue. Longitudinal studies of Alzheimer's disease and frontotemporal dementia are carried out in collaboration with Uppsala PET-center. Population based investigations have been performed on samples from the Uppsala Longitudinal Study of Adult Men (ULSAM). The major aim for the dementia research group in the future is to establish immunotherapeutic strategies to treat dementia.

## **Health Service Research**

Health services research is interdisciplinary, as the research theories and methods used have their origins in many different scientific disciplines. The researchers as well have very different backgrounds, such as psychology, medicine, nursing, political science and economy. There are many approaches to health services research. Some of these approaches are represented in present research projects at the Department of Public Health and Caring Sciences as follows: One approach is to study the health care system from the view of the individuals involved, for example, doctors, medical care personnel, students and patients. This approach focuses mainly on how the medical caring personnel understand their work, and how their professional competence develops and can be influenced by education and professional guidance. Another approach is the study of political, administrative and medical decision making process. Studies presently in progress with this approach focus on management of different political reforms within health care.

## **Preventive Medicine**

The chair in preventive medicine was established late in 2008 and is the first chair in preventive medicine at Uppsala University. The profile of the research and the formation of the research group are under development and studies will address theories of the life course approach in current epidemiology and 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.

## **Psychosocial Oncology and Supportive Care**

The group has through extensive funding and a unique collaboration with all six Swedish Centres for Paediatric Oncology, the Health IT research group at Linköping University, and the Health-Economics research group at Lund University succeeded in reaching a leading-edge research concept in the area of psychosocial research in paediatric oncology. We have since 1999 mainly worked with four projects: Cancer during adolescence. Psychosocial and health-economic consequences (1999-); Occurrence and development of posttraumatic stress disorder among parents of children with cancer (2000-); Treatment of posttraumatic stress disorder among parents of children with cancer with cognitive behavioural therapy over the Internet (2008-), and Randomized, controlled studies investigating the effects of non-pharmacological and pharmacological interventions on emotional distress experienced by children in connection to invasive procedures (2004-). Our research is cross-disciplinary and our research group consists of researchers, clinicians, post doc researchers, and PhD students from different disciplinary backgrounds.

## **Research Ethics and Bioethics**

The researchers conduct research on Research Ethics, Bioethics and Medical Law. Research Ethics involves the application of ethical principles and values to a variety of research topics. It aims to create good research, while at the same time studying what good research is. Bioethics, on the other hand, includes philosophical, theological, legal and social scientific aspects of medicine and biology. Medical law spans a wide range of traditional branches of law and is associated to the Centre through our collaboration with the Department of Law at Uppsala University.

Research Ethics and Bioethics has become increasingly important for Uppsala University. As a result, the Centre for Research Ethics and Bioethics was established on January 1 2008. The centre is placed at the Faculty of Medicine and administratively associated to the Department of Public Health and Caring Sciences.

## **Social Medicine**

The Division of Social Medicine focuses on three major and inter-related research areas. A common factor for the research is enhancing the scientific understanding of risk- and resiliency factors, as well as related bio-psycho-social mechanisms, of relevance for sustained and equitable occupational and social health and well-being, in addition to effective use of limited financial and human resource.

Bio-psycho-social mechanisms contributing to health disparity and resource utilization is the first research area. Research in this area looks at the relationship between psychosocial determinants, including socioeconomic, coping, lifestyle, and biological disease pathways and its relationship to important public health outcomes, such as disease, mortality, mental health and sick leave behaviour.

Stress factors and psychophysiological consequences of the modern lifestyle is the second research area, and modern health care, implications for patients, health care

organizations and society is the third. A number of studies following the implications of current structural and economic changes to patients, employees, health care organizations and society have been carried out.

### **Social Medicine/ Sociomedical Epidemiology,**

The research integrate social epidemiology, prevention research and health services research. The aim of the research programme is to 1) develop methods for identifying and analysing the mechanisms behind preventable disease patterns in the population. 2) evaluate the impact of the health care system and other parts of the society on these preventable disease patterns.3) analyse the associations between the social situation and psychosocial, behavioural and biological risk factors for ill health and how these associations may be influenced in order to improve preventive strategies, 4) develop, plan and evaluate preventive programmes.

This program line is implemented for different fields of public health, in accordance with the Swedish National Public Health Goals, such as the health of children and families, health related to working life, health related life styles as well as health orientated medical care and the prevention of adverse events in medical care. Several doctoral students are involved in these studies and several collaboration projects are included.

It is a pleasure to report that 2008 has been a good year for the Department of Public Health and Caring Sciences. A lot of challenges and achievements have been met and accomplished by the staff and the students. Now, new economical, educational, scientific and organizational challenges are to be met in 2009.

Uppsala 2009-03-23

Marianne Carlsson

Head of Department

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# Organization

## **Head of Department**

Marianne Carlsson

## **Deputy Head of Department**

Mats G Hansson

## **Department board**

Carina Ahlstedt, teacher representative

Hanna Bengtsdotter, student representative

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Monica Blom Johansson, graduate student representative

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Engström Sevek

Ernesäter Annica

Ferdous Tamanna

Fredriksson Mio

Glad Johan

Gottvall Maria

Gumucio Gatica Astrid

Gustavsson Catharina

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Paulsson Ulrica  
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Philipson Ola  
Pöder Ulrika  
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## Centres

During 2008, the Department of Public Health and Caring Sciences was the host of three Centres: The Centre for Disability and Habilitation, the Centre for Research Ethics and Bioethics and the Nordic Centre for classification in Health Care.

### **Centre for Disability and Habilitation**

The centre was established in 1998 to coordinate research 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.

### **Centre for Research Ethic and Bioethics**

The Centre for Research Ethics & Bioethics is an interfaculty centre that is governed by a board University representatives and led by a Director. The Centre is administratively associated to the Department of Public Health and Caring Sciences at the Faculty of Medicine. The centre was established in January 2008. ([www.crb.uu.se](http://www.crb.uu.se))

### **Nordic Centre for Classification in Health Care**

The Nordic Centre is responsible for the coordination of classifications used within the health care systems in the Nordic countries. As a WHO Collaborating Centre for the Family of International Classifications (WHO-FIC), the Centre represents the Nordic countries in the international coordination of health related classifications.

# Scientific Reports

## Caring Sciences

### Research group leader Tanja Tydén, RN, PhD, Professor

Caring Sciences is a broad concept that includes theory, methods and techniques for the study of problems and intervention for individuals and groups within the health care system. Outcome and relations between different, clinically relevant factors are evaluated, as well as the processes involved. Research in Caring Sciences emanates from a multi scientific and multi professional perspective which includes preventive, supportive, caring and rehabilitative actions. One area of the Caring Sciences emphasizes social and behavioral science, including such theories and methods. An important field of study is the interaction between personnel, patients and their family/significant others. The individual's resources for keeping and regaining optimal health, as well as his/hers ability to adjust to change in health status is another important focus for research. Resources within the health care system for support to the individuals and their families are also of great interest, particularly when such resources are lacking and in palliative care. Finally, research concerning health care organizing and education is within the scope of the Caring Sciences.

#### **Researchers/group leaders**

Our group consists of several researchers of which many are very experienced and have interesting ongoing projects of high quality. The group is multi professional, but the majority is nurses. The following researchers/group leaders belonged to Caring Sciences during 2006-2008:

Aartz Clara, nurse, senior lecturer

Arving Cecilia, nurse, research assistant

Carlsson Maria, nurse, associated professor, senior lecturer

Carlsson Marianne, psychologist, professor

Edlund Birgitta, nurse, associated professor, senior lecturer

Hedström Mariann, nurse, senior lecturer (new member 2008)

Lampic Claudia, psychologist, associated professor, senior lecturer (Gävle University, partly at Caring Sciences)

Lindberg Per, psychologist, professor (left 2008 for professor at the dep. of psychology, Uppsala Univ.)

Lundberg Pranee, nurse, associated professor, senior lecturer

Nordin Karin, psychologist, associated professor (50% at Bergen University, Norway)

Pöder Ulrika, nurse, senior lecturer (new member 2008)

Tydén Tanja, nurse midwife, professor

Wadensten Barbro, nurse, associated professor, senior lecturer (new member 2008)

Winblad Ulrika, political scientist, PhD, research assistant (new member 2008)

#### **Fundings over 100.000 SEK, 2006-2008**

The Swedish Research Council

The Swedish Cancer Society

The Swedish Council for Working Life and Social Research  
Uppsala/Örebro Regional Research Council  
The Swedish Association of Local Authorities and Regions (SKL)  
Försäkringskassan

### **Dissertations 2006-2008**

Kristina Haglund, "Patient and Staff Perceptions of Medication Administration and Locked Entrance Doors at Psychiatric Ward", 2006

Christine Leo Swenne, "Wound Infection Following Coronary Artery Bypass Graft Surgery. Risk factors and the Experiences of Patients", 2006

Helena Lindstedt, "Daily Occupations in Mentally Disordered Offenders in Sweden. Exploring Occupational Performance and Social Participation", 2006

Jeanette Winterling, "Hope and Despair. Philosophy of life, expectations and optimism in cancer patients and their spouses", 2007

Cecilia Arving, "Individual psychosocial support for breast cancer patients", 2007

Caring sciences in cooperation with the Domain of Humanities and Social Sciences

Henna Hasson, "Nursing staff competence, psychosocial work environment and quality of elderly care: impact of an educational intervention" 2006

Marja-Leena Kristofferzon, "Coping, social support and quality of life over the first year" 2006

Maria Engström, "A Caregiver Perspective on Incorporating IT Support into Dementia care" 2007

Bernice Skytt, "First –line Nurse Managers: Preconditions for Practice" 2007

Elisabet Wasteson, "Living and coping with cancer, Specific challenges and adaption" 2007

Eva Landström, "To choose or not to choose functional foods? – Attitudes to and use of functional foods among Swedish consumers and health care professionals" 2008

Kjerstin B Larsson, "Quality of Life and Coping with Ulcerative colitis and Crohn's Disease" 2008

Annika Nilsson, "Health Care Staff: Riskfactors for Pain, Disability and Sick Leave" 2008

### **PhD students at caring sciences in 2008**

Demmelmaier Ingrid

Gottvall Maria

Gustavsson Catharina

Hedlund Mathilde

Jönson Birgitta

Kullberg Kerstin  
Lindberg Magnus  
Lindberg Maria  
Muntlin Åsa  
Mårtensson Gunilla  
Rashanai Afsaneh  
Rastad Cecilia  
Star Kristina  
Josefin Westerberg

### **Aarts Clara**

The focus of research has been within primary health care and international collaboration of student exchange programs.

### **Publications**

1. Aarts A & Greiner T. 2006. Regarding the review article by Erlanson-Albertsson and Zetterstrom, *Acta Paediatr* 2005;94:1523-31. *Acta Paediatr.* 2006 May;95(5):623-4; author reply 624-5.
2. Larsson M, Aldergarmann U, Aarts C. 2007. Professional role and identity in a changing society - three paradoxes in Swedish midwives' experiences. *Midwifery*, 2007 Nov 5;electronic.
3. Ndomba ALM, Smide B, Aarts C. Preventing IUC infections in Tanzanian patients; nurses' knowledge, clinical practice and patients' views. *International Journal of Urological Nursing*, *International Journal of Urological Nursing* 2008, Vol 2 No 1:33-41.

### **Carlsson Maria**

Research about information seeking behavior in cancer patients, fatigue in relatives to dying cancer patients cared for in a palliative care setting and the professional encounter in a hospital setting, perspective of the patients and the nurses

### **Publications 2006-2008**

Carlsson M, Nilsson I. Bereaved spouses' adjustment after the patients' death in palliative care. *Palliative and Supportive Care* 2007 5:397-404.

### **Carlsson Marianne**

Quality of life and coping in everyday life in different life situations in a health care context. The focus of this research group is primarily psychometric. Quality of life and coping of patients with acute pain, cancer, dementia, heart disease, stroke and wound infections and also of persons colonized with MRSA are different research foci. Other

areas are work satisfaction and organizational problems of nursing staff and the development of a diagnostic tool for detection of early signs of dementia.

### **Publications 2006-2008**

1. Muntlin Å, Gunningberg L, Carlsson M. Patients' perceptions of quality of care at an emergency department and identification of areas for quality improvement. *Journal of Clinical Nursing*, 2006; 15: 1045-1056.

2. Arman M, Backman M, Carlsson M, Hamrin E. Women's perceptions and beliefs about the genesis of their breast cancer. *Cancer Nursing* 2006; 29(2): 142-148.

3. Swenne CL, Borowiec J, Carlsson M, Lindholm C. Prediction of and risk factors for surgical wound infection in the saphenous vein harvesting leg in patients undergoing artery by-pass. *The Thoracic and Cardiovascular Surgeon*. 2006; 54: 300-306

4. Engström M, Ljunggren B, Lindqvist R, Carlsson M. Staffs' satisfaction with work, perceived quality of care and stress in elderly care. Psychometric assessments and associations. *Journal of Nursing Management*. 2006; 14: 318-328.

5. Rödahl G, Innala S, Carlsson M. Verbal and non-verbal heterosexual assumptions in nursing. *Journal of Advanced Nursing* 2006; 56(4): 373-381.

6. Carlsson M, Arman M, Backman M, Flatters U, Hatschek T, Hamrin E. A five-year follow-up of the quality of life in women with breast cancer in anthroposophic and conventional care. *eCAM* 2006; 3 (4): 523-531.

7. Engström M, Lindqvist R, Ljunggren B, Carlsson M. Relatives' opinions of IT-support, perceptions of irritations and life satisfaction in dementia care. *Journal of Telemedicine and Telecare*, 2006; 12: 246-250.

8. Rödahl G, Innala S, Carlsson M. To hide or not to hide, that is the question! Lesbians and gay men describe experiences from nursing work environment. *Journal of Homosexuality* 2007; 52(3/4) 211- 233.

9. Kristofferzon ML, Löfmark R, Carlsson M. Striving for balance in daily life: experiences of Swedish women and men shortly after a myocardial infarction. *Journal of Clinical Nursing* 2007; 16: 391-401

10. Skytt B, Ljunggren B, Carlsson M. Reasons to leave: The motives of first-line nursemanagers' for leaving their posts". *Journal of Nursing Management* 2007; 15: 294-302.

11. Swenne CL, Skytt B, Lindholm C, Carlsson M. Patients' experiences of mediastinitis after coronary artery bypass graft procedure. *Scandinavian Cardiovascular Journal*, 2007; 41 (4): 255-264.
12. Skytt B, Ljunggren B, Sjöden PO, Carlsson M. The role of first-line nurse managers from four different perspectives. *Journal of Nursing Management* 2008; 16 (8): 1012-20
13. Hedlund M, Ronne Engström E, Ekselius E, Carlsson M. From monitoring physiological functions to using psychological strategies. Nurses' view of caring for the aneurismal subarachnoid haemorrhage patient. *Journal of Clinical Nursing*, 2008; 17(3): 403-411.
14. Mårtensson G, Carlsson M & Lampic C. Do nurses and cancer patients agree on cancer patient's coping resources, emotional distress and quality of life? *European Journal of Cancer Care*, 2008; 17:350-360.
15. Carlsson M. Can coping predict quality of life and survival over a five-year period in women with breast cancer in anthroposophic and conventional care? In Jacobs LK: *Coping with Cancer*, Nova Science Publishers Inc. 2008, 107-126.
16. Skytt B, Ljunggren B, Carlsson M, Engström M. Psychometric testing of the Leadership and Management inventory. *Journal of Nursing Management* , 2008; 16(7): 784-94
17. Muntlin A, Gunningberg L, Carlsson M. Different patient groups request different emergency care- A survey in a Swedish emergency department. *International Emergency Nursing*, 2008;16: 223-232.
18. Kristofferzon M-L, Löfmark R, Carlsson M. Managing consequences and finding hope – experiences of Swedish women and men 4-6 months after myocardial infarction. *Scandinavian Journal of Caring Sciences*, 2008; 22: 367-375.

### **Edlund Birgitta**

Research within health- and lifestyle behaviours in children, adolescents and young adults; protective factors and risk factors for the development of eating disorders.



## **Publications 2006-2008**

1. Lundstedt, G., Edlund, B., Thurfjell, B., Engström, I., & Marcus, C. (2006). Eating disorders inventory for children (EDI-C) in obese and eating disordered Swedish children. *Eating and Weight Disorders*, 11, 45–50
2. Askelöf, M., Halldin Stenlid, M., & Edlund, B. (2007). Eating behaviour and body image in overweight adolescent girls with or without hyperandrogenicity. *Eating and Weight Disorders*, 12, 41–47.
3. Stenhammar, C., Sarkadi, A., & Edlund, B. (2007). The role of parents' educational background in healthy lifestyle practices and attitudes of their 6-year old children. *Public Health Nutrition*, 10 (11),1305-1313.
4. Knutsson-Medin, L., Edlund, B. & Ramqvist, M. (2007) Experiences in a group of grown-up children of mentally ill parents. *Journal of Psychiatric and Mental Health Nursing*, 14,744-752
5. Aila, S., Edlund, B., Kjellin, L., & Norring, C.(2008) Personal standards, self-evaluation and perceived benefits of thinness in girls and young women with disturbed eating attitudes. *European Eating Disorders Review* 16, 463-471.
6. Galvin, K, Emami , A., Dahlberg, K., Ekeberg, M., Rosser, E., Powell, J., ,Bach,S., Edlund, B., Terese Bondas, T., Uhrenfeldt L. (2008) Challenges for future caring science research: a response to providing evidence for health- care practice. *International Journal of Nursing Studies*. 45, 971-4.
7. Westerberg, J., Edlund, B., & Ghaderi, A. (2008). A 2-Year longitudinal study of eating attitudes, BMI, perfectionism, asceticism and family climate in adolescent girls and their parents. *Eating and Weight Disorders*,13, 64-72.

Since 1 august 2007, Edlund is awarded as a visiting professor at Bournemouth University. Cooperation partner is Professor Kate Galvin, at the Institute of Health and Community studies, Bournemouth University.

## **Lampic Claudia**

Research is conducted within two main areas: 1) Cancer patients' quality of life, satisfaction with care and other aspects, including both patient and staff perspectives. and 2) Psychosocial aspects of fertility and infertility, with a focus on treatment with donated gametes.

### **Publications 2006-2008**

1. Lampic C, Skoog Svanberg A, Karlström PO, Tydén T (2006). Fertility awareness, intentions concerning childbearing and attitudes towards parenthood among female and male academics. Hum Reprod, 21: 558-564.
2. Skoog Svanberg A, Lampic C, Karlström PO, Tydén T (2006). Attitudes toward parenthood and awareness of fertility among postgraduate students in Sweden. Gender Medicine, 3: 187-195.
3. Tydén T, Skoog Svanberg A, Karlström PO, Lihoff L, Lampic C. (2006). Female university students' attitudes to future motherhood. Eur J Contracep Reprod Health Care, 11: 181-189.
4. Fröjd C, Larsson G, Lampic C, von Essen, L (2007). Health related quality of life and psychosocial function among patients with carcinoid tumours. A longitudinal, prospective and comparative study. Health Quality of Life Outcomes, 5:18.
5. Sydsjö G, Lampic C, Sunnerud S, Skoog Svanberg A (2007). Nurses promote openness regarding the genetic origins after gamete donation. Acta Paediat, 96: 1500-1504.
6. Fröjd C, Lampic C, Larsson G, Birgegård G, von Essen, L (2007). Patient attitudes, behaviours and other factors considered by doctors when estimating cancer patients' anxiety and desire for information. Scand J Caring Sci, 21:523-9.
8. Skoog Svanberg A, Sydsjö G, Ekholm Selling K, Lampic C (2008). Attitudes towards gamete donation among Swedish gynaecologists and obstetricians. Hum Reprod, 23(4): 904-11.
9. Mårtensson G, Carlsson M, Lampic C (2008). Do nurses and cancer patients agree on individual patients' coping resources, emotional distress and quality of life? Eur J Cancer Care, 17: 350-360.
10. Sundberg K, Lampic C, Arvidsson J, Björk O, Wettergren L. Positive and negative consequences of childhood cancer influencing the lives of young adults. Eur J Oncol Nurs. Oct 6 2008. Epub ahead of print.

Lindberg Per

**Research is focused on problems related to health and self-care within a bio-psycho-social and behavioural medicine theory framework.**

### **Publications 2006-2008**

1. Åsenlöf, P., Denison, E., & Lindberg, P. 2006. Idiographic outcome analyses of the clinical significance of two interventions for patients with musculoskeletal pain. Behavior Research and Therapy, 44, 947-965.
2. Jönsson, B, Lindberg, P, Oscarson, N & Öhrn, K 2006. Improved compliance and self-care in patients with periodontitis – a randomized control trial. International Journal of Dental Hygiene, 4, 77-83.
3. Denison, E, Åsenlöf, P, Sandborgh, M & Lindberg, P. 2007. Musculoskeletal pain in primary health care: subgroups based on self-efficacy, fear-avoidance variables, pain and disability. The Journal of Pain, 8(1), 67-74.

4. Sandborgh, M. Lindberg, P. & Denison, E. 2007. The Pain Belief Screening Instrument – Development and preliminary validation of a screening instrument for disabling, persistent pain. *Journal of Rehabilitation Medicine*, 39, 461-466.
5. Lindberg, M., Lindberg, P. & Wikström, B. 2007. Medication discrepancy: a concordance problem between dialysis patients and caregivers. *Scandinavian Journal of Urology and Nephrology*, 41(6), 546-552.
6. Lindberg, M., Wikström, B & Lindberg, P.. 2007. Fluid Intake Appraisal Inventory (FIAI): Development and psychometric evaluation of a situation specific measure for haemodialysis patients' self-efficacy to low fluid-intake. *Journal of Psychosomatic Research*, 63(2), 167-173
7. Söderlund, A. & Lindberg P. 2007. Cognitive behavioural components in physiotherapy management of chronic Whiplash Associated Disorder (WAD) – A randomised group study. *Giornale Italiano di Medicina del Lavoro ed Ergonomia*, 29, (Supplemento A, Psicologia 2007), A5-A11. (re-publication of Söderlund & Lindberg 2001)
8. Sandborgh, M. Lindberg, P. & Denison, E. 2008. The Pain Belief Screening Instrument (PBSI) – Predictive validity for disability status in persistent musculoskeletal pain. *Disability and Rehabilitation*, 30(15), 1123 - 1130
9. Rastad, C., Ulfberg, J & Lindberg, P. 2008. Light room therapy effective in mild forms of SAD. - A randomised controlled study. *Journal of Affective Disorders*, 108, 291-296.
10. Demmelmaier, I. Lindberg, P. Åsenlöf, P. & Denison, E. 2008. The associations between pain intensity, psychosocial variables, and pain duration/recurrence in a large sample of persons with non-specific spinal pain. *The Clinical Journal of Pain*, 24(7), 611-619.
11. Lindberg, M. & Lindberg, P. 2008. Overcoming obstacles for adherence to phosphate binding medication in dialysis patients: a qualitative study. *Pharmacy World and Science*, 30, 571-576.

### **Lundberg Pranee**

The main topics of my research are nursing and health related to culture and ergonomics.

### **Publications 2006-2008**

- Lundberg, P.C., & Rattanasuwan. O. (2007). Experiences of fatigue and self-management of Thai Buddhist cancer patients undergoing radiation therapy. *Cancer Nursing*, 30(2), 146-155.
- Lundberg, P.C. (2007). Use of traditional herbal remedies by Thai immigrant women in Sweden. In Pieroni, A. and Vandebroek, I. (eds), *Travelling Cultures, Plants and Medicines. The Ethnobiology and Ethnopharmacy of Migrations*, Berghahn Books, New York, 104-121.
- Thrakul, S., Lundberg, P.C., Chaladthanyagid, K., Unsanit, P. (2007). Traditional postpartum practices and food consuming among women in rural Thailand. *Journal of Public Health*, 37(3), 179-190.

Lundberg, P.C., & Gerezgiher, A. (2008). Experiences from pregnancy and childbirth related to female genital mutilation among Eritrean immigrant women in Sweden. *Midwifery*,24, 214-225.

## **Nordin Karin**

The research is within two main areas

- 1) Quality of life, coping and psychological well-being in patients with different diagnosis and their relatives
- 2) Ethical and psycho-social implications of the medical adaptation of the new knowledge within human genetics

## **Publications 2006-2008**

1. Wasteson, E., Sjäodén, P-O., Glimelius, B. and **Nordin, K.** (2006) Comparison of a questionnaire commonly used for measuring coping with a daily-basis prospective coping measure. *Journal of Psychosomatic Research*,61, 813-820.
2. Winterling, J., Wasteson, E., Sidenvall, B., Sidenvall, E., Glimelius, B., Sjäodén, PO. and **Nordin, K.** (2006) Relevance of philosophy of life and optimism for psychological distress among individuals in a stage where death is approaching. *Support Care Cancer*.14, 310-319
3. Strömsvik, N., **Nordin, K.**, Berglund, G., Engebretsen, L., Hansson, MG. and Gjengedal, E. (2007) Living with Multiple Endocrine Neoplasia Type 1: Decent Care - Insufficient Medical and Genetic Information. *Journal of Genetic Counselling* 16, 105-117.
4. Berglund, G., Peterson, L-M., Eriksson, K., Wallenius, I., Roshanai, A., **Nordin, K.**, Sjäodén, PO, and Häggman, M. (2007) "Between men" - a psychosocial rehabilitation programme for men with prostate cancer. *Acta Oncologica*, 46, 83-89.
5. Wolff, K., Brun, W., Kvale, G., **Nordin, K.** (2007) Confidentiality versus Duty to Inform - An empirical Study on Attitudes towards the Handling of Genetic Information. *American Journal of Medical Genetics*, 143A, 142-148.
6. Winterling, J., Wasteson, E., Arving, C., Johansson, B., Glimelius, B., Sjäodén, PO. and **Nordin, K.** (2008) Factors affecting spouses' psychological distress and grief resolution after the death of a patient with advanced gastrointestinal cancer. *Psycho-Oncology*, 17(2)190-198.
7. Winterling, J., Glimelius, B. and **Nordin, K.** (2008). The importance of expectations on the recovery period after cancer treatment. *Psychooncology*. Feb;17(2):190-8. PMID: 17534865

## **Pöder Ulrika**

Psychosocial- and supportive care, within the field of pediatric oncology. The focus is on parents of children diagnosed with cancer: parental posttraumatic stress, satisfaction with care and perceived emotional support.

### **Publications 2006-2008**

1. Pöder U., Ljungman G., von Essen L. Posttraumatic stress disorder among parents of children on cancer treatment: a longitudinal study. *Psychooncology*. 2008; 17: 430-437
2. Pöder U., von Essen L. Perceptions of support among Swedish parents of children on cancer treatment: a prospective, longitudinal study. *European Journal of Cancer Care*. 2008; Nov 27: E-pub ahead of print, DOI 10.1111/j.1365-2354.2008.00935.x

## **Tydén Tanja**

Research mainly within sexual and reproductive health; fertility awareness and sexual behavior among teenagers and young adults, unwanted pregnancies, use of contraception and sexually transmitted diseases

### **Publications 2006-2008**

1. Lampic C, Svanberg AS, Karlström P, Tydén T. Fertility awareness, intentions concerning childbearing, and attitudes towards parenthood among female and male academics. *Hum Reprod* 2006;21:558-64.
2. Larsson M, Eurenus K, Westerling R, Tydén T. Evaluation of a sexual education intervention among Swedish high school students. *Scand J of Public Health* 2006;42:124-31.
3. Tydén T, Svanberg AS, Karlström PO, Lihoff L, Lampic C. Female university students' attitudes to future motherhood and their understanding about fertility. *Eur J of Contracept Reprod Health Care* 2006;11:181-9.
4. Ragnar I, Altman D, Tydén T, Olsson S-E. Comparison of the maternal experience and duration of in two upright delivery positions - a randomised controlled trial. *BJOG* 2006;113:165-70.
5. Larsson M, Aneblom G, Eurenus K, Westerling R, Tydén T. The adoption of emergency contraceptive pills in Sweden - a repeated cross-sectional study among abortion applicants. *Acta Obstet Gynecol Scand* 2006;85:1142-3.
6. Larsson M, Tydén T. Increased sexual risk taking behavior among Swedish female university students: repeated cross-sectional surveys. *Acta Obstet Gynecol Scand* 2006;85:966-70.
7. Svanberg A, Lampic C, Karlström P, Tydén T. Attitudes toward parenthood and awareness of fertility among postgraduate students in Sweden. *Gender Medicine* 2006;3:187-95.

8. Häggström-Nordin H, Sandström J, Hanson U, Tydén T. 'It's everywhere!' young Swedish people's thoughts and reflections about pornography. *Scand J Caring Sci* 2006;20:386-93.
9. Altman D, Ragnar I, Ekström Å, Tydén T, Olsson SE. Anal sphincter lacerations and upright delivery postures – a risk analyses from a randomized controlled trial. *Int Urogynecol J Pelvic Floor Dysfunct* 2007;18:141-6.
10. Ekstrand M, Tydén T, Darj E, Larsson M. Preventing pregnancy: a girls' issue. Seventeen-year-old Swedish boys' perceptions on abortion, reproduction and use of contraception. *Eur J Contracept Reprod Health Care*. 2007 Jun;12(2):111-8.
11. Larsson M, Tydén T, Hanson U, Häggström-Nordin E. Preventivt arbete på bred front behövs för att främja sexuell hälsa bland ungdomar. Title in English. Preventative work is needed in order to promote sexual health among adolescents. *Läkartidningen* 2007;10:1992-5
12. Ekstrand M, Tydén T, Darj E, Larsson M. Male perception on abortion, adolescent fatherhood, sexual behaviour and use of contraception among 17-year old Swedish boys. *Eur J of Contracept Reprod Health Care* 2007; 2:111-8.
13. Larsson M, Tydén T, Hanson U, Häggström Nordin E. Contraceptive use and associated factors among Swedish high school students. *Eur J Contracept Reprod Health Care*. 2007 Jun;12:119-24.
14. Ekstrand M, Larsson M, Darj E, Tydén T. Advance provision of emergency contraceptive pills reduces treatment delay: a randomised controlled trial among Swedish teenage girls. *Acta Obstet Gynecol Scand* 2008;87:354-9.

## **Wadensten Barbro**

Main research area: gerontological nursing

Publications 2006 -2008

1. Wadensten B. & Hägglund D. (2006). Older people's experience of participating in a reminiscence group with a gerotranscendental perspective - Reminiscence group with a gerotranscendental perspective in practice. *International Journal of Older People Nursing* 1, 159-167.
2. Wadensten B. (2006). An analysis of psychosocial theories of ageing and their relevance to practical gerontological nursing in Sweden. *Scandinavian Journal of Caring Sciences*, 20, 347-354.
3. Hägglund D. & Wadensten B. (2007). Fear of humiliation inhibits women's care seeking behaviour for long-term urinary incontinence. *Scandinavian Journal of Caring Sciences*, 21; 305–312
4. Wadensten B. (2007). Life situation and daily life in a nursing home as described by nursing home residents in Sweden. *International Journal of Older People Nursing* 2, (3), 180-188.

5. Tang Ping Fen, Johansson C, Wadensten B, Wenneberg S & Ahlström G. (2007). Chinese nurses' ethical concerns in a neurological ward. *Nursing Ethics* 14(6) 810-824.
6. [Wadensten B. \(2007\) Part I: The theory of gerotranscendence as applied to gerontological nursing.](#) *International Journal of Older People Nursing* 2, (4), 289-294.
7. Wadensten B. & Carlsson M. (2007). [Part II: The theory of gerotranscendence in practice: Guidelines for nursing.](#) *International Journal of Older People Nursing* 2, (4), 295-301.
8. Wadensten B. & Carlsson M. (2007). [Part III: Adoption of an innovation based on the theory of gerotranscendence by staff in a Nursing home.](#) *International Journal of Older People Nursing* 2, (4), 302-314.
9. Wadensten B., Condén E., Wahlund L. & Murray K. (2007). How nursing home staffs deal with residents who talk about death. *International Journal of Older People Nursing* 2, (4), 241-249.
10. Silén M, Ping Fen Tang, Wadensten B & Ahlström G. (2008). Workplace distress and ethical dilemmas in neuroscience nursing; A qualitative study of Swedish nurses' experiences. *Journal of Neuroscience Nursing* 40, (4) 222-231.
11. Häggström E, Mabusa E & Wadensten B. (2008). Nurses perspectives of workplace distress and ethical dilemmas in Tanzanian healthcare. *Nursing Ethics* 15 (4), 478-91.
12. Fogelberg Dahm M. & Wadensten B. (2008). Nurses' experiences of and opinions about using standardized care plans in electronic health records - a questionnaire study. *Journal of Clinical Nursing* 17, 2137-2145.
13. Wadensten B, Wenneberg S, Silén M, Ping Fen Tang & Ahlström G. (2008). A Cross-cultural comparison of nurses' ethical concerns. *Nursing Ethics* 15 (6) 745- 760.

### **Winblad Ulrika**

The research focus on the political, administrative and medical decision making processes within health- and elderly care.

Ulrika Winblad belonged to Health Services Research 2006-2007, and to Caring Sciences and Health Care Research 2008 –

### **Publications 2006-2008**

1. Winblad U “ Do Physicians care about patient choice?” *Social Science & Medicine. Social Science & Medicine* 67 (2008) 1502-1511.

2. Fredriksson, M., Winblad, U (2008). "Consequences of a decentralised healthcare governance model: Measuring regional authority support for patient choice in Sweden." *Social Science & Medicine* 67 (2008) 271-279.
3. Arnetz J. E, Höglund A.T, Arnetz B., Winblad U. "Staff views and behaviour regarding patient involvement in myocardial infarction care: development and evaluation of a questionnaire." *Eur J Cardiovascular Nursing*, (2008), March, 7 (1): 27-35.
4. Arnetz J. E, Winblad U, Arnetz B., Höglund, A. T. "Physicians' and nurses' perceptions of patient involvement in myocardial infarction." *Eur J Cardiovascular Nursing*, (2008) Jun 7 (2):113-120.
5. Arnetz J. E., Höglund, A. T., Arnetz B., Winblad U. "Development and evaluation of a questionnaire for measuring patient views of involvement in myocardial infarction care." *European Journal of Cardiovascular Nursing* 7 (2008) 229–238
6. Vrangbæk, K, Østergren, K, Okkels Birk, H, Winblad, U., "Patient reactions to hospital choice in Norway, Denmark and Sweden". *Health Economics, Policy and Law*, 2007, Vol. 2(2): 125-152.

#### **Fundings over 100.000 SEK, 2006-2008**

- The Swedish Association of Local Authorities and Regions (SKL), 2008 (260 000 SEK), project leader Ulrika Winblad.
- The Swedish Research Council (VR), 2008-2010, (2.2 million SEK), project leader Paula Blomqvist.
- "The governance of the Swedish health care". Post-doc fellowship from the Swedish Council for Swedish work and Social research (FAS) 2005-2008.
- Försäkringskassan, 2005-2007, (1,6 million SEK). Project leaders: Ingrid Anderzen, Ulrika Winblad and Per Johansson.
- The Swedish Council for Swedish work and Social research (FAS), 2004-2008 (2,4 million SEK). Project leader Paula Blomqvist.



## Clinical Nutrition and Metabolism

Research group leader: Tommy Cederholm, MD, PhD, Professor

The research at Clinical Nutrition and Metabolism (CNM) focuses on dietary intake and metabolism during health and disease. It covers aspects of preventive public health nutrition, clinical disease- and age-related nutrition, child and adult obesity, circadian metabolism and physical activity. Research activities and methodology circle around fatty acid (FA) and carbohydrate metabolism, oxidative stress, inflammation, dietary interventions, dietary assessment, energy metabolism and body composition measurements. CNM runs two laboratories focusing on analyses of FA profiles in various tissues by gas-chromatography and isoprostanes and prostaglandins by unique RIA techniques, as well as measurements of body composition by air-displacement and bioelectrical impedance and energy expenditure. In epidemiological studies nutritional, metabolic and dietary factors, e.g. dietary fatty acid composition and dietary anti-oxidants, are related to long-term clinical outcomes, e.g. diabetes type 2, metabolic syndrome, cardiovascular disease in middle-aged populations, and functional limitation, cognitive dysfunction, morbidity and mortality in elderly populations.

### Members of the group during 2008

	<b>Academic title</b>	<b>Professional title</b>
Tommy Cederholm	Professor	MD
Samar Basu	Associate professor	Researcher
Wulf Becker	Adjoint professor	Chief nutritionist
Brita Karlström	Associate professor	Dietitian
Bengt Vessby	Professor emeritus	MD
Ulf Riserus	Post-doc	Researcher
Ulf Holmbäck	Post-doc	Researcher
Anja Saletti	Post-doc	Dietitian
Per Sjögren	Post-doc	Researcher
Annika Smedman	Post-doc	Researcher
Johanna Helmersson	Post-doc	MD
Arvo Hänni	Post-doc	MD
Eva Warensjö	Post-doc	Data manager
Elisabet Rytter	PhD student	
Roger Olsson	PhD student	University teacher

Tamanna Ferdous	PhD student	
Helena Petersson	PhD student	
Johanna Törmä	PhD student	Dietitian
David Iggman	PhD student	MD
Viola Adamsson	PhD student under reg.	
Erika Olsson	Lic student under reg.	Dietitian
Siv Tengblad		Laboratory technician
Barbro Simu		Laboratory technician
Eva Lena Andersson		Tutor
Linda Bratteby-Tollerz		Physiotherapist
<b>Partly affiliated to CNM:</b>		
Stefan Branth	Postdoc	MD
Anders Forslund	Postdoc	MD
Torbjörn Åkerfeldt	PhD student	MD
Marie von Post Skagegård		Dietitian
Susanne Eriksson		Dietitian
Maria Lennernäs	Professor	
Anders Sjödin	Ass professor	MD

### **Publications 2006-2008**

1. Al-Ani A, Samuelsson B, Tidermark J, Norling A, Ekstrom W, Cederholm T, Hedstrom M. Early operation on patients with a hip fracture improved the ability to return to independent living: a prospective study of 850 patients. *J Bone Joint Surg* 2008;90:1436-42.
2. Andersson K, Karlström B, Fredén S, Petersson H, Ohrvall M, Zethelius B. [A two-year clinical lifestyle intervention program for weight loss in obesity](#). *Food Nutr Res* 2008;52. doi: 10.3402/fnr.v52i0.1656.
3. Basu S, Helmersson J, Jarosinska D, Sallsten G, Mazzolai B, Barregård L. [Regulatory factors of basal F\(2\)-isoprostane formation: Population, age, gender and smoking habits in humans](#). *Free Radic Res* 2008 Dec 11:1-7.
4. Bräuner EV, Forchhammer L, Møller P, Barregard L, Gunnarsen L, Afshari A, Wåhlin P, Glasius M, Dragsted LO, Basu S, Raaschou-Nielsen O, Loft S. [Indoor particles affect vascular function in the aged: an air filtration-based intervention study](#). *Am J Respir Crit Care Med* 2008;177(4):419-25.

5. Cho K, Cederholm T, Löck J. Calcium intake in elderly patients with hip fracture. Food & Nutrition Research [Epub 2008].
6. De Jong A, Plat J, Bast A, Godschalk RW, Basu S, Mensink RP. [Effects of plant sterol and stanol ester consumption on lipid metabolism, antioxidant status and markers of oxidative stress, endothelial function and low-grade inflammation in patients on current statin treatment.](#) Eur J Clin Nutr 2008;62(2):263-73.
7. Elkan AC, Engvall IL, Tengstrand B, Cederholm T, Hafström I. [Malnutrition in women with rheumatoid arthritis is not revealed by clinical anthropometrical measurements or nutritional evaluation tools.](#) Eur J Clin Nutr 2008;62(10):1239-47.
8. Engvall IL, Elkan AC, Tengstrand B, Cederholm T, Brismar K, Hafstrom I. Cachexia in rheumatoid arthritis is associated with inflammatory activity, physical disability, and low bioavailable insulin-like growth factor. Scand J Rheumatol 2008;37(5):321-8.
9. Faxén Irving G, Freund-Levi Y, Eriksdotter-Jönhagen M, Basun H, Brismar K, Hjorth E, Palmblad J, Vessby B, Vedin I, Wahlund L, Cederholm T. N-3 fatty acid supplementation effects on weight and appetite in patients with Alzheimer's disease: The OmegAD Study. J Amer Ger Soc [In press 2008].
10. Ferdous T, Nahar Kabir Z, Wahlin Å, Streatfield K, Cederholm T. The multidimensional background of malnutrition among rural older individuals in Bangladesh – a challenge for the Millennium Development Goal. Publ Health Nutr [In press 2008].
11. Ferdous T, Cederholm T, Razzaque A, Wahlin Å, Nahar Kabir Z. Nutritional status and self-reported and performance-based evaluation of physical function of elderly persons in rural Bangladesh. Scand J Public Health [Accepted 2008].
12. Freund-Levi Y, Basun H, Cederholm T, Faxén-Irving G, Garlind A, Grut M, Vedin I, Palmblad J, Wahlund LO, Eriksdotter-Jönhagen M. [Omega-3 supplementation in mild to moderate Alzheimer's disease: effects on neuropsychiatric symptoms.](#) Int J Geriatr Psychiatry 2008;23(2):161-9.
13. Helmersson J, Arnlöv J, Axelsson T, Basu S. [A polymorphism in the cyclooxygenase 1 gene is associated with decreased inflammatory prostaglandin F\(2\)\(alpha\) formation and lower risk of cardiovascular disease.](#) Prostaglandins Leukot Essent Fatty Acids [Epub 2008].
14. Ingelsson E, Risérus U. Effects of trans10cis12CLA-induced insulin resistance on retinol-binding protein 4 concentrations in abdominally obese men. Diabetes Res Clin Pract 2008;82:23-4.
15. Irving GF, Freund-Levi Y, Eriksdotter-Jönhagen M, Basun H, Brismar K, Hjorth E, Palmblad J, Vessby B, Vedin I, Wahlund LO, Cederholm T. [Omega-3 fatty acid supplementation effects on weight and appetite in patients with Alzheimer's](#)

- [disease: the omega-3 Alzheimer's disease study](#). J Am Geriatr Soc 2009;57(1):11-7 [Epub 2008].
16. Jong AD, Plat J, Bast A, Godschalk RWL, Basu S, Mensink RP. Effects of plant sterol and stanol ester consumption on lipid peroxidation, antioxidant status and markers of oxidative stress, endothelial function and low-grade inflammation in patients on current statin treatment. Eur J Clin Nutr 2008;62:263-74.
  17. Koochek A, Mirmiran P, Azizi T, Padyab M, Johansson SE, Karlström B, Azizi F, Sundquist J. [Is migration to Sweden associated with increased prevalence of risk factors for cardiovascular disease?](#) Eur J Cardiovasc Prev Rehabil 2008;15(1):78-82.
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3. Cederholm T. Sarkopeni – ett ”nytt” begrepp med klinisk betydelse för den äldre. *Nordisk Geriatrik* 2008;11(1):30-32.
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## **Dissertations 2006-2008**

1. **Eva Warensjö.** Fatty Acid Desaturase Activities in Metabolic Syndrome and Cardiovascular Disease-Special reference to Stearoyl-CoA-Desaturase and Biomarkers of Dietary Fat. Uppsala University 2007.
2. **Anja Saletti.** Nutritional status and mealtime experiences in elderly care recipients. Karolinska Institutet 2007.
3. **Stefan Branth.** Energy Metabolic Stress Syndrome: Impact of Physical Activity of Different Intensity and Duration. Department of Medical Sciences, Uppsala University 2006.
4. **Achraf Daryani.** Diet and Metabolic Risk Factors in Immigrant Women from the Middle East and Swedish-Born Women: A Cross-Sectional Study of Women from Iran, Turkey and Sweden. Uppsala University 2006.
5. **Cecilia Nälsén.** Measurement and Evaluation of Antioxidant Status and Relation to Oxidative Stress in Humans. Uppsala University 2006.

## **Project 1: Nutrition and ageing**

Tommy Cederholm, Brita Karlström, Anja Saletti, Johanna Törmä, Tamanna Ferdous, Erika Ohlsson, Per Sjögren, Sigvard Sobestiansky

### **Age, dependency and appetite**

Collaborators: Anja Saletti, Tommy Cederholm, Ylva Mattson Sydner, Azita Emami  
The aim of this study was to describe how old people, dependent on help and care, experience and express appetite in relation to food and meals in every day life. The study of qualitative interviews was undertaken during 2005 and 2006. There were four different accommodations involved and they differed between around-the-clock care (ATC) and service flats (SF). Fourteen elderly persons who lived in different accommodations was interview about their meals, food and appetite.

### **Implementing nutritional routines into institutionalized elderly care**

Collaborators: Johanna Törmä, Anja Saletti, Brita Karlström, Marianne Sellgren, Tommy Cederholm.

Despite a good awareness of the problem and several years of educational efforts, malnutrition and insufficient food intake is still common among elderly in community care. In order to find a feasible process for effective implementation of actions to address nutrition, food and meals, a study in collaboration with the Uppsala Commune has been launched. The municipal county of Uppsala has decided upon a certain formula for nutrition and dietary routines. In interactive models of action research the research team together with the community care staff will develop an effective model of implementation of the formula. In a combination of qualitative and quantitative

techniques the effects of the efforts will be studied in a controlled trial where four units will be targeted for the implementation intervention, whereas four stratified units will receive a limited educational effort. Both the staff attitudes and behavior, as well the food and mealtime effects for the care-takers will be studied.

**Dietary intake and risk of cognitive disorders: A 12-year follow-up study.**

Collaborators: Erika Olsson, Brita Karlström, Tommy Cederholm, Lena Kilander, Per Sjögren

Aim: To study the impact of dietary intake at the age of 70 in the ULSAM population and the risk of incident Alzheimer's disease, all-type dementia and mild cognitive impairment, respectively, in late life.

Methods: The study will be based on the third and fifth follow up of the ULSAM study. Data from the first dietary survey will be used and will be related to incidence of Alzheimer's disease, all-type dementia and mild cognitive impairment, respectively. All participants in the first investigation of the ULSAM study were invited to a third follow up for a new investigation at the age of 70 years old. The food record used was a precoded menu-book with an optically readable form (OMR).

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

Collaborators: Erika Olsson, Brita Karlström, Tommy Cederholm, Karl Michaëlsson

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

**An investigation of the joint influence of dietary vitamin D, vitamin A and calcium intake on bone mineral density, bone size and fractures with effect modification by polymorphisms of the vitamin D, vitamin A and calcium receptors.**

Collaborators: Erika Olsson, Brita Karlström, Tommy Cederholm, Karl Michaëlsson

Aim: To examine if dietary vitamin D, vitamin A and calcium intake is associated with bone mineral density, bone area and fracture outcome in 82 year old men in the ULSAM study and if these possible dietary influences on bone health might be modified by the genetic constitution of the vitamin D, vitamin A and calcium receptor polymorphisms.

Methods: The study will be based on the third and fifth follow up of the ULSAM study. Data from the dietary surveys at the age of 70 and 82 years old will be used and will be related to body composition, BMD and bone area of the total body, the proximal femur and of the lumbar spine measured by DXA (Lunar Prodigy, Lunar corp., Madison, WI, USA) at the fifth follow-up.



## **Determinants of nutritional status and functional capacity in elderly rural subjects in Bangladesh**

Collaborators: Tamanna Ferdous, Tommy Cederholm, Åke Wahlin, Zarina Kabir

The overall aim of this research project is to analyze the magnitude and significance of malnutrition that prevails among elderly population in rural Bangladesh, in order to inform government and non-government policy-makers and planners at national and international organisations and specifically to investigate the aetiology of malnutrition, impact of nutritional status on functional and cognitive ability. The study group comprises a cohort of 500 subjects >60 years old living in a rural area of Bangladesh.

## **Sarcopenia in geriatric care – the importance of skeletal muscle in elderly patients**

Collaborators: Sigvard Sobestiansky, Tommy Cederholm, Ann-Christin Åberg, Thomas Gustafsson, Per Tesch

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

## **Omega-3 fatty acid supplementation to patients with Alzheimer's disease - The OmegAD Study**

Collaborators: Tommy Cederholm, Samar Basu, Hans Basun, Yvonne Freund-Levi, Gerd Faxén Irving, Inger Vedin, Maria Jönhagen Eriksdottir, Lars-Olof Wahlund, Marianne Schultzberg, Jan Palmblad.

Epidemiological evidence indicates that high intake of fish oils rich in omega-3 fatty acids may protect against incident Alzheimer's disease. In a collaborative study close to 200 patients with AD were given omega-3 fatty acids, mainly docosahexaenoic acid, in a randomized protocol for 6 and in an open protocol for another 6 months. Effects on cognition, behavior, nutrition, oxidation, inflammation and gene expression are studied.

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

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

In the frame work of the Stockholm Hip Fracture Group, a research joint action between the University hospitals in Stockholm, the effects on muscle and skeleton by the combined treatment with protein supplementation and bisphosphonates are studied. Lean elderly patients with hip fracture are randomized to active treatment or placebo for 6 months. Function, muscle mass and bone mineral density are the main outcome variables.

### **Inflammation and nutritional status in patients with rheumatoid arthritis**

Collaborators: Tommy Cederholm, Lotta Elkan, Inga-Lill Engvall, Birgitta Tengstrand, Ingiöld Hafström

Together with the Dept. of Rheumatology, Karolinska University Hospital, the importance of inflammation driven catabolism and nutrition is studied in patients with chronic rheumatoid arthritis. In one group of 80 in-ward patients and in one corresponding group of out-clinic patients, the nutritional status, body composition, muscle mass integrity and function in relation to inflammatory markers and cardiovascular disease are studied.

### **Project 2: Fat and carbohydrates in the diet and the body**

Collaborators: Ulf Risérus, Brita Karlström, Siv Tengblad, Per Sjögren, Bengt Vessby.

#### **Effects on appetite and cognitive performance of meals with different glycaemic load**

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

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

### **Possible mechanism explaining positive health effects of whole grain foods.**

Collaborators: Agneta Andersson, Siv Tengblad, Brita Karlström, Afaf Kamal-Eldin, Rikard Landberg, Samar Basu, Per Åman and Bengt Vessby.

High intakes of whole grain foods are inversely related to the incidence of coronary heart diseases and type 2 diabetes in epidemiological studies. The aim of this study is to evaluate the effects on insulin sensitivity and markers of lipid peroxidation and inflammation of a diet rich in whole grain when compared with a diet containing the same amount of refined grain foods. This hypothesis is tested in a randomized cross-over study on healthy moderate overweight men and women. The study is part of a large research project in collaboration with Department of Food Science, the Swedish University of Agriculture Sciences (SLU) and Umeå University. The project is supported by grants from the Swedish Governmental Agency for Innovation Systems (VINNOVA), the Swedish Research Council for Environment, Agricultural Sciences and Spatial Planning (FORMAS), the Swedish Research Council and the Swedish Diabetes Association. Food products are supported by Lantmännen Food R&D AB, Wasa Bröd AB and ICA AB.

### **Lipgene. Diet, genomics and the metabolic syndrome: an integrated nutrition, agro-food, social and economic analysis.**

Collaborators: Bengt Vessby, Brita Karlström, Agneta Nilsson, Barbro Simu, Ulf Risérus and researchers from 25 other universities and colleges across Europe.

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

### **Fatty acid composition in serum lipids and desaturases in relation to metabolic disease**

Collaborators: Annika Smedman, Bengt Vessby, Ulf Risérus, Eva Warensjö

It is well known that the fatty acid composition in serum lipids and estimated desaturase activities, as a marker of fat quality, is linked to obesity, insulin resistance, cardiovascular disease and diabetes. Associations between fatty acid composition, estimated desaturase activities and clinical variables, metabolic disease and dietary intakes are studied.

### **Fatty acid composition in serum lipid esters and desaturases in relation to metabolic disease - Dietary and genetic aspects.**

Collaborators: Eva Warensjö, Bengt Vessby, Tommy Cederholm och Ulf Risérus

The aim of our studies is to learn more about the FA-composition and estimated desaturase activities in relation to the metabolic syndrome. We will also study how the FA composition and estimated desaturase ratios change after a diet rich in either saturated fat or unsaturated fat. In addition, genetic differences (SNPs) in the SCD-gene will be studied in relation to obesity, insulin sensitivity and FA-ratios. Several of these studies will be carried out in the ULSAM-cohort. These studies might influence future dietary recommendations since FA composition and desaturase activities are modifiable by diet.

### **Clinical measures of abdominal obesity and the link to insulin resistance, metabolic disorders and cardiovascular risk**

Collaborators: Ulf Risérus, Helena Petersson, David Iggman, Tommy Cederholm

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

### **Project 3: Dietary habits, dietary patterns and effects of diet**

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

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

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

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

#### **Do milk products have positive effects on health?**

Collaborators: Annika Smedman, Siv Tengblad, Bengt Vessby and researchers in Norway and Finland

Project description: In a six-month controlled intervention study, run parallel in Uppsala, Oslo and Helsinki, the effects of supplementation with milk products on abdominal obesity, markers for the metabolic syndrome and dietary habits are investigated. In a total 120 participants, 40 in each country are included.

#### **Validation of an optical readable food record**

Collaborators: Wulf Becker, Margareta Nydal

The study comprised 73 free-living, healthy 70-year-old men from ULSAM cohort. Dietary data were collected during 7 consecutive days using either an Optical Readable Food Record (ORFR) or a weighed record (WR). The results with respect to food and

nutrient intake are compared and also validated against protein intake calculated from 24-h urinary nitrogen excretion.

### **Dietary patterns and long-term health**

Collaborators: Per Sjögren, Erika Olsson, Brita Karlström, Tommy Cederholm, Lena Kilander, Karl Michaelsson, Wulf Becker

Dietary data collected in the ULSAM Study at 70 years of age, around 1100 males, is compiled into dietary patterns; i.e. Mediterranean-like Diet, WHO-recommended Diet and Carbohydrate Restricted (Atkins-like) Diet, according to previously described methods. Adherence to the diets is expressed as low, medium and high and the degree of adherence is related to long-term health outcome, e.g. mortality, cardiovascular disease, cognitive function and osteoporosis. Corresponding studies are planned for the PIVUS cohort.

### **Project 4: Inflammation, oxidative stress and effects of antioxidants**

Samar Basu and Johanna Helmersson

#### **COX-1 gene polymorphisms, prostaglandin F<sub>2a</sub> and cardiovascular disease**

Authors: Johanna Helmersson, Johan Ärnlöv, Tomas Axelsson, Samar Basu  
Study design: SNPs (single nucleotide polymorphisms) in the COX-1 gene are studied in relation to prostaglandin F formation and risk of cardiovascular diseases in the ULSAM-cohort. The project is performed in collaboration with the section of Molecular Medicine and is financially supported by Wallenberg Consortium North.

#### **Formation of prostaglandin F in healthy humans**

Authors: Johanna Helmersson, Samar Basu  
Study design: Daily variation of inflammatory prostaglandin F formation in healthy humans is studied by quantification of 15-keto-dihydro-prostaglandin F in urine during the day

#### **Vitamin C, vitamin A and vitamin E in the diet and relation to inflammation and free radicals in man**

Authors: Johanna Helmersson, Johan Ärnlöv, Anders Larsson, Brita Karlström/Bengt Vessby, Samar Basu  
Study design: Vitamin C, vitamin A and vitamin E in the diet in 700 men in the age of 70 years is estimated by food-diaries. Intake of vitamins is studied in relation to measurements of inflammation and oxidative stress. Participants from the ULSAM-cohort.

#### **Ambulatory (24-hour) bloodpressure, inflammation and free radicals**

Authors: Johanna Helmersson, Kristina Björklund Bodegård, Samar Basu  
Study design: A cross-sectional study of ambulatory bloodpressure during 24 hours and prostaglandins and isoprostanes in elderly men from the ULSAM-cohort.

### **Atherosclerosis, inflammation and free radicals.**

Authors: Martin Wohlin, Johanna Helmersson, Johan Sundström, Lars Lind, Samar Basu

Study design: Estimated amount of atherosclerosis by ultrasound of the intima media artery in 75-year old men in relation to prostaglandin F2a, C-reactive protein and isoprostanes.

### **Betacarotene, tocopherol and the development of diabetes**

Authors: Johan Ärnlöv, Björn Zethelius, Christian Berne, Bengt Vessby, Samar Basu, Johanna Helmersson

Study design: Betacarotene and tocopherols in blood and diet in 50 year-old non-diabetics in relations to the risk of diabetes development during a 27-year follow-up.

### **Selenium and cardiovascular risk**

Authors: Johanna Helmersson, Johan Sundström

Study design: Selenium in blood in men at 50-years of age is related to cardiovascular morbidity and mortality in 30 years of follow-up.

### **Magnesium intake and diabetes development**

Authors: Arvo Hänni, Brita Karlström/Bengt Vessby, Johanna Helmersson

Study design: Estimated intake of diet magnesium in relation to the risk of diabetes development in the ULSAM-cohort.

### **Isoprostane formation and demography**

Authors: Samar Basu, Johanna Helmersson, Lars Barregård

Study design: Cross-sectional study of isoprostanes in different populations and the significance of age, gender and smoking. In collaboration with miljömedicin, Göteborgs universitet.

### **Polymorphisms in the PLA2, COX-2, PG endoperoxide reductase, 15-PGDH, 13-reduktase, interleukin-6, CRP, SAA, cystatin C gene and cardiovascular risk**

Authors: Johanna Helmersson, Anders Larsson, Samar Basu

Study design: The project is performed in collaboration with the section of Molecular Medicine and is financially supported by Wallenberg Consortium North.

### **Polymorphisms in the NF and TTPA gene, oxidative stress and cardiovascular risk**

Authors: Johanna Helmersson, Samar Basu

Study design: The project is performed in collaboration with the section of Molecular Medicine and is financially supported by Wallenberg Consortium North.

### **Polymorphisms in the prostaglandin-, thromboxane- and prostacyclin- synthase and receptor genes, inflammation and risk for cardiovascular diseases**

Participants: Lisa Kurland, Johanna Helmersson and Samar Basu

The project is performed in collaboration with Molecular Medicine, Uppsala University and is financed by Wallenberg Consortium North.

**Polymorphisms in the 5-LO, 15-LO, FLAP, LTB4-R and LTC-4 synthase genes and inflammation and risk for cardiovascular diseases**

Participants: Lisa Kurland, Johanna Helmersson and Samar Basu

The project is performed in collaboration with Molecular Medicine, Uppsala University and is financed by Wallenberg Consortium North.

**Oxidative stress, inflammation and angiogenesis during normal and complicated pregnancy and under normal menstrual cycle**

Participants: Maria Palm, Ove Axelsson, Anders Larsson and Samar Basu

The project is performed in collaboration with the Department of Women's Health and Clinical Chemistry, Uppsala University.

**Oxidative stress among pregnant women exposed by iron, arsenic and cadmium**

Participants: Eva-Charlotte Ekström, Marie Vahter and Samar Basu

The project is performed in collaboration with the International Maternal and Child Health, Uppsala University, MINIMAT (Bangladesh) and Karolinska institutet and financed by The Swedish Research Council.

**Oxidative stress, inflammation and kidney function among 82-years ULSAM men and cardiovascular risk**

Participants: Johanna Helmersson, Anders Larsson and Samar Basu

The project is performed in collaboration with the Clinical Chemistry, Uppsala University.

**Acute inflammation and oxidative stress in septic shock**

Participants: Mats Eriksson and Samar Basu

The project is performed in collaboration with the Department of Surgery and Anesthesiology, Uppsala University and financed by various sources.

**Effect of vitamin A on low-grade endotoxemia and inflammation**

Participants: Christine Stabell Benn, Christian Erikstrup and Samar Basu

Study design: The project is performed in collaboration with the University in Copenhagen, Denmark and Uppsala University.

**Oxidative stress and neuroprotection following cardiac arrest by different therapy**

Participants: Samar Basu, Sten Rubertsson and Lars Wiklund

The project is performed in collaboration with the Department of Surgery and Anaesthesiology, Uppsala University.

**Antibody and assay development on resolvins**

Participants: Samar Basu, Charles Serhan

The project is performed in collaboration Brigham and Women's Hospital, Harvard Medical School, Boston, USA and Uppsala University.

**Ischemia, free radicals, inflammation and EC-SOD gene transfer**

Participants: Olli Leppänen with colleagues, Samar Basu

in Kuopio. The project is performed in collaboration with Kuopio university, Finland.

**Oxidative stress during kidney and liver transplantation and antioxidant therapy**

Participants: Claus Krenn, Samar Basu

The project is performed in collaboration with University of Vienna, Austria

**Free radicals, inflammation during heart surgery**

Participants: Mika Lahtinen, Samar Basu

The project is performed in collaboration with Clinical Chemistry, Uppsala Akademiska Hospital.

**Association between diet, obesity, oxidative stress and inflammation**

Participants: Samar Basu, Bengt Vessby, Alan Sinaiko

The project is performed in collaboration with University of Minnesota Medical School, USA.

**Association of oxidative stress and inflammation in coronary revascularisation and NSAID**

Participants: Samar Basu, Kirsti Berg, Per Jynge

The project is performed in collaboration with Norwegian University of Science and Technology, Trondheim, Norway.

**Dietary supplementation and lipid oxidation**

Participants: Anu Turpeinen, Maria Mutanen, Samar Basu

The project is performed in collaboration with University of Helsinki, Finland.

**F -isoprostane metabolism and detection**

Participants: Denis Calleweert, Jason Morrow, Samar Basu

The project is performed in collaboration with University of Oakland (MI) and Vanderbilt University, USA.

**Multi-laboratory study on biomarkers of oxidative stress (BOSS-study)**

Participants: 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)

**Isoprostanes as biomarker of oxidative stress**

Participant: Samar Basu

**Prostaglandins as biomarker of vasoconstriction and inflammation.**

Participant: Samar Basu

**In situ localisation of oxidative stress and inflammation injured tissues in the brain**

Participants: S. Basu, M. Smith with colleagues

The project is performed in collaboration with Case Western Reserve University, Ohio, USA



### **Effects of antioxidants on oxidative stress, inflammation and metabolic control in humans.**

Co-worker: Elisabet Rytter, Rikard Åsgård, Samar Basu, Lennart Möller, Anders Sjödin, Lilianne Abramson-Zetterberg, Bengt Vessby

The aim of the studies is to investigate if supplementation with a large number of antioxidants (found in fruits, vegetables and berries and in amounts corresponding, to a healthy diet rich in fruits and vegetables) could influence oxidative stress, inflammation and metabolic control.

The studies are performed on subjects with metabolic syndrome characteristics and on subjects with type 2 diabetes. The hypothesis is to study if antioxidant supplementation in this way can increase the levels of antioxidants, improve the metabolic control and decrease the tendency of inflammation and the influence of oxidative stress. The project represents Elisabet Rytters dissertation.

### **Project 5: Obesity and overweight in children and adults**

Tommy Cederholm, Anders Forslund, Ulf Riserus, Ulf Holmbäck

#### **What physiological and psychological variables are changed in severe childhood obesity and how will these variables change during treatment?**

Collaborators: Anders Forslund, Ulf Holmbäck, Jan Gustafsson

During spring 2008 the children's obesity clinic will open in Uppsala. A multidisciplinary approach with the aim of individualizing the treatment, both in terms of cognitive treatment but also dietary approaches, and by that keep patient satisfaction high and attrition low.

#### **Physiological and Psychological changes after weight loss surgery.**

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

Project: Morbid obesity is treated with various techniques, such as diet and behavioral modification, surgery and pharmacological treatment. We know a fair amount about the various therapies long term results regarding weight reduction, but less about the effect on body composition, biochemistry and gene expression. During a five-year study in obese adults, we will assess body composition, energy expenditure, psychometric variables, expression of lipogenic genes, appetite regulation, inflammation and oxidative stress, and markers for fat, protein and muscle turnover.

### **Project 6: Circadian Metabolism**

Ulf Holmbäck, Maria Lennernäs, Torbjörn Åkerfeldt

#### **Metabolic, endocrine and mental performance effects of nocturnal eating**

Participants: Ulf Holmbäck, Anders Forslund, Torbjörn Åkerfeldt, Mats Stridsberg, Maria Lennernäs (Högskolan i Kristianstad), Arne Lowden (Stockholms universitet), Torbjörn Åkerstedt (Stockholms universitet).

Project: The aim is to increase the knowledge about the metabolic effects of shift work.

Subjects are given meals at regular intervals during a 24-h period, the size and composition of the meals varies. During these 24-h, data are collected from blood samples, questionnaires, indirect calorimetry and computer tests.

### **Metabolic, endocrine and mental performance effects of sleep restriction with and without sleep misalignment**

Participants: Ulf Holmbäck, Rachel Leproult (University of Chicago), Eve Van Cauter (University of Chicago)

Project: Subjects are tested before and after sleeping 5 h per night, with or without sleep restriction. Among others, the following variables are studied: glucose metabolism, energy intake, mental performance, hormones and cardiovascular function.

### **SLOPUS: Will short sleep in adolescents affect energy expenditure, glucose metabolism and appetite?**

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

Project: Adolescents will take part in a randomized interventions trial looking at the effects of short sleep on energy expenditure, glucose metabolism and subjective and objective appetite.

## Undergraduate Teaching

**Biomedical Laboratory Science Program** - Biomedicinsk analytiker (BMA)-programmet.

Energy balance, body composition and nutrition status in the course “Biochemistry”; lectures and seminars, together with the Department of Medical Biochemistry and Microbiology

**Biomedical Program** - Biomedicinarprogrammet

Energy balance, body composition and nutrition status in the course “Medical physiology and pharmacology”; lectures and seminars, together with the Department of Medical Cell Biology

**Medical Program** - Läkprogrammet

First semester – Energy balance and nutrition status; lectures and seminars, together with the Department of Medical Cell Biology

Sixth and seventh semester – Clinical nutrition and public health nutrition: lectures, seminars, case reports and discussion.

**”Livsmedelsagronom”-programmet**

Energy balance, body composition, substrate metabolism and nutrition status in the course “Human nutrition”; lectures and seminars together with the Department of Food Science, the Swedish University of Agricultural Sciences

**Master in Public Health** - Master i Folkhälsa

Responsible for the 15 HTPS course “Diet, nutrition and health; lectures, seminars, projects and examination.

### **Nursing Program** - Sjuksköterskeprogrammet

First semester – Energy balance and nutrition status; lectures and seminars, together with the Department of Medical Cell Biology

Third semester: "Nursing for obese patients"; lectures, seminars, and memo

Sixth semester: "Nutrition for elderly"; lectures

## Centres and Facilities

**Euronut** – 15 European institutions with high quality nutrition research collaborating around Diet and ageing, in accordance with EU:s 7th Frame Program.

**Diabetes Nutrition Study Group** – DNSG is a part of the European Association for the Study of Diabetes (EASD) and comprise of researchers mainly involved in the development of nutritional guidelines for the treatment of diabetes.

**Gerontonet** – around 40 European Centres of Excellence for nutrition and ageing.

**EFSA** – Scientific cooperation & Assistance Directorate within European Food Safety Authority

**ESPEN Special Interest Group - Geriatric nutrition** – The SIG GN works on a European level to coordinate research efforts and recommendations for nutrition in the elderly.

**EuroFIR** – European Food Information Resource. A EU 6<sup>th</sup> Framework Network of Excellence in the area of food composition databases. 47 partners across Europe.

**Nordic Centre of Excellence in Food, Nutrition and Health (NoCE)** - Systems biology in dietary intervention studies (SYSDIET). KNM at Uppsala university is one of 3 Swedish academic research groups included in this Nordic network funded by NordForsk.

**OPUS** - the OPUS centre is a collaboration between various Danish and international universities to orchestrate the worlds largest intervention study on the effect of diet and lifestyle on children and adolescents.

**ICTUS/ULSAM** - ULSAM is a unique, ongoing, longitudinal, epidemiologic study based on all available men, born between 1920 and 1924, in Uppsala County, Sweden. The men were investigated at the ages of 50, 60, 70,77 and 82 years. Interdisciplinary Collaboration Team on Uppsala longitudinal Studies (ICTUS) is a centre for several researchers from various institutions in Uppsala.

**National Food Administration – Expert group on Diet and Health**– An advisory group comprised of stakeholders in nutrition research dealing with issues related to dietary recommendations for public health purposes.

**Network: Epidemiology & Nutrition (NEON)** – NEON consists of a nutritional epidemiologists. The aim of the network is to support and improve competence in nutritional epidemiology in Sweden.

**Dietitians in Geriatrics** – DIG facilitate national clinical and research collaboration between dietitians working in geriatric medicine.

**Uppsala Centre for Food and Nutrition (Uppsala Livsmedelscentrum, ULC)** – ULC is a network of research groups in Uppsala that work with issues related to food and nutrition.

**Obesity Centre (Obesitascentrum OC)** – OC is instituted as a collaboration between Uppsala County Council and Uppsala University in order to facilitate and promote research activities in the field of obesity.

**Nutrition Council (Nutritionsrådet) Akademiska Sjukhuset** – NC comprise representatives from all divisions of Uppsala University hospital in order to improve clinical nutrition routines at the hospital.

# Disability and Habilitation

## Research group leader Karin Sonnander, PhD, Professor

Research in disability is interdisciplinary and multi-professional with a fundamental perspective focussing the interface between individuals and environment. A joint conceptual tool is found in Who's classification ICF (International Classification of Functioning, Disability and Health), that extends beyond the medical perspective in that it includes a societal and environmental perspective. Habilitation, services to persons with disabilities, constitutes planned formal multi-professional interventions provided to individuals with permanent disabilities and their networks in order to promote an optimal level of function and well-being. Current research activities focus studies of living conditions including physical and mental health, gender, everyday perspectives and experiences, quality of life, measurement and evaluation in implementation, prevention and intervention.

### **Members of the group during 2008**

Monica Blom Johansson, BA, PhD student

Johan Glad, BA, PhD student

Carina Gustafsson, PhD, Faculty of Medicine, associated researcher

Gerth Hedov, PhD Faculty of Medicine, associated researcher

Helena Lindstedt, PhD Faculty of Medicine, senior lecturer

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Amanda Reimer, MA, research assistant

Karin Sonnander, PhD, professor

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Zhixiang Zhang, MD, professor, Department of Paediatrics, First Hospital, Beijing University, China

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**External agencies that support the work/External Funding 2006-2008**

Regional Research Council in Uppsala-Örebro Region: 120 000

Swedish International Development Cooperation Agency (SIDA): 600 000

The Sävstaholm Foundation: 420 000

The Sävstaholm Foundation: 670 000

Uppsala County Council: 128 000

**Project 1: Living with aphasia: communication and communication strategies from the perspectives of significant others, speech and language pathologists, and persons with aphasia – a description of experiences, and a trial of intervention**

**Monica Blom Johansson, Marianne Carlsson, Karin Sonnander**

The aim of this thesis is to obtain more knowledge about how the person with aphasia, the significant other and the speech and language therapist perceive the communicative situation between the significant other and the person with aphasia. A second aim is to develop a model of intervention and carry out a trial of intervention for improving the couple's communication skills.

**Project 2: The HOME Inventory, Home Observation for Measurement of the Environment - A Swedish Adaptation**

**Johan Glad, Carina Gustafsson, Ulla Jergeby, Karin Sonnander**

The aim of this thesis is to assess the relevance of an international published instrument (HOME) for assessing parental ability to satisfy children's needs and to develop a reliable and valid Swedish version. Psychometric properties and issues pertinent to administration and implementation in a Swedish context will be established based on a national sample (n=150).

**Project 3: A pilot study of a Swedish version of the Parent Assessment Manual (PAM) in a field setting**

**Carina Gustafsson, Lydia Springer**

PAM (Parent Assessment Manual) is a comprehensive tool for identifying family strengths and weaknesses. Although it can be used with all parents, it is geared towards parents with intellectual disabilities. The aim of this pilot study is to evaluate the clinical relevance of PAM in the Swedish social services context and to evaluate the face validity and the preliminary interrater-reliability of the PAM scoring criteria (n=5).

**Project 4: Support and information to parents of children with Down syndrome**

**Gerth Hedov**

Down syndrome (DS) is the largest group of children born with a chronic condition. Today the incidence of DS in Sweden is 1/800 new-borns. In contrast to an international outlook there are few Swedish studies focussing this group of parents. The purpose of the project is to formulate evidence-based guidelines (based on empirical studies as well as experienced practice) on how to give initial support and information to parents of children with DS followed by a quasi-experimental intervention study. The project also includes a 10-year follow-up study of 165 Swedish parents (in 86 families) concerning work load, employment and sick-leave rate and parental stress.



**Project 5: People with mental health disorder, implementing individual treatment goals and long-term follow-up in psychiatric rehabilitation and community care**

**Helena Lindstedt, Marianne Carlsson, Ann-Britt Ivarsson**

The aim is to implement and evaluate a treatment concept with individualized measurable methodology of treatment and structured long-term follow-up (Goal Attainment Scaling, GAS) for people with mental health disorders. Patients (n=80) report subjective occupational performance, daily occupation satisfaction and quality of life. Occupational therapists (n=20) report work satisfaction.

**Project 6: Assistive Technology for adults with ADHD a new program for Cognitive Assistance: an evaluation**

**Helena Lindstedt**

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

**Project 7: Early identification of children with developmental delay in China**

**Karin Sonnander**

The aim of this sub study, part of a comprehensive Sino-Swedish Cooperation Project, is to estimate the need of habilitation in children with significant developmental delays/intellectual disabilities and to establish and develop practical skills in developmental screening and developmental evaluation in local child health services in selected areas in rural China.

**Project 8: Living conditions of people with intellectual disabilities: a study of health, housing, work, leisure and social relations in a Swedish county population.**

**Öie Umb-Carlsson, Frits-Axel Wiesel, Karin Sonnander**

The general aim of this thesis was to describe mortality, health and living conditions in an administratively defined county population of people with intellectual disabilities born between 1959 and 1974 (N=213). Information on the living conditions of persons with intellectual disabilities was provided by proxy (relative and staff) questionnaire reports and national welfare statistics conducted by Statistics Sweden (SCB). Moreover, the reports of relatives and staff were compared on the living conditions of people with intellectual disabilities. Medical examination and medical case records were used to obtain data on health and medical services.

### **Project 9: Special support and service in retrospect to persons with intellectual disabilities**

**Öie Umb-Carlsson**

The purpose is to study the reflection of legislative changes on service and care provision and whether interventions are tailored to individual needs. In a retrospective record review (1959 – 2005) public services and health care provided to an administratively defined county sample of persons in Sweden with intellectual disability from early childhood to adulthood (n=83) are described.

### **Project 10: Men and women with intellectual disabilities and quality of life**

**Öie Umb-Carlsson**

The aim is to uncover the essence of the phenomenon quality of life from the perspective of women and men with intellectual disabilities. Women and men with mild and moderate intellectual disability are interviewed concerning their lived experiences of quality of life (n=21).

### **Project 11: Support in housing- a comparison between people with psychiatric disability and people with intellectual disability**

**Öie Umb-Carlsson, Lennart Jansson**

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

### **Project 12: Evaluation of an in-service training in using the ICF and ICF-CY**

**Mia Pless, Nina Ibragimova, Margareta Adolfsson, Eva Björck-Åkesson, Mats Granlund**

The aim is to report on effects of an in-service training in using the International Classification of Functioning, Disability and Health, ICF/ ICF-CY (Children and Youth version) on staffs' self-reported knowledge, understanding and use. The design was quasi-experimental with one questionnaire before the training and another one year after. The intervention was an in-service training in using ICF and ICF-CY. Subjects were 113 professionals working in habilitation services, one subgroup who one year after the training reported they had used the ICF and ICF-CY in daily practice and one subgroup that had not.

# Family Medicine and Clinical Epidemiology

Research group leader: Kurt Svärdsudd, MD, PhD, Professor

Family Medicine is the dominating academic branch in Primary Health Care. Moreover, it is the mother speciality for all other non-surgical physician specialities. The content of Family Medicine is reflecting the fact that primary health care is in the health care front line, i.e. the health care facility that patients are expected to consult in the first place when needed. For this reason Family Medicine research focuses on the most common diseases and illnesses in the population, for instance cardiovascular disease, diabetes, asthma, chronic obstructive lung disease, social insurance medicine (sick-listing and disability retirement), musculo-skeletal disorders, low back pain, tennis elbow, fibromyalgia, pharmaco-epidemiology, and the most common infectious diseases. We teach in the undergraduate curriculum within the medical and nursing programmes. In our research programme we focus on patient centred research using clinical as well as epidemiological techniques. We also cooperate with other clinical and basic research units domestically and abroad.

## Members of the group during 2008:

	<u>Academic title</u>	<u>Professional title</u>
Kurt Svärdsudd	Professor	MD
Mari-Ann Wallander	Associate professor	Epidemiologist
Gunnar Johansson	Associate professor	MD
Margaretha Eriksson	Postdoc	Researcher
Håkan Jansson	Programmer	Datamanager

### *Medical Programme - Professional Development*

Annika Bardel	Postdoc, responsible for training of student tutors	MD
Karin Björkegren	Postdoc, responsible for term 1 and 2	MD
Mats Gulliksson	PhD student, responsible for term 3 and 4	MD

### External

Dan Andersson	Associate professor	MD
Johan Bogefeldt	PhD student	MD

Kristina Bröms	PhD student	MD
Anders Carlberg	PhD student	Psychotherapist
Jan Cederholm	Associate professor	MD
Dag Elmfeldt	Associate professor, emeritus	MD
Sevek Engström	PhD student	Dentist
Marie Grunnesjö	PhD student	Doctor of Naprapathy
Mikael Hasselgren	Postdoc	MD
Anna Hofsten	Associate researcher	MD
Sara Holmberg	Postdoc	MD
Stefan Jansson	PhD student	MD
Bo Karlsson	PhD student	MD
Per Kristiansson	Associate professor	MD
Karin Lisspers	Postdoc	MD
Sveinn Magnusson	PhD student	MD
Lars Nilsson	Associate researcher	MD
Gunilla Norrmén	PhD student	MD
Lena Olai	PhD student	RN
Magnus Peterson	PhD student	MD
Nils Rodhe	Postdoc	MD
Åke Schwan	Postdoc	MD
Jan Stålhammar	Postdoc	MD
Björn Stållberg	Postdoc	MD
Malin Swartling	Postdoc	MD
Keld Vaegter	PhD student	MD
Rolf Wahlström	Associate professor	MD
Thorne Wallman	Postdoc	MD
Ture Ålander	Postdoc	MD

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The Vårdal Foundation – for Health Care Sciences and Allergy Research	150.000
Hjerpstedts stiftelse	40.000
Dalarna County Council	1.300.000
Gävleborg County Council	400.000
Stockholm County Council	800.000
Södermanland County Council	1.500.000
Uppsala University and Uppsala County Council	2.160.000
Västernorrland County Council	200.000
Örebro County Council	1.000.000

## **Project 1: Social Insurance Medicine**

Kurt Svärdsudd, Rolf Wahlström, Thorne Wallman, Malin Swartling

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

A consortium including The Research Group for Cardiovascular Epidemiology at Sahlgren's Academy, Gothenburg, the national Social Insurance Agency and our unit was created to perform a project aiming at analysing the course of events leading to disability pension (track record), to find factors that in addition to the underlying disease affects the course and what the consequences are in terms of health situation, quality of life continued health care utilisation and survival compared to that of the corresponding general population. The study population was created by using data from five on-going population studies with approximately 7000 men and women who have been followed since 1980-1993 and onwards. Two PhD students (Thorne Wallman dissertated in 2008 and Johan Bogefeldt doctoral student) are working in the study, which is financially supported by the Social Insurance Agency, the Medical Research Council, Sörmland County Council, Västra Götaland County Council and Uppsala University.

The first report shows that the health care utilisation continued to be 3-4 times higher among the disability pensioners than among the corresponding general population still 13 years after the retirement. The health care diagnoses had no relation to the retirement diagnoses [1]. The retirement thus had no obvious curative effect which has been claimed previously.

In the second report the survival after disability retirement as compared to the corresponding general population was presented. Male pensioners had more than 3 and female pensioners approximately 2.5 fold increased mortality rate, even when the influence of age, education, smoking habits, family structure, cause of retirement and health care diagnoses after retirement (underlying disease) was taken into account. The

increased mortality rate is thus non-specific, *i.e.*, not related to the underlying disease and may possibly be a damage caused by the retirement process *per se* [2].

In a third report the track record measured as duration of sick-listing periods before the retirement will be analysed and compared with that of the corresponding general population. The analyses are not yet concluded [3].

In the fourth report the quality of life before and after the retirement was analysed. Quality of life has been measured on several occasions and in various points in time in relation to the retirement. Time-dependent analysis was used in order to disclose a possible relationship to the retirement [4].

### ***To be or not to be sick-listed***

The project is based on approximately 600 appointments in Örebro primary health care, where sick-listing was a possible option. The physician and the patient each gave their view of what factors were of importance for the outcome, *i.e.*, to be or not to be sick-listed. In the first report, physician related factors were analysed. Age, a long professional career, part-time work and participation in the seminars held by the Social Insurance Agency all increased the probability of sick-listing [5]. In the second report patient related factors were analysed [6]. One PhD student (Gunilla Normén) is involved in the project.

### ***Physicians view of the sick-listing commission***

The project is performed in collaboration between our research group, the Rehabilitation section of Department of Neuroscience, Uppsala University, and the Social Insurance Centre at the Department of Clinical Neuroscience, Karolinska Institute. It is focussed on obtaining information on what view physicians take regarding patients' wish to be sick-listed and the duty as a society gate keeper to the social insurance system. Deep interviews and postal questionnaires were used. Two groups of physicians, general practitioners and orthopaedic surgeons, were approached. The project is led by Rolf Wahlström and financially supported by the Social Insurance Centre and Uppsala University. One PhD student (Malin Swartling) dissertated in 2008 [7].

## **Project 2: Muskuloskeletal disease**

Kurt Svärdsudd and Stefan Blomberg

### ***The Säter and Gotland studies***

The projects are based on two randomised controlled clinical trials of manual therapy (orthopaedic medicine therapy) versus traditional treatment (traditional physiotherapy and own physical activities) with the aim to assess if manual therapy affects the pain level, use of analgesic drugs and return to work better than traditional physiotherapy. The two trials had a somewhat different design. In the Säter study the manual therapy was performed by one therapist and primary health care performed the control treatment. In the Gotland trial general practitioners trained in manual therapy performed the manual therapy and orthopaedic surgeons the control treatment. In both trials those

who got the manual therapy had a faster return to work, had less sick-listing and used less analgesics [8-9].

In the Gotland trial pain drawings were tested for their clinical value as predictors of pain course [10] and the nomenclature used by different physician categories for the same pain condition [11]. One PhD student (Stefan Blomberg) graduated in the project and another two (Johan Bogefeldt and Marie Grunnesjö) are involved. The projects are financially supported by Stockholm Stay-Active Clinic, the Province of Gotland, and Uppsala University.

### ***Prevalence and consequences of low back pain***

This project is based on data from a large number of on-going population studies in Gothenburg, Eskilstuna, and Uppsala with altogether 14000 observations and with an age range of 25-99 years in both sexes and data collected during the time period 1980-1993. Some of the instruments used in the population studies were identical and will be used in the project. The aims are to analyse the prevalence of low back pain by sex and age, adjusted for a large number of possible other outcome affecting variables, to analyse possible secular trends (cohort effects) with increasing or decreasing back pain reporting over time, and to analyse the consequences of low back pain in terms of well-being, sick leave, health care utilisation, disability pension, and survival. One PhD student (Johan Bogefeldt) is involved. The project is carried out in cooperation with the Cardiovascular epidemiology group in Gothenburg, the National Insurance Board, and the National Board of Health and Welfare.

### ***Epicondylitis***

Tennis elbow (epicondylitis) is a common pain condition that in 90% spontaneously heals within three months. In the remaining 10% the condition becomes “chronic” or persistent and then changes name to epicondylitis. This project has three main purposes, to map treatment methods currently used in primary health care, to test a new treatment method, and to shed some light on the pathophysiology of the condition.

The first purpose was fulfilled by a postal questionnaire study involving general practitioners and physiotherapists showing that a large number of methods were used, some of which were not tested for efficacy, and some even had been shown ineffective [12]. The second purpose will be fulfilled by a double randomised controlled clinical trial in which, first, the effect of exercise versus wait-and-see will be tested, and, secondly, the effect of two treatment methods (eccentric and concentric exercise) are compared involving more than 200 patients in a multicentre setting in Uppsala and Linköping.

The third part of the project is a study of the pathophysiology by obtaining tissue specimen from the health and the affected elbow for microscopic and histochemical investigation (Uppsala and Halmstad) and positron emission tomography (PET) of the health and the affected elbow. The PET scan data are almost analysed and a report is under way. One PhD student (Magnus Peterson) is involved, and the project is financially supported by the Medical Research Council, PET Centre, and Uppsala University.



### ***Cognitive behavioural therapy in fibromyalgia***

The project, which is performed in collaboration with the sections of Social Medicine and Caring Sciences in our department and the section for Biological Research on Drug Dependence at Uppsala University, is a randomised controlled trial of cognitive behavioural therapy (CBT) in fibromyalgia where the purpose is to assess the effect of CBT in this condition. Fifty women with a fibromyalgia diagnosis in Northern Uppland were randomised to one of two groups, where one received CBT for one year with the other group as control. After one year the control group also received CBT. A large number of variables have been collected through questionnaires and blood samples. The data are now being analysed. One PhD student (Bo Karlsson) is involved and the project is financially supported by Uppsala University.

### ***Subcutaneous injections of sterile water or saline solution in fibromyalgia tenderpoints***

Previously a number of therapies have been tried with doubtful or only short-term effect in fibromyalgia. However, subcutaneous injections of small amounts of sterile water in other pain conditions have been shown to decrease pain with variable effect duration. Moreover, there are two prevalent hypotheses of the origin of the fibromyalgia pain syndrome, both hypotheses predicting influence on the nociceptor (causing the tenderpoint) of for instance substances with osmotic effect or mechanical irritation. In two pilot studies we could show that injections of sterile water were more effective than those of saline solution. In collaboration with the Clinical Chemistry and Immunology laboratories at Uppsala University Hospital and the section for Biological Research on Drug Dependence at Uppsala University we now perform a full-scale randomised controlled clinical trial of subcutaneous injections of sterile water versus saline solution in 60 women, half of them randomised to water and the remaining to saline solution. In addition blood samples have been taken for neuropeptide measurements. The project is financially supported by the Medical Research Council and Uppsala University.

### ***The VIP study***

Mari-Ann Wallander, Kurt Svärdsudd and Karin Björkegren

The project is a postal questionnaire based case referent study of 150 women in Uppsala County diagnosed for fibromyalgia (cases) and 750 matched reference persons from the general population. The purpose of the study is to compare cases and referents regarding psycho-socio-economic status, symptom reporting, and prevalence of functional gastrointestinal problems. This is the first controlled study in the world of symptom reporting among fibromyalgia patients showing that a considerable proportion of the fibromyalgia patients report not only traditional fibromyalgia symptoms but also high frequencies of other symptoms. This has not been shown earlier. A first report has been submitted for publication [13].

### **Project 3: Asthma, allergy and COPD**

Gunnar Johansson, Kurt Svärdsudd, Karin Lisspers and Björn Stållberg

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

The project is a national study of the health in preschool children regarding asthma and various types of allergies, and of their home and school environment. The main purpose is to assess if special allergy avoidance day care centres would improve the situation for allergic children. All such existing day care centres in the country were identified and for each such centre two ordinary day care centres in the vicinity were chosen as controls, in total 593 day care centre sections. All these sections received a postal questionnaire regarding the physical environment of the school, cleaning routines, rules regarding smoking and having pets at home. A first report showed a considerably less allergogenic environment in the allergy avoidance centres than in the control centres [14]. Later a postal questionnaire about the children's health situation and home environment was sent to the parents of the 8700 children in the allergy avoidance and control centres. All children who had signs of asthma in the returned questionnaires received a symptom diary to be filled in during two weeks in order to get a better measure of asthma severity than was possible in the questionnaire. In early 2007 a follow-up questionnaire similar to the first one was sent out to the parents.

The first results from the big questionnaire are focussed on providing a reliable age and sex specific prevalence. Several earlier studies have been presented but they have been regional, local or small. We have computed one-year age class prevalence for boys and girls using five diagnostic criteria. Using physician based criteria there are large regional prevalence differences, whereas physician neutral criteria show no regional differences. Moreover, in an analysis of geographical asthma prevalence gradients the strongest geographic/demographic variable was population density, as a proxy for degree of urbanisation. One PhD student (Kristina Bröms) is involved. The project is financially supported by Vårdalstiftelsen, the Asthma and Allergy Patient Foundation, Uppsala University, and a number of smaller funds.

#### ***The AIM study***

In this project the asthma treatment in adults in the 240 primary health care centres in the Uppsala-Örebro Health Care Region is investigated. The purpose was to assess the proportion of centres with special asthma clinics [15]. Less than half had a complete asthma clinic based on the national criteria, approximately one third had an incomplete clinic and the remaining had none.

Then a random sample of approximately 1100 patients from the 240 centres was drawn and a questionnaire regarding socio-economic background, asthma symptoms, treatment quality of life, etcetera, was sent. Two reports have been published showing a strong association between perceived quality of life and the asthma disease control [16] and quality of life and severity of asthma [17].

The project is led by Gunnar Johansson and is financially supported by the Cooperation Council of the Uppsala-Örebro Region, and Uppsala University. Two PhD students (Karin Lisspers and Björn Stållberg) are involved and both dissertated in 2008.

### ***The ALMA study***

The ALMA project ("Att Leva Med Astma") is a national study of the limitations that the asthma disease conveys. The project was performed by a national project group as a telephone interview study in a random sample of 10350 men and women nationwide, of whom 240 later were subjected to an in depth interview. Moreover, a postal questionnaire was sent to a random sample of general practitioners. It was found that asthma patients generally had more symptoms than their general practitioners were aware of [18]. Björn Stållberg is leader of the project which is now concluded.

### ***Asthma during childhood and adolescence***

The project is based on a series of measurements in 150 school children in a small municipality. The purpose was to evaluate the course of asthma with onset in childhood. A first report has been published [17] showing a decreased prevalence across age, and another one is under way. Björn Stållberg is leader of the project, which is supported by Trosa municipality.

### ***Asthma treatment practice***

This project is a study of asthma treatment practice at the 240 primary health care centres and 11 lung disease departments in the Uppsala-Örebro Health Care Region. A random sample of 1100 patients from these health care units was drawn and their medical records have been obtained. The records are now being scrutinised for the purpose to assess the proportion in which the national quality of care criteria (similar to the GINA criteria) are followed. The data collection is finalized and the scrutiny is now being done. The project leads by Gunnar Johansson, Karin Lisspers and Björn Stållberg and is financially supported by Cooperation Council of the Uppsala-Örebro Region, and Uppsala University.

## **Project 4: Utilisations of pharmaceuticals**

Mari-Ann Wallander, Annika Bardel and Kurt Svärdsudd

### ***Women's utilisation of pharmaceuticals***

The project is based on a postal questionnaire sent to a random sample of 4200 women in the Uppsala-Örebro region, 35-64 years old. The purpose of the project is to study utilisation of pharmaceuticals among women. In a first report the pharmaceutical panorama and the diseases for which the drugs were given was presented [19]. In a second report the use of hormone replacement therapy at menopause and symptoms reported by users and non-users was presented [20]. In a third report adherence to prescribed drug and its determinants were presented [21]. The adherence increased with age, if a reappointment was scheduled, if the disease was serious or the drug necessary, while the adherence decreased if the respondent had negative feelings about the safety of the drug. In a fourth report show the symptom prevalence across age and use of pharmaceuticals [22]. The project leaders are Mari-Ann Wallander and Annika Bardel

(disserted in 2007). The project is supported financially by Vårdalstiftelsen and Uppsala University.

### ***Rational drug prescribing***

The project is based on the registration of prescribed pharmaceuticals in Storstrøms Amt, Southern Denmark. Ninety four general practices participated in the project. The purpose is to study factors leading to a rational drug prescribing. In the first report prescription data for the 94 practices (DDD/1000 listed patients for 13 drug groups) was abstracted from the database. Every six months for seven years a letter was sent to all practices where their level of prescription in relation to all practices was indicated. A report is now to be finalised.

In a second part of the project a trained general practitioner visited all practices twice with a one-year interval. During the visit the general practitioners were asked to indicate their level of prescription in relation to all other practices. After the first visit the responses were no better than chance, but significantly better on the second occasion. A report is under way.

In the third part of the project the 94 practices were randomised to two groups. One became the intervention group and the other one control group for intervention directed against prescription of antibiotics (ATC group J). The groups were interchanged regarding intervention against prescription of relaxants (ATC group M and N). The same general practitioner as in part 2 visited regularly the 94 practices and discussed the use of antibiotics in half of the practices and the use of relaxants in the other half. The effect on prescriptions was followed by register data. This part of the project is not finalised. One PhD student (Keld Vaegter) is involved and the project is financially supported by Storstrøms Amt and Uppsala University.

## **Project 5: Cardiovascular disease and diabetes**

Kurt Svärdsudd, Marianne Omne-Pontén, Jan Cederholm, Dan Andersson, Jan Stålhammar, Margaretha Eriksson

### ***The impact of birth weight***

This project is a recently finalised study of the impact of birth weight on the prevalence of cardiovascular risk factors, and the incidence of cardiovascular disease, diabetes and prostate cancer. The study population consisted of 1800 boys born in Gothenburg in 1913, of whom a fraction participated in the Study of Men Born in 1913. Birth weights and other obstetric data were retrieved from various archives. The boys were followed regarding survival until age 85. For a fraction (the Study of Men Born in 1913) screening data were available from several occasions. In a first publication a quality control of the collected data was performed indicating sufficient quality for scientific use [23]. In a second report an inverse relationship between birth weight on the one hand and adult blood pressure and serum cholesterol on the other [24]. However, no relationship to adult myocardial infarction incidence, death from cardiovascular disease or death all causes [25]. Moreover, there was a curvilinear relationship between birth weight and adult diabetes incidence, with high incidence levels among those with a low and those with a high birth weight. Finally, a direct relationship was found between

birth weight and adult prostate cancer incidence [26]. Barker's hypothesis of intrauterine priming could thus be verified in certain aspects but not in other. One PhD student (Margaretha Eriksson dissertated in 2005) was involved in the project that was supported financially by the Medical Research Council, Heart-Lung Foundation and Uppsala University.

### ***Morbidity and mortality among diabetes patients***

The project is based on the 1500 diabetes patients in the Tierp Health Care Database during the years 1976-1994 and a matched control group of 4500 persons from the population register. The Tierp Health Care Database is a longitudinal registration of all visits to the Tierp Health Care Centre, the only one in the area. The purpose of the project was to test the hypothesis that the aggressive diabetes treatment with a better metabolic control during recent years might have improved the survival outlook for diabetes patients. The final report is now being prepared. Preliminary data indicates that the diabetes patients have had less decline in mortality rate than the general population. Jan Stålhammar has graduated in the project [27], which was supported by the Medical Research Council and Uppsala University.

### ***Determinants for the survival of diabetes patients***

The project is based on the 800 diabetes patients followed and treated at Laxå Primary Health Care Centre since 1972 and approximately 4000 referents from the general population matched to the cases by age, sex, and year of onset for the diabetes patients. The purpose is first to see if 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 [28]. The project leader is Dan Andersson and one PhD student (Stefan Jansson) is involved in the project, which is supported financially by Örebro University and Uppsala University.

### ***The National Diabetes Register***

The National Diabetes Register, now covering 100% of all hospitals and approximately 50% of the primary health care in the country, forms the base for this project. One of our senior researchers (Jan Cederholm) is engaged in the research of the dataset [29-40].

### ***Metabolic control in diabetes patients***

The project is a large-scale study of all diabetes patients in Uppsala County during a long time period, approximately 10000 patients, and based on data collection in all electronic medical records in the 30 primary health care centres in Uppsala county. The data set includes not only diagnosis but also lab-data, drug treatment, etcetera. The purpose is to analyse the influence of the change of treatment attitude during recent decades on metabolic control variables and a number of other factors. The project leader is Jan Stålhammar. One PhD student (Mats Martinell) is involved in the project which is supported by the Primary Health Care in Uppsala and Uppsala University.

## ***SUPRIM***

The project deals with secondary prevention after a coronary heart event and is a randomised controlled clinical trial of two prevention concepts, optimised risk factor control and behavioural modification. The study population consists of 362 patients discharged from Uppsala University Hospital to their general practitioners who were cross randomised according to a factorial design. First, their general practitioners were randomised into two groups, one receiving education in optimal risk factor control, the other was left to the market information. The patients in each of these two groups were then cross-randomised into behavioural modification or no modification. The factorial design allows evaluation of the two concepts separately.

After a baseline examination right after discharge the patients were followed with new examinations every six months for 30 months, where the risk factor levels were measured, a nutritional examination was done twice, a video interview has been done twice to measure the effect of the behavioural modification programme and a large number of psycho-socio-economic variables have been measured by questionnaire. The trial is now concluded. The first publication where the patients' psycho-socio-economic situation during the first year after baseline is compared with about 1000 age-sex-living are matched referents, showing that not only disease status but also gender seems to be strong determinants for well-being after a coronary event [41]. Another publication with the main results from the study is under way. One PhD student (Mats Gulliksson) is involved in this project which is supported by the Medical Research Council, FAS, Vårdalstiftelsen, the Social Insurance Agency, Uppsala University and a number of other funding agents.

## ***Secular trends in myocardial re-infarctions***

The project is performed in collaboration with Epidemiology Centre (EpC) at the National Board of Health and the Cardiovascular Epidemiology Group at Sahlgren's Academy, Gothenburg. It is based on the National Myocardial Infarction Register at EpC, which contains all incidents of myocardial infarction since the early 1970s, in total 1.2 million incidents. The purpose is to study the risk for myocardial re-infarctions during the years following a first infarction, and how this risk has changed over the years. The risk for a new event decreased rapidly during the first year after an event, had its lowest level after five years and then slowly increased. Over the years the risk function for a new event was fairly stable but from 1980 and onwards it has been declining, indicating that the risk for a new event irrespective of the time frame from the first event has gone down considerably [42]. One PhD student (Mats Gulliksson) is involved in the project, which is supported by EpC and Uppsala University.

## ***Damaged brain and susceptible life***

The project is a one-year long follow up of all 390 stroke patients discharged from Falun Hospital during a specified period of time, and who before the admission were living in their own home. At discharge the staff was asked to indicate their view of the patient's prognosis. The patients were followed with an interview at home immediately after discharge, and after 3 and 12 months. On the same occasion a close relative responded to a matching questionnaire. Furthermore, all health care utilisation at hospital, primary health care and municipality social service and the caring efforts of close relatives have been recorded.

In the first publication the prognostic ability of the staff was analysed. The prognoses were given regarding health development, need of help and living as three alternatives (better, unchanged or worse). The prognoses were correct in 67%, much better than chance (33%) [43]. Currently an evaluation of care utilisation during the first year is analysed. One PhD student (Lena Olai) is involved in the project, which is supported by Vårdalstiftelsen, Dalarna County Council and Uppsala University.

### ***Screening for diabetes and hypertension in the Dental Care Service***

The dental service is the only clinical area where patients on a large scale come for health check-ups without having symptoms. This project deals with the possibility to use the dental health service as a screening function for high blood pressure and diabetes. The purpose is to evaluate to what extent new diabetes or hypertension cases that were not known previously in the health care may be detected. Three dental services in Gävleborg County, in places with only one primary health care centre, measured blood pressure and blood sugar in all patients attending the service, approximately 1500 patients. All patients who had blood pressure or blood sugar above preset levels were referred to the primary health care centre for evaluation. Data from these unit regarding the referred persons cover 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, if not so, if he or she came for evaluation and if so if he or she got a hypertension or diabetes diagnosis. A first publication based on a pilot study showed a strong relationship between high blood pressure and the prevalence of deep gingival pockets [44]. One PhD student (Sevek Engström) is involved in the project which is financially supported by Gävleborg County Council, Dental Service Gävleborg and Uppsala University.

## **Project 6: *Varia***

Kurt Svärdsudd, Lars Englund and Nils Rodhe

### ***Infections in the elderly***

The purpose of the project is to find out if asymptomatic bacteriuria in old people should be treated or not. The project is based on all persons 80 years or older in a health care district of Falun. The study population was followed during a few years with repeated assessments, bacterial cultivations and other lab tests. Four reports have been published showing the prevalence of asymptomatic bacteriuria as measured by means of urine cultures, determinants of asymptomatic bacteriuria, change of bacterial strains indicating that the infections come and go, and the possibility to differ between innocent asymptomatic bacteriurias and those in need of treatment with simple lab tests [45-48]. The project leader is Lars Englund and one PhD student (Nils Rodhe dissertated in 2008) is involved in the project, which is financially supported by Dalarna County.

### ***Psychiatric secondary prevention – Case management***

The project is focussed on psychiatric secondary prevention. The purpose is to find out if case management in psychiatry reduces the risk of readmission to hospital. Case management using managers from outside the health care has been tried earlier with moderate success. In this project we evaluated the effect of professional managers, *i.e.*, psychiatric ward staff. All patients discharged from a psychiatric ward unit after at least three days in hospital and who agreed to participate (50 patients) were randomly allocated to one of two groups. One group was offered a case manager among the staff in the ward, while the other group was referred to a psychiatric out-patient clinic. The case manager contacted or met the patient regularly. Every third month questionnaires were filled in by the patient and the case manager. Also the control group sporadically was in touch with the managers. After one year the control group was offered a case manager while the former intervention group could go on with their contact on their own initiative. After one year the case manager group had significantly fewer re-admissions to hospital than the control group. The project leader is Lars Nilsson and the project is financially supported by the Social Insurance Agency, Karolinska Institute and Uppsala University.

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## **Undergraduate Teaching**

### **Medical programme**

- responsibility for “Professional Development” on term 1-4
- responsibility for the students practice in Family Medicine on terms 6-7
- responsibility for the students practice in Family Medicine on term 11

### **Registered Nurse Programme**

- teaching on various levels

### **Centres and Facilities**

Epidemiology Centre (EpC) at the National Board of Health, Stockholm

The Cardiovascular Epidemiology Group at Sahlgren’s Academy, Gothenburg

National Social Insurance Board

Centre for Clinical Research, Örebro County Council/Uppsala University

Centre for Clinical Research, Dalarna County Council/Uppsala University

Centre for Clinical Research, Gävleborg County Council/Uppsala University

Centre for Clinical Research, Södermanland County Council/Uppsala University

# Geriatric Research

Research group leader Lars Lannfelt, MD, PhD, Professor

## **Geriatric research**

The dementia research unit was established in 2001 and is thus a relatively new research unit at Uppsala University. The three areas of research are:

1. Molecular studies of dementia
2. Clinical and epidemiological research in these disorders
3. Clinical and epidemiological research in other diseases affecting the elderly population

## **Molecular studies of dementia**

We are using cellular- and transgenic mice models of Alzheimer's disease to better understand mechanisms of amyloid formation in the brain and to develop disease-modifying therapeutics. At present there is a growing interest within the research community of soluble amyloid beta (A $\beta$ ) peptide intermediates as being the main pathogenic species in Alzheimer's disease. In our transgenic mice we are evaluating the possibility that aggregation of A $\beta$  peptides starts inside the nerve cells and our hypothesis is that large A $\beta$  aggregates, e.g. A $\beta$  protofibrils, are responsible for the neurotoxicity in Alzheimer's disease. We have developed monoclonal antibodies (mAbs) specifically recognising A $\beta$  protofibrils to be able to immunologically study this A $\beta$  species. Moreover, we have developed a transgenic mouse model for the disease. Using the mAbs in an ELISA, we have enabled measurement of A $\beta$  protofibrils in cellular models as well as in the transgenic mice. In addition, biological tissue such as brain, CSF, plasma and fibroblasts from Alzheimer patients are being evaluated for A $\beta$  protofibril content. If successful, our method can be developed and used for the early diagnosis of Alzheimer's disease and as a biomarker to monitor amyloid-directed therapies. We have also started to study passive vaccination with the conformation-specific mAbs against A $\beta$  protofibrils as a therapeutic strategy in the transgenic mice. The ultimate goal is to use the A $\beta$  protofibril specific antibodies both as a tool for early diagnosis and as therapeutics for Alzheimer's disease. The close contact between the laboratory and the Geriatric Clinic at Uppsala University Hospital facilitates the access of appropriate clinical samples. In a close collaboration with Prof. Ulf Lindahl we are also investigating the possibility of disease-modification of A $\beta$ -amyloidosis by means of heparane sulfate proteoglycans (HSPGs). Transgenic and cell culture models are being used in these studies. In a recently initiated project we are trying to generate a transgenic model with more complete Alzheimer's disease neuropathology. The research is pursued using a broad repertoire of experimental approaches such as molecular biology, biochemistry, histology and behavioural analyses.

We have recently initiated projects related to tau- and  $\alpha$ -synuclein protein pathology. Tau is a protein that gets deposited in the brain as neurofibrillary tangles in a number of neurodegenerative disorders, including Alzheimer's disease and another dementia disorder, frontotemporal dementia. Our research is focused on characterizing the aggregation process, with the aim of exploring potentially critical intermediary steps in

this process. Also, we are studying how various isoforms and mutants of the tau protein, known to influence the disease process in frontotemporal dementia behave in an in vitro aggregation assay.

The  $\alpha$ -synuclein protein is the principal component of Lewy bodies, intraneuronal fibrillary protein deposits in disorders such as dementia with Lewy bodies and Parkinson's disease. We are describing early steps in the fibrillogenesis, with the aim to observe critical steps that can be developed as targets for new diagnostic and therapeutic approaches. This project is utilizing a combination of modern techniques, such as high-performance liquid chromatography (HPLC), atomic force microscopy, circular dichroism and mass spectrometry.

The research group is also involved in genetic analysis of dementia in human samples. This entails mutation screening and copy number studies of previously identified disease causing genes, as well as genetic mapping of previously not described genes with effect on dementia. For this purpose we have access to a large and well characterised collection of dementia patients and their relatives. Most patients have been diagnosed with Alzheimer's disease, but other forms of dementia are also represented. In addition we carry out association studies searching for susceptibility factors which influence the risk of developing Alzheimer's disease.

### **Clinical research**

The clinical research unit is currently categorizing dementia patients clinically and neuropathologically. This research is based on our own tissue bank that include DNA, CSF, plasma, serum, fibroblasts and brain tissue. Longitudinal studies of Alzheimer's disease and frontotemporal dementia are carried out in collaboration with Uppsala PET-center, especially using the newly developed amyloid-binding ligand PIB. These investigations were initiated 2007.

Population based investigations have been performed on samples from the Uppsala Longitudinal Study of Adult Men (ULSAM). We have recently measured A $\beta$  in plasma in this cohort and evaluated its predictive value for the development of Alzheimer's disease. Insulin-resistance at age 50 has also been used as a predictor of the development of Alzheimer's disease at 82 years of age. Another population based collection of AD patients and healthy controls have been collected, in which to carry out replication studies of genes that show significant association to Alzheimer's disease within ULSAM.

The major aim for the dementia research group in the future is to establish immunotherapeutic strategies to treat dementia. Immunotherapy is at present the most promising strategy for treating Alzheimer's disease and the interest for this approach is huge all over the world. Moreover, as the mechanisms of many neurodegenerative disorders are thought to centre around protein misfolding and aggregation and thus to some extent similar to Alzheimer's disease, immunotherapy is thought to be promising also for other dementia disorders as well. We are collaborating with a number of national and international research groups (listed below) in order to produce and evaluate antibodies for their possible immunotherapeutic effects both for Alzheimer's disease and other dementias.

The major aim for the dementia research group in the future is to establish immunotherapeutic strategies to treat dementia. By using our A $\beta$  protofibril specific monoclonal antibodies we hope to set up methods for early diagnosis of Alzheimer's

disease and therapeutic intervention. Also the projects on  $\alpha$ -synuclein and tau have great potentials. If successful, these lines of research may provide us with new targets for the development of both diagnostic and therapeutic approaches for frontotemporal dementia, dementia with Lewy bodies and Parkinson's disease, disorders for which there are today no therapies directed against the disease pathogenesis.

The close contact with the Geriatric Clinic provides access to unique well characterized human clinical material. Moreover it gives us opportunities for the collection of samples from rare families with monogenic forms of dementia where previously unknown dementia genes can be discovered.

## **Type 2 Diabetes Mellitus, Obesity and Coronary Heart Disease. Research using Registries, Cohorts and Case Control Studies.**

Björn Zethelius, associate professor.

1. Clinical and epidemiological studies in type 2 diabetes and cardiovascular disease.
2. Optimizing statistical methods in epidemiological studies
3. Clinical studies in obesity after bariatric surgery
4. Genetic studies of diabetes

1. Type 2 diabetes and cardiovascular disease.

The research is performed as longitudinal studies of type 2 diabetes and cardiovascular diseases in large scale register studies using the Swedish National Diabetes Registry (NDR), Swedish Cause of Death and Hospital Discharge Registers and population based investigations, the ULSAM cohort and the PIVUS cohort. We have recently published an article in the NEJM on the use of multiple risk marker strategy allowing for improved risk discrimination on the individual level using new techniques as well as ROC analyses. Further we recently published data from the NDR on risk determination in type 2 diabetes patients using a newly developed risk engine which is a vast improvement of previous existing risk engines constructed in the 1990s.

2. Optimization of statistical methods for replication studies, correcting for regression dilution bias, are performed using the ULSAM cohort. Two papers on the development of a new strategy, the extreme selection and maximum likelihood regression have recently been published in Statistics in Medicine.

3. Proinsulin and insulin secretion dynamics has been studied in clinical studies in obesity and after three types of bariatric surgery, totally, partially or not by-passing the stomach. We have recently published results on gastric by-pass surgery where proinsulin-insulin dynamics are normalized after surgery.

4. The genetic studies project analyze the importance of genetic determinants and their associations with phenotypes, i.e. quantitative traits such as proinsulin and insulin secretion and action and their possible interactions in relation to hard endpoints type 2 diabetes (T2DM) and its associated complication coronary heart disease (CHD) adjusting for possible modulating effects of lifestyle factors and established CHD-risk factors using phenotype data from investigations in three large epidemiological studies including the ULSAM, the PIVUS and a case control study. Also clinical studies on obese subjects after bariatric surgery are performed. Two important recent findings in ULSAM were that proinsulin predicted the development of T2DM, and that proinsulin and cTnI, respectively independently predicted CHD. The study enabled us to study the impact of proinsulin and insulin resistance on hard endpoints (T2DM, and CHD). Genotype variation (SNPs, Uppsala SNP-genotyping platform) are analysed in relation

to quantitative traits and hard endpoints in investigatory and replicatory studies using the three epidemiological study samples. A large number of individuals at high risk of developing T2DM and CHD and functional gene variants having known mechanisms to cause T2DM and CHD and gene-environment interactions will be evaluated.

## **Studies on Physical Activity and Health of the Elderly**

Anna Cristina Åberg, adj clinical lecturer

The research in this field is aimed at investigations of motor function and physical activity in relation to health among elderly people. This implies that both quantitative and qualitative methodologies are combined and complementarily used. This area includes methods development of clinical and laboratory based assessments of motor function, as well as studies on associations between motor function and subjective health aspects, in particular 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 Alzheimer's disease. One main focus is prevention of falls among older people, specifically for those with an increased risk of falling.

### **Members of the group during 2005-2007**

#### **Researchers**

Professor Hans Basun, associate professor Björn Zethelius, associate professor Lars Nilsson, senior lecturer Lena Kilander, Drs Maria Lindau, Martin Ingelsson, Frida Ekholm-Pettersson, Vilmantas Giedraitis, Xiao Zhang, Anna Glaser, adj. clinical lecturer Anna Cristina Åberg and PhD students, technicians and other participating in the research: approximately 30 persons.

#### **Publications 2008**

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**2008**

**Elin Blom**, Genetic studies of Alzheimer's disease. Doktorsavhandling 2008-12-12; ISBN 978-91-554-73476-4

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## Health Services Research

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

Health services research is interdisciplinary, as the research theories and methods used have their origins in many different scientific disciplines. The researchers as well have very different backgrounds, such as psychology, medicine, nursing, political science and economy. There are many approaches to health services research. Some of these approaches are represented in present research projects at the Department of Public Health and Caring Sciences as follows: One approach is to study the health care system from the view of the individuals involved, for example, doctors, medical care personnel, students and patients. This approach focuses mainly on how the medical caring personnel understand their work, and how their professional competence develops and can be influenced by education and professional guidance. Another approach is the study of political, administrative and medical decision making process. Studies presently in progress with this approach focus on management of different political reforms within health care.

### Members of the group during 2008

Inger Holmström, associate professor, group leader

Ulrika Winblad, PhD, vice group leader

Caroline Andersson, research assistant

Pia Bastholm Rahmner, PhD student

Cecilia Bernsten, associate professor

Ingeborg Björkman, PhD

Madeleine Boll, PhD student

Eva Boström, PhD

Helène Eriksson, administrative assistant

Annica Ernesäter, PhD student

Mio Fredriksson, PhD student

Nils-Olof Hedman, PhD student

Finn Hjelmblink, PhD

David Isaksson, research assistant

Elenor Kaminsky, PhD student

Dorte Kjeldmand, PhD

Jan Larsson, PhD

Martin Rejler, PhD student

Urban Rosenqvist, Professor em

Marta Röing, PhD

Margareta Sanner, associate professor

Ragnar Stolt, licentiate

Anikó Vég, PhD

Ulla Wihlman, PhD student

## Publications 2006-2008

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

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 Mid Sweden University  
 Swedish Associations of Local Authorities and Regions (SKL)

### **Research projects**

#### **Anaesthetists' experiences of difficulties at work**

**Participants: Jan Larsson, Inger Holmström, Urban Rosenqvist.**

Trainee anaesthetists often feel insufficient at work and are exposed too much stress, whereas many specialist anaesthetists report being content with their job. Trainees would benefit from understanding how their senior colleagues have learned to live well at work. The aim of this study was to examine how experienced anaesthetists handle and cope with situations that can be perceived as difficult and that are potentially stressful. Two sets of interviews were performed with 19 anaesthetists. The first set consisted of in-depth interviews focusing on how the interviewees experienced difficulties at work. In the second set the interviews were semi-structured with questions based on themes found in the first set of interviews and focused on how the anaesthetists handled different kinds of difficulties. The first set of interviews resulted in five themes: A) anaesthesiology as an inherently difficult work; B) ethically difficult decisions; C) hard working conditions; D) disrespect from surgeons; and E) no external obstacles to doing a good work. The second set of interviews showed two categories of ways of handling difficult situations at work. The first category focused on problem solving, on how to act in medically complex situations or in situations with acute work overload. The second category consisted of appraising difficult situations in ways that would convert them from threats to challenges, even if the actual problems could not be solved. It is a task for teachers of anaesthesiology to help trainees to develop into

anaesthetists who know how to live well at work. Many experienced anaesthetists have developed highly functional ways of handling different kinds of difficulties. Getting access to these coping strategies might help young anaesthetists to come to terms with their work.

## **Learning anaesthesia induction - how to facilitate anaesthetists - professional development**

**Participants: Jan Larsson, Professor Andrew Smith, Department of Anaesthesia, Royal Lancaster Infirmary, Lancaster, UK**

This research project aims to study how trainees' learning of anaesthesia induction can be improved in a powerful way. We will study how trainees and specialist anaesthetists perform anaesthesia induction and we will explore how they think about it. Our aim is to understand the variation in thinking about induction that lies behind the variation in how anaesthetists perform and learn induction. Qualitative research methods, appropriate for this kind of research, will be used.

In *study 1* we will do focus group interviews with nurse anaesthetists from four hospitals to get their narratives on how anaesthetists perform induction.

*Study 2* will be based on video-recordings of trainees and specialist anaesthetists performing induction. The anaesthetists will be interviewed about anaesthesia induction after having seen their own video-recording to stimulate their recall about their own thinking during the induction. A grounded theory approach will be used.

In *study 3* we will interview trainees and specialists on how they understand and use guidelines and algorithms for anaesthesia induction. For this study, we will use a phenomenographic approach. Observational studies during everyday anaesthesia work have shown numerous incidents which can be characterised as lack of smoothness but such minor events are seldom reported. Furthermore, a great percentage of reported adverse events during anaesthesia concern the induction of anaesthesia. As there is an association between minor events (not harmful to patients and often not reported) and major events with serious consequences for the patient, it is important, for the sake of safety, to strive to induce anaesthesia smoothly. This, however, is a demanding task: the anaesthetist must make use of information of different kinds, such as patient history, sensory information (what he/she can see, hear and feel) and data, sometimes misleading, from electronic equipment. At the same time he/she must communicate with the anaesthesia team and also with the patient as long as he/she is awake.

This research is important because the induction of anaesthesia can serve as a model for learning the practical work of giving anaesthetics: it is an often repeated procedure, it is associated with a number of potential risks for the patient, and it combines needs for practical skills and theoretical knowledge. It is our hypothesis that this procedure must be learnt by transfer of knowledge from the experienced anaesthetist to the trainee; that includes the development of tacit knowing; and that the process may be disturbed by the trainee focusing too much on explicit knowledge. Our aim is to explore and develop this hypothesis, because it may have a great impact on the training of anaesthetists, and on physicians' training in general. Taking the step from novice to expert means to let go the grip on protocols as safe and secure rules of action. It means to take own responsibility for rules, protocols and algorithms, admitting their inherent insecurity and the relative character of the different pieces advice for action that follows from the protocols. With this project we aim to increase our knowledge about how teachers of anaesthesiology can facilitate such trainees' practical learning.

## **Towards improved medication Use: Increasing understanding of professional efforts**

**Participants: Ingeborg Björkman, Cecilia Bernsten, Inger Holmström, Margareta Sanner**

Pharmacists are developing new professional roles and try to find methods to counsel patients/pharmacy-customers. However, pharmacists develop different tools and seem to perceive their role in different ways. Two studies were designed; 1) to explore similarities and differences in four classification systems for drug related problems (DRPs) and 2) to study how pharmaceutical care was perceived. In the first study patient cases with DRPs were reclassified by using four different classification systems. Similarities and differences in the four classification processes were 107 noted and analyzed. In the second study four central figures representing each of the pharmaceutical care perceptions were interviewed. In both studies a qualitative method inspired by grounded theory was used. The processes to classify DRPs were different and thus the systems had different functions. The patients were given different roles in the different perceptions of pharmaceutical care.

One perception was based on a patient-centred ideology and the others on the ideology expressed in evidence-based medicine. A third study was aiming to explore the attitudes among pharmacy personnel to public health work and to their new roles. The work at community pharmacies today includes both the dispensing of medication, giving information on how to use medication, helping customers to treat minor ailments, and lately also to promote a healthy lifestyle. Texts from 8 focus group discussions held in the years 2004/05 were analyzed by a qualitative inductive method. Five themes were identified - "Public health work includes pharmacy activities"; "Apoteket AB (the employer) sets the working framework", "Positive feelings dominate", "Traditional pharmacy challenged", and "Need of change and support". A fourth study was based on the fact that the level of antibiotic resistance (AR) relates to the level of antibiotic use and the choice of antibiotic preparations. The aim of this study was to explore perceptions among hospital physicians of prescription of antibiotics in relation to the threat of AR. Twenty hospital physicians of three different specialties were interviewed (in year 2006) and the texts were analyzed by phenomenographic method.

## **DruGs and patient behaviour – the influence of organizational and professional actors**

**Participant: Cecilia Bernsten**

How people use and do not use medicines have been highlighted since the beginning of the 1980:s. Drugs do not work if people don't 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.

Recent research has pointed to the importance not only of trust between the two actors but also to the importance of mutual understanding and agreement in actions to be taken. Still there is much research that needs to be done in the area of why drugs are being taken in the way that they are and how to change unwanted behavior. These two issues both have to do with human behavior, structure and organizational factors and thus have to be researched using methods and theories from behavioral and humanistic

sciences. Social pharmacy research and pharmacy practice research form the surrounding framework. The aim of this research is 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.

The perceptions among DTC key persons reveal an ongoing development of the role of the DTCs, including a more complex notion of the DTC goals and strategies (The trend was to focus both on improving economic and quality aspects of medication use and to consider new target groups for DTC activities. Patients were considered, but involving patients as subjects was not a major concern. The results also show that different ways to perform Pharmaceutical Care have been developed based on different care ideologies, e.g. patient-centered ideology and EBM, which includes a biomedical understanding of health. In another study it was shown that a large proportion of older people living in the community have difficulties with Medication Management (MM). A fairly large proportion of older people were not able to open three different kinds of medicine containers. A large proportion among those that did not manage to open the containers did not receive help with their own medications. Also, results from a (more comprehensive) MM test correlated poorly to the self-reported ability to manage medications. In the study it was also shown that there are older people that experience difficulties when swallowing medicines and that these people took a larger volume of tablets than others. In a study of necessary counseling in community pharmacy it was shown that 16 % of the patients were not asked necessary questions nor received necessary information when purchasing their prescribed medicine at a community pharmacy. Counseling was affected by type of drug, staff education and age, number of waiting customers, type of pharmacy and time of day. It is clear from the results that there are many factors influencing patients' and customers' drugs use behavior. There is room for improvement when it comes to pharmacist, and other health care workers performance. A change towards a more patient-centered perspective would probably lead to a better use of medications and probably to a decrease in drug related morbidity.

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

**Participants: Inger Holmström, Urban Rosenqvist**

This is a PhD project run in collaboration with the Karolinska Institute. Using qualitative methods, we have investigated emergency physicians' expectations of a computerized drug prescribing support system before it was implemented. The expectations were high and the physicians were eager to use it.

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

were not an integrated part of their drug prescribing work. Instead, they leaned on personal experiences and discussion with colleagues.

## **Embodied Competence of Physiotherapy**

**Participants: Madeleine Boll, Urban Rosenqvist, Eva Boström**

The purpose of the project is to describe ways of understanding and approaching physiotherapy by interviewing professionals who no longer work with individuals but with groups or organizations. In Study I seven physiotherapists in primary care working with health promotion in compulsory schools have been interviewed. The aim of this study is to describe their understanding of their job in a new context. In Study II twenty one physiotherapists now working on organizational levels in health care organizations have been interviewed about their understanding of their work. Qualitative methods have been used in the two studies.

## **Telenursing in SWEDEN: can competence and safety be developed?**

**Participants: Annica Ernesäter, Elenor Kaminsky, Inger Holmström, Urban Rosenqvist**

During the last years centralization of telenursing services has occurred in Sweden with a national telephone number for the entire country. In connection with this, the use of computerized decision support has increased. Hence, two studies have focused on telenurses' experiences of working with computerized decision support from different angles. Qualitative methods were used to analyze interviews with telenurses. One analysis resulted in three main categories and two formed a theme: *Being strengthened, but simultaneously controlled and inhibited*. The content of two of the main 109 categories which formed the theme were latent, allowing interpretation of the content into a theme. The decision support was perceived to be incomplete and lacking information, and not fully adapted to telenurses way of working. Yet it was a useful tool that provided a sense of security. During 2007 we collected and analyzed 450 incident reports regarding perceived errors within the context of Swedish Health Care Direct (SHD). The aim of that study is to describe errors that lead to an incident report and to analyze differences among incident reports based on who is reporting the error.

One third to 40% of calls to telenursing services is estimated to be about children, but few studies address this subject. This highlights the need to study authentic telephone calls from parents calling the telenursing service about children issues. A study of one hundred and ten telephone calls between mothers / fathers and telenurses has begun during 2008, and intend to describe call length, word spoken by each part respectively, reasons for and results of calls and gender aspects regarding parents and children. The knowledge generated about paediatric calls can be used in competence development for telenurses and for administrators working with telenursing development. We also hope to increase the scientific interest for this subject from an international perspective.

In another study we investigated the variation in ways of understanding work among a group of Swedish telenurses. Data from 17 interviews telenurses was analyzed using a phenomenographic approach. Five different ways of understanding work were identified: (1) Assess, refer and give advice to the caller. (2) Support the caller. (3) Strengthen the caller. (4) Teach the caller. (5) Facilitate the caller's learning. The first way can be seen as a base for the work of telenursing, the second has components of

traditional caring and the third is a coaching function. In the fourth way the work of telenursing contains a teaching component, but having the caller's learning in focus is only expressed in the fifth way. Telenurses who expressed the fifth way included all other ways of understanding. No new categories emerged in the new interviews. The categories can be seen as a telenursing work map. They are all valuable and can be used for reflection, to expand the understanding of work, when developing tomorrow's telenursing profession.

Furthermore, ethical dilemmas and gender related problems in Swedish telenursing have been studied. Both these aspects seem to be common in day-to-day clinical practice of telenursing. Ethical dilemmas concerning patients' autonomy and integrity were common, and cross-cultural encounters were highlighted as particularly challenging due to the new multicultural Swedish society. Priority setting between caregivers might put additional strain on telenurses. Regarding gender aspects telenurses found it easier to talk to female callers, as they were perceived to be more submissive and take on a "wait-and-see" advice. Male callers were experienced as being more aggressive and not as trustworthy in their parental role.

## **Understanding Oral Cancer – A Life world Approach**

**Participants: Marta Röing, Inger Holmström**

Dental involvement with oral cancer patients during their treatment and rehabilitation can be long and intense. How can dental personnel better understand their role in the treatment of these patients? How does treatment affect the patients and their spouses? In searching for answers, the theories of phenomenography, phenomenology and hermeneutics are used to describe and interpret the experiences of the hospital dental treatment teams, oral cancer patients, and their spouses.

Study I reveals that hospital dental treatment teams perceive the encounter with head and neck cancer patients in three qualitatively different ways; as an act of caring, as a serious and responsible task, and as an overwhelming emotional situation, indicating that they are not always able to lean on education and professional training in dealing with situations with strong emotional impact.

Study II gives insight into the life world of oral cancer patients, and how the patient becomes embodied in a mouth that is increasingly 'uncanny', as it slowly ceases to function normally.

Study III shows that oral cancer puts a hold on the life world of the patients' spouses which can be described as 'living in a state of suspension'. These findings suggest that the support needs of patients and spouses appear to be greatest at treatment end, when, upon returning home, they are faced with the accumulated impact of the patients' sickness and treatment. Study IV gives insight into what it may mean to live with the consequences of oral cancer, revealing a silent physical, emotional and existential struggle to adjust to a changed way of living.

These studies raises the question if today's' organization of oral cancer care can meet the varying emotional and existential needs of treatment teams, patients and spouses that were brought to light.

## **Balint groups for general practitioners – a means of developing new understanding in the physician-patient relationship**

**Participants: Dorte Kjeldmand, Urban Rosenqvist, Inger Holmström**

The general practitioner has a central position in the health care system, but demands have increased and there are signs of exhaustion in the corps. Patient-centeredness is beneficial for patients and probably for the outcome of health care, but patients are dissatisfied with their encounters with physicians. In Balint group's general practitioners study and gain further understanding of the physician-patient relationship by reflection on their own experiences. A patient-centered view is inherent in the Balint method. The study aims at exploring effects of Balint groups as experienced by members and leaders.

General practitioners with and without Balint group experience are compared by means of a questionnaire, using statistical methods. General practitioners with Balint group experience are interviewed. Balint groups are viewed critically in interviews with Balint group leaders, with focus on difficulties and dropouts from the groups.

The study shows positive experiences of Balint group participation in the physicians' working life in terms of feeling of control and satisfaction, and in relations to patients, particularly patients with complex problems. Balint groups are found to fit into modern theories of small groups as complex systems, submitted to group dynamics that are sometimes malicious. Professionally conducted Balint groups seem to be a gentle, efficient method to train physicians, but with limits. Participation of a member demands a stable psychological condition and an open mind, and obligatory Balint groups are questioned.

The study concludes that Balint groups are generally beneficial for general practitioners' working life as a means to enable the physicians to endure, even thrive in their job. The method facilitates development of new understanding of the physician-patient relationship with possible positive effects for the patient as well.

## **Understanding life after stroke**

**Participants: Finn Hjelmblink, Cecilia Bernsten, Margareta Sanner, Inger Holmström, Urban Rosenqvist**

Qualitative methods based on different theories are used to investigate the meaning of stroke and subsequent rehabilitation to 19 stroke survivors. The essence of the meaning of stroke to those who postponed treatment was: *Need of not giving up control*. Three themes made up this structure: *Acting as if nothing has happened*, *Need of control of decision-making*, *Need of being emotionally met as persons, not patients in consultations about stroke*. Health care information has to convey the notion that emergency care of early stroke symptoms is a prerequisite, and not a threat to control. The core category of rehabilitation was social re-integration. The survivors responded with defenses and coping strategies to overcome loss of certainty, and rehabilitation strategies to regain play in togetherness with near ones. Elderly Swedish stroke survivors need support from professionals in developing constructive defenses and coping strategies to achieve social reintegration.

The stroke accident had caused a disruption in the lives of the patients, and a new awareness of human temporality and their uncertain future. Confronted with these problems of time, the stroke victims constructed narratives on the time models: time cycles and dissolution of time limits, exchange of time and exclusion from time. In this way, stroke patients handled their uncertain future by using temporal models in their narratives. Professionals can support stroke patients by reinforcing these models. Furthermore, we tried to reveal the meaning of rehabilitation to an aphasic person in a case study. The informant lived in a dichotomized situation. He was supposed to train in



a goal oriented way and to believe in recuperation. At the same time he had to prepare himself and his next of kin for the consequences of failure. The impairment of aphasia misled the informant and his physician to exclusively focus on language therapy, leaving the informant unsupported in other important aspects of rehabilitation

## **Elderly Care on Contract-basis: How Can Quality be Ensured?**

**Participants: Ulrika Winblad, Ragnar Stolt**

This is a project that is run in collaboration with the Dept of Government, Uppsala University (project leader Paula Blomqvist, associate prof). This project examines how Swedish municipalities supervise the quality of care services contracted out to private firms. The practice of contracting is fairly new in Swedish elderly care, but currently about 12% of all publicly financed care services for the elderly are carried out by private providers, mostly large, for-profit firms. There is great local variety, where many of the 290 municipalities have no private contracting, whereas others contract out more than half of all services they provide for the elderly to private firms. Even if care services are contracted out, local authorities (municipalities) are still legally obliged to ensure that the services are of high quality. The main question in the project is how they perform this function and what sanctions they use against the private providers if they find the care quality to be low?

The methods used in the project includes analysis of juridical and political documents (contracts, policy statements) as well as interviews with politicians, civil servants and private providers in four selected Swedish municipalities. The project brings knowledge of the new phenomenon of privatization which is a new mode of governance in Swedish health and social care.

## **The Political Governance and Control of Swedish Health Care**

**Participants: Ulrika Winblad, Mio Fredriksson**

The democratic governance of Swedish health care has some specific features. One of these is the high degree of municipal self-determination, which in 1992 was reinforced through municipal legislation. Another specific feature is the strong tradition of what may be termed *consensus-based steering*, where the intentions of the Swedish parliament and government are carried through in consensus with local government rather than through compelling measures or binding legislation. However, this model has been challenged recently. The national state has made efforts to increase the equivalence in the whole country by imposing more binding regulations. At the same time, many of the county councils emphasize their self-determination and focus more on the regional political collaboration. The potential power conflict between the national and local political government is studied in this project.

More precisely, the implementation of the patient choice reform is studied. Our results so far show that some of the county councils have not implemented the intentions of the patient choice reform. For instance, they have not informed the patients of their rights to choose, or they have introduced hindrances for their choices. The aim of the project is to explain *why* some of the counties have chosen to hinder the reform. What do the county councils see as their primary concern when it comes to the implementation and what are their perceived hindrances? Important as well in the study is to find out how the national political level reacts toward county councils that do not implement the reform. For instance, have they sanctioned these counties? To answer these questions a survey will

be sent to all counties and case studies will be made in three county councils in order to get a more thorough picture of the development. Key persons in the three county councils and on the national political level will be interviewed. The study will bring us knowledge of what principles guide the relation between national and local government and thereby problematize the issue of how extensive the self-determination of the county councils is in practice.

## **Clustering and inertia: structural integration of home care in Swedish elderly care**

**Participants: Nils-Olof Hedman, Urban Rosenqvist**

One project investigates how different ways of implementing the ADEL reform affects the care for the elderly. The empirical data is collected throughout Sweden to enable the study of differently structured organizations. To study the design and distribution of different organizational solutions regarding the responsibility for and provision of home care for elderly in Swedish municipalities, directors of the social welfare services in all Swedish municipalities received a questionnaire about old-age care organization, and especially home care services and related activities. Rate of response was 73% (211/289). Three different organizational models of home care were identified. The models represented different degrees of integration of home care, i.e. health and social aspects of home care were to varying degrees integrated in the same organization. The county councils (i.e. large sub national political-administrative units) tended to contain clusters of municipalities (smaller sub national units) with the same organizational characteristics. Thus, municipalities' home care organization followed the county council pattern. In spite of a general tendency for Swedish municipalities to reorganize their activities, only 1% of them had changed their home care services organization in relation to the county council since the reform. The decentralist intention of the reform - to give actors at the sub-national levels freedom to integrate home care according to varying local circumstances - has resulted in a sub-national inter-organizational network structure at the county council, rather than municipal, level, which is highly inert and difficult to change.

## Preventive Medicine

Research Group Leader Johan Hallqvist, MD, PhD, BSc,  
Professor

The chair in preventive medicine was established in September 2008 when Johan Hallqvist was installed as the first professor in preventive medicine at Uppsala University. Before, he was professor in social medicine, especially social epidemiology and health policy research at Karolinska Institutet (KI) in Stockholm. His research focuses on mechanisms explaining the social inequalities in risk of disease and the aim is to contribute to evidence based health policy development, health promotion and risk management. Research areas of special interest:

- theories of the life course approach in current epidemiology and pertinent empirical topics like the combined effect of early life and later life risk factors on health and morbidity
- the role of social context in the causation of disease and how it interacts with human biology
- risk factors triggering the onset of health problems

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### **Dissertations 2006-2008**

1. Rickard Ljung. Socioeconomic Inequalities in Health - Epidemiological studies of disease burden, mechanisms, and gender differences. Stockholm: Karolinska Institutet 2006.

2. Carolina Bigert. Cardiovascular disease among professional drivers and subway staff in Stockholm. Stockholm: Karolinska Institutet 2007.

### **Ongoing PhD-projects**

Kristiina Rajaleid: Early and later effects on cardiovascular disease. Supervisors: Johan Hallqvist and Denny Vågerö (CHESS, Stockholm University).

Hanna Hultin: Non-medical risk factors and triggers of sickness absence – cohort and case-crossover studies. Supervisors: Jette Möller (KI), Johan Hallqvist, Kristina Alexandersson (KI), Ingvar Lundberg (Occupational medicine, Uppsala University).

Jenny Hansson: Health effects of snus. Supervisors: Cecilia Magnusson (KI), Rosaria Galanti (KI), Johan Hallqvist, Anders Ahlbom (KI).

Kyriaki Kosidou: Etiology of and trajectories in depression and suicidal behavior in young adults. Determinants and gender differences. Supervisors: Cecilia Magnusson (KI), Christina Dalman (KI), Göran Isacsson (KI), Johan Hallqvist.

Lena Lundholm: Use of psychoactive substances as a risk factor for extrovert and introvert violence. Supervisors: Ingemar Thiblin (Forensic medicine, Uppsala University), Johan Hallqvist, Claudia Fahlke (Psychology, Gothenburg University).

Emma Björkenstam: Socioeconomic inequalities in mental illness Epidemiological life course studies of morbidity, medication and mortality. Supervisors: Rickard Ljung (EpC), Christina Dalman (KI), Johan Hallqvist.

Charlotte Björkenstam: Socioeconomic inequalities in the risk of suicide – epidemiological studies of school grades, criminal records, and medications in young adults. Supervisors: Rickard Ljung (EpC), Johan Hallqvist, Gunilla Ringbäck (EpC), Peter Nordström (KI).

Frida Fröberg: Ung vuxna och problem med spel om pengar. Supervisors: Anders Tengström (KI), Johan Hallqvist.

Mats Martinell: Behandling, morbiditet och mortalitet vid typ 2 diabetes – en praxisstudie i Uppsala län åren 1993-2005. Supervisors: Jan Stålhammar (Public health and Caring Sciences, Uppsala University), Johan Hallqvist.

## **Other research projects**

Most of these projects are external but with active on-going collaboration and in almost all Hallqvist was joint applicant for funding.

### **1. Case-crossover projects**

In these projects we aim to identify triggers of acute health events, that is, risk factors with very short induction times, and to quantify their effects. We use the novel epidemiological methodology called the case-crossover design. In the first four case-crossover projects we are trying to apply the design to data bases extracted from Swedish National registers.

- a. 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). Collaborators: Jette Möller (KI), Johan Hallqvist, Mauricio Malfert (KI), Johan Fastbom (KI), and Kristina Johnell (KI).
- b. Psychiatric care as acute deterrant or trigger of suicide. The study is based on record linkage between inpatient, outpatient and cause-of-death registers. Collaborators: Jette Möller (KI), Johan Hallqvist, Mauricio Malfert (KI), Christina Dalman (KI), Susanne Wicks (KI), Eleonor Mittendorfer-Rutz (KI).
- c. Surgical procedures as triggers of myocardial infarction. Based on record linkage between hospital registers and myocardial infarction incidence registers. The trigger effect is well known and a RCT testing beta blockers as profylaxis is ongoing. We aim to quantify the risk with different types of surgical procedures. Collaborators: Jette Möller (KI), Johan Hallqvist, Mauricio Malfert (KI), Anders Ekbohm (KI), Per Gannedahl (KI).
- d. Acute life events (like death of close relative) as triggers of acute diseases like myocardial infarction and stroke. Based on record linkage between multigenerational register and the hospital and the cause of death registers. Collaborators: Jette Möller (KI), Johan Hallqvist, Mauricio Malfert (KI), Anders Ekbohm (KI).
- e. TUFS (Swedish acronym for triggers triggers of sickness absence). Part of Hanna Hultin's thesis work. Based on extensive data collection from more than 1000 spells of sickness absence at six work places. Collaborators: Jette Möller (KI), Johan Hallqvist, Kristina Alexandersson (KI), Ingvar Lundberg

- f. TOFA (Triggers of falling). Based on data collected from old men and women with hip fractures. Collaborators: Lucie Laflamme (KI), Jette Möller (KI), Johan Hallqvist, Karin Engström (KI).
- g. Psychoactive substances as triggers of violence. Lena Lundholm's thesis work. Based on data collection from individuals in custody in Stockholm because of criminal activities including violence (The Stockholm Social Medicine Custody Project). Collaborators: Anders Thiblin (Forensic medicine, Uppsala University), Lena Lundholm, Claudia Fahlke (Psychology, Gothenburg University), Johan Hallqvist.
- h. Air pollution triggering myocardial infarction. Based on the Onset part of the SHEEP study with data on air pollution added. Collaborators: Niklas Berglind (KI), Johan Hallqvist, Petter Ljungman (KI), Tom Bellander (KI), Göran Pershagen (KI), Jette Möller (KI).

## **2. Life Time Health: the effect of social trajectories and social transitions on subjective 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. Collaborators: Johan Hallqvist, David Blane (London University), Eva Vingård (Uppsala University), Jette Möller (KI), Mauricio Malfert (KI), Christina Halford (Uppsala University).

## **3. Pain in the body and the soul**

The aim is to identify life course influence on psychological well-being, psychological ill-health, depression and musculoskeletal pain. In this project we also use the new Stockholm Public Health Cohort (SPHC) and national register data bases. Part of the funding is from FAS's Women's Health Program. Kyriaki Kosidou's thesis work is part of this project but there are also other sub-projects. Collaborators: Cecilia Magnusson (KI), Johan Hallqvist, Christina Dalman (KI), Lars Alfredsson (KI), Eva Skillgate (KI).

## **4. How gender equality in early parenthood affects health and further welfare development among parents and children.**

Based on register information for all children in specific birth cohorts and their parents. Collaborators: Anna Månsdotter (KI), Lars Lindholm (Umeå University), Johan Hallqvist, Michael Lundborg (KI), Aki Tsuchiya (Sheffield University).

## **5. Etiologic and prognostic risk factors in myocardial infarction.**

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



information makes it possible to study new question. Collaborators: Imre Janszky (KI), Staffan Ahnve (KI), Rickard Ljung (EpC), Anders Ahlbom (KI), Johan Hallqvist.

## **6. Social capital, social inequality and health (different outcomes)**

Investigates the health effects of various forms of contextual social capital on the parish level. Based on SPHC and registers of the total population in Stockholm County. Collaborators: Karin Engström (KI), Johan Hallqvist (KI).

## **7. How much of the population burden of disease can be attributed to socioeconomic inequality.**

Several meta-analyses are first conducted to obtain estimates of the necessary parameters and then calculations of attributed disability adjusted live years (DALYs) will be made. Collaborators: Tahereh Moradi (KI), Johan Hallqvist, Colin Mathers (WHO), Peter Allebeck (KI), Edison Garcia (KI), Anna Sidorchuk (KI).

## **8. Psychosocial work environment and stroke.**

Investigates this question in several different data bases. Collaborators: Sanna Toivanen (CHESS, Stockholm University), Johan Hallqvist, Birgitta Stegmayr (EpC), Petra Lindfors (Psykology, Stockholm University), Urban Janlert (Umeå University), Tomas Hemmingsson (KI). Örjan Hemström (Board of higher education).

## **Other projects**

### **The work environment and musculoskeletal disease.**

A project set up by SBU – The Swedish Council on Technology Assessment in Health Care to examine the amount of scientific evidence supporting a causal effect of various work environment characteristics on risk of musculoskeletal diseases. The aim is to establish the evidence base for health promotion, prevention and for decisions regarding health and social insurance. Chaired by Christer Edling. Experts: Maria Feychting, Johan Hallqvist, Carina Nordander, Jorma Styf, Kjell Thorén, Ewa Wiggeus-Törnquist.

### **SINGS (Stockholm Interdisciplinary Graduate School in Register Based Research)**

This graduate school in epidemiology received funding from the Swedish Research Council to become the teaching support to the research group nodes that were created at different universities as a result of the Swedish Research Council's SIMSAM grant application call in 2008. Hallqvist is a member of the steering committee which is chaired by Olof Akre (KI).

# Psychosocial oncology and supportive care

Research Group Leader Louise von Essen, PhD, Professor

## **Members of the group 2008**

Therese Berglund, MSc, Research assistant, Department of Public Health and Caring Sciences, Uppsala University

Per Carlbring, Associate professor, Department of Behavioural Sciences and Learning, Linköping University

Martin Cernvall, MSc, PhD student, Department of Public Health and Caring Sciences, Uppsala University

Gunn Engvall, MSc, PhD student, Department of Women's and Children's Health, Uppsala University

Camilla Fröjd, MSc, PhD student, Department of Public Health and Caring Sciences, Uppsala University

Kristina Haglund, PhD, Senior lecturer, Department of Neuroscience, Uppsala University

Mariann Hedström, PhD, Senior lecturer, Department of Public Health and Caring Sciences, Uppsala University

Lena Högberg, MSc, PhD student, Department of Women's and Children's Health, Uppsala University

Annika Lindahl Norberg, PhD, Researcher, Department of Women's and Children's Health, Karolinska Institutet

Björn Lindgren, Professor, Lund's University Centre of Health Economics, Department of Health Sciences, Lund University

Gustaf Ljungman, Associate professor, Head of pediatric oncology unit, Academic Children's Hospital, Uppsala

Susanne Lorenz, Research assistant, Department of Public Health and Caring Sciences, Uppsala University

Elisabet Mattsson, MSc, PhD student, Department of Public Health and Caring Sciences, Uppsala University and The Vårdal Institute

Ulrika Pöder, MSc, PhD student, Department of Public Health and Caring Sciences, Uppsala University

Inger Skolin, PhD, Senior lecturer, Department of Laboratory Medicine, Karolinska Institutet

## **Publications 2006-2008**

1. Hedström, M., Kreuger, A., Ljungman, G., Nygren, P. & von Essen, L. (2006). Accuracy of assessment of distress, anxiety and depression by physicians and nurses in paediatric oncology care. *Pediatric Blood & Cancer*, 46, 773-779.

2. Haglund, K., von Knorring, L. & von Essen, L. (2006). Psychiatric wards with locked doors – advantages and disadvantages according to nurses and mental nurse assistants. *Journal of Clinical Nursing*, 15, 387-394.
3. Fröjd, C. & von Essen, L. (2006). Is doctors' ability to identify cancer patients' worry and wish for information related to doctors' self-efficacy with regard to communicating about difficult matters? *European Journal of Cancer Care*, 15, 371-378.
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11. Jörngården, A., Mattsson, E. & von Essen, L. (2007). Health-related quality of life, anxiety, and depression among Swedish adolescents and young adults with cancer. *European Journal of Cancer*, 43, 1952-1958.
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15. Högberg, L., Ljungman, G. & von Essen, L. (2008). Randomized interventions for needle procedures in children with cancer. *European Journal of Cancer Care*, 21, Epub ahead of print.
16. Pöder, U. & von Essen, L. (2008). Perceptions of support among parents of children with cancer: a prospective, longitudinal study. *European Journal of Cancer Care*, 21, Epub ahead of print.
17. Mattsson, E., Lindgren, B. & von Essen, L. (2008). Are there any positive outcomes related to childhood cancer? A review of the literature. *Acta Oncologica*, 47, 199-206.

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2. Mattsson, E. (2008). *Cancer During adolescence: Psychosocial Consequences and Methodological Issues*. Acta Universitatis Upsaliensis Uppsala.
3. Pöder, U. (2008). *Posttraumatic Stress Among Parents of Children on Cancer Treatment, Support, Care and Distress*. Acta Universitatis Upsaliensis Uppsala.

## **Agencies that support the work/Funding 2006-2008**

### **2006**

The Swedish Children's Cancer Foundation: 2,600,000 SEK

The Swedish Cancer Society: 400,000 SEK

The Vårdal Institute: 220,000 SEK

### **2007**

The Swedish Children's Cancer Foundation: 2,100,000 SEK

The Swedish Cancer Society: 400,000 SEK

The Vårdal Institute: 60,000 SEK

### **2008**

The Swedish Children's Cancer Foundation: 1,700,000 SEK

The Swedish Cancer Society: 500,000 SEK

The Swedish Research Council: 350,000 SEK

## **Project 1: Cancer during adolescence. Psychosocial and health economic consequences**

### **Co-workers**

Gunn Engvall, Louise von Essen, Gustaf Ljungman, Elisabet Mattsson, Inger Skolin

### **Aim**

To (A) investigate the potential psychosocial and health economic consequences of cancer during adolescence; (B) compare the psychosocial and health economic situation for those struck by cancer during adolescence and those not struck by cancer during adolescence, and (C) explore whether there exist any positive psychosocial consequences of cancer during adolescence, and if so explore whether these will wear off or are permanent.

### **Methods**

The project is based on a longitudinal design with seven assessments from one month to ten years after diagnosis and a comparative design. Sixty adolescents with cancer and 300 healthy matched controls were included. Adolescents with cancer have been included at three of the six Swedish centres for paediatric oncology: Lund, Umeå, and Uppsala. Questions about quality of life, depression, and anxiety are answered over the telephone. In addition, those struck by cancer answer questions about disease- and treatment related concerns, how they handle these concerns, and about potential negative and positive experiences of cancer.

## **Project 2: Occurrence and development, and treatment of posttraumatic stress disorder among parents of children with cancer**

### **Co-workers**

Per Carlbring, Louise von Essen, Annika Lindahl Norberg, Björn Lindgren, Gustaf Ljungman, Susanne Lorenz, Ulrika Pöder

### **Aim**

The main aims are to, among parents of children with cancer: (A) describe occurrence and development of cancer-related posttraumatic stress symptoms (PTSS) and posttraumatic stress disorder (PTSD), and perceptions of support and of the child's illness-related situation; (B) inductively explore experiences of having and caring for a child with cancer; (C) investigate the health-related costs for those who are: PTSD negative, PTSD positive and not treated for it, and PTSD positive and treated for it, and (D) investigate whether PTSS and PTSD while the child is on treatment, perceptions of support, perceptions of the child's illness-related situation, and/or experiences of having and caring for a child with cancer predict PTSS and PTSD after end of treatment

### **Methods**

Aims A-D are investigated in a study with a longitudinal design covering seven assessments from one week after the child's diagnosis to five years after end of treatment. 259 parents have been included at four of the six Swedish centres for paediatric oncology: Gothenburg, Linköping, Umeå, and Uppsala. To quantify health-related costs in comparison with the general population the sample will be compared to a sub-sample of the data base HILDA (Health and Individuals, Longitudinal Data and Analysis, consisting of parents with children in the same age range (0-18 years). HILDA includes all people who have been interviewed at least once in the Survey of Living Conditions (ULF), administered by Statistics Sweden since 1975. The control group is, hence, a sub-set of the random sample of the Swedish population, aged 16-84, which is used for the ULF surveys and is approximately 3-4 times larger than the study group. Also included in HILDA are individual data from the National Board of Health and Welfare on inpatient care and on cancer incidence and treatment, all linked to the individual ULF interview data. Data is collected from parents over the telephone and from registries.

## **Project 3: Treatment of posttraumatic stress disorder among parents of children with cancer with cognitive behavioral therapy over the Internet**

### **Co-workers**

Louise von Essen, Per Carlbring, Martin Cernvall, Gustaf Ljungman

### **Aim**

The overall aim is to, among parents of children with cancer: evaluate the clinical efficacy and cost-effectiveness of an Internet-based CBT treatment for cancer-related PTSS and PTSD among parents of children with cancer. A second aim is to evaluate the

clinical efficacy and cost-effectiveness of the treatment when initiated six vs. seventy weeks after the child's diagnosis.

### **Methods**

The study is based on an experimental design with two conditions to which parents are randomly assigned approximately five weeks after their child's diagnosis: an Internet-based CBT treatment program starting approximately a) six or b) seventy weeks after the child's diagnosis. Parents (N=120) will be included at all six Swedish centres for paediatric oncology. Assessments take place shortly before, shortly after and twelve months after each treatment. The last assessment takes place approximately thirty-three months after the child's diagnosis. Data will be collected over the telephone.

## **Project 4: Research projects on procedural pain in children with cancer**

### **Co-workers**

Louise von Essen, Lena Högberg, Gustaf Ljungman

### **Aim**

To investigate whether children with cancer experience less anxiety, distress and/or pain connected to a routine needle insertion in an intravenous port when subjected to one of four different pharmacological interventions vs. placebo.

### **Methods**

The effects of midazolam, morphine, paracetamol and ibuprofen is examined in four separate double blinded RCTs in parallel groups with intervention vs placebo. Children, parents, and nurses answer questions about children's anxiety, distress, and pain on Visual Analogue Scales.

## **Project 5: Health-related quality of life and needs of care and support among adult Tanzanians with cancer**

### **Co-workers**

From the research group: Louise von Essen. In addition: PhD, Senior lecturer Lena Wettergren, Department of Neurobiology, Care Science, and Society, Karolinska Institutet, and Thekla Kohi, RN, PhD, Head of Nursing School, Golden Masika, RN, Master student, Nursing School, and Edith Mroso, RN, PhD student, Nursing School, Muhimbili University College of Health Sciences, Dar es Salaam, Tanzania.

### **Aim**

To investigate the health-related quality of life and explore the needs of care and support among adult Tanzanians with cancer.

### **Methods**

The project is based on a comparative, explorative design. Patients are interviewed in focus groups and answer questionnaires.

# Research Ethics and Bioethics

Research group leader Mats G Hansson, PhD, Professor

Research Ethics and Bioethics has become increasingly important for Uppsala University concerning research on Research Ethics, Bioethics and Medical Law. Research Ethics involves the application of ethical principles and values to a variety of research topics. It aims to create good research, while at the same time studying what good research is. Bioethics, on the other hand, includes philosophical, theological, legal and social scientific aspects of medicine and biology. Medical law spans a wide range of traditional branches of law and is associated to the Centre through our collaboration with the Department of Law at Uppsala University.

## Members of the group during 2008

Atry, Ashkan, MA, PhD student  
Axelsson, Ewa, LL.M., LL.D. student  
Eninger, Lillianne, PhD, researcher  
Eriksson, Stefan, ThD, researcher, editor: [www.codex.vr.se](http://www.codex.vr.se)  
Evers, Kathinka, Associate Professor of Philosophy, researcher  
Fernow, Josepine, BA, co-ordinator  
Forsberg, Joanna, MD, PhD student  
Gottvall, Maria, RN, PhD student  
Hansson, Mats G., Professor of Biomedical Ethics, centre director  
Hanson, Bo, Associate Professor of Ethics, senior lecturer  
Höglund, Anna T., Associate Professor of Ethics, senior lecturer  
Johnsson, Linus, MD, PhD student  
Kälvemark Sporrang, Sofia, PhD, associated researcher  
Kuhlau, Frida, MSc, PhD student  
Masterton, Malin, BSc, PhD student  
Rodriguez, Alina, PhD, researcher  
Rynning, Elisabeth, Professor of Medical Law, researcher  
Segerdahl, Pär, Associate Professor of Philosophy, researcher  
Svalastog, Anna Lydia, Associate Professor of Religious studies, associated researcher

## Publications 2006-2008

1. Arnetz, JE, Höglund AT, Arnetz, BB, Winblad, U: Development and evaluation of a questionnaire for measuring patient views of involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing*. 2008, 7: 229-238.
2. Arnetz, J.E., Höglund A.T., Arnetz, BB, Winblad Spångberg, U: Staff views and behaviour regarding patient involvement in myocardial infarction care: Development and evaluation of a questionnaire. *European Journal of Cardiovascular Nursing* 7 (2008) 27-35.



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5. Eriksson S, Helgesson G, Höglund A T: Being, Doing, and Knowing: Developing Ethical Competence in Health Care, *Journal of Academic Ethics* 5 (2007), pp. 207-216.
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8. Evers, K., Philosophical challenges for neuroethics. *European Neuropsychopharmacology, Journal of the European College of Neuropsychopharmacology*, Volume 18 Supplement 4 (2008).
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24. Helgesson, G., Eriksson, S., Swartling, U. Limited Relevance of the Right Not to Know—Reflections on a Screening Study, *Accountability in Research: Policies and Quality Assurance*, Volume 14 Issue 3 (2007), pp. 197-209.
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34. Johnsson L, Hansson MG, Eriksson S, Helgesson G., Patients' refusal to consent to storage and use of samples in Swedish biobanks: cross sectional study, *BMJ (Clinical research ed)*. 2008;337:a345
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## Dissertations 2007

1. Källemark Sporrang, S: Ethical Competence and Moral Distress in the Health Care Sector. A Prospective Evaluation of Ethics Rounds, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine 224. Uppsala: Acta Universitatis Upsaliensis. 2007.

## Agencies that support the work/Funding 2008

### Web resource and symposia

#### CODEX

Vetenskapsrådet 666 500

#### Dual Uses of Biomedicine: Whose responsibility?

The Swedish Research Council (Vetenskapsrådet) 50 000

Swedish ministry of foreign affairs (Utrikesdepartementet) 50 000

Swedish Emergency Management Agency (Krisberedskapsmyndigheten) 50 000

Stockholm International Peace Research Institute (SIPRI) 23 000

Riksbankens Jubileumsfond (Bank of Sweden Tercentenary Foundation) 69 000

### Research

#### Cancer Control using Population-based Registries and Biobanks (CCPRB)

EU 467 237

#### Ethical aspects of longitudinal studies involving children

FAS 142 100

#### Is Fair Play Compatible with Doping in Sport?

The Swedish National Centre for Research in Sports (Centrum för Idrottsforskning) 100 000

#### Are codes and guidelines the right way to go?

Riksbankens jubileumsfond (1 472 000 over three years) 490 000

#### Neuroethics

Swedish Brain Power (via Karolinska Institutet) 100 000

**2 207**

Total **837**

## Research projects:

### **AutoCure - Curing autoimmune rheumatic diseases**

#### **Participants**

Mats G. Hansson, Professor of Biomedical Ethics  
Linus Johnsson, PhD student  
Lars Klareskou, Karolinska Institutet (Co-ordinator)

#### **Funding**

European Union

#### **Aims**

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

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

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

### **Autonomy and trust in biobank research**

#### **Participants**

Linus Johnsson, MD, PhD Student  
Mats G. Hansson, Professor of Biomedical Ethics (Supervisor)  
Gert Helgesson, PhD (Supervisor)  
Stefan Eriksson, ThD (Supervisor)

PhD project

**Time table**

- 2006-2012

**Aims**

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

**Cancer control using population based registries and biobanks (CCPRB)**

**Participants**

Mats G. Hansson, Professor of Biomedical Ethics  
Joakim Dillner, Professor, Lund University (Co-ordinator)

- EU network of excellence

**Aims**

The CCPRB network has joined large biobanks with up to 30 years of follow-up and >60.000 prospectively occurring cancer cases and cancer registries with >40 years of population-based registration in order to provide the study base for uniquely large population-based prospective studies on cancer and define and implement a European Quality Standard for Biobanking. The aim is also to enable large-scale, population-based research on evaluation of cancer treatment and design optimal strategies for cancer prevention and its evaluation. Professor Joakim Dillner at Lund University is coordinator of the CCPRB network.

In CCPRB collaboration between large national and international biobank studies is aimed at validating the biological significance of previous research and detecting previously unknown causes of cancer. In order to achieve this goal discrepancy in national policies and regulation regarding information and consent procedures must be overcome. During the first period a comparative analysis of national and international ethical and legal frameworks has been made and on this basis a common ethical framework for all partners have been formulated, and also decided by the assembly of CCPRB. The ethical framework is consistent with general European guidelines, e.g. The Convention on Biomedicine and Human Rights by the European Council. Solutions to specific problems regarding international biobank collaboration are based on sound ethical research and results are

published or submitted to international peer review journals in order to gain academic credibility and international recognition. More information about CCPRB is available at: <http://www.cancerbiobank.org/>.

## **Return of information to individuals – an ethical problem in biobank research**

- PhD project

### **Time table**

- 2007-

### **Aims**

Biobank research generates results and other types of information that may be of clinical relevance to the individual patient or donor, and also to groups of people (e.g. families). The information can for instance concern hereditary disposition or environmental risk factors. It can also be an incidental finding that has nothing to do with the research project and is therefore unforeseeable. How such information should be handled has not been clarified and completely different recommendations have been issued by authorities and other interested parties. The aims of this project are to ethically analyze in which way the different interests regarding return of information should be balanced, and having done this, to propose a manner in which to handle possible return of information to individuals that is both practically doable and ethically acceptable.

### **More information**

- [Joanna Stjernschantz Forsberg](#), MD

## **The dual use nature of biomedical research - security consciousness in bioethics**

- PhD Project

### **Time table**

- February 2007 - 2011

### **Aims**

This project will examine the responsibility of biomedical researchers in preventing proliferation of biological material, technology and knowledge to actors with malicious intents. Much of the biomedical research conducted today is of 'dual-use' nature, which



means that it can have both peaceful (civil) and military applications. The current perception of a bio-terrorist threat (due to recent terrorist events) and the subsequent security countermeasures, demands the scientific community to take responsibility and assist in protecting biological material and knowledge of concern. Central questions include; if biomedical researchers have a responsibility to develop (ethical) guidelines and practices to minimize the risk of proliferation, how ethical security consciousness can be strengthened and if increased security risk resulting in potential conflict with research interest e.g. by compromising the ideal of free research?

#### **Contact and more information**

- [Frida Kuhlau](#), MsC, PhD Student

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

- Research project (Work Package 13 in the COMBINE Consortium).

#### **Funding**

- COMBINE Consortium

#### **Background**

There are both national and international studies on public perceptions of medical research: How we perceive genetic research, and how scientists use human biobanks and animal models. There is, however, a lack of knowledge about how patients, or end users, of this knowledge, perceive these issues. From an ethical point of view, this is a major concern since it is these groups, the patients, that most directly suffer or benefit from the results of the research the scientists conduct. Patients are actively participating by donating blood, medical information and by testing medicines, and patients are in the end also the most important: the end users.

#### **Aim**

- To investigate how patients perceive research on chronic inflammation.

#### **COMBINE**

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

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

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

### **Project Group (Work Package 13) at the Centre for Research Ethics & Bioethics**

- [Mats G. Hansson](#), Professor of Biomedical Ethics
- [Sofia Källemark](#), PhD, Researcher

More information about COMBINE

- [Lars Klareskog](#) (coordinator), Professor, Rheumatology Unit, Karolinska Institutet.
- [www.combinesweden.se](http://www.combinesweden.se)

### **Empower the patient: Hip fracture as outpatient care**

R&D project

#### **Funding**

**Stockholm County Council**

#### **Time table**

- 2005-

#### **Aims**

Within the health-care system, patients are often seen as helpless and in need of caretaking by healthcare professionals. This view may many times be disabling for the health-care process, extending rehabilitation, resulting in great costs both to the patient and to the health-care sector. It would clearly be beneficial if the health-care process could be made more efficient, with more expedient care, a shorter rehabilitation process involving more outpatient care and at the same time could be tailored more specifically to the individual

patient's needs and resources. Empowering patients to take charge of their own health and rehabilitation process is an important step in actualizing the overall goal of a more efficient health-care process.

Hip fracture patients constitute a large and resource-consuming group which could benefit from an increasing extent of outpatient care. A research project has been started, aimed at providing a new treatment framework by combining vertebroplasty, as an effective operative technique for hip fractures, with the patients' personal involvement and control of the rehabilitation process.

Addressing and changing the views and attitudes commonly held within the health-care system was determined to be essential in order for patient empowerment to be feasible. The first phase of the project, which is currently underway, therefore involves an evidence-based program, focused on educating health-care providers in a different way of interacting with patients, highlighting individual patient strengths and resources. After completion of this program, the subsequent phase of the project, involving the development of an individualized treatment and care process, will ensue. This process is designed to be sensitive to the multiplicity of personal values at stake and with self-control of the patient as the fundamental aim. The process starts from the moment of emergency admission of the patient to the clinic and ends when the end point in terms of quality of life during the post-operative rehabilitation phase has been attained.

This is a R&D project funded by the Stockholm County Council that started in 2005. The project is a collaboration between Professor Leif Ryd (Principal Investigator) at the Karolinska University Hospital, Huddinge, and researchers at the Centre for Bioethics.

#### **Contact and more information**

- **Leif Ryd** (Principal Investigator)  
Karolinska University Hospital, Huddinge
- **[Mats G. Hansson](#)**, Professor of Biomedical Ethics  
E-mail: [mats.hansson@crb.uu.se](mailto:mats.hansson@crb.uu.se)
- **[Lilianne Eninger](#)**, Associate Professor, Senior Researcher  
E-mail: [lilianne.eninger@psyk.uu.se](mailto:lilianne.eninger@psyk.uu.se)

### **Ethical dilemmas in telenursing**

Research collaboration

#### **Background**

A qualitative interview study revealed that telenurses experience a wide range of ethically troubling situations, covering subjects such as autonomy, integrity and prioritizing. Although several of the identified dilemmas also occur in other areas of nursing it is reasonable to argue that these situations are particularly challenging in telenursing, as the encounter with the patient is faceless and the nurse can not be sure of the callers' identity.

A similar study has investigated how gender impacts the encounter between the caller and the telenurse. The results revealed several aspects of how gender norms are present in

telenursing. Questions of power relations, the picture of the mother/woman as the primary care taker of small children and distrusting men in their parental role were particularly highlighted.

### **Publications**

1. Holmström, Inger, Höglund, Anna T.: The Faceless Encounter. Ethical Dilemmas in Telephone Nursing. *Journal of Clinical Nursing*. 2007, 16, pp. 1865-1871.
2. Höglund, Anna T.; Holmström, Inger: "It's Easier to talk To a Woman." Aspects of Gender in Swedish Telenursing. *Journal of Clinical Nursing*. In press.

### **More information**

- [Anna T. Höglund](#), Associate Professor of Ethics, Senior Lecturer, Centre for Research Ethics & Bioethics
- **Inger Holmström**, Associate Professor, Department of Public Health and Caring Sciences, Health Services Research

## **Patient participation – implications for myocardial infarction care**

Research collaboration

### **Background**

The project investigates how the demand for involving the patient in the decision-making process concerning his/her treatment and care can be achieved in all phases of myocardial infarction care, from the acute phase to the secondary prevention process. In a qualitative study, made with focus group interviews, patients' and personnel's understanding of patient participation is investigated. Similarly, whether they see it as a desirable concept and if there are situations when participation is not appropriate is studied. Preliminary results show that often patient participation is interpreted as being equivalent to informing the patient or obtaining informed consent from the patient, without involving the patient in the medical decision-making. To seek participation from a patient suffering from acute myocardial infarction poses great ethical challenges upon the staff. To inform the patient in such a situation might be seen as one way to fulfil the legal demand for patient participation in health care.

### **Publications**

1. Arnetz, JE., Höglund A.T., Arnetz, BB, Winblad, U: Staff Views and Behaviour Regarding Patient Involvement in Myocardial Infarction Care: Development and Evaluation of a Questionnaire. *European Journal of Cardiovascular Nursing*. 7 (2008), 27-35.

2. Arnetz, J. E., Winblad Spånberg, U, Arnetz, BB, Höglund AT: Physicians' and Nurses' Perceptions of Patient Involvement in Myocardial Infarction Care. *European Journal of Cardiovascular Nursing*, 2007, doi: 10.1016/j.ejcnurse.2007.05.005.

3. Arnetz, JE, Höglund AT, Arnetz, BB, Winblad, U: Development and evaluation of a questionnaire for measuring patient views of involvement in myocardial infarction care. *European Journal of Cardiovascular Nursing*. In press.

#### More information

- [Anna T. Höglund](#), Associate Professor of Ethics, Senior Lecturer, Centre for Research Ethics & Bioethics
- **Judy Arnetz**, Associate Professor, Department of Public Health and Caring Sciences, Social Medicine
- **Ulrika Winblad Spångberg**, PhD, Department of Public Health and Caring Sciences, Health Services Research

## Vaccine against HPV – Ethical and social aspects: Survey, exploration and intervention

PhD Project

#### Funding

The Swedish Cancer Society ([Cancerfonden](#))

#### Background

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

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

## **Purpose**

The purposes of this project are:

To survey youth's knowledge on sexually transmitted infections and their consequences, together with their views on the use of condoms, with special focus upon HPV and the new vaccine against it.

Through an explorative interview study, using focus group method, examine how midwives and school nurses view their task of informing youths and their parents on the vaccine against HPV.

With these results as a base, carry out a targeted intervention, with the aim of increasing youth's knowledge of STIs in general and of HPV in particular.

To present constructive suggestions of clinical guidance for midwives and school nurses concerning the social and ethical aspects of the new HPV vaccine.

## **Project Group**

- **Tanja Tydén**, Professor of Caring Sciences, Department of Public Health and Caring Sciences (project leader)
- [Anna T. Höglund](#), Associate Professor of Ethics, Senior Lecturer, Centre for Research Ethics & Bioethics
- **Margareta Larsson**, Associate Professor, Department of Women's and Children's Health at Uppsala university
- [Maria Gottvall](#), PhD Student, RN, Caring Sciences, Department of Public Health and Caring Sciences and Centre for Research Ethics & Bioethics

## **Are codes and guidelines the right way to go? On ethical competence in medical practice**

Research project

### **Funding**

Riksbankens Jubileumsfond (Bank of Sweden Tercentenary Foundation) [www.rj.se](http://www.rj.se)

### **Time table**

2006-01-01-2008-12-31

## Description

The number of professional guidelines, research ethics codes and legal regulations have increased tremendously in the last few years. In bioethics there is a strong focus upon such codes and guidelines. However, the fact that ethical concerns increasingly take on a legal form might create a situation where a procedure of legal interpretations replaces ethical reflection.

In this project, the concept of “ethical competence” within the field of medical practice and research is investigated. Further, the importance of ethical guidelines in the development of such competence is studied. In a philosophical study a number of ethical guidelines are analyzed. In an empirical investigation doctors and nurses involved in medical practice and research are interviewed about how they make ethical decisions and whether or not they are familiar with any ethical guidelines for their work.

Finally, the results from these investigations are analyzed through a critical philosophical method where the contemporary attitude to ethical regulations is related to models of virtue ethics and communicative theory. The analysis is also made from a gender perspective. The project aims to reach a reasonable model of ethical regulation, given the goal of developing responsible researchers and health care givers in order to protect patients and research persons.

### Collaborators

- [Stefan Eriksson](#), ThD, Senior Researcher
- [Anna T. Höglund](#), Senior Lecturer, Associate Professor (Project
- [Gert Helgesson](#), PhD  
Department of Learning, Management and Ethics (LIME), Karolinska Institutet

### More information

- [Anna T. Höglund](#), Senior Lecturer, Associate Professor
- 

## Is Fair Play Compatible with Doping in Sport?

PhD project

### Funding

- The Swedish National Centre for Research in Sports ([Centrum för idrottsforskning](#)).

### Time table

- 2008-2012

## Aims

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

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

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

## Contact and more information

- [Ashkan Atry](#), PhD Student

## Retrospective DNA technologies and integrity for historical persons

- PhD project

## Time table

- September 2004 -

## Aims

The project investigates the question whether or not dead people in general, and historical persons in particular, can be harmed. With the substantial successes of DNA technology it is now possible to acquire genetic information from very old DNA. DNA-analysis could help to answer questions regarding historical persons, for example whether or not Queen Christina of Sweden was a pseudo-hermaphrodite. Should the dead be respected in these situations or are we free to satisfy our curiosity? What duties (if any) do we have vis-à-vis the dead and what would be the basis of these duties?

## Publications

1. Masterton M, Hansson MG, Höglund AT, Helgesson G: Can the Dead be Brought into Disrepute? *Theoretical Medicine and Bioethics*, 2007, 28: 137-149.
2. Masterton M, Helgesson G, Höglund AT, Hansson MG. Queen Christina's moral claim on the living – justification of a tenacious moral intuition, *Medicine, Health Care and Philosophy*, Vol 10, no 3, pp 321 - 327 (2007), doi: [10.1007/s11019-006-9044-0](https://doi.org/10.1007/s11019-006-9044-0)



### Contact and more information

- [Malin Masterton](#), PhD Student
- Centre for Research Ethics & Bioethics  
Uppsala Science Park  
SE-751 85 Uppsala
- 

### Quality assurance in Swedish health care. Responsibility and regulation

- LLD Project

#### Time table

- 2004-2009

#### Aims

Quality assurance is a vital part of good health care, not least for the avoidance of adverse events and safe-guarding a high level of patient safety. The Swedish Health and Medical Services Act thus explicitly stipulates that the quality of health care shall be guaranteed and systematically and continuously developed (section 31). In order to comply with this requirement, health care providers use a variety of tools. Additionally, there are also several external public agencies providing supervision and different types of legal sanctions in the area of health care.

An ongoing PhD project in Medical Law maps and critically investigates the division of responsibilities in Swedish quality assurance of health care. How do the different parts of the regulatory system interact and is the system as a whole well adapted to its purpose?

In the European context, quality assurance in health care needs to be looked at from a broader perspective. Patients and health care personnel migrate between different member states of the European Union, and health care providers co-operate across borders. How is quality and patient safety guaranteed when patients receive medical treatment abroad, at the expense of their home country? To what extent do present EU regulations offer appropriate protection against substandard performance of migrating health care personnel?

The interaction between EU law and different domestic systems for quality assurance is becoming increasingly important.

- [Ewa Axelsson](#), LLD Student  
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- 

## Ethical aspects of longitudinal studies involving children

- Research project

### Time table

- Publications forthcoming

### Funding

- The Swedish Research Council ([Vetenskapsrådet](#)) and Swedish Council for Working Life and Social Research ([FAS](#)).

### Aims

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

The project is a collaboration between researchers at the Centre for Research Ethics & Bioethics and the ABIS group at the Department of Molecular and Clinical Medicine, Linköping University.

- More information about the [ABIS study >](#)
- ABIS related research on [children's assent and participation in a longitudinal cohort study of child health](#)
- **Collaborators**
- Professor [Mats G. Hansson](#) (Uppsala University)  
Professor Johnny Ludvigsson (Linköping University)  
Gert Helgesson, PhD (Karolinska Institutet)  
[Stefan Eriksson](#), ThD (Uppsala University)  
Ulrika Gustafsson Stolt, PhD (Linköping University).

### More information

- [Stefan Eriksson](#), ThD
- [Mats G. Hansson](#), Professor of Biomedical Ethics

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

### Key words

- Prioritization, patients, ethics, cataract surgery, major joint replacement

### Financial support

- The project is made possible by a grant from The Vardal Foundation For Health Care Sciences and Allergy Research ([Vårdalstiftelsen](#)) and the Uppsala County Council (Landstinget i Uppsala län).

### Objectives

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

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

- **More information:**
- [Mats G. Hansson](#), Professor of Biomedical Ethics
- [Lilianne Eninger](#), Associate Professor, Senior Researcher

### Collaborators:

- **Li Tsai**, MD, Associate Professor, Orthopaedic Surgery, Karolinska University Hospital, Huddinge
- **Kjell Keisu**, MD, Orthopaedic Surgery, Karolinska University Hospital, Huddinge
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## Monitoring and improving ethical and medical praxis in perinatal medicine

- Research project

### Time table

Publications forthcoming

We examined ethical praxis related to medical care of children. The first segment of this project consisted of parental attitudes and behavioural intentions among expectant parents which yielded several studies. We examined parents willingness to allow their children and children in general to participate in clinical research. Children's participation in research is limited. However, their participation is essential for the understanding of various disorders in children and for the development of safe and age-appropriate treatments. Participation in research takes time and in the case of clinical research, involves certain risks to children that must be outweighed by the possible benefit. It is this balance between risk – benefit that is ethically important. Our desire to shield children from unnecessary harm has turned into systematic exclusion of children from the benefits of research! We found that parents were open to research and were willing to allow their children to participate. Two other studies concerning expectant parents are in preparation. We examine the interplay between medical risk status and willingness to receive information concerning risk factors. We also look at parents' role in decision-making in the treatment of their child.

The second segment of this project is anchored in clinical praxis. We examine objective verbal and non-verbal behaviours in relation to components of ethical praxis during real-life medical consultations concerning inguinal hernia in paediatric patients. Consultations were digitally recorded and the presence of objective behaviours was scored. These behaviours were related to subjective global ratings of important aspects of the ethical praxis such as respect for integrity and components of informed consent (provision of information, patients'/parents' understanding of information, patients'/parents' participation in decision-making). Our results point to important situational factors such as child's age and the duration of the consultation. Positive non-verbal behaviours, e.g. related to showing interest to the patient, were related to good ethical praxis.

### Contact

- For more information, please contact Dr. [Alina Rodriguez](mailto:Alina.Rodriguez@psyk.uu.se), [Alina.Rodriguez@psyk.uu.se](mailto:Alina.Rodriguez@psyk.uu.se)

### Project group

- [Mats G. Hansson](#), Professor of Biomedical Ethics
- [Alina Rodriguez](#), PhD, Senior Researcher
- [Elisabeth Rynning](#), Professor of Medical Law

**Collaborators:**

- **Gustaf Arrhenius**, PhD  
Department of Philosophy, Stockholm University
- **Uwe Ewald**, Associate Professor  
Pediatrics, Uppsala University Hospital
- **Ulrik Kihlbom**, PhD  
Örebro University
- **Leif Olsen**, Associate Professor  
Surgery, Uppsala University Hospital
- **Torsten Tuvemo**, Professor  
Pediatrics, Uppsala University Hospital
- 

## Undergraduate Teaching

**Vårdfilosofi och etik samt teorier och modeller inom omvårdnad (7,5 hsp) [*Health Care Philosophy & Ethics, Theories and Models in Nursing*]** given every autumn.  
This course is part of OLVO A and Caring Sciences B.

### In educational programmes

#### **Master of Genetic Counselling:**

##### **Etik [*Ethics*] (7,5 hsp)**

Part of the master programme in genetic counselling, the course is given once a year (Autumn)

#### **”New” medical doctor programme (start Autumn 06)**

**Medicinsk etik och medicinsk rätt [*Medical ethics/Law*] (3 hsp)**

#### **”Old” medical doctor programme**

**Medicinsk etik [*Medical Ethics*] (1,5 hsp)**, part of the old medical doctor’s programme, term 7.

#### **Registered nurse programme (7,5 ECTS)**

**Term 1:** Two introductory lectures and two seminars in groups (3 ECTS)

**Term 2:** Lecture on gender and health

**Term 3:** Lectures on prioritizations and ethics at the end of life, seminars in groups (3 ECTS)

**Term 4:** Lectures and seminars on ethics at the beginning of life (0,5 ECTS)

**Term 5:** Lecture on research ethics

**Term 6:** Lecture on ethics in geriatric care (1 ECTS)

**Midwife programme (4,5 ECTS)**

Lectures and seminars (4,5 ECTS)

**Radiology nursing programme**

**Term 1:** Teaching in the Omvårdnad course [*Caring*]

**Term 6:** Teaching in the Omvårdnad vid röntgenundersökningar course [*Caring in radiology examinations*]

**Specialist nursing programmes**

Lectures on demand and in Onkologisk vård [*Oncology*] - Lectures in palliative ethics

**District/Public Health Care nursing programme**

Lectures in the Primary care course (Autumn term)

Lectures in Children's health course (Autumn term)

Anaesthetics and Intensive Care

# Social Medicine

## Research Group Leader Bengt Arnetz, MD, PhD, Professor

The Division of Social Medicine focuses on three major and inter-related research areas. A common factor for all our research is enhancing the scientific understanding of risk- and resiliency factors, as well as related bio-psycho-social mechanisms, of relevance for sustained and equitable occupational and social health and well-being, in addition to effective use of limited financial and human resources. We are also focusing on the changing role of clients and patients in the current transformation of health care and social services systems its implications for important stakeholders and efficacy.

### **1. Bio-psycho-social mechanisms contributing to health disparity and resource utilization.**

Research in this area looks at the relationship between psychosocial determinants, including socioeconomic, coping, lifestyle, and biological disease pathways and its relationship to important public health outcomes, such as disease, mortality, mental health and sick leave behaviour. We are especially interested in furthering the understanding of determinants of sustained health. A new research project is focusing on identifying post-displacement contextual and individual factors related to occupational and social integration of refugees.

Together with The Swedish Social Insurance Administration and the Primary Health Care sector we evaluate the “the Pathway to Work” process. Different research projects develop and evaluate strategies to decrease sick leave, to improve the sick leave processes and facilitate people’s return to work. The Pathway to Work focusing 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.

### **2. Stress factors and psychophysiological consequences of the modern lifestyle.**

Some of our projects focus on the impact on health and well-being from our technology-driven society. The effects on health and sustained performance from wireless technologies, specifically mobile (cell) phones are studied. We have previously reported that exposure to cell phone radiofrequency under controlled laboratory conditions results in changes in cognitive functions, decreased deep sleep, and changes in salivary secretion of cortisol – a key hormone in the body’s stress response.

We are involved in exploratory research assessing the functionality of wireless sensor technologies and mobile phones to assess in real-time stress-related mental and cardiovascular responses.

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. These groups of professionals are critical to maintain a

civil society and to counteract acts of violence and terrorism, still little targeted work to strengthen first responders' health and well-being has been done to date.

### **3. Modern health care – implications for patients, health care organizations and society.**

A number of studies following the implications of current structural and economic changes to patients, employees, health care organizations and society have been carried out. We look at the implication for staff, patients and hard treatment outcome, including cost, morbidity and mortality, from enhancing patient involvement. We have expanded the definition of moral distress and look at the impact on moral competence from ethical rounds in a prospectively controlled intervention study. We also study the inter relationship between health care environment and quality of care patient care.

We are also involved in looking at the implications of patient involvement and “patient centred care” on patient alignment with treatment goals, treatment outcomes, and, possible implications for health care staff work environment and professional role. These studies make use of both self-rated as well as electronic medical records based data, thus allowing for the comparison of patient-based and health system-based outcomes.

### **Research Area 1: Health disparities, resource utilizations and Healthy organizations**

#### **Research group leader: Bengt Arnetz / Ingrid Anderzén**

Healthy organizations are defined as organizations that promote employee and patient/client health and well-being and performance (effective use of resources). The relationship between psychosocial determinants, including socioeconomics, coping lifestyle, and biological disease pathways and its relationship to important public health outcomes, such as disease, mortality, mental health and sick leave behaviour is studied. We have made a number of controlled intervention studies linking improved management too improved stress physiology, well being, productivity and decreased absenteeism in employees. A number of these studies focus on enhancing employee health and productivity within health care organizations. Research projects involve hospital and health care organizations in Scandinavia, the USA as well as increasingly in the Middle East.

In collaboration with the Swedish Social Insurance Administration and the Primary Health Care sector, we have projects assessing the efficacy of various innovative return-to-work strategies, including the concept “Pathway Back to Work” The aims of these project are focusing on the pathway back to work and to identify factors that could help long-listed individuals return to the working life. We develop and evaluate strategies to decrease sick leave and to improve the sick leave process.

A new research area is focusing on identifying professionally-derived risk- and resiliency factors among first responders, incl police, fire fighters, coast guards, and EMS. The multi-year study, carried out in Sweden as well as in the USA, aims at better understanding the characteristics of first responders' risk and resiliency factors, there prevalence as well as means to strengthen sustainable and healthy coping with these challenges.



## **Project 1: Determinants of Individual and Organizational Health in Human Service Professions**

**Participants: Ann-Sophie Hansson, Eva Vingård, Bengt Arnetz, Ingrid Anderzén**

The overall aim of this projects is to identify determinants of individual and organizational well-being among employees in human service professions from a multifactor perspective (involving societal, work-related, biological, individual, health- and sickness absence factors), based on the research question: “What kind of exposures in the complex psychosocial work environment are found to be determinants for individual and organizational well-being among those working in human service professions?”

The project is based on four different studies of various aspects of psychosocial work exposures. The first, examines determinant factors of psychosocial work environment in the Church of Sweden from a top-down perspective. The second study, assesses effects of goal clarity work on organizational well-being in the Church, the third, examines exposures resulting in stress-related sick leave among health care employees and the fourth, is a longitudinal study, assessing effects of organizational change on health and sickness absence also among health care employees.

## **Project 2: Stress and global Self-Rated Health: Exploration of Possible Psycho-physiological Mechanisms and Implications for Public Health**

**Participants: Christina Halford, Lisa Ekselius, Kurt Svärdsudd, Ingrid Anderzén, Bengt Arnetz**

The main aim of this longitudinal project is to investigate associations between psychobiological markers of daily-life stressors and global self-ratings of health, among healthy adult men and women. Results show that global SRH is consistently associated with personal coping resources, psychological well-being and levels of exhaustion. Among men a decrease in SRH below the level of good was associated with significant differences in levels of testosterone and increased levels of prolactin. Results concerning women are under analyses.

## **Project 3: “NySatsa Haninge” – A project to support individual’s on long term sick leave to return to working life through individual development and guidance.**

**Participants: Ingrid Anderzén, Ann-Sophie Hansson, Per Lytsy**

The project ”NySatsa Haninge” has the overall aim to support individuals to return to working life through individual guidance. Fifty participants on long term sick leave have been given the opportunity to personal development and training through various tools for guidance. The objective has been to facilitate the return to working life, full-time or part-time, school studies, or other working life related activities based on the individual’s conditions, motivation and participation. The project started in July 2008

and so far we do not have any results. The project will finally be evaluated after one year.

#### **Project 4: Evaluation of a multidisciplinary collaborative team to optimize complicated rehabilitation processes at the orthopaedic and psychiatric clinics**

**Participants: Ingrid Anderzén, Per Lytsy, Birgitta Pleijel**

The orthopaedic and the psychiatric clinics face a lot of patients who are unable to work due to their health condition. A multidisciplinary collaborative team, including a representative from the Swedish Social Insurance Administration, has been formed at each clinic in order to aid physicians and facilitate and optimize the rehabilitation process for patient at risk for long term sick absence. The value and importance of this work has been evaluated in the work force at the clinics, using a pre- and post questionnaire method.

#### **Project 5: “NySatsa 2” – A project to support individual’s on long term sick leave to return to working life through individual development and guidance.**

**Participants: Ingrid Anderzén, Per Lytsy, Anna Löfgren and Annica Åbring**

The project ”NySatsa 2” has the overall aim to support individuals to return to working life through individual guidance. Fifty participants on long term sick leave have been given the opportunity to personal development and training through group therapy. The objective has been to facilitate the return to working life, full-time or part-time, school studies, or other working life related activities based on the individual’s conditions, motivation and participation. The project started in October 2008 and so far we do not have any results.

#### **Members of the group during 2008**

Ingrid Anderzén, PhD  
Bengt Arnetz, PhD, Professor  
Judith Arnetz, PhD, Associate Professor  
Christina Halford, MD, doctoral student  
Ann-Sophie Hansson, PhD  
Per Lytsy, MD, MD, doctoral student,

#### **External**

Lisa Ekselius, Professor  
Kerstin Hedborg, doctoral student  
Henna Hasson, PhD,  
Bo Karlsson, MD, doctoral student  
Carin Muhr, docent, överläkare  
Birgitta Pleijel, Physiotherapist

Kurt Svärdsudd, Professor  
Eva Vingård, Professor  
Annica Åbring  
Anna Löfgren  
Lena Frenzel

### **Agencies that support the work/Funding 2006-2008**

The Royal Foundation of Sweden (Kungafonden) SEK 1 400 000  
The Municipality of Södertälje SEK 2 100 000  
The Swedish Social Insurance Agency in Uppsala SEK 1 940 000  
The Swedish Social Insurance Agency in Uppsala SEK 112 000  
Arbetsförmedlingen i Uppsala SEK 1 095 000  
Samordningsförbundet I Haninge SEK 1 400 000  
Landstinget i Uppsala Län 1.500 000 SEK  
Dagmar (The Swedish Health Insurance System, The Uppsala County Council),  
Söderström Königska foundation, ALF.  
50% research fellowship at the Gävle high school/university, 50% research fellowship  
at the Uppsala University, Selander's foundation, and research funds from the Uppsala  
University.

### **Dissertations and Awards 2008**

Ann-Sophie Hansson, Determinants of Individual and Organizational Health in Human  
Service Professions, ISSN 1651-6206, Dept of Public Health and Caring Sciences,  
Uppsala University. Supervisor: Ingrid Anderzen.  
Awards: The Personal Renewal project was awarded the Uppsala County County's  
Public Health Award ( Projektet NySatsa/ Uppsala Läns Folkhälsopris, 2008).

## **Research Area 2: Stress factors and psychophysiological consequences of modern lifestyle**

**Research leader: Bengt B Arnetz**

### **Project 1: Mobile phones and health**

**Participants: Bengt B Arnetz, Clairiy Wiholm, Scott Moffat, Lena Hillert, Arne  
Lowden, Torbjörn Åkerstedt, Niels Kuster**

Laboratory-based, double-blind exposure studies using 884 MHz radiofrequency fields  
corresponding to GSM mobile phone use have been carried out. The project has started  
generating publications that have received large international media coverage. The  
project involves researchers at Uppsala University, Karolinska Institute, IT IS  
Foundation-Zurich Technical University, and Wayne State University, Michigan.  
Briefly we have investigated the possible effects on human self-rated health, cognitive  
functions, and physiological reactions to everyday use of mobile phones. Our results  
show that exposure to cell phone like electromagnetic fields under controlled conditions  
relates to changes in cognitive function, headaches, worse deep sleep, and changes in  
the stress hormone cortisol. Overall, the study suggests that cell phone EMF acts as an

unspecific stressor. Possible long-term health and performance implications remain to be elucidated.

## **Project 2: Low impact stress among first responders. Implications for Health and Performance**

**Participants: Bengt B Arnetz, Sarah Thomsen, Dana Nevedal**

Low impact stress among first responders (first line employees within the military, coast guard, customs control, and the police) are at increased risk to suffer from low-level, chronic stress exposure. We were interested to identify more in detail operational, organizational and personal sources of low impact stressors, their impact on health and performance, as well as means to cope with such stress. We carried out focus groups interviews with seventeen first responders. Results generated distinct areas of low impact stress. Results will be used in a subsequent survey-based, large-scale study in which we will collect prevalence data on specific low impact stressors, their relationships to health and performance and effective means to increase stressor resiliency. The research is done in close collaboration with the Swedish Kungafonden.

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

Mobile Manufacturers Forum (MMF)/Euro 830 000.

The Royal Foundation of Sweden (Kungafonden) SKR 1 400 000

### **Members of the group during 2008**

Bengt Arnetz, Professor

Clairy Wiholm, PhD

### **External**

Scott Moffat, Associate Professor

Lena Hillert, Associate Professor

Arne Lowden, PhD

Torbjörn Åkerstedt, Professor

Niels Kuster, Professor

## **Research Area 3: Modern health care – implications for patients, health care organizations and society**

### **Research group leader: Judy Arnetz**

This group conducts multidisciplinary research studying the associations between health care systems, the healthcare work environment, health care processes, patients' and relatives views of care, and treatment outcome. Research in recent years has focused on parental involvement in pediatric hospital care; competence and stress among nursing staff in elderly care; and patient involvement in myocardial infarction care. In all of these projects, the working situation of health professionals is viewed as a key factor for the quality and efficacy of care. Our projects have utilized both quantitative and qualitative research techniques, with a major focus on development and validation of questionnaire instruments.

## **Project 1: The involved patient: implications for treatment outcome and secondary prevention of myocardial infarction.**

**Group participants: Judy Arnetz, Anna Höglund, Ulrika Winblad, Bengt Arnetz**

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

## **Project 2: Questionnaire study of quality of dental care from the patient perspective**

**Participant: Judy Arnetz**

This was a follow-up of a questionnaire study conducted by the research leader in 2004. The project was carried out at the request of Community Dental Care, County Council of Uppsala, Sweden, who also financed this work.

### **Members of the group during 2008**

Judy Arnetz  
Bengt Arnetz

### **External**

Anna Höglund  
Ulrika Winblad

### **Research Grants 2006-2008**

The Swedish Association of Local Authorities and Regions, 800 000 SEK. 2004-2006.

### **Publications 2006-2008**

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### **Centres and Facilities**

CEOS, Center for Environmental Health and Stress Research is a collaborative effort between Uppsala Academic Hospital and Uppsala University. This is a academic research and development center with the overall purpose to improve basic and applied scientific understanding of the mechanisms behind and effective treatment and prevention of stress-related disorders. The Center also evaluates and treat patients referred from the health care sector. The Center is truly translational in nature, with a multidisciplinary composition of researchers and clinicians.

## Social Medicine/ Sociomedical Epidemiology

Research Group Leader Ragnar Westerling, MD, PhD, Professor

In the research of the group we are integrating main fields in social medicine, such as social epidemiology, prevention research and health services research. The aim of the research programme is to 1) develop methods for identifying and analysing the mechanisms behind preventable disease patterns in the population. 2) evaluate the impact of the health care system and other parts of the society on these preventable disease patterns. 3) analyse the associations between the social situation and psychosocial, behavioural and biological risk factors for ill health and how these associations may be influenced in order to improve preventive strategies, 4) develop, plan and evaluate preventive programmes.

This program line is implemented for different fields of public health, in accordance with the Swedish National Public Health Goals, such as the health of children and families, health related to working life, health related life styles as well as health orientated medical care and the prevention of adverse events in medical care. Several doctoral students are involved in these studies and several collaboration projects are included. The research group is multi professional including persons with the backgrounds as medical doctors as well as from behavioural and economical sciences. Several studies have been performed in collaboration with national and international groups and organisations.

### **Members of the group during 2008**

Ragnar Westerling, Professor

Annika Åhs, Dr. Med Sci, Researcher.

Marcus Westin, Med Dr, Research physician

Stefan Kunkel, Dr. Med. Sci.

Marianne Hanning, Dr Med Sci

Peter Berg, Doctoral Student, Research physician

Per Lytsy, Doctoral Student, Research physician

Ulrika Paulsson, Doctoral student

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Susanne Sundell Lecerof, Research engineer, collaboration with Lunds University

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1. Annika Åhs . Health and Health Care Utilization among the unemployed. Uppsala University 2006.
2. Marcus Westin. Health and Healthcare Utilization Among Swedish Single Parent Families. Uppsala University 2007.
3. Stefan Kunkel. Quality Management in Hospital Departments : Empirical Studies of Organisational Models. Uppsala University 2008
4. Lars Age Johansson. Targeting Non-obvious Errors in Death Certificates. Uppsala University 2008.

### **Agencies that support the work/Funding 2006-2008**

Regional variation in avoidable mortality in Sweden. The Swedish National Public Health Institute. 180 000. 2006.

Health and health care utilization among lone parents and their children. Academic hospital, Uppsala, ca 250 000. 2006-2008.

Expectations of statin treatment. Academic hospital, Uppsala. Ca 200 000, 2006-2008.

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### **Project 1: Health and health care utilization among the unemployed**

**Annika Åhs, Gunilla Burell, Ragnar Westerling**

The last decades there have been considerable changes in the Swedish labour market. During the 1990s the level of unemployment increased considerably and the last years the level of sick leave has been high. In a number of studies we are analysing the risk factors for ill-health among different employment groups. We have found that poor self-rated health was significantly higher among the unemployed, than among the employed during both high and low levels of unemployment. The self reported ill health was a predictor of an increased mortality risk independent of the presence of a chronic disease among the unemployed.

In a recent study we have found that the unemployed experiences depressive mood and indications of potential depression already after a few months of unemployment to a higher extent than employed persons. This depressive pattern occurs irregardless of sociodemographic factors, economic situation and social network factors. However, the unemployed abstained from seeking medical care although when they perceived a need for that more often than the employed did.

### **Project 2: Health and health care utilization among lone parent families**

**Marcus Westin, Claes Sundelin, Ragnar Westerling**

We have studied inequity in health and health care utilization with regard to whether parents in Sweden are single or couple. Besides traditional sociodemographic factors, economy and social network.

In the project we also analyse what contribution the concept of social capital may give to the understanding of the health situation of the families.

Both single fathers and single mothers were reporting worse health than their married or cohabiting counterparts. However, single fathers had contact with a physician more frequently than married or cohabiting fathers, whereas single mothers had not. On the contrary, single mothers refrained from seeing a physician, despite a medical need, much more often than non-single mothers. Low level of social capital, when adjusted for socio-economic and socio-demographic variables, was clearly and positively associated with less than good self-rated health. Social capital was unevenly distributed between single and couple mothers but not between single and couple fathers. The thesis also showed, that both lone parenthood and low level of social capital influences also the children's mental health negatively. The analyses were based on SDQ (Strengths and Difficulties Questionnaire) measures of the children's mental health.

### **Project 3: Bicycle helmet use among school-children**

**Peter Berg, Claes Sundelin, Ragnar Westerling**

In a doctoral project for Peter Berg we have analysed the use of bicycle helmets among school children as well as the associations with the involvement of parents and school. There was a clear link between parental involvement, children's attitudes and children's helmet use. However, parental involvement decreased as the children grew older. In a recent study we have further analysed the impact of socioeconomic and psychosocial factors on helmet use as well as the association with other health related behaviours, such as alcohol, smoking, exercise and eating habits.

An intervention study has been performed in a Swedish municipality – Bålsta – aiming at increasing the voluntary bicycle helmet use among school children. A nearby municipality is a reference area in the study. The activities has been conducted towards parents, children and schools. There has been a significantly higher increase of bicycle helmet use among schoolchildren in ages 11-14 years in the intervention community compared to the reference community. Thus it seems as broad community interventions directed not only to the pupils but to the surrounding adults and their organisations has positive effect on the children's health related habits. We have also continued the evaluation after the introduction of a bicycle helmet law for children under the age of 15. Our preliminary results show that the helmet law had limited effect on the children's helmet use, especially when it was not combined with intervention campaigns like those performed in our study in Bålsta.

### **Project 4: Quality systems in hospital departments**

**Stefan Kunkel, Urban Rosenqvist, Ragnar Westerling**

In a recent thesis Stefan Kunkel has analysed what organisational factors that influence the quality of quality systems in medical care. Stefan Kunkel, has analysed interviews with heads and quality managers of hospital departments and surveys to about 600 such



departments. The studies include both qualitative analyses and advanced statistical modelling, such as LisRel-analyses.

The result was a new framework with three organisational aspects of quality systems each with two sub-aspects: structure (resources and administration), process (culture and cooperation), and outcome (evaluation of goal achievement and development of competence). Strong positive relationships were confirmed among structure, process, and outcome. Quality systems could be classified into three organisational degrees. For instance, quality systems of high organisational degree often had adequate resources and administration as well as positive organisational cultures and high cooperation among different professions. Advanced designs required quality systems of high organisational degrees. Examples of such designs were coordination between departments, random check ups, and accreditation. The organisationally demanding quality systems had been implemented through cooperative implementation, that is, directed by managers while at the same time giving opportunities for staff to participate in planning and designing.

### **Project 5: Targeting non-obvious errors in cause of death statistics**

**Lars Age Johansson, Harry Rosenberg, Charlotte Björkenstam, Ragnar Westerling**

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

In a recent study we have performed a structured assessment of the causes of death based on 1200 medical acts. The death certificates identified to be problematic by the ACME-test were about twice as often as other death certificates questioned also in this assessment. For these death certificates a change of the choice of cause of death was suggested. Thus, this test should be useful in screening for potential quality problems in the cause of death statistics. These assessments would be useful also since we in a methodological review published in *Journal of Clinical Epidemiology* have found considerable quality problems in studies aiming at evaluating the quality of causes of death statistics.

### **Project 6: Patients and physicians expectations on lipid-lowering drugs**

**Per Lytsy, Gunilla Burell, Ragnar Westerling**

Preventive treatment with statins is shown to significantly reduce the absolute risk of coronary heart disease; yet long-term compliance is poor. We have studied the expectations and factors that might affect expectations on statin treatment among

patients. A total of 909 Swedish statin users were identified and a questionnaire was used to obtain information on the health of the study objects, cardiovascular risk factors, life style and expectations on statin treatment.

On average, statin treated patients believed that 53.6% of statin users would avoid a coronary event as a result of a five-year treatment period. Thus, patients highly overestimate the general preventive effect of statins. Higher education lowered expectations, but factors commonly used to assess cardiovascular risk, such as age, sex, BMI and previous coronary heart disease, did not affect expectations at all. Patients' expectations of their own possible treatment benefits were found to be more negative among those with a poor social network and patients not socially active.

The study is part of a doctoral project for Per Lytsy. In an ongoing study the physicians expectations and attitudes towards statin treatment are analysed This study is performed in collaboration with the *pharmaceutical committees in the county of Uppsala and Gävle* and supported by the Academic hospital in Uppsala

### **Project 7: Studies of Avoidable mortality and diffusion of innovations** **Ragnar Westerling, Marcus Westin**

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

Our research group is one of the partners of a European research initiative aiming at further developing the method. (Main partner is professor Mackenbach's group at the Department of Public Health at Erasmus University in Rotterdam). Several European countries such as Estonia, France, Germany, The Netherlands, Spain, Sweden, and the United Kingdom, are represented in the project group. The project includes a systematic review of the literature to assess the extent to which different causes of death can now, in the light of available evidence, be considered avoidable, in order to update a set of avoidable mortality-based indicators of the effectiveness of health systems which can be used in surveillance systems. The project also include trend analyses as well as analyses of the timing of introduction of innovations, i.e. whether these coincides with measurable declines in deaths from the corresponding causes. Furthermore the potential influence of changes and variations in cause of death classification rules will be assessed.

## **Project 8: International health advisors**

**Achraf Daryani, Ragnar Westerling**

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

In the first part of the project a cross-sectional study of health and health care utilization and experiences of contacts with health advisors among refugees from Iraq has been performed as a post-doctoral project for Achraf Daryani. In another part a longitudinal study has been designed aiming at analysing the effects of contacts with health advisors on the health as well as on the health related knowledge and behaviours of immigrants to Sweden. The studies are performed in collaboration with *Lund's University, MIM School of Research, Malmö and the Region of Skåne*. The project is funded by the European Refugee Fund. In the longitudinal study, Ragnar Westerling is jointly supervising research engineer Susanne Sundell Lecerof.

## **Project 9: Unhealthy life habits and vulnerability among school-children**

**Ulrika Paulsson, Birgitta Edlund, Ragnar Westerling**

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

The study is based on two questionnaires to school children in school classes 7-9. The first is the survey Life and Health conducted by the county of Uppsala. This material includes data from about 10 000 pupils in 2007. The second is a questionnaire developed for this project and directed to a strategic sample of schools in Sweden. Structural equation models will be used in order to analyse the relation between sociodemographic factors, psychosocial vulnerability factors, health behaviours in general as well as specific health related behaviours. The studies will be included in a doctoral thesis by Ulrika Paulsson.