

## **B: Documentation regarding the level of the Clusters and Research Programmes**

- B.1 Cluster Primary Care**
- B.2 Cluster Innovation of Care**
- B.3 Cluster Public Health**



## B. Documentation regarding the level of the Clusters and Research Programmes

The School for Public Health and Primary Care: Caphri has three clusters of research programmes: Primary Care, Innovation of Care, and Public Health. In this part of the self-evaluation we will describe the research in the three clusters. For each of the clusters, we will discuss focus, objectives and future developments. After this general information on the clusters, we will present information on the research programmes within each cluster.

For each programme, we will give an overview of the tenured scientific staff and the PhD-students. It should be mentioned that only PhD students are counted who have an formal PhD appointment at the School for Public Health and Primary Care: Caphri on reference date 31.12.2006. Also for the input of tenured staff we chose for this reference date.

We also give an overview of the outcome results for each programme. The sum of the output results of the 15 programmes in part B does not match with the output figures in the tables 5.2 and 10.2 in part A. This is due to the fact that a number of Caphri projects are not part of any of the 15 programmes. Therefore the output of these projects are included in the total output at the level of the institute, but not at the level of the programmes. Some of the scientific staff is labelled to two programmes. The publications and PhD theses of these staff members are included as output in both programmes concerned. This means that the sum of the publications and PhD theses of the 15 programmes will be higher than the aggregated results of the institute as shown in table 10.2 in part A. Furthermore, a description is provided of the state of the art, research and key publications and research goals. Finally, for each programme an analysis will be provided.

At the start of the programme structure, in the beginning of 2005, 22 programmes were defined on the basis of retrospective analysis of the quality of research. The programmes were evaluated recently. The conclusion was that 15 programmes are in a stable situation with good to excellent scientific output. These are presented in this part of the self-evaluation. Two programmes (Intellectual disabilities; Infections and antibiotic resistance in primary care) are in a relatively early phase of development and have a small number of staff. The expectation is that these programmes will grow into stable programmes over the next years. Four programmes have been stopped; three have been integrated in other programmes (Evidence based nursing practice, Gender and diversity, Social epidemiology of alcohol use); one programme (Social participation and self-management) will be integrated into a new programme, dealing with Social Medicine. Two research areas (Rehabilitation, European public health) are potentially important themes for the School. How these themes will be incorporated, as independent research programmes or as new issues within available research programmes has to be decided upon in the near future.

## B.1 Cluster Primary Care

### Focus

In primary care the most frequently presented signs, symptoms and chronic diseases belong to four organ systems. Within the Cluster Primary Care, research concentrates on these four systems: the locomotor tract, the respiratory tract, the cardiovascular tract and the gastrointestinal tract. The cluster represents clinical research in diagnosis, prognosis and treatment, with patient health as the central outcome. Many studies are based on large cohorts from population and primary care based registration networks, in which 150,000 patients are continuously followed up. Research on the locomotor tract is done in programme 1 (non-inflammatory conditions), programme 2 (degenerative conditions including osteoporosis) and programme 3 (inflammatory diseases). The respiratory tract is under study in programme 2 (respiratory tract infections) and programme 5 (asthma and COPD), whereas cardiovascular diseases are investigated in programme 4 and gastrointestinal diseases in programme 2. Since inflammatory diseases of the locomotor tract are relatively scarce in daily primary care, these conditions are preferably studied in patients visiting the out-patient department of the rheumatologist (programme 3).

### Objectives

The main objective of this cluster of multidisciplinary research programmes is to optimize patient outcome. Research is focused on clinical improvement of patients with chronic diseases and less on the improvement of organizational aspects of care. This objective is reached by improving the diagnosis and treatment of the chronic diseases studied. Clinical efficacy, effectiveness and cost-effectiveness of innovative interventions are studied. The research methodology and statistical analysis used are comparable in the different programmes. Consequently, exchange of knowledge between the programmes in the area of clinical epidemiology and health technology assessment is crucial.

### Future developments

Because of the ageing population and the fact that patients are more and more dying with a chronic disease than due to this disease, a considerable increase in prevalence of chronic diseases is observed. Moreover, many patients have more than just one disease. This multi-morbidity and consequent multi-treatment (among which multi-drug treatment) leads more and more to a complex health care in which a multidisciplinary approach is of utmost importance. In terms of research it is important that real life situations are studied in which older patients and patients with an accompanying chronic disease than the one studied are not excluded but included. Moreover, due to the ever increasing health care costs, not all diagnostic possibilities and treatments can be applied in all circumstances. This leads to the need of clear guidance on the achievable efficacy in relation to the costs and ethical considerations involved. These developments will probably lead in the coming decades to a shift from a basically curative primary care towards a more preventive primary health care. All these developments will ask for larger study populations in which subgroups with different combinations of diseases and in different circumstances can be studied. Large research cohorts (such as RNH and SMILE) are very necessary but probably not enough. Therefore the School intends to collaborate with other research institutions, both on a national and international scale. The present research cooperatives of Oxford-Leuven-Caphri, AMC-Julius-Caphri, Groningen-IRAS-Caphri, GRIN, SAS and OMART should be supported and strongly developed.

## B.1.1 Primary Care Programme 1: Epidemiology of musculoskeletal Disorders

### B.1.1.1 Leadership

Programme leader: Rob de Bie, Professor of Physiotherapy

Tenured scientific staff (1,55 fte)	PhD-students
Mw. dr. Carolien Bastiaenen	Esther Bols
Prof.dr. Rob de Bie	
Prof.dr. Philip van Kerrebroeck	
Drs. Pieter Leffers	
Prof. dr. Henk van Mameren	
Prof.dr. Lodewijk van Rhijn	
Mw. dr. Judith Sieben	
Dr. Bart Staal	
Prof.dr. Geert Walenkamp	

Table: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	21	35	33
PhD-theses	1	3	2
Funding (Research and contracts)	€ 164.493	€ 313.945	€ 189.287

### B.1.1.2 State of the Art

In the Netherlands, approximately 3 million people (19% of the population) suffer from musculoskeletal complaints. These include non-specific complaints such as back pain, neck pain or repetitive strain injury, chronic inflammatory or degenerative rheumatic disorders and a wide range of sports injuries. Most of these complaints have a tendency to become chronic, especially later on in life. Apart from the personal suffering endured by patients, musculoskeletal disorders cause substantial social economic problems because of the high costs incurred by work absenteeism and work disability.

Musculoskeletal disorders are one of the main reasons for which patients visit their general practitioner and physiotherapist. Due to the ageing of the population and unhealthy life-styles, it is anticipated that the incidence and prevalence of musculoskeletal disorders will increase substantially in the near future. Despite the magnitude of the problem, surprisingly little is known about the etiology and clinical course of most musculoskeletal disorders, or about the determinants of a healthy musculoskeletal system. Moreover, insight into the value of available diagnostic tests and commonly used therapeutic interventions is often lacking. These circumstances have led to the formulation of a consensus document, 'The Bone and Joint Decade 2000-2010 for prevention and treatment of musculoskeletal disorders' (Acta Orthop Scand [Suppl 281] 1998;69). This is an initiative of multiple national and international medical scientific societies and medical journals, with the general purpose of improving the health-related quality of life for people with musculoskeletal disorders throughout the world.

In the Netherlands a substantial number of multiprofessional guidelines for the diagnosis, treatment and prevention of musculoskeletal disorders exist, however successful implementation is hampered by lack of knowledge on implementation, lack of fundamental and intervention research necessary to infuse evidence into guidelines and lack of willingness to use guidelines by the medical profession. The latter is being caused mainly because use of guidelines does not give the professional the impression that it leads to better health care or improved health for the patient.

The expertise of the programme will be positioned and used in ZKO chronic disease as well as in the public health profile and clinical epidemiology field. The programme collaborates with research groups and departments in the academic hospital (physiotherapy, rehabilitation, orthopedics, internal medicine, surgery, urology and radiology), departments in the faculty of medicine (anatomy, general practice, occupational

health epidemiology) and the faculty of health sciences (health counseling and promotion, physical activity and health, nursing sciences). The programme staff also actively participates in research efforts of the azM and the RSI treatment center (joint collaboration between azM, UM and Hogeschool Zuyd).

### B.1.1.3 Research (2004 – 2006) and key publications

#### *Theme: Back*

A comprehensive programme studying effects of interventions in back and neck pain, including systematic reviews and development of guidelines, as well as new surgical and conventional therapies.

#### Projects:

- Etiology & prognosis in Peri Partal Pelvic Girdle Pain, a cohort study among 7500 pregnant women.
- Implementation of pelvic pain treatment according to the KNGF guideline.
- Army low back pain study (ALBATROS) studying rehabilitation of fast exercise programs in army personnel
- Implantation of artificial cervical discs, a randomized clinical trial
- Development and implementation of a low back pain guideline in exercise therapists

#### *Theme: Upper extremity*

This theme studies effects of interventions, especially in relation to KANS (RSI) and shoulder diagnostic procedures

#### Projects:

- CANS in office workers in Sudan, a cohort study among government employees
- CANS in office workers: an aetiology and intervention study
- Dutch shoulder cohort study, incorporating 3 RCT's
- Injection therapy for specific shoulder complaints in a hospital population: an RCT
- Shoulder sonography: a diagnostic triage study
- Physiotherapy in shoulder complaints: an RCT
- Paratonia in the elderly: effect of passive movement therapy, a nested cohort RCT
- Joint protection trial in RA patients

#### *Theme: Lower extremity*

Cohort and intervention driven research, studying etiology, prognosis and interventions in lower limb diseases

#### Projects:

- Knee rehabilitation after TKA: a cluster of three RCTs
- Ankle Sprain guidelines in an international perspective
- Supervised walking therapy in claudication: a cohort nested RCT

#### *Theme: Incontinence*

Fecal and urinary incontinence care and cure projects, as well as clinimetrics

#### Projects:

- Incontinence Care in the elderly in a Swiss nursing home
- Electrical stimulation modalities in urinary incontinence
- Fecal Incontinence guidelines & a physiotherapy clinical trial
- Stress Urinary Incontinence guidelines

#### *Umbrella projects*

These projects link closely with thematic projects but serve mainly for the systematic development of guidelines, process indicators and clinimetrics for diseases under study.

#### Projects:

- NZA – prestatie indicatoren in de zorg
- PSK and pain as benchmarks across guidelines
- Implementation of EPD's
- Functional outcomes in PT rehabilitation – based on ICF

*Key publications*

- Wees Ph J van der, Lenssen AF, Hendriks EJM, Stomp DJ, Dekker J, Bie RA de. Effectiveness of exercise therapy and manual mobilisation in acute ankle sprain and functional instability: a systematic review. *Aus J Physiotherapy* 2006 (52);27-37.
- Hulzebos EH, Helders PJ, Favie NJ, De Bie RA, Brutel de la Riviere A, Van Meeteren NL. Reoperative intensive inspiratory muscle training to prevent postoperative pulmonary complications in high-risk patients undergoing CABG surgery: a randomized clinical trial. *JAMA*. 2006 Oct 18;296(15):1851-7.
- Smits LJ, de Bie RA, Essed GG, van den Brandt PA. Time to pregnancy and sex of offspring: cohort study. *BMJ*. 2005 Dec 17;331(7530):1437-8
- Hoving JL, de Vet HC, Koes BW, Mameren H, Deville WL, van der Windt DA, Assendelft WJ, Pool JJ, Scholten RJ, Korthals-de Bos IB, Bouter LM. Manual therapy, physical therapy, or continued care by the general practitioner for patients with neck pain: long-term results from a pragmatic randomized clinical trial. *Clin J Pain*. 2006 May;22(4):370-7.
- Bastiaenen CH, de Bie RA, Wolters PM, Vlaeyen JW, Leffers P, Stelma F, Bastiaansen JM, Essed GG, van den Brandt PA. Effectiveness of a tailor-made intervention for pregnancy-related pelvic girdle and/or low back pain after delivery: short-term results of a randomized clinical trial [ISRCTNo8477490]. *BMC Musculoskelet Disord*. 2006 Feb 27;7:19.

**B.1.1.4 Towards the future: research goals (2007 – 2009)**

The programme has reached a stabilizing phase given it's four topic area's of research (back, lower- and upper extremity and incontinence), however the 5th theme, guideline development and implementation infuses knowledge from the other four research topic area's and needs therefore extra attention.

In the Netherlands a substantial number of multiprofessional guidelines for the diagnosis, treatment and prevention of musculoskeletal disorders exist. However, they are lacking in adequate description of relevant subgroups or prediction of therapy success in these subgroups, nor can they deliver a prognostic profile. Moreover, even when in some disorders data are available, implementation is hampered by lack of fundamental and intervention research necessary to infuse evidence into guidelines and lack of willingness to use guidelines by the medical profession. The latter is mainly being caused because use of guidelines does not give the professional the impression that applying guidelines leads to better health care or improved health for the patient.

It is also noteworthy that innovation and new evidence take a long time to be incorporated into guidelines. Current processes of updating, maintaining and initiating new guidelines is still relying on time-consuming and personnel intensive methodology, taking on average 3 to 5 years. New and existing guidelines in the physiotherapy domain should be developed in an interactive way, readily accessible to all physiotherapists and validated by means of benchmarking and electronic surveillance of patient and physiotherapist data.

The programme will therefore spearhead additional research efforts in order to enable:

- To study prognosis in musculoskeletal disorders, when patients receive standardized and evidence based interventions according to guidelines
- To develop benchmarks and process indicators, both condition specific, as well as across conditions to more adequately monitor quality and quantity of care
- To study whether guidelines, when continuously updated / improved with relevant prognostic profiles for subgroups, do facilitate implementation of evidence based practice and penultimately leads to better adherence to guidelines and better health outcomes

**B.1.1.5 Final Analysis for Primary Care Programme 1, based on SWOT**

The SWOT analysis of the programme epidemiology of musculoskeletal disorders is largely comparable to the SWOT analysis of the institute / school as a whole. Additionally, the emphasis placed on guideline and cohort driven research, identifying relevant prognostic variables in the course of identified musculoskeletal and chronic diseases, will remain an important spearhead for current and future research. Further, in addition to our traditional clinical epidemiological approach and expertise, cooperation with workers in the (related) field of basic research will be established or intensified (translational medicine).

## B.1.2 Primary Care Programme 2: Diagnostic and treatment of frequently occurring diseases in primary care

### B.1.2.1 Leadership

Programme leaders: Geert-Jan Dinant, Professor of Clinical Research in General Practice;

Dr. Marjan van den Akker

Tenured scientific staff (3,05 fte)	PhD-students
Dr. Marjan van der Akker	Jochen Cals
Prof.dr. Frank Buntinx	Tineke van Geel
Drs. Cees van der Beek	Arjan Plat
Prof.dr. Geert-Jan Dinant	
Prof.dr. Piet Geusens	
Prof.dr. Andre Knottnerus	
Prof.dr. Job Metsemakers	
Dr. Jean Muris	
Dr. Piet Portegijs	
Dr. Mark Spigt	
Dr. Jelle Stoffers	
Drs. Paul Stalenhoef	
Dr. Bjorn Winkens	

Table 1.2: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	59	49	67
PhD-theses	2,5	3,2	2,5
Funding (Research and contracts)	€ 110.143	€ 170.206	€ 127.452

### B.1.2.2 State of the Art

Delivery of primary health care has a clear general basis: (1) open access, implying that everyone can present any problem at any time, and (2) continuity of care, with responsibility in all phases of the health care process. Accordingly, in primary care, the spectrum of patients and health problems encountered is essentially different from referred care, and the ongoing improvement and innovation of clinical and health care interventions represents major challenges.

### B.1.2.3 Research (2004 – 2006) and key publications

This programme concentrates on clinical research in prevention, diagnosis, treatment and prognosis, with patient health as the central outcome variable. The emphasis lies on diagnostic and intervention studies, including the innovation of methods for diagnostic research. In primary care the most frequently presented signs, symptoms and diseases belong to four organ systems. The programme concentrates on these four systems: the respiratory tract, the locomotor tract, the cardiovascular tract and the abdomen. Signs and (medically unexplained) symptoms that relate to more than one system are typical for primary care and thus a part of the program. The international orientation of the programme is reflected by important roles its participants play in international programs for education in primary care research, the presence of PhD students from abroad and the close cooperation with leading groups in and outside Europe. As a logical spin off, cross border differences between primary care systems are investigated. The programme consists of six partly system-oriented subprograms.

#### 1. Respiratory tract infections (RTI)

More than 50% of primary care initiated antibiotic prescriptions for RTI are of questionable value, leading to antimicrobial resistance, described as one of the most serious public health issues of our time. To its

background belong lacking knowledge of the diagnostic accuracies of signs, symptoms and easy to perform laboratory tests for (bacterial) pneumonia. The subprogramme concentrates on these diagnostic and the prognosis issues of RTI, and on interventions on prescription behaviour. In addition, the relationship between environment and respiratory tract diseases in children is studied in industrial areas in Rumania.

#### 2. *Chronic disorders of the locomotor tract*

The effectiveness of primary care intervention programs on the prevention of chronic shoulder pain is studied in patients attending their GP for shoulder pain. Osteoporosis and osteopenia are present in more than half of all post-menopausal women, forming serious risk factors for developing a clinical fracture. In a large cohort we study the diagnostic and prognostic accuracies of easily obtainable determinants for osteoporosis and incident fractures, over a period of five to ten years after assessment.

#### 3. *Cardiovascular signs, symptoms and diseases*

Studies include a major cardiovascular prevention trial, and studies on the association between genetic polymorphisms and cardiovascular risk and disease; alcohol and cardiovascular disease; dia-prognosis of peripheral arterial disease, and cardiovascular risk factors in Romanian primary care.

#### 4. *Abdominal signs, symptoms and diseases*

In primary care, relevant chronic abdominal problems are dyspepsia, irritable bowel syndrome, inflammatory bowel disease and colorectal cancer. On these topics therapeutic trials have been started.

#### 5. *Generic aspects of primary care*

In patients presenting with unexplained complaints, doctors tend to do more laboratory investigations than strictly needed. We study the diagnostic accuracies of blood investigation in patients presenting with unexplained complaints, as well as the cost-effectiveness of an intervention programme on postponing blood investigation in these patients. The *pluis – niet pluis* concept is studied on its determinants and precise meaning for daily primary care. One project on diagnostic determinants of hemochromatosis is being prepared. Multi-morbidity is a frequent phenomenon in the general population with a reported prevalence of over 60% in people aged 60 and older. Until now little is known about clustering of diseases and disease patterns in the general population and about demographic and psycho-social features in relation to the occurrence of multi-morbidity. Several studies focusing on specific diseases, clustering in general and related patient characteristics are being initiated. These studies make use of data available from the RNH and SMILE. Much information is available on the impact of serious cardiac diseases or events on patients. Far less has been published on their impact on family relations. This topic is studied using three different research designs: (1) a meta-analysis of observational studies, (2) a qualitative study in which both patients and partners have been interviewed before and after a cardiovascular event, (3) an epidemiological study comparing the occurrence of diseases in patients after a myocardial infarction with age- and sex-matched patients without an infarction, using data from the RNH.

#### 6. *Methods of diagnostic research*

Within an international working group on diagnostic research (MEDION) a number of methodological papers on the meta-analysis of diagnostic studies in primary care have been produced. In addition, a database of published systematic reviews of diagnostic studies was set up (available on the internet). Different methods for the multivariable analysis of diagnostic studies are being compared and new designs are tested with respect to the relations between diagnostic tests, diagnoses, treatment decisions and patient outcome.

#### *Key publications*

- Akker M van den, Vos R, Knottnerus JA. In an exploratory prospective study on multimorbidity general and disease related susceptibility could be distinguished. *J Clin Epidemiol* 2006;59:934-39
- Helden S van, Cals J, Kessels F, Brink P, Dinant GJ, Geusens PP. Risk of new clinical fractures within two years following a fracture. *Osteopor Int* 2006;17:348-54
- Hopstaken RM, Stobberingh EE, Knottnerus JA, Muris JWM, Nelemans P, Rinkens PELM, Dinant GJ. Clinical items not helpful in differentiating viral from bacterial lower respiratory tract infections in general practice. *J Clin Epidemiol* 2005;58:175-83

- Spigt MG, Knottnerus JA, Westerterp KR, Olde-Rikkert MG, Van Schayck CP. The effect of 6 months of increased water intake on blood sodium, glomerular filtration, blood pressure, and quality of life in elderly (aged 55-75) men. *J Am Geriatr Soc* 2006;54:438-43
- Schuitmaker GE, Dinant GJ, Van der Pol GA, Verhelst AFM, Appels A. Vital exhaustion as a risk indicator of first stroke. *Psychosomatics* 2004;45:1-5

#### B.1.2.4 Towards the future: research goals (2007 – 2009)

- further development of innovative methods of diagnostic and prognostic research in primary care and (methods for) genetic/genomic research in primary care
- set up of a European comprehensive programme for education of primary care research
- capacity building through enlarging the group of Aiotho's (combined traineeship for PhD research and general practice) and international exchange of staff and PhD students

#### B.1.2.5 Final Analysis for Primary Care Programme 2, based on SWOT

The participants to the programme have an excellent expertise in clinical, diagnostic and large population based research in daily primary care. Consequently, the majority of the results is applicable in this setting, increasing its evidence base. Furthermore, close collaboration with target groups through the network of academic family practices and two large primary care registration networks (RNH and SMILE) is realized. A multidisciplinary approach including good collaboration between primary care physicians and hospital specialists, resulting in transmural research projects, is another strength of the programme. Opportunities include the flexibility of the programme: (new) subjects relevant for primary care can easily be added and further development of innovative methods of clinical (diagnostic) research in primary care easily follows. Weakness regard difficulties in building up a profit centre, since the programme largely relies on researchfunding, and the part-time labelling on research of all seniors. The increasing workload of participating clinicians must be seen as a threat.

### B.1.3 Primary Care Programme 3: Effectiveness of Diagnosis and Intervention in patients with Rheumatic Diseases

#### B.1.3.1 Leadership

*Programme leaders: Sjef van der Linden, Professor of Rheumatology;  
Desiree van der Heijde, Professor of Rheumatology (till 31.12.2006)*

Tenured scientific staff (1,55 fte)	PhD-students
Dr. Annelies Boonen	
Prof.dr. Piet Geusens	
Prof.dr. Desiree van der Heijde (till 31.12.2006)	
Prof.dr. Sjef van der Linden	
Dr. Robert Landewé	

Table 1.3: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	37	54	46
PhD-theses	5	3	3
Funding (Research and contracts)	€ 33.363	€ 65.100	-

#### B.1.3.2 State of the Art

The mission of the programme is to evaluate the effectiveness of diagnosis and interventions in the improvement of outcomes of patients with rheumatic diseases. The approach to the research of this

programme is clinical-epidemiological. The determinants of outcome of the diseases under investigation are accuracy of diagnosis, effectiveness of therapeutic interventions, clinical competence (skills and knowledge), performance in daily practice, compliance by patients and health providers, but also availability and access to health resources and providers of health care, including reimbursement issues.

These aspects are addressed in the research programme. The focus is mainly on ankylosing spondylitis and rheumatoid arthritis. In the recent past our research dealt significantly with diagnostic and classification criteria, but also the development and validation of instruments to assess aspects of patient outcome. With new pharmaceutical agents becoming available the focus can shift towards assessment of improving patient outcome and therapeutic responses. This calls for scientific attention for response and prognostic criteria, i.e. prediction of patient outcome.

### **B.1.3.3 Research (2004 – 2006) and key publications**

The main research activities in the years 2004-2006 have concentrated around the programs “Outcome in Ankylosing Spondylitis (AS)” and “Outcome in Rheumatoid Arthritis (RA)” (see below). Briefly, this deals with development, validation, adjustment, and monitoring of guidelines for therapy with new treatment modalities (biologicals), in particular (developing and validation of) instruments to assess efficacy and effectiveness, and prediction of response (improvement of prognosis due to therapy). Research includes economical analysis and developing ICF classification for ankylosing spondylitis, predicting progression and response using biomarkers of bone and cartilage (bony changes and secondary osteoporosis among patients with rheumatoid arthritis and ankylosing spondylitis). These activities are undertaken in the context of networking: WHO-ICF (Muenchen and Nottwil, Switzerland), the international OMERACT initiative (Outcome Measures in Rheumatoid Arthritis), which comprises working groups and international consensus conferences, and the international ASAS (Assessment in Ankylosing Spondylitis) working group.

The “Outcome in AS” programme is positioned around the prospective cohorts OASIS and ESPAC. The former cohort is now (2007) having a follow-up time of 10 years, and is expected to be the world-wide major source of outcome data with regard to AS. The latter has a follow up of more than 5 years, and will become the worldwide oldest cohort including patients with “early AS”.

Outcome in AS has been further expanded along lines of collaboration with industry partners that own databases of clinical trials with biological drugs. Aspects of outcome that are being investigated in OASIS/ESPAC will be cross-validated in these databases.

Domains of outcome with a particular focus in this programme continue to be imaging, prediction of structural damage (prognostication) and prediction of treatment efficacy, and socio-economic outcome and quality of life.

The “Outcome in RA” programme is partly positioned around the COBRA follow-up cohort. Patients participating in the in Maastricht originated COBRA study have been contacted again, in order to obtain a 10-year follow-up. More than in “Outcome in AS”, research in RA is performed in databases owned by third parties, among which cohorts from international collaborative groups and pharmaceutical industries, that have consulted us because of our experience in the methodology and analysis of outcome research. Such “third parties” cohorts enable us to cross-validate principles of outcome developed in our group.

Domains of outcome with a particular interest in this programme are the methodology of structural repair, the prediction of structural damage (prognostication) and prediction of treatment effect, and the relation between markers of bone and cartilage metabolism (CTXI and CTXII) and radiographic damage.

For both programmes we have access to large databases from clinical trials from various industrial partners. In contrast to the focus from industry, which is the efficacy and safety of their drug, we have a completely methodological focus. We use the databases as far as possible to get more insight in the correct way of measurement, in validation of outcome measures, in general burden of illness questions, in relationship between disease activity and inflammation and damage depicted by imaging, on relation to damage with biomarkers, etc. A wealth of information on these topics is available in these databases. Industrial parties are willing to let us use the databases for these purposes, but they are in principal not interested in this type of research and are not or only very limited willing to fund this research. By being able to use these databases, we are able to perform a lot of this type of research with rather limited investment.

*Key publications*

- Geusens P, de Nijs RNJ, Lems W Laan R, Struijs A, van Staa TP, Bijlsma J. Prevention of glucocorticoid osteoporosis: a consensus document of the Dutch Society for Rheumatology. *Ann Rheum Dis.* 2004; 63:324-5.
- Landewe R, van der Heijde DMFM. The validity of a rheumatoid arthritis medical records-based index of severity compared with the DAS28. *Arthritis Res Ther.* 2006; 8: 107. Published online 2006 March 31. doi: 10.1186/ar1937.
- Heuft-Dorenbosch L, Weijers R, Landewe R, van der Linden S, van der Heijde D. Magnetic resonance imaging changes of sacroiliac joints in patients with recent-onset inflammatory back pain: inter-reader reliability and prevalence of abnormalities. *Arthritis Res Ther.* 2006; 8: R11. Published online 2005 December 1. doi: 10.1186/ar1859.
- Landewe R, Rump B, van der Heijde, D, van der Linden S. Which patients with ankylosing spondylitis should be treated with tumor necrosis factor inhibiting therapy? A survey among Dutch rheumatologists. *Ann Rheum Dis.* 2004 May; 63:530-4.
- Boonen A, Severens JL, van Tubergen A, Landewe R, Bonsel G, van der Heijde D, van der Linden S. Willingness of patients with ankylosing spondylitis to pay for inpatient treatment is influenced by the treatment environment and expectations of improvement. *Ann Rheum Dis.* 2005; 64:1650-2.

**B.1.3.4 Towards the future: research goals (2007 – 2009)**

In the next few years the research of the group will shift somewhat. These changes will mainly be quantitative rather than qualitative. The focus will be directed to change in outcome and in particular prediction of outcome and to a lesser degree to development and validation of instruments to assess outcome. The proposed Caphri chair Prognosis and Outcome of Rheumatic Diseases is expected to facilitate and promote these developments.

**B.1.3.5 Final Analysis for Primary Care Programme 3, based on SWOT**

The SWOT analysis of the programme Effectiveness of Diagnosis and Intervention of Rheumatic Diseases is by and large comparable to the SWOT analysis of the institute / school as a whole. Some items merit special emphasis. In particular, the (eu)regional clinical cooperation will be intensified to increase the number of patients that might be included in clinical research activities. This will remedy the weakness of problems with recruitment or bias due to small patient populations. Moreover, the focus will be more directed towards changes in patient outcome (due to new therapeutic interventions, i.e. biologicals) and also to prediction of outcome and response to treatment. Further, in addition to our traditional clinical epidemiological approach and expertise, cooperation with workers in the (related) field of basic research will be established or intensified (translational medicine).

**B.1.4 Primary Care Programme 4: Clinical epidemiology****B.1.4.1 Leadership**

*Programme leader: Martin Prins, Professor of Clinical Epidemiology*

Tenured scientific staff (3,55 fte)	PhD-students
Prof.dr. Piet van der Brandt	Simone Sep
Dr. Isabel Ferreira	
Dr. Dinanda Kolbach ( till 01.04.2007)	
Dr. Pieter Leffers	
Dr. Monique Mommers	
Dr. Patty Nelemans	
Prof.dr. Martin Prins	
Dr. Luc Smits	
Dr. Jelle Stoffers	
Dr. Carel Thijs	
Dr. Adri Voogd	

Table 1.4 programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	67	61	50
PhD-theses	1	4	4
Funding (Research and contracts)	€ 554.311	€ 399.485	€ 464.557

#### B.1.4.2 State of the Art

The research programme 'Clinical Epidemiology' focuses on the application of clinical epidemiologic methods towards clinical research, with special attention for use of innovative methods and innovation of these methods. Research topics include the full spectrum of clinical epidemiology, i.e. aetiology, diagnosis, prognosis and treatment, and include the performance of meta-analysis within these research areas. There is a focus on research that uses patient-important outcomes and has a strong potential for incorporation of its results into guidelines and implementation of its concepts in medical practice. The medical context is based on the specific interest fields of tenured staff, and in addition guided by interest for participation of clinicians.

#### B.1.4.3 Research (2004 – 2006) and key publications

##### *Cardiovascular Diseases*

Staff members involved in this field of research include dr. M. Prins, dr. P. vd Brandt, drs. P. Leffers and dr. P. Nelemans. A close cooperation exists with, dr CDA Stehouwer, dr H ten Cate and dr K Hamulyak (CARIM, Internal Medicine). Several projects are running in this area, mostly focused on optimization of antithrombotic treatment, exercise therapy, diagnosis of deep venous thrombosis, pulmonary embolism and peripheral arterial disease.

Outside of these formal projects, there is close cooperation with the departments of internal medicine, cardiology and dermatology of the azM and (vascular) surgery of the Atrium hospital Heerlen. This cooperation has led to several research grant proposals that are currently being evaluated or developed. In addition a number of Cochrane reviews are being prepared.

During the last years this cooperation has led to two completed PhD theses within this programme and considerable output.

##### *Oncology*

Staff members involved in this field of research include dr. M. Prins, dr. P. vd Brandt, dr. D. Kolbach, drs. P. Leffers, dr. P. Nelemans and dr. A. Voogd.

In this field a cohort study (n=120,000) assessing the relationship between traffic-related air pollution and mortality (total, cause-specific) and lung cancer incidence. In this project the department of risk assessment IRAS of UMCU also participates. UM part of this grant (paid by HEI: Health Effects Institute) amounts to 209.000 Euro. There are several other projects with the departments of oncology, haematology, dermatology and neurology of the azM, MAASTRO clinic and hospitals in Eindhoven and Veldhoven. This cooperation has led to considerable output and several research grant proposals that are currently being evaluated or developed.

##### *Chronic Disorders*

Staff members involved in this field of research include Dr. M. Prins, dr. P. vd Brandt, drs. P. Leffers, dr. M. Mommers, dr. L. Smits and dr. C. Thijs. A close cooperation exist with dr J. Schouten and dr C. Weber, ophthalmology. Within this focus there is a birth cohort of 2500 neonates that is followed for 4 years to relate the development of allergy and inflammation related disorders to gene and environment. In half of the participants biosamples are biobanked (blood in pregnancy, infant's stool, maternal milk, DNA in infants and parents). The total grant amounts to 2.5 MEuro.

Additionally there are several project on glaucoma, including meta-analyses on the efficacy of intra-ocular pressure lowering drugs and a cohort assessment of their efficaciousness in clinical practice and a decision analytic model, to identify the optimally cost-effective strategy for case finding in the prevention of blindness due to glaucoma.

An internal AIO assessed the optimal reporting of pharmacogenetic studies.(completed 2006)

**Key Publications:**

- Baaten G, Voogd AC, Wagstaff J. A systematic review of the relation between interleukin-2 schedule and outcome in patients with metastatic renal cell cancer. *Eur J Cancer* 2004; 40: 1127-1144.
- Bank I, Libourel EJ, Middeldorp S, Van Pampus EC, Koopman MM, Hamulyak K, Prins MH, Van der Meer J, Büller HR. Prothrombin 20210A Mutation: A mild risk factor for venous thromboembolism but not for arterial thrombotic disease and pregnancy-related complications in a family study. *Arch Intern Med* 2004; 164: 1932-1937.
- Bendermacher BL, Teijink JA, Willigendael EM, Bartelink ML, Buller HR, Peters RJ, Boiten J, Langenberg M, Prins MH. Symptomatic peripheral arterial disease: the value of a validated questionnaire and a clinical decision rule. *Brit J Gen Pract* 2006; 56: 932-937.
- Smits LJM, de Bie RA, Essed GG, van den Brandt PA. Time to pregnancy and sex of offspring: cohort study. *Br Med J* 2005; 331: 1437-1438.
- van Belle A, Büller HR, Huisman MV, Huisman PM, Kaasjager K, Kamphuisen PW, Kramer MHH, Kruij MJHA, Kwakkel-van Erp JM, Leebeek FWG, Nijkeuter M, Prins MH, Sohne M, Tick L. Effectiveness of managing suspected pulmonary embolism using an algorithm combining clinical probability, D-dimer testing, and computed tomography. *J Am Med Assoc* 2006; 295: 172-179.

**B.1.4.4 Towards the future: research goals (2007 – 2009)**

Complete all running projects and get funding for new ones in each of the Focuses

Three main research lines subprogrammes, well embedded within the ZKO'2's focuses, in close cooperation with clinicians, that have each 2 to 3 running grants and 3 to 4 PhD students (including external PhD students).

**B.1.4.5 Final Analysis for Primary Care Programme 4, based on SWOT**

A potential weakness is the broad clinical orientation of the programme, which might hamper grant acquisition. However, the programme includes tenured staffs that have a track record on their clinical field, ensuring a clinically focused grant application. A weakness is the relatively weak position of patient-based research in cancer patients in UM/azM. On the other hand, the intention of the ZKO'2 oncology, the newly appointed epidemiologist as director of GROW and the availability of a clinical epidemiologic researcher within this programme with an excellent track record in oncology, might provide an opportunity.

**B.1.5 Primary Care Programme 5: Asthma and COPD****B.1.5.1 Leadership**

*Programme leaders: Dr. Geertjan Wesseling and Dr. Jean Muris*

Tenured scientific staff (2,70 fte)	PhD-students
Dr. Edward Dompeling	Jolien Boesten
Dr. Han Hendriks	Cindy Gielkens-Sijstermans
Dr. Rein Jöbssis	Kim van de Kant
Dr. Janneke Kaper	Daniel Kotz
Prof.dr. André Knottnerus	
Dr. Tiny van Merode	
Dr. Jean Muris	
Prof.dr. Onno van Schayck	
Dr. Geertjan Wesseling	
Prof.dr. Emiel Wouters	

Table 1.5: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	58	67	60
PhD-theses	3,5	10,1	5,1
Funding (Research and contracts)	€ 971.963	€ 1.351.916	€ 572.236

### B.1.5.2 State of the Art

#### *Research area and mission*

Research with the asthma and COPD programme of Caphri is employed in primary care and in the interface of primary and secondary care with focus on early detection of risk-factors and symptoms of obstructive airways diseases. Also, development and implementation of prevention and early interventions strategies are studied. This programme was started in the nineties and current research is done in collaboration with researchers from Health Risk Analysis and Toxicology, NUTRIM, Health Education and Health Promotion, Health Care Studies and the departments of Paediatrics, Respiratory Medicine, Primary Care Medicine and Health Care Studies.

### B.1.5.3 Research (2004 – 2006) and key publications

#### *PREVASC*

This programme started in 1997 (Prevention Fund 26-146, NAF 96-34, KNAW fellowship 1997-1999). In this study children with a familial predisposition to allergic sensitisation and/or asthma were followed from the prenatal period until the age of 2, and subsequently until the age of 6. In the FOCUS study (ZON 2300.0009, NAF 34.99.05, NAF 32.99.39) the compliance to the preventive measures has been evaluated in order to be able to tailor these in general practice.

In the RAKKER study (ZON 2100.0002) the natural course of the development of allergy and asthma has been evaluated in children with or without a familial predisposition.

Results from these studies have been published over the past few years and have been presented and defended in a number of PhD theses.

The At-Risk project (NAF 3.4.01.51), that is that is now in its final phase, aims at secondary prevention of asthma in familiarly predisposed children, in the format of a placebo-controlled trial investigating the effectiveness of inhaled corticosteroids in wheezing children.

#### *Effectiveness of smoking cessation strategies*

Smoking is by far the most important causative factor in obstructive airways diseases. Various interventions can improve the success rate of smoking cessation attempts. In the asthma/COPD programme research in smoking cessation intervention includes the use of anti-depressants, nicotine vaccines, confrontational counselling and integrated care modalities in smokers with or without airways disease. For the study on the effectiveness of the newly developed nicotine vaccine, a TOP-grant was recently awarded.

The research in this chapter of the programme is employed in close collaboration with investigators of GRAT, Psychology, redesigning Health Care and GVO.

#### *Integrated care for patients with Asthma/COPD*

The importance of patient-centred, multidisciplinary care modalities has been emphasised in recent years. In the Maastricht area, a disease management programme has been implemented for all patients with obstructive airways diseases, that is currently being evaluated by investigators of the programme in collaboration with researchers from the Redesigning Health Care programme. Topics are determination of risk factors for and early intervention in asthma and COPD, gender differences in clinical presentation and needs of patients with obstructive airways diseases, effects of multidisciplinary outpatient and primary care management, and optimal drug and medical treatment of these patients.

#### *Key publications:*

- Schönberger HJ, Dompeling E, Knottnerus JA, Maas T, Muris JW, Van Weel C, Van Schayck CP. The PREVASC study: the clinical effects of a multifaceted educational intervention to prevent childhood asthma. *Eur Respir J* 2005; 25(4): 660-670.

- Wagena EJ, Knipschild PG, Huibers MJ, Wouters EF, van Schayck CP. Efficacy of bupropion and nortriptyline for smoking cessation among people at risk for or with chronic obstructive pulmonary disease. *Arch Intern Med* 2005; 165: 2286-2292
- Van Schayck CP, Maas T, Kaper J, Knottnerus AJ, Sheikh A. Is there any role for allergen avoidance in the primary prevention of childhood asthma. *J Allergy Clin Immunol* 2007; 119: 1323-1328
- Yanbeava DG, Dentener MA, Creutzberg EC, Wesseling GJ, Wouters EFM: Systemic Effects of Smoking. *Chest* 2007; 131:1157-1566
- De Ruyscher D, Pijls-Johannesma M, Bentzen SM, Minken A, Wanders R, Lutgens L, Hochstenbag M, Boersma L, Wouters B, Lammering L, Vansteenkiste J, Lambin P: Time between the first day of chemotherapy and the last day of chest radiation is the most important predictor of survival in limited-disease small-cell lung cancer. *Journal of clinical oncology* 2006; 24: 1057-1063

#### **B.1.5.4 Towards the future: research goals (2007 – 2009)**

Asthma and COPD are diseases with a high and increasing prevalence, imposing a huge burden on primary and secondary care resources. Prevention, early identification of risk factors and appropriate management will remain important topics in the research agenda of this programme. To this end, collaboration with researchers from the Nutrition and Metabolism Research Institute Maastricht (NUTRIM) will be intensified, focussing on determinants of susceptibility, early markers of inflammation in asthma and COPD, risk factors for and markers of systemic involvement in COPD. Together with investigators of GVO (de Vries and Mesters), research on smoking cessation strategies will be intensified, including trials on pharmacotherapy of nicotine addiction:

1. new aids in smoking cessation treatment with nicotine vaccination, motivational interviewing and confrontational counselling
2. research on cost-effectiveness of smoking cessation strategies
3. research on care-models and integrated care for smoking cessation

Case-finding and early identification of risk factors for asthma and COPD in high-risk populations will remain important topics. Together with investigators from GRAT (Van Schooten) genetic predisposition for the susceptibility to cigarette smoke (and pharmacogenetics) will be studied, including early evidence of inflammation and biomonitoring of gene-environment interactions related to cigarette smoke and particulate matter.

Disease management and integrated care aimed at health promotion, prevention, diagnosis and treatment, rehabilitation and reintegration will be studied together with investigators from the Redesigning Health Care programme (Vrijhoef, Steuten). The effectiveness of the Quattro-model, introduced to improve care with the optimal collaboration of primary care (GP and practice nurse) and specialist care (pulmonologist and specialized nurse) will be studied in the patient cohorts that have been compiled in the disease management programme, both in terms of patient outcomes and in terms of logistics of health care processes.

#### **B.1.5.5 Final Analysis for Primary Care Programme 5, based on SWOT**

The SWOT analysis of the asthma/COPD programme of Caphri is largely comparable to the SWOT analysis of the institute as a whole. Group coherence however can and should be improved within the programme. The creation of the MUMC+ gives opportunities for closer collaboration with clinical groups, but this is hampered by the RVE/CCZ structure that has been adopted within the University Hospital. That structure is aimed at improving care within the hospital but does not accommodate disease management and research for chronic diseases across the scope of primary and secondary care.

As the research within the programme is related to the highly prevalent diseases asthma and COPD and nicotine addiction, the weakness that is noted in the institute's SWOT analysis related to small patient populations does not apply to the programme.

## B.2 Cluster Innovation of Care

### Focus

The cluster Innovation of Care covers programmes which focus on the development of new approaches (technologies, interventions, strategies and models) in health care, especially for dependent patients and consumers in vulnerable situations (patients with chronic diseases, frail elderly) or in the situation of complex patient preference –sensitive decision making. The aim is to improve care, by describing and interpreting problems, developing interventions and strategies, and stimulating practitioners to make use of interventions which have proven to be effective. These interventions can be located at various places in the chain of care (from prevention and primary care to specialist care and after care). Attention is paid to the organisation of care, to changing roles of professionals (for example nurses taking over traditional tasks of physicians) and to the changing position of the patient and consumer, who can play an active role in their care process. Innovations are developed in close cooperation with practitioners and patient and consumer groups. This strengthens the practical applicability and provides a firm basis for implementation. Innovations are evaluated from various perspectives: effectiveness, cost-effectiveness and normative consequences (concerning the responsibilities of professionals and patients) and pay attention to content, process and structure.

### Objectives

The overall aim is to contribute to improvements in health care by means of

- Research
- Development of methodologies
- Cooperation with stakeholders (patient and consumer groups, professionals and health care institutions, policy makers, insurers etc)
- Interactive development of knowledge in cooperation with the field
- Development of tools, guidelines, models, training for health care innovations and methods to implement these instruments

### Future Developments

Research will be designed in anticipation of current developments in society and health care:

- Increase of the number of elderly and patients with chronic disease
- Active participation of patients and consumers in health care and health care research
- Growing importance of manpower and task division in extramural and transmural care
- Growing rationalizing of health care delivery and emphasis on evidence based and cost effectiveness
- Bridging public health and curative care in order to prevent chronic diseases by detecting high risk groups and influencing health styles

## B.2.1 Innovation of Care Programme 1: Innovations in Health Care for the Elderly

### B.2.1.1 Leadership

Programme leaders: Ruud Kempen, Professor of Social Gerontology and Jan Hamers, Professor of Care of the Elderly

Tenured scientific staff (2,95 fte)	PhD-students
Dr. G. Bours	Daniëlle Eskens-Groffen
Dr. Annemie Courtens	Gonnie Gartsen-Klabbers
Dr. Ruud Halfens	Anna Huizing
Prof.dr. Jan Hamers	May Offermans
Prof.dr. Wim van den Heuvel	Esther Smeulders
Drs. L. Hollands	Hilde Verbeek
Dr. Nynke de Jong	Rixt Zijlstra
Prof.dr. Ruud Kempen	
Dr. Erik van Rossum	
Prof.dr. Jos Schols	
Dr. Frans Tan	
Dr. Luc de Witte	
Prof.dr. Rianne de Wit	
Prof.dr. Jouke van der Zee	

Table 2.1 programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	19	27	30
PhD-theses	2	3	0
Funding (Research and contracts)	€ 794.411	€ 1.052.644	€ 921.157

### B.2.1.2 State of the Art

Due to the aging of the population and developments in medical technology, the number of older persons with (chronic) health problems will increase substantially during the next decades. Nowadays, the proportion of persons of 65 years of age and older is twelve to eighteen percent in most western societies. We expect that this will be nearly doubled in the next three to four decades what inevitably has consequences on the health care system, in particular on (services and facilities in) home care and care in nursing homes. Although (biological) age in itself is considered as an important risk factor for processes of disablement and need of care in older persons and patients with chronic health problems, research suggested that environmental and psychosocial factors may be at work as well. Three main challenges for the future in this area of research are (a) to disentangle the role of medical, environmental and psychosocial factors in trajectories of disablement in older persons, (b) to investigate specific health care problems in older persons in the clinical setting and nursing homes, and (c) to develop innovative, client-oriented, and targeted health care arrangements which maximizes independence, social participation, quality of life and quality of care and reduces disablement in older persons with (chronic) health problems. The third challenge is inevitable related to the first two. Although (international) research in this area is growing, the knowledge is fragmentary and needs further encouragement to find innovative solutions for the challenges of ageing and health care in the next decades.

### B.2.1.3 Research (2004 – 2006) and key publications

The mission in the research programme Innovations in health care for the elderly is two-folded: (1) to develop and disseminate knowledge and expertise on psychosocial, clinical, and environmental determinants (including – organization of - health care arrangements) of health (care) problems, need of care, social participation, independency and quality of life among older persons, and (2) to develop, evaluate and implement related innovative health care programmes and interventions for older persons to slow down

processes of disablement and to improve socialization of health care. The research programme includes observational research (particularly related to the first part of the mission) as well as intervention research (second part of the mission).

*A selection of current research projects include:*

- Reduction of fear of falling and associated increase in functional ability, activity level and quality of life in community-living older adults who are at risk for falling: a randomized controlled trial (NWO/ZonMw; GIJM Kempen)
- Effects of home visits by home nurses to elderly people with health problems (ZonMw; E van Rossum & GIJM Kempen)
- Pain in elderly with dementia (ZonMw; JPH Hamers, MPF Berger)
- Reduction of physical restraints in nursing homes (MeanderGroep ZL, Province of Limburg, SWBV; JPH Hamers, MPF Berger)
- Prevalence of malnutrition within health care organizations in Germany and the Netherlands (Ministry of Health, Welfare and Sports; RJG Halfens, R de Wit)

*Selection of recently received grants for research projects:*

- Evaluating the effectiveness of an in-home self-management intervention to prevent psychological distress in frail older people living in the community. (ZonMw; GIJM Kempen)
- The impact of orientation and mobility training on mobility, participation and quality of life in older adults with visual impairments; a randomized controlled trial. (ZonMw; GIJM Kempen in collaboration with VU and RUG).
- Small-scale housing for elderly persons with dementia: effectiveness of care innovation (Province of Limburg and Nursing Homes; JPH Hamers, GIJM Kempen, E van Rossum)
- A new approach to nonverbal measurement of pain. (University of Maastricht; MPF Berger, JPH Hamers, LMG Curfs)
- Effectiveness and cost-effectiveness of screening and treatment of malnutrition in elderly hospital patients (azM; R de Wit, RJG Halfens, JM Schols)

*Key publications*

- Kempen GIJM, Ranchor AV, Sonderen E van, Jaarsveld CHM van, Sanderman R. Risk and protective factors of different functional trajectories in older persons. Are these the same? *J Gerontol Psy Sci* 2006; 61B: 95-101.
- Huizing AR, Hamers JPH, Candel M, De Jonge J, Berger MPF. Organisational determinants of the use of physical restraints: a multilevel approach. *Soc Sci Med* 2007; 65: 924-933.
- Zijlstra GAR, Tennstedt SL, Haastregt JCM van, Eijk JThM van, Kempen GIJM. Reducing fear of falling and avoidance of activity in elderly persons: The development of a Dutch version of an American intervention. *Patient Educ Couns* 2006; 62: 220-227.
- Zwakhalen SMG, Hamers JPH, Berger MPF. The psychometric quality and clinical usefulness of three pain assessment tools for elderly people with dementia. *Pain* 2006; 126:210-220.
- Meijers JMM, Janssen MAP, Cummings GG, Wallin L, Estabrooks CA, Halfens, RJG. Assessing the relationships between contextual factors and research utilization in nursing: systematic literature review. *J Adv Nurs* 2006; 55: 622-35.

#### **B.2.1.4 Towards the future: research goals (2007 – 2009)**

The future of the research programme can be described from a long-term and a short-term perspective:

The long-term perspectives and challenges of the programme are:

- to build a strong infrastructure of aging research at Universiteit Maastricht;
- to develop a multi-disciplinary scientific network on aging research with national and international linkages;
- to embed the theme of this programme structurally within the framework of Maastricht UMC+;
- to increase the tenured staff to 2.5 fte within a period of 3 to 5 years;
- to realize on average one PhD defense a year.

*The short-term goals of our research programme are:*

- to develop a structural (regional) academic network with health care providers (i.c., nursing homes, homes for the elderly, home care) to create a strong infrastructure for scientific aging research;
- to build on clinical research on care problems of elderly at the University Hospital Maastricht
- to create thesis groups and increase interest among Bachelor and Master students with respect to aging research;
- to recruit one Caphri PhD student on a structural basis;
- to investigate the possibilities for piloting innovations in collaboration with Hogeschool Zuyd;
- to intensify the collaboration with other research programmes within Caphri.

### B.2.1.5 Final Analysis for Innovation of Care Programme 1, based on SWOT

The SWOT analysis of the School largely holds for this specific research programme as well. A specific strength of this programme is the collaboration with national and international research groups. A specific opportunity is the development of an academic network in the region for aging research and the possibilities for funding for such networks and other research. However, there is a relatively small structural critical mass of researchers in the programme, particularly on post-doc level. Another weakness may be that aging research is not attractive for (master) students. A potential threat is a strong medical and intramural (i.c. academic hospital) focus of the UMC+. Challenges for the (near) future are to create two post-doc positions (for preparing grants, supervising PhD students) and to embed the programme structurally within the framework of UMC+.

## B.2.2 Innovation of Care Programme 2: Redesigning Health Care

### B.2.2.1 Leadership

*Programme leader: Dr. Bert Vrijhoef*

Tenured scientific staff (3,00 fte)	PhD-students
Prof.dr. Ton Gorgels	Sandra Boessen
Dr. M. Govers	Re Adil Ibnouf
Dr. Siebren Groothuis	Audrey Merry
Prof.dr. Hans Maarse	Leonne Prompers
Prof.dr. Frits van Merode	J. Havas
Dr. Ingrid Mur	H. Creemers
Dr. Arno van Raak	B. Doove
Prof.dr. Nicolaas Schaper	E. Dera-de Brie
Prof.dr. Cor Spreeuwenberg	
Dr. Lotte Steuten	
Dr. Bert Vrijhoef	

Table 2.2: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	16	18	23
PhD-theses	1	3	3
Funding (Research and contracts)	€ 387.375	€ 506.129	€ 312.162

### B.2.2.2 State of the Art

By redesigning the process of health care delivery it is aimed to better meet the needs of patients, while safeguarding the affordability of good quality health care now and in the future. Currently, scientific knowledge on how to best redesign health care, on how to implement redesigned health care, on factors to be considered, and on the effectiveness and efficiency of redesigned health care in terms of structure(s),

process(es) and outcome(s) is scarce. Moreover, it is argued that applied methods do not meet the criteria of scientific rigor. Policy makers hardly make use of results from scientific studies as most of these report short term effects within local settings. Since recently also in Europe and the Netherlands there is growing interest in scientific knowledge with regard to this topic. This programme produces and transfers scientific knowledge on how to best redesign health care, on how to implement redesigned health care, on which factors should be considered, and on the effectiveness and efficiency of redesigned health care in terms of structure(s), process(es) and outcome(s).

### B.2.2.3 Research (2004 – 2006) and key publications

Four main research themes are being addressed within the scope of this program:

- *the organisation of health care*: health care needs to be organised around the patient to adopt a patient-centred approach. With respect to the care for chronically ill patients the chronic care model, as developed by Wagner et al. and expanded by the WHO into the Innovative Care for Chronic Conditions Framework, presents a “road map” for redesigning health care for people with chronic conditions towards patient-centred care, provided by multi-disciplinary teams which continuously improve the quality of care for which they need to monitor patients by means of advanced ICT. It remains questionable if current models meet up to the features of the chronic care model as experienced by both patients as health care providers. How can self-care activities of patients successfully be organised? How effective are redesigned models of care and how can existing gaps be diminished? How can competencies of professionals best be matched to meet up the needs and expectations of patients? When considering the delivery of care from a more broad perspective it needs to be understood which critical factors influence the success of integrated care, including cross-border initiatives. The layout of an organization should facilitate the care delivery and should be able to cope with new redesigns or other future developments. The organizational research will also pay attention to the relation between the care concept and the organization of work. In this respect, care concepts are considered to be distributed decision systems;
- *the planning and logistics of health care*: the health care process should be a continuous process without unnecessary waiting by the patients and the health care providers. How can optimal health care systems be designed? Which factors must be considered? The organization, the logistics and ICT should support in an efficient and effective way of the delivery of care. Logistics and operations management concerns optimising distance, transport and the transfer of patients, care providers and patient samples. It also concerns the optimising of the physical layout and its infrastructure. ICT should provide the appropriate information to plan the delivery of care. The (logistical) effects on the patients and health care providers of a redesigned health care organization should be assessed before it is implemented;
- *the policy and finance of health care*: the prospects of redesigning health care are influenced by the general structure of health care including health care financing, health care purchasing and health care policy. A key theme in this respect is how the ongoing reforms of health care directed at the introduction of elements of market competition and pay for performance will affect the prospects of redesigning health care. Will they lead to health care that is more efficient, more quality driven and/or more client-oriented?;
- *the measurement of effectiveness and efficiency of redesigned health care*: for this purpose a specific combination of measurement instruments and methodological procedures is needed. There is a need to establish which techniques of evaluation research are most adequate to assess the effectiveness and efficiency of redesigned health care. Advanced methods like system dynamics modelling might be applied to gain further insight into the relation between structures, processes and outcomes of care. Both short-term as well as long-term cost-effectiveness of new concepts for the delivery of care need to be assessed. Methods and techniques from the field of operations research, like different types of simulation and optimising using e.g. multi agent systems, will be applied. Instruments to assess the performance of integrated care from the perspective of professionals or patients need to be developed or translated.

The first three research themes are being studied within 5-10 projects per theme. The latter theme is being studied as part of projects which belong to the other themes.

**Key-publications**

- Steuten LMG, Vrijhoef HJM, Wesseling GJ, Van Merode GG, Spreeuwenberg C. Evaluation of a regional disease management programme for patients with asthma or chronic obstructive pulmonary disease. *Int J Quality Health Care* 2006;18(6):429-36.
- van Merode GG, Groothuis S, Hasman A. Enterprise resource planning for hospitals. *Int J Med Inform* 2004 30;73(6):493-501.
- Kumpers S, Mur I, Hardy B, Maarse H, van Raak A. The importance of knowledge transfer between specialist and generic services in improving health care: a cross-national study of dementia care in England and The Netherlands. *Int J Health Plann Manage.* 2006 Apr-Jun;21(2):151-67.
- Maarse H. The privatization of health care in Europe: an eight-country analysis. *J Health Polit Policy Law* 2006;31(5):981-1014.
- Steuten LMG, Vrijhoef HJM, Van Merode GG, Severens JL, Spreeuwenberg C. The Health Technology Assessment-Disease Management instrument reliably measured methodologic quality of health technology assessments of disease management. *J Clin Epidemiol* 2004;57:881-8.

**B.2.2.4 Towards the future: research goals (2007 – 2009)**

The programme will be developed into a programme with a more precise research focus i.e. evaluating the effectiveness and efficiency of redesigning processes of health care delivery As well as influencing factors. Additionally, attention will be paid to specific components of care, i.e.:

- self-management by patients;
- linkage between health care and community;
- use of ICT in health care delivery, i.e. e-health.

Finally, projects will include research questions concerning methods for evaluating.

Illustrative for this are recently gained projects, e.g.:

- NWO project 'The position of the consumer/patient in a market-oriented health care system'. Starting date 01/11/2005.
- PICASSO project 'Long term cost-effectiveness of smoking cessation support for people with COPD: information for justified reimbursement'. Starting date 01/06/2007.
- Project 'Telemonitoring for patients with heart failure (TEHAF II). Starting date 01/10/2007.

**B.2.2.5 Final Analysis for Innovation of Care programme 2, based on SWOT**

The SWOT analysis of the School largely holds for this specific research programme as well. In addition, this programme is characterised by its intensive multidisciplinary cooperation and extensive local, national and international networks. The programme is faced by growing opportunities for grants, by a growing interest for collaboration from reputable national and international researchers, including researchers from the department of integrated care of the academic hospital Maastricht. However, the programme holds no post-doc researchers and administrative support. The staff faces a segmentation of workplaces and the challenge to integrate the different disciplines. For this the programme has to overcome the scarce structural financial means, the modest internal visibility of the –results of the– programme, and the unclear career opportunities for junior researchers.

**B.2.3 Innovation of Care Programme 3: Autonomy and participation in chronic care****B.2.3.1 Leadership**

*Programme leader: Dr. Tineke Abma*

Tenured scientific staff (1,80 fte)	PhD-students
Dr. Tineke Abma	Sandra van der Dam
Dr. Arie van der Arend	
Dr. Ron Berghmans	
Dr. Rob Houtepen	
Dr. Bert Molewijk	
Prof.dr. Guy Widdershoven	

Table 2.3: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	13	12	13
PhD-theses	3,5	1	1
Funding (Research and contracts)	€ 765.139	€ 98.240	€ 479.843

### B.2.3.2 State of the Art

The programme focuses on ethical aspects and moral dilemmas in chronic care, especially in the care for the elderly, and psychiatric and intellectually disabled patients/consumers. The mission is to study the quality of chronic care from the perspectives of various stakeholders (patients/consumers, family, healthcare and other professionals, management and policymakers) and to foster improvements in the quality of care via interactive dialogues between stakeholders. In organized dialogues about stakeholder issues shared values, norms and guidelines can be constructed. Theoretical insights from ethics can further deepen the understanding of the inherent moral dilemmas and (conditions for) good care. In dialogical processes about the definition of good care a central role is reserved for the (empowerment of the) position of the patient/consumer, but also of the informal caregiver and professional (and his responsibility). Finally, attention is paid to the implementation of dialogical care innovations at the level of healthcare organizations and national policy level.

### B.2.3.3 Research (2001 – 2006) and key publications

The focus of this programme is the improvement of the quality of care through dialogical interactions between stakeholders at various levels. The programme consists of three lines of investigation: 1) ethical aspects of care, including empirical ethics; 2) moral deliberation in healthcare organizations, and 3) patient participation in healthcare, health policy and health research. Research projects are concentrated in the fields of psychiatry, care for intellectually disabled persons, rehabilitation and care for the elderly.

Within this programme mixed methods, responsive, interactive, participatory and other social-scientific research methods are applied in order to both articulate and foster processes of moral deliberation and dialogues on ethical aspects of care.

Research questions:

- To define and evaluate good care from the perspectives of stakeholders, and to foster processes to improve good care.
- To develop and apply methodologies for stakeholder and patient participation in health research.
- To develop a Maastricht model for moral deliberation in clinical settings, including implementation strategies and evaluation approaches of its effectiveness.
- To reflect on research projects in terms of their implications for existing theoretical frameworks in ethics.

Highlight of the current projects:

*Ethical aspects of care:*

- o Development and implementation of quality criteria for coercion in psychiatry.
- o Evaluation of the Psychiatric Hospitals Compulsory Admissions Act (Wet Bopz).
- o Quality criteria for freedom restrictions in the care for intellectually disabled persons.
- o Development Int. Course Ethics and Mental health care (with Cleveland, Ohio)

*Moral deliberation*

- o Several long term (PhD) projects (2 to 6 year) have been set up in various healthcare institutions, among them psychiatry and elderly care.
- o Development of 4 networks of professional collaborations, partly funded by Ministry of Health: a) The European Clinical Ethics Network (ECEN); b) the Dutch Moral Deliberation Platform; c) National moral deliberation working conferences; and d) regional moral deliberation meetings between UM and health care institutions.

*Patient participation*

- o Health research agenda setting processes with and for various patient populations (spinal cord injury, neuromuscular diseases, renal failure and intellectual disabilities), financed by charity funds and the Dutch council for medical research (ZonMw).
- o Publication of a book for health researchers entitled: 'Zeggenschap in wetenschap' (Abma and Broerse, 2007).

*Key publications*

- Abma, T.A. (2005) Patient participation in health research. Research with and for people with spinal cord injuries, *Qualitative Health Research*, 15(10): 1-19.
- Abma, T.A. and Widdershoven G.A.M. (2006), Moral deliberation in clinical psychiatric nursing practice, *Nursing Ethics*, 13(5): 546-557.
- Abma, T.A. and Widdershoven G.A.M. (2005) Sharing stories: Narrative and dialogue in responsive nursing evaluation, *Evaluation and the Health Professions*, 28(1): 90-109.
- Goldsteen, M, Abma TA, Oeseburg B, Verkerk MA, Widdershoven GAM (2007) What it is to be a daughter? Identities under pressure in dementia care, *Bioethics*, 21(1): 1-12.
- Molewijk, B, Abma TA, Widdershoven GAM (2007) Teaching ethics in the clinic. The theory and practice of moral case deliberation, *Journal for Medical Ethics*, accepted for publication.

**B.2.3.4 Towards the future: research goals (2007 – 2012)**

Focus for the coming years:

- Enhanced academic reputation in bio- and healthcare ethics by means of editorships and publications in international ethics journals, and key note lectures and presentations at the European networks.
- Continuation of the three lines of investigation, including more research projects and collaborations within the field of elderly care, and the development of international networks on patient participation in health research.

**B.2.3.5 Final Analysis for Innovation of Care programme 3, based on SWOT**

This programme shares the issues identified in the presented overall SWOT. The programme has, however, a relatively short history, and is still in the phase of development. Particular strengths include: programme leadership and motivated group of PhD students. Particular weakness: academic profile in bioethics. Particular opportunities: emerging network (ACZIO) in regional elderly care; ZonMw programmes and the HEALTH programme Europe; and ECEN funding for (academic) research. The goal/ambition to strengthen our dialogical ethics profile in bio- and healthcare ethics and to position ourselves more prominent in these academic communities is still up to date. Opportunities, such as the ACZIO network care, require a slight adjustment in terms of developing a profile in elderly care, and investing in collaborations within Caphri.

**B.2.4 Innovation of Care Programme 4: Health Technology Assessment****B.2.4.1 Leadership**

*Programme leader: Hans Severens, Professor of Medical Technology Management*

Tenured scientific staff (2,30 fte)	PhD-students
Dr. André Ament	Anna Gaytandjieva
Dr. Sylvia Evers	Sylvia Gerhards
Prof.dr Wim Groot	Ties Hoomans
Dr. Aggie Paulus	
Dr. Milena Pavlova	
Prof.dr. Hans Severens	

Table 2.4 programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	16	28	28
PhD-theses	1	2	1
Funding (Research and contracts)	€ 165.981	€ 39.155	€ 60.176

#### B.2.4.2 State of the Art

Health Technology Assessment aims to perform and methodologically develop human/patient oriented evaluation research, studying costs, effects, and cost-effectiveness of health care. HTA concerns the total spectrum of the organisation and implementation of preventive, diagnostic, therapeutic, rehabilitation, and care interventions in any health care setting (intramural, extramural, and transmural), in order to support policy decision-making within health care on a micro, meso, and macro level. First, the focus of studies was on high tech medical interventions but nowadays any kind of intervention, being either a patient level diagnostic or therapeutic intervention or organisational and implementation intervention can be subject of study. Therefore, MTA was changed in the more comprehensive term Health Technology Assessment (HTA) to reflect the complexity of innovative care that can be studied.

Core viewpoint of HTA is the economic evaluation of health care technologies and health care interventions to determine the cost-effectiveness of such an intervention, thus studying both costs and effects and to determine the efficiency (cost-effectiveness). Nowadays, the aspects that drive the cost-effectiveness uncertainty are subject of evaluation. Still the research methods used in this field are rapidly developing and improving.

#### B.2.4.3 Research (2004 – 2006) and key publications

Funded by the programme Doelmatigheid of ZonMw several projects are ongoing. The role of the HTA-researchers is to support or execute economic (modelling) studies in this respect. The subjects cover the full range of clinical research area's of the university Maastricht and the university hospital of Maastricht and are too numerous to be reported in detail. Furthermore, the HTA-researchers are involved in 'external' collaborating projects with for instance rehabilitation centers, audiology centers, psychiatric hospitals, primary care and public health organisations and so on. Some clinical studies are used as 'vehicle' for HTA-methodological studies such as the WTP and patient-outcome method-project and conjoint analysis in implementation research. The PhD project Implementah, studying the methods of economic evaluation of implementation strategies has reached the phase of reporting. In this study international collaboration was realised with researchers in Canada and the UK. Several industry projects have been granted and are ongoing (Cholesterol lowering strategies by AstraZeneca; Literature review Costs of RA and AS by Wyeth; Value of a statistical Life by Roche; Cost-effectiveness of herceptin-treatment by Roche). In addition a PhD project on transferability of cost-effectiveness studies has started as part of the thesis of one of our research master students (see below). International projects are ongoing in the field of economic evaluation reviews (CHEC), the earlier mentioned implementation studies, cross-national transferability of economic evaluations, and a European mental health care project (MHEEN).

#### Key publications:

- Brunenberg DEM, Joore MA, Veraart CPWM, Berghmans BCM, van der Vaart CH, Severens JL. Economic evaluation of duloxetine for the treatment of women with stress urinary incontinence: a Markov model comparing pharmacotherapy with pelvic floor muscle training. *Clin Ther* 2006; 28 (4): 604-618.
- Essers BAB, Dirksen CD, Nieman FHM, Smeets NWJ, Krekels GAM, Neumann M. Cost-effectiveness of Mohs micrographic surgery versus surgical excision for basal cell carcinoma of the face. *Archives of Dermatology* 2006; 142: 187-194.
- Evers S, Goossens M, de Vet H, van Tulder M, Ament A. Criteria List For Assessment Of Methodological Quality Of Economic Evaluations – CHEC International Journal of Technology Assessment in Health Care: *Int J Technol Assess Health Care* 2005; 21(2):240-245.
- Groot W, Maassen van den Brink H. 'The compensating income variation of cardiovascular disease', *Health Economics* 2006; 15: 1143-1148.

- Paulus A, Van Raak A, Keijzer F, Informal and formal caregivers' involvement in nursing home care activities: impact of integrated care, In: Journal of Advanced Nursing, 2005;49(4):354-66.

#### **B.2.4.4 Towards the future: research goals (2007 – 2009)**

Recently a NWO-Toptalent-fellowship has been granted to A Goebbels (supervisors Severens and Ament). This PhD-project is the follow up of a previous grant by Roche, studying the topic the Value of a Statistical Life and will commence by the end of 2007. Goebbels will visit the EMGO institute (prof. Van Tulder) for this reason from October 1st. This year another PhD project started (July 1st, S. Knies, supervisors Severens, Ament, and Evers; funding by Caphri) studying the methods of transferring cost-effectiveness results from one jurisdiction to another.

Major objectives for the HTA programme in the near future are to expand ongoing HTA-methodological projects (implementation, conjoint analysis, discrete choice experiments, transferability, value of statistical life, WTP-WTA-disparity, activity based costing, valuing informal care) focus on the evaluation of complex, innovative health care interventions, to explore possibilities for early evaluation of (medical) technologies (constructive technology assessment, CTA) and to expand international collaboration and funding form European research programmes.

Upon request of the College voor zorgverzekeringen (Health Care Insurance Board) a proposal has been granted describing a longer term cooperation to support CVZ in their task to assess industries' pharmaco-economic dossiers, to develop CVZs' knowledge on the principles of pharmaco-economic studies, and to further develop the principle methods of this field of research, especially with regard to innovative care. Within the programme Doelmatigheid of the ZonMw, as is the case each year, several projects have been submitted in cooperation with clinical departments. The role of the HTA-researchers is to support or execute economic (modelling) studies in this respect. The clinical studies are often used as 'vehicle' for proposals for HTA-methodological studies as mentioned above.

#### **B.2.4.5 Final analysis for Innovation of Care programme 4, based on SWOT**

Within the HTA programme research methods are performed according to the state of the art, besides methodological development regarding with an emphasis on implementation, international comparison patient outcome, conjoint analyses, discrete choice experiments and willingness to pay. These methods are applied on wide range of clinical subjects based on a high level of fund raising in cooperation with clinical partners. HTA is seen as an up to date, valuable and trustworthy research partner having excellent relationships, internally, nationally and internationally. However, there is no focus on specific disease area or HTA-method, independent HTA researchers are labeled within other research programmes and there is insufficient lobbying power, as well internally as externally. Opportunities for the HTA programme are the start of university medical centre, a growing interest from decision makers in HTA and their need for HTA evidence and the shift from 'pure' technologies to innovative care.

In summary, the HTA programme represents a small, enthusiastic, informally organised group of researchers that cooperate in full strength amongst each other, with other programmes and with clinicians, leading to an enormous output. In the past few years HTA-Maastricht has gained the reputation to be a national centre of excellence.

## B.2.5 Innovation of Care Programme 5: Implementation of Evidence

### B.2.5.1 Leadership

Programme leader: Dr. Trudy van der Weijden

The programme leader meets the senior investigators every month for management of the programme. Twice yearly there is a programme meeting for all staff involved, organised around a specific theme (e.g. development of implementation strategies, development of outcome indicators, evaluation designs).

Tenured scientific staff (2,00 fte)	PhD-students
Drs. Loes van Bokhoven	Paul Houben
Prof.dr Richard Grol	
Dr. Frans van der Horst	
Dr. Piet Portegijs	
Dr. Jelle Stoffers	
Dr. Huibert Tange	
Dr. Trudy van der Weijden	
Dr. Yvonne Winants	

Table 2.5: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	42	20	35
PhD-theses	0	3,3	0
Funding (Research and contracts)	€ 251.981	€ 194.173	€ 459.551

### B.2.5.2 State of the Art

The programme's focus is on development and implementation of EBM practice guidelines and 'best practices'. The mission is to study determinants of successful implementation of evidence (by e.g. assessment and analysis of professional performance) and to study strategies for implementation of evidence and quality improvement in health care. Health care can be qualified as good if it is delivered according to accepted professional guidelines. However, health care delivery should also meet objective and subjective needs of patients, it should be consumer-friendly and should take into account an appropriate and rational use of resources. High quality care should conform to requirements regarding effectiveness (evidence-based), efficiency, patient centeredness, safety, timeliness and equity.

### B.2.5.3 Research (2004 – 2006) and key publications

The focus of this line of research is the improvement of performance in daily clinical practice by (general) practitioners, their daily medical decision making. Special attention is paid to the microlevel of health care, the interaction between professional and patient, that professionals may experience as the conflict between rationalising work (the application of guidelines) and patient-centred work (the practice of the consultation). There is no restriction to certain clinical fields, nor to clinical settings, although the vast majority of projects is embedded in primary care.

Within this programme observational studies (both quantitative and qualitative) are executed, with the purpose to shed light on current health care performance, determinants of high quality performance, professionals' and patients' needs in quality improvement, and barriers and facilitators for guideline implementation, in which the effect of implementation strategies on professionals' performance and patients' outcomes is evaluated. A large part of the programme consists of multi-centre cluster RCTs and (quasi-)experimental studies, in which the effect of implementation strategies on professionals performance and patients outcomes is evaluated.

Next to this research activities can be found in the field of systematic literature reviews, and evaluations of implementation strategies from the ethical and from the MTA-perspective. Specific theme's are ICT in health

care, gender issues, decision aids for both patients and physicians.

Research questions:

1. To define appropriateness of care in daily practice in terms of (evidence based) guidelines and protocols, rules of conduct and standards.
2. To study determinants of (variation) in the quality of competence and professional performance; this concerns factors related to professionals, patient setting and the organisation of care.
3. To study the (cost) effectiveness of methods and interventions to improve the quality of care and strategies to implement them.
4. To study the value of patient involvement in the strive for high quality of care:
  - a. How to reach patient involvement in health care: how to perform communication of risks to patients and shared decision making?
  - b. What are the effects of patient involvement on relevant outcomes on patient (risk perception, satisfaction with the decision, adherence to medical treatment) and professional's level (adherence to guidelines, satisfaction with the decision)?

Some highlights of current observational and (quasi-)experimental projects:

- Observation of the general practitioner's (GP's) management in pursuance of test results. UM
- Demands for (health) care in the helpseeking process of people with a visual impairment. ZonMW
- Improving cardiovascular prevention in general practice. Implementation of the CVRM risk table. ZonMW + NHS
- Improving lifestyle adherence in patients with high risk for cardiovascular diseases in general practice. Costs and effects of patient involvement. ZonMW
- Effect of small group quality improvement on prescribing and test ordering performance of GPs. A large scale implementation study. ZonMW + CZ-OZ + VGZ

*Key publications*

- Verstappen WHJM, Weijden T van der, Riet G ter, Grimshaw J, Winkens R, Grol RPTM. Block designs in quality improvement research enable control for the Hawthorne effect. *J Clin Epidemiol* 2004;57:1119-23.
- Veldhuijzen W, Ram P, van der Weijden T, Wassink MR, van der Vleuten C. Much variety and little evidence: a description of guidelines for doctor patient communication in vocational training. *Med Educ* 2007;41:138-45.
- van Steenkiste B, van der Weijden T, Stoffers HEJH, Kester ADM, Timmermans DRM, Grol R, Improving cardiovascular risk management: a randomized controlled trial on the effect of a decision support tool for patients and physicians. *Eur J Cardiovasc Prev Rehabil* 2007;14:44-50.
- de Kok M, Frotscher CNA, van der Weijden T, Kessels AGH, Dirksen CD, van de Velde CJH, Roukema JA, Bell AVRJ, van der Ent FW, von Meyenfeldt MF. Introduction of a breast cancer care programme including ultra short hospital stay in 4 early adopter centres: framework for an implementation study. *BMC Cancer* 2007;7:117.
- van der Weijden T, van Steenkiste B, Stoffers HEJH, Timmermans DRM, Grol R. Primary prevention of cardiovascular diseases in general practice. Mismatch between cardiovascular risk and the patient's risk perception. In press *Med Dec Making*

#### **B.2.5.4 Towards the future: research goals (2007 – 2009)**

Focus for the coming years:

- a. to strengthen the collaboration with Nijmegen and to function as local expertise centre for quality of care research,
- b. to consolidate the focus on the microlevel in health care and to extend the research on patient involvement in clinical decision making.

New projects:

- CZ +VGZ: Internet-based feedback on prescribing performance to GPs by validated performance indicators.
- ZonMW: How to present findings of the Quality Consumer Index to future health care consumers.
- ZonMW: Improving consumers behaviour in self-testing. Study on trends in frequency, determinants of use, consequences, information needs and effect of improved information strategies.

**B.2.5.5 Final analysis for Innovation of Care programme 5, based on SWOT**

Most of the findings of the general SWOT-analyses do also apply to this programme. This programme can further develop into a general centre of expertise for research in the field of quality of care improvement, both for the faculty and the academic hospital. A current weakness is the relatively small size of the projects. The challenge is to grow in this respect and to benefit from the increasing collaboration at the European level, where we do participate although we are not in the lead position (yet), and the increasing societal need for research on patient involvement

## B.3 Cluster Public Health

### Focus

Public Health has been defined by the RGO (2003) as 'The science and art of preventing disease, prolonging life and promoting health through the organized efforts of society'. These efforts consist of collective measures in various areas, necessary to improve public health and to maximize the outcome of care on public health with the ultimate goal of enhancing quality of life. Although interventions may be very diverse, they should all be firmly based in theory and evidence. The missions of Caphri's programmes in public health is to contribute to this scientific base; to translate theory and evidence into tailored solutions for societal health problems; to develop instruments and tools for sustainable and effective interventions, and to deliver these solutions effectively to individuals, organizations and national bodies.

Caphri has five programmes in Public Health: Design and analysis of studies in health sciences; Occupational epidemiology and health; Health communication; Theory and practice in health promotion; and Normative aspects of biomedical and public health technologies. These programmes represent the major aspects of public health: developing research tools (theory and methods) for diagnosis, intervention and evaluation, with ethical and methodological reflection. The main activities of the five programmes can be described as a chain of activities in public health: establishing risk factors, studying the etiology of health problems, diagnosing specific problems and contexts, developing theory for diagnosis and intervention, translating this to specific interventions, implementing interventions and evaluating the different steps.

### Objectives

The cluster Public Health aims to develop new models, theory, methodology and tools for the enhancement of Quality of Life. Sustainable change is assumed to presuppose equity in health and health care, and the development of evidence base and best practices.

#### Strategy

The programmes share a strong international orientation, while the work is often embedded in local practical and professional organizations with participation of relevant stakeholders (including GGD, occupational health services, companies, health insurance companies). Effective public health interventions require an interdisciplinary approach that is innovative in theoretical approach, methodology and normative reflection.

### Future developments

The field of Public Health will be affected by societal developments such as a tendency towards privatization and a growing emphasis on personal accountability, but also by demographic developments (increasing population age), changes in society (e.g. need for increase in labor participation, late retirement) and care dynamics (chronicity of disease and comorbidity), demanding the further development of normative and ethical models, longitudinal research methods and dynamic models of causality. Consequently, innovative statistical research is also needed focussing on e.g. the analysis of different clusters of (un)healthy people and organizations, new strategies for longitudinal research, advanced techniques to address nested models and causal modeling.

The increased attention for comprehensive person and patient centred approaches – both in public health as well in primary care settings - require the development of effective interventions that need be attuned to each other. As theory development requires sound designs, participation in cohort studies will become more important in which various perspectives from public health are integrated and also extended to other disciplines such as primary care. Effective interventions can only have a national public health impact (effectiveness x reach) when they are implemented, hence implementation research will need to receive increasing attention. Consequently, more joint projects between public health programmes are called for, creating more synergy between the different expertise areas.

## B.3.1 Public Health Programme 1: Design and analysis of studies in health sciences

### B.3.1.1 Leadership

Programme leader: *Martijn P.F. Berger, Professor of Methodology and Statistics*

Tenured scientific staff (1,80 fte)	PhD-students
Dr. Ton Ambergen	Baerbel Maus
Prof.dr. Martijn Berger	Shirley Ortega-Azurdy
Dr. Gerard van Breukelen	Fetene Tekle
Dr. Math Candel	
Dr. Arnold Kester	
Dr. Vinca Lima Passos	
Dr. Frans Tan	
Dr. Wolfgang Viechtbauer	
Dr. Bjorn Winkens	

Table 3.1: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	22	14	26
PhD-theses	1	2	0
Funding (Research and contracts)	€ 32.796	€ 36.553	€ 82.984

### B.3.1.2 State of the Art

#### Mission Statement

One of the aims of Caphri is to improve the quality of research in Health Sciences. Quality improvement plays a role in the design stage of a study, in the measurement stage and in the final stage where the data are analysed. The methodologists and statisticians participating in this programme have expertise in these three areas.

The aim of this research programme is threefold. The first focus is on the improvement of the **design** of health studies. The aim is to find highly efficient or optimal designs for studies in the health sciences, which not only are efficient in terms of parameter estimation, but also in terms of power and costs of performing the study. The second focus is on the optimal **analysis** of the data from these hierarchical studies. Robustness and sensitivity of the analysis techniques are important aspects in this context. The last aim is to provide researchers from Caphri with adequate guidelines for the design and analysis of their hierarchical studies.

#### State of the Art

Health science studies most often have a hierarchical (multilevel) design structure. For example, the registration network Smile, where measurements of patients within general practices are obtained over longer periods of time, has such a hierarchical sampling and design structure. The analysis of the data requires complicated statistical modelling, which takes the hierarchical data structure and the correlations of the time-structured measurements into account.

Only in the past few years the focus of optimal design research has shifted from models with independent errors to multilevel or random effects models. This shift has been necessary to facilitate practitioners from the medical and health sciences to design their study in an optimal way, i.e. to obtain efficient parameter estimators, with maximum power and with minimum costs of performing the study. Optimal design problems (robustness and power computations) in cluster randomized and multi centre trials and in longitudinal (cohort) studies have been studied. Multilevel (random effects) models have become increasingly important and are now commonly used in intervention studies, diagnostic research, meta-analysis, clinical trials and genetic (micro-array) studies. Improved computer programs (MLwin, Stata, SAS, SPSS) facilitate such analyses.

### B.3.1.3 Research (2004 – 2006) and key publications

#### *Short description of projects*

The projects in this research programme can be grouped in two main themes.

#### 1. *Efficiency and robustness of a design*

In hierarchical and longitudinal studies the statistical model, the number and allocation of the measurement points, the number of groups (clusters), the group sizes and the inclusion of covariates play a role in finding an optimal or highly efficient design. Because optimal designs may be quite different for different statistical models, it is important to find out how much efficiency a design will have when different models are used to analyse the data. This problem may be referred to as the robustness of a design. If such a robust design is found, it may serve as a basic design in those cases where it is not known in advance what statistical model will fit the data best.

#### 2. *Sample size and power*

Before a health science study is carried out, it is necessary to estimate the optimal sample size, i.e. the sample size needed to find a significant effect. An estimate of such an optimal sample size is usually based on the probability of making type I errors, the effect size and the statistical model. Moreover some kind of cost function will have to be formulated. For the hierarchical and longitudinal studies such an estimate of the optimal sample size is quite complicated, but if such optimal sample sizes can be estimated it will save a lot of time and money for future studies. Preliminary results indicate that, in terms of sample size and costs of performing a study, a reduction of 30-50% may be obtained.

#### **Projects:**

- I. Optimal designs for experimental studies with a nested data structure (Berger, van Breukelen, Candel)
- II Robustness of estimators (Candel, Berger)
- III Optimal designs for fMRI studies (Berger, Van Breukelen, Maus, NWO project)
- IV Optimal and robust designs for GLM models (Berger, Tan, Tekle, and Ortega, NWO project)
- V Diagnostic research and survival analysis (Kester)
- VI GLM models and meta-analysis (Viechtbauer).
- VII Design and analysis of clinical trials with repeated measures (Winkens, van Breukelen and Berger, van Abswoude, NWO project)
- VIII Statistical techniques for genetic data (Berger, Ambergen and Lima Passos, Tan)
- IX Non-verbal measurement of pain (Candel, Berger, Hamers, Curfs, vacancy)

#### *Key publications*

- Berger, M.P.F. & Tan, F.E.S. (2004). Robust designs for linear mixed effects models. *Journal of the Royal Statistical Society, series C*, 4, 569-581.
- Candel, M.J.J.M. (2004). Performance of empirical Bayes estimators of random coefficients in multilevel analysis: Some results for the random intercept-only model. *Statistica Neerlandica*, 58, 197-219
- Ouwens, M.J.N.M., Tan, F.E.S. & Berger, M.P.F. (2006). A maximin criterion for the logistic random intercept model with covariates. *Journal of Statistical Planning and Inference*, 136, 3, 962-981
- Van Breukelen, G.J.P., Candel, M.J.J.M. and Berger, M.P.F. (2006). Relative efficiency of unequal versus equal cluster sizes in cluster randomized and multicentre trials. *Statistics in Medicine*, 26, 2589-2603
- Winkens, B., Schouten, H.J.A., van Breukelen, G.J.P., Berger, M.P.F. (2006). Optimal number of repeated measures and group sizes in clinical trials with linear divergent treatment effects. *Contemporary Clinical Trials*, 27, 57-69.

### B.3.1.4 Towards the future: research goals (2007 – 2009)

The future long term and short term goals of the research programme are:

*Long term goals:* To expand knowledge and expertise on design and statistical analysis in the area of longitudinal and genetic research and to apply this expertise in the various research projects of Caphri, other schools and UMC+.

*Short term goals:* To increase the number of projects funded by second and third stream money.

### B.3.1.5 Final Analysis Public Health programme 1, based on SWOT

Public Health Programme 1 recognises itself in the general SWOT of the School. The programme has many

strengths, such as high quality output, a homogeneous research programme, whose results (especially optimal design studies) will save money and time in research projects and is also applicable for other research programmes, both inside and outside the School for Public Health and Primary Care: Caphri. The programme sees it as their challenge to strengthen their PR to gain recognition of the importance of the research topic and improve the position of the research group in the research masters, in the Caphri research projects and in other research programmes, outside the School. One way to get widely known as a research group is to organise meetings and symposia around the topic of improvement of research designs and analysis. This will take place on the short term.

The fact that the budgets of the funding agencies decrease every year, makes the topic of optimal design increasingly important. Obtaining efficient estimators and power for finding real effects with a minimum of costs of performing the study is therefore worthwhile pursuing. This forms a great opportunity for the group and thus a long term perspective is to participate in a centre for clinical trials research and quality improvement in UMC+, where the expertise of the group of researchers will be optimally incorporated.

### B.3.2 Public Health Programme 2: Occupational Health Epidemiology

#### B.3.2.1 Leadership

Programme leader: Dr. Ilmert Kant

Tenured scientific staff (1,45 fte)	PhD-students
Dr. Ludovic van Amelsvoort	Monique Lexis
Prof.dr. Piet van der Brandt	Stephanie Leone
Dr. Nicole Jansen	Lore de Raeve
Dr. Ilmert Kant	
Dr. Gerard Swaen	

Table 3.2: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	46	28	20
PhD-theses	0	2	0
Funding (Research and contracts)	€ 504.475	€ 232.037	€ 249.999

#### B.3.2.2 State of the Art of public health programme 2

The research programme 'Occupational Health Epidemiology' focuses on the health of employees. Using an epidemiological approach, the aetiology, natural course and treatment of different health complaints and diseases in the working population are studied. The goal of the research programme is to expand the knowledge on health in relation to work in order to contribute to the increased need of evidence-based (occupational) medicine. The research programme aims to develop tools and strategies for prevention, treatment and socio-medical counselling of employees. In this way the research programme contributes to the improvement of health and well being of the working population and the reduction of sick leave and work disability in the Netherlands. The programme focuses on current occupational health issues in which special attention is given to changes in the psycho social work environment. These changes are the result of economic and demographic changes which have led among others to flexibilisation of labour, changes in retirement age, increased workload, and a larger influx of women into the labour force. Specific groups of workers will receive special attention; it is the aging workforce, workers with a chronic disease and work family conflict.

#### B.3.2.3 Research (2004 – 2006) and key publications

Within the research programme two main research lines exist:

Etiological and prognostic research on psychosocial work environment and (mental) health

This research line focuses on the relation between the psycho social work environment and workers' health

and well being. The research group participated in Netherlands Concerted Research Action on Fatigue at Work (1996-2004). As part of this concerted action the research group initiated and conducted the Maastricht Cohort study (MCS) granted by the Netherlands Organization for Scientific Research (NWO). The Maastricht Cohort Study is a large scale prospective cohort study in which a heterogeneous population of employees (n=12,140 at baseline measurement) from 45 different companies and organizations in the Netherlands are surveyed. Employees were followed from 1998 to 2002 by means of 10 self-administered questionnaires, in which a very wide range of exposure variables in the psychosocial work environment and private situation were assessed. Additionally, data on certified sickness absence and work disability were gathered through record linkage with the sick leave and work disability registry systems of the participating companies. Within the MCS the aetiology and natural course of fatigue and mental health complaints are studied. Moreover different treatments were evaluated. Within the MCS already 6 PhD projects were successfully carried out. With the conduct of this cohort study, the group has now increased and built up an extensive expertise and knowledge on the epidemiological approach of mental health and well being among employees which is nationally and internationally acknowledged. This is also reflected in the high output of the research group in terms of scientific publications and the number of PhD students. The MCS is still a good framework for many new research questions. At this moment the MCS is the basis for two PhD projects

- Chronic fatigue and burnout: course, prognosis and perception (S.Leone)
- Transitions in work status and health (L. De Raeve).

Furthermore, the MCS is the basis for research on work-family conflict and cardio vascular diseases. Moreover, research within the MCS has initiated a number of innovative research projects.

#### **Research on early interventions for workers at increased risk for sickness absence**

Based on data of the MCS a screenings instrument (the Balansmeter) has been developed to identify workers at increased risk for future sick leave. The development and validation of the instrument was done in close cooperation with ABN AMRO Arbo Services. This screening instrument enables a more preventive strategy, in which employees at increased risk for future sick leave receive early treatment and socio medical counselling. Three different early interventions (Occupational medicine based, Cognitive Behaviour Therapy and Coaching) are now evaluated in different RCT's (2 PhD projects).

Apart from these two main research lines, an ongoing concern within the programme is research regarding the effect of occupational chemical exposures on workers health. By means of a cohort approach the effect of different chemicals (e.g. acrylonitril, TFE, Drins) on cause specific mortality is studied. Studies are conducted in close cooperation with national and international companies like Shell, Dupont, and Cyanimid. Moreover the programme participated in the Toxicological evaluation of the immune function of pesticide workers: A European wide assessment (EUROPIT). In this European project, in which 6 different countries participate, the different immuno-toxicological effects of pesticides are studied.

#### *Key publications*

- Duijts SF, Kant I, Swaen GM. Advantages and disadvantages of an objective selection process for early intervention in employees at risk for sickness absence. *BMC Public Health* 2007;7:67.
- van Amelsvoort LG, Jansen NW, Kant I. Smoking among Shift Workers: More Than a Confounding Factor. *Chronobiol Int* 2006;23(6):1105-13.
- Leone SS, Huibers MJ, Kant I, Van Schayck CP, Bleijenberg G, Andre Knottnerus J. Long-term predictors of outcome in fatigued employees on sick leave: a 4-year follow-up study. *Psychol Med* 2006;36(9):1293-300.
- Jansen NW, Kant I, van Amelsvoort LG, Kristensen TS, Swaen GM, Nijhuis FJ. Work-family conflict as a risk factor for sickness absence. *Occup Environ Med* 2006;63(7):488-494.
- Bultmann U, Huibers MJ, van Amelsvoort LG, Kant I, Kasl SV, Swaen GM. Psychological distress, fatigue and long-term sickness absence: prospective results from the Maastricht Cohort Study. *J Occup Environ Med* 2005;47(9):941-7.

#### **B.3.2.4 Towards the future: research goals (2007 – 2009)**

The research programme has a good track record on epidemiological research of the psycho social work environment. The programme has the ambition to expand its role as a key player in the field of the epidemiology of occupational Health especially with respect to the role of the psychosocial work environment on mental health (and recognized as such by peers).

The programme has defined the following future research goals:

**Research on the long-term health effects of the psycho social work environment**

So far only short term and midterm (0-5 yrs) health effects of the psycho social work environment are studied. However, the current changes in the work environment due to demographic and economic changes require insight in the long term (> 5 yrs) effects of psycho social work environment. By means of an extension of the Maastricht Cohort study (2007-2012) the long-term effects in terms of morbidity and diagnosis specific mortality will be studied. Moreover the role of medication usage in the relation between the psycho social work environment and long-term health effects will be studied. Research projects within this extended MCS will be:

- Shiftwork and depression (1 PhD project)
- Methodological aspects of epidemiological research on the relations between psychosocial work environment on cardiovascular diseases (2 PhD projects)
- Long-term health effects of psychosocial work environment on depression and related mortality (1 PhD project)
- The aging worker: health, labour participation and the psycho social work environment (2 PhD projects)

**Research on early interventions of workers at increased risk for future sickness absence.**

The first results of the study on the efficacy of occupational medicine based early intervention show that early intervention in workers with an increased risk for future sickness absence is effective in reducing future sickness absence. In a joint venture with ABN AMRO Arbo Services and ACHMEA, the programme will further develop, validate and exploit the screenings questionnaire: de Balansmeter. Furthermore, in close cooperation with ABN AMRO Arbo Services and ACHMEA new early interventions for specific groups of workers and/or specific health complaints will be developed, evaluated and implemented.

**B.3.2.5 Final Analysis for Public Health Programme 2, based on SWOT**

The programme Occupational Health Epidemiology is characterized by high scientific output, high earning power, high research valorization, high societal impact and excellent network of companies, occupational health services and health insurance companies participating in research projects. The programme will expand its role as a key player in the field of the epidemiology of occupational Health, especially with respect to the role of the psychosocial work environment on (mental) health. The focus for future research will be on:

- long-term health effects of the psychosocial work environment in terms of morbidity and mortality. For this purpose the successful Maastricht cohort study will be extended.
- Early interventions among employees to reduce future sickness absence. In close cooperation with ABN AMRO Arbo Services and ACHMEA new early interventions for specific groups of workers and/or specific health complaints will be developed, evaluated and implemented.

### B.3.3 Public Health Programme 3: Normative Aspects of Biomedical and Public Health Technologies

#### B.3.3.1 Leadership

*Programme leaders: Rein Vos, Professor of Theory of Health Sciences, Klasien Horstman, Professor in Philosophy and Ethics of Bio-Engineering from a Humanistic Perspective; Guido de Wert, Professor of Biomedical Ethics*

Tenured scientific staff (2,70 fte)	PhD-students
Dr. Ron Berghmans	Erik Aarden
Dr. Wybo Dondorp	Patricia Jaspers
Prof.dr. Klasien Horstman	Fleur Parabirsing
Dr. Rob Houtepen	Bart Penders
Dr. Ine van Hoyweghen	Josy Ubachs
Dr. Ineke Klinge	Philip Romer (till 01.02.2007)
Dr. Anja Krumeich	
Dr. Agnes Meershoek	
Prof.dr. Rein Vos	
Prof.dr. Guido de Wert	

Table 3.3: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	10	9	20
PhD-theses	3	0	0
Funding (Research and contracts)	€ 473.465	€ 390.895	€ 539.700

#### B.3.3.2 State of the Art

Nowadays medicine and health care are changing fundamentally into what is called 'predictive medicine': the increasing use of techniques for assessing risks for health and disease and for diagnosis, treatment, screening and prevention of risk factors. Technologies, ranging from 'hard' technologies like genomics, stem cell research, reproductive technologies, imaging techniques and tissue engineering to the so-called 'soft' technologies like screening, health education/promotion are becoming more and more prominent. Moreover, they stimulate multidisciplinary cooperation and border crossing between different domains of health care. Together with the introduction of these new technologies, we see a renewed emphasis on health care as a market and a further pressure on citizens taking 'individual' responsibility for their health risks. These developments put the issues of public, professional and individual responsibility high on the agenda. The mission is to study through sociological and stakeholders network analyses these changing public, professional and individual responsibilities and the a-symmetries and injustices that might be developing and to rethink the key normative concepts in health care and public health such as responsibility, autonomy, privacy, freedom, justice, equity, quality of life and professionalism.

#### B.3.3.3 Research (2004 – 2006) and key publications

In this programme we will do 1. **sociological and political** research of technological developments and stakeholder networks; and 2. **normative** research analyzing, assessing and reshaping normative frameworks regarding research, health care and public health.

Research focuses on cardiovascular diseases, mental health, chronic diseases, reproductive medicine and tissue engineering. The programme has three lines: (1) ethics and policy analysis of reproduction and (genetic) screening; (2) governance and normative research of prevention, social justice and solidarity, and (3) gender, diversity and equity issues. The common ground of these three lines of research is to develop theory and methodologies in order to conceptualize and investigate individual and social responsibility for health and disease and to cope with public accountability, trust and confidence in health care and public health chains and stakeholder networks.

*(Inte)rnational collaboration*

There is a strategic linkage as core member of the NWO funded Dutch Centre of Excellence for Society and Genomics. The programme has built up a strong position in international (EU, funded by FP5, FP6, FP7) networks of ethicists, sociologists, science and technology studies, law and policy studies, but also in research and practice networks of life sciences, clinical science and public health. The programme has particularly collaboration with the Caphri programmes of Abma, Wesseling/Muris and Dinant/Van Den Akker, but also integrates with research groups in the other UM Schools, particularly in the neurosciences, cardiology, reproductive medicine and nutrition (Hersenen & Gedrag, CARIM, GROW, Nutrim).

## Highlight of the current projects:

*Ethics and policy analysis of reproduction and (genetic) screening*

- Charlene Versluys (PhD student) on the ethics of predictive genetic testing in children, funded by NWO
- Johan de Jonge (post-doc): the gen-ethics of alcoholism – an exploration of ethical issues of a rising social problem, funded by NWO

*governance and public ethics research of prevention, social justice and solidarity*

- Klasien Horstman, Rob Houtepen (senior scientists, 0.5 and 0.2), a sociological and normative analysis of normative presumptions of the prevention programme HARTSLAG, funded by ZonMW
- Erik Aarden (PhD student), Ine van Hoyweghen (post-doc): the construction of normal and abnormal risks in genetics and health and life insurance, funded by MC-Genomics NWO
- Laurens Landeweerd (PhD student), Enhancement in biomedicine: the enhancing of mood, cognition, fitness and extending age, funded by EU (UM = co-contractor, coordinating centre prof.dr. R. ter Meulen, Bristol UK), funded by EU FP6

*Gender, diversity and equity issues*

- gender mainstreaming of EU 6th Framework projects on Food Quality and Safety (NuGO, Safefoods, Europrevall), funded by EU FP6
- mainstreaming diversity and patients' perspective in health care research policies, funded by ZonMw, GDKZv

*Examples of recently received grants for research projects*

- postdoc project on social and normative issue of responsibility related to prevention and screening in sport amongst youth and adults: the case of sudden death in athletes and brain damage in boxing and soccer, funded by NWO-CSGender, start March 2007
- PhD project on normative issues (next to two other PhD projects in the TOP program) on smoking, vaccination and prevention (applicant prof. Onno van Schayck, in collaboration with prof. Jelle Jolles and profs. Guido de Wert/Rein Vos), funded by ZonMW and starting end 2007
- postdoc project on the ethics of screening and prevention of antisocial behavior in children, funded by NWO-CSG, start January 2008
- Biotechnology, policy, ethics and communication in the EU: websites and training, funded by EU (FP7), starting and websites (UM co-contractor, coordinator: prof. D. Lanzerath, Bonn, Germany)

*Key publications:*

- Hoyweghen I van, Horstman Klasien, Schepers Rita. Making the normal deviant: the introduction of predictive medicine in life insurance. *Soc Sci Med* 2006; 63:1225-1235.
- Wert G de. Reimplantation genetic diagnosis; the ethics of intermediate cases. *Hum Reprod* 2005;20:3161-3266.
- Vos R, Willems D, Houtepen R. Coordinating the norms and values of medical research, medical practice and patient worlds – the ethics of evidence based medicine in 'orphaned fields of medicine'. *Journal of Medical Ethics* 2004; 30(2):166-170.
- DunnGalvin, A, Hourihane, J.O'B., Frewer, L., Knibb, R.C., Oude Elberink, J.N.G., Klinge, I. Incorporating a gender dimension in food allergy research: a review. *Allergy* 2006; 61(11):1336-1343.
- Harper PS, Gevers S, Wert G de, Creighton S, Bombard Y, Hayden MR. Genetic testing and Huntington's disease: issues of employment. *The Lancet Neurology* 2004;3:249-252

### B.3.3.4 Towards the future: research goals (2007 – 2009)

The group has succeeded the past years to enter research networks on the EU and international level, not only in terms of ethics, gender and sociology networks, but more particularly so also in collaborative network of scientists. The prospects for such research are very good since national and international (e.g. EU) scientific research networks eagerly want to integrate in their research practices health technology assessment, ethics, gender studies and patient participation. This integrative approach all along the line of basic, translational and clinical and public health oriented research strives for a public accountable science and for public trust in science and technology in health care and public health.

### B.3.3.5 Final Analysis for Public Health programme 3, based on SWOT

The programme has a strong EU and international research profile and there are ample opportunities to further integrate the programme in European and international research networks. Normative issues such as equity, gender and diversity and individual and social responsibility regarding health and risk are generally appraised as needed topics in life sciences and public health research. The threat is too much emphasis on the instrumental nature of ethics (“quick fix solutions for research or clinical problems”); there is a need for systematic, normative analysis. It will be important to develop sociology, health law, governance and gen-ethical studies. This will help to further elaborate the collaboration with the emerging research networks relating to biobanking, genomics, screening and cohort studies, and other prevention technologies in public health, which forms an important focus within MUMC+. In this way the programme hopes to contribute to the societal need for redefining normative frameworks for professionals and patient (groups) in public health (‘governance’)

## B.3.4 Public Health Programme 4: Health Communication

### B.3.4.1 Leadership

*Programme leaders: Hein de Vries, Profossor in Cancer Prevention and Health Promotion, and dr. Ilse Mesters*

Tenured scientific staff (1,60 fte)	PhD-students
Dr. Math Candel	Iman Elfeddali
Dr. Ilse Mesters	Hilde Keulen-van Dijk
Dr. Astrid Reubsat (till 31.12.2006)	Liesbeth Mercken
Prof.dr. Hein de Vries	Fam te Poel
	Jonathan van 't Riet
	Chris Smerecnik

Table 3.4: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	23	15	30
PhD-theses	0	1	3
Funding (Research and contracts)	€ 529.344	€ 657.440	€ 576.846

### B.3.4.2 State of the Art

The mission of this programme is to conduct research aiming at developing, testing and implementing new health communication interventions for the adoption of a healthy lifestyle in the general public and in patients using personal counselling and computer tailored counselling.

### B.3.4.3 Research (2004 – 2006) and key publications

In general our research concentrates on:

- Improvement of theory.* In the past years the integration of various social cognitive theories using the I-Change Model to explain health behaviour were further developed by analyzing the role of social networks, parenting, framing, risk perceptions, emotional beliefs; action planning and goal setting.

- b. *Improvement of interventions.* 1. In the past years computer tailoring and eHealth strategy were further developed. We are recognized as one of the main centers in the Netherlands and globally. Two grants were obtained to test new eHealth technology; 2. Health Counseling and Motivational Interviewing interventions (e.g. MIS protocol) are renowned and accepted as a national standard for several settings and specialists. The effects of a new Motivational Interviewing protocol are currently under study.
- c. *Implementation of successful methods.* Projects have been conducted to test the implementation of our interventions (e.g. the MIS protocol via cardiac wards/midwives). We currently test the implementation of the Dutch Tobacco law, and we will be starting one project to implement computer tailoring nationwide through the health monitor of the Health Education Authorities (GGD-en).

The programme has the following objectives intended at:

- a. The development of pre-intervention research aimed at the analysis of relevant determinants of behavioural change and effective communication;
- b. The development and testing of the efficacy of new interactive health communication intervention methods focusing in particular on personal counselling, new computer tailored e-health techniques and principles of cognitive ergonomics;
- c. Studying the possibilities of altering multiple behaviour change in (groups of) individuals (as opposed to isolated single health behavioural change);
- d. The development of research analyzing diffusion strategies to analyze and change barriers of the adoption of effective new health communication techniques on a larger scale and the evaluation of such strategies;
- e. Theory building that pertains to health communication and to primary, secondary and tertiary prevention of diseases in general and for cancer prevention in particular.

#### *Key publications*

- De Vries, H. Candel, M. Mudde, A. Kremers, S. & Engels, R. (2006). Challenges to the peer influence paradigm: Results from six European countries. *Tobacco Control* 2006,15, 83-89
- De Vries, H. Dijk F., Wetzels, J., Mudde, A., Kremers, S., Ariza, Cl., Duarte Vittória, P., Fielder, A., Holm, K., Janssen, K., Lehtovuori, R., Candel, M. The European Smoking Prevention Framework Approach (ESFA): Effects after 24 and 30 months *Health Education Research*, 21, 116-132.
- Kremers, S.P.J., De Vries, H., Mudde, A. & Candel, M. (2003). Motivational stages of adolescent smoking initiation: predictive validity and predictors of transitions. *Addiction*, 29, 781-789.
- Mesters, I., Ausems, M., & De Vries, H. (2005). General public's knowledge, interest and information needs related to genetic cancer: an exploratory study. *European Journal of Cancer Prevention*, 14(1):69-75.
- De Vries, H, Mesters, I., Van 't Riet, J., Willems, Reubsat A. (2006). Motives of Belgian adolescents' for using sunscreen: the role of action plans. *Cancer, Epidemiology and Biomarkers*, 15 (7) 1360-1366.

#### **B.3.4.4 Towards the future: research goals (2007 – 2009)**

The research programme's focus continues on : 1) the analysis of health behaviour determinant within our current intervention trials and future trials; 2) development and testing of eHealth interventions and health counselling interventions for the general public and patients; 3) analyzing and testing implementation strategies.

Projects that started last year : 1. Relapse prevention via computer tailoring; 2. Counselling on genetic risks; 3. Smoking prevention in Saudi Arabia. Projects that will start in 2008: 1. Smoking cessation via the primary care practice; 2. Testing three new lifestyle computer tailoring methods; 3. Implementation of computer tailoring via health education authorities. New proposals will be prepared to test the effects of: Video and Text eHealth; New smoking cessation protocols; pre-diabetes intervention; COPD interventions; Colon Cancer Screening; Skin cancer prevention.

#### **B.3.4.5 Final Analysis for Public Health programme 4, based on SWOT**

Public Health Programme 4 has a good publication track and scores high in fundraising, especially in the prestigious research funds (EU/ ZonMW/Aspasia). Our programme is strong in theoretical elaborations and innovations and applying them to interventions that are also used in practice. Additionally, our focal topics such as multi-morbidity, multi-life style behaviors, eHealth, health counseling are highly relevant topics in public health research. However, a large threat to our research capacity is the enormous teaching load that the limited amount of tenured staff is facing. A better balance in this respect is however beyond our control.

Appointing permanent ICT support for ICT interventions is a challenge as well. Hence, we do aim to continue our successful research on social cognitive models, eHealth and Health Counseling and to carry on with the development of researchers through our post-doc policies.

### B.3.5 Public Health Programme 5: Theory and Practice in Health Promotion

#### B.3.5.1 Leadership

*Programme leader: Nanne de Vries, Professor of Health Education and Health Promotion*

Tenured scientific staff (2,55 fte)	PhD-students
Dr. Patricia van Assema	Laura van Alphen
Prof.dr. Bart van den Borne	Nicole Boot
Dr. Anton Dijker	Daksha van Dijck
Dr. Cees Hoefnagels	Evelien Heinrich
Prof.dr. Ronald Knibbe	Liwen Hung
Dr. Paul Lemmens	Jade Janssen-Luitgaarden
Dr. Ree Meertens	Irene Korstjens
Dr. Jascha de Nooijer	Ngozi Mbono
Prof.dr. Nanne de Vries	Cristina Quevedo
	Mieke Steenbakkens
	Anita Vermeer
	Judith van der Waerden

Table 3.5: programme outcome

Number of publications / year	2004	2005	2006
Refereed journals (WI-1 publications)	31	33	33
PhD-theses	0,6	6,2	2,2
Funding (Research and contracts)	€ 698.924	€ 768.811	€ 538.574

#### B.3.5.2 State of the Art

The field of Health Promotion is characterized by an interdisciplinary and ecological approach towards health. Although theory is at present best developed on the individual level, more emphasis gradually goes to the group, organization, community and society as levels of analysis. A strong tradition in combining personal and environmental approaches is reflected in the literature. The field has thus moved from individualized persuasive interventions to more comprehensive strategies. Theory and intervention development for this integrated approach have a strong need of evidence.

The programme Theory and Practice in Health Promotion reflects these characteristics. Within the programme fundamental, psychological research (e.g. concerning the establishment and change of habits) is done as well as sociological studies concerning alcohol abuse and stigmatization and applied research concerning the introduction of new methods for school health promotion or HIV-prevention in Sub-Saharan Africa. The multidisciplinary nature of the programme has been enhanced by the recent inclusion of a group of medical sociologists specializing in addiction research. The need for an ecological approach is especially felt through the expanding involvement in projects in developing countries. To tackle the need for evidence- and theory based health promotion, the programme uses models for planned development of interventions, notably the Intervention Mapping protocol.

#### B.3.5.3 Research (2004 – 2006) and key publications

In the Netherlands, health behaviors (e.g., smoking, substance abuse, physical activity, nutritional patterns, sexual behaviors) and other determinants of health (social equality, import of infectious disease) are deteriorating. The average life expectancy of the population is increasing at a slower pace than in other European countries. These developments require efforts to increase the effectiveness of interventions for the

prevention of disease and the promotion of health. Medical developments enable patients to live longer with their problems. This however necessitates the development of interventions to help patients cope with their disease, help them recover and help attain better quality of life. This also asks for effective tertiary prevention and self-management interventions.

Over the past few decades, activities in health promotion and disease prevention have increasingly been based on scientific theory and evidence, although not yet to a sufficient extent. Within the Netherlands, the University Maastricht and the members of this programme have been among the strongest advocates of this approach. Yet, there is still much to be gained by providing the field with tools and competencies for scientifically based health promotion.

This programme aims to further contribute to the development of theory-based and evidence-based health promotion and prevention, by:

- conducting basic research about determinants of behavior and behavior change;
- developing tools and protocols for the translation of theory and evidence into effective interventions at different ecological levels;
- doing applied research facilitating the use of those tools; and
- demonstrating the utility of such an approach by participating in projects and evaluating these.

At present, much of the research focuses on specific domains of health risks such as cardiovascular problems (including behavioral factors such as alcohol use, unhealthy nutrition, lack of physical activity, smoking, stress, diffusion of genetic risk information), diabetes and HIV/AIDS. However, to a large extent health promotion approaches including the development and application of its theories, methods and strategies are not confined to any health domain. Therefore, many results and insights are not disease-specific but generic by nature.

Some exemplary projects:

Habitual behavior – Unna Danner and Esther Papies – ZonMW

SchoolSlag – the development of integrated school health promotion - Mariken Leurs - ZonMW/GGD

Development, implementation and evaluation of an aids-education programme for black and migrant women from Surinam and the Dutch Antilles - Madelief Bertens – ZonMW

Stigmatization in hospital care and support for HIV/AIDS in Nigeria - Ngozi Mbono

Social roles and alcohol consumption in an international perspective – S. Kuntsche - SIFA

Communities in dialogue with data - Anita Vermeer – ZonMW/ Academic Centre for Public Health Limburg

#### *Key publications*

- Harting, J., van Assema, P., & de Vries, N.K. (2006). Patients' opinions on health counseling in the Hartslag Limburg cardiovascular prevention project: Perceived quality, satisfaction and normative concerns. *Patient Education and Counseling*, 61, 142-151.
- James, S., Reddy, P., Ruiter, R.A.C., McCauley, A., Van den Borne, B. (2006). The impact of an HIV and AIDS life skills programme for secondary school students in Kwazulu-Natal, South Africa. *Aids Education and Prevention*. Vol 18, 281-294.
- Knibbe RA, Joosten J, Derickx M, Choquet M, Morin D, Monshouwer K, Vollebergh W (2007) Culture as an explanation for substance-related problems: a cross-national study among French and Dutch adolescents. *Social Science and Medicine*, 64, 604-616.
- Reubsaet, A., Brug, J., Nijkamp, M.D., Candel, M.J., Van Hooff, J.P., Van den Borne, H.W. (2005). The impact of an organ donation registration information programme for high school students in the Netherlands. *Social Science and Medicine*. Vol 60, 1479-1486.
- Van den Nieuwenhoff, H.W.P., Mesters, I., & De Vries, N.K. (2006). Public awareness of the existence of Inherited High Cholesterol. *European Journal of Cardiovascular Prevention and Rehabilitation*, 13, 990-992.

#### **B.3.5.4 Towards the future: research goals (2007 – 2009)**

In the Netherlands, the legal and administrative frames for Health Promotion and Prevention have recently been adapted. Regional Public Health Services, important players in the field, have merged and developed new systems of governance with their financiers who are also their customers. Simultaneously, the field of public health has been criticized for underusing theory and evidence, leading to the founding of Academic Centres for Public Health, one of which is located in the Limburg region. This collaboration will be strengthened.

A further relevant development in Limburg is the establishment of the Maastricht UMC+, in which the 'plus' denotes the goal to include public health in the medical center. Within this development, a collaborative effort to build up a Diabetes cohort in the Limburg region has been started.

The recent inclusion of the group around prof. Knibbe within the programme will lead to renewed efforts to build up a centre for addiction research. Internationally, the work in developing countries will be continued.

Projects that are being started in 2007:

SchoolSlag: nationwide implementation (ZonMW) (September 2007)

Further development and adaptation of the Diabetes Information and Education Programme (ZonMW) (december 2007)

Academic Centre for Public Health (ZonMW) (3 PhD's, recently started, focusing on schools, community and municipal policies)

The programme is highly dependent on the earning power of a few senior researchers. Therefore, we will concentrate on developing human resource especially at the level of the PhD's (also in view of the importance of competing in the Veni-Vidi-Vici schemes). Furthermore, the project leadership feels there is an overrepresentation of intervention research and not enough theory-driven projects. In the near future balance will be restored.

#### **B.3.5.5 Final Analysis for Public Health Programme 5, based on SWOT**

In addition to the SWOT-analysis of the total institute, there are some specific aspects for the programme Practice and Theory in Health Promotion. First, the productivity and earning power is highly skewed, depending on just a few of the senior researchers; two of these will retire within a few years. This points to the importance of talent scouting and development. Although a strong point is the large number of PhD-students in the programme, many of these are practitioners in health promotion who do not pursue an academic career; some even work abroad. This illustrates the high societal impact. Earning power of talented younger researchers will however need to be developed. The recent inclusion of the alcohol dependency research group calls for an effort to increase group cohesion and leadership. A strong point is the interrelation with other programmes within Caphri. Within the MUMC+ development, the group finds new opportunities in cooperating with the Cardiovascular centre and the Centre for Chronic disease. Outside FHML, the links with the Psychology Department and with the Regional Health Service (a.o. in the Limburg Academic Centre for Public Health) are productive and promising.