Self-rated Health in Public Health Evaluation

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ABSTRACT

There is still a debate concerning the evidence base for community interventions. The randomised clinical trial design (RCT) is increasingly challenged as a gold standard for their evaluation. This thesis takes the Norsjö health programme in Västerbotten as the starting point for a discussion about the ethical platform of community interventions and for exploring the role of self-rated health. The specific objectives are: 1) to better understand barriers to community participation and to assess the role of ethical premises among decision-makers, 2) to explore how health related norms and attitudes interact with self-rated health and the risk factor outcome of an intervention and 3) to analyse the gender and socio-cultural interplay of self-rated health with biomedica1 risk factors for cardiovascular disease.

The participation and views of different actors in the planning and implementation phases of the intervention were studied by contrasting information between official documents, interviews with decision makers and professionals and questionnaires to community members. The role of basic values in setting priorities and choosing intervention strategies utilised a questionnaire design with hypothetical scenarios sent to a representative sample of Swedish health care politicians. Qualitative research interviews were used to explore health related norms and attitudes. Health examination measurements and questionnaire data formed the basis for analysis of the development of self-rated health and risk factor load during a 10-year follow-up of the intervention. Access to a stroke registry enabled a case-referent approach for studying the interaction between bio-medical risk factors, socio-demographic factors and self-rated health. Data from the Västerbotten Intervention Programme (VIP) could be utilised for a cross-country comparison with a “sister project” in Otsego, U.S.A.

The results point to both strengths and limitations of the efforts made to involve people in the intervention. The problem definition mainly remained with the professionals and participation as a goal in itself, strengthening local democracy was felt to be an exaggerated ambition. However, there was an overall agreement about the seriousness of the health problem, the need to intervene and about the implementation mode. Self-rated health and reported behavioural change were important indicators of participation and young men with bad health seemed to have been least involved. Among Swedish health care politicians there was an overall agreement to allocate resources for prevention directed towards communities when there are serious health problems. The majority preferred an intervention strategy that involved primary health care. The risk of harm by creating some degree of anxiety or stigma was for many considered an acceptable drawback of a successful intervention. The follow-up study revealed a positive risk factor reduction accompanied by a positive development of self-rated health, especially for men. Additional support for an intervention effect was given through a comparison with a reference area. The interaction pattern between risk reduc-
tion and self-rated health was more polarised for men than for women, with a corresponding pattern for the lower compared to the higher educated. These results could be linked to a transition in the health related norm system and to “ideal types” representing attitudinal sets towards the intervention. The case-referent analysis suggested an interaction effect between self-rated health and bio-medical risk factor load in predicting stroke that was greater for men than for women. The cross-country comparison revealed a stronger influence of education in the U.S.A. The lower educated, with a high risk load, had a greater risk of self-rated poor health than their Swedish counterparts.

The thesis suggests that self-rated health is an unexplored indicator, potentially important for understanding the complexity of community interventions. Self-rated health may predict disease development as well as modify the impact of established risk factors.

Key words: process evaluation, community intervention, self-rated health
GLOSSARY

This glossary is mainly derived from:
Public Health Dictionary (Janlert, 2000) and Qualitative Approaches for International Public Health (Dahlgren et al., 2004, in press).

Bias
Every influence on the study that leads to a deviation of the results from “the truth”. There are several types of bias, including design bias, gender bias, instrument bias, observation bias and publication bias.

Cluster sampling
A sampling procedure where the population is divided into groups that share some important characteristic under study. A random sample of clusters is selected, from which subsequently all or a random sample of individuals can be studied. The method is often used to limit the geographical spread of the sampled population.

Confidence interval
An interval that, with a specified probability of for example 95%, will include the true parameter in the population (when the value has been calculated on a basis of a representative sample of this population).

Confounding
Mixing of more than one effect. A confounding factor is one that is associated with the studied exposure while at the same time being a risk factor for the dependent outcome variable.

Cross-sectional study
A study that examines the relationship between diseases or other health-related characteristics and other variables of interest, as they exist in a defined population at one particular time.

Determinant
The exposure variable or an independent variable. A variable that is expected to determine in some way the outcome or the dependent variable under study.

Effect modifier
A variable that statistically interacts in a study of the association between an independent (x) and a dependent variable (y). If the modifying variable precedes the independent variable it is called an effect modifier while if it is simultaneous or follows it is called a conditional modifier.

Evaluation
The systematic judgement and assessment of a process or effects/outcomes. A summative evaluation refers to an assessment of the expected effects while a formative evaluation is a continuous undertaking following the ongoing activities.

Factor analysis
A statistical approach to reduce the number of variables in an analysis on the basis of their association to each other. Can be used to study to what extent one or several variables are expressions of the same underlying phenomena.
Generalise
To make conclusions from one or several separate phenomena to something general by distinguishing their special characteristics and identifying what they have in common.

Grounded Theory
A systematic methodological approach for the analysis of qualitative data with the purpose of generating theory.

Ideal type
A concept that isolates the typical or characteristic in a general or particular phenomenon. It is an analytical and abstract construct to illustrate the meaning of the phenomenon under study.

Nested incident case-referent study
A prospective case-referent study performed within a defined study base. As some of the variables are already known, the risk of confounding is to a certain extent limited.

Indicator
A state or characteristic that is used as a marker for something else. It is a theoretically constructed variable, such as education as a marker for social class.

Interaction
Interplay. Refers to the joint operation of two or more causes to produce a different effect than just the sum of the separate effect. If one variable decreases the effect of another it is called antagonistic while if it increases the effect it is called synergistic.

Logistic regression
A regression analysis where the association between two or more quantitative variables is a function of the included determinants. A logistic regression is based on an equation modelling the logarithmic odds as a linear function of determinants.

Member check
To bring back the results to members of the studied group with the purpose of focussing the analysis.

Odds ratio
The ratio between two odds. The odds of a particular exposure among persons with specific (diseases) characteristics divided by the corresponding odds of exposure among persons without the characteristics (diseases) of interest.

Panel study
A series of cross-sectional studies performed with the same individuals on different occasions. A panel study gives the possibility to study how changes in one variable are related to changes in another variable.

Power estimation
The estimation of the strength of the sample size to be able to reject the null hypothesis when it is false.

Predictor
A variable that can tell something about future events.

Random sampling
A method of choosing a sample from a target population based on everybody having equal chances of being sampled.

Purposive sampling
Non-random, non-probability sampling procedure used mainly for qualitative analysis. Each informant is selected deliberately with the expectation that they, on a theoretical basis, will represent the phenomena under study.
<table>
<thead>
<tr>
<th><strong>Qualitative research interviews</strong></th>
<th>Open-ended and conversational interviews for the purpose of exploring specific themes or phenomena under study.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Randomised control trial (RCT)</strong></td>
<td>A research design where the effect of certain exposures are measured through comparison with a non-exposed control group. Which individuals are to be included in the exposed or the non-exposed group will be determined before the study starts through a random procedure. The exposure dose and intensity is also controlled by the investigators.</td>
</tr>
<tr>
<td><strong>Reliability</strong></td>
<td>The extent to which a study is free from errors of measurements. Careful testing of the instruments is required. In qualitative studies this refers to the ability of the researcher to account for changing conditions. To allow other researchers to follow the decision trail is one possible measure to increase reliability.</td>
</tr>
<tr>
<td><strong>Risk factor</strong></td>
<td>Characteristic of an individual that indicate an increased risk of ill-health, disease, injury or unfavourable health behaviour. This characteristic can be related to any aspect of an individual (hereditary, social, economic or environmental). Risk factors precede the phenomenon that they are indicating. A risk factor can be either congenital or acquired. Factors that are caused by the problem under study are not considered risk factors. A risk factor need not belong to the causal chain. If its presence increases the risk statistically then it is considered a risk factor.</td>
</tr>
<tr>
<td><strong>Saturation</strong></td>
<td>The stage in the research process when an additional interview or observation is not expected to add new information. This is the stage where, in qualitative studies, you ideally should stop data collection.</td>
</tr>
<tr>
<td><strong>Standardisation</strong></td>
<td>A set of techniques used to remove, as far as possible, the effects of differences in age or other confounding variables, when comparing two or more populations.</td>
</tr>
<tr>
<td><strong>Triangulation</strong></td>
<td>A technique of using different data collection methods, data sources, informants, analytical approaches or investigators in a study of a joint problem to enhance the trustworthiness.</td>
</tr>
<tr>
<td><strong>Trustworthiness</strong></td>
<td>The extent to which the results extracted from empirical data are valid and reliable.</td>
</tr>
<tr>
<td><strong>Validity</strong></td>
<td>The ability of the study to capture what was stated in the aims. <em>Internal validity</em> refers to the performance of the study. For statistical analysis it refers for example to selection criteria and other types of bias, while for qualitative analysis triangulation, prolonged engagement and member checks are important. The <em>external validity</em> refers to the possibility to transfer or generalise the results to other populations or settings.</td>
</tr>
<tr>
<td><strong>Value statement</strong></td>
<td>A proposition which cannot be reduced to an arguable statement of fact but which effectively asserts that something is good or that something ought to happen</td>
</tr>
</tbody>
</table>
This thesis is based on the following papers:


III Emmelin M, Weinehall L, Stenlund H, Wall S, Dahlgren L. To be seen, confirmed and involved - a ten year follow-up of perceived health and cardiovascular risk factors in a Swedish community intervention programme. Submitted


V Emmelin M, Nafziger AN, Stenlund H, Weinehall L, Wall S. Cardiovascular risk factor burden is a stronger predictor of self-rated poor health in adults in U.S.A. than in Sweden, especially for the lower educated. Submitted

Papers I, II and IV are reprinted with the permission of the publishers:

- Paper I: Oxford University Press
- Paper II: Oxford University Press
- Paper IV: Lippincott Williams & Wilkins
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BACKGROUND

There is still a debate concerning the evidence base for community interventions (SBU, 1997; Oakley, 1998; Eriksson, 2000; Judd et al., 2001; Pearson et al., 2001a; Pearson et al., 2001b; Merzel & D’Afflitti, 2003). The randomised clinical trial design (RCT) is increasingly challenged as a gold standard for their evaluation in recognizing that promoting health among populations must build on mobilisation and social dynamics rather than rely on traditional health messages.

In the field of cardiovascular disease prevention the discussion goes back to the different generations of programmes initiated since the mid 60s. The first generation had a clinical high risk approach often targeting single risk factors and not directed to the community. The second generation had a bio-epidemiological population approach and was often directed towards multiple risk factors combined with a high risk strategy. Both had the RCT as the evaluation paradigm but also used quasi-experimental designs comparing intervention and reference populations. The third generation programmes, starting from the late 80s, were often small scale, addressing multiple risk factors but with a pronounced participatory and action orientation built on local co-operation and local networks. Suggestions for more realistic evaluation designs were gradually developed that included longitudinal process evaluation using both qualitative and quantitative methods (Brännström et al., 1994b; Nutbeam, 1998; Eriksson, 2000; Patton, 2002).

The Västerbotten Intervention Programme (VIP) belonged to this third generation, and was launched in 1985. It started in the municipality of Norsjö as a demonstration and feasibility project (Patton, 2002) for measuring effects of cardiovascular disease prevention for later dissemination to the whole county. Cardiovascular disease had been identified as a major public health problem in the area both by the health care system and the community (Rosén, 1987). Experiences from other health interventions, such as the North Karelia Project (Puska et al., 1996), and social projects aiming at mobilising disadvantaged communities influenced the design (Swedner, 1982; Sundh & Turunen, 1992; Swedner, 1996). The programme was designed to combine a population strategy with efforts to meet, examine and give health advice individually.
Background

to people at certain ages. Using the primary care system as a partner, the programme carried out systematic risk factor screening and counselling by its primary health care providers at the same time as the whole municipality was involved in different strategies to raise public awareness. Seen in retrospect the measures used were a combination of conventional “top-down approaches” (surveillance, mass media information and health policy) and “bottom-up approaches” (partnerships and resource identification, community organisation and the local health care system). The goal for any cardiovascular disease intervention is “to shift the social norms toward improved health behaviour” (Pearson et al., 2001b). To encourage people to change or maintain a life style with low saturated fat, less cholesterol and calories, non-smoking, and more physical activity together with monitoring of blood pressure and cholesterol level was expected to decrease cardiovascular disease and death. In Norsjö the strategy to shift the social norms mainly suggested life style changes in dietary habits and increased physical activity. The activities were organised through social networks of the rural community, including the local health provider, local media, voluntary organisations and educational groups. The formation of a collaborative committee created a link between local government, health care providers and voluntary organisations. Strategies to encourage new food habits in schools, workplaces and shops were also important to create a healthier environment. Concepts like participation and empowerment are relevant in describing these ambitions.

The programme was linked early on to the research community. An advisory group from Umeå university (the VERNA group) representing medicine, epidemiology and social science was formed to follow the implementation of the project and to contribute with specified guidelines for risk factor screening and counselling. A multi-disciplinary research team followed the intervention activities and a framework for a scientific process evaluation was developed (Brännström et al., 1994b). The observed overall risk factor reduction (Brännström et al., 1993; Brännström et al., 1994a), the equal distribution of health benefits (Lindholm et al., 1996b) and the positive assessment of the health provider approach (Weinehall et al., 1998a; Weinehall et al., 1999) later guided the intervention strategies in the whole county. The programme gained international interest for comparisons of cardiovascular prevention strategies (SBU, 1997; Persson et al., 2001; Wall et al.,
2003), and for its attempt at dissecting the “black box” of community interventions (Pearson et al., 2001b). Together with a “sister project” in the U.S.A. the Norsjö programme was used to discuss what is essential for successful cardiovascular disease prevention. By detailed descriptions of the exposures (what was done) and some joint bio-medical outcome measures part of the “black box” was dissected. Different needs for early and late adopter communities were identified and suggestions given for which components were sufficient and which were necessary to have an impact.

Community interventions are directed towards social systems trying to influence people’s norms, attitudes and actual behaviours. They aim to create a positive infrastructure for change and a will to initiate action on both community and individual level (Pearson et al., 2001b). However, social systems are complex and it is difficult to foresee all consequences, positive as well as negative. Targeted risk factor outcomes may for instance be positively influenced while self-rated health develops in a negative direction due to labelling or stigmatisation. The effects can differ unfairly by age, gender and educational level. The unanticipated consequences can also be positive in terms of increased social interaction or improved self-esteem. Together the mechanisms resulting in unanticipated effects can be seen as part of the “black box” of interventions that need to be further understood.

Self-rated health was included in the survey questionnaire in Norsjö from the start. During the first six years of intervention, participants had a less favourable perception of their health than those in the reference area even if the difference did not remain after adjusting for sex, age and emotional and social support (Brännström et al., 1993). A significant association was observed in both areas between increased cardiovascular risk factor burden and self-rated health for men as well as women (Brännström et al., 1994a). Self-rated ill-health increased the risk of future acute myocardial infarction (AMI) fivefold for those with a high risk factor burden (Weinehall et al., 1998b). The health economic analysis pointed to the importance of including more subjective health measures for assessing the net-balance of an intervention (Rosén & Lindholm, 1992).

These results gave rise to further questions about self-rated health as an outcome variable of community interventions and its association to risk
factor load, gender and educational level. The role of self-rated health as an effect-modifier in predicting future cardiovascular disease needed further exploration, focusing on gender and educational differences. A question about different determinants for self-rated health in different cultural settings was also brought up on the research agenda. Finally, the need of including qualitative data to study health perceptions, norms and attitudes was emphasised.

Thus, this thesis wants to contribute to a further dissection of the “black box” of cardiovascular disease prevention. A comparison of determinants of self-rated health in different country settings and an analysis of the interaction between self-rated health and bio-medical risk factors in predicting future disease may contribute to that discussion. Key informants and community members in the intervention area may help describe and understand views on participation, collaboration and constraints on different levels. Norms, knowledge and feelings may influence the process and ethical values among decision-makers are seen as a basis for collective actions.
THEORETICAL FRAMEWORK

Community interventions as social movements

The collective action that characterised the community intervention in Norsjö was based on a vision of a humane society where health and well-being are societal goals. Citizens were invited to participate and identify themselves with the programme goals also on an individual level. They were expected to take action against an enemy, i.e. disease and illness. The three concepts; societal goals, identity and an enemy/adversary, are all present in Alain Touraine’s typology of social movements (Touraine, 1965; Castells, 1997). He states that a premise for collective action to be successful is that it transforms individuals into subjects. Following this line, participation in a social movement turns individuals into collective social actors operating on both community and individual levels.

Castells defines a social movement as being “purposive collective actions whose outcome, in victory as in defeat, transforms the values and institutions of society” (Castells, 1997). The key word in his definition is “transform” and the changes he refers to are social norms, values and attitudes. In relation to cardiovascular intervention the transformation of social norms would put health more directly on the agenda, while changes in values and attitudes would be associated more with individual ambitions and motives. This implies that individuals try to construct new ways of thinking that may result in a changed life style. This new life style has assumed consequences of increased quality of life and better health. Perceived or self-rated health become crucial concepts that are expected to mirror the view of the subjects, a view that in turn is influenced by changing norms in the community.

The dominant theories about social movements and the mobilisation of people have focused on organisational circumstance, resource mobilisation and research on social capital in local communities (Swedner, 1982; Sundh & Turunen, 1992; Ronnby, 1995; Swedner, 1996; Strykers et al., 2000; Weinhehall et al., 2001a). They were powerful tools to change the political agenda, with their emphasis on a joint struggle, participation and empowerment. Even if the Swedish application, in the field of social work, implied recognition of emotional aspects, it was the cognitive
components that were the main focus of the mobilising process. These theories also influenced the socio-epidemiological approach in the third generation of small scale cardiovascular prevention programmes, like the in Norsjö. However, with a history in the bio-medical paradigm and in the clinical and bio-epidemiological generations, they were still influenced by cognitive top down pedagogics (Eriksson, 2000). Criticism against the cognitively oriented one-sidedness of the efforts to mobilise people has lately been formulated by representatives of the sociology of emotions (Goodwin et al., 2001). They state that emotions as well as other aspects of culture are crucial in processes of social action and social mobilisation. This discussion of social movements has guided our understanding of the participation process in the intervention area and the suggestions for further action and research.

**Intended and unintended consequences**

Consequences of public health interventions are often discussed in relation to the ethical principles of autonomy, beneficence, no harm and justice (Beauchamp & Childress, 1989; Nilstun, 1994). Paper II describes the ethical considerations faced by health care politicians when deciding about if and how to intervene. We discuss the importance of a pol-ethical balance sheet as a basis for evaluating community interventions. However, our discussion about intended and unintended consequences of interventions is also influenced by theories developed by Robert Merton (Merton, 1956; Ritzer, 2000). Merton belonged to the sociologist’s active in the U.S.A. from the 1930s. He was known to favour theories of “the middle-range”, with a limited scope and based on empirical studies rather than theoretical constructs. Early on he was a proponent for combining qualitative and quantitative analysis of social actions and social structures. He wanted to focus on social functions rather than individual motives in studies of social processes and cultural patterns. He introduced and re-defined some important concepts to aid the analysis. Function should not only be related to adaptation or adjustment. A social process or act can have both positive and negative consequences for a system. He labelled the negative consequences dysfunctions and added the concept of non-function for those consequences that could be regarded as irrelevant. To be able to weigh different types of consequences he talked about a net-balance, not as a quantitative measure of plus and minus but as a relative weighting of consequences at dif-
different levels. Merton also distinguished between manifest and latent functions, where the manifest ones are the intended and recognized functions and the latent are those that are neither intended nor recognized. His claim was that unanticipated consequences of action can be latent functions, dysfunctions or non-functions. This framework guided us to look beyond the obvious manifest functions of interventions when evaluating their outcome. Merton emphasised that “the distinctive intellectual contributions of the sociologist are found primarily in the study of unintended consequences (among which are latent functions) of social practices, as well as in the study of anticipated consequences (among which are manifest functions)” (Merton, 1956). For Merton the importance of studies including negative consequences (dysfunctions) was their ability to make visible constraints that could be dealt with and turned into manifest or latent functions. Merton also called our attention to the connection between culture, structure and behaviour. In his analysis of American society he viewed anomie (deviant behaviour) as a result of a disjunction between cultural norms and goals and the structural possibilities given to reach the goal within the prevailing norm system. Seen from a community intervention perspective his analysis may help explain the socially patterned reaction to new and healthier norms and the need for structural means to reach them. In this thesis we have not aimed at capturing all manifest and latent functions of the intervention activities. However, we have tried in different ways to look beneath the surface, discussing barriers and constraints that might help us understand patterns of participation. We have studied the development of self-rated health with a notion that a negative change would be an indication of a latent dysfunction of the intervention that needs to be further understood.

The influence of social norms and values on behaviour

Social norms are influential in guiding people’s behaviour. They are the sets of expectations that individuals are expected to act from in a given culture. Some of the sets are global while others are directed to specific groups or towards specific social roles. Social norms are often accompanied by rewards or punishments. These sanctions can be partly formal (legal) but most often they are part of a sophisticated web of cultural
phenomena. Examples of informal punishments are to make fun of somebody, causing shame or loss of prestige.

The relation between social norms and human behaviour is reciprocal. Norms rule behaviour in the sense that they shape habits, skills and life styles. In a long-term perspective new norms are constructed and old norms are de-constructed in collective processes of interaction. Social norms are important properties of a social system. They characterise a traditional culture as well as modernity. Norms are rooted in tradition but can also shift when people develop empathy for new ideas and perspectives. Ferdinand Tönnies’ classical theory of the social transformation from “Gemeinshaft” (tradition) to “Gesellschaft” (modernity) reflects this process (Tönnies, 1887/1988). Knowledge about the traditional norm system as well as emerging new values is important for implementation of any health promotion activity.

Social norm is a basic concept in social science. The concept of social role is for instance not meaningful if not related to norms and culture. In medical sociology, the sick role is influenced by expectations and norms. The expectations may differ between work places as well as between communities and they may change over time. Pierre Bourdieu’s habitus concept is close to social role in that it also emanates from social norms present in specific fields or social contexts (Bourdieu, 1984). Habitus comprises the mental or cognitive structures, internalised and embodied, that help people deal with the social world. It directs behaviour, taste and preferences and reflects class structure, age and gender. The habitus concept is useful for discussing the mechanisms behind the social variation in health-related behaviour (Lindbladh et al., 1996). For discussing the influence of community intervention the general social constructionist perspective on social norms, based in symbolic interactionism is relevant. Mead and Blumer’s view about the development of a self is our point of departure (Mead, 1934/1962; Blumer, 1969). The self consists of “I” and “me” where “I” is the spontaneous and intentional part, while “me” is the reflecting and evaluating part. The “me” part is what other people see and also the part which is depending on feedback from other people, especially the “significant others”. Behind these significant others are social norms and values that can be described as cultural properties. In symbolic interactionism they are labelled “generalised others”. The generalised other is a construct expressing the common expectations from the social environment. People internalise these expectations in their mind
and they become part of the evaluation of their own behaviour as “I”. With the help of these concepts we can view community interventions as directed towards the “me” part of the self of community members. The aim is to transform existing traditional norms regulating behaviour into being healthier than before. To do this social networks and social capital have to be mobilised with efforts on both individual and collective levels. There is a need for targeting the “generalised other” by using “significant others”, well anchored in the local culture.

However, mobilising people is not only a matter of providing them with new norms based on improved knowledge about risks. The emotional part of the new social norms is crucial, especially when trying to influence basic life style behaviours. One has to feel good, joyful or proud to even think about change. To use stable and well-anchored networks in the local community is one feasible strategy that has been suggested by Young (Young, 1997). Giddens also refers to this type of adoptive strategies where community members act through existing traditional structures and thereby become part of their change (Giddens, 1984).

**Perceived or self-rated health**

Self-rated health is the central concept in this thesis. It is the subjective summary of how individuals perceive their own health (Björner et al., 1996). The concept has been widely used in health surveys during recent decades, and also in patient studies. With a few simple questions, respondents are asked to indicate how they rate their health in general and/or in comparison with other people of their own age. It is an inexpensive instrument and the reliability has been shown to be high in all age groups and for both men and women (Lundberg & Manderbacka, 1996; Martikainen et al., 1999). It has also been argued that the actual wording of the questions is immaterial as long as they include an overall rating (Eriksson et al., 2001; Fayers & Sprangers, 2002). Idler and Benyamini conclude in their reviews of a total of 47 population based studies that self-rated health is an independent predictor of mortality also when other health status indicators are taken into account (Idler & Benyamini, 1997; Benyamini & Idler, 1999). Some studies have shown self-rated health to be a predictor also of functional decline, chronic disease and recovery (Wilcox et al., 1996; Ferraro et al., 1997; Shadbolt, 1997; Idler et al., 2000). There is still a debate about the relative
importance of underlying medical and social variables in predicting future ill-health or mortality (Idler & Angel, 1990; Kaplan et al., 1996). Many studies have addressed the determinants of self-rated health to be able to understand the role that self-rated health plays for survival or future disease. Medical health status and functional impairment are the major contributing factors but physical fitness, psycho-social well-being, social network and social support are also associated with self-ratings as well as some health behaviours (Fylkesnes & Forde, 1991; Östergren, 1991; Moum, 1992; Manderbacka et al., 1999). Self-rated health seems to be a better predictor for mortality for men than for women but the mechanisms behind are still under discussion (Benyamini et al., 2000; Benyamini et al., 2003). In Sweden self-rated health has been shown to be a good predictor for mortality in all social strata (Burström & Fredlund, 2001). However, there is still a need to better understand the perceptions of health in different social and cultural settings (Fylkesnes & Forde, 1992; Jyla et al., 1998; Benyamini & Idler, 1999; Idler, 1999; Sibthorpe et al., 2001; Kaplan & Baron-Epel, 2003). This thesis focuses on three aspects of self-rated health described below.

**Self-rated health as an outcome measure of community intervention**

Few studies have addressed self-rated health as an outcome of public health interventions. The North Karelia study showed that the self-rated good health ratings improved significantly more in the intervention than in the reference area and that the perceived risk of developing cardiovascular disease decreased (Kottke et al., 1984). In a community intervention in Cuba to promote health in a slum-area both self-rated health and perceived health risk were to evaluate the intervention effects (Spiegel et al., 2003; Tate et al., 2003). However, these analyses did not include any comparison of men and women or educational groups. We found no studies that specifically focussed on how self-rated health, as an outcome measure for cardiovascular prevention, combines with risk factor changes and whether self-rated good health may contribute to a better prognosis of future risk factor burden.
Determinants of self-rated health

There are few epidemiological studies about the relationship of self-rated health to bio-medical health risk factors across cultures (Carlson, 1998). In addition, the influence of socio-demographic factors upon self-rated health, when adjusted for known cardiovascular risk factors, has not been compared between European countries or for instance with the U.S.A. With access to two health databases from two communities with some geographic similarities but cultural differences we had the possibility to further explore the relationship of socio-demographic and cardiovascular risk factors to self-rated health, and to discuss the possible influence of differences in health related norms and attitudes.

Self-rated health as a predictor for future disease

In their review Idler and Benyamini called for population based studies on morbidity outcomes that are also mortality risks (Idler & Benyamini, 1997). Weinehall et al. studied the interaction between self-rated health and bio-medical risk factor burden in predicting acute myocardial infarction (AMI), showing a fivefold AMI odds ratio for individuals with a high risk factor burden not rating their health as good, compared to those rating their health as good but with the same risk factor burden (Weinehall et al., 1998b). These results were potentially important for future disease prevention. However, to broaden the discussion regarding the mechanisms by which self-rated health acts as a predictor for morbidity or mortality we wanted to study this interaction for another disease diagnosis and include gender and education in the analysis. Other studies had shown that self-rated health is a risk factor for mortality for patients’ with experience of serious cardiovascular disease (including stroke and AMI), also after adjusting for co-morbidities, disease severity and several socio-demographic factors (Bosworth et al., 1999). However, we found no population based studies specifically reporting the role of the interaction between self-rated health and bio-medical risk factors in predicting stroke.
Gender and health

Following Annandale and Hunt, I have tried to avoid the “twin trap” of liberal feminism, with its concentration on social roles and radical feminism’s emphasis on gender as a primacy in explaining inequalities in health (Annandale & Hunt, 2000). I wanted to avoid getting stuck in exclusively biological or socio-cultural explanations. That there are socially constructed differences between men and women have dominated my view but bio-medical differences in cardiovascular disease patterns and vulnerability have been taken into consideration when discussing the role of their risk factors. My premise is that social and biological factors are hard to separate and that they most often interact (Hammarström, 1999). Annadale and Hunt point to four emerging methodological approaches to gender and health (Annandale & Hunt, 2000). The first is a gender comparative approach, implying that the analysis should aim at identifying both differences and similarities between and within groups of men and women. It also includes an awareness of intersectionality, i.e. a reciprocal and context dependent interaction between categories like gender, social class, education and age (Young, 1997). The gender comparative approach is also relevant within social constructionism (Burr, 2003). The claim is that alternative discourses offer different views of what it is to be, for example, a healthy woman or a healthy man. The second approach attempts to incorporate gender order in the analysis. The analysis should aim at capturing the links between structural properties of a society, social agency and individual variation. A shift, for instance, from traditional to modern norms in a local community implies changes in the gender and social structures, with consequences for health and illness. The third approach combines qualitative and quantitative methodologies. The quantitative approach is good for studying the association between intervention and outcome measures and the interaction between bio-medical and subjective health while a qualitative approach may be a better choice for discovering and interpreting people’s perceptions about the mechanisms involved. However, depending on the research question, both methods can be used to analyse gender aspects of health. The fourth and final component of the proposed framework is the link to social change. The description of trends in self-rated health, risk factor burden and norm systems are interrelated. To discuss the attitudes towards the health intervention in relation to changes in the life-course for men and women is therefore important.
THE STUDY CONTEXT

Public health and cardiovascular disease prevention

This thesis emanates from a renewed public health interest from Swedish health authorities during the 1970s (Rosén, 1987; Wall et al., 2003). A changing focus from medical care policy towards health policy influenced preventive measures to combat an emerging rise in cardiovascular disease. The underlying causes in Western countries had been debated since the 1940s without reaching consensus on how to meet the problem. Early theories included explanations involving the transition from an active, agricultural life style into a physically less active city life style, with continued consumption of fat food (Dublin & Spiegelman, 1949). However, in international comparisons Sweden still had lower cardiovascular disease associated deaths than for example Finland and the U.S.A. Within Sweden the prevalence of acute myocardial infarction was lower in the north than in the south (Ekvall, 1955). Later international comparisons suggested an association between calories from fat in the average diet and coronary heart disease, where Sweden fell somewhere between the “Mediterranean diet” in Italy and the fat rich U.S.A. food culture (Malmros et al., 1954). Sweden did not continue to participate in the international collaboration within the Seven Country Study, with its ambition to intervene. Weinehall noted that in the WHO Conference on Health Education in 1957, Swedish medical representatives questioned the ethical justification to intervene in people’s dietary habits and expressed a fear of para-medics taking control of health education (Biörk, 1957; Weinehall, 1997). This is maybe one explanation why Swedish epidemiologists, at that time, decided to follow cardiovascular disease development through large longitudinal cohorts in two big Swedish cities, rather than being involved in community interventions (Biörk et al., 1966). In the mid 70s the scene started to change in northern Sweden. Researchers in social medicine wrote medical accounts of their journey to all municipalities and health care centres in the province of Västerbotten (Axelsson & Tibblin, 1976). They initiated a study on the burden of cardiovascular disease which led to the project “Health problems in a county – a basis for health planning”. This was a collaboration between the Västerbotten County Council, the Department of Social Medicine at Umeå University and SPRI (the Swedish
Planning and Rationalization Institute for Health Services). Cardiovascular diseases were shown to be more common in the Västerbotten and Norrbotten provinces than in the country as a whole. Some areas, like Norsjö, were specifically hard hit. The Västerbotten County Council thus formed a task force to advice in the planning and implementation of a community intervention project. Study visits were made to learn from experiences in North Karelia resulting in contacts with the WHO MONICA project. Around the same time the Swedish Parliament adopted a new health care Act (Hälso- och sjukvårdslag, 1982) that obliged the County Councils to implement preventive programmes to improve public health. Thus, in 1984 the Västerbotten County Council decided to launch its Community Intervention Programme (VIP) (1984). As the health services and the municipality in Norsjö had jointly expressed their concern about the high cardiovascular disease burden in their area it was decided to start a pilot project in 1985, for later implementation in the whole county.

An increased public health concern can also be seen from the suggestions for a systematic description of the population and its health risks, health problems and care facilities that came out of “the Health for All by the year 2000 strategy”, proposed by the WHO (WHO, 1981). In Sweden the National Board of Health and Welfare in 1987 was given the task of regularly publishing Public Health Reports later followed by Social Reports in parallel. These reports have been instrumental in monitoring public health developments. Thus, knowledge was disseminated about increased life expectancy and a further decline in infant mortality, but also an increase in self-rated bad health and widening gaps between gender and social groups.

A National Committee for Public Health was commissioned in 1997 to propose national goals for public health including strategies for achieving them (The Swedish National Committee for Public Health, 2001). The overall strategies proposed were:

- Strengthening the social capital
- Enabling growing up in a satisfactory environment
- Improving conditions at work
- Creating a satisfactory physical environment
- Stimulating health-promoting life habits and
- Developing a satisfactory infrastructure for health.
The study context

One of the specific goals clearly emphasised a need for long-term investment in research and education. There should be intensified research on the usefulness, costs and consequences of intervention methods in public health, improved methods of public health work, and increased investment in public health science.

The long-term commitment between our department (Epidemiology and Public Health Sciences) and the County Council started back in the 1980s when the framework for the evaluation of the Västerbotten Intervention Programme (VIP) was developed. Members from the unit of community health joined with researchers at the University in the planning and implementation of the programme as well as in the suggested process evaluation. With additional financial support from The National Public Health Institute and other research funds a programme focussing on the structural, economic and social conditions for public health interventions was developed. Many of the research questions emanating from that programme have been addressed. The pilot area in Norsjö was described in terms of the social patterning of cardiovascular disease and the risk factor changes (Brännström, 1993; Weinehall, 1997) and an economic analysis of the cost and equity consequences of the programme was performed (Lindholm, 1996). This thesis continues with an analysis of consequences more related to people’s self-perceptions and attitudes. It also benefits from larger data sources with longitudinal follow-up that have been developed from both the Västerbotten Intervention Programme and the Northern MONICA project.

The Västerbotten County Council is unique in its long-term commitment in maintaining and developing community health competence. Although resources are scarce, the council has been determined to continue supporting preventive efforts and research. In its public health programme since 1998 the joint responsibility for public health between the state, the County Council and municipalities has been emphasised, but also the link to the research community. Following the newly decided national goals the council has recently made an agreement with the Medical Faculty at Umeå University to finance four senior posts; in reproductive health, child health, health care research and community health. These posts are accompanied by four posts for doctoral training and support for international collaboration.
The experiences and the data sources that have been generated since the late 1980s through the VIP and the MONICA project will be the basis for continued public health research. Together with national registries headed by the Centre for Epidemiology (EpC) they can help in assessing mortality, morbidity and health utilisation outcomes in the development of an evidence-based future public health.

Below is a short summary of the types of data that are included in the two main data sources used for this thesis.

**The Västerbotten Intervention Programme (VIP)**

Today the Norsjö Health Programme is part of the Västerbotten Community Intervention Programme for the prevention of Cardiovascular Diseases (VIP). The prevention concept from Norsjö (with some local adjustments) has gradually been implemented in all 14 municipalities and since 1995 the activities are part of the regular primary health care services. Physical health examinations followed by health counselling are offered to individuals aged 40, 50 and 60 years by the local primary health clinic. In connection with the visit the participants are asked to fill in a questionnaire with background information and lifestyle questions. They are also asked to donate a blood sample to be stored for future research purposes. The cumulative number of participants from 1985 to 2003 is approximately 75,000 and approximately 90% of these have agreed to donate a blood sample for future research. About 60% of those eligible have agreed to participate. The differences in social characteristics between participants and non-participants are marginal indicating a small selection bias (Weinehall et al., 1998a). The County Council is responsible for maintaining the database of all collected data. An advanced training programme has been developed providing further education to all family physicians and district nurses in the county. A manual for guiding the health education counselling is continuously updated.

**The Northern Sweden MONICA project**

Since 1985 the Northern Sweden MONICA project has been a part of the WHO MONICA (Multinational Monitoring of Trends and Determinants in Cardiovascular Disease). The project contains information from the two northern-most counties of Sweden, Norrbotten and
Västerbotten. It includes an invitation to a total of 2,000 inhabitants, aged 25-64 years, randomly selected from the population registers in 1986, 1990, 1994 and 1999, to take part in a screening examination for cardiovascular risk factors and to fill in a questionnaire on their socio-economic and psychosocial situation as well as traditional lifestyle factors. Similar to the VIP surveys around 90% have agreed to donate a blood sample to be stored for future research purposes. The cross-sectional data contains information on about 7,000 persons and have been used as a reference population for the evaluation of changes in the intervention area. In connection with the 1999 cross-sectional survey a follow-up of the previous cohorts was performed. This involves access to four cross-sectional surveys and three panel cohorts (1986-99, 1990-99 and 1994-99). A fifth cross-sectional survey will be performed during 2004, extending the possibilities for following cardiovascular developments. The MONICA project also includes an incidence registry for stroke and myocardial infarction, including all cases identified since January 1, 1985. Basic results from the cross-sectional surveys 1986-1999, including a description of event registration and survey procedures, have recently been published as a supplement to Scandinavian Journal of Public Health (Janlert, 2003; Stegmayr et al., 2003).

The VIP health surveys were designed to fit the MONICA criteria to facilitate comparison of results when evaluating the intervention programme.
The study context

Figure 1. Location of the intervention and reference areas.

The intervention area

Norsjö municipality is situated in the very north of Sweden, in the inland part of the Västerbotten province (Norsjö Kommun, 2004). The first settlers probably came in the 13th century but not until the late 17th century did Norsjö become a municipality of its own. Today, nearly half of the 4,800 inhabitants live in the “town” of Norsjö while the rest are distributed in one other fairly big “town” and 30 smaller villages. Since the 1960s the municipality has been characterised by a decline in population of more than 30%. The main population decrease took place between the years 1960 and 1975 but also during the 1990s, when many of the manufacturing industries collapsed. From the age pyramid it is clear that Norsjö has an aging population with out-migration and a low birth rate. The out-migration is highest among women in the reproductive age-group. For a long time farming and forestry were the main occupations in the municipality. Later mining became the dominant employment due to the development of ore processing in the area. Today, most work opportunities are in the public, manufacturing and mining sectors. Women are over-represented in the public sector, often working in part time posts. Norsjö has been characterised as both rich and bounded in tradition. The non-conformist churches as well as
temperance movements were strong in the 19th century alongside the labour and adult education movements. Traditionally, working meant hard physical work with accompanying food habits based on milk, flour, sausage and salted pork meat to keep strong. This was something that was later found to be important in cardiovascular disease development.

Norsjö is also known for having a very rich and varied cultural life with many good sportsmen, self-taught musicians, craftsmen and writers. Today there are around twenty community centres serving as focal points for joint activities in the villages. In the “town” there is a community hall where local associations offer a rich variety of theatrical and musical performances as well as bingo and dance evenings. These local networks were present when the intervention programme started and formed the basis for the social capital still present and important for social cohesion in the municipality. Thus, they were also crucial in the development of the local intervention strategy.

The intervention area from my perspective

For me Norsjö is the health programme. It is the place where I was educated in practical public health work. My teachers were the doctors, the dietician, the nurses and the secretaries at the primary health care centre. I interviewed many of them and I helped them with the socio-economic classification system for the survey questionnaires. They shared their views about the programme, how they performed counselling or how they viewed their role in preventive work. I was also told by representatives of the municipality - politicians, administrators, and representatives from different organisations - about the less medically oriented part of the intervention activities. All of these informants witnessed having felt an increase in cardiovascular disease in the 70s. Many middle-aged men visited the primary health care and had to be sent by ambulance to Skellefteå or Umeå, sometimes too late. Others had family members or close relatives who had suffered. They really felt a concern and a will to help people change for the purpose of preventing future disease. But they also recognised the difficulties and the deep-rooted traditions that influence food and other habits. Most of them were part of the same culture. The patterns of how norms and values guided “ordinary community members” were something I learnt more about later.

Norsjö is also the place where an important and personal “turning point” took place (Strauss, 1997). I clearly remember the day when I arrived to
start the key-informant interviews. It was winter and very cold. “The doctor’s house” had been reserved for me. It was a big family house facing the primary health care centre. I entered and started to organise my things because some of the interviewees had asked to meet me in that house instead of at their workplace. Now my dilemma started. I was a smoker. How could I be surrounded by a smell of smoke and still be a respected research interviewer? How would my informants feel about sharing their views on cardiovascular disease prevention, about how to make people stop smoking or to change other lifestyle habits? To hide the smell I decided to smoke only on the balcony. However, the balcony faced the primary health care clinic and my new friends could easily see me. Still, that is what I did a couple of times, but I froze and felt like a fraud. I was ashamed of myself and there was no real escape. Either I would have to openly admit to being a smoker or quit immediately. I do not really know how I got the strength to stop, but this time I did it. I had tried several times before but only managed during pregnancies. When reflecting, later on about this situation, I realised how strong the feelings of shame and deception are. We are extremely dependent on what other people think about us or what we imagine they think of us. This was a practical lesson in symbolic interactionism with “I” acting and “me” reflecting under the influence of “significant” and “generalised others” (Mead, 1934/1962). It became clear to me that such strong feelings can either help people change or make them feel worse because of failure. In my case I had many reasons to stop smoking and once my decision was made I had support, even during relapse periods. Not everybody has this.
OBJECTIVES

General objectives

The overall aims of this thesis are to contribute to the ethical platform of community interventions and to explore the role of self-rated health in their evaluation.

Specific objectives

- To better understand barriers and promoting factors for community participation and to assess the role of ethical premises among decision-makers (Paper I & II).
- To explore how health related norms and attitudes relate to self-rated health and the risk factor outcome of an intervention (Paper III).
- To analyse the gender and socio-cultural interplay of self-rated health with biomedical risk factors for cardiovascular disease (Papers III, IV, V).
A multi-methodological approach

This thesis has emerged from multi-disciplinary collaboration and is based on a multi-methodological approach. To use a combination of quantitative and qualitative methods in public health research is no longer controversial, even if there is still a discussion about the trustworthiness of the different approaches (Berman et al., 1998; Morgan, 1998; Barbour, 2003). Some quantitatively oriented researchers find qualitative methodology too imprecise and subjective while qualitative ones regard epidemiological projections too simplifying for studying a complex reality. The American ethnographer Agar goes as far as suggesting a new discipline of ‘qualitative epidemiology’ (Agar, 2003). He is convinced that the traditional epidemiological tool box has lost its importance for understanding the mechanisms behind the occurrence and distribution of disease. Epidemiologists have also questioned the possibilities of their discipline to capture the complexity of a suggested web of causation (Krieger, 1994; Susser & Susser, 1996b; Susser & Susser, 1996a; Susser, 1998; Krieger, 2000). They propose a eco-social framework for epidemiological theory and a broadened scope of the discipline to include also qualitative methods (Wall, 1999; Wall et al., 2003).

The discussion about the role of different methodological approaches is not new. Already in the mid 40s the sociologist Robert Merton and his colleagues developed procedures for collecting qualitative data using focussed interviews with individuals or groups (Merton et al., 1956). This work was greatly influenced by his close collaboration with the sociologist and communication researcher Paul Lazarsfeld who was also a strong proponent for including qualitative methods in sociological research, especially when studying intermediate variables (Lazarsfeld & Henry, 1968). For Merton “qualitative focussed group interviews were taken as sources of new ideas and new hypotheses, not as demonstrated findings with regard to the extent and distribution of the provisionally identified qualitative patterns of response” (Merton, 1987). He would probably have agreed that within epidemiology and public health, qualitative and
Materials and methods

Quantitative methods cannot substitute for each other but give answers to different types of research questions.

Thus, qualitative tools, developed mainly within the social sciences, like sociology and ethnography, gradually became important in public health research. Baum suggests that a qualitative approach is needed to study the mechanisms through which health and disease are influenced by economic, social and cultural factors (Baum, 1995). It is equally important in studies of people’s perceptions and experiences of health and illness. Studies of the interaction between actors in the public health arena also need qualitative methods to capture for instance power relations and influence. Process oriented evaluations of social and educational interventions since long have included qualitative methods as important components (Patton, 2002). During the last decade it has become increasingly recognized to include also a qualitative analysis of the process in evaluations of public health interventions.

Qualitative and quantitative approaches in public health research therefore should be regarded as complementary and not as polarised. Questions of how people perceive their situation and their motives for action need a qualitative approach while questions of how many, how much and how often probably need a quantitative approach. In public health the overall research question is often broad, focussing on the magnitude of a problem, its medical and social determinants as well as on understanding the mechanisms involved in its development. A multi-methodological design is needed. Practically, there is a call for multi-disciplinary research teams and varied methodological competence. Morgan suggests four different ways of combining qualitative and quantitative methodologies where one takes precedence over the other in importance or in sequence (Morgan, 1998). However, it can be questioned whether there is always one principal method. A pragmatic view may be more realistic and encourage mutual respect. They are equal partners in an empirical paradigm, searching for answers in lived experience rather than in theoretical constructs (Silverman, 1993; Baum, 1995; Pope et al., 2000; Dahlgren et al., 2004, in press). The claim that the approaches have their origin in different epistemological paradigms (naturalistic and positivistic) has some bearing, and should be considered when developing the skills to use them (Lincoln & Guba, 1985). But the epistemology of researchers is not as simple as being naturalistic or positivistic or as working with ‘soft’ or ‘hard’ data. Epistemology has more to
do with values and ideology connected to choice of research questions and views about the role and responsibility of the researcher (Meyer, 2000). Sometimes this coincides with a preferred methodology, sometimes not.

**General design of the studies**

My research journey started within a framework developed for a combined process and effect evaluation. The suggested components included a combination of qualitative and quantitative methodologies to study community participation, socio-epidemiological outcome, attitudes and perceptions of key informants and the social, cultural and political context of the programme (Brännström et al., 1994b). The research questions developed for this thesis have their origin in discussions within the multi-disciplinary research group representing social work, health economics, medicine, public health, epidemiology, education and sociology. The research questions guided the choice of data collection and analysis.

An elaborated questionnaire to all community members aimed at measuring the engagement and participation in the programme as well as attitudes and perceptions about the intervention strategies. Semi-structured interviews with decision-makers, planners, medical staff and researchers were used to capture their views and perceptions about constraining and promoting factors. Official notes from different administrative levels served to give an overview of the decision-making process during the different phases of the project (Paper I).

The role of basic values in priority setting and choice of intervention strategies utilised a questionnaire design with hypothetical scenarios about disease prevention. We wanted to go beyond the actors that had been involved in the intervention programme and therefore approached a representative sample of health care politicians in Sweden (Paper II).

Qualitative research interviews were used to explore health related norms and attitudes while health examination measurements and questionnaire data reflected the development of self-rated health and risk factor load during a 10-year follow-up. This study had already been envisaged during the development of the evaluation framework and regarded as important for understanding how collective normative systems are involved and can influence the outcome (Paper III).
To understand the potentials of including self-rated health in the evaluation there was a need to understand more about the concept, and its gender and socio-cultural interplay with risk factor load. A design to address some of these aspects was made possible through access to cross-sectional and longitudinal health examination and questionnaire data from the intervention area (Norsjö) and the reference area (MONICA). The MONICA project also provided a registry that includes all cases of stroke in both the VIP and MONICA cohorts. This enabled a case-referent study on the interaction between bio-medical risk factors, socio-demographic factors and self-rated health. The Västerbotten Intervention Programme could also be utilised for a cross-country comparison with a “sister project” in the U.S.A., within the Otsego-Schoharie healthy heart programme, available through an institutional collaboration (Papers III, IV, V).

Table 1 gives an overview of the thesis in terms of research questions, data sources, analytical approaches and corresponding papers.
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<td>- To better understand barriers and promoting factors for community participation and to assess the role of ethical premises among decision-makers</td>
<td><em>Quantitative and qualitative</em> Cross-sectional</td>
<td>Questionnaires SEMI-STRUCTURED qualitative research interviews Official records about the programme</td>
<td>Total sample of community members aged 25-64 (n=1687) Purposive sample of politicians, planners and medical personnel (n=52) All notes from municipality-, County Council- and district level (n=93)</td>
<td>Descriptive - quantitative Descriptive - qualitative Descriptive - qualitative (content analysis)</td>
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<td><em>Quantitative</em> Cross-sectional</td>
<td>Health examinations Questionnaires</td>
<td>Participants in the 1999 VIP, Sweden (n=5461) Participants in the 1999 Otsego Health Census, USA (n=7643)</td>
<td>Descriptive and analytical (multivariate logistic regression)</td>
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General analytical approaches

The main difference between a qualitative and quantitative approach lies in the research question and the modes of analysis (Starrin, 1994). Most qualitative approaches share some common assumptions which have implications for the design and implementation of a study (Lincoln & Guba, 1985). A premise is that realities are multiple and socially constructed. Knowledge is produced in interaction with others. Thus, researcher and informants are regarded as inseparable. Research is value-bound which has to be taken into account in the analysis. Methodologically qualitative research is mainly inductive, time- and context bound and follows an emergent design. The researcher is “the human instrument” and has to get to know the “natural setting” in order to make relevant purposive sampling of informants. He/she has to learn to listen and probe well. It is also necessary to start the inductive analysis already in the field and be flexible in re-orienting the study on the basis of preliminary findings. Qualitative research has its scientific roots in symbolic interactionism, social constructionism, hermeneutics and phenomenology. Symbolic interactionism contributes with an emphasis on socialisation as an interaction process and on human ability in role taking and generalisation (Mead, 1934/1962). Social constructionism is important for its notion that reality is partly socially constructed (Berger & Luckman, 1967; Burr, 2003) Phenomenology adds a concern that knowledge about human beings should be grounded in “lived experiences” and hermeneutics with a right to interpret observations trying to understand the meaning of people’s actions or statements. In the analysis the researcher has a choice to focus on a phenomenological description or a more hermeneutic interpretation and to oscillate between being close and distant to the informants in the presentation of results (Dahlgren et al., 2004, in press).

Grounded Theory

Grounded Theory was developed in the late 1960s by Glaser and Strauss (Glaser & Strauss, 1967). The aim was to create a methodology that would assist in generating theory, constructing models or state hypotheses based on empirical findings. It offers a systematic approach for the whole research process with an emphasis on the analysis phase. Data most commonly consist of transcripts from focussed research interviews with a purposive sample of informants. Constant comparison of data, to
look for similarities and differences, is an important feature throughout the research process. During open coding the data will be opened up and characterised in detail to help decide on certain concepts/categories to focus on. The next step includes a selective coding of relevant parts of the data, now knowing what to look for. This step may include looking for properties and dimensions of identified categories to better understand their substance. The theoretical coding puts things together again. It helps to decide what aspects of the studied phenomena to theorise about, such as strategies, stages or consequences. The presentation of results should preferably include a description of the development of the concepts, formulation of hypotheses and a model or a theory based on the findings.

The qualitative sub-studies in this thesis were used to complement quantitative results in answering joint research questions. For the analysis of the interviews with the public health actors in Paper I we used a general qualitative approach to describe how the actors perceived the intervention for certain pre-defined criteria emanating from the semi-structured questionnaire (Patton, 2002). In Paper III the study addressed health related norm systems in the intervention area as well as their experiences of and perceptions about the intervention activities. The presentation of norm systems is descriptive, utilising the high face validity of the informants’ own words. However, in an attempt to interpret how attitudes and feelings to the intervention may have influenced self-rated health and risk factor change we followed more closely the steps of Grounded Theory (Glaser, 2001) and our interpretation of attitudinal sets are presented with the help of conceptual “ideal types” grounded in the data.

Quantitative analysis relies on both inductive and deductive approaches to explore possible associations between variables and to test *a priori* hypotheses about a selected number of variables. The requirements for quantitative data collection, sampling and analysis differ, mainly because of the aim to make statistical inference to defined populations. Both qualitative and quantitative research analysis implies oscillating between exploring and testing hypotheses. As in qualitative analysis there is a choice to analyse data on a descriptive or more analytical level. In this thesis we have used different statistical approaches to analyse the statistical relationship between the variables under study, with factor analysis and logistic regression being the most important.
Materials and methods

An exploratory factor analysis is a method for reducing the number of variables in an analysis to detect a structure in the relationship between variables measuring for instance the direction and strength of certain attitudes. After having established the relevant factors to be included in a model (based on their factor loading) you can perform a confirmatory factor analysis to test the associations between the included factors, some background variables and a defined outcome. This method was the basis for the final analysis about the value basis for decision makers in Paper II.

Logistic regression is a statistical technique that allows for analysis of a relationship between a dichotomous dependent variable and one or more explanatory variables (Kleinbaum, 1994). It can be used to determine the joint effect (including interaction) of the explanatory variables on the dependent variable and to adjust for the confounding effects of the remaining factors. The result of logistic regression is presented as odds ratios and 95% confidence intervals. Odds ratio is the association of exposure to one or several factors among one group (cases) compared with another group (referents), i.e. the number of exposed individuals to non-exposed individuals among the case group relative to the corresponding ratio among the referents (Persson & Wall, 2003). In our regression models self-rated health was sometimes the dependent and sometimes an independent variable in combination with biomedical risk factors and possible confounders.

Logistic regression analyses were performed for the case-referent, cross-sectional and panel studies. The case-referent approach is an economical way (compared to following a whole cohort) to study the role of different exposures in a defined outcome. The analysis is restricted to a set of cases and a sample of referents from a study base. In a nested case-referent study both cases and referents are chosen from a defined cohort, for which information on exposure and risk factors is already available (Persson & Wall, 2003). For Paper IV we had access to a disease registry where cases could be identified as belonging to two defined cohorts where the referents could also be sampled. Most importantly, information on exposures and risk factors were collected prior to the disease event. The panel approach that was used for analysing the gender and socio-cultural interplay of self-rated health and risk factors in Paper III followed a defined population over time. Data from those still remaining in the study population at follow-up could be analysed focussing on observed changes. The comparison of cross-sectional data from two
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different countries (Paper V) used logistic regression analysis for estimating the interplay between background factors and risk factor load to self-rated health at one point in time.

The case-referent analysis (Paper IV) led to a theoretical additive model for synergistic interaction between risk factor load and self-rated health and the odds ratio for stroke. Based on Rothman’s formula for estimating a synergy index (SI) and the number of cases attributable to interaction, we developed a method for quantifying the influence of three separate factors. The principles for these calculations are presented in more detail when describing the analysis for this study.

Community participation and the role of ethical premises (Papers I & II)

Data sources and analysis

A questionnaire was sent to all adults in the intervention area aged 16-80 years (n=4,111) in 1990, five years after the intervention had started. They were identified through a population based register. All analyses were based on the age group 25-64 years, covering the ages invited to health examinations. The response rate was 67% (n=1,687), with a higher response rate for women, except for the oldest age group. All 48 questions had pre-coded responses but always included an open-ended alternative. Three main issues were in focus: (i) self-rated health and health action, (ii) perceptions about the intervention programme and (iii) public opinion about mass media coverage.

The questionnaire was analysed using chi-squared for comparisons between sex and age groups. For the purpose of this study only a minor part of the questionnaire information was used, looking specifically at the sex and age distribution of the public’s views on the initiative to the intervention, their general attitudes to the intervention programme, their health behaviour changes and how these were related to perceptions of health.

Semi-structured open-ended interviews were held with 52 out of 53 invited decision makers, planners and medical staff in leading positions. They were purposively selected on the basis of being involved with the intervention programme (Patton, 2002). The interview guide covered four main themes; (i) perceptions of health problems, initiatives and pri-
orities, (ii) community participation and non-participation, (iii) co-operation, conflicts and ideology faced in public health and (iv) views on prevention in general and to the health programme in particular. The interviews took place during 1988-89, most of them at the workplace of the informants. However, many of the local actors preferred to meet outside their work environment. Each interview lasted from one to three hours and was tape-recorded and transcribed verbatim afterwards.

The transcripts from the interviews rendered a huge material that was first read through by the co-researchers to get an overview of the material - “the grand tour”. In a second round the reading was more focussed and the material coded and sorted based on the overall research questions. The third round included a comparison of the data from actors at different levels, looking specifically for consensus and divergent opinions. These procedures were performed during workshop sessions where individual reviews preceded negotiating the outcome and making a joint summary of the analysis. This step also included decisions about the presentation mode and choosing relevant and illustrative quotes that captured the main results (Patton, 2002).

Notes from official records during the period 1984–1988 were regularly sent to the research group. They comprised notes from the county, district and municipality level, but also unofficial notes from the local collaborative committee were included. Before the analysis started the material was summarised, sorted and checked for completeness. The 93 paragraphs from the collected official notes were coded according to their main content. They were used to describe the type and amount of decisions that had been taken on different administrative levels.

Paper I was based on a synthesis of the results from the three different data sources described above. Table 2 illustrates the relative weight that was put on the different data sources in the analysis.
Table 2. Relative weight of different data sources in the analysis

<table>
<thead>
<tr>
<th>Key questions</th>
<th>Public Questionnaire</th>
<th>Official Interviews</th>
<th>Official Paragraphs</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Initiatives, problem identification and interest</td>
<td>++ +</td>
<td>++ +</td>
<td>+</td>
</tr>
<tr>
<td>- Who initiated</td>
<td>+</td>
<td>++ +</td>
<td>+ +</td>
</tr>
<tr>
<td>- Who decided which health problem?</td>
<td>+</td>
<td>++ +</td>
<td>+ +</td>
</tr>
<tr>
<td>- What were the perceptions of the prevention strategy?</td>
<td>++ +</td>
<td>+ + +</td>
<td>+</td>
</tr>
<tr>
<td>(2) Participation and non-participation</td>
<td>++ +</td>
<td>++ +</td>
<td>+</td>
</tr>
<tr>
<td>- How was the concept of community participation perceived?</td>
<td>++ +</td>
<td>++ +</td>
<td>+</td>
</tr>
<tr>
<td>- Who participated?</td>
<td>++ +</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>- Has the influence of the citizens of the health programme increased?</td>
<td>++ +</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>(3) Constraints and ideology</td>
<td>++ +</td>
<td>+ + +</td>
<td></td>
</tr>
<tr>
<td>- What were the conflicts and barriers?</td>
<td>+ + +</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- How were class and gender related to health?</td>
<td>+ + +</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For studying the ethical premises for decision making in Paper II a postal questionnaire was sent to health care politicians in 10 of the 24 local authorities (counties) in Sweden that are responsible for health care. We made a cluster sampling where the counties were selected to represent both the north and south of the country, as well as rural and urban areas. From each of the ten counties we received complete lists of members of committees with a particular responsibility for health care and public health finance. The total sample was 631 persons which mean around 40% of all Swedish health care politicians at the county level. The response rate was 71% (n=451), somewhat lower among males and conservatives but not significantly different.

The questionnaire included a scenario to reflect on and 17 value statements to take a stand to before choosing one of six suggested intervention strategies. The value statements were all related to the ethical principles of 1) autonomy, 2) justice, 3) beneficence and 4) not doing harm (Figure 1, Paper II). Table 3 reproduces the scenario specifically used for this analysis and the intervention strategies that the respondents could choose from.
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Table 3. The scenario and intervention strategies for the questionnaire to health care politicians.

**Scenario**

A municipality has a 50 percent higher mortality rate from disease A than the national average. The most important cause is that the population in the municipality have unusually high body concentrations of a certain mineral. The contents and composition of one’s food are extremely important factors behind the concentration of the mineral in one’s body, and experiences from other places indicate that disease A can be prevented if people change their dietary habits. In recent years the value of a lowered mineral concentration has been questioned, however, as there seems to be a connection between very low mineral concentrations and increased mortality from disease B. The risk that disease B mortality will increase as a consequence of an intervention scheme focusing on changed eating habits is, however, judged to be very small, since practically everybody in the municipality has concentrations far above the limit under which negative consequences are deemed to be a real possibility.

**Intervention strategies**

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>No intervention. Mortality from disease A will remain at today’s high level.</td>
</tr>
<tr>
<td>B</td>
<td>Health checks are offered to all through the press. Anyone who chooses to take part in the screening will be informed about the medical test results and about the fact that lowered values for the mineral will reduce the risks for disease A, but also that there may be risks connected with very low values. No concrete advice about eating habits will be given. Instead decisions are completely left to the individual.</td>
</tr>
<tr>
<td>C</td>
<td>Everybody is offered a health check, information and counselling in a personal letter from the health centre. Those who take part will be informed about the results from the medical tests, and the fact that lowered values for the mineral will reduce the risks for disease A, but also that there may be risks connected with very low values. Those who are responsible for the intervention, however, judge that the risks associated with high values are greater, and people with high values are advised to try to lower them through changes in what they eat. The principle difference between B and C involves information and concrete advice.</td>
</tr>
<tr>
<td>D</td>
<td>No general screening is done. Instead there are projects aimed at socially pressured groups such as single parents, those living alone and those who are unemployed, as these people are more prone to contract disease A but also have a lower health status generally. The first step in the strategy is an attempt to strengthen these people’s feelings of self-reliance and their will to take initiatives of their own. As a first goal the project should be carried out through the mediation of labour unions and other organisations and popular forums, and secondly through concentrated measures by the health centres and the municipality.</td>
</tr>
<tr>
<td>E</td>
<td>Special focus on local, but general, measures such as food labelling, changes in school lunches and extension of no-smoking regulations. Local Members of Parliament are approached in order to win them over to more far-reaching national policies regarding people’s health, which among other things would mean increases in tobacco and alcohol taxes and subsidies on healthy foods.</td>
</tr>
<tr>
<td>F</td>
<td>None of the above. Instead I would like to suggest the following ....</td>
</tr>
</tbody>
</table>
The choice of intervention strategy related to sex, political affiliation, age or length of political work was estimated through cross-tables and the significance of the associations was tested using chi-squared. The respondents’ grading of the value statements were subject to a varimax rotated factor analysis. The aim was to explore and identify factors that could be related to the ethical principles. Five factors with an eigenvalue above one were extracted and four of those could be interpreted as connected to the ethical principles, autonomy, equity, beneficence and no harm. They could explain 50% of the total variance. A simple index for the identified factors was constructed before testing the significance of the differences between the indices according to political affiliation and choice of intervention. For this test we performed one-way ANOVA test using Bonferroni post hoc testing of multiple comparisons. Finally, to test the associations between the factors identified (ethical principles), choice of intervention strategies and political affiliation, we estimated a structural equation model and carried out a confirmative factor analysis using LISREL 8.12.

Norms, attitudes, self-rated health and the risk factor outcome (Paper III)

Data sources and analysis

In this study we combined survey data and qualitative research interviews. Figure 2 gives an overview of how the two sub-studies relate to the overall structure of the annual health surveys in the intervention area.
Figure 2. Sub-studies in relation to the overall structure of the annual health surveys.

The surveys for those turning 30, 40, 50 and 60 had been on-going since 1985. As everybody was invited every tenth year, individual follow up information was available from 1995. This study was based on a panel of those that participated in the health examination in 1986 and re-examined in 1996. The survey in 1996 was expanded to include also those turning 70 years. Out of the 260 participants in 1986, 174 attended also in 1996, i.e. a participation rate of 67%. Participants were a bit older than non-participants, i.e. 53% belonged to the older age group compared to 47% among the non-participants. However, there were no significant differences between participants and non-participants regarding education or biomedical risk factors. The data from the health examinations and the questionnaires included information about bio-medical risk factors for cardiovascular disease; smoking, hypertension, hypercholesterolaemia and high body mass index (BMI). A risk factor load was calculated for having 0, 1 and 2 or more of these risk factors. Information about self-rated health as well as socio-demographic factors, sex, age and education, were also available. In 1996 the survey was supplemented with questions about subjective well-being, attitudes and perceptions related to health and illness, some of which were included in the analysis.
The health survey data were analysed to describe the self-rated health and risk factor change in the intervention area, comparing percentage distributions at base-line and at follow-up. Cross-table analyses described the movements from one group to another. All analyses were performed separately by sex, age group and education. Multivariate logistic regression analyses were performed using a combination of self-rated good health and low risk factor load in 1996 as the outcome variable. The main background variable in the regression was a combination of self-rated health and risk factor load in 1986. The adjustment variables were sex, educational level and age group. The additional questions included in the 1996 health survey were used to supplement the research interviews by describing the percentage distribution of some health perceptions and self-perceptions of health by sex and educational level.

The qualitative research interviews were conducted with a purposive sample of informants (Dahlgren et al., 2004, in press). They were selected on the basis of their experiences of the intervention programme and identified with the help of the primary care unit. All of the informants had participated in the 1986 survey and were soon going to be re-invited for a 10-year follow-up. They were expected to inform us about their own health related attitudes, experiences about the programme as well as about changes in health related norms over time. We wanted them to represent some variation in age and sex but also to be known as reflecting persons with varying experiences from the health examination. An emergent design was followed (Lincoln & Guba, 1985) in the sense that preliminary analysis of the first two interviews formed the basis for the continued sampling of participants. The interview guide was explorative and open. The themes included: i) the informant’s life story, schooling, upbringing, work experiences, ii) health related norm systems and perceptions about health and illness, iii) experiences, perceptions and attitudes about the intervention programme and iv) hopes for the future. In total nine interviews were performed with two men and seven women. The men were 60 years and of the women one was 60, two were 50 and two were 40 years during their first health examination. In response to requests from the informants all interviews were performed at the primary health centre. The interviews took between 1.5 to 2 hours and were tape-recorded and transcribed verbatim.

The analysis followed the basic steps of the Grounded Theory approach described earlier (Glaser & Strauss, 1967; Glaser, 2001). The open
coding of the interviews was performed using the OpenCode computer software (Umdac, 2001). This programme was specifically developed to facilitate the process of coding and sorting qualitative data in the form of text. Figure 3 illustrates the search function looking for text linked to specified concepts labelled during the open coding.

![Figure 3. Finding text from Open Codes.](image)

On the basis of a comparison of all the open codes, extensive notes/memos were taken and relevant sections of the interviews were appointed for selective coding procedures. We decided to focus on attitudinal sets, identified the sub-categories/properties of cognitive and affective components and linked them to the open codes. In the next step we constructed, what Weber labelled, ideal types (Ritzer, 2000). The six ideal types were theoretical constructs that in the shape of metaphors tried to capture what the attitudinal set represented. However, in contrast to Weber’s logically constructed types ours were grounded in empirical data. Finally we went back to the material and looked for the properties that would help us describe these ideal types in relation to the intervention programme and to the quantitative findings. Thus, there was a constant comparison of the concrete data and the emerging categories and theoretical concepts. Figure 4 illustrates the steps from text via open codes, properties and dimensions to categories and ideal type.
Figure 4. From text to categories and ideal type.

Paper III presents a joint analysis of the quantitative and qualitative data. The final analysis includes an interpretation of the relationship between changes in norm systems, ideal types and direction of change in risk factor load and self-rated health.

The gender and socio-cultural interplay (Papers III, IV, V)

Data sources

The 10-year follow-up of the 174 participants from the 1986 health survey also contributed to the discussion about interaction between biomedical risk-factors and self-rated health (Paper III). Data from the Northern MONICA cross-sectional survey in 1986 and the follow-up in 1999 enabled a comparison of the interplay of risk factor load and self-rated health in the intervention area with that of a reference area (Paper in progress).
The study of the interaction between gender, educational level, self-rated health and cardiovascular risk factors in predicting future disease utilised a nested case-referent design (Paper IV). The cases were incident definite first-ever stroke events during January 1, 1985 to September 31, 2000. Individuals with a previous acute myocardial infarction or a cancer diagnosis within the past 5 years were excluded. A total of 473 cases were identified, who after participation in either the MONICA or the VIP health surveys suffered from a stroke event before the age of 75. Two referents for each case (945) were randomly selected among participants in the same study cohorts. They were matched for sex, age, type of survey and date of health survey and geographical area. If they had moved away from the region or had been identified as having had an AMI, a stroke or a cancer diagnosis within the last 5 years, they were excluded. The incidence registry and the MONICA survey data are kept and maintained by the MONICA secretariat. The County Council is responsible for maintaining the VIP database. Access to the data was made possible through an application procedure and as part of long-term research collaboration.

The country comparison (Paper V) addressed the interplay between gender, educational level and risk factor load in predicting self-rated health. The analyses were based on two cross-sectional surveys, one in Sweden and one in the U.S.A. The Swedish data emanated from the VIP health surveys described earlier. For this study, data from the 1999 health surveys were used. They included 5,461 adults, 47% of which were men and 53% women. The U.S.A. data were available through our research collaboration with Bassett Health Research Institute in Cooperstown, Upstate New York. They had conducted a study to assess the overall health status of the Otsego County population in 1999. This survey measured the prevalence of chronic disease, certain health behaviours and disease risk factors comparable to those measured in the VIP health surveys. Details of the methodology have been published elsewhere (Nafziger et al., 2001). Data were collected for 12,801 men and 14,653 women between 18-86 years, corresponding to a response rate of 79 %. For this study the U.S.A. data were restricted to adults between the ages of 35 and 65 who provided self-rated health data. In total, data from 7,643 adults were included, 38% of which were men, and 62% women.
Variables included in the different analyses

The definitions and selection of bio-medical risk factors as well as socio-demographic and self-rated health variables varied depending both on theoretical considerations and availability of data. Below is a summary of how they were defined in the different studies.

Cardiovascular risk factors

Smoking, high BMI, and hypertension were included as risk factors in all the studies, with some differences in definitions. Cholesterol level was not in the U.S.A. material and therefore replaced with physical activity in the country comparison. History of diabetes was only included as a risk factor for predicting stroke.

Smokers in the Swedish data were defined as those reporting daily smoking of cigarettes, cigarillos, cigars or a pipe. Occasional smokers were classified as non-smokers. For the country comparison the U.S.A. data only included cigarette smoking and no other form of tobacco use.

BMI was calculated as weight (kg)/height(m)^2. When dichotomised for calculation of risk factor load, high BMI was defined as >30. In the U.S.A. the weight and height were adjusted for inaccuracies due to self-reporting through validated corrections for this population.

Hypertension was based on a systolic blood pressure ≥160mmHg and/or diastolic blood pressure ≥95mmHg (according to previous WHO guidelines) and being on anti-hypertensive treatment. However, as a predictor for stroke, reported hypertension was included while those on medication were excluded from the definition. In the country comparison hypertension was defined as being on hypertensive medication in both populations.

Hypercholesterolaemia was defined as total cholesterol ≥ 6.5mmol/l when included as a general risk factor. However, as a predictor for stroke it was based on the clinically relevant level of ≥7.8.

History of diabetes was based on a question asking the respondents to indicate if they had diabetes.

A risk factor load or burden was calculated by adding the presence of any of the included risk factors into a score of zero to four or five. A risk factor load was calculated for having 0, 1 or 2 or more of any of the
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included risk factors. When the load was dichotomised, low load was defined as 0-1 risk factors and high load as 2 or more risk factors.

Socio-demographic factors and self-rated health

Gender, age group and educational level were included in all analyses, while marital status was only included in the country comparison.

Educational level covered total years of school completed with up to 9 years as low, 10-12 years as medium, and 13 years or more as high. However, due to a different educational system the U.S. defined up to 11 years as low educational level, 12 years as medium and 13 years or more as high. For some analyses educational level was dichotomised into low and medium/high education.

Age group in the Swedish material was by definition 30, 40, 50 and 60. When dichotomised, two groups were formed from 30-40 and 50-60 years. The U.S.A. adults were grouped into ten-year age groups as 35-45, 45-55 and 55-65.

Marital status was classified as married (including consensual union) and single (including divorced, widowed and separated).

Self-rated health was based on a single question asking people to grade their general health. The wording has been slightly different as well as the response alternatives. Table 4 describes how we treated the different variables in relation to each other.

Table 4. Grouping of the self-rated health question for analysis

<table>
<thead>
<tr>
<th>Response alternatives</th>
<th>Sweden</th>
<th>U.S.A.</th>
<th>Trichotomised</th>
<th>Dichotomised</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good</td>
<td>Good</td>
<td>Excellent</td>
<td>Very good</td>
<td>Good</td>
</tr>
<tr>
<td>Pretty good</td>
<td>Fair</td>
<td>Very good</td>
<td>Good</td>
<td></td>
</tr>
<tr>
<td>Fairly good</td>
<td>Good</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pretty bad</td>
<td>Bad</td>
<td>Fair</td>
<td>Poor</td>
<td>Poor</td>
</tr>
<tr>
<td>Bad</td>
<td></td>
<td>Poor</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Analysis

In the analysis of predictors for future stroke, means for baseline cardiovascular risk factors were calculated for cases and referents. The data were analysed by univariate and multivariate logistic regression using the conditional maximum likelihood routine designed for matched analysis to estimate odds ratios (OR) with 95% confidence intervals (CI).

Interactions between self-rated ill-health and having two or more of the included risk-factors were measured using the synergy index (SI) as proposed by Rothman (Rothman, 1986) where the synergy index will be equal to unity under additivity and exceed unity when more cases are subject to joint exposure than can be expected from the separate risk estimates. Confidence intervals for the synergy index were calculated by a method developed by Hosmer and Lemeshow (Hosmer & Lemeshow, 1992).

Based on the relative excess risk due to interaction (RERI) the attributable proportion (AP) was calculated according to Rothman, estimating the proportion of disease among those with two exposures that was attributable to their interaction. Rothman’s definitions of interaction were also used for developing a formula for calculating aetiological cases of stroke attributable to three separate risk factors as well as to their interaction (Paper IV, Figure 4). Table 5 shows the number of cases and referents in four of the eight exposure groups, the corresponding OR for stroke, and the aetiologic cases due to exposure group. An illustration of how we decomposed the attributable stroke cases in one of the eight exposure groups, i.e. hypertension and smoking, among those who rated their health as good is also given.
Table 5. Distribution of cases and referents in four of the eight exposure groups, the corresponding OR for stroke, and the etiologic cases due to exposure group (- = not present, + = present risk factors).

<table>
<thead>
<tr>
<th>Exposure</th>
<th>Bad health (C)</th>
<th>Hypertension (A)</th>
<th>Hypertension (A)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Smoke (B)</td>
<td>Smoke (B)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Cases</td>
<td>99</td>
<td>33</td>
<td>79</td>
</tr>
<tr>
<td>Referents</td>
<td>379</td>
<td>83</td>
<td>151</td>
</tr>
<tr>
<td>Odds Ratio</td>
<td>1</td>
<td>1.5</td>
<td>2.0</td>
</tr>
<tr>
<td>Etiologic cases</td>
<td>0</td>
<td>11.3</td>
<td>39.5</td>
</tr>
</tbody>
</table>

Formulae used:

Attributable proportion:

\( AP = \frac{(OR-1)}{OR} \)

Relative excess risk due to interaction:

\( (RERI) = OR(AB) - OR(A) - OR(B) + 1 \)

AP due to interaction:

\( RERI/\text{OR(AB)} \)

The OR for stroke for those both smoking and having hypertension is 4.4. Thus the aetiologic or attributable proportion was \( \frac{(4.4-1)}{4.4}=0.77 \). This meant that out of the total 32 cases 77% (24.7) could be explained by this exposure. The relative risk due to interaction could then be calculated on the basis of the ORs for smoking and hypertension alone; 4.4-2.0-1.5+1=1.9. The attributable proportion due to interaction was then 1.9/4.4=43% of the 32 cases, i.e. 13.6. The remaining 18.4 cases with an associated OR of 2.5 would be the ones expected under additivity which were de-composed further. The excess risk for hypertension was 2.5/1.5 =1.7 among smokers and excess risk for smoking 2.5/2=1.25 among those with hypertension. Using the AP we find that 1.7/1.7 *18 =7.5 cases were due to hypertension and 1.25-1/1.25 * 18.4 =3.6 cases were due to smoking. Thus we have decomposed the 24.7 attributable cases.
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into 13.6 due to interaction, 7.5 due to hypertension and 3.6 due to smoking. The remaining 7.3 cases in this exposure group are obviously explained by other factors. This means that the total number of cases due to hypertension among non smokers is 39.5+7.5=47.0 and 11+3.6=14.6 are due to smoking for the non-hypertensives among those rating their health as good. Figure 5 illustrates these results graphically.

Figure 5. Decomposing the stroke cases attributable to hypertension and smoking, among those rating their health as good.

The country comparison data for Sweden and the U.S.A. were analysed by bivariate and multinomial logistic regression. In a multinomial multivariate analysis, the odds ratios with 95% confidence intervals for self-rated poor health versus very good, good health versus very good for socio-demographic factors, and the separated risk factors were calculated. These analyses were performed separately for men and women for the two countries. In multivariate logistic regression equations, the influence of cardiovascular risk factor burden on self-rated poor health was compared by sex and educational level in the two countries. Educational level was included in the model (adjusted for sex, age group and marital status). The odds ratios for self-rated poor health were compared for the different groups using Swedes with high education as the reference group.
**My role in the research process**

As part of my research training I participated in all stages of the studies. However, my specific role in the different study components has varied over the years.

For the key-informant study (Paper I) I performed the interviews alone except on the national level where one of the other investigators joined. To avoid an evaluator effect it was regarded important that an outsider, not having been involved in the intervention activities, performed the interviews (Patton, 2002). However, experiences from the interview sessions were always shared and discussed within the research group as it was important to be able to make adjustments to the interview guide and the probing. The analysis was a joint venture within the research group with me and the principal investigator having overall responsibility.

The questionnaire study to health care politicians (Paper II) belonged to a larger framework focusing also on the respondents’ views on the relationship between equity and efficiency (Lindholm et al., 1996a; Lindholm et al., 1997). Thus, the development of the questionnaire and the analysis were shared in a larger research group with me and the health economist taking a specific responsibility for the sub-study included in our respective theses.

The studies addressing different aspects of self-rated health (Papers III, IV and V) were based on data sources where others had been responsible for data collection and variable construction. However, much work had to be put into checking the data, and fitting them into a joint format. In the quantitative sub-studies I had the overall responsibility for design and data handling. The analysis was a joint venture within the research group with me responsible for performing the statistical calculations under supervision. For the country comparison (Paper V) I shared the overall responsibility of the analysis with one of the co-researchers from the U.S.A. who has a special interest in comparisons of the interplay between BMI/obesity and other risk factors in the development of cardiovascular disease in the two countries. For the qualitative sub-study in Paper III, I was responsible for planning and performing all the interviews. However, in four of the interviews one other member of the research group joined. The open and selective coding processes were performed in collaboration with one co-researcher before negotiating the interpretation with the others.
MAIN FINDINGS

Community participation and the role of ethical premises (Papers I & II)

How was the participation process recalled by decision-makers, professionals and community members?

In Paper I information was contrasted between official documents, decision-makers, professionals and community members to capture main areas of consensus and divergence. According to the documentation, the overall aim of the intervention was to reduce morbidity and mortality from cardiovascular diseases and diabetes by influencing their main risk factors, i.e. high cholesterol, smoking and high blood pressure in the whole population. Neither key actors nor the public questioned these goals. Cardiovascular diseases were seen as serious health problems. However, actors often mentioned other threats to health, such as back pain, accidents, environmental influence, social problems and unemployment as equally important. The public also commented by giving alternative explanations for the observed high morbidity and mortality in cardiovascular disease, such as environmental pollution and heredity. We pointed out six observations which were important in understanding the participation process. Firstly, problem definition and goals had, in accordance with Swedish health care policy and in tacit agreement with the public, mainly remained with the actors (Table 4, Paper I). Secondly, the programme was seen by both actors and the public as life-style oriented. Thirdly, community participation was a means to bring about these changes through conveying health knowledge and increased awareness. Strengthening local democracy through participation was an exaggerated ambition for most actors. However, some envisaged participation in health promotion as a potentially strong social movement: “We have no equivalent of tree-lovers as regards health …there is no Greenpeace in public health. It would be exciting to have eager participation and people who would fight for this concept”. Fourthly, there was a great interest and an active participation by the community members. More than 60% in the older age groups took a personal interest in the programme and half of the subjects had changed some aspect of their lifestyle, more so for women than men. Men in the youngest age group reporting bad health seemed to be least affected by
Main findings

the programme (Figure 1, Paper I). Fifthly, the programme implementation was characterised by overall consensus. The intervention strategy built on co-operation between local stakeholders that worked well together. Thus, new links were established between the research community, the health care system, the municipality, voluntary organisations and the public. However, in some areas ideological disagreements became visible: 1) the imbalance between health care and prevention, 2) the scientific disagreement regarding cholesterol as a risk factor, 3) the right to interfere in people’s traditional habits (autonomy), 4) the control and ownership of the intervention programme between the health care services and the municipality, 5) professional competition and 6) collective versus individual responsibility for health. The actors discussed drawbacks of too much authority-based health education. They were concerned about the risk of frightening people by too much information on risks. Some of these issues were also raised in the questionnaire responses, in which 30% of community members agreed that the programme had led to fixed ideas about health and 20% thought that sick people had felt neglected. Finally, only a few complained about the resources spent on the programme and the majority wanted the programme to continue.

How do political ideology and ethical considerations influence public health decision-making?

Public health policy is often concerned with the conflicting values emanating from individually formulated ethics for curative care and more collectively oriented ethics. Through our questionnaire study (Paper II) we wanted to describe the relationship between ideology and ethical principles among Swedish health care politicians when assessing public health interventions. Both ideology and ethical considerations were expected to have a significant impact on the level of resources available for public health.

When faced with a scenario of 50% excess mortality from a certain disease in the community, only one health care politician preferred “no intervention”. The majority favoured an intervention that included active involvement from primary health care, one fifth only wanted to offer a health screening, 12% thought that interventions should be socially directed and 3% suggested general measures only. There was a significant association between the choice of intervention strategy and
political affiliation (p<0.01). The screening offer was preferred by the right wing and the screening invitation both by the left wing and the middle group. There were no significant associations between choice of intervention, sex, age or length of political work.

The exploratory factor analysis of value-statements largely confirmed a theoretical grouping according to ethical principles. The analysis resulted in five indices: autonomy, equity, beneficence, no harm and fear of stigmatisation. We found significant differences between all political groups concerning the principles of autonomy and equity while the principle of beneficence differed significantly only between the left and right groups. For the indices capturing the principles of no harm and fear of stigmatisation there was no difference between any of the groups (Table 3, Paper II). Those politicians that preferred “a general screening offer” had higher scores on the autonomy index than all other groups. For the equity index the highest scores were provided by those who suggested a “socially targeted intervention” or a “combination of their own”. However, the score differed significantly only for those who preferred “screening offer” and “screening invitation”. The same applied for the ethical indices of beneficence, no harm and fear of stigmatisation (Table 4, Paper II).

The confirmative factor analysis for ethical values, political affiliation and choice of intervention strategy indicated that only autonomy and equity could be fitted into an equation model (Figure 1, Paper II). The choice of intervention strategy could be described as a function of the scores for autonomy and equity. A high score for autonomy corresponded to a low score for the choice of intervention (individual) while a high score on equity corresponded to a high score for choice of intervention (general). The association between autonomy, equity and political affiliation was described in a similar way. A high score for autonomy indicated a high score for political affiliation (right), while a high score for equity indicated a low score for political affiliation (left). When the analysis was performed separately for the different political groupings we found that the right wing was more homogeneous in their views on autonomy and equity, their ethical values being interlinked with their political affiliation forming the basis for their choice of intervention. No association between autonomy and choice of intervention was evident among the left wing, probably because they all scored low and had voted for the same health intervention strategy. For equity the choice was more diver-
sified reflecting the ethical principles of the whole group. For the middle parties the choice of intervention strategy was more individualised with their ethical values taking precedence over political affiliation.

**Norms, attitudes, self-rated health and the risk factor outcome (Paper III)**

This study was based on a 10-year follow-up of a panel within the community intervention programme in Norsjö. With both quantitative and qualitative approaches, the interaction between changes in self-rated health and risk factor load was addressed, discussing how the outcome may have been influenced by norms and attitudes. By including self-rated health as an outcome measure we wanted to capture unintended consequences of the intervention activities, such as increased anxiety and worry. To validate the findings we have included some preliminary results comparing the development in the intervention area with that of the Northern Monica reference area (Paper in progress).

*How did risk factor load and self-rated health develop during the 10-year period?*

Weinehall et al evaluated the risk factor reduction in the intervention area compared to the reference area up to 1994 (Weinehall et al., 2001b). Our analysis confirms a risk load reduction in the intervention area also between 1986 and 1996 (Figure 2, Paper III). Preliminary results of the development in the reference area indicated further support for a positive intervention effect (Paper in progress). In the intervention area the risk factor load improved from 68% having a low load in 1986 to 78% in 1996. In the reference area the percentage having a low risk load decreased from 78% in 1986 to 69% in 1999. In the intervention area the flow from high to low risk load, was 55% compared to 27% in the intervention area. Moving from low to high risk load was 12% compared to 19% in the intervention area. All risk factors were involved in the risk reduction in the intervention area. Of those having high cholesterol at baseline 63% had low levels at follow-up. Smoking decreased by 60%, hypertension by 38% while only 14% reduced their BMI. The corresponding figures for the reference area showed that 42% had improved their cholesterol levels, 46% of the smokers had stopped, 15% lost their hypertension and 10% reduced their BMI. There was also
a flow in the other direction. In the intervention area 15% of those with no hypertension at baseline had developed it at follow-up. High cholesterol was acquired by 9%, 12% became overweight and 4% started to smoke. In the reference area 24% developed hypertension, 16% acquired high cholesterol, 11% became overweight and 3% started to smoke.

Self-rated health developed in a positive direction in the intervention area. In spite of an aging panel, self-rated good health increased from 68% in 1986 to 73% in 1996. The reference area started slightly higher with 75% rating their health as good, ending up with 73% rating their health as good in 1999. The movement between the groups were rather similar in the two areas with 19% of those with self-rated good health in 1986 changing to rating their health as poor at follow-up and around 50% moving from bad to good. Figure 6 presents the development of risk load and self-rated health in the two areas together.

**Intervention area**

<table>
<thead>
<tr>
<th>Risk factor load</th>
<th>Self-rated health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low risk</strong></td>
<td><strong>Good</strong></td>
</tr>
<tr>
<td>118 (68%)</td>
<td>119 (68%)</td>
</tr>
<tr>
<td>1986</td>
<td>1986</td>
</tr>
<tr>
<td>88%</td>
<td>82%</td>
</tr>
<tr>
<td>12%</td>
<td>18%</td>
</tr>
<tr>
<td><strong>High risk</strong></td>
<td><strong>Bad</strong></td>
</tr>
<tr>
<td>56 (32%)</td>
<td>55 (32%)</td>
</tr>
<tr>
<td>1996</td>
<td>1996</td>
</tr>
<tr>
<td>45%</td>
<td>47%</td>
</tr>
<tr>
<td>55%</td>
<td>53%</td>
</tr>
</tbody>
</table>

**Northern MONICA reference area**

<table>
<thead>
<tr>
<th>Risk factor load</th>
<th>Self-rated health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low risk</strong></td>
<td><strong>Good</strong></td>
</tr>
<tr>
<td>898 (78%)</td>
<td>864 (75%)</td>
</tr>
<tr>
<td>1986</td>
<td>1986</td>
</tr>
<tr>
<td>81%</td>
<td>81%</td>
</tr>
<tr>
<td>15%</td>
<td>19%</td>
</tr>
<tr>
<td><strong>High risk</strong></td>
<td><strong>Bad</strong></td>
</tr>
<tr>
<td>261 (22%)</td>
<td>284 (25%)</td>
</tr>
<tr>
<td>1996</td>
<td>1996</td>
</tr>
<tr>
<td>73%</td>
<td>73%</td>
</tr>
<tr>
<td>27%</td>
<td>50%</td>
</tr>
</tbody>
</table>

**Figure 6.** The development of risk load and self-rated health in the intervention and reference areas (follow-up 1996 for the intervention area and 1999 for the reference area).
Main findings

In the intervention area men’s risk factor load developed more positively than women’s with 93% maintaining low risk and 65% moving from high load to low compared to 83% and 47% among the women. In the reference area the observed changes were similar for men and women. For self-rated health there was no significant difference between sexes in the two areas. In both settings the lower educated had an initial higher risk load. In the intervention area the percentage decreasing their risk factor load was higher among the lower educated, 62% compared to 48% among the higher while in the reference area they were similar for the lower (26%) and the higher educated (27%). For self-rated health the higher educated in the reference area had an initial better health perception than the lower educated, while the opposite was true for the intervention area. Still it was the lower educated in the intervention area that improved their self-rated health most, 57% compared to 48%. In the reference area the development was the opposite with 46% of lower educated improving, compared to 54% among the higher educated.

The regression model for a combined positive outcome of self-rated good health and low risk factor load at follow-up was based on self-rated health status and risk factor load in 1986, with good health as reference, adjusted for age, sex and education. Bad health at baseline reduced the chances of a positive outcome 10 years (intervention) or 13 years (reference) later by around 70%. In the intervention area, adding low risk to good health increased the odds of a combined positive outcome at follow-up to twice that for those starting with a high risk (p=0.022). However, in the reference area the corresponding odds were eight times higher for those with low risk and good health at baseline. Adding high risk to bad health decreased the chance of a combined positive outcome at follow-up in the reference (0.3/0.04) while it remained the same in the intervention area (0.3/0.3). Together these results suggested an overall intervention effect, greater for those rating their health as good at baseline.

Including the reference area in the analysis gave additional support due to an interaction effect that was stronger for men than women. Figure 7 illustrates the combined results for the intervention and reference areas. For men in the reference area adding high risk to good health decreased their chance of a positive outcome much more than in the intervention area and the same was true when adding high risk to bad health. For women, adding high risk to good health decreased their chance of a
positive outcome nearly as much as in the reference area while adding high risk to bad health did not decrease their chances of a positive outcome as much. Thus, there was a polarised pattern for men, where those with high risk load and self-rated good health had benefited more than those feeling bad. Women, on the other hand seemed to have benefited more if rating their health as bad in combination with a high risk load at baseline, but the pattern was not as polarised as for men.

![Figure 7](image-url)  

**Figure 7.** Odds Ratio for good health and low risk at follow-up (1996 for intervention area and 1999 in the reference area).

In the intervention area there was a similar pattern for the lower educated as for men, i.e. adding high risk to good health did not decrease their odds of having a positive outcome 10 years later as much as for the higher educated. When including self-reported illness from the survey questionnaire, as a covariate in the regression model, the observed patterns between educational groups and sex remained.
Main findings

*How might health related norms and attitudes have influenced the development of risk factor load and self-rated health?*

The analysis of the qualitative research interviews suggested a transition regarding health related norms in the community. Views about health strongly related to work capability, had been challenged and partly replaced by a health concept more related to feelings and a goal in itself. However, the traditional norm systems seemed to have had a greater impact on some groups (older and lower educated) but lost some of its influence on others. The pride of having strength to work was still present. Not being able to work created feelings of shame, especially among “those above 50 years of age”. We also observed a shift in that the psychological aspects of health had come to the fore. This development was perceived as good and bad at the same time. "Today you are more allowed to feel ill”, but the disadvantage is that “you may not make enough efforts and give up too easily”. To be unhealthy was viewed as being both physiologically and psychologically ill, i.e. when “something is wrong with the whole body”. The informants would “rather have a disease and feel good” than “have a disease and feel bad about it”. A link between feelings and disease was also indicated: “There was something psychologically wrong that caused pain everywhere”. Panel participants ranked “Being physically fit and having energy” as equally important to “not being sick or having a disease” while “leading a healthy lifestyle” was not considered very important. These results added to our observation of a shift towards a more psychological view of health where “being psychologically fit” had become increasingly important, especially for the higher educated middle-aged men. (Table 1, Paper 3).

The interviews supported our previous description of a well-anchored intervention programme. A joint problem of cardiovascular disease had been identified and become a collective concern. The Grounded Theory analysis identified both affective and cognitive components of attitude sets towards the programme. These sets were used to construct six ideal types to help discuss the quantitative results. Table 6 presents a shortened version of the interpretation of how “ideal types” may react towards an intervention.
### Table 6. Ideal types and possible reactions towards the intervention.

<table>
<thead>
<tr>
<th>Ideal type</th>
<th>Interpretation of attitudinal sets</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The Blessing</strong></td>
<td>Saw the intervention as something bigger, outside themselves that came to their rescue. Knew something was wrong but did not know how to cope with it. Had not started to communicate their worries and not consulted the primary health care. Were influenced by the prescribed norms, not allowed to <em>feel</em> and be concerned about their own health. Saw the implementers as necessary for improving their situation, and even to survive. Felt grateful and cognitively also acquired knowledge to modify their risk behaviours. When successful they felt grateful for the support given.</td>
</tr>
<tr>
<td><strong>The Opportunity</strong></td>
<td>Felt relief but not so connected to the health care system or other external forces. This ideal type was more associated with pride and people’s own choices and behaviour. The representatives were not hiding perceived illness. Tried to do something and made attempts to mobilise their own resources. The intervention programme gave them an opportunity to reflect and make constructive changes. When they succeeded they felt good and proud of themselves.</td>
</tr>
<tr>
<td><strong>The Confirmation</strong></td>
<td>Regarded themselves as parts of a whole, in need of being confirmed. The feelings expressed were related to participation and empowerment. Saw themselves as responsible members of a collective. The intervention programme substantially increased their possibility for self-control and their opportunity to interact with others in similar situations. The distinction between illness, sickness and disease was small for them. Did not necessarily feel a need for changing the targeted risk factors but felt recognised for being on the right track already.</td>
</tr>
<tr>
<td><strong>The Disappointment</strong></td>
<td>Felt ignored and left out, in need of more help than the programme could offer. May not have fitted into the risk groups identified by the programme but had other problems to attend to. Became disappointed because they had high expectations which were not met by the programme.</td>
</tr>
<tr>
<td><strong>The Insult</strong></td>
<td>Expressed ambivalence towards the programme even if they may have applauded it at the start. Participation was more based on feelings than their own health problems. May have had the targeted risk factors but felt that they could not meet the demands from the programme. Felt criticised and worried about not being able to do something. For this type there was a greater suspicion about the collective ambition of the programme.</td>
</tr>
<tr>
<td><strong>The Watchman</strong></td>
<td>Viewed the programme as a common good to be proud of. It represented a general concern for the community and created a feeling of trust. The programme was compared to a regular check-up for cars.</td>
</tr>
</tbody>
</table>
Main findings

The gender and socio-cultural interplay (Papers III, IV, V)

The results from Paper III indicated an interaction between risk factor load and self-rated health in predicting the outcome of an intervention that differed between men and women and educational groups. Paper IV and V addressed more directly the interaction between self-rated health and bio-medical risk factors as predictors for future disease outcome and the role of different risk factors in determining self-rated health. Through the Northern MONICA project and the Västerbotten Intervention Programme (VIP) we had access to a stroke registry. This made possible a nested case-referent design with all exposure information collected prior to the onset of the disease. Through the VIP and a “sister project” in the U.S.A. the influence of bio-medical and social determinants on self-rated health between the two countries were compared.

How does self-rated health interact with bio-medical risk factors in predicting a future stroke outcome?

Our study supported findings from other studies that diabetes, smoking, obesity and hypertension were significant risk factors for stroke both for men and women. The risk increased significantly by level of risk factor load for both sexes. Self-rated ill-health had an independent role in the prediction of stroke, specifically for men. The pattern remained after accounting for risk factor load, education and civil status in a multivariate analysis.

The results suggested that the interaction effect between self-rated health and biomedical risk factor load is greater for men than for women. Men having two or more of the biomedical risk factors and rating their health as bad had a more than twofold risk of stroke compared to those rating their health as good (12/4.6; 95% CI 1.4-5.0), while the influence of bad health was only marginal for women (3.9/3.2; 95% CI 0.6-2.4), (Figure 1, Paper IV). Additional support for a stronger interaction effect for men than for women was illustrated by calculating the attributable proportion (AP) due to interaction between a risk factor load of 2+ and self-rated ill-health. For men, 42% or 20 cases were attributable to the interaction while for women it was only 15% or 5 cases. The synergy index (SI) was also higher for men (SI=1.8; 95% 0.90-3.4) than for women (SI=1.2; 95% CI 0.46-3.30), although not statistically significant. Stratifying the
Main findings

analysis for educational level indicated that the higher educated were more sensitive to the combination of self-rated bad health and an increased number of risk factors, also when looking at men and women separately (Figure 2, Paper IV).

The contribution of each of the separate risk factors in the risk load gradient was calculated by omitting them from the risk load one at a time in a matched analysis. Hypertension and smoking were found to have a major role in the risk score. When including only these risk factors in the model the effect modification from ill-health still clearly differed between men and women. Men had a fourfold stroke risk (15/3.6; 95% CI 0.9-8.1) when both having risk factors and rating their health as bad versus those rating their health as good, while for women with the same risk score the stroke risk increased only 1.5 times (6.6/4.7; 95% CI 0.3-6.8), (Figure 3, Paper IV). The attributable proportion of stroke cases due to any of the included exposures was 46%, i.e. 204/446 cases. The aetiological cases due to the separate risk factors, as well as to their interaction, were calculated using a formula developed from Rothman and described in the materials and methods section. We concluded that self-rated health had a role in 20% of the stroke cases and that more than one third of those cases reporting bad health could be explained by that factor alone (Figure 4, Paper IV). More of the male cases (50%) reporting bad health could be explained by that factor than for women (15%). Self-rated health had a role in 29% of males and 15% of females.

*How do bio-medical and socio-demographic risk factors interact as determinants of self-rated health in different settings?*

Most individuals in the Swedish and the U.S.A. populations rated themselves as having good health. However, a higher percentage of the Swedish population graded themselves in the two healthiest groups compared to the U.S.A. population and fewer in Sweden rated their health as poor (Table 1, Paper IV). All the evaluated cardiovascular risk factors (BMI ≥ 30, smoking, hypertension and physical inactivity) were common in both populations. The prevalence of obesity and smoking was higher in the U.S.A. population, antihypertensive medication was equally common, and physical inactivity more common in the Swedish population. The percentage grading their health as poor was higher among the U.S.A. population for each of the included risk factors (Table 2, Paper
V). Low education increased the risk of poor versus very good self-rated health up to 7-fold for both men and women in the U.S.A., but had no impact on self-rated health in Sweden. Each of the included biomedical risk factors was associated with poor self-rated health but the odds ratios were two to three times greater in the U.S.A. (Table 3, Paper V). Using Swedes with high education as reference group (OR=1), adults in the U.S.A., with low education and 2 or more risk factors, had a greater than three-fold risk (OR=6.3) of self-rated poor health compared to Swedish low educated adults with the same risk factor burden (OR=1.9). The better educated among the U.S.A. adults, with 2 or more risk factors, also had a significantly higher risk (OR=3.4) of reporting poor health compared to their Swedish counterparts (OR=2.4), (Figure 1, Paper V). When comparing men and women (Swedish men with high education as reference) the pattern remained.

Summary of the findings about self-rated health

This thesis started with an ambition to discuss the ethical platform for community interventions and to study unanticipated consequences of public health activities. It came to focus on how self-rated health could be utilised in such analyses. In the first paper (Paper I) self-rated health was regarded a measure influencing participation. In the decision making paper (Paper II) self-rated health was seen as an indicator of the balance between beneficence and the risk of doing harm. The following papers (Papers III, IV and V) showed that self-rated health played an important role in modifying the effect of several well-known social and bio-medical risk factors for cardiovascular disease. Table 7 revisits the research question, the corresponding papers, the self-rated health focus and summarises the main findings.
<table>
<thead>
<tr>
<th>Research question</th>
<th>Paper I</th>
<th>Self-rated health focus</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>- To better understand barriers and promoting factors for community participation and to assess the role of ethical premises among decision-makers</td>
<td>Co-operation, participation and conflicts faced in public health – lessons learned from a long-term prevention programme in Sweden</td>
<td><em>As an indicator of participation pattern</em>&lt;br&gt;How were reported changes in life style habits related to people’s rating of their health in the intervention area?</td>
<td>- Reported life style changes to promote health were least common among young men that reported bad health</td>
</tr>
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<td></td>
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<tr>
<td></td>
<td><em>As an indicator of the balance between risk of harming and beneficence (doing good)</em>&lt;br&gt;How do politicians view the risk of public health intervention strategies being harmful or stigmatising?</td>
<td></td>
<td>- Swedish health care politicians favoured a personal invitation to health screening. A low score on the stigmatisation index indicated that they were prepared to take some risks of harm, such as increased anxiety or stigma, when there is a serious public health threat.</td>
</tr>
<tr>
<td>Paper II</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- To explore how health related norms and attitudes relate to self-rated health and the risk factor outcome of an intervention</td>
<td>Pol-ethical considerations in public health – the views of Swedish health care politicians</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paper III</td>
<td>To be seen, confirmed and involved – a ten year follow-up of perceived health and cardio-vascular risk factors in a Swedish community intervention programme</td>
<td><em>As an outcome measure of community intervention</em>&lt;br&gt;How does self-rated health interact with risk factor changes in predicting a positive outcome on an intervention?&lt;br&gt;How might these results be influenced by health related norms and attitudes?</td>
<td>- An overall positive intervention effect compared to the reference area.&lt;br&gt;- A polarised interaction pattern for men with a more positive intervention effect when adding high risk load to self-rated good health at base-line than for adding it to self-rated bad health.&lt;br&gt;- For women adding high risk load to bad health did not decrease the chance of a positive outcome as much as adding it to good health, but the polarisation was not very big.&lt;br&gt;- Lower educated people had a similar polarised interaction pattern to men.&lt;br&gt;- The results could be linked to a transition of health related norm and to ideal types representing different attitudinal sets towards the intervention such as “the Confirmation” and “The Insult”.</td>
</tr>
<tr>
<td>Paper IV</td>
<td>Self-rated ill-health strengthens the effect of biomedical risk factors in predicting stroke, especially for men – an incident case referent study</td>
<td><em>As an effect-modifier in predicting future disease</em>&lt;br&gt;How does self-rated health interact with bio-medical risk factors in predicting first event stroke in the general population?</td>
<td>- The interaction effect between self-rated health and biomedical risk factor load was greater for men than for women as well as for the higher educated&lt;br&gt;- Self-rated ill-health had a role in 20% of the stroke cases and could explain more than one-third of the cases among those with bad health&lt;br&gt;- In the U.S.A. lower educated with two or more risk factors had a greater than three fold risk of self-rated poor health compared to Swedish lower educated with the same risk factor burden.&lt;br&gt;- When comparing men and women the pattern between countries and educational groups remained.</td>
</tr>
<tr>
<td>Paper V</td>
<td>Cardiovascular Risk Factor burden is a stronger Predictor of Self-rated poor health in Adults in the U.S.A. than in Sweden, especially for the lower educated</td>
<td><em>As an outcome itself, influenced by social and bio-medical risk factors</em>&lt;br&gt;How do bio-medical and socio-demographic risk factors interact in predicting self-rated health in different country settings?</td>
<td></td>
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</tbody>
</table>
TRUSTWORTHINESS

The trustworthiness of a research project is judged by the ability of the study components to capture the aims. It is equally important in qualitative and quantitative research to be transparent and reflect upon how design, data collection or modes of analysis might have influenced the result. However, the procedures to manage the threats may vary depending on the type of study. Lincoln and Guba and others argue for a specific terminology for discussing the trustworthiness of qualitative studies while others are content with the old concepts as long as the measures taken are properly described (Lincoln & Guba, 1985; Sandelowski, 1986); (Kvale, 1996; Mays & Pope, 2000).

In all research it is central to be able to grasp the reality of those being studied. Prolonged engagement and persistent observations are important ways to meet this end. When I started to work with this research project, I had to familiarise myself with the study area, both geographically and socially. I met with people involved in the implementation of the project, joined public meetings, theatre performances and other intervention activities and I had informal talks with people. In connection with interviews with actors and community members I stayed in the municipality for a week at a time, to understand more about the social context. I used my overall outsider perspective to encourage and open up elaborated discussions. I realise that the studies might have benefited from longer field visits. Components of participant observation at the primary health care centre as well as in the community could have been included in the study design. However, the long-term research collaboration, the close connection with the project implementers and the regular feed-back of results to the community can be seen as a part of a continuous prolonged engagement needed for a sound interpretation of both qualitative and quantitative results.

This thesis is built on triangulation of data sources, data collection methods, investigators and theories. Whether mixing qualitative and quantitative approaches increases the validity of a study or not has been discussed. Ford-Gilboe et al emphasise the scientific value of combined strategies, provided good quality data and usefulness of study findings (Ford-Gilboe et al., 1995). Mays and Pope argue that a mix may erroneously assume that any weakness in one method will be
compensated for by the strength of another (Mays & Pope, 2000). Instead they view triangulation as more valuable because it ensures comprehensibility and encourages a reflective analysis. Barbour highlights the difficulties of interpreting data collected using different qualitative methods (Barbour, 1998). Her suggestion is to be more open to utilising the potential of analytical induction by merging the analysis of different types of data. Thereby it would be possible to take contradictory findings into account in the analysis. This thesis is based on the assumption that triangulation is beneficial to the quality of the study. We analysed data on self-rated health from different sources. We combined qualitative and quantitative data to discuss participation and the role of norm systems on attitudes and behaviour. The research group included competence in health economics, sociology, epidemiology, statistics, medicine and social work. This enriched the theoretical discussion and hopefully enhanced the possibility of broadening and deepening the interpretation of results.

In qualitative research the researcher is *the human instrument*. This takes a good listener and an ability to probe well. Both interview studies were preceded by training in qualitative methodology and pilot interviews to test the interview guide and to discuss, in the research group, possible adjustment of the questions and the suggested probing.

*Peer-debriefing* by presenting preliminary findings to colleagues is a common tool to help the researcher evaluate his or her role in the research process and to advance the interpretation of results. The doctoral seminars and internal presentations that have been part of the doctoral training have served this purpose.

*Thick description* or transparency refers to making a clear account of the process of data collection and analysis (Geertz, 1973). In qualitative analysis it is important to allow the reader to judge how classification and coding systems have evolved and to justify how the presented interpretation is grounded in data. For quantitative analysis it is equally important to be transparent about methods, included variables and types of analysis. However, there are more standardised techniques and specified statistical approaches which may shorten the presentation format. The papers in this thesis include fairly short descriptions of the research process due to the limited space offered in scientific publications. A cover story allows for a more thorough description and therefore I have included two
examples of the analytical process, one qualitative and one quantitative in the material and method section.

*Relevance and generalisability* are important aspects of all research. The question of whether this thesis is relevant and adds new knowledge to the field of evaluation of community interventions has to be assessed by others. Equally complex is the extent to which the findings can be generalised beyond the studied populations. For the quantitative sub-studies we used cluster, total and probability sampling techniques to be able to make statistical generalisations about the target population. However, the extent to which the targeted population resembles other populations has to be judged through qualitative assessment of the context. Qualitative studies use purposive sampling with a small number of informants and do not aim at statistical generalisation. In Grounded Theory each selected subject is expected to contribute to a theory or hypotheses under development. If the analysis includes comparisons of groups the sampling has to cater for this. In the ideal situation the decision about when to stop data collection should be guided by level of saturation of the categories, hypotheses or theories under development. In the interviews with actors (Paper I) the comparison component was important and therefore as many as 50 informants were selected. The interviews with community members (Paper III) included only a small number of informants. In retrospect I wish that some more interviews had been performed, especially with men. Even if, during data collection, I felt that we had captured the variation in attitudes towards the intervention, additional interviews might have deepened our understanding about the observed differences in self-rated health and risk factor changes between men and women. However, a sort of *member check* of the analysis was performed when the analysis was presented to the scientific advisory group. The discussion strengthened our observations and interpretations.

In three of the studies we utilised self-constructed questionnaires (Papers I, II and III) that had to be tested in the field. The questionnaire to the community members included a total selection of the inhabitants in the Norsjö study area between 16 and 80 years of age. Before it was sent out it was checked for inconsistencies and tested among colleagues. In spite of three reminder letters and a notice in the local press the response rate for the whole group was 65%, 33% non-responders and 2% not reached or too sick to answer. For the analysis in Paper I only data for those between 25–64 years were analysed to resemble the participants in the
health examinations. The response rate for this sub-sample was 67%. This limited the possibility of forming sub-groups for comparison.

The questionnaire to the health care politicians (Paper II) was piloted in a non-selected county and we adjusted the wording of both the scenario and several of the value statements before the actual study commenced. The ten selected counties were not selected randomly since we wanted to make sure to represent the north and the south as well as the rural and urban dimensions. After three reminders we reached a response rate of 71%. The non-response analysis did not indicate any significant difference between males and females or with respect to political affiliation.

The panel study (Paper III) faced a problem of a relatively low participation in 1996. This is partly explained by a sudden introduction of competing primary health care centres in the study area. This meant that the trained personnel from the old centre were not as involved in the programme as previously. However, great efforts were taken from the County Council (the community health unit) to encourage and train the newcomers. For the additional questionnaire that was introduced through this study two of the co-researchers visited the new health centre, initiated contact between the responsible nurses and organised information meetings to explain the purpose of the questions. Taking this into consideration we were satisfied with the 67% response rate. However, the fact that participants were somewhat older and that among the younger age groups males were over-represented, limited our possibility of sub-group analysis.

Others have evaluated the selection bias in the MONICA and VIP surveys and found it to be quite small (Weinehall et al., 1998a; Eriksson et al., 2003). For the analysis in this thesis I had no direct influence on the procedures for data collection within these two cohorts.

The cross-country comparison (Paper V) built on data sources that were not originally meant for comparisons, which should be considered. All the U.S.A. data were based on self-reports while the measurements in Sweden were performed at the health care facilities. Therefore cholesterol was excluded from the risk factor score and hypertension was defined by medication use instead of by measurement data. Physical activity was introduced as an indicator of fitness. We had a fairly skewed gender distribution in the U.S.A. material with more women than men. However, in most of the analyses we analysed men and women separately.
All studies in this thesis have directly or indirectly included an analysis of self-rated health and its interaction with bio-medical factors, gender and education. We used the one single question measure of global non-comparative self-rated health. Non-comparative measures have been evaluated as the most appropriate measure in longitudinal studies and differences in number of response alternatives have been shown to represent parallel assessments of subjective health (Eriksson et al., 2001). Manderbacka et al have discussed the implications of using an age-referential or a non-referential question of self-rated health as a predictor for future mortality (Manderbacka et al., 2003). They conclude that in the Swedish population the non-referential question is a better predictor for future mortality for both men and women. Many studies have shown how this summary assessment of health is related to background factors like social class (Blaxter, 1989; Kelleher et al., 2003), gender and ethnicity (Jyla et al., 1998), as well as to actual diseases and symptoms (Kaplan et al., 1996), functional ability (Idler et al., 2000), risk behaviour (Manderbacka et al., 1999), and social support (Östergren, 1991). Self-rated health is also an independent predictor for future morbidity and mortality both in population and patient based studies (Idler & Benyamini, 1997; Bosworth et al., 1999). Our studies did not focus on the relative importance of these factors but the results about gender and social differences have guided our interpretation. We specifically addressed the interaction between bio-medical risk factors and self-rated health for men and women and for educational groups. In the panel study, when assessing the intervention effect, we adjusted for self-reported disease at follow-up to see the consequences, but the pattern did not change significantly.
DISCUSSION
Community interventions as social movements

The Norsjö programme can be described as a social movement (Touraine, 1965; Castells, 1997). It was based on collective societal goals, individual participation and had defined a joint enemy in “the heart attack”. Even if problem identification, suggested measures and implementation remained with the actors the programme was well seen by the local community. Still, the questionnaire study indicated a complex pattern where not everybody felt equally involved and where young men with self-rated bad health were hardest to reach. Touraine’s claim that collective actions have to transform individuals into subjects seems valid. The programme was not designed to reach the young. They probably had not developed the targeted risk factors and therefore they were not recognised nor did they see the point of behavioural change. Middle-aged women and men, on the other hand, were given concrete advice and new health knowledge on how to change their habits to prevent a disease that felt threatening. The importance of a new language offered by the programme was evident. It was needed to describe and analyse both the past and the future (Strauss, 1997). Cholesterol came into ordinary people’s vocabulary as a lever to describe the problems as well as their solutions. The medical language was effectively transformed with the help of metaphors (Mutembei et al., 2002). The local theatre group utilised the history of scurvy to make it easier for people to grasp the importance of dietary change. They used the two-stroke engine to illustrate a need for a balanced fat content to prevent the cardiac blood vessels from becoming blocked. These efforts to transform norms, values and attitudes are viewed by Castells as key elements of social movements. The theatre put health on the agenda with entertainment as the vehicle (Castells, 1997). Other efforts came through voluntary organisations that encouraged people towards collective physical activity. The food labelling initiative was equally important. The individualised efforts to change values and attitudes were mediated through the health care and dietary counselling activities. The different activities supported each other. The community participation may not have resulted in changing existing power structures but it was an essential and encouraged feature in the transformation of norms. In a recent review of 32 community based health promotion programmes, including all the major cardiovascular
programmes in the U.S.A., their limited positive outcome was discussed (Merzel & D'Afflitti, 2003). Design issues, influence of secular trends, limited intervention dose as well as challenges to community participation were given as possible explanations of a low impact. Community participation was seen as a complex concept not taking power relations or disparate interests into account, often building on consensus models but seldom on true partnerships. The only health promotion programmes in their review that showed considerable positive outcomes were “small-scale HIV projects with an emphasis on modifying social norms regarding risk behaviours and increasing the social acceptability of risk avoidance”. The Norsjö programme resembles this description. However, it can also be compared to the types of health programmes discussed by Laverack and Labonte (Laverack & Labonte, 2000). They talk about the tension between a bottom-up and top-down approach that often characterizes disease prevention programmes initiated within well organised societal health promotion activities. To overcome this tension they suggest a framework within which top-down approaches can be accompanied with an empowerment/participation approach. They propose a parallel track in the implementation as well as in the evaluation phase. The idea is that specific outcome measures should be directed towards evaluating the empowerment or participation aspects which is similar to what has been suggested within our evaluation framework (Brännström et al., 1994b). The concept of community participation and empowerment has been discussed anew by Rifkin who sees equity and empowerment as the twin pillars of a contemporary primary health care strategy (Rifkin et al., 1988; Rifkin, 2003). Empowerment as a concept has come to replace participation in that it also points to capacity building among individuals. However, she views the conceptual change also as a sign of a more individualised society, increasingly depending on individual strengths. Even if Rifkin’s applications mainly come from the developing world she suggests an interesting framework, based on the works of the health economist Amartya Sen. Assessing health outcomes should build on CHOICE, an acronym for capacity building, human rights, organisational sustainability, institutional accountability, contributions and enabling environment. Neither Laverack and Labonte nor Rifkin has operationalised the health outcomes of their evaluation strategies. However, self-rated health could easily fit within their frameworks and add a subjective dimension to empowerment.
In modern sociology, feelings and emotions are increasingly regarded as important as cognitive aspects in the mobilisation processes of health promoting activities (Goodwin et al., 2001). Even if our studies did not specifically focus on emotional components we found several indications of their importance both for the involvement of actors and community members. Some of the health care personnel expressed it when saying that “working with the programme is my life’s work”, and that “it gives more than it takes”. It was also obvious when the municipality representatives talked about the pride they felt being involved in a programme that also attracted so much interest outside its own setting. The same was true for the interviewed community members when they took pride in having changed some of their food habits or felt shame when having failed to make any of the suggested life-style changes. Self-rated health captures feelings of health and can therefore be seen as part of the mobilisation process itself. Social movements and participation are related to the concepts of social and emotional capital (Collins, 2001). Participation in civil social activities is seen as a crucial element of social capital (Subramanian et al., 2002; Baum & Ziersch, 2003). Thus, existing social capital in a community and participation are interrelated. Social capital should be critically considered because from an ideological standpoint, it may be used to argue both for withdrawal of the welfare state in social provisions and for the crucial role that the state plays in its accumulation (Baum, 1999). This is a future challenge for cardiovascular prevention, already in some ways tested in the field of HIV/AIDS prevention (Campbell & Mzaidume, 2002; Campbell et al., 2002).

**Intended and unintended consequences**

*The views of Swedish health care politicians*

Community participation can have a role in fostering equity in health. However, societal efforts to encourage involvement in health promotion are influenced by the conflicting values emanating from ethical principles such as autonomy, equity, beneficence and non-maleficence (Nilstun, 1994). To evaluate includes an empirical description of a phenomenon but also statements about the norms and values that may separate desired from undesired effects. Hermerén has suggested that a normative conclusion has to be preceded by both facts and value premises (Hermerén, 1987). There is a need to decide what facts are relevant and
which value premises have precedence. This means that the type of facts selected for a scientific evaluation depends also on the values of the researcher or the scientific traditions that he/she belongs to (Lindholm, 1996). The model can help pointing out the borders between the arenas of the public, the politicians and the professions. The value premises for intervention should preferably have their roots among community members and their political representatives while the fact premises ought to be based on scientific theory and method. On the other hand the choice of facts and desired consequences has to be made on the grounds of values of the public and politicians. In Sweden there is more or less agreement about the desirability to strive for equal possibilities not to contract illness and to develop good health. In public health it is primarily when discussing different intervention strategies that ethical dilemmas become evident. There is an inherent conflict between the individually oriented ethics for curative care and the more collectively oriented ethics, i.e. the balance between the risk of harming and avoiding making sins of omission. The risk of harming or threatening people’s autonomy has been used to defend no action. Cole takes the American constitution as a basis for always giving the principle of autonomy precedence while Skrabanek views the risk of harming as most important, demanding conclusive evidence of a positive effect before intervening in a healthy population (Skrabanek, 1990; Cole, 1995). Others, like Rose and Rosén have used the principle of beneficence primarily to argue for action especially in the field of cardiovascular prevention (Rosén, 1988; Rose, 1992). Equity has only marginally been used as a ground for action but more for demonstrating existing health inequalities (Vågerö & Norell, 1989; Diderichsen, 1990; Lundberg, 1990; Lindbladh et al., 1996).

Our study among health care politicians (Paper II) suggested a consensus for allocating resources for preventive measures in communities with serious public health problems. A majority favoured intervention strategies with a personal invitation to health screening, a risk profile and direct advice about changes needed. The risk of harming through stigma or anxiety was considered an acceptable drawback of a successful intervention. For the right wing a more neutral collective offer of health screening through the media was preferred, autonomy taking precedence over the other principles. One alternative suggested intervention measures addressing socially vulnerable groups. This raised a dilemma between beneficence and equity and also the risk of harming by stigma-
tising already weak groups. Lindbladh et al. (Lindbladh et al., 1998) have discussed the risk that socially targeted interventions are recommended on the basis of equity gains, at the expense of general measures to reduce inequalities. They see them as threatening both autonomy and equity and inconsistent with the basic moral premise of the paradigm to which they belong, i.e. the respect for individual autonomy. At the same time socially targeted interventions come in conflict with the principle of equity, by treating some people differently from others. This type of strategy was given a little support by our respondents. It probably came into conflict with the basic features of the welfare state but also with “the preventive paradox” emphasising the additional benefits of a population approach as opposed to a high-risk approach in prevention (Rose, 1992).

In our study very few were in favour of general measures. However, it would probably be unfair to interpret this as an overall negative attitude. It may rather reflect scepticism towards what results could be expected in the particular situation described in our scenario. We found a strong link between political affiliation, ethical principles and choice of intervention strategies. However, those from the right wing did not seem to face the same intrinsic conflicts between ethical values as those belonging to the left wing and middle parties. Our interpretation is that within the field of public health the role and scope of politics have been reduced. Economic and market solutions receive greater influence but at the same time ethics is used to de-politicise issues. Guidance by the principle of autonomy at any cost can then create political paralysis. There is thus a need for politicians to be more explicit and transparent about the value bases for their decisions.

The overall support for equity and beneficence and the preference of an intervention strategy based on active involvement of primary health care were important when we compared with the results from the intervention area. On the basis of empirical facts from previous evaluations we knew that the type of intervention that the politicians favoured could reduce both the level and the unequal distribution of risk factors (Lindholm, 1996; Weinehall, 1997). What had not yet been studied were the value premises for making a trade-off between subjective measures indicating risk of harm and other aspects of the intervention. Self-rated health came into focus again.
Experiences from the community health intervention

Public health interventions are directed towards social systems that are complex. A reduction of risk factors may occur while self-rated health develops in a negative direction. Is that the acceptable drawback that the politicians indicated? Is it acceptable if the effects differ unfairly by age, gender and educational level? Should other positive or negative effects be taken into account? By putting the intervention into a context of manifest, latent and dysfunctions as well as anticipated and unanticipated consequences we wanted to come closer to making a trade-off or a net-balance of the observed changes (Merton, 1956).

The manifest function, i.e. the intended and recognised aims of the programme, can be described as behavioural change to reduce risk factor burden with an expected general reduction in cardiovascular disease morbidity and mortality. The means was the mix of population based activities and a health care approach described previously (Brännström, 1993; Weinell, 1997). They included components such as cultural programmes, newsletters, introduction of food labelling system, study groups, public meetings, media exposure, physical activity, health surveys and health and dietary counselling.

Our panel study (Paper III) revealed an overall positive risk-factor reduction which confirmed results covering a shorter time period (Weinell, 1997). The attention that came to the community due to the programme can be labelled a major latent function, neither directly intended, nor anticipated. The positive consequences were often mentioned in the interviews with local actors. They claimed that the programme had contributed to an overall collective positive feeling, not only regarding health. A political will had been shown when asked to be the trial area. This was seen as a sign of collective commitment and a willingness to act. It was believed that because of the programme people thought twice before moving out. It was not only the media exposure that created this positive attention. The scientific interest in public health prevention led to visits from far away by professionals wanting to learn and to share experiences. For the health care personnel it meant capacity strengthening and further educational training. As summarised in a conference paper “one important side effect of the Norsjö programme was that people were seen and confirmed” (Olsson, 1989). At least during the initial phase of the programme, all medical doctor posts were filled,
unusual for an inland municipality at the time. Media were intentionally used to convey health messages which also had some unanticipated negative consequences, revealed in the evaluation process (Brännström & Lindblad, 1994). Brännström et al pointed to a medical male dominance in the reporting. They also discussed that the media’s focus on health examinations and individual dietary habits led to a neglect of the more population based activities, downplaying the connections between health and structural conditions. Local media sometimes increased suspicion against the programme by overestimating negative aspects like the fear expressed about sick people not being treated, the threats to local food habits and stigmatisation.

Other latent functions were linked to the local collaborative committee. The programme brought people together that normally had limited contacts with each other. Now, people from different municipality boards had to talk to each other, meet with voluntary organisations and health personnel to report and negotiate about both individual and population based activities. The community had a long tradition of organising people in labour movements, adult education as well as in free churches and temperance movements that were encouraged to engage in health matters. For many actors this was a positive experience. However, the increased contacts also revealed competition and disclosed power relations and tensions.

The risk of harming through health screening and counselling was intensely debated both in the scientific advisory group, the local collaborative committee and by the counselling personnel. The health personnel had developed and designed a card presenting an individual risk profile of the targeted risk factors. This card was meant to serve as an entry point for a discussion about risks and dietary habits. Fears were raised over increasing medicalisation of healthy people, for causing unnecessary anxiety, increased stigmatisation of vulnerable groups and individual blame for unhealthy behaviour (Eriksson, 1983; Eriksson, 1990). Some researchers had on ethical grounds questioned this type of intervention but there were few scientific results at the beginning of the programme (Heynes et al., 1978). Thus, care was taken to formulate guidelines for the counselling sessions. National guidelines on risk factor levels were not yet developed and temporary ones had to be decided upon. As for dietary change it was decided to focus on the overall fat intake. The motto for the sessions became: “One piece of advice to
Discussion

"remember is better than a wish list to forget" and the prevention paradox was translated into "better small changes by everyone than large changes by a few". So what happened? Within the process evaluation, interviews were already held with participants during the first year health examinations (personal communication, not published). It was evident that people were both worried and afraid if their risk factors were above the limit. Cholesterol was a new and scary word that had to be better understood. The medical language was new and the concept of risk was not clear. It took some time both for the health care personnel and the participants to bring a balance into the counselling sessions and of course the reactions were different at both individual and group levels.

The qualitative interviews with participants from the 1986 health survey identified both affective and cognitive components of attitudes towards the intervention, including the health counselling. The analysis became essential for a discussion about why not everybody perceived the programme positively and how this may have influenced their disposition for action or behavioural change. The positive feelings were those such as gratitude, recognition, blessing and relief. Thus, for some the programme really became “the turning point” for change while for others the counselling and other activities were just nice confirmations of being on the right track. However, feelings of being left out, forgotten, threatened, irritated or angry were also expressed. This meant that some participants perceived the programme as an insult, creating worry, shame and anxiety for being asked to do things that were felt to be out of reach. An important insight from these interviews was the attitudinal set labelled “The Disappointment”. It refers to peoples’ feelings of not being listened to, forgotten, not confirmed or not seen by the programme. The statement “it might have been better to have had some cholesterol” was interpreted as illustrating this. Maybe the concern among the medical personnel not to worry or upset participants caused some unintentional harm. We are back to sins of omission. Thus, from the interviews there was ground for looking further into these latent negative and unintended functions of the programme.

In the 10-year follow up of the panel participants, self-rated ill-health was regarded as an indicator of negative latent or unintended effects of the intervention. However, it was important for us to relate the changes in self-rated health to the manifest functions of the programme, i.e. behavioural change and risk reduction. We wanted to discuss the trade-
off or net-balance between beneficence and harm. The quantitative analysis suggested an overall positive development in risk factor reduction and self-rated health. Self-rated health improved in spite of the panel growing older. The difference compared to the reference area was not great but if the intervention had had a major negative impact we would have expected a decrease in self-rated good health.

Good health and low risk load at baseline were the best predictors of a positive outcome 10 years later while bad health reduced the odds of an overall positive outcome by 70%. However, we saw a larger polarisation process for men, with a greater distance between those with self-rated good and bad health, than for women. A similar pattern was observed for the lower compared to the higher educated.

Based on the qualitative analysis our hypothesis was that males were over-represented in the positive ideal type “The Confirmation” as well as in the negative type “The Insult”. Men who felt good at baseline, with high risk load had probably been more seen, listened to and helped than those who felt bad. Those rating their health as bad may have felt the new norms more threatening. Women were probably not confirmed in the same way and therefore over-represented among “The Disappointment”, wishing to have been seen even if not having the targeted risk factors. A similar interpretation was made for educational groups. The lower educated with good health and the targeted risk factors had probably benefited more than those with bad health, while the difference was not as big for the higher educated.

From our joint analysis we are prepared to conclude that the latent dysfunction had not taken precedence over the intended manifest risk factor reduction. Given the great influence of self-rated good health for a future positive outcome interventions may benefit from targeting more directly those who in combination with bio-medical risk factors perceive their health as bad and make sure these groups feel seen, confirmed and involved by the efforts made. It is also important to note that latent dysfunctions may be transformed into intended manifest functions. By observing and calling attention to negative latent functions new goals may be set, e.g. changing the guidelines for counselling. Thus, when the Norsjö experiences were taken out to the other municipalities much effort was put in developing a teaching manual for the counsellors and to provide for continuous updating based on their experiences.
The role of norms and attitudes for behavioural change and self-rated health

In the qualitative research interviews the informants were asked to describe the health related norm systems from their childhood and to reflect about changes over time. Many of them told us about a traditional society where health was a gift from God or formed by structural circumstances difficult for people to influence. Many of them were raised in families where small-scale farming was combined with salaried work in mining or railway companies. The norms prescribed that you should not ask for help, i.e. everybody was expected to manage on their own. To be able to work was crucial and a goal in itself. It was a gendered society where men were expected to provide for their family and women to contribute with home-based hard work. Nobody was supposed to waste any time, even more so for women than for men. Health was a means of being able to work and thus seen as a duty. Ill-health was something that had to be denied until you were unable to perform your tasks. A real man or woman was not supposed to give up and seeing the doctor was the last resort. Many of these traditional norms were also guiding current behaviour. Our informants made it clear when saying that "It is inside our heads, even if we know it is wrong ....". The internalised norms representing "the generalised other" could not have been described better (Mead, 1934/1962). These collective norms are social constructs that also influence attitudes and feelings. The pride connected to work and the shame connected to illness were still there. Even if some changes had taken place the intervention programme reinforced the trend by challenging many of the prescribed norms at one time. Health was introduced as a goal in itself; and people were expected to come to health care centres and to reflect on their risk factors. They were also expected to take responsibility for changing some of their habits to prevent future disease. To involve and influence people it was crucial for the programme to develop empathy for the new ideas and to address these prevailing norm systems. As described earlier the different activities included in the programme were supposed to reinforce each other. We have discussed the cultural activities, the voluntary organisations, the school and the workplace activities as important for participation but have also indicated their role in shifting the social norms. Many of these interventions were directed towards the "me" part of the "self" of community members. By using existing social networks and social capital resources,
efforts were made on both individual and collective levels. “Significant others” in the form of health care personnel, politicians and other key persons, well anchored in the local culture, were taken advantage of in the mobilisation process. However, we know that this is a long-term process not possible to evaluate until later. What we could see in our interviews and from our questionnaire was a shift towards the psychological aspects of health becoming more dominant. The informants, none of whom were young themselves, said that today you are more readily allowed to feel ill which was something that they feared also might lead to people giving up too easy. It was also clear that the psychological shift had had more influence on higher educated middle-aged men than on others. Using Bourdieu’s concept of habitus, the higher educated were quicker in adopting an emotional health concept not necessarily leading to better self-rated health (Bourdieu, 1984). It is well-known that self-rated health is not only related to presence or absence of disease (Blaxter, 1989). When we asked the panel participants to distinguish between feelings and having a disease, many more of the higher educated indicated that they felt bad but had no disease compared with the lower educated. Correspondingly, the lower educated to a greater extent said they had a disease but still felt good. We could also note a shift in the attitudes towards the health care. If people had been frightened and reluctant to visit the primary health care centre for consultations about their health, the personal invitation for screening had started a change, especially among the older and lower educated. The new norms prescribed that it was okay to care for your health and wise to make regular check ups. Many informants said that if it hadn’t been for the invitation they would never have come to the health care centre. The importance of people acting through or within traditional structures of, for instance, health care is that they also become a part of their change (Giddens, 1984).

Self-rated health is a social construct and as such influenced both by collective norm systems and individual attitudes (Burr, 2003). Thus, when using self-rated ill health as an indicator of negative effects of an intervention we have to take into account the shift in health related norm systems. Our participants may at base-line have been more reluctant to grade themselves as not healthy because the norms prescribed so while 10 years later norms and attitudes had changed and it was more accepted to feel ill. In our evaluation base-line self-rated health may therefore have
been positively overestimated while at follow-up it may have been negatively downplayed. This has implications for interpreting trend data on self-rated health if not knowing or taking into account shifts in health related norms and attitudes.

**The gender and socio-cultural interplay**

*Self-rated health as an outcome of an intervention*

In the intervention area we observed an overall risk factor reduction among the panel participants that was greater for men than for women. There was no corresponding gender difference for changes in self-rated health even if more men moved from the negative to the positive pole. We may interpret these findings in many ways. One would be to say the programme was male oriented. Men were the ones identified having the problem; men were the ones seen going by ambulance to Skellefteå and men were the ones dying. Men were also the ones described and talked about in the media. We observed a larger polarisation in the intervention effect for men than women. Men rating their health as good in combination with high risk load seemed to have benefited more from the programme than those with self-rated bad health. Women, on the other hand, appeared to benefit more if having a combination of bad health and high risk at baseline. The observed pattern is complex. In the initial phase of the programme men were the targeted group. Based on medical knowledge it was even discussed to economise on the intervention by only inviting men for health screening and counselling. Men’s risk factor burden was regarded as more serious as they had a fourfold risk of developing cardiovascular disease (Messner et al., 2003). Thus, men may have received more attention due to the health care system being aware of the increased medical risks for men. Men may also have had more embodied experience of disease (Lawton, 2002) that in turn motivated them to act and change their life style. In addition the construction of gender in a traditional society put expectations on women to support their spouses and take responsibility also for their change. Many women described their efforts to introduce new types of food for the whole family, and meeting less and less resistance. Men may also have been more influenced by the new health related norms. Traditionally they were not supposed to be ill, not visit the doctor or bother about disease but now they were invited to the health care. However, the polarised pattern indicated that
those rating their health as good to greater extent could cope with the situation. They were seen, confirmed and involved while those with self-rated bad health were at greater risk of becoming afraid or insulted. Women may not have felt the same support and were not seen or confirmed unless they had both a high risk load and rated their health as bad. However, it is important to note that the population-based activities may have been more equally targeted towards men and women than the individual health care screening. The questionnaire study (Paper I) and previous cross-sectional analysis actually indicated a greater self-reported change in behaviour as well as a larger reduction in some of the cardiovascular risk factors for women (Weinehall et al., 2001b).

A higher proportion of the lower educated had a high risk burden at the baseline and also less good health. The lower educated may have benefited more when allowing themselves, to enter the primary health care and be bothered about their health, while for the higher educated, the difference was not great and it did not make them feel better.

_Interaction between self-rated health and bio-medical risk factors in predicting future stroke_

In the case-referent analysis (Paper IV) we observed a gender differentiated pattern where self-rated health increased the risk of stroke, more for men than for women. The interaction effect between self-rated health and biomedical risk factor load was also greater for men than for women as well as for the higher educated.

The role of gender in predicting future mortality has been discussed in many studies with varying results, depending on design and what variables were included in the models (Jyla et al., 1998; Bath, 2003; Benyamini et al., 2003; Deeg & Bath, 2003; Spiers et al., 2003). In their review Idler and Benyamini concluded that self-rated health seem to have a greater predictive value for men and suggested a difference in how men and women incorporate information into their self-rating (Idler & Benyamini, 1997). In a study specifically addressing gender differences Benyamini et al showed that self-rated ill-health is influenced by experiences of negative affect (feelings of depression, anxiety and fatigue) and that women’s self-ratings seem to be based on “a wider range of health related and non-health-related factors than are men’s” (Benyamini et al., 2000). If men’s poor self-ratings are more related to serious disease or
symptoms and women’s reflect both life-threatening and non-life-threatening experiences, this could partly explain the lower predictive ability of self-rated health for women than for men. One mechanism put forward is that affect/emotions have a regulatory function, indicating readiness for action that is different for men and women. Some claim differences in “evolutionary programming” for men and women to be part of the explanation. However, taking some arguments from Rose we would rather argue that different ways of processing information about health is better understood by the social construction of gender (masculinity and femininity) specific to the cultural context of the studied areas (Rose & Rose, 2000); (Courtenay, 2000; Hochschild, 2003). It makes sense, in the cultural setting where our study was performed and in the gender structure we have described, to expect women to be more inclusive and reflective in their self-ratings. Thus, it can be part of the explanation of a lower predictive value for women and stroke, which is a life threatening disease. However, for other outcomes, like depression and fatigue, self-rated health would then be more predictive for women. But it could also be that for women poor self-ratings act as a regulator for action at an early stage, increasing their ability to alter risk factors and thus be part of the explanation of a lower predictive accuracy. For men, not rating their health as poor until things have become very serious, self-rated health will act more as a self-fulfilling prophecy.

Our data also indicated that the better educated, who rate their health as bad in combination with two or more bio-medical risk factors have a higher risk of stroke than the less educated with the same risk factors. In a study by Blaxter the less educated were more inclusive in their self-ratings, taking into account more experiences that are less life-threatening in their assessment and thereby lowering the predictive value for a disease like stroke (Blaxter, 1989). The higher educated were more risk factor oriented in their evaluation of health consequences, which may explain why they may not rate their health as bad until symptoms appear.
Determinants of self-rated health across countries

In the country comparison (Paper V) we found the odds for poor-self-rated health to be much greater in the U.S.A. both generally and for each of the studied cardiovascular risk factors. Our main observations were related to education. Low education considerably increased the risk of poor health in the U.S.A. but hardly at all in Sweden. The cardiovascular risk factor burden was also a stronger predictor of self-rated poor health in the U.S.A than in Sweden, especially for the lower educated.

The overall lower self-ratings of health in the U.S.A. support other studies indicating a high ranking for Sweden in a European comparison (Carlson, 1998). Studies addressing general welfare indicators have pointed to disadvantages for the U.S.A. population compared to countries like Sweden (Estes, 1998).

The observed greater influence of risk factors on self-rated health in the U.S.A. can be discussed with help of a Swedish study indicating that risk factors mainly influence self-rated health through their functional consequences (Manderbacka et al., 1999). Our results suggest that the functional consequences or resulting health problems from the included risk factors are greater in the U.S.A. population. Those who smoke, smoke more, those who are fat are fatter and those who have hypertension are more hypertensive. Knowing that extreme obesity is more common in the U.S.A. this may lead to more severe hypertension and so on. Manderbacka et.al. suggest that certain risk factor combinations have an independent influence on self-rated health. We introduced emotions and health related norm systems into our interpretation. Both countries have been criticised for exaggerated health promotion efforts, especially the U.S.A. We suggest that an increased pre-occupation with health issues, increased knowledge, and risk awareness, greater in the U.S.A., may result in poorer self-rated health. However, it may also be that pre-occupation with health leads to a transition in the norm system where having the included risk factors becomes more associated with fear, worry, shame or feelings of failure, all with negative influence on self-perceptions and actual health (James, 1996). In the U.S.A. there was no significant difference between men and women in general self-rated health but there was a clear difference in the influence of certain risk factors indicating a gender differentiating health related norm system.
The U.S.A. is known for disparities in income and education as well as in access to health care. The included cardiovascular risk factors are more prevalent among the lower educated (Pearson, 2003). The risk awareness as well as their emotional implications can be an additional burden for the lower educated. Compared to the U.S.A. Sweden has a more equal educational and income distribution and therefore education may not, to the same extent, influence access to health care or emotional distress.
CONCLUSIONS AND IMPLICATIONS

The participation process in the intervention area was characterised by a reasonable division of labour between politicians, researchers and community members. Researchers and politicians had a joint role in the problem definition. The researchers provided the fact premises for intervention and the politicians discussed the value premises. Local actors and practitioners were essential in the design and implementation phases while community members responded by a tacit agreement about goals and by active participation in intervention activities. The collective feeling of pride for community activities as well as the individual feelings of confirmation and involvement that the health examination provided were crucial in the mobilisation process.

The intervention strategy used in the Norsjö programme, with an invitation for health screening and community activities directed to the whole population, corresponds well to what Swedish health care politicians choose when faced with a hypothetical scenario of a serious public health problem. Their strong support for equity and beneficence implied reluctance towards socially targeted interventions. The threat to autonomy and the inherent risk of stigmatising already vulnerable groups made them less attractive. However, it was still possible to accept some individual harm for a successful intervention in order to avoid sins of omission.

Politicians need to be explicit and transparent about their value basis for decisions so that community members can judge the measures taken based on their own ideology and support for ethical principles. Public health researchers should provide politicians with factual premises and discuss the ethical considerations that are involved in decisions to act or not.

Evaluation of community interventions is a long-term commitment. Changes in norm systems and attitudes take time and the effects of resulting lifestyle changes may take even longer. The randomised controlled trial is not a realistic evaluation strategy, nor does it account for the social dynamics which lifestyle changes, especially in small communities, take advantage of. When intervening, it is not possible to have full control over exposure and it may not be ethically justifiable to try out an intervention strategy only on some community members. A comparison
with a reference area is more feasible, where intermediary outcome measures, such as risk factor reduction, morbidity and mortality estimates, can be combined with a process evaluation of the efforts made. Using self-rated ill-health as an indicator of unintended consequences we conclude that they did not take precedence over the intended risk factor reduction. Interviews with key informants helped to identify and consider also latent positive functions and to understand the importance of emotional reactions in the participation process. Our observation of a social and gender differentiated intervention effect suggests that future interventions may benefit from targeting more directly those who in combination with high risk load perceive their health as bad and to make all participants feel seen, involved and confirmed.

Self-rated health is still a largely unexplored indicator for community intervention effects. This thesis has shown that when combined with targeted bio-medical outcomes it helps in evaluating the complex interplay between perceptions of health and medically diagnosed risks. It supplies a tool to analyse both social and gender differences and identify who has benefited from the programme and who are most vulnerable/resistant. Its independent role in the aetiology of future disease suggests a need to include more emotional aspects as risk factors for disease development. We also need to understand more about the mechanisms through which bio-medical risk factors influence self-rated health and the reverse, and how these processes are related to structural conditions, material and normative, in different socio-cultural settings.
SUGGESTIONS FOR FURTHER STUDIES

The educational health screening that was developed within the Norsjö programme has, since 1991, been introduced in the whole county and it is important to include possible negative side-effects in the evaluation. By linking the Västerbotten Intervention (VIP) cohort with available national health registries differences in morbidity and mortality between participants and non-participants can be estimated. We can describe and compare the health care utilisation pattern for the two groups and see if there are differences in the pattern for men and women. Including base-line information about self-rated health will enable us to elaborate on its role in future health care utilisation and disease development. Qualitative interviews with counselling personnel and participants will help describe the development of the educational component of the screening and be part of an analysis of how attitudes and feelings are involved in the process.

The role of community participation and social capital for self-rated health needs to be further understood. Intervention studies to improve social capital could help analyse this relationship. This thesis has underscored the importance of participation in influencing norms and attitudes leading to both individuals and groups being seen and confirmed. Within a planned thesis project qualitative studies will address the promoting factors for social capital. Further studies will focus on the gender and power aspects that need to be considered before implementation into a local community. Suggested innovative intervention strategies will be tested and evaluated also on the basis of their influence on self-rated health.

In the Kagera AIDS Project (KARP) we have followed the magnitude and social aspects of the AIDS epidemic in the Kagera Region since the late 1980s. In a future sub-study we plan to further elaborate on the role of social and emotional capital in the observed decline of HIV-infection. Quantitative and qualitative approaches will be used to compare the interplay between participation, behavioural change and self-rated health with our experiences from the Swedish setting.

The preliminary analysis of self-rated health and risk factor load in the reference area has supported our analysis of the development in the intervention area. However, the longitudinal follow-up within the
Suggestions for further studies

Northern MONICA project will also allow for more elaborate and statistically powerful analyses of the differences between men and women and educational group regarding the role of self-rated health in developing bio-medical risk factors as well as the reverse. Given the three panels; 1986-99, 1990-99 and 1994-99 short and long-term effects can be elucidated.

The observed differences of how self-rated health and risk factors interacts in predicting future stroke for men and women and educational groups need to be further explored. We suggested that differences in how different groups incorporate information into their self-ratings could be part of the explanation. Thus, the pattern might differ for other types of diseases. To test this hypothesis further we would like to link the VIP and the Northern MONICA cohorts to the Swedish cause of death register as well as to specific disease registers.

Our findings pointed to differences in how cardiovascular risk factors influenced self-rated health in Sweden and in the U.S.A. Thus, there is a need to understand more about self-rated health as a social construct. Comparative qualitative sub-studies in the two study settings could help clarify these aspects.

We also would like to broaden the discussion of the determinants for self-rated health and its role as an effect modifier in predicting future disease in different socio-cultural settings. The Department’s collaborative projects with Ethiopia, Vietnam and Indonesia include three PhD programmes that utilise longitudinal study bases to explore the driving forces behind and consequences of the emerging epidemic of cardiovascular diseases. By including self-rated health as a possible risk factor in cardiovascular disease development it will be possible to address the gender and social interplay between bio-medical risk factors and self-rated health in base-line studies and at different stages of follow-up.
LOCATING MYSELF

My first work experience was to code questionnaire data within an action research project for social rehabilitation in one of the slum areas in Malmö. Through my family I was “programmed” into the field of social work and after some hesitation I took my degree. When I came to Umeå, in 1977, it was difficult to find a job in social work and I decided quite happily to re-orient myself. After a short period caring for elderly and disabled persons I got a job in the University Library. I learned to care for books and journals instead of people. It gave me time to reflect about life choices. Soon my “social librarian” dream faded away and personnel administration took over in combination with maternity leave. However, when in 1982 a temporary administrative post was advertised at the Medical Faculty I decided to try something new. MEDIFO was a national project to assist in computerising and handling medical information. My post was transferred and I entered a new world, both professionally and academically. I learned typewriting the old way and computer handling the new. I was taught a new language and the ropes of epidemiological methods. A major task was to document the transfer of the “Register of all 15\textsuperscript{th} born” into a computerised format. It was detective work to understand the handwritten cards and the coding changes made over the years, but it resulted in a manual for future research. When MEDIFO was merged into our department I had the chance to be part of its development, an organic growth starting with a few devoted researchers and administrators. It was a challenge to be involved in administrating epidemiological research both in Sweden and developing countries in areas such as the evaluation of cardiovascular disease prevention in Northern Sweden, primary health care in Somalia and the epidemiology of HIV/AIDS in Tanzania. There were many research questions demanding input also from social sciences. My qualifications in social work were useful and my short experience of social interventions relevant. I joined the evaluation of the Norsjö programme to interview politicians and medical actors about their views on community participation. Still, I hesitated to enter the field of research. I had seen both the positive and negative sides of the devotion and commitment needed to be a good teacher and researcher. But gradually, curiosity took over. I studied qualitative methodology and medical sociology and was granted a Minor Field Study stipend to look
Locating myself

at stigma and HIV/AIDS in the Kagera Region in Tanzania. When an intervention trial was planned, I wrote a research training proposal and was lucky to be granted a PhD post. I wanted to compare the experiences from the cardiovascular prevention programme in northern Sweden (Norsjö) with the intervention activities suggested for preventing HIV/AIDS in Tanzania. Both interventions targeted behavioural change for preventing serious disease in rural community settings. The aim was to study how interventions interact with the social norm systems, to illuminate actors’ and participants’ perceptions of the activities and to discuss positive and negative consequences mainly using qualitative methodology. Due to financial constraints the intervention in Kagera did not materialise but the epidemiological surveillance of the epidemic as well as sub-studies on social and linguistic aspects were supported. I gained field experience, interviewing competence and data handling skills, still planning to include the experiences in my thesis. Within the evaluation of the cardiovascular intervention I gradually decided to focus on ethical issues and on the role of self-rated health in public health evaluation. Slowly I accepted excluding the Kagera studies from the thesis. I had to re-orient again and broaden my research training to include more quantitative methodology.

During this period the dynamic development of the Department gave opportunities to teach within the Master of Public Health programme. Together with good mentors I came to love it. We developed a computer software programme for handling qualitative information (OpenCode) and started to write a book on qualitative methodology for public health. When asked to contribute in qualitative studies within other research collaborations in Ethiopia and South Africa I took the chance, as I did when offered to work as a consultant at Sida/SAREC and when I was later given the possibility of being the Managing Editor of Scandinavian Journal of Public Health.

This thesis discusses manifest and latent functions of community interventions. It emphasises the connection between norms and feelings in decisions to act. The main manifest outcome of PhD training is the final thesis. It took me ten years to accomplish that goal. From an academic career point of view I lost some years. Not having “a licence” sometimes made me feel a failure. However, the latent functions of a “delayed” doctoral training have been more rewarding. My engagement with the Tanzanian and Ethiopian collaborations gave me second homes and
Locating myself

valuable insights. They made me feel privileged and rich in experience. Teaching and tutoring master students gave me appreciation and confidence. The journal work gave me recognition for managing skills in scientific publishing. When this thesis has been defended I hope to continue the teaching, research and journal work that I have been part of developing. For me it is definitely “the journey that made this thesis possible”.

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REFERENCES


Axelsson, N. and Tibblin, G. (1976) Resa i Västerbotten [A journey in the Västerbotten Province], Umeå: Department of Social Medicine, Umeå University.


References


Hermerén, G. (1987) Prioriteringens etik - om avvägningen av resursinsatser och vem som skall bestämma [The ethics of priority setting - about allocating resources and who shall decide]. Läkartidningen, 84: 3492-3499 [In Swedish].


References


References


Olsson, Ä. (1989) Ett nappatag med hjärtinfarkten [Efforts to fight heart attacks], *Hälso- och Sjukvårdstämman 1989* [Health Care Congress], Stockholm February 16-18 [In Swedish].


SBU (1997) *Att förebygga sjukdom i hjärta och kärl genom befolkningsinriktade program: en systematisk litteraturöversikt [Preventing cardiovascular disease through community intervention programmes: a systematic literature review]*, Stockholm: SBU & Folkhälsoinstitutet [In Swedish].


Starrin, B. (1994) Om distinktionen kvalitativ-kvantitativ i social forskning [The distinction between qualitative and quantitative in social research], In: Starrin, B. and Svenson, P.-G. (eds.), *Kvalitativ metod och vetenskapsteori [Qualitative methodology and philosophy of science]*, Lund: Studentlitteratur [In Swedish].

References


References


Västerbottens Läns Landsting (1984) *Protokoll från förvaltningsutskottets sammanträde 1984-12-17* [Minutes from the Västerbotten County Council board meeting].
