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Health-promoting health services:

Personal health documents and empowerment

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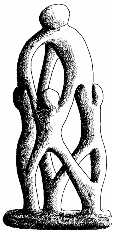

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Abstract

In 2003, the Swedish Parliament adopted a national public health policy that included the domain - "A more health-promoting health service". Strategies and tools are needed in the work to reorient health services. Personal health documents are documents concerning a person's health, and are owned by the individual. Several studies that have evaluated such documents indicate that they could be of interest in health-promotion work. However, there is insufficient knowledge concerning personal health documents that target adolescents, and little is known about the feasibility of such documents in a Swedish cultural context. The concept of empowerment is gaining increased interest for health services, but the associations between empowerment, self-rated health and health behaviour are sparsely studied.

The overall aim of the thesis is to explore a strategy - empowerment - and a tool - personal health documents - that might facilitate the work of the public health goal of a health-promoting health service. Specific aims are to examine the feasibility of using personal health documents in health promotion; to examine professionals' experiences of working with health promotion and personal health documents; to examine the association between personal health documents and self-reported health behaviour change; and to examine the perception of empowerment in relation to self-rated health and health behaviour among adolescents.

Two personal health documents that targeted adults and adolescents were developed and evaluated. Distribution to adults in different settings was compared in a cross-sectional study (n = 1 306). Adolescents received the document in school, and surveys were performed at baseline and after one year (n = 339). Practical use and attitudes by document owners were studied by questionnaires. Teachers (n = 69) answered a questionnaire, and community health nurses were interviewed (n = 12). The interviews also explored nurses' experiences of working with health promotion in general, and were analysed by qualitative methodology. Adolescents' empowerment was examined by a questionnaire (n = 1 046).

Most participants reported reading in the documents; writing in the documents varied between 16% (distribution in occupational health) and 87% (adolescents). The health document was perceived as useful by 35% of the adolescents. Factors significantly related to personal usefulness were being born outside Sweden, experiencing fair treatment by teachers, being a non-smoker and having a positive school experience. Community health nurses were striving for a balance of being a doer of practical, disease-oriented tasks and a health-promotion communicator. The structural organisation in health care centres was important for their work with health promotion and the health document. Teachers were generally in favour of continued work with the document. In different settings, between 10% and 26% of adults reported changes in their health situations as a result of reading the booklet. Self-reported changes in health situations were less likely using postal distribution, and there were no significant differences between the other types of distribution. Adolescents with low empowerment scores reported poorer self-rated health and more risk-taking behaviours such as smoking and binge drinking.

To conclude, personal health documents are feasible to use in different settings. Health promotion in health services needs active support from leaders as well as adequate support systems. Findings suggest that personal health documents can be tools for promoting self-reported lifestyle changes among adults in different settings. There is a close relation among adolescents between low empowerment in the domain of health, low self-rated health and health behaviours such as binge drinking and smoking.

Keywords: Empowerment, health promotion, health behaviour, self-rated health, medical records, adolescents, health services, primary health care, nursing, cost-effectiveness.

Sammanfattning på svenska (Summary in Swedish)

Hälsofrämjande hälso- och sjukvård: Personlig hälsodokumentation och självbestämmande

Sveriges riksdag beslutade 2003 om nationella mål för folkhälsan. Ett av elva målområden är ”En mer hälsofrämjande hälso- och sjukvård”. Det behövs strategier och verktyg i detta arbete för en ny inriktning av hälso- och sjukvården. Personlig hälsodokumentation är dokumentation som handlar om en persons hälsa och som ägs av personen ifråga. I många länder har metoden större spridning jämfört med Sverige. Studier världen över ger starkt stöd för att personlig hälsodokumentation används och uppskattas av målgrupper som gravida kvinnor, småbarnföräldrar, friska vuxna, och patienter med kronisk sjukdom. Intresset för begreppet självbestämmande (empowerment) har ökat inom hälso- och sjukvården. Självbestämmande har definierats som ”en process, en mekanism genom vilken människor, organisationer och samhällen skaffar sig kontroll över sina angelägenheter”. Trots åtskilliga förslag finns ingen översättning av empowerment till svenska som är allmänt accepterad. Förslagen har haft nackdelar som att de entydigt sett empowerment som något som utförs av någon annan än den som är berörd (”patientbemyndigande”; ”bekrafta”). Andra förslag har sett empowerment som endast en form av personlighetsutveckling: ”självförstärkning”; ”stärkt självkänsla”. Maktaspekten har tagits upp, men ofta förminskats: till ”patientinflytande”, till att gälla vardagen (”vardagsmakt”), eller till att gälla den egna personen (”egenmakt”). ”Maktmobilisering” saknar denna förminskning, men har en militant klang som det engelska begreppet saknar. Nationalencyklopedin anger ”självbestämmande”, vilket kan föra tanken till att empowerment enbart gäller den enskilda individen, men ordet har även använts för kollektiv (jämför ”nationernas självbestämmande”). Ordet för dock inte tankarna till en process. Ordet empowerment används i ökande utsträckning i svenska språket, och är kanske på väg att införlivas i detsamma.

Trots många studier kring personlig hälsodokumentation världen över har sådan dokumentation som riktar sig till ungdomar studerats sparsamt, liksom sambandet mellan personlig hälsodokumentation och förändring av hälsobeteende. Likaså finns få studier hur personlig hälsodokumentation fungerar i Sverige. Sambandet mellan självbestämmande, självskattad hälsa och hälsobeteende är också otillräckligt studerat. I avhandlingen undersöktes

självbestämmande på individnivån. Vår uppfattning var att självbestämmande på denna nivå har tre dimensioner: självtillit (upplevelsen av sin egen förmåga att uppnå ett uttalat mål), kompetens (upplevelsen av att vara tillräckligt kvalificerad), och socialt samspel. Självtillit och kompetens mättes inom hälsoområdet, eftersom vårt intresse var att studera självbestämmande och hälsa.

Avhandlingens övergripande syfte är att undersöka en strategi – självbestämmande – och ett redskap – personlig hälsodokumentation – som kan tänkas underlätta arbetet med en mer hälsofrämjande hälso- och sjukvård. Avhandlingens detaljerade syften är att undersöka om spridning av personlig hälsodokumentation accepteras; personalens erfarenheter av att arbeta hälsofrämjande och med personlig hälsodokumentation; förhållandet mellan personlig hälsodokumentation och självrapporterade förändringar av hälsobeteende; och hur självbestämmande står i förhållande till självskattad hälsa och till hälsobeteende.

Två personliga hälsodokument framställdes och utvärderades: 'Min bok om hälsa', som vände sig till vuxna (www.ltdalarna.se/minbokomhalsa), och 'VIP (Väldigt Intressant Person)', som vände sig till högstadieelever (www.ltdalarna.se/vip). Distribution av 'Min bok om hälsa' i primärvård, företagshälsovård, på arbetsplatsmöten, och per brev jämfördes i en tvärsnittsstudie (sammanlagt 1 306 personer studerades). Elever fick VIP-dokumentet av sina lärare i skolan, och fyllde i frågeformulär dessförinnan och efter ett år (339 elever). Lärare besvarade ett frågeformulär efter tre år (69 lärare), och distriktssköterskor intervjuades (12 distriktssköterskor). Intervjuerna berörde även hur de uppfattade sitt allmänna hälsofrämjande arbete, och de analyserades genom kvalitativ metodik. Elevernas självbestämmande undersöktes genom ett frågeformulär (1 046 elever).

De flesta deltagare rapporterade att de läst i dokumenten, medan rapporterat skrivande varierade mellan 16% ('Min bok om hälsa' distribuerad via företagshälsovård) och 87% (VIP-dokumentet). 35% av eleverna upplevde att de haft personlig nytta av VIP-dokumentet. Faktorer som hade ett samband med upplevd nytta var att vara född utomlands, att uppleva rättvis behandling av lärarna, att vara icke-rökare, och att trivas i skolan. Distriktssköterskorna strävade efter en balans mellan att vara en sjukvårdspraktiker och en hälsofrämjande kommunikatör. Vårdcentralernas strukturella organisering var viktig för deras hälsofrämjande arbete inklusive arbetet med 'Min bok om hälsa'. Lärarna var allmänt sett för ett fortsatt arbete med VIP-dokumentet.

Beroende på de olika distributionssätten rapporterade mellan 10% och 26% att de ändrat något i sin hälsosituation till följd av att ha läst 'Min bok om hälsa'. Fysisk aktivitet, matvanor, vikt och stress var de områden som nämndes i störst utsträckning. Självrapporterade beteendeförändringar var minst vanliga bland dem som fått boken per post. Elever med lågt självbestämmande hade lägre självskattad hälsa och rapporterade oftare riskbeteenden som rökning och berusningsdrickande.

Slutsatserna blir att spridning av personlig hälsodokumentation accepteras i olika miljöer. En hälsofrämjande hälso- och sjukvård kräver aktivt stöd från ledare såväl som lämpliga stödsystem. Fynden tyder på att personlig hälsodokumentation kan vara redskap för att understödja livsstilsförändringar bland vuxna i olika miljöer. Bland ungdomar finns ett nära samband mellan lågt självbestämmande inom hälsoområdet, låg självskattad hälsa och riskfyllda hälsobeteenden.

Original papers

This thesis is based on the following papers:

I Jerdén L, Weinehall L. Does a patient-held health record give rise to lifestyle changes? A study in clinical practice. *Fam Pract* 2004, 21(6):651-653.

II Jerdén L, Hillervik C, Hansson AC, Flacking R, Weinehall L. Experiences of Swedish community health nurses working with health promotion and a patient-held record. *Scand J Caring Sci* 2006; 20:448-454.

III Jerdén L, Lindholm L, Weinehall L. Cost-effectiveness of a personal health document in different distribution settings (submitted).

IV Jerdén L, Burell G, Stenlund H, Weinehall L, Bergström E. Empowerment: a key to a better understanding of adolescent health? *Int J Child Adolescent Health* 2008; 1: *(in press)*.

V Jerdén L, Bildt-Ström P, Burell G, Weinehall L, Bergström E. Personal health documents in school health education – a feasibility study. *Scand J Public Health* 2007; 6: *(in press)*.

The publishers have given permission for reprinting of published papers.

Abbreviations

CHN	Community health nurse (Sv.: Distriktssköterska)
CHR	Child health record
ePHR	Electronic personal health record
GP	General practitioner
MBAH	"My Book about Health" (Sv.: "Min bok om hälsa")
PHR	Personal health record
RCT	Randomised controlled trial
SBU	The Swedish Council of Technical Assessment in Health Care (Sv.: Statens beredning för medicinsk utvärdering)
SES	Socio-economic status
VIP	"VIP (Very Important Person)" (Sv.: "VIP [Väldigt Intressant Person"])
WHO	World Health Organization

Contents

PROLOGUE

Being a family doctor since 1984, I have always been actively interested in prevention and health promotion. In 1997, on the train journey back home to Dalarna after the SBU conference “Longer life and better health”, an idea was born of giving patients a little booklet about their own health. The next year, and with the help of many people, the idea was realized by the 28-page “Min bok om hälsa”. Somewhat surprisingly, the booklet was warmly received by quite a number of patients, and also appreciated by health professionals and politicians. I started another journey to find out the reasons behind this positive appraisal. During this intellectual trip, I found out that similar ideas had been realised long since by devoted health professionals around the world, not the least in far-distant countries like Lesotho and Australia.

In 2001, I was introduced to the concept of empowerment, which seemed to be important when trying to explain why some people liked the booklet. This concept was an inspiration during the planning of another project, in which the adolescent target group were involved in the planning from the very beginning. One teenager actually named the project as “VIP – Very Important Person”.

In 2004, I became involved in the National Institute of Public Health in supporting the objective domain “A more health-promoting health service”. Experiences from distribution of the two personal health documents seemed relevant in this task. In interviews, community health nurses had evaluated “Min bok om hälsa”, but also described possibilities and impediments in their general health-promotion work. And the strategy of empowerment had a tendency to sneak into most discussions about how to improve the health-promotion work.

Thus, for me, different personal working life threads have become woven together during the research process. I hope this thesis will provide the reader with a suitable web to contribute to the ongoing discussion about health promotion.

INTRODUCTION

"A more health-promoting health service"

In Sweden, there has been a national interest in public health since at least the 17th century (1). A growing interest in the 20th century was manifested by the establishment of a National Institute for Public Health in 1941 (Statens Institut för Folkhälsan). The Institute closed down in the early 1970s, but was re-established in 1992. In 1995, a process concerning public health policy started with the formation of a parliamentary National Public Health Committee. A Swedish national public health policy was adopted by the Parliament in 2003 with the overarching goal "to create social conditions that will ensure good health, on equal terms, for the entire population" (2). All levels of public authorities should be guided by the 11 public health objective domains which cover a number of established policy areas including economic policy, social welfare, the labour market, agriculture, transport and the environment. The National Institute of Public Health has been commissioned to coordinate the monitoring of the objective domains. The first Public Health Policy Report was published by the Institute in 2005 (3).

During the process initiated in 1995, health services was one arena that received interest, resulting in the report "A health-oriented health service" in 2000 (4). One of the public health domains decided upon in 2003 was "A more health-promoting health service" (2). Health services are said to be of great importance for long-term public health through their specific competence, authority, broad knowledge, and numerous contacts with the population. A health-promoting and disease-preventing perspective shall characterize the whole health services and be a self-evident part of all medical care and treatment (2). In the 2005 Public Health Policy Report (3) a number of development needs are listed, among them to increase research in health-promotion methods, investments in non-pharmaceutical methods, and efforts of primary health care in health promotion.

Health promotion

The concept of health promotion was established in public health and health services by the 1986 World Health Organization (WHO) Ottawa conference. At the conference, the Ottawa Charter was adopted, wherein health promotion is defined as “the process of enabling people to increase control over, and to improve, their health” (5). The charter defined five action areas for health promotion: build healthy public policy; create supportive environments; strengthen community actions; develop personal skills; and reorient health services. Since this conference, there has been a world wide health promotion movement, supported by a frame work of WHO conferences, the latest conducted in Bangkok in 2005 (6). The concept of health promotion has also been adopted by many non-governmental organisations, e.g. the International Union of Health Promotion and Education (http://www.iuhpe.org).

To understand health promotion, a definition of health is vital. The word health has its roots in the word "heal”, which originally meant "whole”, and also from the Greek word "holos" which also means "whole" (7). This implies considering a person in his/her entirety and including both the inner dialogue and the individual as a social being. The concept of disease refers to definitions of the defects that cause disturbance in a person's functions and primarily relates to the individual as a biological being (8, 9). One example of a holistic perspective of health is the WHO definition from 1946: “A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (10). The definition implies that aspects of well-being and of freedom from disease are included in the health concept. Following the same tradition, Katie Eriksson discussed the concept of health based on a two-dimensional model with well-being along one axis and dysfunction along the other (11). Naturally, the dimension of well-being could only be assessed by the individual. This self assessment has been used for measures of “self-rated health”, i.e. the perceived subjective summary of health (12). Different two-dimensional models of health have been presented (4, 11, 13). Based on these models, Figure 1 is an illustration of a two-dimensional health model.

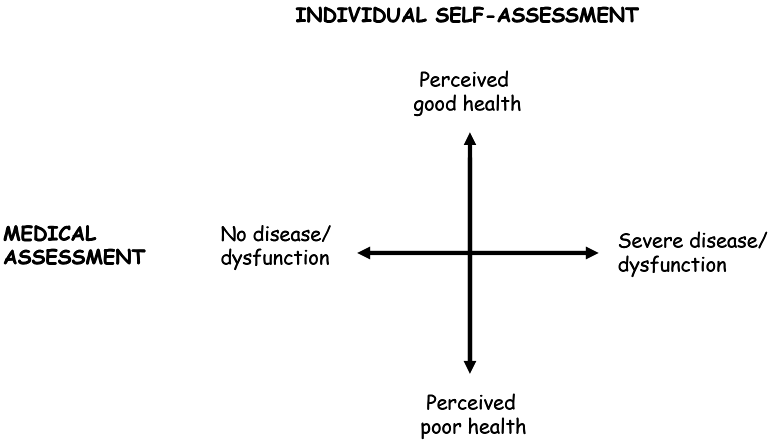


Figure 1. Two dimensions of health

Health-promoting health services

The Ottawa Charter stated: "The role of the health sector must move increasingly in a health promotion direction, beyond its responsibility for providing clinical and curative services" (5). Referring to Figure 1, one implication is that the axis of perceived health should be emphasised. However, the objective of reorienting health services has not always come to the foreground in the emerging health promotion movement (14). None of the subsequent WHO conferences has focused health services. In a recent reflection on the five action areas of the charter, reorienting health services was found to offer the least observable change since 1986. Sweden was mentioned as one of few countries where organized national efforts had been made in this respect (14).

While the potential for primary health care in the promotion of health was underlined at the WHO Alma-Ata conference in 1978 (15), since 1986 the most organised efforts for reorientation of health services have probably been performed in hospitals which are the main components of health services in Sweden and many other countries. Since 1988, WHO Europe has developed an international network of health-promoting hospitals that includes more than 700 hospitals (htpp://www.euro.who.int/healthpromohosp). In Sweden, primary health care has a long tradition of using strategies that would currently be termed health promotion. In 1822, physicians in primary health care were instructed to “put attention to all things that may contribute to the maintenance of the health of the population, and to all things that might have harmful effects on health”. Lifestyle, housing, physical activity and nutrition were areas specifically mentioned (16). Partly influenced by promising biomedical innovations, prevention and health promotion gained less attention in Swedish health services after the Second World War. A change in priorities was seen in the 1970s, and manifest by a clear responsibility for prevention being included in the 1982 Health and Medical Service Act. In the 1980s, the role of Swedish primary health care in prevention was emphasized (17). However, during recent decades, there have been increased demands on primary health care to perform disease-oriented work, especially for the growing elderly population. This has especially been the case for community health nurses (CHN) (18, 19). In 1998, CHNs reported a decrease in their opportunities to perform preventive care (19). A lack of health-promotion activities was frequently mentioned by CHNs in a recent Problem Detection Study (20), and a follow-up report indicated that CHNs involved in health-promotion projects were critical of the amount of support they received (21). As for doctors in primary health care, many health-promotion projects have been launched since the Alma-Ata conference. However, since the mid-1990s, the doctors’ role in prevention has been debated in Sweden (22, 23). The criticism of the current policy of preventive programmes has increased in Nordic countries and focused on the continuous widening of the risk factor concept (24).

Schools have been recognized as one important arena for health promotion. The concept of the “health promoting school” was established by WHO in 1986. Today, there is an active European network for health-promoting schools (http://www.euro.who.int/ENHPS). In Sweden, school health services have a long tradition, with the first doctors employed in the 1830s and the first nurses in the 1910s. The initial task was screening for disease and disabilities. Eventually, health education became increasingly important and is now a compulsory part of the school curriculum. Teachers, together with the other school personnel, have a key role in creating a health-promoting environment at schools (25). In Sweden, doctors and nurses in school health services are a part of the general health services. They are presumed to be active participants in the team work for health promotion in schools (26). School health services (mainly school nurses) are also expected to work with health education. There is an on-going discussion about the direction and priorities of school health services in Sweden, where it is argued that psychosocial factors should be given greater attention, and health education a more central role (26).

Work places has also been identified as an important arena in health promotion (5). In Sweden, health services connected to workplaces emerged in the twentieth century. Screening for disease and treatment of occupational diseases have been traditional work tasks. Health promotion has become an increasing work task for occupational health, with health examinations a part of this work. Doctors, nurses and physiotherapists are legally regarded as a part of health services. Occupational health has had a strong position in Sweden. However, since the end of governmental financial support in 1994, the situation is more varied and some employers provide extensive services while others provide only those services that are obligated by law.

Empowerment

The concept of empowerment was advocated by the Ottawa Charter, and empowerment is a prevailing and central idea in the health promotion movement (6). The Ottawa definition of health promotion emphasizes personal control, and proposes a close relation to the concept of empowerment. Empowerment has been suggested as a strategy for many arenas (27), including health promotion in schools (28) and health services (29).

The concept of empowerment

For a long time, the word “empowerment” has been used for the act of conferring legality or sanction (30). During the 1970s, empowerment began to be used as a strategy in U.S. developmental projects among underprivileged groups (31, 32). These projects emphasized activities from the target groups involved. The contexts contributed to a shift in the meaning of empowerment, from a focus on the person transferring the authority or power, to the one actively trying to access to it. The concept is currently used both to describe processes where individuals, groups or communities try to empower themselves, and where professionals try to empower their clients or patients.

In 1984, the U.S. community psychologist Rappaport noted that “we do not know what empowerment is, but like obscenity, we know it when we see it" (33). Since then, there has been an increasing interest in the concept, both in using empowerment as a strategy in different sectors, and in defining it for the purpose of research. Today, several definitions of empowerment are presented in literature (34-40). In 1987, Rappaport defined it as “a process, a mechanism by which people, organizations, and communities gain mastery over their affairs” (35). In addition to seeing empowerment as a process, the concept is used as a state, an outcome of empowering or disempowering processes (40). Empowerment is regarded as a multilevel construct (40), with some scholars emphasizing the community level of empowerment (35), and others focusing on the individual level like Connelly et al: “Empowerment is defined as a process wherein people assert control over factors which affect their lives” (38). With a rationale to enable repeated measurements of empowerment, Rappaport and Zimmerman were among the first to operationalize the concept at the individual level (41). Zimmerman has argued that the development of a universal and global measure of empowerment may not be a feasible or appropriate goal, as empowerment is dependent on the cultural and social context (40). As a result, many scales to measure empowerment have been established, e.g. among users of mental health services (42), staff in social programmes (43) and health services (44), diabetics (45), and people with disabilities (46).

An operationalizing of empowerment requires relating empowerment to other similar psychological constructs. *Self-efficacy*, the individual's estimate of his/her ability to succeed in reaching a specific goal (47), is such a construct. Zimmerman has argued that self-efficacy is one part of empowerment on the individual level, implying empowerment as a broader concept (40). Zimmerman also argues that the individual’s perceived *competence*, i.e. the state or quality of being adequately or well qualified (48), could be one part of empowerment (40). Analysing the instruments referred to above, these two concepts are uniformly present. Another related concept is s*ense of coherence,* with its aspects of manageability, comprehensibility and meaningfulness (49). Antonovsky has noted that manageability is closely related to *perceived control* (49), and a perception by the individual to control his/her situation is close to empowerment on the individual level. Comprehensibility could also be seen as a prerequisite to empowerment. However, the connection between meaningfulness and empowerment is less obvious. Furthermore, while sense of coherence is an intrapersonal psychological construct, aspects of social interaction are most often present when empowerment is defined and operationalized.

Empowerment in health services

When reorienting health services, calls for empowerment among patients have been voiced (29). The Swedish health services' development to strengthen patients' rights (50) might be seen in this context. During recent decades, a supposed authoritarian tradition by health professionals has been challenged. In a SBU report from 1999, "The patient-doctor relationship" (51), these questions are described in depth. One model for the patient-doctor relation is paternalism, where the doctor has the role as a guardian for the patient who is assumed to follow the doctor's recommendations without questioning. The doctor dominates the conversation and controls the opportunities for the patient to speak out, as well as decides themes of the conversation (51). The paternalistic model has a long tradition in health services. Contrary to the paternalistic model, there are models based on patient-doctor dialogue on as equal terms as possible, and with the patient perspective at the centre of the conversation (51). "Patient-centeredness" has been advocated as a basic concept for the dialogue between patients and health professionals, and as a strategy for health services (52).

Empowerment and health

Following the discussion above, empowerment is related to concepts like control, manageability and comprehensibility - concepts that have been linked to salutogenesis or the shaping of health (49). Thus, empowerment could be hypothesized to have a positive influence on the vertical axis in Figure 1. Although the concept of empowerment has been widely used in health promotion, few efforts have been made to examine the relation between empowerment and the individual's self-assessment of health. In Ireland, rural dwellers aged 15 years and older with low self empowerment were significantly more likely to rate their health poorly (53). Among adolescents, it has been shown that self-efficacy is correlated with perceived health among U.S. seventh grade students (54). The relationship between empowerment and self-rated health among adolescents has not been reported to the best of our knowledge.

Empowerment and health behaviour

"Health behaviour" is defined in this thesis as behaviour that compromises, sustains or promotes health (55). Theoretically, there is a potential link between empowerment and health behaviour. Behaviour is regarded as an integrated part of empowerment at the individual level (40). Hypothetically, empowerment may set the stage for behaviour initiation, and a strengthening of empowerment might therefore result in positive changes in health behaviour. Although the relation between empowerment and health behaviour is sparsely studied, some results from intervention studies that targeted adolescents support this hypothesis (56). Studies of a student-centred health education model targeting Swedish 15-16-year-olds demonstrated mixed results: clarification of individual health issues and an increase in self-reported health-enhancing activities (57), but no effect on alcohol consumption (58).

Personal health documents

In health promotion, health literacy is a central concept. It has been defined as "cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (59). A potential tool to gain and utilize such skills is health documents. The dominating tradition in health documentation is the medical record, established and owned by health services. Since the Second World War, there have been efforts to create health documents used in parallel to the medical record that are owned and controlled by the individual, i.e. personal health documents. As will be argued below, there is a potential for health documentation to increase health literacy and initiate health behaviour change; empowerment could be another potential benefit.

Terminology

A personal health document is defined as a document concerning a person's health that is owned by the individual. The term "personal health record" has been used since the 1980s (60), and today is extensively used for electronic personal health documents (61). As "record" could imply a pure medical perspective, the wider term "document" is used in this thesis. The terms "patient-held" (62), "client-held" (63) and "parent-held" (64) have been used for personal health documents and mirror a professional perspective. The definition of personal health documents implies a demarcation from the medical record that is based on the ownership of the documents. Thus, projects aimed at facilitation of patient access to his/her medical record, either by electronic solutions or by placing the medical record in the home of the patient, are by this definition not developments of personal health documents. However, personal health documents and medical records could communicate by patients documenting in medical records or health professionals documenting in personal health documents. Who is doing the actual documentation in personal health documents is of special interest when discussing concepts like participation and empowerment. The owner of the document could do all of the documentation (i.e. a diary), or the opposite would be that documentation is done solely by health professionals (i.e. a copy of the medical record). A mixture of the two has been a common solution, with both the owner and health professionals documenting in the record.

Aims and arenas

Initiatives to introduce personals health documents have almost entirely been taken by health professionals and health administrators, and seldom by patients. Outspoken aims have focused on the needs of health services: improved communication between health professionals (60, 65); improved screening programmes (66); and quality assurance (67). Other aims have been more patient-centred, and include: patient participation (65, 68); patient empowerment (69-72); improvement of communication between patient and professionals (73, 74); and facilitation of health behaviour change (70, 73, 75). Personal health documents could focus on disease and dysfunction, or on prevention. Most commonly, the focus has been treatment of disease, either as a copy of the medical record (76), or as a separate, parallel, document for patients with chronic disease (e.g. diabetes (77, 78), asthma (79), mental disease (80, 81), cancer (82), stroke (83)). Since the 1940s, there has also been development of personal health documents focused on prevention (84). Personal health documents have been widely used in child health care (74, 85, 86), maternal care (87, 88) and as immunization documents (62). Other arenas have been health services for adult (89, 90) and geriatric patients (91), and occupational health (92). School health has been an infrequent arena for personal health documents, and few studies are available in literature (70, 93-95).

Types and formats

Types and formats of personal health documents vary. The size has shifted from wallet cards (89) to extensive folders (63, 70). Electronic personal health documents have developed since the 1990s (96). In addition to documenting personal health, the potential for communication with electronic medical records used in health services has been emphasized (97).

In the following, literature is reviewed concerning questions regarding personal health documents examined in this thesis: feasibility; the association with empowerment; and the association with health behaviour change. In an appendix, results are summarised from a search of the literature concerning personal health documents focused on prevention.

Feasibility

Feasibility has been defined as “the quality of being doable” (98). Feasibility is first and foremost tested during routine circumstances and not experimental ones. For a method to be feasible in health services, it should be accepted both by health professionals and patients. Costs are also an important aspect when feasibility is assessed.

The literature demonstrates strong evidence for adults’ support of initiatives that provide personal health documents. Adult owners’ unanimously report support for personal health document provision (72, 87-89, 99-108). Many studies report that a low proportion of users lose their documents. When documents have been kept both by the health service and at home, the frequency of loss has sometimes been compared. Such studies report a higher frequency of loss of home-based documents (109), an equal frequency (88, 107), and a lower frequency (87, 110). Studies that explore the reasons for patients’ apprehension are rather sparse. A qualitative study examining pregnant women found the themes “information at hand,” “empowerment” and “sharing with partner/family/friends” to be important (103). One problem illustrated in this study was the theme “concerns about losing the record” (103). Another problem has been to understand text and figures (106, 111, 112). Practical use of documents varied considerably between studies. Frequencies of self-reported reading in the documents varied between one third (113) and 88% (114). Self-reported documentation varied between 12% (113) and 98% (115). The few studies that targeted adolescents provide a mixed picture about general attitudes. In a U.S. pilot study, the majority of students were positive (70), while a majority were indifferent or negative to the UK personal child health record adapted to adolescents (94). In the latter study, after one year 39% of adolescents reported writing in the document and 38% had lost their document permanently.

Patients/clients and health professionals have different attitudes to, and expectations of, personal health documents. In Australia, patients typically perceived a personal health record as a personal document for reference while general practitioners perceived it as a management and communication tool (65). Patients and parents tend to be more positive than health professionals (100, 101, 108). Although there are studies reporting the same level of support by different groups of health professionals (116), others demonstrate less support among doctors (99, 108, 114). In doctor groups, studies demonstrate very different attitudes among different individuals (65, 89). Concerns among health professionals have been the provision of time-consuming information (89), extra paper-work (65, 99, 108), confidentiality (65, 108), accuracy of documentation (65) as well as hypochondriasis and 'doctor-shopping' among patients (65).

Concerning costs, a review of personal health documents described them as relatively inexpensive (117). Actual costs of their provision have rarely been reported, with an exception being a study from a U.S. primary care clinic where printing and distribution costs were estimated to be moderate (89).

Empowerment

Empowerment has sometimes been the outspoken aim for personal health documents (69-72). In everyday life, documentation is often used as a method of control. Documentation by patients might decrease a "power gap" between health professionals with easy access to medical records that rapidly increase in volume, and patients who have limited or no access to documents concerning their own health. The presumed association between usage of personal health documents and variables related to empowerment has predominately been studied among pregnant women. In a qualitative study, empowerment was a theme among interviewed pregnant women who carried their own records (103). In randomised controlled trials that targeted pregnant women, patients who held their own antenatal records felt better informed (87), were more likely to feel in control of their care (118), felt it was easier to talk to the health personnel (118), were less likely to feel anxious and helpless (88), and were more likely to have information on their records explained to them by their caregiver (88).

Health behaviour

Theoretically, there are potential pathways between the provision of personal health documents and health behaviour change. One theoretical pathway is through a positive influence of empowerment, which has been argued above to have a theoretical association with health behaviour change. Another pathway is through reflection and writing in the documents. Personal health documents often provide health information that is included with an aim to influence health behaviour. Print health education material has been widely used worldwide (119). Health behaviour change has sometimes been a stated aim, e.g. pamphlets aimed at smoking cessation. Self-help materials where the individual is active by writing, answering questions etc., are being used in increasing frequency in an effort to increase behaviour change. A Cochrane review found that self-help materials may increase quit rates in smoking cessation (120). If the owner of a personal health document is an active documenter, these positive effects might be evident. Using the Stages of Change theory (121), personal health documents can be assumed to influence behaviour in different stages of the process. Health information and self-assessments might elicit thoughts in the pre-contemplation phase. An inventory of pros and cons might have a positive impact in the contemplation phase, and goal setting might influence the preparation phase. Self-monitoring might give positive feed back in the action and maintenance phases.

Self-reported lifestyle changes after interventions with personal health documents have occasionally been studied. Two uncontrolled pilot studies, one of which targeted adolescents in schools, could not demonstrate significant behaviour change after an intervention (63, 70); neither did a randomised controlled trial of an antenatal record (87). An uncontrolled study reported substantial efforts to control smoking but did not give exact figures (75). A randomised controlled trial comparing different health documents showed a reduced alcohol intake for the users of one document, but no effect on smoking, exercise or diet, but a small sample decreased the statistical power to detect differences between groups (90). In another randomised controlled study, patients who shared medical records with their physicians after a health examination reported a significantly increased rate of smoking reduction or quitting after six months (73).

Summary

To summarise, the concepts of personal health documents and of empowerment are of interest to a health-promoting health service. Many studies have examined personal health documents and demonstrated the feasibility of providing them. However, there is little knowledge about personal health documents that target adolescents. There have also been few, and small, studies that examined the association between personal health documents and health behaviour change. There are few reports about the costs of providing documents in different settings, and about the feasibility of personal health documents in a Swedish cultural context. The associations between empowerment, self-rated health and health behaviour are insufficiently studied. In the studies of this thesis, we wanted to gain knowledge about the provision of personal health documents that targeted different groups in different Swedish settings. Also, we wanted to explore the concept of empowerment and its relation to health. Our main interest was to examine empowerment on the individual level. Our understanding of empowerment on this level was that it has three dimensions: self-efficacy, competence, and social interaction. As our interest was to study empowerment and health, we wanted to measure the dimensions of self-efficacy and competence in the health domain.

AIMS

The *overall aim* of this thesis is

- to explore strategies and tools for a more health-promoting health service

Specific aims are

- to examine the feasibility of using personal health documents in health promotion
- to examine professionals' experiences of working with health promotion and personal health documents
- to examine the association between personal health documents and self-reported health behaviour change
- to examine the perception of empowerment in relation to self-rated health and health behaviour among adolescents

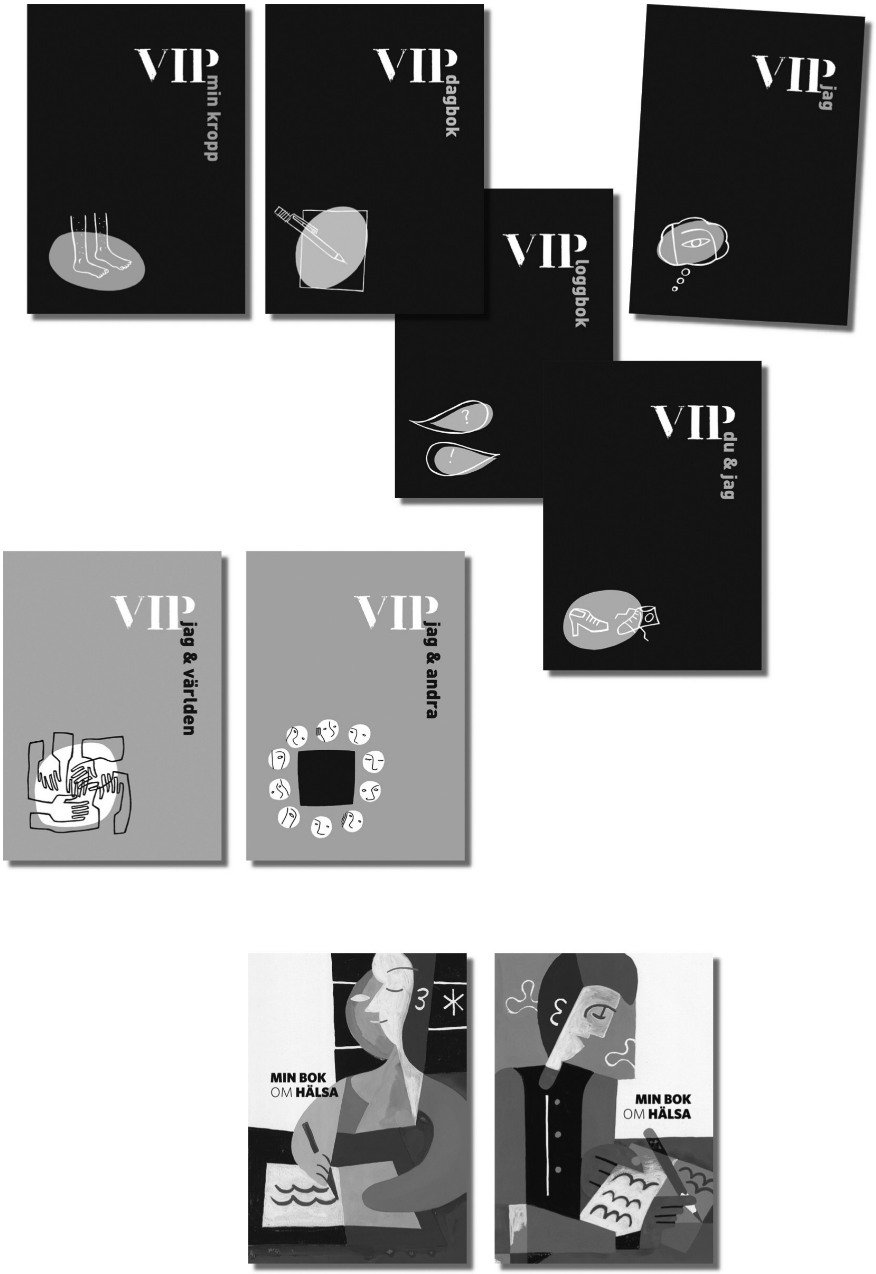


Figure 2. The nine booklets developed for the thesis´ studies

MATERIAL, STUDY POPULATIONS AND METHODS

First, the two personal health documents that were developed especially for the studies are described in this section. The documents were "My Book about Health" to target adults and "VIP (Very Important Person)" to target adolescents. Second, there is a description of the study populations. 'My Book about Health' was distributed at primary health care centres, at workplaces and by mail. The VIP document was tested at two schools and students at five schools served as controls. The practices and attitudes of community health nurses and teachers that distributed the documents are also examined. Third, the mode of education of the document distributors is described, as well as the way documents were provided to the owners. Fourth, the measurement tools are described. Questionnaires were developed for the studies and used by the document owners and teachers. Community health nurses were interviewed, and the interviews were analysed using qualitative methodology. Lastly, statistical methods used in the studies are described. In Table 1, the studies in the thesis are summarized.

Table 1. Overview of thesis studies

Name	Design	Study populations	Data collection	Outcome measures	Papers
My Book about Health	Cross-sectional	a) Primary health care patients (n = 418) b) Personnel home care (n = 164) c) Paper mill personnel (n = 279) d) Population (n = 445)	Questionnaire	Self-reported behaviour change (I, III) Cost calculations (III)	I, III III III III
My Book about Health	Qualitative	Community health nurses (n = 12)	Interviews	Descriptions from interviews	II
VIP	Cross-sectional	Students (n = 1 046)	Questionnaire	Empowerment, self-rated health, self-reported health behaviour	IV
VIP	Panel	Students (n = 339)	Questionnaire	Practical use and perceived usefulness of document	V
VIP	Cross-sectional	Teachers (n = 69)	Questionnaire	Practical use of and attitudes toward document	Thesis cover story

Development of personal health documents

My Book about Health

In the county of Dalarna, Sweden, a personal health document, ‘Min bok om hälsa’ (‘My Book about Health’ - MBAH), was developed by health professionals. The document was tested in a pilot study from 1998 - 1999 at a primary health care centre (105). The target population was patients aged 20 to 64 years, but older patients could also obtain the document with an additional page that adjusted the information for their age. The main objective of the document was to encourage patient initiatives to improve health. The document was meant primarily as a personal document for reflection and reference, and only secondarily as a tool for communication with health professionals. The main topic of the 28-page document was lifestyle, including stress and social network. There was a female and a male version. The use of the document was inspired by theories of behaviour change (121-123). Documentation of personal lifestyle was encouraged, as were the definition of personal goals. Personal advantages and disadvantages to a behaviour change were explored along with obstacles and facilitating factors. The document also contained health information through ‘fact squares’, and had space for documentation of blood pressure and laboratory tests. The document has been revised twice since the pilot study, and the most recent 32-page version from 2006 is available on the web (http://www.ltdalarna.se/minbokomhalsa).

VIP (Very Important Person)

In 2000 – 2003, another personal health document, ‘VIP Väldigt Intressant Person’ (‘VIP Very Important Person’) was developed and tested in a pilot study with close cooperation between a project team and groups of adolescents. First, 10th grade students from different school programs discussed the initial idea and possible topics together with the project team at a one-day seminar. Secondly, eighth and ninth grade students from one municipality were invited to write about health matters and a selection of the contributions were part of the VIP document. The disposition and text were discussed with and approved by a reference group of adolescents. In interviews, these adolescents were satisfied with their opportunities to influence the planning process (124). Finally, the document was tested among seventh graders in a pilot study and subsequently some modifications were made. The final document consisted of a folder with booklets. The emphasis in the text was on personal reflection concerning personality, a set of values, relations, health and health behaviour. Personal writing in the booklets was encouraged. Established components of health education (125), such as information, strategies for decision making, value clarifications, goal setting, stress handling, self-esteem strengthening, resistance skills, and life skills training were included in the document. For the seventh graders, five booklets were presented: “me”, “you&me”, “my body”, “diary” and “logbook”. In eighth grade, students received “me&others”, and in ninth grade “me&the world”. Parts of the booklets are available on the web (http://www.ltdalarna.se/vip).

Similarities and differences of these two personal health documents are summarized in Table 2.

Table 2. Properties of the two studied personal health documents

My Book about Health	VIP (Very Important Person)
Similarities	
Focus on health promotion	
The owner provides almost all of the documentation	
Personal reflection is encouraged	
Printed material (not electronic version)	
Health information included	
Differences	
Male and female versions	One version
Constructed by professionals	Joint professional – layman construction
Focus on lifestyle	Focus on values and relations
Booklet	Folder with booklets
Medium size (28 pages)	Large size (252 pages)
Diary and communicative tool combined	Mainly diary, separate communicative tool

Study populations

The studies were performed in Sweden in the counties of Dalarna and Västerbotten (Figure 3).

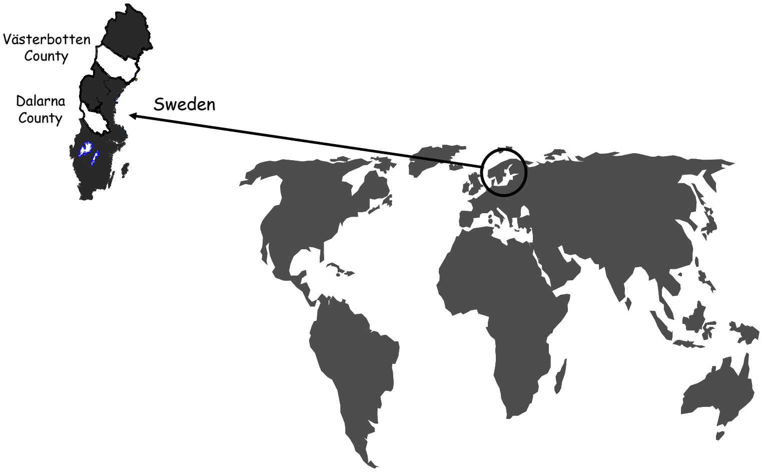


Figure 3. Map of Sweden with the counties were studies were performed

Table 3 summarizes participation in studies where questionnaires were used.

Table 3. Overview of participants and respondents in studies where questionnaires were used

	My Book about Health				VIP baseline		VIP 1-year		VIP 3-year
	Primary health care	Work sites	Occu-pational health	Postal	Inter-vention	Control	Inter-vention	Control	Teachers
Participants	418	164	279	445	339	707	339	707	69
Responded to questionnaire	314	125	171	233	328	656	321	669	62
Respondents, %	75	76	61	52	97	93	95	95	90

Figure 4 shows the geographical areas were the sampling was performed in the MBAH studies.

Figure 4. 'My Book about Health' studies' sampling areas in the County of Dalarna, Sweden

Patients at primary health care centres (Paper I, III)

Patients aged 20 to 64 years were recruited at primary health care centres in the County of Dalarna, Sweden (n = 418). In 2000, all primary health care centres in the county were invited to distribute MBAH. Those centres that agreed were asked to participate in a study in consecutive order. Centres were recruited until six centres agreed to participate. The regular population survey of the county (126) was analysed in order to see if there were any differences between patients visiting the six participating centres and patients visiting other centres in the county. Socio-economic and demographic characteristics, and patients' apprehensions of lifestyle discussions at their health centre were compared. There were fewer patients born outside Sweden at the participating centres (5% vs. 7%, $p = 0.03$); otherwise no significant differences could be demonstrated.

In order to estimate whether the patients who received MBAH were representative of all patients at the participating health centres, the background characteristics were compared. Data for non-participants in the MBAH studies were obtained from the population survey (126). Compared with all patients visiting doctors at participating centres the latest twelve months, age above 50 years and treatment for hypertension were significantly more common among patients who received the MBAH document (Table 4).

Table 4. Background characteristics of patients receiving 'My Book about Health' and those who had visited a doctor at the participating primary health centres during the latest twelve months. 95% confidence intervals are specified.

	MBAH study		Population survey	
	Respondents among patients receiving 'My Book about Health' (n = 314)		Respondents having visited doctors at participating centres during last twelve months (n = 466)	
Variables	%	(95% CI)	%	(95% CI)
Age, years				
50 – 64	57	(52-63)	44	(40-49)
Sex				
Female	69	(64-75)	64	(59-68)
Ethnicity				
Born in a country other than Sweden	7	(4-9)	5	(3-6)
Education				
College or university	22	(18-27)	21	(17-25)
Occupation				
Employed full time	41	(36-47)	44	(39-48)
Self-reported health status				
Not so good or bad	26	(21-31)	29	(25-34)
Chronic disease				
Diabetes	7	(4-10)	5	(3-7)
Hypertension	28	(23-33)	11	(8-14)
Cardiac disease	8	(5-11)	6	(4-9)
Cigarette smoking				
Daily	15	(11-19)	22	(18-25)
Occasionally	8	(5-11)	9	(6-11)

Home care personnel (Paper III)

In Sweden, home care among the elderly is the responsibility of the municipality. The personnel start their work from home care units which are often placed in residence houses for the elderly. All personnel at the home care units of the municipality of Gagnef, Dalarna were offered MBAH when they attended regular administrative meetings at the work site (n = 164).

Paper mill personnel (Paper III)

At a paper mill in Borlänge, Dalarna, all employees have been offered an ongoing five-year general health examination for many years. During the study, the employees were offered MBAH as an extra element of the health examination (n = 279).

General population (Paper III)

A random sample of the population, aged 20 to 64 years, in the municipalities of Borlänge and Gagnef were sent MBAH by mail (n = 445).

Community health nurses (Paper II)

Community health nurses (CHN) in the county of Dalarna were interviewed (n = 12). In a first phase of data collection, four primary health care centres participating in the patient study were chosen. The centres differed in size and urban/rural location. CHNs responsible for contact with the project team were asked to select personnel who had distributed at least one copy of MBAH. In this way, eight CHNs were recruited in 2001. A second phase of data collection was performed in 2005. One primary health care centre was chosen where MBAH was thought to be continuously used since 2000, and where no interviews had been performed during the first phase of data collection. The four CHNs at the centre agreed to be interviewed.

Students (paper IV, V)

All students in seventh grade in seven schools in three Swedish municipalities (Borlänge, Falun and Umeå) were invited to participate in the study by a letter to their home (n = 1 046). The size of the study sample was based on an estimation of statistical power. With the estimated sample size, it will be possible to demonstrate a 10-15% difference in single empowerment items after the intervention in 80% of the cases with a significance level of 5%. The chosen municipalities represented different levels of parental education. Using data from Statistics Sweden, schools for pupils in the seventh to ninth grades were stratified according to the education level of parents, i.e. the proportion of students who came from families in which at least one of the parents had an education at the college/university level. Schools representing the highest and lowest educational levels in each municipality were invited to participate. All schools accepted the invitation. All pupils in the seventh grade at the schools were invited to participate in the study by a letter sent to them and their parents. Schools in one municipality were selected as intervention schools, while schools in the other municipalities became controls.

Background characteristics of participating students are shown in Table 5.

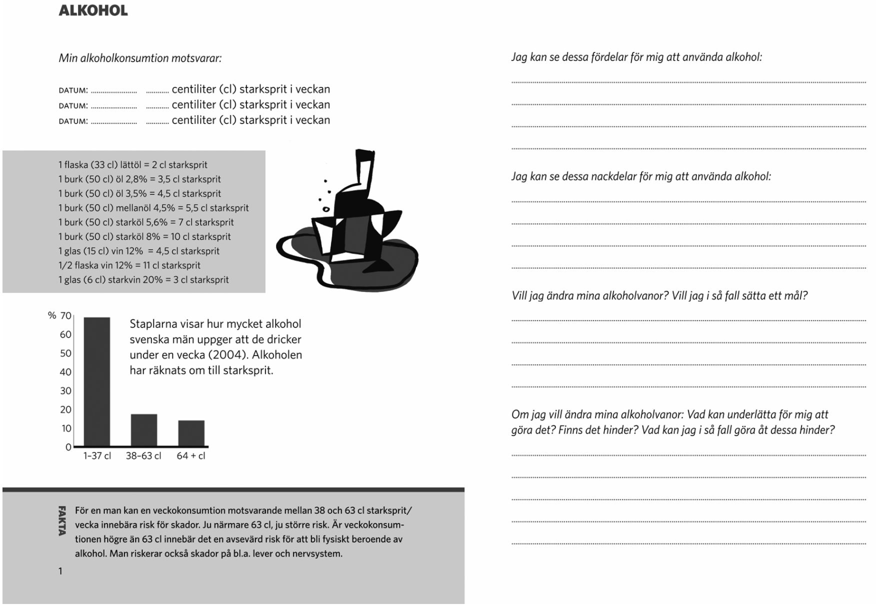
Table 5. Baseline characteristics of intervention and control groups (percentages)

Variable	Intervention %, (n = 328)	Control %, (n = 656)
Sex		
Female	49.7	50.6
Age (years)		
12	22.6	22.0
13	74.9	74.7
14	2.4	3.4
Place of birth		
Sweden	94.8	92.8
Residence		
City/town	28.2***	70.6
Village	38.3***	17.3
Rural area	33.4***	12.1
Educational level of parents		
College/university	49.7	51.1
School experience		
Positive	83.8	83.0
Self-rated health		
High	93.5	92.0

p-values were calculated by Pearson chi-square.
*** p less than 0.001.

Teachers (data only presented in thesis cover story)

All teachers who were working at the two intervention schools in March 2006 and had been educating the study cohort were invited to fill out a questionnaire (n = 69). Thus, the sample included teachers employed after the start of the study in 2003.



ALKOHOL

Min alkoholkonsumtion motsvarar:

DATUM: ……………… ……… centiliter (cl) starksprit i veckan
DATUM: ……………… ……… centiliter (cl) starksprit i veckan
DATUM: ……………… ……… centiliter (cl) starksprit i veckan

1 flaska (33 cl) lättöl = 2 cl starksprit
1 burk (50 cl) öl 2,8% = 3,5 cl starksprit
1 burk (50 cl) öl 3,5% = 4,5 cl starksprit
1 burk (50 cl) mellanöl 4,5% = 5,5 cl starksprit
1 burk (50 cl) starköl 5,6% = 7 cl starksprit
1 burk (50 cl) starköl 8% = 10 cl starksprit
1 glas (15 cl) vin 12% = 4,5 cl starksprit
1/2 flaska vin 12% = 11 cl starksprit
1 glas (6 cl) starkvin 20% = 3 cl starksprit

Staplarna visar hur mycket alkohol svenska män uppger att de dricker under en vecka (2004). Alkoholen har räknats om till starksprit.

FAKTA

För en man kan en veckokonsumtion motsvarande mellan 38 och 63 cl starksprit/vecka innebära risk för skador. Ju närmare 63 cl, ju större risk. Är veckokonsumtionen högre än 63 cl innebär det en avsevärd risk för att bli fysiskt beroende av alkohol. Man riskerar också skador på bl.a. lever och nervsystem.

1

Jag kan se dessa fördelar för mig att använda alkohol:

……………………………………………………
……………………………………………………
……………………………………………………
……………………………………………………

Jag kan se dessa nackdelar för mig att använda alkohol:

……………………………………………………
……………………………………………………
……………………………………………………
……………………………………………………

Vill jag ändra mina alkoholvanor? Vill jag i så fall sätta ett mål?

……………………………………………………
……………………………………………………
……………………………………………………
……………………………………………………

Om jag vill ändra mina alkoholvanor: Vad kan underlätta för mig att göra det? Finns det hinder? Vad kan jag i så fall göra åt dessa hinder?

……………………………………………………
……………………………………………………
……………………………………………………
……………………………………………………
……………………………………………………

Figure 5. An example from ‘My Book about Health’: two pages concerning alcohol

Introduction of documents to professionals and distribution to study populations

'My Book about Health'

Professionals at primary health care centres and the occupational health unit at the paper mill were educated about MBAH distribution during approximately one hour. In home care, the document was provided by the thesis writer.

Primary health care: doctors and community health nurses were asked to distribute records to as many patients as possible at regular visits. At the same time, it was emphasized that the pace of distribution should be adapted to the amount of other required work. Patients could also request records through the receptionists. In the study, 73% of patients received the document from a nurse, 14% from the health centre reception and 3% from a doctor. Ten percent received MBAH in other ways, or did not know.

Paper mill: during the first visit for a health examination, MBAH was given to the participants. Participants were told to bring the document when they returned for a second visit. At this visit, an occupational health nurse informed the client about the results of the health examination. She also provided brief information about MBAH.

Home care: Information about MBAH was provided by the thesis writer during regular administrative meetings at the work site.

Postal: MBAH and an informational letter were sent by mail to the home address.

'VIP'

The VIP document was introduced to the students by the school personnel. Teachers at intervention schools and the school nurse at one school were educated during a three-hour session and received brief written information. Teachers were advised to let the students read and fill in the booklets during school time. Teachers were instructed that the purpose of the "logbook" was to have a continuous written dialogue between student and teacher, while the personal integrity of the other booklets was emphasized. These other booklets were to be kept private by the adolescents and not shown to the teacher. Teachers were also encouraged to initiate class discussions about suitable booklet subjects such as mobbing, relationships and smoking. After one and two years, teachers at the intervention schools and the school nurse at one school met members of the project team for an hour-long introduction of booklets for eighth and ninth graders.

Measurements

Questionnaire MBAH studies (Paper I, III)

Six months after receiving MBAH, the participants received a postal questionnaire. The questionnaire contained questions about MBAH and background characteristics. Questions concerning background characteristics were chosen from the regular population survey in the county of Dalarna, Sweden (127). Self-reported behaviour change was decided by a modified question from the population survey: “Is there something in your health situation you have changed as a result of reading the book?” For those who answered “yes”, the respondents were requested to fill out one or more of the alternatives: “physical activities”, “weight”, “tobacco habits”, “dietary habits”, “alcohol habits”, “stress” and “other.” Other questions concerning MBAH were constructed based on the findings in the pilot study (105). “Reading in document” was determined by the question “Have you looked through/read ‘My Book about Health’ since you received it?” Subjective valuations of the document were estimated by the question: “What is your general impression of the book?”. Self-initiated contacts with health professionals were determined by the question “Have you contacted health professionals because of your reading of ‘My Book about Health’?”

Interviews MBAH studies (Paper II)

The study used a qualitative approach. A qualitative content analysis (128) with aspects of the Grounded Theory approach (129) was adopted. In a first phase of data collection, interviews were semi-structured, and open-ended questions focused on the professional role, attitudes towards health promotion and disease prevention, and experiences of working with MBAH. The interviews lasted between 25 and 45 minutes and were tape-recorded.

A qualitative content analysis was performed (128). The interviewer (ACH) transcribed interviews verbatim. “Natural meaning units” of the text were listed (130). The theme that dominated a natural meaning unit was stated as simply as possible. A short descriptive statement was made to summarize each interview. This statement and the themes of the interview were presented to the informant who had the opportunity to verify the accuracy. The interviews were read and categorized independently by the authors ACH and LJ. Themes and subcategories were identified and compared until an agreement was reached.

In order to deepen the analysis, a second phase of data collection was performed in 2005. In-depth interviews were performed by one of the authors (RF), who previously had read and discussed the results of the first analysis. This information was used during the second phase of data collection, especially when exploring certain themes. The interviews lasted between 70 and 95 minutes. All together, the transcribed interviews consisted of 277 double-spaced pages. The last four interviews were read by all authors, and coded by the first and fourth authors. All twelve interviews were repeatedly read and examined for their interpretation of the informants' thoughts and experiences. Themes and subcategories from the additional interviews were identified and independently compared to themes and subcategories from the first eight interviews by the first and fourth authors. The categories were then compared and themes were discussed until an agreement was reached by all authors.

Cost calculations MBAH studies (Paper III)

A model was constructed to compare distribution costs based on the results of the study (paper III). Costs were divided into direct and indirect costs. The indirect cost was participants' productivity losses during the time of distribution of the personal health document. Costs for participants to read and use the document were not included in the model.

Questionnaire to students VIP studies (Paper IV, V)

A questionnaire was constructed with questions about empowerment, socio-demographic characteristics, sexual harassment, self-rated health and health behaviour. In order to make a quantitative measurement of empowerment as a state, and to enable repeated measurements, a measuring instrument in the form of a set of questions was developed. Empowerment was measured in the domain of health. Three dimensions of empowerment were measured: self-efficacy, health-related competence, and social interaction. After an evaluation of questionnaires identified through a literature search, half of the questions related to empowerment were selected from the Swedish part of the Health Behavior in School-Aged Children survey (HBSC) (55, 131), and from other established Swedish surveys (132, 133). The remainders were newly constructed. Efforts were made to use a language easily understood by the age group. In a pilot study, questions were tested upon 150 students in seventh grade. Respondents were invited to make written comments after each question. The questionnaire was also discussed with students and teachers in two classes. Reliability of the questionnaire was assessed in a test-retest that included 204 students in seventh grade. The students were invited to answer the questionnaire at two occasions with a one week interval. One hundred seventy-one students (84%) filled in both questionnaires. Kappa values for questions concerning empowerment varied between 0.29 and 0.59. Four empowerment questions were excluded due to low Kappa values (below 0.40). The final empowerment questions are included in Paper IV. The mean item score of each dimension constituted the individual dimension score. The three dimension scores were added to form an individual empowerment score. The reason for using the mean scores instead of the total scores when constructing the dimension scores was the assumption that the three dimensions were of equal importance for the concept of empowerment.

The questionnaire was answered at school at baseline and after one year. Twenty-two adolescents changed schools during the year and the questionnaires were mailed to their homes.

Questionnaire to teachers VIP studies (data only presented in thesis cover story)

A teacher's questionnaire was tested at the pilot study school and then modified. It included five questions about background characteristics (gender, school, number of years working as a teacher, and mentorship), two questions concerning practical use of the document, and five questions about attitudes towards VIP provision. The questionnaire was distributed at school and filled out during working hours. Sixty-two teachers (90%) filled out the questionnaire. Non-responders were three teachers out of 45 at one school and four out of 24 at the other.

Statistical methods

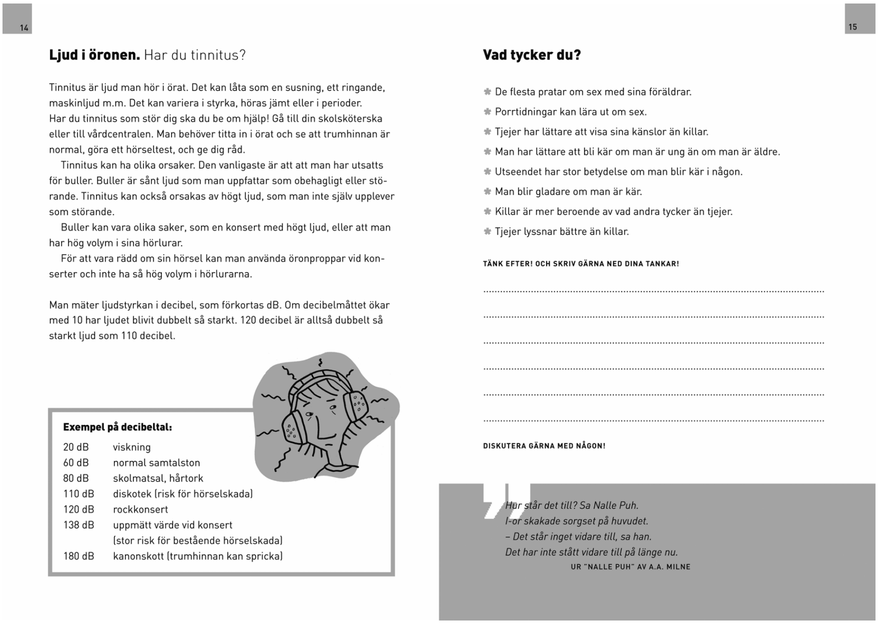
In paper I, data concerning behaviour change were analysed by univariate logistic regression to estimate odds ratios (ORs) with 95% confidence intervals (95% CIs). Confidence intervals for proportions were calculated according to Fleiss using Yate's correction for continuity (134). In paper III, Yate's correction was also used when confidence intervals were calculated. In paper IV, the theoretic model with three empowerment dimensions was tested by a confirmatory factor analysis using AMOS 5.0 software. In order to test if drop-outs differed from those included in the score analyses, the confirmatory factor analysis was repeated several times where missing values for a variable were replaced with randomly selected values from the observed distribution of the variable. Results demonstrated that the drop-outs did not change the analysis, and missing values were not replaced in the final analysis. In Paper IV, the Mann-Whitney U-test was used to calculate p-values when empowerment scores were compared between groups. In Paper IV and V, Pearson chi-square was used to calculate p-values from cross-tables. P-values less than 0.05 were considered significant. SPSS for Windows was used in the four quantitative studies.

Ethics

The MBAH Study was approved by the Gävle-Dala Research Ethics Council. The VIP Study was approved by the Research Ethics Committee of the Medical Faculty, Umeå University.

All participants received written information that emphasized the voluntary nature of participation in the studies. It was also stressed that documents would be provided even if one did not participate in the study. The high participation rates among adolescents might illustrate a "group pressure" to participate. Some students (24 in the baseline study, and 68 at one year) destroyed the index number on their questionnaire in order to obtain full anonymity. Practices were put into place to assure that teachers could not take view the students' opinions. The teacher's questionnaire was anonymous, but information such as school, sex, and years as a teacher could make this anonymity rather artificial. Teachers were informed about that they could exclude information in order to obtain full anonymity, but none of the teachers did so.

Both the documents and the questionnaires dealt with sensitive questions that could evoke negative emotions among participants. Routines were established to give participants the option to discuss such reactions with professionals. In two cases, a child expressed his/her mental health in such strong words in the questionnaire that the project leader (i.e. the thesis writer) contacted their respective school health personnel. Both children were known to the school health personnel and supportive actions had been taken.



14

Ljud i öronen. Har du tinnitus?

Tinnitus är ljud man hör i örat. Det kan låta som en susning, ett ringande, maskinljud m.m. Det kan variera i styrka, höras jämt eller i perioder.
Har du tinnitus som stör dig ska du be om hjälp! Gå till din skolsköterska eller till vårdcentralen. Man behöver titta in i örat och se att trumhinnan är normal, göra ett hörseltest, och ge dig råd.

Tinnitus kan ha olika orsaker. Den vanligaste är att att man har utsatts för buller. Buller är sånt ljud som man uppfattar som obehagligt eller störande. Tinnitus kan också orsakas av högt ljud, som man inte själv upplever som störande.

Buller kan vara olika saker, som en konsert med högt ljud, eller att man har hög volym i sina hörlurar.

För att vara rädd om sin hörsel kan man använda öronproppar vid konserter och inte ha så hög volym i hörlurarna.

Man mäter ljudstyrkan i decibel, som förkortas dB. Om decibelmåttet ökar med 10 har ljudet blivit dubbelt så starkt. 120 decibel är alltså dubbelt så starkt ljud som 110 decibel.

Exempel på decibeltal:

20 dB	viskning
60 dB	normal samtalston
80 dB	skolmatsal, hårtork
110 dB	diskotek (risk för hörselskada)
120 dB	rockkonsert
138 dB	uppmätt värde vid konsert (stor risk för bestående hörselskada)
180 dB	kanonskott (trumhinnan kan spricka)

15

Vad tycker du?

- De flesta pratar om sex med sina föräldrar.
- Porrtidningar kan lära ut om sex.
- Tjejer har lättare att visa sina känslor än killar.
- Man har lättare att bli kär om man är ung än om man är äldre.
- Utseendet har stor betydelse om man blir kär i någon.
- Man blir gladare om man är kär.
- Killar är mer beroende av vad andra tycker än tjejer.
- Tjejer lyssnar bättre än killar.

TÄNK EFTER! OCH SKRIV GÄRNA NED DINA TANKAR!

....

....

....

....

....

....

DISKUTERA GÄRNA MED NÅGON!

> *Hur står det till? Sa Nalle Puh.*
> *I-or skakade sorgset på huvudet.*
> *– Det står inget vidare till, sa han.*
> *Det har inte stått vidare till på länge nu.*
> UR "NALLE PUH" AV A.A. MILNE

Figure 6. An example from the VIP document: two pages concerning tinnitus, and set of values about sexuality

RESULTS

Feasibility of personal health documents

Practical use of 'My Book about Health' by participants

After six months, the majority of those who responded to the questionnaire reported reading the document in all settings; the proportion of writers was considerably lower (Table 6).

Table 6. Participants' practical use of 'My Book about Health' in different settings

Setting	Participants (n)	Responded to questionnaire (n)	Read in document (n)	%	Wrote in document (n)	%
Primary health care	418	314	250	79.6	103	32.8
Work sites	164	125	102	81.6	34	27.2
Occupational health	279	171	104	60.8	28	16.4
Postal	445	233	147	63.1	45	19.3

Document owner evaluations

Among readers, the majority gave an overall assessment of the document as "very good" or "rather good" in all settings (Figure 7).

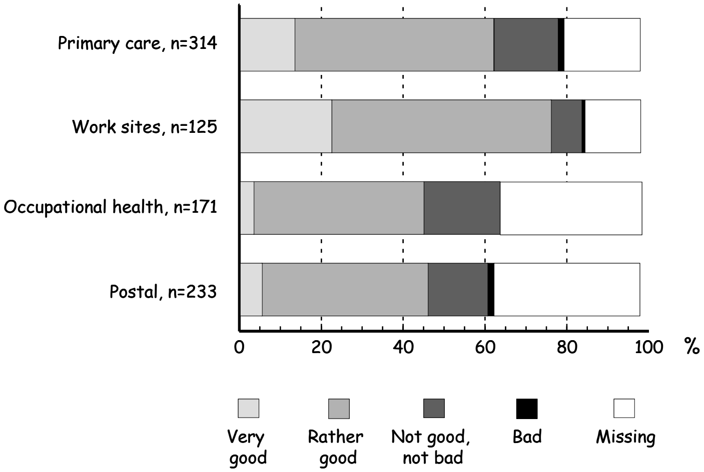


Figure 7. Participants' assessment of 'My Book about Health' in different settings. Proportion of responders to a questionnaire after six months.

Optional comments about 'My Book about Health'

Positive remarks dominated among the free comments. The document was considered easy to read:

> *"Your book is very easy to understand and good to read, it gave me something to think about"*

> *"A very good book. Easy to read. Should be read by everyone"*

Aspects of goal setting and reflection generated positive remarks, the document was said to be inspiring, and to emphasise personal responsibility concerning health:

> *"It's good to be able to write things down, it makes it more real. You can forget your intentions very quickly if you don't write them down. The book gives you an opportunity to read again what you have written and to be reminded"*

> *"Nice book! A good 'diary' to write in and reflect about all parts of your health! Inspiration to improve your health - those aspects that you want to and are able to"*

> *"I think the book is good! If nothing else, it's a reminder that you can do a lot yourself for your health"*

Personal relevance in periods of ill health was pointed out:

> "*When I was sick-listed last year because of a stress-related illness, the book became a part of my rehabilitation*"

> *"It's a book that is easy to read, you can look through it when you don't feel well. There is some advice about how to change some habits. I have the book at hand and look through it regularly"*

The possibility of documentation was emphasised as a positive aspect:

> "*The book is good as a notebook for myself. I have tried to fill in any illnesses and vaccinations I have had during the years*"

> *"It's good to have a book like this, to be able to take it to every visit to a doctor. To be able to fill in yourself any results from examinations (blood pressure, ESR, haemoglobin). It would be good if it also had space for notes: any illnesses you have had, medicines you have been treated with, when, and by which doctor "*

There were also negative assessments:

> "*I think the design is dull and it doesn't give anything new – only the same old story as I, at least, have heard the last ten years!"*

> *"Sorry, but I don't believe in the book, as one's health varies day by day, which makes it difficult to write down one's state of health"*

Negative aspects of self-reflection were exemplified:

> "*I remember I felt a bit depressed when I completed the page about my social network, as I felt that I don't have a strong one. Most of my contacts are superficial. I don't know if the book is really useful, I think it's a somewhat unnecessary thing"*

> *"I threw the book away after reading it. I feel that if I start to get engaged in this then I must be sick, or will be from all the thoughts about how I really feel. I have a high ? cholesterol value but nobody seems to care, one minute it's very serious, and the next minute you are totally forgotten, so I have put it aside, otherwise I will perhaps die tomorrow. I feel good anyway"*

The document was considered by some to be too general:

> "*I have been sick-listed because of depression, anxiety and burned out syndrome, and I don't think that health can very often be assessed by putting crosses in questionnaires. The relevant question is 'What is your life like?' and that can't be answered either quickly or easily"*

There were also comments about a lack of personal relevance*:*

> *"I'm satisfied with my health and felt no need for such literature"*

> *"No, I realise that it doesn't suit me… I'm not the kind of person who keeps a note of everything. You can't keep a record of your life all the time"*

Self-initiated contacts with health professionals about 'My Book about Health'

Document owners did not often report contacts with health professionals because of their reading of the document. The proportions were between 1.3 percent (primary health care and postal) and 4.0 percent (work sites). However, a desire for an organised follow-up by health professionals was evident among the optional comments:

> *"I think the book should be part of a voluntary health check, when the state of health of the person is examined and all data are entered in the book. The person will then have a platform to start from, in his or her striving towards better health"*
>
> *"Perhaps 'health groups' should be formed, with the idea of supporting one another"*
>
> *"A joint follow-up with our team at the workplace would be appreciated, with our nurse, and sampling etc"*

Among those who received the document by mail, some pointed out a need for personal information:

> *"It would have been better if one had been personally informed in one way or another. As the health services function today you feel that there's a long way to go to get such a project to function. If I phone my health care centre and ask for an appointment I get the answer that it's impossible, so I don't trouble them with questions about health promotion either"*

Cost calculations of distribution of "My Book about Health" in different settings

The cost calculations showed the lowest direct costs for postal distribution and the highest for distribution at primary health care centres. The high cost at health care centres was due to high training costs (Figure 8). Including indirect costs, (i.e. productivity losses), in the model resulted in high costs for distribution connected to meetings at the work sites. This was due to the more extensive information provided during this type of distribution (Figure 8).

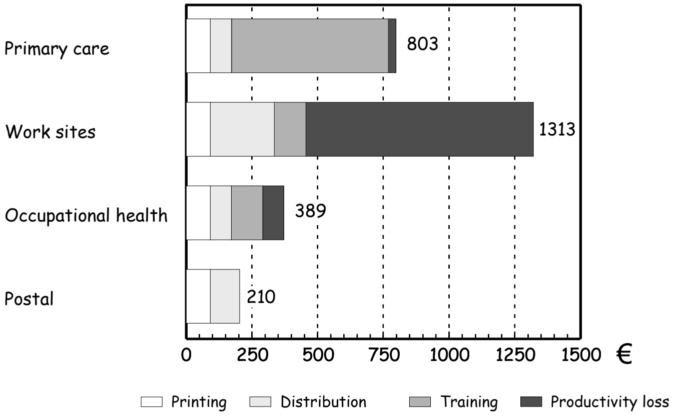


Figure 8. Cost calculations in Euro of 100 copies of MBAH document by method of document distribution

Practical use of the VIP document by students

After one year, 83% of adolescents reported reading the VIP document and 87% reported writing in the document (paper V, table I).

Seventy-seven percent of adolescents reported classes with discussions about subjects in the VIP document (Figure 9).

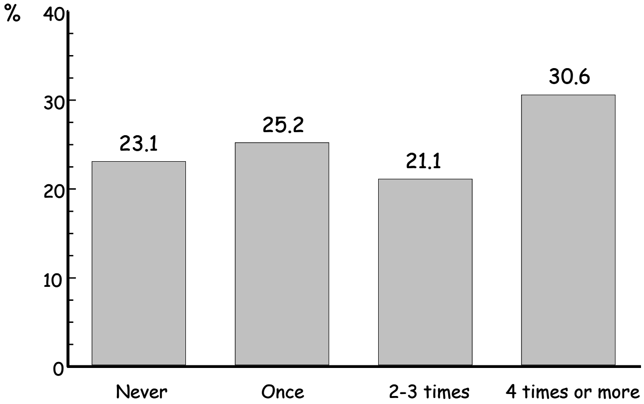


Figure 9. Student reports after one year of classes led by teachers with discussions about subjects in the VIP document (%) (n = 294)

Student attitudes

After one year, 35% of the adolescents reported personal usefulness of VIP. Variables were examined concerning proportions of the adolescent perceptions of personal usefulness (Paper V, table III). Factors significantly related to personal usefulness were being born outside Sweden, experiencing fair treatment by teachers, being a non-smoker, and having a positive school experience (Figure 10).

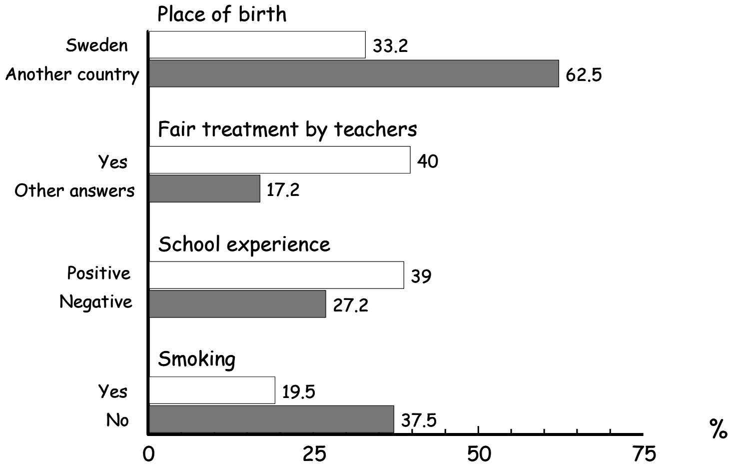


Figure 10. Perception of personal usefulness of the VIP document related to variables in 1-year questionnaire (%)

Optional remarks about the VIP document

Positive comments dominated among the optional comments. Most common were general positive remarks including approvals of the design:

> *"It's very good… We have used the folder rather a lot at school. The folder is neat and the disposition of the books is good"*

The possibility for reflection was acknowledged:

> *"You learn to understand yourself and others. You reflect more, about things like bullying"*
>
> *"Have been forced at school, but it's good. Have been in peace, have been able to write about my feelings in the diary, got a break, so to speak"*

The document as a source for knowledge was pointed out:

> *"You learns a lot"; "It's good because you read about things other people have gone through"*

Personal usefulness was described:

> *"Very interesting book. I have learned new things from this book, I have learned things about myself and other people too"*

Negative comments, however, were also made, most commonly describing the document as boring and useless:

> "*It's boring. I don't understand why we have to have it. But on the other hand it's better than a Swedish language lesson"*

> *"I think VIP is rather boring and I don't understand its usefulness. You can't get better self-confidence just by writing about it in a book"*

Some comments expressed aggression against the document:

> *"I have used the folder to let off steam and really maltreated it, as I hate it"*

Personal negative or adverse effects were revealed by two students:

> *"I don't get the point. Don't distribute it again, it only makes you feel worse"*

> *"The document is both good and bad, 'cause it's bothersome. I have had use of it sometimes, but not so often!"*

Professionals' experiences of working with health promotion and personal health documents

'My Book about Health' – community health nurses

Central to the analysis was the CHN experience of struggle for balance in being both a doer and a health-promotion communicator. Being a doer comprised the disease-oriented practical work such as distributing medicine, taking blood pressures, removing stitches or giving injections. In general, health promotion was regarded as a communication process in which the patient's beliefs of his/her own health and needs were the focus and discussed in a supportive way, sometimes using the personal health document as a communication tool. The CHNs' descriptions of their struggles to balance their work were grouped into three themes: working alone and as a part of a team; nurse-related and patient-related interest; and patient responsibility and shared responsibility between patient and nurse.

Working alone and as a part of a team

CHNs described themselves as both part of a team and as lonely actors. They experienced both the advantages and disadvantages of this dualism in their work as health-promotion communicators. Being a collaborator included them in an organisation that regarded health-promotion work as subordinate to disease-oriented work. On the other hand, as management formally acknowledged MBAH as a tool, the nurses' work in health promotion was a sanctioned activity. When there was congruence in attitudes between CHNs and the management on MBAH and health-promotion work in general, there were no conflicts of interest. But when the nurses described a discrepancy between their own personal attitude and the health care management attitude, a conflict of interest arose in which the nurses subordinated themselves to the management. These conflicts were mostly related to overarching attitudes and structures such as the increased need of home care, and attitudes towards health promotion as a low priority task. 'Lack of time' was a stated general impediment for working with health promotion and CHNs described health-promotion work as decreasing over time in favour of disease-oriented care. The shift in balance towards being a doer and away from being a health-promotion communicator was mainly attributed to the need to provide home care to an increasing number of elderly people.

As CHNs regarded themselves not only as team members but also autonomous, they sometimes used strategies to cope with this conflict by acting in the way they personally wanted to, regardless of the health care management attitudes. This was indicated by the nurses reserving time for a patient consultation (longer than what was the routine) and giving out or not giving out MBAH despite conflicting attitudes of the management or by doctors. Although the management held a formal positive attitude towards MBAH, nurses experienced a decline in the distribution over time. This was referred to as partly due to a lack of long-term encouragement from leaders, and partly to an attitude towards MBAH provision as a campaign rather than a long-term commitment.

Working alone increased self-esteem as the CHNs were acknowledged to perform their work in an autonomous way. CHNs who had a speciality area like diabetes, hypertension or child health care, described themselves as more independent in terms of dividing time among their patients in order to work with health promotion. In addition, being assigned a speciality area was regarded as a endorsement from the management to perform health promotion, and this was especially the case in child health care. But working alone as a nurse also entailed feelings of being on a 'treadmill' as they experienced structural barriers to communicate, reflect upon, and organise their health-promotion work together with colleagues. These activities were described as essential for working with health promotion in a profound and effective way.

Nurse-related and patient-related interest

CHNs described how they included health promotion in everyday work. Health-promotion work was described as discussions with, and advice to, patients at regular visits or during telephone conversations. Some CHNs had ideas of how to develop activities to reach groups not visiting the centres, but most nurses were satisfied to do health promotion among their current patients. CHNs described their personal strategies to maintain and increase their own health as a basis for working with health promotion. Nurses who did not smoke, who exercised, performed relaxation or lived 'a healthy life' described themselves as positive towards health promotion and described nurses with an opposite lifestyle as negative towards health promotion and MBAH. The patients' verbally expressed needs were also of importance in the process of communicating health. Patients who initiated discussions about their health and were positive about making progress in health behaviours such as wanting to quit smoking, reducing blood pressure or losing weight were encouraged, communicated with, and were often given MBAH. Only a few CHNs used MBAH as a tool for introducing patients' thoughts on health issues in a facilitative way. CHNs also described the patients' need of integrity. This was closely related to the nurses' reluctance to discuss more sensitive issues like alcohol and abuse. Some nurses described MBAH as a tool for discussing such areas. Other nurses avoided these areas and described them as "something the doctor dealt with". The level of interaction in the nurse-patient communication was a concern of the CHNs. Sometimes the nurse's advice to the patient was regarded as the best way to improve patient health. But most nurses regarded health promotion communication as something that proceeded from the patient's needs. However, in order to establish such a communication process, the CHNs described the need for both time and emotional strength. Health promotion was regarded as a more relational and emotional process than disease-oriented work. As health promotion was mainly regarded as something proceeding from a patient perspective, this demanded an empathetic and sensitive ear. CHNs described such nurse-patient interactions as a form of emotional labour that resulted in both stimulating and draining feelings. Therefore, nurses tried to balance these communication processes with more practical chores.

Patient responsibility and shared responsibility between patient and nurse

The health of the patient was regarded as both a patient and nurse responsibility but the boundaries were undefined in issues concerning how much the nurses should interfere, and the amount of feedback they should expect from patients. As MBAH was described as something the patients owned, CHNs experienced their responsibility for MBAH as limited to being inspirers and distributors. The empowerment potential of MBAH was positively described in terms of patient responsibility.

The feedback from patients in their health improvements and in how they used MBAH was of concern for the CHNs. The nurses often experienced a positive progress at each visit when their work was disease-oriented, but in their health-promotion work improvements and feedback were less obvious. They described doubts that the patients used MBAH and that there was an obvious risk that MBAH would be forgotten when the patient returned home. Ideas for a personal health document that was better adapted to reiterative communication between patients and health professionals were therefore put forward by some CHNs. Other nurses suggested a more adjustable personal health document.

Practical use of the VIP document by teachers

Thirty-four of the 62 teachers allowed the students to work with the VIP document on their own at school. These activities were most frequent in seventh and eighth grades (27 and 26 teachers, respectively), and decreased to fifteen teachers in ninth grade. Eleven teachers let students work on their own four times or more during at least one school year. Forty-six teachers held at least one class where subjects from the VIP document were discussed. These activities were also most frequent during seventh grade (38 teachers having one or more classes), and least frequent in ninth grade (21 teachers). Twenty-one teachers had held four or more classes during at least one school year, and four of them held four or more classes during all three years. Teachers that were mentors more often used the VIP document actively, but there was no significant difference between genders.

Attitudes to document and project

A question concerning general attitude ("How do you like 'VIP'?") resulted in 22 teachers considering it "very good", 22 "rather good" and five "neither good or bad". None of teachers choose the alternatives "rather bad" or "very bad". When asked if their school should continue to work with the VIP document, 33 said "yes, something the way we have done till now", six teachers choose "yes, but in another way than hitherto", and three said "no". Twelve teachers choose an "I don't know" alternative, and most of these teachers were recently employed.

In their optional comments, teachers found the material useful. They suggested that the mode of using it should be adapted to the class and the teacher. Students were not automatically positive, and resistance was described. Some teachers found it difficult to prioritize VIP.

> *"Interesting subjects, nice design. It has touched upon questions of topical interest to the students"*
>
> *"It's good that it's available! A good aim, good for our 'farmer kids'"*
>
> *"Much depends upon what group one has. With a good group it can be really good"*
>
> *"Nice contents, helps me to not forget anything. A help, support, inspiration"*
>
> *"I feel that I could do more but the students are somewhat resistant and not always very positive"*
>
> *"I find quite a few interesting and sensible questions in the VIP material, but I don't feel there has been enough time to work with VIP – either in my own subject or in the mentor time"*

A manual for teachers was requested, including suggestions for practice in class:

> "*There should be a manual for teachers to enable us to see the point of the development. There should be suggestions on how to use the material without exposing the person too much*"

A problem with storage of the folder at school or at home was pointed out:

> "*I think it has been contradictory. On the one hand it's the student's own personal folder, on the other hand we are instructed to store it at school. Some student, mainly girls, have taken the folder home, and they have not wanted to bring it back to school. We have worked together with some texts and exercises – but one always has to balance between the fact that the folder is their diary to reflect over, and not to make it an obligatory teaching material*"

One teacher was negative towards the idea of adolescent private documentation at school:

> "*Yes, more group practices and not so many secrets as a diary. It doesn't suit the classroom. A manual for exercises would be nice. Now it becomes a material which students work with but which is not used or made visible. Then they lose interest*"

The association between personal health documents and self-reported health behaviour change

Self-reported health behaviour change and 'My Book about Health'

Background characteristics showed no obvious association to self-reported behaviour change as a result of reading the document (Paper III, table II). Additional data did not demonstrate significant differences in this respect concerning participants born in another country (OR 1.5 [0.6 – 4.0]), patients on sick leave at least 3 months or on current sick leave pension (OR 0.9 [0.5 – 1.7]) or patients with chronic disease (OR 1.1 [0.7 – 1.9]).

Of the participants who received the document at their workplaces or at primary health care centres, 20 to 26 percent stated that they had changed their health situation as a result of reading the booklet. This figure was significantly lower among those who obtained the booklet by mail (Figure 11).

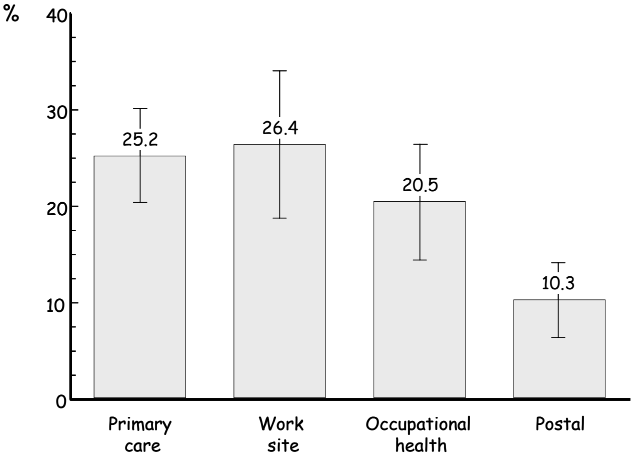


Figure 11. Changed health situation "as a result of reading 'My Book of Health'" by method of document distribution. 95% confidence intervals

During all four types of distribution, physical exercise, diet, weight and stress were the most common habits mentioned when patients reported lifestyle changes. At work sites, tobacco habits were mentioned as frequently as stress management. In primary health care, six patients stated that they had changed tobacco habits as a result of reading 'My Book about Health'. Answering another question, 26 patients reported that they had changed their smoking habits during the previous six months, i.e. the period since they had received MBAH. All of them reported smoking cessation or a decrease in smoking. Four of them were among the six patients who stated that they had changed tobacco habits as a result of reading the booklet (in Sweden, there is a marked difference between tobacco and smoking habits, as the use of oral snuff is common). Thus, 22 out of 26 patients who had changed smoking habits did not report the change as a result of reading the booklet.

Optional remarks emphasized the role of the document in connection with health behaviour:

> *"Thanks from one who has lost 8 kilograms because of the book"*
>
> *"I really got something to think about and stopped smoking and I am losing weight"*

> *"Very nice book. Got inspiration to change my dietary habits, reduce stress, and start exercising. The book was a good resource, but without my own will it would not have worked, one has to be motivated, otherwise there's no point"*

Cost-effectiveness

Using direct costs, distribution at work sites and in occupational health were significantly more cost-effective compared to distribution in primary health care (Figure 12).

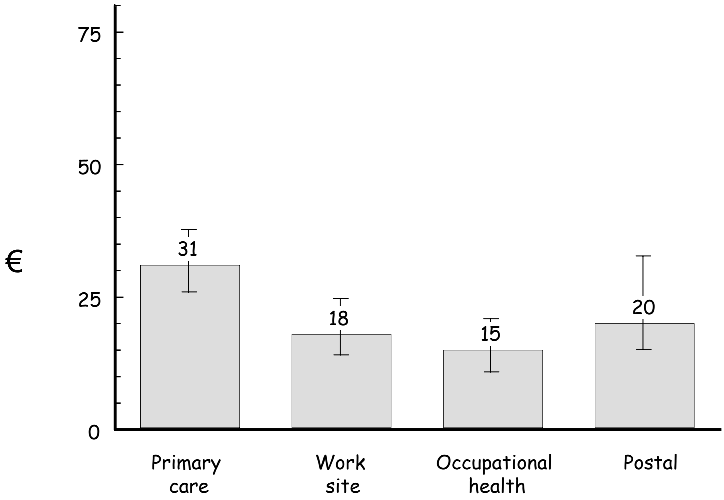


Figure 12. Cost-effectiveness for different ways to distribute 'My Book about Health'. Total direct costs in Euro for one person who reported one or more changes as a result of reading the document. 95% confidence intervals

When indirect costs were included, the cost-effectiveness was significantly better during postal distribution and distribution in occupational health, compared to distribution at work sites (Figure 13).

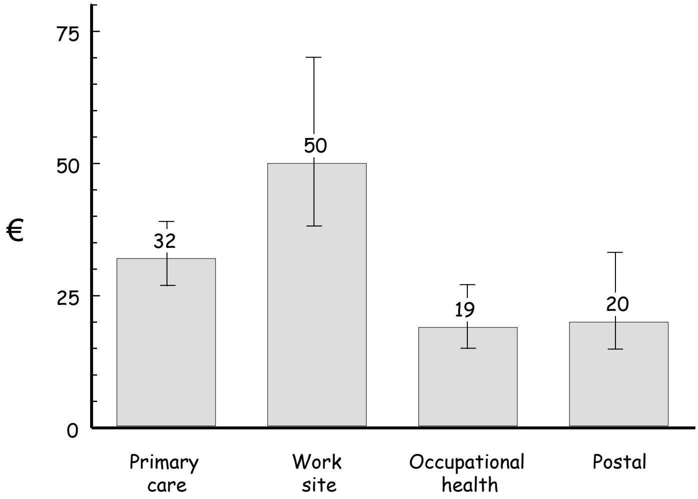


Figure 13. Cost-effectiveness for different ways to distribute 'My Book about Health'. Total direct and indirect costs in Euro for one person who reported one or more changes as a result of reading the document. 95% confidence intervals

Empowerment in relation to self-rated health and health behaviour

Influence of socio-demographic factors

As socio-demographic factors might be related to empowerment, health behaviour and self-rated health, such potential relationships were explored. Gender, ethnicity and educational level among parents were examined. These characteristics were not associated with self-rated health or health behaviour, except for the finding that adolescents whose parents had a college or university education had been drunk less often than adolescents with parents having a lower level of education (paper IV, table II).

There was no difference in empowerment scores between ethnic groups (paper IV, table III). Adolescents whose parents had a college/university education had a higher self-efficacy score, and a higher total empowerment score (figure 14).

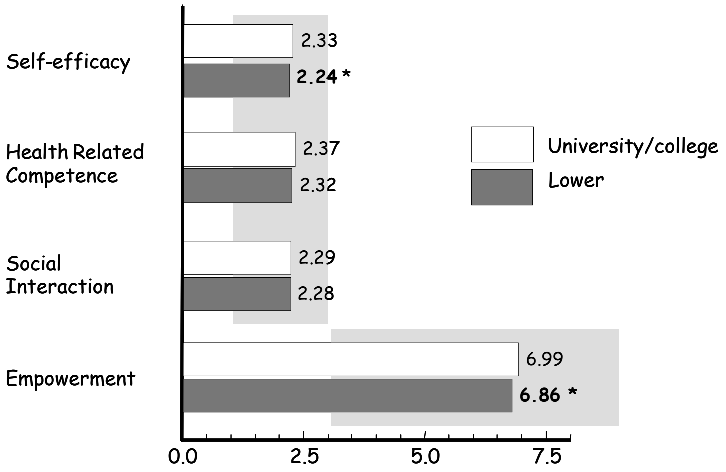


Figure 14. Mean level of empowerment dimensions and total empowerment in relation to parental educational level. Shadowed areas show possible score ranges. P-values were calculated by Mann-Whitney U test. * p less than 0.05

Girls had a lower self-efficacy score and a higher social interaction score than boys, but there was no gender difference in the total empowerment score (Figure 15).

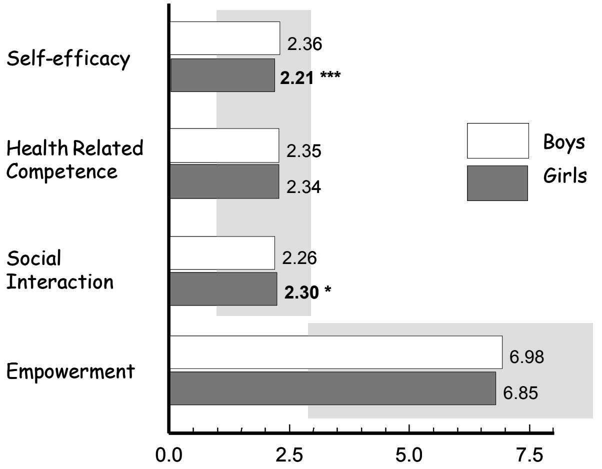


Figure 15. Mean level of empowerment dimensions and total empowerment in relation to gender. Shadowed areas show possible score ranges. P-values were calculated by Mann-Whitney U test. *** p less than 0.001, * p less than 0.05

Empowerment versus self-rated health and health behaviour

Adolescents with low self-rated health showed lower empowerment scores (Figure 16).

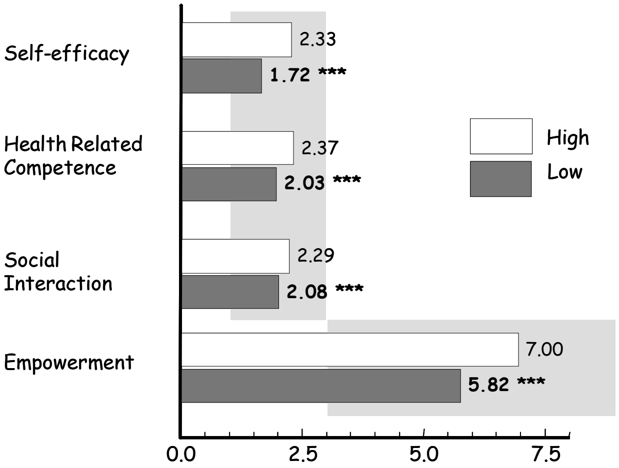


Figure 16. Mean level of empowerment dimensions and total empowerment in relation to self-rated health. Shadowed areas show possible score ranges. P-values were calculated by Mann-Whitney U test. *** p less than 0.001

Low total empowerment scores were also present among students with more negative health behaviours, i.e. smoking and binge drinking (paper IV, Figure 1B, 1C). The significant differences in total empowerment for self-rated health, smoking and binge drinking were present in both boys and girls and in different socio-economic strata of the families, with the exception that the difference in empowerment between smoking categories was only present among adolescents whose parents had a low level of education.

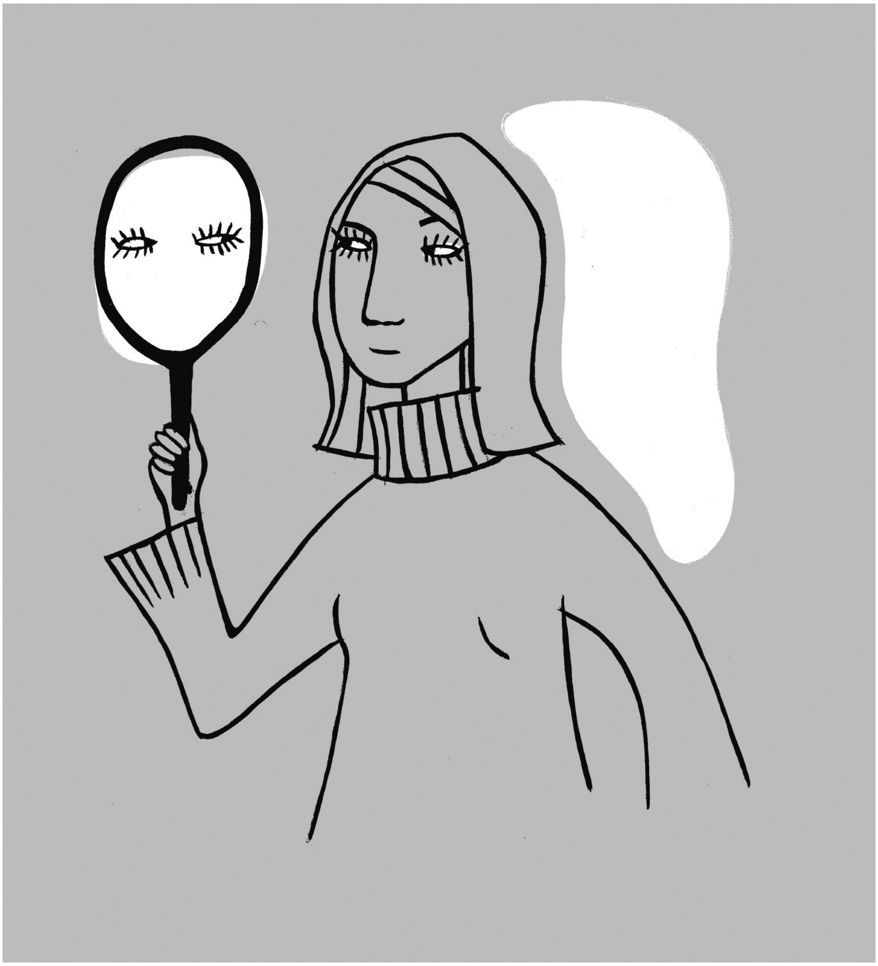


Figure 17. A drawing from the VIP document

DISCUSSION

When this thesis was written, the eleven objective domains that constitute the framework of the Swedish national public health policy had been established for more than four years. It has been said more than once that in our country, work concerning the sixth domain ("A more health-promoting health service") is progressing more slowly compared to other domains. However, this problem is not unique to Sweden. Reorienting health services in a health-promotion direction is a difficult task, and such efforts are said to have met "stubborn resistance" worldwide (14). When changes in the reorientation of health services since the Ottawa conference were summarised recently, Sweden were placed in the forefront (14). Such assessments underline the importance of the 2003 Swedish Parliament decision, and experiences of the implementation of the new public health policy appear to be of international importance. Results presented in this thesis should be seen as one of many contributions that are needed to transfer political will into practical action in health services. Our findings underline that health promotion in health services needs active support from leaders as well as adequate support systems. This thesis suggests that personal health documents are tools that should be given greater attention and resources. The thesis also deals with the concept of empowerment, which as well deserves greater attention in Swedish health services.

Reorienting of health services

The role of family doctors and community health nurses in health promotion

Besides rather fierce discussions concerning screening and prevention, there seems to be consensus among Swedish family doctors of the importance to discuss lifestyle (e.g. alcohol, smoking) with patients who are seen because of symptoms that might be caused by the same lifestyle factors. An illustration could be "Riskbruksprojektet," which deals with over-consumption of alcohol and is well-accepted among family doctors (http://www.fhi.se). During one year, of the population in one Swedish county, 6% of women and 4% of men had discussed their lifestyle with family doctors. These figures were the highest among different health professional groups (135). However, the fact that "My Book about Health" included many items that are common causes of patients' symptoms did not stimulate doctors to distribute the booklet. Doctors distributed only three percent of MBAH documents, while CHNs distributed at least twenty times as many. Doctors were not interviewed about their experiences, so one can only speculate about the reasons behind this striking difference. The discussions since the 1990s, referred to above, might have influenced family doctors to avoid public health tasks. A deeper understanding of the meaning of health promotion might increase the interest of family doctors. Health promotion is close to the concept of patient-centeredness, which is often discussed and positively understood by family doctors.

The practice of Swedish doctors of placing heavy responsibility on CHNs could be especially problematic if CHNs experience problems in their health-promotion work. Different reports show similar results - Swedish CHNs are experiencing a decline in their health-promotion work (19-21). The same picture was present in our study: CHNs experienced a shift towards disease-oriented and practical working tasks. The nurses' feeling of having a lack of time for health promotion was mainly due to the priority placed on disease-oriented work. The priority of practical, disease-oriented work has been identified as an obstacle for health promotion by CHNs both internationally (136, 137) and in Sweden (138). As CHNs rarely deal with emergency situations, the disease-oriented work of CHNs could, in most cases, be planned in advance, thus supporting a balance between health-promotion and practical disease-management activities. Interestingly, the same priority was not present in connection with child care, a domain where a balance between CHNs' disease-oriented work and their health promotion through the child health care clinics was more evident. Child health care has a long, established position in Swedish health care (18, 139). In the context of child health, health promotion is a vital part of CHNs' work and is sanctioned by all levels of health care management. As has been emphasized in other studies (21, 136, 138, 140), such an endorsement is essential for nurses to be able to successfully perform health promotion.

Teachers and school nurses: who should perform health education?

The intervention in schools demonstrated interesting results concerning the role of teachers and school nurses in health promotion. In the project team, persons with experience from school health services were more highly represented than teachers (four versus one). The question of how to divide the work between teachers and school health services was not decided by the project team. One option for intervention schools was to let the school nurse have a central role in the introduction of the VIP document to students. However, during project planning at the schools, the teachers soon decided to take ownership of the introduction. The result was that in one school the school nurse introduced the booklet “my body”, while the school health nurse was not involved in the project at the other. Considering that only two schools took part in the intervention, one can not draw any solid conclusions, but results might reflect the current variations in participation of school health services in health education at Swedish schools (26). Our results were contrary to Scottish experiences of a child health profile, where school nurses were more active and teachers had little involvement (95). The interest shown by teachers in our study is a valuable basis for health promotion at schools. Schools health services have the challenging task of seeking to cooperate with teachers and utilize their interest in order to achieve optimal health-promotion results.

Suitable ways to use personal health documents

The studies of this thesis contribute to the discussion about suitable ways to use personal health documents. In *primary health care*, both patients and health professionals could initiate provision of a MBAH document. In practice, patient initiation was limited by difficulties in outreach with the information. This was in spite of efforts that included posters and articles in the local newspapers. Professional initiation was limited by many factors that are described in paper II. Many of these factors are the same as those that hamper opportunistic screening for problems such as high alcohol consumption (141). Our studies indicate that it is difficult to predict whether a person will be an active user of a personal health document. Health professionals were not very successful in choosing the “right” people, i.e. those who would use and appreciate the document. At least it was shown that the proportion of participants who experienced benefit was not lower when documents were distributed to the whole target group at work places. Literature demonstrates that it is not an easy task to find practical ways for continuous, frequent distribution of health documents in health care. There is at least one example where health records were accepted and frequently distributed by health personnel during ordinary visits at health centres (142). In other studies, records have either been distributed to a small number of patients (143), were provided by receptionists (91), or required employment of extra personnel (89).

Few of the patients who used and appreciated MBAH utilized the document as a communicative tool with health professionals. This result was contrary to initial expectations among community health nurses who were afraid of being overwhelmed by patients asking for examinations and health discussions (105). Health professionals might overestimate the proportion of health activities within a population that are made in cooperation with health services. On the other hand, experiences from distribution of MBAH show widespread, popular expectations of increased health promotion by health services. This finding is supported by Swedish population surveys (127).

As many professionals had to be trained and rather few documents were distributed, costs were comparatively high in primary health care. A suggestion might be to decide in which situations it is optimal for the personnel to distribute documents. If all patients are provided with the document in these particular situations (e.g. blood pressure measurements), the problem of "choosing the right patient" is avoided, and the cost-effectiveness will probably rise. Another conclusion of the MBAH studies is that in order for community health nurses to be long-term distributors of personal health documents, developing more communicative versions might be crucial. In this respect, targets could be patient groups that are commonly follow-up by nurses (e.g. hypertensives, diabetics), and at-risk patients who receive insufficient attention in health services currently (e.g. patients living with obesity or the metabolic syndrome).

Another model of document provision was used in *occupational health*, where the document was offered to all members in target groups. This method of document provision used existing working structures, and this could increase feasibility and cost-effectiveness. The cost-effectiveness in our study was high in occupational health. Medical research concerning interventions is most often focused on the intervention method and sometimes neglects the importance of adequate structures in which the methods can be successfully used. Without such structures, even the most evidence-based and efficient methods cannot be widely disseminated. Occupational health is such an existing structure, has a tradition of health-promotion work, and perhaps has been somewhat ignored in the work of "a more health-promoting health service".

Postal distribution was not as effective as the other models of document distribution. This finding might partially explain the contradictory results from studies with similar health documents but different types of distribution (113, 142). One health document that was distributed at regular visits to a health centre resulted in a significant rise in the ordering or performance of preventive services (142), while another health record that was mailed did not result in significant increases in the rates of Pap tests, mammograms, or skin operations (113). Although cost of postal distribution was inexpensive per distributed document, the cost-effectiveness was not greater than distribution in occupational health or at primary health care centres. The role for postal distribution might be to enable rapid distribution when other distribution channels are not readily available.

At *schools*, almost all students were provided with documents and in practice, use was mandatory in some classes. As one could expect in this age group, there were some negative reactions from the adolescents. One can discuss whether these reactions were caused by the VIP document, by the subject "life skills", or by the teacher's guidance. Optional comments showed that some adolescents experienced VIP as boring, uninteresting and dull. For other students, the document and/or the themes were provocative. Some reactions seemed to be rooted in a disapproval of the whole subject "life skills". Other negative reactions were related to VIP being seen as purely a "reading and writing" subject. Some adolescents, mainly boys and often experiencing poor school results, reacted negatively to this aspect. To focus on discussions or exercises may be an easier way to support this particular group, i.e. developing other skills with the same health-promotion aim. Adolescents who perceived their teachers to be unfair were more negative to the intervention, as well as students with a negative school experience. Our findings were similar to Danish experiences of health dialogues between pupils and school health nurses in which high school satisfaction was associated with perceived adolescent benefit (144). As the VIP document was introduced by the teachers, an interpretation of the association between a negative relationship to the teacher and a negative perception of the VIP document could be that the project, from the adolescents' point of view, was regarded as a "school matter". Adolescents in opposition to adult guidance were not particularly attracted by the intervention. The fact that adolescents had influenced the document to a large extent, in contrast to the development of previous adolescent health documents (68, 70, 94), did not solve this problem. In the pilot study, we planned to let older students introduce the document, but we found this method was not feasible in our setting. A Child to Child technique (145) might have a positive impact with regard to adolescents who are in opposition to teachers. Interestingly, negative reactions from adolescents were hardly mentioned by teachers in their questionnaire. Perhaps adolescent reactions were unspoken or teachers are used to students being negative to many pedagogical activities during the last years of compulsory school. It has been difficult to find studies examining adolescents' perception of the usefulness of long-term health interventions in schools. Thus, one can only speculate. However, it is a positive finding that teachers were not discouraged from working with VIP and support for a continued work was almost unanimous. Based on our findings, one suggestion for future work in schools could be to provide students with documents, but be sensitive to student attitudes when deciding about forms of use in class. Teachers are already used to adapting to the situation and developments in class.

One could question the importance of the outcome measured in this thesis. Is it a satisfactory result that one out of five reports behaviour change or that only a third report personal usefulness? Considering the relatively small size of the intervention effort, and the frequency of behaviour change in the general population (127), the level of reported behaviour changes after reading MBAH might be regarded as high. Successful interventions for behaviour change often exhibit a small proportion of participants who benefit from the intervention. For example, when doctors advise about smoking cessation, only 2,5 percent of smokers benefit during the first year (146). Our results should also be evaluated in light of the fact that participants, except for patients in primary health care, were almost all members of target groups. In previous adolescent interventions with an empowerment perspective, participants have often been volunteers (57, 147, 148), youth at-risk (149), or a sample without adolescents at low risk (56). The design of our interventions was based on a population strategy in prevention. With such a perspective, one could expect many exposed individuals to have little or no use for an intervention. Another factor influencing adolescent perception of usefulness might have been that they did not receive marks for their work with the VIP document. In Sweden, students receive their first marks in eighth grade, i.e. three months after completing the 1-year questionnaire. To summarise, we regard the proportion of participants experiencing benefit in our studies as a reasonable outcome in the light of intervention efforts.

Personal health records and the social "health gap"

An important question is whether personal health documents are attractive for groups with increased risk of ill-health and disease. The opposite could be the case, as documentation is an intellectual work, and as the novelty of the method might attract socially powerful groups. The problem was illustrated by a study of the UK personal child health record, where less effective use was associated with factors reflecting social disadvantage (74), while other studies haven't found such differences between social groups (99), or higher usage among low-educated groups (62). When self-reported behaviour change (MBAH) or perception of personal usefulness (VIP) were compared between groups with different risk for poor health and disease, results did not indicate better or worse results for females, elderly people, individuals with low socio-economic status or low self-rated health, or students with self-reported poor school results. Concerning smoking, there were no differences concerning MBAH, while smokers found VIP less useful. Students with parents born outside Sweden found VIP more useful, while the influence of ethnicity was statistically insignificant concerning MBAH. Students who did not like school were more negative toward VIP, as were students who experienced their teachers as unfair. A conclusion could be that MBAH provision was neutral with regard to the social "health gap". VIP provision did not attract groups who oppose adult society, while results suggest that such documents could assist in supporting immigrant children. An interpretation of the latter finding is that adolescents born outside Sweden might have less exposure to discussions about health topics found in the VIP document and therefore welcomed this opportunity. In our study, being born outside Sweden was not a risk factor for low self-rated health among early adolescents. In contrast, low self-rated health is more common among adult immigrants in Sweden (150). The VIP intervention might be a tool to support immigrant children, thus participating in efforts to decrease the "health gap".

Personal health documents and patients' rights

Today, certain personal health documents have an established position in health services. Few would question the benefit of patient documentation of blood glucose measurements, or of parents having a document about their child's health. The challenge is to find optimal ways of using existing personal health documents as well as identifying promising directions for further development. Perhaps the most striking study result of personal health documents around the world is the uniform positive comprehension by adult document owners (72, 87-89, 99-108). This thesis confirms in a Swedish cultural setting an interest by a considerable part of the adult population for using personal health documents. Based on a patient-centred strategy, it seems natural that this patient interest results in efforts to provide interested patients with personal health documents. Literature, as well as results from our studies, suggests that negative side effects are small. Costs can hardly be a deterrent if compared to the extensive resources allocated to medical records during the last fifteen years. In addition, costs covered by health services will be comparatively small if patients rather than health professionals do the bulk of the documentation. Our findings suggest that among the generally positive majority of adult document readers, there are a core group of more active users. Parts of this core group will probably eventually find ways to obtain personal health documents even if they are not provided by health services. As will be discussed later, there is great commercial interest in personal health documents. A lack of interest in health services will not stop provision of personal health documents, but will only give the medical community less influence in the development process.

One could also argue that provision of personal health documents is primarily a question of patient rights, not of the effects on health and health services. Increased patient access to their medical records, a worldwide trend since the 1970s (151, 152), has been made on the basis of patient rights and not of scientific studies. In a modern society, it seems natural that every citizen has the right to obtain a personal health document. The implication is that it is a duty for health services to participate in the development of such documents.

Personal health documents and health behaviour change

When assessing our results concerning the relation between personal health documents and health behaviour, one should be aware that no objective measurements of behaviour change were made. The most commonly mentioned lifestyle habits were physical exercise, diet, stress and tobacco. There are methods available for objective measurements of these habits (e.g. pedometers, measurements of stress hormones, cotinine), although objective diet measurement is feasible only under experimental circumstances. Weight was frequently mentioned by patients, and would have been the easiest objective measure to obtain. With the self-reported findings, there was no pre-test valuation and no control group. Thus, there were no measured changes between two levels of behaviour, and no estimation of whether changes were due to a natural course in the studied population, and/or a result of the change and observation itself (i.e. “Hawthorne effect”(153)). Instead, behaviour change was judged by a subjective valuation that a change had occurred and that this change was the result of reading ‘My Book about Health’. Certainly, there are pitfalls to using this method. The first question might be whether is it reasonable to assume that participants were able to judge the reasons behind their behaviour change. Most often behaviour change is multifactorial and this may make such judgements difficult. Another concern could be that participants attributed all behaviour change to the influence of the document. Population surveys in Dalarna have demonstrated that a considerable proportion of this Swedish population feel that they have made behaviour changes in the last year (154). However, evaluations of tobacco habits show that only a few patients who claimed changes in tobacco habits attributed these changes to the influence of MBAH. These findings suggest that behaviour change was not automatically credited to MBAH.

There are also other results that speak in favour of the relevance of the findings concerning behaviour change. Such changes were consistently reported in all settings. There were better results with oral information compared to postal distribution, i.e. more extensive and personal information. This seems reasonable if there are true effects. In the free comments, some participants communicated distinct statements of behaviour change. In the population surveys in the county of Dalarna for the years 2003 and 2006, respondents stated that their “best source of inspiration to improve lifestyle” was ‘My Book about Health’ (among 18 response alternatives) (135, 154). The frequency of such statements among those who had received the document was estimated to be between 2% and 4% (135).

To summarize, our findings are not rigid or definitive, but they suggest that personal health documents can be tools for promoting lifestyle changes among adults in different settings. Certainly, they suggest that behaviour change and personal health documents are an interesting field of future research.

Are electronic personal health documents the future?

Are printed personal health documents a dead end? Are electronic personal health records (ePHR) the sole future? In Sweden, ideas in the 1990s about developing printed personal health documents were rejected in favour of the idea of providing every citizen with a “Smart Card” containing their medical record. These Swedish developmental projects have continued to a limited extent, but not focused on the patient as the documenter (155). Internationally, there has been a rapid development of ePHRs and commercial interests have sped up the pace. In 2006, more than 60 ePHRs were available on the internet (156). In the USA, there has been widespread enthusiasm over ePHRs in recent years. In 2004, an official plan was outlined to ensure that most Americans have electronic health records within 10 years (157). Voices questioning the rapid development in the USA have also been heard. From a health professional perspective, an evaluation demonstrated limited functionality of the information in records for use in clinical practice (158). The wish of patients to control their health records through a computer vary. Age and level of education are some demographic variables that influence this wish (159). A preference for viewing the health record in written rather than computerized form has been demonstrated (159). Such findings are similar to findings in the VIP studies. In 2001, at a planning seminar, it was suggested to adolescents that the VIP document would be an ePHR, but they were clearly in favour of a printed version. Studies of ePHRs usually focus on technical solutions and possible future benefits for patients and society and there is a lack of studies that examine the feasibility. In one of the few such studies, five percent of patients who were offered an ePHR connected to their doctor’s electronic medical record used it at the time of an evaluation after ten months (160). Hopefully, public preferences will solve the question of printed or electronic personal health documents. Presumably, both forms will exist together for a long time.

Empowerment as a strategy in health services

Empowerment is frequently used when discussing health promotion internationally (6, 161), but empowering strategies have not often been discussed in health services in Sweden. The first article that mentioned the concept in the journal of the Swedish Medical Association (Läkartidningen) was published in 1999 (29). A recent literature search in Medline combining the items “empowerment” and “Lakartidningen” ended up with a total of four articles. “Empowerment” was first mentioned in 1999 in “Vårdfacket”, the journal of the Swedish Association of Health Professionals. A recent search produced six citations. A widened discussion about empowerment in Swedish health services should be important.

Empowerment as a strategy

Empowerment is a broad concept and using it as a health services strategy will have effects in different areas. One effect will be to put a focus on patient demands, as individuals and as groups. This is in line with a proposed reorientation of health services towards having perceived good health of patients as the central objective (4). Using empowerment as a strategy will also focus questions of control and power, concepts that health services are not used to analysing or discussing. The evidence that powerlessness is related to poor health and increased mortality has been longstanding (162), but health services seldom take practical steps to use this knowledge. Our findings also demonstrated that low adolescent empowerment was associated with low self-rated health. Low empowerment was also related to a high frequency of risk-taking health behaviours like smoking and binge drinking. There seems to be a mutual relationship between low self-rated health, low empowerment and the behaviour. It is important to consider such findings when planning interventions aimed at behaviour change. The interest in health promotion has, to a certain extent, been focused on health behaviour as a "single item", not integrated with social and psychological factors.

Using empowerment as a strategy would also focus questions on the power relation between patients and health professionals. Studies demonstrate that a powerful relation with the sick patient is common to different health professional groups (51, 163). The attitude towards power among health professionals could be characterized as ambivalent. Losses of parts of one's own power might be more difficult to accept than gains in patient responsibility. During the interviews in our study, such ambivalence was present. The ambivalent attitude toward power might partly explain why personal health documents have difficulty achieving full acceptance in health services worldwide.

An increased use of empowerment in health services will also focus social determinants for poor health and disease. Our knowledge about social inequities in health is rising, both on a national (3) and a global level (161). In our study, having a parent with higher education was associated with higher empowerment among these 12 – 13 year old children. Powerlessness may be an important mechanism for social determinants of poor health (162). In 2008, the WHO Commission on social determinants of health, headed by Michael Marmot, will present a report that will put the light on these important questions. There is a growing gap between our knowledge about the situation and the actions that are taking place. Using empowerment as a strategy in health services could be one way of turning knowledge into action.

Empowerment as a scientific concept

The nature of empowerment as a broad concept could be an advantage when it is used as a strategy. At the same time it makes the concept challenging to handle in research. The scientific concept of empowerment is not as distinct as some other related concepts such as self-efficacy. Empowerment is used as a concept in many scientific traditions but they use somewhat different definitions. Empowerment is also an everyday word and this means that people might have a pre-conceived understanding. One implication is that the word must be clearly defined when used in research.

A problem with the scientific use of empowerment is that the concept is dependent on the cultural context and this implies that one seldom can use existing measurement scales (40). Constructing and reliability testing a measurement scale for each setting is laborious and requires considerable resources.

Another challenge for scientists is the need to produce better descriptions of empowerment processes as a supplement or substitute to repeated measurements of empowerment as a state. Such descriptions, based on qualitative methodology, would be of substantial practical importance for health services.

Methodological considerations

In the questionnaire used in MBAH studies (paper I and III), questions about background characteristics were chosen from a population survey (127). The question concerning behaviour change was chosen from the same survey, and modified for the study. No formal reliability testing was performed, but the questions have been used in large and repeated surveys that yielded low internal non-response rates. In paper I, reference is given to logistic regression analyses concerning the correlation between self-reported behavioural change and background characteristics, and to comparisons between receivers of MBAH and all patients visiting doctors at the health centres. These analyses are presented in Paper III and in this thesis.

In the interview study (paper II), recruitment was done in two phases. The result was a richer material that covered both medium- and long-term provision of the health document. A member of the project team did most of the interviews. This could cause a bias if the respondents avoided mentioning critical comments about the project. However, results from the MBAH project were similar when a neutral interviewee performed interviews in the second phase of data collection.

In paper III, we used different target groups and compared different methods of distribution. One could argue that it would have been preferable to compare different types of distribution to the same target group, e.g. to distribute MBAH by mail to one group of the employees at the paper mill, as a part of the health examination to another, and at regular administrative meetings at the work site to a third group of the paper mill personnel. However, such a design would not have permitted a comparison with distribution to patients in primary health care and this is the most frequently used distribution method worldwide. Such a distribution method could only have been compared to postal distribution (patients could have been randomized to either postal distribution or to provision of the document in connection to a health centre visit).

During sampling in the VIP study, the primary sampling unit was schools, the secondary unit was classes within schools, and the third sampling unit was students within classes. As teachers educated in different classes and cooperated to a large extent with other teachers, using school classes as the primary sampling unit would have risked resulting in the intervention also being performed in control classes. A problem with the sampling method was that only two schools were intervention schools. Background characteristics for the intervention schools were similar to the control schools except for a village/rural dominance in the intervention schools. Although the number of exposed students was comparably high, results are sensitive to the actual "school culture," and also to the culture and traditions in the local communities that provided the students in the intervention schools. Including more schools in the intervention group would have been preferable but was not possible because of the allocated resources.

The instrument constructed for measurement of empowerment was adapted to the particular age group and setting, and therefore a generalization of our findings to other age groups and cultural settings should be made with caution. Empowerment was measured in the domain of health and measurement in other domains might have resulted in different results.

CONCLUSIONS

Personal health documents are feasible for use in school health, primary health care and occupational health. Such documents are accepted both by professionals and document owners. At schools, a health education model that includes the VIP document could be implemented without large external resources. The model might be of special interest in supporting adolescents born outside Sweden. There is an interest in personal health documents among a considerable proportion of adults in different settings. Using existing structures for distribution could increase the cost-effectiveness. Our findings also suggest that personal health documents can be tools for promoting lifestyle changes among adults in different settings.

Community health nurses strive to find a balance between doing practical work tasks and health-promotion communication. Health-promotion work is hampered if too much emphasis is put on disease-oriented work tasks. Health promotion in health services needs active support from leaders as well as adequate support systems. It is not sufficient to develop health-promotion methods that are acceptable to community health nurses. Analyses of working conditions and the content of daily work are needed to ensure an emphasis on health promotion.

Among adolescents, there is a close relation between low empowerment in the domain of health, low self-rated health and health behaviours such as binge drinking and smoking. High empowerment is related to high parental educational level. Our findings suggest that empowerment is of importance for self-rated health and health behaviour among adolescents.

IMPLICATIONS FOR FUTURE RESEARCH

Based on the discussion above, a suggested model for relations between central concepts in this thesis is illustrated in Figure 18. Most arrows in the model could be directed in both directions, as the concepts can be assumed to influence each other in a mutual way. The direction indicated in the figure is intended to suggest the main direction of influence. Future research is needed to confirm or reject the model.

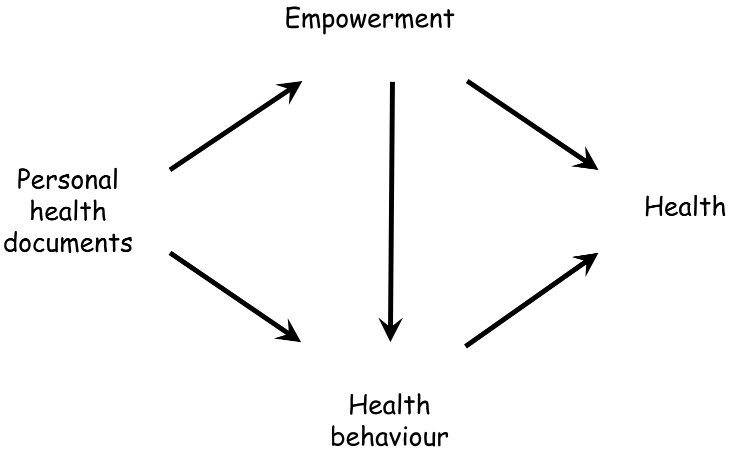


Figure 18. A model of presumed relations between studied concepts

Planned continuation of VIP studies

The effect of the VIP intervention method on adolescent empowerment, self-rated health and health behaviour after three years of intervention will be reported, thus examining personal health documents, empowerment and health behaviour (the left part of Figure 16). Teachers have been interviewed about their attitudes toward health promotion and about their 3-year experiences of the VIP intervention. The interviews are being analysed with qualitative methodology. In-depth interviews will be performed during 2007 - 2008 with a sample of girls from the cohort. The aim is to describe how adolescent girls experience their social and cultural context in relation to their health. We want to describe factors, courses of events and resources that are experienced by these girls as influencing their health. We also want to understand their strategies and the consequences of these strategies. Thus, the planned study will explore health, empowerment and health behaviour (the right part of Figure 16). Gender issues affecting the above model will be studied on the basis of the questionnaires from 2003, 2004 and 2006. These surveys included questions about sexual harassment that will be analysed from a gender perspective and in relation to other studied variables. In 2009, a follow-up postal questionnaire will be performed with the whole cohort of students. Possible long-term effects of the intervention will be studied, as well as the development of self-rated health, sexual harassment, health behaviour and empowerment.

Personal health documents

Effects of personal health documents on empowerment are scantily studied but an interesting research field. The relation between personal health documents and health behaviour change also deserves further study. Future research could include studies of personal health documents for new target groups. Pregnancy is an important time period for health promotion. Existential questions often arise for the pregnant woman and her partner. Examination of the effects of personal antenatal documents that include components like diaries and self-reflections would be interesting. Another interesting target group is the elderly. They showed interest in “My Book about Health,” and were irritated that it was targeted for younger people. A third target group could be people at risk for newly recognized and sometimes difficult-to-define conditions such as “burn-out syndrome” or “exhaustion depression.” Use in such settings would require for more comprehensive documents, and might more closely resemble the VIP than the MBAH version.

Another area that could be developed is communicative personal health documents for patients with chronic diseases. Changes toward a holistic view of health and disease, with an emphasis of self-rated health and personal reflection, would be desirable. Other possible target groups are the obese or individuals with the metabolic syndrome. These groups currently receive too little attention by health services.

Electronic personal health records are developing rapidly, and much faster than the research of their role is progressing. This should be a prioritised area of research.

Implementation of "a more health-promoting health service"

There is a need to study structures and attitudes in health services and how they support or obstruct health promotion. Such research is mostly neglected in favour of studying distinct intervention methods. Structures such as regular health examinations or nurse health-promotion clinics would be interesting to examine. Another interesting field is structural impediments that prevent family doctors, community health nurses, and school nurses from increasing their health-promotion work. Research is needed about how to scale up effective health-promotion methods. To use empowerment as a strategy in health services requires research about attitudes among health professionals, and simple measurements of patient empowerment that can be used in quality development and clinical practice. Last, the understanding of the concept of health in health services is an interesting and crucial question in reorientation work, and should be further analysed.

IMPLICATIONS FOR HEALTH SERVICES

Our findings support the use of personal health documents to a larger extent than is the case in Sweden today. Our findings also suggest that it is preferable to offer documents to everybody in target groups through oral communication and with an offer of support upon patient request.

Personal health documents that target new groups should be developed, with an overt aim to promote patient empowerment, and in cooperation with the target groups. Existing personal health documents, such as personal records for diabetics or hypertensives, could be reviewed in the light of patient empowerment and a holistic view of health and disease.

The role of community health nurses in health promotion deserves greater attention. Leaders in health services could initiate examination of working conditions and the content of CHN daily work to ensure an emphasis on health promotion. Adequate support systems for a sustainable work are needed. The role of school nurses in health education should be discussed further to ensure participation in this important working task.

Last, but not least: empowerment is important in relation to self-related health and health behaviour. Empowering strategies should be included in health promotion programmes.

EPILOGUE

Since I became a family doctor, I have always regarded quality development as an interesting and enjoyable part of my work. Cautiously entering into the field of research, it turned out to be a joyful activity, too. Hopefully, the results will help in the work of reorienting health services in a health-promoting direction. Looking to the future, the reorientation work is a big and interesting challenge. I hope to be able to take an active part in it, working together with the large and increasing group of professionals and researchers that are interested in prevention and health promotion.

Figure 19. A drawing from the VIP document

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Appendix: Personal health documents focusing on primary prevention

A literature search was done in PubMed in 2001, from the start of the database until October 2001. Personal health documents were recognized using the definition: “written documentation about the health and/or disease of an individual, owned and held by the individual (or his/her parent/guardian in case of impaired autonomy), that covers a time period”. Thus, one-time assessments of health status were excluded. Other examples of excluded material were tailored health education material, medication lists, decision-support material, and plates or badges showing special disease or medical treatment.

When a personal health document was identified, it was estimated whether the document mainly handled health and (primary) preventive care or disease and curative care. The document was excluded if it primarily handled disease and curative care. For instance, documents handling the follow-up of diabetes were not included. Neither were copies of medical records produced by general practitioners.

The search items used were chosen based upon the results of thorough literature searches during 2000. The search items “patient-held records”, “patient held records”, “client-held,” “patient retained records”, and “passport to health” using “any fields”, and the combinations of the MeSH search item “medical records” with, respectively, “patient participation” and “self care” were used to identify personal health documents.

The search items “patient-retained”, “personal health records”, and combinations of the search items “pamphlets” and “books” with “patient participation”, “self care”, “power (psychology)” and “self-efficacy” provided no further results. Neither did “documentation” combined with “patient participation”, “self care”, “power (psychology)” and “self-efficacy”, or “medical records” with “power (psychology)” or “self-efficacy”.

A search in PsychInfo database, using the search items “patient held records”, “client-held”, “client-held records”, “patient-held records” and combinations of the search item “medical records” with “self care”, “power (psychology)” and “self care”, and “documentation” with “power (psychology)” was done without additional findings. A search using the search item “medical records” in the Cochrane Database for Systematic Reviews confirmed two articles already identified.

In 2001, 111 articles were identified, of which 34 referred to personal health documents primarily handling health and preventive care. Through the reference lists of these 34 articles, 44 further articles were identified. All together, these 78 articles described studies concerning 56 different personal health records.

In 2007, a new search was done in PubMed using those search items that produced positive results in 2001. Seven new articles were found and are included in the appendix table.

Appendix table: Personal health documents focusing on primary prevention

Title of health document	Year	Country	Target group(s)	Study Design	Main finding(s)
Growth chart	1962	Nigeria	Parents	Descriptive	A health and weight chart was found to be helpful to the mothers and the medical staff (85).
Maternity records (3)	1974 1983 1986	United Kingdom	Pregnant women	Descriptive (164) Descriptive (165) Controlled trial (112)	Women-held maternity records are feasible (164). Records are not lost and the women feel more involved (165). Most women found advantages in carrying the complete record. Both groups experienced difficulty in understanding what was written in their notes (112).
Antenatal record	1976	Kenya	Pregnant women	Descriptive	A record was designed for antenatal care in rural health services. The percentage of adequate care rose from 12% to 71% (166).
Home-based record system (3)	1977	Tanzania	Parents, pregnant women, family planning	Descriptive	Usually within six months of starting a home-based record system, the number of mothers who lose or forget their record goes down to 1 – 2% (167).
The Mother's Card	1978 1981	India	Pregnant women	Descriptive	The use of a simple, action-oriented card in a rural community is described (168). 88% of the eligible women in sixty villages were reached (169).
WHO growth chart	1978	Centres in different parts of the world	Parents	Controlled trial	After 4 months, 5 of 24 respondents reported a home card loss above 5%, compared to 1 respondent for the service card. The personnel preferred a combination of home and service cards (109).
Mother-Child Health Passport	1978	Austria	Pregnant women, parents	Descriptive	The rapid decrease in infant mortality rate is mainly due to the Mother-Child Health Passport, used by about 95% of all pregnant women (170).
The Personal Life Health Plan	1978 1979 1987	USA	Adult patients, adolescents	Before-after (63) Before-after (70) RCT (89)	Interest among participants, significantly increased compliance with medical recommendations (63). Interest among participants, no effect on health habits or attitudes (70). Record acceptance and use were decided by physicians' support of the process and the type of the record. The wallet-sized record was most often brought to health service visits, while the Personal Life Health Plan was most often written into. Costs were moderate (89).
Health Passport/ Know Your Body Study	1978 1993	USA	Children	Descriptive (68) Controlled trials (metanalysis) (71)	Wide range of acceptance from inner city, low SES areas to upper class, professional populations (68). Consistent, positive results after 5 years for smoking and health knowledge. No significant results for self-esteem/self-efficacy or locus of control (71).
Pictorial maternal and neonatal record	1981	India	Pregnant women	Descriptive	A pictorial card was devised for illiterate, traditional birth attendants (171). The records contribute towards early detection of women at risk and encourages self-care (172).

Action-oriented antenatal card	1981	Papua New Guinea	Pregnant women	Before-after	Using the conventional card, 55% of high risk factors were correctly recorded. This rate improved significantly to 86% using an action-oriented card (173).
Immunization record	1981	USA	Parents	Descriptive	Completion rates higher for infants for whom immunization records were available. Records more likely to be available among low-educated mothers (62).
Maternity case notes (St. Thomas Hospital)	1982 1987	United Kingdom	Pregnant women	Descriptive (174) RCT (87)	Integrated care including carrying own case notes significantly reduced numbers of doctors involved in visits (174). More of the notes group expressed satisfaction with most aspects of care and significantly more women felt well informed and satisfied with their companion during labour. More assisted deliveries among the notes group (87). After the study, the policy was expanded and all women now carry their own notes (175).
Carnet de santé	1983	France	Parents	Descriptive	The linchpin of the French child health services has long rested with the "carnet de santé" (84).
Antenatal record	1984	Botswana	Pregnant women	Descriptive	An antenatal record is described (176).
Pictorial child weight scales	1984	Indonesia	Parents	Descriptive	Traditional birth attendants were able to identify high risk infants (171).
Road-to-Health card	1984 1986 1987 1990 1998	South Africa	Parents	Descriptive (177) Descriptive (111) Descriptive (178) Descriptive (179) Qualitative (106)	When properly used, the card is an inexpensive and effective measure (177). Almost half of the mothers were unable to understand the growth chart (111). At local clinics all children were accompanied with cards, but only 55% at a hospital outpatient department (178). Only 22% of the children identified as underweight by weighing would have been identified by available and up-to-date cards (179). Mothers and health personnel would like to replace the card with a notebook in the parents' native language, a "baby's own document," with more space and information (106).
Child health records (CHR) (6)	1984 1985 1990 1991	United Kingdom	Parents	RCT (180) Controlled trial (64) RCT (181) Descriptive (116) Descriptive (101) Descriptive (182) Controlled trial (107)	The CHR was appreciated by mothers and professionals. No effect on immunization or developmental assessment service uptake (180). Parents who receive detailed oral and written information will use the record more effectively (64). High degree of acceptance from parents, health visitors and general practitioners (GPs) (181). Over 90% of the GPs and health visitors with experience of parent-held records favour them (116). Parents favour the use of parent-held records (101). Parent-held records improve the work of child health services (182). Parents do not lose records more often than personnel (107).
Home-based antenatal card	1985	India	Pregnant women	Descriptive	Effective in enhancing the mothers' knowledge. Seven per cent of the cards were lost (171).
Medical Passport	1985	USA	Parents	Descriptive	Many benefits can be anticipated with effective Passport use (183).
Antenatal card	1986	Guinea Bissau	Pregnant women	Descriptive	The card is a considerable help in improving the performance of traditional birth attendants (184).

Health examination medical record	1986	USA	Adult patients	RCT	Significantly more patients in the intervention group reported smoking reduction or quitting after six months (73).
Computer generated health check card	1986	United Kingdom	Adult patients	Before-after	4 months after the issue of cards there was an increase in the uptake of cervical cytology screening, blood pressure recordings and tetanus immunization (185).
Wallet-size health record	1987	USA	Adult patients	RCT (89)	Record acceptance and use were decided by physicians' support of the process and the type of the record. The wallet-sized record was most often brought to health service visits, while the Personal Life Health Plan was most often written into. Costs were moderate (89).
Passport-size health record	1987	USA	Adult patients	RCT (89)	Record acceptance and use were decided by physicians' support of the process and the type of the record. The wallet-sized record was most often brought to health services' visits, while the Personal Life Health Plan was most often written into. Costs were moderate (89).
Maternity case notes (Newbury)	1987	United Kingdom	Pregnant women	RCT (118) Descriptive (175)	Women holding their records were significantly more likely to feel in control of their antenatal care, and to feel it was easier to talk to the personnel (118). The experimental policy was discontinued before the research results became available (175).
Alberta Child Health Passport	1987	Canada	Parents	Descriptive	Almost 98% of parents made some entry into the passport and 66% kept it completely up-to date. The community health nurses stated that the passport was a good idea but felt that it should be delivered by someone else (115).
Personal health record (South Australia)	1987 1993	Australia	Parents	Descriptive (99) Descriptive (72)	10% of parent held records were not available after eight to eleven months. Most parents liked the records, as did 93% of the community health staff, but only 44% of the doctors (99). High level of understanding of the record on the part of parents and an increase in the use by general practitioners (72).
Personal preventive checklist	1990	USA	Elderly patients	RCT	Those who received the checklist obtained significantly more cancer detection services, while blood pressure measurements and influenza immunizations were the same (91).
Health cards	1990	India	Occupational health	Descriptive	Substantial efforts to control smoking (75).
Health diary	1990 1992	USA	Adult patients	Descriptive (66) Controlled trial (142)	High rate of pre-test provider acceptance (66). Significantly improved compliance with preventive services (142).
Personal health record (New South Wales)	1990 1994	Australia	Parents	Descriptive (186) Descriptive (187) Descriptive (100)	98% of inpatients had a PHR, but it was available at the time of hospital admission for less than half of the children (186). 48% of children seeing a GP had their PHR with them. 92% of the PHRs had completed immunization data. Low usage among all doctors (187). 93% of parents expressed satisfaction with the PHR, while 64% of all health providers also felt that the PHR was beneficial, although only 53% of these used it regularly (100).

Patient-carried reminder card	1990	USA	Adult patients	RCT (91)	The card group had a significant increase in the performance of influenza vaccination, rectal examination and hemoccult test, Papanicolaou smears, and physician breast examinations, but not for pneumococcal vaccination or mammography (91).
National parent-held child health record	1991	United Kingdom	Parents	Descriptive (188) Descriptive (189) Controlled trial (108)	Describes the introduction of the national record (188). The development of the national record is an ongoing dynamic entity that consumes much time and work, but also offers great rewards (189). 98% of the parents, 92% of the health visitors and 60% of the doctors liked the record (108).
The Lifespan Personal Health Record	1991	USA	All ages	Descriptive	A system is described for entry of health data in a computer-based patient record by lay individuals (96).
Personal Health Record	1993	Australia	Adult patients	Descriptive	Patients mostly perceived the record as a personal document for reference while GPs perceived it as a management and communication tool. Patients and doctors have different attitudes to and expectations of PHRs (65).
Home-based maternal record (WHO)	1993 2000	Centres in different parts of the world (102) Zimbabwe (190)	Pregnant women	Controlled trial (102) Qualitative (190)	Favourable impact on utilization of health care services and continuity of health care. Promotes self-care. Increased the diagnosis and referral of at-risk pregnant women and newborn infants, improved family planning and health education. Increased tetanus immunization. The record was liked by the mothers and health care personnel (102). The introduction of the record is important. The mothers' understanding of the record was variable, as was the completion of the different sections (190).
Immunization card	1993	USA	Parents	Descriptive	Twenty-nine percent of children attending an emergency department had their immunization card with them. Six out of 32 cards were inaccurate when compared to the medical records (191).
Vaccination card	1993	USA	Parents	Descriptive	Eleven percent of children attending an emergency department had their vaccination card with them (192).
Put Prevention in Practice	1995	USA	Occupational health	Descriptive	Use of the Put Prevention in Practice program is a valuable resource (92).
Hepatitis B vaccination card	1995	United Kingdom	Parents	Descriptive	A Hepatitis B vaccination card is described (193).
Personal health record	1996	United Kingdom	Adult patients	RCT	Those who received both PHR and a computerized medical summary were more likely to keep and use the record. Those who only received PHR reported a reduced alcohol intake, and were less likely to report that there was no need to change lifestyle. Those who only received the computerized medical summary were more likely to attend a health check (90).

Computerized medical summary	1996	United Kingdom	Adult patients	RCT	Those who received both PHR and the computerized medical summary were more likely to keep and use the record. Those who only received PHR reported a reduced alcohol intake, and were less likely to report that there was no need to change lifestyle. Those who only received the computerized medical summary were more likely to attend for a health check (90).
Mother Passport	1996	Germany	Pregnant women	Descriptive	Almost all risk factors were most frequently mentioned by the mothers themselves, less by the Mother Passport (194).
Immunization card	1996	USA	Parents	Descriptive	The hand-held immunization card is a suitable alternative to the medical record when immunization status is assessed (195).
Patient-held record	1996 1999	Australia	Pregnant women	Controlled trial (196) RCT (88)	Women with PHR reported significantly higher level of satisfaction with care (196). Women in the control group were more likely to feel anxious and helpless and less likely to have information on their records explained to them by their caregiver (88).
Denver Child Health Passport	2001	USA	Adolescent parents	RCT	No significant differences between groups (teenage mothers) with regard to immunizations or emergency department visits (197).
Woman-held antenatal record	2001	Australia	Pregnant women	Qualitative	Overwhelmingly positive reaction of women. Themes were “information at hand,” “sharing with partner/family/friends,” “empowerment,” and “concerns to lose the record” (103).
Better Health Booklet & Diary	2002	Australia	Parents	RCT	One third had read at least half of the booklet, 12% had completed a portion of the diary. No significant increase in Pap tests, mammograms or skin operations (113).
The Child Health Profile	2003	UK	Adolescents	Descriptive	A majority of students were indifferent or negative. After 1 year, 39% of adolescents reported writing in the document and 38% had lost their document permanently (94). Adults supported the idea, but health professionals prioritised other work tasks, and teachers had a limited role (95).
Personal child health record	2004 (114) 2006 (74)	UK	Parents	Cross-sectional (74, 114)	88% had read half or more. Teenagers and first-time parents experienced most usefulness. A majority of GPs were satisfied, but health visitors were more often satisfied (114). 97% had the latest weight documented. 83% effective use by mothers, social disadvantages associated with less effective use (74).
Parent-held child health record	2006	Norway	Parents	RCT	First-time parents were excluded. 73% of parents had written in the record. 65% of parents were satisfied. Their knowledge did not increase, nor their experience of finding it easy to speak to health care personnel (104).

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