# The changing role of gatekeepers:
# Rationing and shared decision-making in primary care

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Dissertation for the degree Philosophiae Doctor (PhD)

University of Bergen, Norway

2006

# Contributors

This PhD project has been a co-operation between the following units at
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ISF has provided main supervision of the candidate through professor Ole Frithjof Norheim and has administrated the PhD training activities.

**Department of Economics (IFØ)**

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**Stein Rokkan Centre for Social Studies (Rokkan Centre)**

The Rokkan Centre has employed the candidate and administered the project.

# Contents

# Acknowledgements

This thesis is the result of an interdisciplinary process. I have been part of several research environments and wish to thank a number of people and groups.

Above all, I am indebted to Ole Frithjof Norheim, my main supervisor. I could not have wished for a better one. Thank you for always starting with the good news (that actually works!), for being reliable and honest, and for your generosity. Your open academic mind and your knowledge of several disciplines made my multidisciplinary work much easier. Your comments are always to the point and your suggestions have helped me transform extensive, poetic, anthropological thoughts to 2000-word IMRD style manuscripts.

I also need to thank Arild Aakvik, my co-supervisor, for accepting the challenge of dragging an anthropologist through the econometric exercises, and for having so much faith in me. Thank you for making me feel able to burst into your office at any time and throw my problems onto your desk even when I have been at my most self-absorbed.

I am also sincerely grateful to:
Alf Erling Risa, for always finding me convincing and for supporting me no matter which hat you have been wearing or in which direction I have been heading.
Claire Glenton, my very good friend and fellow multi-anthropologist, for mixing work and gossip and for your invaluable help with the English language and with making messy qualitative research data edible for the medical journals.
Jan Erik Askildsen, for always putting aside urgent matters for a valuable discussion, and for finding a place for me among the economists at HEB.
John Cairns for meticulous reading, helpful advice, good wine and for being a door-opener to your British colleagues.
Hilde Lurås and Tor Iversen, for sharing your extensive knowledge about Norwegian primary care and for inspiring collaboration. Hilde, for generous advice on the literature, and Tor, for helpful comments on the health economic perspective.
Sturle Næss for competent advice about the questionnaires.
Gaute Torsvik, for your friendship, long lunches and inspiring and useful discussions about rationality and biology.

Kristine Bærøe, for discussions about the meaning of words and for reading and commenting during Christmas.
Kjell Haug, for encouraging words about the possibilities of changing one’s mind.
Kari Tove Elvbakken, for believing in me and for good advice.
Kari Fuglseth, Aslaug Ytrearne, Arne Ibsen, and everyone in the Rokkan administration, for offering professional service and friendly chats.

Hanne, for your friendship, your ability to take interest in every detail of any study and for long and late conversations about the anthropologicalness of everything.
Cecilie, for your broadly intelligent view on things, for sisterhood, friendship, colleagueship, for reading and giving critical linguistic comments and most importantly; for your never failing sense of humour.
My parents, for your immense generosity and all practical help.
Michelle and Jannicke, for your empathetic support and patience with a distracted and, recently, often short-tempered mother.
Kjell, for being my safe shelter, my most challenging critic and for not always taking me seriously.

I would also like to acknowledge the financial support from the Research Council of Norway through The Evaluation of the Regular General Practitioner Scheme and through Health Economics Bergen (HEB). Special thanks to Signe Bang for your competence and positive attitude.

I am grateful to the HEB-steering committee for your decision to finance my PhD-work, to the Stein Rokkan Centre for Social Studies for employing me, the Department of Economics for hosting me, the Faculty of Medicine for accepting me in your PhD-programme and the Priority setting group for sharing the comparative and medical approach to health services research. I have benefited from inspiring conversations and support in all of these environments. Special thanks to the natives at Department of Economics for including me in the everyday life as well as in the rituals of your tribe and for teaching me your view of the world.

Finally, I would like to express my gratitude to the GPs who contributed by distributing the survey and to all the GPs and patients who participated in the study.

# Summary

The Norwegian health care system is increasingly dependent on the general practitioner's (GP's) gatekeeper function for cost containment and for fair and effective resource allocation. GPs enjoy extensive professional freedom and there is considerable room for discretionary choices. At the same time, during recent decades, the patient's power and rights have been strengthened. This situation calls for a better understanding of GPs' allocative decision making and the patient's role in it. Hitherto the literature on resource allocation tends to overlook the patient's role in GP decision-making while the literature about GP–patient interaction tends to omit questions of resource allocation.

This thesis takes an interdisciplinary approach to GPs' rationing decisions and the ideals of patient involvement. It is based on two separate studies. The first study explores how GPs experience the gatekeeper role under the influence of patients and other factors such as medical responsibility, economic incentives, competition and the desire to preserve professional autonomy. The second study analyses how attitudes towards patient involvement influence patient satisfaction and referral rates.

Study 1 (Paper I and II) is based on focus group interviews with a strategic sample of 81 GPs from the municipalities of Bergen and Oslo combined with a short questionnaire survey among the same participants. The interviews took place in 2002. Interviews were coded by hand and analysed qualitatively through framework analysis. The survey data were analysed descriptively. Study 2 is a questionnaire study among GPs and their patients carried out during 2004 in Bergen. The data are based on questionnaires handed out by 56 GPs and the responses from 1268 of their patients. Descriptive statistics, linear and logistic regressions were the main forms of analysis. The key finding of the first study was that Norwegian GPs' commitment to the gatekeeper role seems to be declining, and that they generally make rationing decisions only when they are able to come to an agreement with patients and avoid conflict. The findings also suggest that many Norwegian GPs do not fully understand the need for rationing while others regard rationing as conflicting with other concerns.

In study 2 (Paper III and IV) the results indicate that Norwegian patients have a strong preference for patient involvement while GPs are relatively less positive to involving patients in medical decision-making. GPs with positive attitudes to patient involvement referred less

and were more likely to have satisfied patients. Agreement of attitudes towards patient involvement between patients and GP had a strong and significant negative effect on referral rate but no significant effect on patient satisfaction.

The suggested interpretation of the results is that the participating GPs have turned their attention towards patients’ preferences and away from unpleasant rationing decisions. GPs and patients’ attitudes towards patient involvement affect resource allocation, but this association is poorly understood. Hence there is a need for further interdisciplinary studies to explore how GP–patient interaction affects resource allocation. Open debate about the role and limitations of patient involvement and how increased patient power affects resource allocation should be encouraged.

# Summary in Norwegian

## Fastlegenes portvaktrolle: Prioritering og brukermedvirkning i primærhelsetjenesten.

Det norske helsevesenet er avhengig av fastlegenes portvaktrolle for å sikre kostnadskontroll samt en rettferdig og effektiv fordeling av ressursene. Primærlegene har tradisjonelt hatt en høy grad av profesjonell frihet og stort rom for skjønnsmessige avgjørelser, samtidig som pasientenes innflytelse og rettigheter gradvis er blitt styrket i løpet av de siste 30 årene. På bakgrunn av dette er det ønskelig med en bedre forståelse av hvordan fastlegene tar beslutninger som får betydning for ressursfordelingen og hvilken rolle pasienten spiller i beslutningsprosessen. Hittil har studier av ressursallokering stort sett utelatt pasientens rolle for legenes beslutninger samtidig som studier av lege-pasientforhold i liten grad har befattet seg med ressursbruk.

Denne studien har en tverrfaglig tilnærming til primærlegers prioriteringsbeslutninger og idealer om brukermedvirkning. Studien består av to deler. Første del er basert på gruppeintervjuer og utforsker hvilke hensyn legene tar i vanskelige avgjørelser som portvakter. Andre del av studien er basert på en spørreundersøkelse blant fastleger og deres pasienter der vi undersøker hvordan legen og pasientens holdninger til brukermedvirkning påvirker pasienttilfredshet og henvisningsrate.

Den første delstudien er basert på fokusgruppeintervjuer med 81 fastleger fra Bergen og Oslo kombinert med et kort spørreskjema blant gruppedeltakerne. Intervjuene ble gjennomført i 2002. Den andre delstudien ble gjennomført i 2004 og er en spørreundersøkelse blant 56 fastleger i Bergen og 1268 av deres pasienter.

Hovedresultatet i den første delstudien var at mange primærleger i vår studie opplever at de i mindre grad fungerer som portvakter og i liten grad identifiserer seg med den rollen. Det ser ut til at fastlegene hovedsaklig sier nei til lavt prioriterte tjenester når de oppnår enighet med pasienten og dermed unngår konflikt. Fastlegene ser ut til å ha liten forståelse for behovet for å prioritere helsetjenester i en situasjon med god ressurstilgang. En del rapporterer også at de i liten grad følger nasjonale retningslinjer. I tillegg kommer portvaktrollen og ansvaret for å forvalte fellesskapets ressurser ofte i konflikt med hensynet til den enkelte pasient og dennes rett til å delta i medisinske beslutninger. Også økonomiske insentiver i fastlegeordningen, økt medisinsk ansvar og tydeligere konkurranse om pasienter oppleves som faktorer som gjør det vanskeligere for fastlegene å prioritere helsetjenester.

Resultatene i den andre delstudien indikerer at norske pasienter har en sterk preferanse for brukermedvirkning, mens fastlegene foretrekker en litt svakere grad av brukermedvirkning. Fastleger som er positive til brukermedvirkning hadde mer tilfredse pasienter og henviste mindre enn de som var mer negative til brukermedvirkning. Samsvar i holdninger til brukermedvirkning mellom lege og pasient påvirket ikke pasienttilfredshet, men hadde derimot en negativ effekt på antall henvisninger.

Konklusjonen av studien er at mange fastleger i vårt materiale retter oppmerksomheten mot pasientenes ønsker og behov og bort fra det de opplever som ubehagelige prioriteringsoppgaver. Fastleger og pasienters holdninger til brukermedvirkning påvirker ressursbruken i helsevesenet, men vi vet foreløpig lite om disse sammenhengene. Følgelig er det behov for videre tverrfaglige studier som kan utforske hvordan lege-pasientinteraksjon påvirker ressursbruk og -fordeling i helsesektoren.

## List of papers

I: Carlsen, Benedicte and Norheim, Ole F. Introduction of the patient-list system in general practice: Changes in Norwegian physicians’ perception of their gatekeeper role. *Scandinavian Journal of Primary Health Care* 2003, 21(4): 209-13.

II: Carlsen, Benedicte and Norheim, Ole F. “Saying no is no easy matter”. A qualitative study of competing concerns in rationing decisions in general practice. *BMC Health Services Research* 2005, 5:70

III: Carlsen, Benedicte and Aakvik, Arild. Patient involvement in clinical decision-making: The effect of GP attitude on patient satisfaction. *Health Expectations* 2006, 9: 148-157.

IV: Carlsen, Benedicte, Aakvik, Arild and Norheim, Ole F. Congruence in attitudes between doctors and patients results in lower referral rates. A questionnaire survey among Norwegian general practitioners and their patients. Manuscript submitted January 2006.

# Abbreviations

EBM Evidence based medicine

GP General Practitioner

MD Medical Doctor

PID Physician induced demand

PPOS Patient-Practitioner Orientation Scale

SID Supplier induced demand

# Background

Norway is one of the countries that spend most resources on health care in the world. In recent years, several costly reforms have been introduced in the health sector. In 2004 we spent 36 000 Norwegian kroner, or approximately 4500 US$ per capita on health care, and there has been a yearly increase in health expenditure of 4%. Only the US and Switzerland use more resources per capita on health in absolute terms (1). This means that Norway uses close to 10% of the gross national product on health care, and this is mainly public spending through universal insurance. Through recent reforms in the health sector, quality and availability of services have been strengthened, while costs continue to rise (2). Hence there is growing public concern about cost containment in addition to the focus on quality and distribution of services. In his recent book on the history of Norwegian health policy during the last 100 years, Ole Berg claims that since the 1970's there has been a shift in Norwegian health policy from a focus on distributive justice to a growing concern with efficiency and cost containment (3). The latter policy is reflected in media publicity and stated in terms of basic values and aims by the health authorities (4-6).

The idea of the welfare state is important in Norway and there is a deeply rooted belief that the public health system should promote equity in health through equal access to health care, as well as a corresponding scepticism towards the use of private payment for health care (7). With the aim of securing fair and efficient distribution of health services and to contain costs, the general practitioner has traditionally held the role of gatekeeper and acted as a filter to the use of public specialist care and reimbursement of costs of medication. In a third party payer-system with practically free access to high-tech health services, the GPs gatekeeper role is crucial. Simultaneously, GPs are fairly independent from health authorities with few restrictions on and little monitoring of their decision-making and services (8), both as compared to other doctors and as compared to GPs in other countries, e.g. the UK or the USA. A substantial proportion of expenditure on health care is used in primary care (16%) (compared to 54% in the hospital sector) and 4200 doctors work as GPs (compared to 9100 in specialist care) (2, 9). More importantly, decisions made in general practice heavily influence resources used on hospital stays, medical drugs and laboratory tests. International studies indicate that GPs influence as much as 80% of health care expenditures (10). In addition, GPs influence expenditure on sickness benefit and disability pensions.

Universal coverage applies to both general and specialist health services but the public do not have direct access to reimbursed specialist health care, which is filtered through the GPs. Accordingly, the Norwegian primary care sector is seen as the foundation of the health care system where the GPs hold the central role as co-ordinators of health services (11). They are therefore supposed to follow the principle that patients should be treated at the lowest appropriate level of the health care system (the *LEON-principle*) (12).

Respect for patient involvement and the patient's subjective view has been emphasized in official documents in recent years (7, 12). Several legal steps have been taken to strengthen patient rights, among them a recent reform in primary care: In 2001, a new, list based system was introduced (4, 7, 13, 14). The new scheme grants every inhabitant the right to choose whether to be under the responsibility of a regular GP and which GP that should be, as well as the right to change GP at will. By 2005, 99.5% of the population have chosen to be part of this system (15). The public's preferences for GPs form the basis of the GPs' personal lists of patients, and the GP is expected to give priority to their list patients. The GPs may have up to 2500 patients on the list but are also free to set a maximum limit below this. Every month, GPs get an update of their list from the National Insurance Service with an overview of newcomers and drop-outs. The GPs' income consists of three components: About 30% consists of capitation-based reimbursement paid by the municipality with whom the GP is contracted. This part of the income is directly dependent on the number of people on the list. The rest of the payment comes from a small out-of- pocket fee paid by the patients combined with activity-based reimbursements paid by the National Insurance Service. In summary, the reform made the GPs financially dependent on patients' willingness to be on their lists. Simultaneously, the patient list system emphasises the GP's position as gatekeeper, both through an increase in referral requirements for secondary care and through giving the GP the co-ordinating role of all healthcare their regular patients receive.

The aims of the list reform, according to the White Paper, were to make the system more responsible to patients, to strengthen the performance of the health care sector with respect to fair distribution of high quality services, as well as to secure a more rational allocation of resources (4). The focus on patients' rights in the reform reflects the culmination of the steadily evolving shift in power in the doctor-patient dyad which has been observed in many western countries (16-18) and the health care systems' responsiveness to consumer demands has been an important subject of reforms in various countries (19-23). A question that is emerging from this development is how the shift of power from the GP towards the patient influences the GP's professional autonomy and thereby her motivation and accomplishment of the gatekeeper task. So far, there has been little empirical investigation of this area (17).

To sum up, in Norway, as in many other countries, we are in a situation of high and rising costs of health services and the sector relies heavily on GPs for rationing health care. This implies that GPs sometimes need to ration health care, i.e. withhold potentially beneficial services (24) that the patient demands (25, 26). At the same time, there is an explicit policy of enhancing consumer influence. This situation, which is seen in several countries with gatekeeper systems, has led to a growing literature on GPs' allocative decision-making in health economics and health services research (27). Still there is a lack of research into patients' influence on GPs' rationing decisions (27-29). In medical anthropology and sociology, on the other hand, there is an extensive literature on the doctor-patient relationship, which tends to focus on power relations and patient's preferences, but these studies seldom consider questions of resource use and distribution (26, 30-35). During the last decade, a normative literature within medical ethics has drawn on both of these traditions and has directed attention to questions of how rationing decisions can be made acceptable to the public, using an ideal of respect for patient autonomy and public accountability (36-42). This important literature touches upon dilemmas of the gatekeeper role related to the doctor-patient relationship, but this literature is mainly theoretical. There is a lack of empirical investigation of how GPs manage to combine ideals and practice of rationing and shared decision-making.

The purpose of this thesis is to explore empirically how GPs' experience the dilemmas of the gatekeeper role, on the one hand, and how attitudes to patient involvement relate to cost and quality of services, on the other. The approach is interdisciplinary as it draws upon theory and findings from medical ethics, general practice research, social anthropology and health economics, and uses both qualitative and quantitative methodology.

The thesis consists of two studies. The first study (Paper I and II) is based on focus group discussions with Norwegian GPs and it explores central and changing factors influencing the GPs rationing decisions. In the focus interviews, the patient's increasingly influential role emerged as a concern among the GPs. Partly because of this finding from the first study, the second study (paper III and IV), which is a questionnaire survey, incorporates both GPs' and patients’ views. This is an attempt to quantify GP attitudes towards patient involvement in clinical decision-making that emerged in the first study and compare them to patient attitudes. In addition, it is an attempt to test the influence of these attitudes on patient satisfaction and referral rates (as indicators for quality and resource allocation).

As this work is carried out in the interface between several fields and disciplines, and the background is quite complex, an overview of the introductory section is given here: I start with the *Theoretical framework for the study of medical decision-making,* where I present the basic division in the behavioural sciences between theories and models of rational actors on the one hand and theories of limited rationality which emphasize the importance of norms, altruism and limited information on decision-making on the other. The two competing approaches are also based on and produce different empirical knowledge about factors influencing GP decision-making. I finish the section by presenting the theoretical approach of my study based on Barth’s model of “process analysis”. In the next section, *Shared decision-making,* I introduce my use of the concepts of “patient involvement” and “shared decision-making”. Then I outline some of the relevant social research about shared decision-making. In the section, *Rationing,* I clarify my use of the concepts “rationing”, “gatekeeper” and “autonomy”. Subsequently, I give a brief overview of the current literature on the dilemmas inherent in the gatekeeper role and some of the suggested solutions to these dilemmas. In particular, I mention the new theoretical focus on the conflict between rationing and shared decision-making. This literature integrates studies in health economics of GPs’ allocative decision-making with studies in health services research of patient involvement, and forms the basis of the empirical study of this thesis.

# Theoretical framework for the study of medical decision-making

## Reasons behind choice

Theories about how people make choices and why they act as they do form the basis of all social sciences. However, there are a number of analytical approaches to the study of social acts and structures, which are a source of never-ending debate and where opinions are divided between and within disciplines. Man can be seen as a rational actor maximising individual utility, as a passive pawn in the social game responding to external rules and norms of conduct, but also as a social being aiming at the social good of important others and capable of acting altruistically. It has been argued that what distinguishes the social sciences from the natural sciences is the interest in man as an intentional being. Human acts are loaded with meaning as opposed to animal behaviour. Weber distinguishes between acts that are rational and goal-oriented, rational and value-oriented, acts motivated by affections and finally acts driven by tradition (43).

Within theories about rational decision-making, it is common to distinguish between the classical theories of pure rational choice and modern theories of limited rationality, which incorporate constraints on rational choice, such as imperfect information, influence of other actors, unclear preferences or the tendency to form habits or decision rules (44). A more severe constraint on rational choice is that many actions are taken not so much because of their intended consequences as because of their appropriateness (44). This approach is taken in theories of identities and cultural norms of behaviour, represented by norm sociologists such as Durkheim (45) and Bourdieu (46). When it comes to the study of doctors' behaviour, such theories add important aspects of professional identity and norms of conduct. Theoretically then, there is a division between models of medical decision-making focusing on norms and appropriateness, in this case represented by medical practice and professional identity, and models of rational choice assuming that the GP deliberately assesses alternatives with a view to the expected consequences (44).

It is not obvious which approach is most suitable in understanding how GPs generally make clinical decisions. In a study of GPs, who are highly specialised actors constantly making discretionary choices within severely limited time, working alone, but in a professional setting, both approaches seem relevant. Medical education and medical guidelines equip the GP with rules to follow when making decisions. Combined with experience earned through practising professional discretion, it is easy to imagine that the GP could reach a level where decisions are taken more or less automatically without much deliberation. For the experienced GP, this is perhaps true for many decisions.

When it comes to understanding the special case of rationing decisions, several valid arguments can be forwarded both for applying the models of rational and goal oriented choice and for the theories of affective or normative motivators:

Firstly, the GP's decisions have direct consequences for another actor with major interests in the choices made, namely the patient, who is normally present when the decisions are taken and who must be expected to be involved and attempting to influence the decision taken. This, in turn, forces the GP to argue her own view and thereby to consider the rationale behind the decisions. On the other hand, depending on the balance of power between GP and patient, the patient may not be involved in the decision-making process and may not question the clinical decision at all. This would give the GP the opportunity to make rationing implicit and thereby act according to routine or guidelines.

Secondly, making rationing decisions implies that the GP refuses to fulfil the patient's desire for services. So, allocative decisions of this kind contain an inherent conflict between GP and patient. In a situation of negotiation or conflict, arguments for and intentions behind decisions are sharpened. Still, face to face rationing involves relating to the emotions and reactions of the consulting patients, which may make the affective and immediate side of the decision-making process more influential, more so the more crucial the decisions are to the patient. In addition, internalised professional norms of doing the utmost for the benefit of the present patient could possibly dominate the decision.

Thirdly, many Western health care systems are, like the Norwegian one, rather affluent. Rationing decisions are therefore, for the most part, enacted in a grey zone concerning interventions where benefits are marginal or contested. In addition, governmental guidelines are often lacking or indeterminate. In these cases, it is not possible merely to rely on medical knowledge when making decisions. It is likely that GPs are influenced by concerns other than purely medical when making treatment choices.

### Influences on doctors’ decision-making

Let us consider the knowledge yielded by the different approaches. This section reports on economic studies of resource allocation, of rational choice and the maximising of utilities versus medical studies of uncertainty in medical decision-making.

Health economic studies of GP behaviour have mainly focused on how economic incentives and preferences for income versus leisure influence decision-making (27, 47, 48). These studies predominantly use data at the macro-level to explain GP behaviour. The majority of the empirical studies of income motivated behaviour conclude that GP behaviour is affected by private economic incentives at least when medical decisions are within the grey zone of uncertainty (49-58). The economic studies of GP behaviour have as their starting point the asymmetry of information between GP and patient, and a contentious subject within this literature is the question of supplier-induced demand (SID). The concept of supplier induced demand or, as in this case, physician–induced demand (PID) was introduced by Evans in 1974 (47), and there is still consensus in the field about his definition of PID: “Physician-induced demand exists when the physician influences a patient’s demand for care against the physician’s interpretation of the best interest of the patient” (25). The hypothesis is that the motivation behind this behaviour is self-interest, usually interpreted as financial motives. PID may obviously have negative consequences for the efficiency of the health care services and cost containment.

The economic approach to GP decision-making has had a mixed reception among other health services researchers who claim that health economic studies tend to overstate the GPs’ private economic interests while professional and altruistic motives (like the satisfaction of curing sick people or the esteem of colleagues), are under-communicated (59-61). Evidence of persistence of practice style over time, in spite of changing economic and organisational influences, is seen as an indication that the individual approach to professional uncertainty is a more important explanatory factor for variation between doctors than non-medical incentives (62-64).

This criticism of health economic studies is understandable; Economic studies have a tendency to focus on incentives that can be altered by health management, while economic incentives are generally not regarded as a legitimate influencing factor among medical practitioners (65). Economists, on their side, accuse medical studies of an unbalanced focus on uncertainty leading to different medical judgements as the dominant explanatory factor (66, 67).

There have also been objections to the economic approach at the theoretical level. Economic models have recurrently been criticised for being reductionistic and deterministic; that the models are simplistic and too focused on economic incentives (46, 68). There is often little appreciation of the rigidity of economic models among other health services researchers, as these models seem to ignore the issue that medical decision-making in practice is often ambiguous and paradoxical.

Economists argue that economic models have to be simple as their purpose is to calculate the probabilities of how much different motives influence behaviour. Still, some of the criticism is indeed being met in modern economic literature, which argues for including a range of different motives besides income and preference for leisure in the utility function modelling GP decision-making, such as, ethical considerations, autonomy, status, medically interesting cases, altruistic concern for patients and interests of the society (10, 47, 48, 69-75). There have also been a few innovative attempts to include both supply and demand elements, and one model attempts to include the distribution of power between doctor and patient (76). However, there has been little success in turning these complex models into empirical research (27).

Consequently, the empirical studies generally focus on one or a few factors of influence. There is no consensus on the relative importance of the different motives and little understanding of the interaction between them. Summarising the empirical research, GPs seem to be influenced by professional norms and colleagues (77, 78), personal economic motives (51, 79, 80), the pharmaceutical industry (81-84), patients' preferences and pressure (85-94) and by knowledge about treatment costs (95).

The factors that to varying degrees seem to influence doctors' decisions can be grouped into three main categories; concerns for the patient, concerns for society, and self interest (10). Not surprisingly, several studies find that professional concerns related to the patient's medical needs are the most important factor influencing medical decisions (10, 59, 94, 96-101).

However, few studies distinguish between the GP's perception of biomedical need and the patient's influence by asserting her subjective desires for medical care (94). Hence, knowledge about the effect of patient involvement on medical decision-making is scarce. One exception is a small UK study which investigated a range of influencing factors on GP prescribing decisions (102). This study found that non-clinical factors such as pressure from patients combined with the concern about preserving the doctor-patient relationship sometimes led the GP to ignore worries about clinical appropriateness, side effects and costs. Several other studies of perceived pressure from patients conclude that GPs' decisions are influenced by a concern for preserving a good doctor-patient relationship (90, 93). However, we have found no study that empirically analyses how the GP's and the patient's attitudes to patient involvement affect rationing decisions.

Another limitation of the literature is that the studies tend to look at decisions on a general level. Not many have specifically studied decision-making within the grey zone. There are indications that when medical knowledge is uncertain or effects are known to be marginal, non-medical factors are of greater importance (10, 103).

There is a large and well documented variation in GPs' practice style which has significant consequences for resource allocation (10, 57, 59, 63, 92, 104-107). Referral rates have been investigated in many of these studies. Variation in referral rates is commonly found to be between twofold and fourfold, and sometimes even 20-fold, and the reasons behind this are poorly understood (27, 85, 92, 107-110). To explain the variation, health economic studies focus on the asymmetry of information and *agency problems* between doctor and patients (and between doctor and health authorities) (25, 111-113), while studies within medical health care research tend to focus on the uncertainty in clinical decision-making and see the variation in practice style as a consequence of this (59, 114, 115). Studies of small area variation find that variation in utilisation rates do not affect health outcome between areas, which suggests that a substantial proportion of health care belongs in the *grey zone* or within *flat of the curve medicine* where benefits are uncertain (57, 116-118). Only about half of this variation can be explained by summarising the influence of the different factors (92). Health authorities are concerned about the unexplained variations as they are taken to suggest inefficiency, but research into this field is lacking and evidence is inconclusive (109). Thus qualitative and processual studies incorporating the interaction between factors, such as for example the doctor-patient relationship, have been called for (92, 107).

## The process-analytical approach

In an attempt to merge the perspective of GPs as rational actors making deliberative choices to maximise utilities with the perspective of altruism and the importance of professional norms, I have taken the holistic approach as interpreted by Fredrik Barth, as my starting point in this work. Fredrik Barth (119, 120) outlined the anthropological approach to Neumann and Morgenstern's T*heory of Games* (121), and Barth's approach has since become an established model for analysing individual choices and social patterns of behaviour. In this approach, societies are modelled as *interactional systems* where actors make rational choices, constrained and formed in interaction with other actors' choices in a framework of cultural values as well as of legislation, economic, geographical and ecological constraints. For the study of GP behaviour, this would mean that the GP makes decisions based on, for example, her interpretation of the medical problem, her internalised professional values, the patient's preferences and the expected reactions of the patient (and other actors) on the different actions the GP could possibly take.

We know that in a substantial proportion of the decisions GPs make, there is no unambiguous medical indication of what would be the right decision and this fundamental uncertainty of medical decision-making is reflected in the variation in practice. In these grey zones GP may have several different motives which she will consider consciously or which will influence her subconsciously as she makes the decision (about treatment, issuing certificates, referring, tests etc). The anthropological approach is based on a process of discovery and observation to extract the informant's own subjective list of significant concerns. Hence we did start out (in Study 1) with ideas and expectations of factors which influence GPs' decision-making. However, during interviews, we were also striving to be open to other motives. This approach contrasts with models and methods in economics, where incentives and motives are normally presupposed.

Although the individual actor is the object of studies of rational choice, the social sciences often aim at explaining the aggregated pattern or the macro-level, and economic models are quite suitable for this. However, the problem of how to combine the micro- with the macro-level in academic work is much debated. According to Barth, the aggregated patterns can neither be thoroughly understood by looking at the formal rules governing society nor by merely observing patterns of behaviour. Therefore the researcher should try to understand the actor's subjective point of view, looking for common values among members of the social system being studied (120). This focus on the everyday meetings between individuals but with the aim of understanding patterns of society, is perhaps the most essential contribution of anthropology to the behavioural sciences. In Barth's words: "I would say that it is one of the strengths in anthropological analysis that we are more consistently concerned and able to interrelate the individual and the aggregate level than most of the behavioural sciences, though this is probably achieved at the cost of some elegance in our analyses of both" (120).

In this study, I aim to gain insight into the interplay between the micro and macro level in GPs' rationing decisions by starting out with the individual informant's views while simultaneously recognising the GP's role in a wide framework of interactions with other actors as well as with more stable organisational structures. Multidisciplinary empirical studies of GP decision-making have isolated several influential factors. In the context of rationing decisions in contemporary general practice, one of the most important factors of influence seems to be the patient. Patient involvement in medical decision-making is also a political aim of the Norwegian health services. Still our understanding of how patient involvement influences rationing decisions is meagre.

# Shared decision-making

## Concepts

There are several ways of conceptualising and ordering the roles of doctor and patient in the consultation according to the degree of patient involvement in decision-making. Moreover, there is considerable disagreement among theorists and researchers about how the different models should be understood (122). Generally, patient involvement is modelled on a continuum from the paternalistic doctor versus passive patient, where the patient is not informed and does not take part in the decisions, to informed decision-making where the patient makes autonomous decisions based on evidence-based information obtained from the GP or elsewhere. The paternalistic model is not much used in current research in general practice as some degree of patient involvement is expected. Likewise, the consumerist model of the patient as sole decision maker does not seem realistic based on empirical evidence (123) and given the fact that the doctor-patient relationship as a rule is one of asymmetric information where the doctor is expected to be the professional expert and has to take the formal responsibility for the medical decisions taken in the consultation. The model of *shared decision-making* is commonly placed somewhere in between these extremes. This is the most broadly used model of patient involvement in research today, even though a commonly agreed definition of how and how much patients should be involved in shared decision-making is still lacking in the literature (122-129). Interestingly, there seems to be a high level of congruence in practitioners' perception of what shared decision-making entails: According to doctors participating in a Canadian study, shared decision-making requires patient and doctor to share the whole process of decision-making, i.e. share information, discuss options and come to an agreement about interventions (130).

In this work, I use the term *patient involvement* to indicate some degree of patient involvement between the extremes of the passive patient and the consumerist patient who dominates decisions. The term *shared decision-making* is used in a more narrow sense and refers to the model of patient involvement, described in the Canadian study.

### Studies of patient involvement in medical decision-making

The literature about attitudes towards doctor- and patient roles in medical decision-making has largely been normative and coloured by the changing ideals in society in general and within general practice in particular. This applies both to studies by medical professionals with the purpose of saying something about how the GP's role may best be performed, and it applies to studies by social scientists who have been concerned with patients' rights and experiences.

During the last 30-40 years, there has been an ongoing process of shifting power from doctor to patient in general practice, and patient involvement in decision-making is now an ideal promoted in a growing number of countries (16, 17, 29, 126, 131). Some of the many explanatory factors that have been suggested for this change have been; general social development has made the public more educated and information more accessible, a greater proportion of patients suffer from chronic diseases and such patients tend to be more experienced and competent. There has also been a growth of patient organisations promoting patients' rights and new movements within medical ethics arguing for shared decision-making, transparency and accountability in medical decision-making. During this period, patients have become more equal in power and status to the GP and more patients are able to share decisions with their GP. In some settings, the GP may even be regarded as merely an expert who offers a service according to the consumer's demand (125).

Some authors do however argue that the effect of the power shift is exaggerated in the literature and is not always supported by patients' reports (132-134). Several empirical studies have attempted to reveal the extent to which decisions are actually shared in modern general practice and to map the preferences of doctors and patients. But findings are not consistent (123, 129). There seems to be a majority of patients and doctors who claim to prefer a high degree of patient involvement in clinical decision making (129, 135-137), but these attitudes are not matched by behaviour. In particular doctors seem to deviate from their alleged ideal in practice situations (29, 129, 135, 138).

It has been argued that the variety of theoretical models and measurement instruments has impeded empirical research on the doctor-patient relationship as well as contributing to the lack of agreement on what patients' and doctors' attitudes are today (122, 123, 130, 139, 140). The measurement scale, which is used in Study 2, is of the more moderate type that puts shared decision-making as the top score and highest level of patient autonomy. Studies using this type of scale, find that between 22 and 81% of patients prefer shared decision-making (135), while, for example, Kraetschmer et al, using a scale with informed decision-making at the top level, find that fewer then three percent of patients prefer to be the main decision-maker (128).

The current state of research in this area seems to be that whether and how much patients are involved in medical decision making depends on the context; i.e. characteristics of the patient, the doctor and the nature of the health problem (129, 134, 138). Haug and Lavin conclude:
"- the answer to the question – practitioner or patient, who is in charge? – is, it depends on who the doctor is, who the patient is and why they have met" (129). In general younger, female and well-educated patients prefer to be involved. Preferences also vary markedly according to cultural background (141).

We know much less about the characteristics of GPs who are liable to let the patients have a say, although female GPs seem to be more in favour of sharing decisions than male GPs (142, 143). While current studies find that most GPs prefer patient involvement, there is, at the same time, a growing number of GPs who voice discontent and concern with what they experience as a loss of professional autonomy, both in relation to health authorities and in relation to patients (17, 144-146). According to an Australian study of how GPs' professional identity is affected by health care reform, professional autonomy is continuously renegotiated in the consultations of contemporary general practice. Professional autonomy is reported to be declining as GPs are scrutinised both by health authorities imposing more monitoring to secure rationing and patients demanding to be more involved in decision-making (17). As noted earlier, there is also some evidence that GPs experience social pressure from patients as a factor of influence on medical decision-making, which sometimes even overrules the GP's clinical judgement (102).

A concern has been raised about the danger of undermining professional norms, such as altruism, which are at the heart of the medical profession and form a prime condition for the trust that both the public and the authorities traditionally have placed in the profession (146-148). Furthermore, this trust has been the basis of the professional authority and freedom that GPs have traditionally enjoyed (147). The *deprofessionalisation thesis* suggests that, on one side, there is a danger that consumerism and competition will undermine professional norms and, on the other, rules and regulations posed by authorities are a threat to professional freedom (18, 149).

In summary, the patient holds a unique position in the GP’s clinical decision-making. How influential the patient is, varies with the characteristics and attitudes of patient and GP and the context of the consultation (e.g. the patient’s state of health). The final decisions can be seen as a compromise resulting from negotiations between GP and patient, depending on the distribution of power between them.

# Rationing

## Concepts

The word *rationing* is used in slightly different ways in the literature. It is often used synonymously with priority setting (150) as a recognition of the fact that resources are being deliberately allocated between different needs, patient groups or individuals according to principles for priory setting and evaluation of needs. Some authors go further and use the term interchangeably with resource allocation. They argue that priority setting and rationing are constantly taking place in general practice simply because resources are experienced as scarce, and through discretionary choices the GP is, and always has been, rationing health care through medical decision making whether the priorities she makes are deliberate or not (41). Other authors reserve the use of the term rationing to cases where priority setting leads to denial of potentially beneficial health care (26).

Although I recognise that gatekeeping and rationing are also about letting people through and allocating resources to where they can best be used in a fair manner, the focus of this thesis is the problematic situation of implementing priority setting at the micro-level, when rationing means saying no in a face to face encounter. Thus I find the narrow definition of rationing most useful here. *Rationing* then, is when the GP intentionally, according to some principle for priority setting, denies patients potentially beneficial care. The disputed part of this definition is the concept of *benefit* that entails both a biomedical *need* and the patient's *desire* and *preferences* (26, 151). I will return to this question in the discussion of the results.

Closely tied to the discussion of rationing is the term *gatekeeper*. In the international literature, gatekeeping usually refers to the filtering of referrals to specialist care through the GPs (152). However, in the Nordic model GPs also have important allocative functions regarding other welfare benefits, such as sickness benefits. Thus, I use the word *gatekeeper* as a synonym for rationing agent. Additionally, and according to the narrower definition of *rationing*, the focus here is when gatekeeping means closing the door.

Another essential concept in this thesis is *autonomy*. In paper II we discuss both the professional autonomy of the GPs and the autonomy of the patients. Generally, *autonomy* refers to the human capacity for making independent choice (153, 154). One could argue that absolute autonomy does not exist, as this requires the actor to be fully informed and free from external influence, which of course is unrealistic. I will therefore add Beauchamp and Childress' specification of the general concept of autonomy: According to their view, autonomous action is intentional, which is an absolute requirement (151). Additionally, autonomy requires a degree of understanding and freedom from controlling influences. Hence in empirical studies one usually speaks of a continuum of autonomy. In medical ethics, *patient autonomy* can be specified as the patient's right to be informed and to be involved in the decision-making process regarding her own medical condition.

### Studies of the dilemma of rationing

Within modern medical ethics, there is consensus that respect for patient autonomy is a professional obligation, and that the patient should be offered the option of choosing, even if this means that some patients opt not to be informed and delegate decision making to the doctor or others (151). However, the GP is also a gatekeeper responsible for the welfare of her other patients and for distributing resources fairly. If rationing is defined as denying potential beneficial care, and we include both the GP and the patient's view of benefit, it implies some limitation on patient autonomy as well as professional autonomy (155). There is therefore a potential scenario of conflicting concerns in the gatekeeper role.

Since the mid-nineties a small body of literature among some North American medical ethicists has succeeded in drawing attention to questions regarding how to combine the considerations for the individual consulting patient with those for the broader population and how to make rationing decisions reasonable in the eyes of the public (36, 37, 40-42). At the institutional level, Gibson et al have conducted a couple of pioneering case studies within Canadian hospitals illuminating different influences on the rationing process and how power relations between decision makers at different levels of the organisation impede a reasonable rationing process (156, 157). Yet, these studies do not focus directly on power relations in the doctor-patient interaction. As a group of British health services researchers has pointed out, there seems to be a dilemma between the need for rationing and the ideal of shared decision-making in consultations (131, 158). If there is a potential conflict of interests between doctor autonomy and patient autonomy regarding rationing, it is relevant to focus on power relations and interactions and how autonomy is negotiated, as Davis so elegantly puts it in the title of an article about autonomy in the doctor-patient relationship: "Just whose autonomy is it?"

(153). Still the concern for professional autonomy has received considerably less attention in the literature than considerations for patient autonomy and the former has seldom been included in the literature on shared decision-making.

Related to this, though not specifically concerned with patient autonomy and shared decision making, a few empirical studies point to dilemmas of the gatekeeper role. Both in Norway and other countries with a gatekeeper system, researchers have noted a recurring dilemma in general practice, namely the gatekeeper versus advocate dilemma between cost and care in the health services (28, 159-164). This research highlights the difficult combination of roles the GP holds as she is responsible for serving the interests of the individual patient and is simultaneously supposed to serve as a rationing agent on behalf of the common resources of society. In a Norwegian study from 1995, 68% of the GPs reported that they had sometimes or often refrained from giving the best treatment to patients because it was too expensive (163). In contrast, a later study found that more than half of the GPs in Norway consider patients' wishes to be more important for medical decisions than their own professional judgement (165). Moreover, almost half of the doctors admitted to have *glossed over the facts* when writing medical certificates in order to support the patient's case. Together, these two studies indicate that the GPs' willingness to hold the gatekeeper role is declining. Similar changes in attitude were also reported in another recent study of Norwegian GPs (166). Additionally, a new Norwegian study shows that guidelines for rationing seldom are adhered to (167). At the same time referral rates have increased after the list reform. These studies confirm the impression from British as well as North American studies, that GPs are increasingly uncomfortable with the gatekeeper role (28, 29, 168, 169).

We have found one recently published qualitative study from the UK which explicitly discusses the conflict between rationing and patient involvement in decision-making (29). Jones et al note a discrepancy between ethical principles and practice regarding ideals for patient involvement and equitable resource use. The study also points to a lack of consensus on how patients should be involved in rationing decisions.

A number of solutions to the rationing dilemma have been put forward in the theoretical literature: Some authors argue for *explicit rationing* (38, 159, 170), others for *accountability for reasonableness* (36, 37); meaning that the doctor should inform the patient about the rationale behind rationing decisions and enhance the patient's awareness that she shares resources with other patients (40). Still others argue against explicit rationing and for *implicit rationing* (41, 171). Also extended use of evidence based medicine (EBM), guidelines (38, 158, 172), monitoring (173), and economic incentives (38, 174) have been suggested as means to encourage GPs to ration.

To conclude, a novel topic emerging in the field of medical ethics is the effect of shared decision-making on fairness and efficiency of resource allocation. There is still very little knowledge about how rationing decisions are negotiated between doctor and patient in consultations at the micro-level.  There is also a need to bring other healthcare models than the managed care model of the USA into this discussion. Further, it is necessary to see GP rationing decisions in a wider framework, i.e., how is the decision-making process related to the input of the macro-level principles of priority setting and patients' rights and the output of the consultation's affecting large scale patterns of resource use.

# Aims

## Overall aim

The overall aim of this thesis is to explore empirically how GPs experience the dilemmas of the gatekeeper role and how attitudes to shared decision-making relate to cost and quality of services.

## Aims of the individual papers

Study 1. *Focus group study of GPs' experience of the gatekeeper role:*

Paper I: *Introduction of the Patient-list System in General Practice: Changes in Norwegian Physicians' Perception of their Gatekeeper Role.*
Aim: To explore whether and how the patient-list system influences GPs' perception of the gatekeeper role.

Paper II: *"Saying no is no easy matter". A qualitative study of competing concerns in rationing decisions in general practice.*
Aim: To explore GPs' experience of dilemmas affecting rationing decisions.

Study 2. *Questionnaire study measuring outcome of attitudes to shared decision-making:*

Paper III: *Patient involvement in clinical decision-making: The effect of GP attitude on patient satisfaction*.
Aim: To investigate attitudes towards shared decision-making in GPs and their patients and how these attitudes affect patient satisfaction.

Paper IV: *Congruence in attitudes between doctors and patients results in lower referral rates. A questionnaire survey among Norwegian general practitioners and their patients.*
Aim: To analyse whether congruence in attitudes between GP and patients towards shared decision-making affects the GP's referral rate.

# Methods

## Study 1. Focus group study

To explore how rationing dilemmas are experienced in everyday practice, we conducted focus group interviews with Norwegian GPs from January to June 2002.

A sample of 11 groups involving 81 participants was recruited from tutorial groups and specialists' continuing education groups in the counties of Hordaland and Oslo. The participants were recruited to represent differences across age and gender as well as typical practices.

The data were collected through the focus group interviews and a short questionnaire handed out to all participants at the interviews. The questionnaire contained background questions about age, gender, work experience, maximum limit on list size, current list size, satisfaction with list size, specialist education and whether the subjects practised in a rural or urban community. The focus interview guide (Appendix 1) was adjusted once, after the first group interview. The interviews were conducted by Carlsen, who is a social scientist trained in social anthropology, and Norheim, who at the time was working as a GP and Professor of Medical Ethics.

The transcripts were coded by Carlsen according to a system of key-words developed jointly by the two researchers. Finally, the interviews were read through again, subject by subject, according to the main categories of codes. To present the findings, we extracted some quotes found to be representative for the results. We made some changes to convert the oral style of the original transcripts to a fluent written style and translated the statements from Norwegian to English.

Some interview data were quantified: We counted the number of lines in the text corresponding to each participant including the researchers and used this to create an index of how much each participant spoke as a proportion of speech in the interview. We also counted the number of positive and negative statements about the patient-list system and compared this with the participants' statements when they were explicitly asked to sum up their attitude to the new system. The quantified data was combined with the data from the questionnaires to supplement and validate the qualitative data. We used Stata software to describe and analyse the quantitative data.

Further details of the study design and sample is provided in paper I and II.

### Study 2. Questionnaire study

As a follow up to the first study, we conducted a questionnaire study among GPs and their patients with the purpose of measuring GPs' attitudes towards shared decision-making, and compare them to the attitudes of their patients. We also wanted to test the association of the different attitudes with patient satisfaction and rationing decisions (referrals).

The study draws on survey data from two sources: one questionnaire completed by GPs and a second by their patients. In the summer of 2004, we sent a letter of invitation to the GPs in Bergen and asked them to distribute a patient questionnaire consecutively to 50 consulting patients, as well as to complete a questionnaire of their own. A reminder was sent to the GPs after three weeks. GPs and patients were linked by corresponding numbers, but no record was kept of the corresponding GP names, which meant that it was impossible to track the GPs who distributed the patient questionnaire but forgot to return their own. A total of 181 GPs were contacted and 56 of these distributed the survey among their patients. However 15 of the GPs did not return their own questionnaire. Thus for the purpose of combining GPs' answers with patients' answers we were left with 41 GPs. A total of 1268 patients belonging to 56 GPs responded. This corresponds to a mean response rate of 45% per GP.

We calculated a *sharing score* based on an earlier validated measure, the Patient-Practitioner Orientation Scale (PPOS) for measuring preferences for shared decision-making (142) (Appendix 2). This is a Likert-scale questionnaire developed in a US study, where patients and doctors are asked to assess identical statements on the role of the doctor and patient in the consultation, where the highest score (=6) reflects preference for shared decision-making.

In addition to the PPOS-scale, the questionnaires included background questions on age, gender, educational level (patients) and years of professional experience (GPs). The GPs reported the number of referrals and the number of consultations during the previous five working days together with some details about the practice, such as number of patients on the list and satisfaction with list size. Patients were asked whether they had chosen this doctor as their regular GP and were asked to rate their overall satisfaction with the doctor on a six-point scale from *not satisfied* to *very satisfied.*

We used the software Stata 8.0 to analyse the data. In addition to presenting descriptive statistics, we used linear and logistic regression analysis to investigate predictors of patient satisfaction and doctors' referral rates. We also conducted multilevel analysis to adjust for clustering effects.

The sharing score was generated as a mean of the scores of eight of the nine PPOS items. Statement no. 6 was excluded because a disturbing number of respondents (181 = 14%) had chosen not to assess this statement.

We made a file where each patient's scores were combined with the scores of the corresponding doctor. In this way we could study each doctor–patient pair and use patient scores (patient satisfaction) as the dependent variable. Then we merged the scores of all the patients connected with the same doctor and allotted the median scores of these patients to the doctors' scores. Since the PPOS instrument was identical for doctors and patients, it was possible to construct a difference score as a measure of the fit in attitudes between doctor and patients. This score was tested as a predictor of patient satisfaction in a logistic regression model. The difference score was also one of the predictors tested in a linear regression model explaining referral rates.

Additional details of the study design and sample are provided in papers III and IV.

## Ethical considerations

The project was reviewed and approved by the Norwegian Social Science Data Service against the privacy and licence requirements of the Personal Data Registers Act and the guidelines for research ethics in the social sciences, law and the humanities according to the National Committee for Research Ethics in the Social Sciences and the Humanities. All respondents were informed about anonymity issues and the purpose of the study.

# Results

## Paper I

### Introduction of the patient-list system in general practice: Changes in Norwegian physicians' perception of their gatekeeper role.

The introduction of the patient-list system implied a change in the organisation of patient relations, favouring continuity and closer links between doctor and patient. The reform also introduced a change in the remuneration system by increasing the activity-based component of GPs income and introducing a capitation component. Accordingly, we expected changes in the influence of patients and of private economic motives on GPs' decision-making in relation to their gatekeeper role. The study explores whether and how the patient-list system influences GPs' perception of the gatekeeper role.

Most of the informants had experienced a change in how they perceived the gatekeeper role and how they performed the role of gatekeeper. The most and least experienced GPs seemed to experience least change, while GPs in areas with a surplus of GPs (Oslo) were more affected by the reform. The main finding was that most GPs perceived themselves as less eager to perform the gatekeeper function in the new scheme, and it appears that GPs act as gatekeepers only when they are able to convince the patient of their opinion. The informants' accounts of the background to this change fell within three main categories; accentuated competition, increased expectations from patients and more responsibility and continuity of care towards patients. The combination of these factors seems to encourage more attention to patients' demands and less deliberate rationing. The reform gives the patient more negotiating power but at the same time the GP is ascribed an increased gatekeeper function. According to our findings, it seems that the success of the first aim undermines the second.

## Paper II

### “Saying no is no easy matter”. A qualitative study of competing concerns in rationing decisions in general practice.

In this paper, we analysed the data of the focus group interviews on a general level, examining the GPs’ attitudes to different factors of influence, not only to those connected to the list reform. We focused particularly on rationing dilemmas and how this affects decision-making.

Four major concerns appeared in the group discussions: The obligation to ration health care, professional autonomy, patient autonomy, and competition. A central finding indicate that GPs find rationing difficult because saying “no” in face to face meetings is often experienced as uncomfortable and in conflict with other important concerns. The obligation to ration health care did not seem to be generally embraced by GPs. Professional norms and respect for patient autonomy on the other hand, were strongly emphasised as at the very core of their professional judgement. When it came to the role of economic incentives, statements were more ambiguous. The idea of economic incentives was sometimes dismissed as an external factor without power to influence GP decision-making, while other informants expressed concern that market mechanisms are gradually undermining professional autonomy. However, the economic incentives of the current system were not felt to be supporting the gatekeeper role.

Professional autonomy in relation to patients was experienced as a necessary requirement for fulfilling the rationing role, and rationing was often seen to be in conflict with respect for patient autonomy. On the other hand, respect for patient autonomy was easily combined with increased competition between GPs and the current economic incentives. In summary, there seemed to be a central tension between rationing health care and maintaining professional autonomy on the one hand and patient autonomy and concerns about competition for patients on the other.

## Paper III

### Patient involvement in clinical decision-making: The effect of GP attitude on patient satisfaction.

Through descriptive statistics and analyses of survey data this paper describes Norwegian GPs’ and patients’ attitudes to shared decision-making, as well as how GPs’ attitudes and congruence in attitudes between GPs and patients, affect patient satisfaction.

On the basis of matched questionnaires of 41 GPs and 829 consulting patients, we found that Norwegian patients have a strong preference for shared decision-making. GPs scored lower than patients, which is the opposite of the findings of a similar study carried out in the USA. This may support the findings in Study 1, which indicate that patients have become more demanding and powerful. We also find that patient age and female gender have positive effects on satisfaction, which is consistent with earlier studies

There was a strong positive effect of the GPs’ score for shared decision-making on patient satisfaction, but no significant effect of congruence of attitudes between patient and GP on patient satisfaction. The suggested interpretation of this finding is that GPs who welcome patient involvement are more responsive to patients’ needs and therefore satisfy patients even when patients’ attitude differs from the GPs’ attitude. Therefore, it makes sense to continue promoting the participatory consultation style even though some patients do prefer a passive role.

## Paper IV

### Congruence in attitudes between doctors and patients results in lower referral rates. A questionnaire survey among Norwegian general practitioners and their patients.

In this paper we used the survey data to test whether congruence in attitudes between GPs and patients towards shared decision-making influences referral decisions.

Analysing the combination of data from 41 GPs and 835 of their patients we found that the score measuring difference in attitudes had a strong positive effect on referral rate. This means that the smaller the difference in attitudes towards shared decision-making between GP and patients, the lower the referral rate.

Of the control variables, only GP gender had a significant effect on referral rate, indicating that male GPs refer more than female GPs. Male GPs had around 28% higher referral rates than female GPs.

Furthermore, we correlated the referral rate with the GP and patient scores for shared decision-making respectively to check how attitudes were associated with referral rate. We found a strong negative correlation between the GP score and referral rate, meaning that GPs who prefer shared decision-making are less likely to refer, a result also confirmed in other studies.

The results indicate that interaction of attitudes towards shared decision making between GP and patients influences medical decisions; similar attitudes enhance the chance of solving the medical problem within the GP's practice. Disregarding the issue of the quality of decisions, the study indicates that a close doctor–patient match may contribute to cost containment and secure that patients are treated at the lowest appropriate level of care, which is a central aim within Norwegian health policy. The patients' right to choose their GP could enhance the doctor-patient match and thereby indirectly limit unnecessary use of specialist care.

## Overall results

Norwegian GPs feel that they have become more attentive to patients' preferences, but still not as much as patients would like. The results also indicate that the transfer of power from GP to patient makes it more difficult to manage resource allocation. Attitudes towards patient involvement affect both quality and quantity of services.

# Discussion

## Methodological considerations

Only methodological considerations not thoroughly considered in the papers are discussed in this section.

### Study 1. Focus group study

According to Barth (120), in order to understand the aggregate pattern of actions, we need to discover the underlying values and subjective views of the actors. In other words, to understand the pattern of resource use in the health sector, a useful starting point is to explore the attitudes of the health workers. In a focus group interview, the interviewees are among peers and it appears that through the discussions between them, core values and norms are acknowledged and articulated (175). Therefore, focus interviews are a recommended tool for investigating attitudes and the norms and considerations that lie behind them (175). This was our main reason for using the focus group method in our study of the GPs' gatekeeper role in a changing primary care system. An additional reason was the lack of pre-reform data, which inhibits a classical evaluation design with before and after comparisons. Qualitative interviews enable participants to consider the present situation in the light of their common memory of their situation before the reform. Qualitative focus interviews are suitable for exploring the past, the present and even thoughts about the future in quite a different manner from quantitative cross sectional data (176).

The downside of focus groups is that they are less suitable for revealing attitudes that deviate from group norms. Neither do they convey much information about the distribution of different opinions or how common the dominating attitudes are. In paper II we argue that this is not a critical issue in this study because we were mainly aiming to reveal the common view among Norwegian GPs at the time and not the whole picture of attitudes. Nevertheless, we checked the proportion of speech by each participant and matched it with their opinions about the reform. The conclusion was that the participants with the most negative or most positive opinions spoke the most. This might be due to a relatively stronger urge to state their opinions, but the results might also be influenced by the researchers' expectations that there would be a change in attitudes connected to the reform, which was reflected in the questions we posed. Naturally, when change and reform is the focus of a study, the participants try to come up with good examples of changing features. Altogether this implies that we might have overstated the effects of the reform. In hindsight, we should perhaps have given more attention to the participants who claimed that they experienced little or no change with the reform.

Another potentially problematic issue concerning reflexivity was our theoretical basis in the idea of rational choice. We deliberately tried to increase the participants’ consciousness about their clinical choices and to distinguish the important factors of influence. For some of the participants, this appeared to be the first time they thought about the reasons, other than the clinical, why they usually made discretionary choices. Still, it might be argued that even decisions that are not made explicitly after considered deliberation, choices that are more habitual or conform to expectations, may ultimately rest on rational reasons. Bourdieu argues that social agents may be strategic without conscious calculation; they might be “absorbed in their affairs” or “have the game under their skin” and therefore not be thinking intellectually about the ends of the game (46). Looking at is this way, it is possible that these ends were discerned during the group discussions so that both the researchers and the participants became aware of them. However, it is possible that our initial focus affected the selection of influencing factors that were discussed. On the positive side, this makes the finding that the gatekeeper role was not one of the important concerns, even more conspicuous.

Study 1 started out on assignment from the health authorities through the Research Council of Norway as part of a national evaluation of the patient-list system in primary care. When conducting applied policy research, there are some special conditions that affect how data are gathered and analysed, which are taken into consideration in the *Framework approach* (177). This methodology in fact shares some of the characteristics of quantitative approaches. One such condition is the request for finding answers to specific questions, which, in Study 1 led to the decision to keep the original interview guide intact (after altering it once after the first, pilot interview). Also Richard Krueger, one of the founding fathers of the focus group methodology, recommends consistency in interview questions across groups, but with the exception of questions that do not seem to work well in the first groups (178). This stands in contrast to much qualitative research which is based on the phenomenological approach of *grounded theory*. Glaser and Strauss advocated the technique of *theoretical sampling* and *constant comparison*, which in this study would require that the questions be constantly altered according to the findings of the latest interview with the aim of illuminating uncovered aspects of the topic of interest (179, 180). Ideally this process continues until nothing new is revealed and the study has reached its point of *theoretical saturation.* A restricting consequence of asking the same questions in all the groups is, of course, that we are imposing more of our preconceptions into the data than normally accepted in qualitative studies. We thereby risk missing concerns of importance to the informants but that they were not encouraged to talk about.

On the other hand, in one of the early interviews with a group of only female GPs, the interviewees reacted quite negatively to some of the questions, claiming that they were provocative and expressing a disinterest in the main focus of the study. At the time we considered altering the interview guide. However, in later interviews, the same questions received positive response and induced lively discussion among the participants. Had we decided to alter the questions, interesting data would have been missed from the later groups. Another positive consequence was a discovery that part of the reason behind the negative response to the questions was that they touched upon topics which the GPs were reluctant to discuss openly, e.g. the loss of professional autonomy because of consumerism. With respect to this, we were then able to compare the different groups and informants and use the reactions to the questions as valuable information. For example, we noted systematic differences in the openness in the discussions according to which of the researchers were present; whether it was the social scientist, the medical professor or both. Participants seemed more willing to discuss influence of other concerns than clinical considerations, when Norheim (who is also a MD) was present, and even more so in the one interview where Carlsen (the social scientists) was absent.

Regarding the selection of informants, we used purposive sampling according to knowledge about influencing factors such as gender, work experience and specialist education. We decided the number of focus groups in advance, and were therefore prevented from continuing until a point of *saturation* as is a common recommendation in the literature on qualitative methodology (180). Looking back, it would probably have been sufficient with about half the number of groups.

### Study 2. Questionnaire study

Here, we chose a quantitative approach because the aim was to get an overview of the distribution of attitudes towards patient influence discussed in the focus group study. Also the quantitative approach could yield information about the relative degree of influence of these attitudes, measured here as influence on patient satisfaction and on referral decisions (as proxies of quality and resource allocation). Questionnaire survey was a natural choice of methodology as it enabled us to pose the questions most suited to our aim. Administrative register data was not an alternative source in this study as data about attitudes towards the patient's role in medical decision-making are not collected on a regular basis, and there is no Norwegian register connecting data about the individual GP to the corresponding patient data on an individual level.

As discussed in papers III and IV, we decided to distribute the patient questionnaires through their GPs, partly to secure an adequate patient response rate. This had consequences for the selections and response rate of the patients, but also for the proportion and number of GPs willing to take part in the study. The limitations created by the sampling procedure have been thoroughly discussed in the two papers. In summary, the patient response rate was adequate, but would probably have been higher if some of the GPs had not withdrawn shortly after initiating the survey among their patients. We also lack information about the non-respondents. The selection of GPs was perhaps even more problematic as only 56 of 181 GPs in Bergen agreed to participate, although we had some information about the non-respondents of this population. However, it might be argued that it is irrelevant to assess the response rate of the participating GPs in normal terms, as they were asked to carry out the data collection, which probably requires a much higher degree of commitment and trust in the research project than had they only been asked to fill in a postal questionnaire themselves.
It is not obvious what could have been done to overcome these difficulties, but in hindsight, we should have applied for permission to keep records of names and numbers of GPs during the data collection period and perhaps should have recruited by telephone.

We used an already validated scale, the Patient Practitioner Orientation Scale (PPOS), to measure attitudes to shared decision-making because of the advantages of consistency in measurement instruments for comparison of results. However, the scale has some limitations that are not discussed in the papers. According to Krupat and colleagues who developed the scale, the sharing score measures – "the extent to which the respondents believe that patients desire information and should be part of the decision making process" (142). Among the nine items of the scale, there are several items related to the sharing of information and to patient autonomy in interpreting the information, there are also items referring to respect for patients and the division of power between doctor and patient but there are no items directly related to decision-making. It is therefore somewhat unclear what the scale measures; whether the results actually measure attitudes related to decision-making or perhaps more general attitudes to patient involvement in the consultation. We know that preferences for sharing information are not necessarily correlated to preferences for sharing decisions (123). On the positive side it could be argued that the scale reflects the complexity of the phenomenon we were focusing on.

The shortcomings of the satisfaction measure are discussed in paper III. In addition to the points raised in this paper, it should be noted that although patient satisfaction is the most widely used measure of quality of general practice, it is far from being a comprehensive measure of quality and outcome (181). Alternatively, quality of referral decisions may be measured in hospital admission rates or by GP's review of degree of unnecessary referrals.

### Informant accuracy

A well-known quandary in both focus interviews and surveys is the problem of *informant accuracy* (182). It is not unusual that there is a discrepancy between people's attitudes or intentions and actual behaviour, either because of a lack of overview over one's own actions, inconsistencies in opinions or a lack of honesty (129, 183). This incongruity and its consequences for social analysis are a problem that has received attention in several social sciences. It is part of the reasoning behind the anthropological methodology of participant observation (182) and an important subject of economic analyses of stated versus revealed preferences (184). In surveys using questionnaires such as the PPOS or other patient-preference studies, it is also often difficult to know when the respondents are describing an ideal world and when they are instead implicitly correcting for what they feel is realistic to expect (176). Hence an observational study would have added to the findings. Still, because of ethical and practical restrictions, we did not consider observations of consultations as an option for this study.

In paper III, we find that preference for shared decision-making in GPs promotes patient satisfaction, while congruence in attitudes does not have the same effect. Our suggested explanation is that GPs, who claim they have an ideal of sharing decision-making, do not always act accordingly: They probably adapt their behaviour to the patient's preferences. This however, does not necessarily mean that they are dishonest when answering the survey. A UK study using focus group interviews with GPs also finds that the ideal of patient involvement in rationing decisions is adhered to at a theoretical level, but proves to be problematic in practice because the ideal of patient involvement collides with other important concerns (29). Still, an observational study would be an interesting follow up to explore the suggestion that GPs who prefer patient involvement have a more flexible consultation style. This is also what we see when we compare our finding in the survey with the data from the focus interviews: In the survey, almost all the GPs say they were more or less in favour of shared decision-making, but the qualitative study revealed that this is a dilemma in practical work. Thus it may be argued that the small variation in GP attitudes found in the survey probably is a pale reflection of the variation in consultation style. This is a reminder of what a complicated task it is to analyse clinical choices in general practice, complicated because they are made in the meeting between GP and patient with its dynamics of power distribution and negotiations, and because the two actors have separate aims and priorities.

## Discussion of results

### Study 1. GPs’ experience of the gatekeeper role.

In Study 1 the central finding was that the GPs seem to be turning away from the gatekeeper role and its unpleasant rationing decisions. One important reason for this, according to the interviewees, was that patients have become increasingly demanding and have gained more negotiating power. Our interpretation is that the patients probably are gradually influencing the GPs’ decisions more. Study 1 also indicated that the GPs are concerned about losing professional autonomy as a consequence of increased patient autonomy and increasing control by health authorities.

It is difficult for the GP to decide when the patient’s view should be overriding and when the GP should have the final word. The doctor is supposed to act in the best interests of the patient but what is meant by the *best interests of the patient*? The question of what is beneficial from the patient’s perspective has only recently been posed in modern medicine (151, 185) and the conceptualisation of it is seldom discussed in theory (26). Yet in practice it is a daily dilemma that was much discussed in the focus groups (Study 1). Central ideals for the GPs, such as respect for patient autonomy and shared decision-making, imply that decisions are made together with patients and that the patient’s subjective view will be part of the basis for decisions. For example will referrals or controls that are unnecessary according to the biomedical model, be justifiable when patients’ worries are considered in the medical decisions. In practice the GPs seemed to avoid the problematic issues of rationing by including patients’ desires in the definition of beneficial care whenever there was a conflict with an insistent patient. We interpreted this attitude as ‘avoidance of rationing’. This supports a recent qualitative study among Australian GPs, where the authors also warn that GPs may hide behind respect for patient autonomy in medical decision-making while driven by less admirable motives (138). This finding is also partly consistent with Jones et al’s study from the UK, which notes a gap between ideals and practice in rationing decisions due to conflicting concerns (29). The UK GPs, however, seemed to solve the dilemma by sacrificing explicit rationing, while they still rationed health care implicitly.

In an affluent health care system such as the Norwegian one, rationing is mainly about marginal health problems and marginal benefits, and our study indicates that most GPs are not motivated to ration under these conditions, even though they recognise the necessity of rationing under other circumstances, e.g. if there was a budget responsibility tied to the gatekeeper role. This leads us to suggested solutions forwarded by the theoretical literature in medical ethics concerned with the advocate versus gatekeeper dilemma of the GP role. Some of these studies aim to offer gatekeepers a key for managing rationing, such as, accountability for reasonableness, EBM and practice guidelines. It is recognised that saying no to patients' wishes is time consuming and risks displeasing and thereby losing patients (160). The effort is, of course, praiseworthy as transparency in medical decision-making is arguably a moral prerequisite for a balanced doctor-patient relationship. However, it is not self evident that GPs who have no budget responsibilities, will ration merely because they are taught how to overcome these obstacles. Still it is time consuming, and the risk of displeasing patients is not eliminated, so why should GPs bother to ration? Our study also indicated that in the Norwegian context, increased professional responsibility and competition discourages GPs from rationing. In conclusion, our study suggests that to Norwegian GPs the question is not so much how to overcome the obstacles of rationing so much as a lack of motivation for rationing.

Most of the dilemmas we note in Study 1 are neither new to the literature nor unexpected; both the advocate-gatekeeper dilemma, the tension of balancing care and cost, the dilemma between ideals of patient involvement and fair and efficient resource allocation, conflicts between professional and patient autonomy and conflicts between private financial gains and rationing have been described earlier. However, our study suggests that the most imperative predicament among these was tension experienced between the obligation to ration and respect for patient autonomy. This dilemma has only recently been pointed out on a theoretical level and has hardly been explored empirically. I also believe Study 1 adds to the literature on the GP's gatekeeper role in that the different concerns and dilemmas are explored as parts of a complex structure of relationships surrounding the GPs. Thus we make some first steps toward understanding how the different dilemmas reinforce or neutralise each other.

### Study 2. Outcome of attitudes to shared decision-making

The findings in Study 1 showed that the GPs were experiencing a transfer of power from themselves to the patients. Modern patients were described as increasingly demanding and competent, and the doctors' ideal of involving patients in the decision-making process, was felt as pressure to give up professional autonomy in favour of patient autonomy. However, this finding left us with the question of whether the GPs' view reflected an actual demand for influence by the patients. In Study 2 we aimed answering this question by mapping and measuring such attitudes and discovering the distribution of attitudes between GPs and patients. Another part of the motivation behind Study 2 was to test whether GP and patient attitudes towards the sharing of decisions influence medical decision-making.

Study 2 adds to the impression given by the participating GPs in Study 1 that patients would like more influence than the GPs would like to give up. Our findings could shed some light on a debate in the literature about shared decision-making, where the consensus of the majority of studies is that shared decision making is the prevailing consultation style and that many modern patients are competent and demanding (16, 126, 129, 131, 142, 186). Opposed to this are a handful of critical studies suggesting that that modern patients are not as influential as we would have expected and that shared decision-making is not a realistic description of most consultations (132). Even groups with chronic ailments do not necessarily experience increased power and autonomy in relation to doctors (134). Particularly, one of the evaluation studies conducted in connection with the Norwegian list reform suggests that chronic illness sufferers and frequent attenders do not feel that the reform has in any way enhanced their power with the GPs. They even experience that the reform has made the GPs stricter regarding patients' demand for referrals to specialist care (187). On basis of our findings in both studies I believe the academic dispute about the current level of patient involvement, may be an artefact, related to whether the studies are based on doctors or patients' experience or researchers interpretations of observational data. Together Study 1 and Study 2 indicate that the diverging views between GPs and patients might be interpreted as a testimony of the struggle for power that the GPs in Study 1 describe. The studies show that both doctors and patients' autonomy is central, and negotiated, and they somehow are in conflict. It is interesting to compare our finding to an observational study by Winefield et al, which suggests that GPs are less satisfied after a participatory consultation, which tends to last longer and include diffuse ailments. Also Haug & Lavin have a perspective of conflict on the GP-patient interaction and point to the struggle for control that takes place in consultation (188). They find that rather independent of ideals about consultation style, most GPs struggle to stay in charge in the consultation, preferably through persuasion. On the other hand, their findings are based on self-reported survey data, which of course leaves us with the uncertainty of whether they correctly report behaviour. The diverging interpretations of negotiations between GP and patient have also been discussed in a fairly recent BMJ editorial where Nicky Britten suggests, “Patient pressure may be stronger in the doctor’s mind than in the patient’s,” which underlines the noted discrepancy between the GP’s perception of pressure and the patient’s expectations (189).

In Paper IV, the findings show that if the GP is positive to shared decision-making, it is less likely that the consultation will result in a referral. It seems like this result does not support the findings in Study 1 that patients are demanding referrals, and that respect for patient autonomy induces the GP to give in to the patients’ demands. This apparent disagreement is also reflected in the literature, as studies of shared decision-making find that patient involvement seems to lower referral rates (140, 190, 191) while studies of variation in referral rates show that perceived patient pressure and the liability to give in to patients’ wishes induces the GP to refer (85, 111). Based on our two studies, several reasons for the discrepancy could be suggested: Firstly, it is possible that the impression from the focus group study (Study 1) is coloured by the researchers’ explicit focus on the gatekeeper role, causing a disproportional number of examples of demanding patients. Secondly, the PPOS-scale used in paper IV, is designed to measure preference for shared decision-making, while in Study 1 the informants are perhaps referring to consumerism; especially determined patients dominating decision-making. Another explanation could be that the informants in Study 1 refer to a package of reasons that makes them refer more, while Study 2 concentrate solely on the attitudes towards shared decision-making. Finally, a medical decision in general practice is a product of the choices and influence of at least two different actors; the GP and the patient, and it is not certain that when the patients are taking a greater role in the decisions, this results in more referrals. There are indications that patient involvement lower intervention rates (190-192). We merely observe that both parties affect decisions.

## Conclusions and implications

The GPs participating in this study left us with the impression that they are passive as gatekeepers in the interaction with what they experience as increasingly powerful patients. The GPs seem to be aiming to avoid conflict with patients because they have a lack of motivation and a scarcity of instruments for rationing. Based on the present study and what we know from earlier studies, I would argue that patients probably affect medical decision-making increasingly at the cost of the GP's gatekeeper role. This seems to make patients satisfied with their GP, but it is uncertain whether the development supports a fair and rational allocation of resources, partly because some groups are more resourceful and capable of getting adequate health services (193). The finding in paper IV that shared decision-making and congruence in attitudes decreases referral rates, is interesting primarily in connection to crude cost containment, but it points to the need for more studies of different activities and of the quality of decisions, which could reveal direct effects of how the GP-patient interaction influence distribution of services.

This thesis adds to a small but growing literature concerning the legitimate limits of GPs' responsibility and of patient demands (132, 138). Shared decision-making in general practice is an important ideal because it puts the patient's needs in focus, but the effect on resource allocation is less clear and should be investigated. Open debate about how the GP-patient interaction affects resource allocation in health care should be encouraged. There is also a need to discuss the role and limitation of patient involvement in medical decision-making.

The study illuminates the doctor–patient dyad as a central arena for implementation of priority setting in the health care sector and touches upon various insufficiently explored topics:

### Suggestions for further research

- In studies of resource allocation and GP rationing, patients' influence should be incorporated.

- Future research about the implementation of priority setting should concentrate on how to motivate and convince GPs of the importance of high quality rationing and filtering.

- Future studies of shared decision-making should also focus on quality of decisions and health outcome, combining measures of patient satisfaction with other quality indicators.

- There is a need for studies exploring how attitudes of patients and GPs are connected to behaviour. Observational or experimental studies are of interest but pose particular methodological and ethical challenges.

- Comparative and empirical studies of GPs' rationing dilemmas are needed.

### Implications for practice

- There are several reasons to promote further shared decision-making in general practice, but its content should be discussed. Particularly questions about the limitation of patients' rights and how to secure a well-functioning gatekeeper role are important.

- Medical education should promote awareness of both respect for patient autonomy and the need for rationing in medical practice. It is vital to make it clear that these principles are often experienced as conflicting in practice.

- To reinforce the GPs' gatekeeper function and thereby reduce inefficient resource allocation, evidence-based practice and more extensive guidelines combined with better monitoring could be implemented.

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# Appendices

## Appendix 1. Study 1: Interview guide.

1. Around the table: First names and a short description of your practices.
2. Do you think the terms ”advocate” and ”gatekeeper” describe central aspects of your role in relation to your patients?
3. Does the fact that you now are responsible for a patient list influence the relationship between yourself and the patients?
4. Does the responsibility for the list patients affect the way you make discretionary choices?
5. What does the new payment system mean to you?
6. Does the payment system influence the way you make discretionary choices?
7. Has the service offered at your office changed with the *Regular General Practitioner Scheme*?
8. Can you give some examples of difficult decisions concerning standard prescriptions?
9. Can you give some examples of difficult decisions concerning referrals?
10. Can you give some examples of difficult decisions concerning sickness certificates?
11. What are the disadvantages of the *Regular General Practitioner Scheme*?
12. What are the advantages of the *Regular General Practitioner Scheme*?

## Appendix 2. Study 2: Sharing score.

### Patient–provider orientation scale items (PPOS) (Krupat et al., 2000)

(1) The patient is the one who should decide what gets talked about during a visit.

(2) It is often best for patients if they do not have a full explanation of their medical condition.

(3) Patients should not only rely on their doctor's knowledge but try to find out about their conditions on their own.

(4) Many patients continue asking questions until they understand the information given by the doctor.

(5) Patients should be treated as if they were partners with the doctor, equal in power and status.

(6) When patients disagree with their doctor, this is a sign that the doctor does not have the patient's respect and trust.

(7) Most patients appreciate to take their time in the doctor's office.

(8) The patient must always be aware that the doctor is in charge.

(9) When patients look up medical information on their own, this usually confuses more than it helps.