From implementing to learning

The importance of a dialogue between practice and science in health care

To the Minister of Health, Welfare and Sport

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In response to your request for advice of January 4th 1999, I present you the report ‘From implementing to learning: the importance of a dialogue between practice and science in health care’, having consulted the Standing Committee on Medicine. The Committee that has drafted this report views the problem of implementation in the light of the aim of ‘optimizing patient care’. It is aware of the fact that a variety of factors contribute to this aim, including health care legislation and educational arrangements. The Committee has left aside these policy issues and has concentrated on professional practice in daily care. It broadens the analysis by also considering the role of patients and the organizational context. In my opinion, this is an interesting addition to the existing view on implementation, which generally focuses on transferring outcomes of health technology assessment. These additional perspectives provide a good clue for the ‘multi-track’ approach concerning implementation advocated by the Committee.

Yours sincerely,
(signed),
Prof. JA Knottnerus

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to:

the Minister of Health, Welfare and Sport

No. 2000/18E, The Hague, 20 July 2000

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Executive summary

Advancements in the scientific underpinning of medical practice and the provision of care in the broadest sense has, for some time now, taken a prominent place in the policies of the Dutch government. Much is expected from medical technology assessment (MTA), which is now often referred to as health technology assessment (HTA). This line of policy holds the view that implementing research outcomes, increasingly laid down in guidelines for professional practice, is the best means of promoting the quality of care. However, in reality the impact of these guidelines on everyday practice is either insufficient or too slow. This results in a ‘gap between knowledge and practice’, a matter referred to by The Minister of Health, Welfare and Sport in her Progress Report on Medical Technology Assessment issued on 14 February 1996. In requesting the Health Council of the Netherlands for advice, the Minister asked the Council to indicate fruitful approaches for bridging this gap.

In this report, the Health Council observes, by means of the hereto appointed Committee, that the formulation of the request for advice follows current policy thinking with respect to MTA, in which epidemiological data carry much weight, and in which guidelines are viewed as the vehicle for bringing newly obtained insights to their intended destination. Without wishing to detract from the value of MTA and guideline development, the Committee has established from the literature that there are certain limitations associated with this approach. The optimization of patient care is the Committee’s chosen point of reference. With this aim in mind, the Committee states that guidelines based on MTA results provide without a doubt an important contribution, but that other issues are also involved in the quality of the care process. In so doing, the Committee broadens the analysis of the implementation problem and distinguishes between the scientific aspect, professional knowledge and expertise, and social developments. This last aspect includes, in particular, the emergence of large organized care provision networks, patients' increased understanding of medical issues and the desire of patients to be involved in determining what constitutes good care. The Committee's emphasis of the aforementioned aspects has arisen from its analysis of the scientific literature concerning implementation and is in tune with recent calls for a broadening of the analysis. Insights from fields outside of medicine, such as the social sciences and management science, are also taken into consideration.

From the scientific literature concerning the implementation of guidelines, it is apparent that medical professionals, in comparison with other health care professionals, have made the greatest advancements with respect to the development of guidelines and that most systematic research has been directed towards the implementation of these guidelines. There is a range of scenarios. It is clear that some doctors faithfully follow recommendations, others do so in part or from time to time, whereas others scarcely follow guidelines at all. The experiences of Dutch general practitioners sound optimistic, especially in the case of recommendations with respect to not performing certain interventions. The implementation of specialist guidelines within the Netherlands has scarcely received any systematic study.

Only a limited number of studies have investigated whether or not the implementation of guidelines actually benefits patients. These reveal a mixed picture, as the effect is not always positive.

The most important conclusion that can be drawn from the diversity of studies, is that various aspects can be distinguished between the development and implementation of a guideline, each of which has facilitating and limiting factors associated with it. The successful implementation of medical-scientific insights, therefore, requires a strategic and efficient mix of targeted activities. As the circumstances under which care provision is carried out as well as its form both vary considerably, the mix applied will need to be specific to the situation in hand. A simple and uniform panacea cannot, therefore, be given. Calls within recent literature for a broadening of the theory used in seeking appropriate implementation strategies are therefore well founded.

Continuing medical education (CME) — currently often referred to in the international literature as continual professional development (CPD) — can to a large extent support the implementation of scientific insights. The same message here: a mixture of activities will provide the greatest chance of success. Interactive modalities, in which personal experience of the professionals is called upon, are especially effective. The Committee also devotes attention to the present vision of evidence-based medicine (EBM). EBM has a far broader meaning now, than when it first came into use in the early 1980s. It is currently understood to mean the use of epidemiological data whereby the meaningful deliberations of professionals, such as pathophysiological knowledge, clinical experience and patient preference, are also taken into consideration.

By broadening the analysis of the implementation problem, the context within which daily practice occurs comes more clearly in view. The Committee discusses several recent theoretical insights concerning professional knowledge and expertise. These insights provide useful viewpoints for a subtle examination of guideline implementation. Generally speaking, professional knowledge and expertise are characterized by the skilful application of ‘theoretical’ knowledge to concrete situations or put another way: being able to ‘translate’ from the generic to the specific. In the case of medical professionals this translation process effectively boils down to integrating epidemiological information (whether or not incorporated in guidelines), patient-specific data (including expressed preferences) and organizational preconditions. It therefore concerns heterogeneous data, which the professional must consider in an ordered manner, classify and integrate into the basis for his clinical decision. Where available, codified knowledge, such as that established in guidelines, can be helpful; the professional will also often use personal experience as a source of information. Finding the best possible basis for the clinical decisions in hand, is the key issue. This process is referred to as the ‘learning professional’. It is vital that ‘learning professionals’ also systematically establish and evaluate their own practice data, so as to build up a reservoir of experiential knowledge which complements the (external) knowledge from epidemiological research. Medical information technology could make a valuable contribution here.

Following on from this, the Committee draws attention to two important social developments, which are typical of contemporary society and have a considerable influence on the care process. These are the development towards larger organized care networks, due to the increasing interconnectedness of care practices, and the more vocal and better informed concerns of patients. Against this backdrop, the implementation of medical-scientific insights takes on a slightly different perspective.

The Committee argues that the professional context in health care is currently characterized by an increasing involvement in networks. Within such networks, doctors not only represent the interests of their own patients, but are also ‘actors amidst other actors’ whereby they are confronted with a diversity of interests. Professional knowledge and expertise remain the most important guiding principle for practice, yet social skills and co-operating with other disciplines are also issues. Due to this development, the process aspect of care provision is increasingly affecting the content — and thus the quality — of the care provision. It follows that management and organizational concepts are also important in health care. Assuming that the professionals in health care are by and large similar to professionals in other knowledge intensive organizations, the Committee draws attention to a concept that is currently under consideration in the business sector, namely, the learning organization. The central premise in this concept is that everyone in an organization, each at their own level, has knowledge which benefits the organization as a whole. A core task of the organization's leadership is to facilitate the production, spread and application of this knowledge, by creating a climate in which the mobilized knowledge is systematically used, whereas old habits and methods of work are brought up for discussion and new forms of work are taught. This concept, therefore, fits in well with the basic aims of EBM: continual learning must and may be required of professionals, but they must also be given the opportunities and the means to realize this.

Optimizing the care process, the central theme of this report, cannot be realized without the input of patients. The latest ideas about guideline development, the so-called third generation guidelines, are clearly developing in this direction. However, the Committee observes that the question as to how patients can best be involved in developing guidelines or, put another way, how they can best express and realize their preferences, remains far from answered. Little has been done in this large and difficult research area.

Research into factors which limit or facilitate implementation has produced many valuable insights and has also highlighted a number of gaps as indicated in the report 'Effective Implementation: Theories and Strategies' issued by The Netherlands Health Research and Development Council (ZON). The Committee subscribes to the recommendations contained in the aforementioned report. In its own report, the Committee has expressed, in a number of ways, that the optimization of the care process is a dialogue between science and practice. Changes to the context in which new insights — whether or not they are in the form of guidelines — must be applied, affect their application. The Committee has further elaborated on several aspects of these changes and indicates the need for more research into everyday practice. Insights from the social, education, and management sciences may be helpful. The value of these insights for care practice has, however, yet to be established. Research efforts should be directed towards developing coherent theories. The Committee is also of the opinion that more attention must be paid to research into the realization of patient preferences. A point which must be considered is the extent to which patients can be better involved in the formulation of research questions, and at an earlier stage.

Making concrete suggestions with respect to research that needs to be carried out, falls outside of the Health Council's remit. The Committee advises the Minister of Health, Welfare and Sport to request the Health Research Council to deliberate the direction in which research needs to develop and the manner in which this could be organized.

Chapter 1

Introduction

Advancements in the scientific underpinning of medical practice and the provision of care in the broadest sense have, for some time now, taken a prominent place in the policies of the Dutch government. Much is expected from medical technology assessment (MTA), which is now often referred to as health technology assessment (HTA).

MTA involves: “scientific research into a medical provision that is geared towards decision making and in which, in addition to medical effectiveness, one or more other aspects (economic, sociocultural, legal, ethical and organizational) are assessed. Research directed expressly to the quality of life is also considered to be MTA research” (RGO98).

The importance of this concept is apparent, among other reasons, from the fact that at the time of its creation the Netherlands Health Research and Development Council was given the legal remit of encouraging implementation. The Quality of Care Research Working Party (WOK) has for more than ten years now been conducting implementation research and the Health Research Council also has this subject on its agenda for the near future (RGO99). The Minister of Health, Welfare and Sport (VWS) in her ‘Progress Report on MTA and Effectiveness’ of 2 April 1997 formulates her thoughts on the implementation of new insights in medical practice as follows: “Medical practice should be based more on scientific underpinning than on tradition, feeling or conviction. By this, moreover, is definitely not meant that tradition, conviction and feeling should have no place in the care process. On the contrary. By implementation of research-based knowledge, I mean, in brief, the need to bridge the gap that sometimes exists between knowledge and practice” (VWS97).

1.1 From the ‘art of medicine’ to the ‘science of medicine’

Medical practice has for centuries been governed by the knowledge and insights of the time. During these times different medical schools coexisted and a varied collection of, from a current viewpoint, ineffective therapies were in vogue. About 1850, the introduction of the scientific method took hold and knowledge about the biological mechanisms operating in the human body gained an increasingly greater role in treatment. In the years following the Second World War, there was a dramatic increase in this knowledge. At the beginning of the sixties, voices were heard which advocated the view that medical practice should also be regarded as a gradually evolving scientific process. The criticism at that time was directed above all to the poor decision-making processes and the lack of transparency in medical practice.

The advent of scientific disciplines such as clinical epidemiology and medical decision-making theory in the following years offered increasing possibilities for both defining and rationalizing the medical decision-making process. Decision-support techniques, expert systems and protocol writing subsequently established their place within this framework. Authors such as Feinstein and Weed argued for a systematic approach to medical practice as they believed that this would provide the best chance of an optimum outcome (Ber95). According to the proponents, this approach should make it possible to abandon the stage of the ‘art of medicine’ and make daily practice a science. Opponents, however, feared that inflexibility would be the ultimate outcome.

Not only within medicine itself was there an insistence on the ‘scientification’ of medical practice and increased insight into the decision-making process. Outside the medical profession the demand for transparency increased as well. More vocal citizens wanted to be better informed about the ‘why’ of medical decisions. Furthermore, government and care providers in the western industrialized countries, wrestling with the rapidly growing demand for health care provision and the associated increase in costs, also insisted on greater transparency.

1.2 Definitions

Decision-support instruments include so-called ‘protocols’, ‘guidelines’ and ‘standards’. Modern developments in this field originate from the United States. Originally it involved the assessment of new medical technologies, particularly in terms of their efficacy, safety and effectiveness. In the seventies, Wennberg and Eddy among others drew attention in the medical literature to the phenomenon of inter-doctor variation. Gradually the idea surfaced that guidelines, as compact summaries of knowledge based on medical practice, could also be used to eliminate unwanted or inexplicable forms of inter-doctor variation (Ber95).

The National Institutes of Health (NIH) at the time took the lead in the development of American guidelines. The NIH method of working involved a systematic pooling of the knowledge of experts, whether or not supported by national consensus meetings. In the Netherlands, the CBO adopted this approach at the beginning of the 1980s. These *opinion-based* guidelines are known as the first generation guidelines. The second-generation guidelines are the so-called *evidence-based* guidelines: the focus no longer lies on the social process, but on the proper systematization and evaluation of the scientific literature. Process and outcome must be transparently expressed in the recommendations so that it is clear whether they are rooted in patient-related scientific research, pathophysiological reasoning or in current practice.

That guidelines are good aids to synthesizing and structuring the rapidly increasing flood of medical scientific data is actually no longer a matter of discussion. In the context of professionalization, and in view of the need to make medical practice transparent to third parties, medical professionals also understand their benefit.

Guidelines, protocols and standards are ‘packages’ of different forms of knowledge and insights into care practice. For many the terms are synonymous. That the concepts are, however, not completely equivalent has often led to confusion during discussions on implementation.

A *guideline* is a formulation of a recommended way of working. The internationally widely used description of *guidelines* is: *“systematically developed statements to assist decisions for patient and practitioner about appropriate health care for specific clinical circumstances”* (Fie90). In general, GPs in the Netherlands refer to this concept as ‘standard’.

Guidelines or standards can underpin care practice because they encapsulate medical evidence such that it is available in a highly usable form. They represent a viewpoint on what is considered correct practice. Guidelines and standards are often part of a quality promotion program.

A *protocol* is a stepwise, detailed description of medical practice or of a multidisciplinary care process in a defined patient group. A protocol is, above all, intended to clarify the question of how a specific treatment can best be implemented. Protocols are outstanding instruments, for example, for scientific research.

Implementation is an all-embracing concept for the whole process that runs from the availability of new insights, techniques, interventions and programmes, etc., to their establishment in fixed routines in patient care. In this advice, the Committee has adopted the description of the Netherlands Health Research and Development Council: “a process- and plan-based introduction of innovations and/or changes of proven value with the aim that these should achieve a structural place in (professional) practice, in the functioning of organization(s) or in the structure of health care” (ZON00).

1.3 Request for advice

On 4 January 1999, the Minister of Health, Welfare and Sport requested the Health Council of the Netherlands to advise her on the possibility of introducing improvements in the implementation of new insights — whether or not formulated in guidelines — in care provision. The complete text of the request for advice is presented in Annex A. A Committee was inaugurated on 11 February 1999 to respond to the request for advice, the composition of which is given in Annex B.

1.4 Structure of this report

The request for advice addresses two subjects. It comprises the question about factors which limit or facilitate the implementation of scientific insights and about possibilities to influence them, and the question as to the most fruitful approaches for promoting the process of dissemination and implementation.

Bearing in mind the previously mentioned activities of the Netherlands Health Research and Development Council (ZON), which have culminated meanwhile in a recent report entitled ‘Effective implementation: Theories and strategies’ (ZON00), the Committee has principally concerned itself with the second question. The first question is to a large extent answered in the ZON report which, in conjunction with this report, gives an overview of the present scientific position. In due course, the Health Research Council will advise on implementation research further to this report (Mul00, RGO99).

The Committee has principally focused on the everyday practice of medical professionals because the literature indicates that they, relative to other practitioners in health care, have made most progress with respect to the development and dissemination of guidelines and standards. In addition, the most systematic research into the implementation of guidelines has been undertaken in their practice. Although nurses and paramedics are formulating guidelines to an increasing extent, little systematic research into the implementation of such guidelines has as yet taken place (Tho98). A further reason for the chosen focus is that the discussion on implementation is conducted in the light of the attempt to achieve cost controls. Through their decisions, medical professionals have a fundamental influence on cost development in the health care sector.

Where the Committee has formulated ideas about professional knowledge and expertise and involvement in the care process and about the developments towards larger organized networks, these are geared to all practitioners involved in the provision of care.

For the sake of brevity, it has refrained from further mentioning the different professional groups.

One final remark concerns the central position of the primary process in health care, the care process, and the *direct* effect of professional practice on it. The Committee has paid no attention to legal measures and macro-economic factors and their effect on the process.

In Chapter 2, the Committee discusses the results of implementation research currently available. Initially this research was geared primarily to the factors limiting or facilitating the implementation of guidelines. This may now be called a ‘narrow’ perspective on implementation in view of the arguments to broaden this perspective through incorporating viewpoints from the social sciences (particularly professional socialization theories), educational theory and management sciences. This has encouraged the Committee to elaborate on a number of these viewpoints in greater detail; subsequently, the nature of professional knowledge and expertise (chapter 3); the developments towards larger care networks (chapter 4) and the position and the preferences of patients (chapter 5). The Committee presents its conclusions in Chapter 6.

Chapter 2

The present scientific position

Although medicine and health care underwent major changes in the second half of the last century, the basic relationship — that between doctor and patient — has remained unchanged (Mol99). The timeless background canvas of medicine and its equally timeless primary aim — the provision of optimum care — have of course evolved over time. According to the request for advice, the Minister sets great store by the rapid implementation in practice of systematically collected information on the effectiveness of diagnostic, therapeutic and care procedures. With the onward march of information technology in particular and the ascendancy of epidemiological research, health care professionals now often have a choice of data on which they can base their decision. The flip side of the coin is that the integration of the many sorts of data is, in most cases, far from easy. Recently in this context the Editor of The Lancet even referred to ‘information wars’ (Hor99). Health care professionals are confronted with information from more sides than ever before.

Typical of the present time is the fact that the relationship between doctor and patient has become inextricably linked with social developments. The primary process is becoming increasingly embedded in larger organized networks. Developments such as the specialist medical service, the health centre and initiatives in the area of transmural care are eloquent examples of this. With this increasing interconnectedness, the quality of care provision is in part dependent upon the co-operation and good agreement between the professionals concerned. Furthermore the information culture is affecting the patient’s position. Although the professional is more knowledgeable, the patient is becoming increasingly better informed about what health care has to offer and is also encouraged to be more vocal. And last but not least there is the drive for effectiveness and cost containment.

Opinions may differ about the assumptions to be adopted here and the methods of calculation to be applied, yet talking to patients about money is no longer wrong in itself.

From this brief survey, it will be apparent that professionals in health care are confronted by both scientific and social dynamics and that, therefore, their actions in very general terms can be viewed from both a scientific and a social viewpoint.

This chapter concerns the question of how the individual *medical* professional practice is influenced by scientific dynamics. Or put into other words: what is known about the effect of guidelines on clinical decisions.

2.1 The medical professional approached scientifically: compliance with guidelines

2.1.1 General impressions

In Chapter 1, the Committee indicated that the request for advice reflects the general way of thinking about how science has become the cornerstone of medicine. Nowadays, reference is often made to *evidence based medicine* (EBM). This expression can give rise to misunderstandings; for example, that medical professionals have only recently been in a position to take decisions based on scientific data. According to modern scholarly opinion, the search for medical evidence has certainly had a tradition of over two centuries (Wie99). For a long time the emphasis was on pathophysiological reasoning. Clinical epidemiology is a branch of science that has only blossomed very recently. Here the gold standard for the determination of effectiveness is the *randomized controlled trial*, RCT.

Scientific information about the possibilities and limitations of medicine has grown dramatically in recent years. Around 1988, more than 5,000 RCTs were published annually. Ten years later that number had increased to more than 12,000 annually (Sac00). Even though job specialization has occurred and medical professionals are in fact concerned with larger or smaller subsectors of medicine, yet the developments in each specialist area are difficult to take on board simply because of their scope and pace of development. Furthermore, previously mentioned developments in society such as patients becoming more vocal, the growing attention to efficiency and the greater interconnectedness between care practices, also affect everyday medical practice. It is, therefore, not surprising that medical professionals have a greater need than ever before for support and advice in their decision-making. In addition, patients, regulatory authorities and insurers also want to know why one thing is done instead of another. In other words, society, more than ever before, demands ‘transparent medicine’.

The flow of data concerning the effectiveness of medical procedures and interventions can be channelled in various ways to the benefit of medical decision-making. Manuals and textbooks have for long represented an accessible medium. As a rule they remain fairly general in their considerations. Review articles in journals can highlight topical matters well, but cannot go into too much detail of practical importance. In the opinion of many, guidelines come closest to achieving the ideal: scientific information adapted to medical practice.

The seemingly endless number of guidelines is hardly surprising when one considers the many subsectors within medicine and the large number of players in the field of health care. In 1997 the American Medical Association counted approximately 2,200 (Mil98). This relates to the United States, the cradle of the guideline movement, and no attempt has been made to classify the guidelines in terms of quality and area of application. In other industrialized countries, however, the numbers also show a marked growth. Thus in the United Kingdom there are currently estimated to be several hundred and in Germany almost a thousand (Day98).

Discussions on the quality of medical practice reflect the culture of the country and are associated with the structure of the health care system involved. National developments and experiences are, however, not entirely independent of developments elsewhere, even though extrapolation of their predictiveness to other countries always requires further analysis. It is useful, therefore, to give an assessment of the general outlines of research into guideline implementation. This general outline may serve as a background against which the Dutch situation can be set in relief.

The Committee notes that research into the effect of guidelines on medical decision making has enjoyed increasing interest, particularly since the 1990s. In 1999 a publication appeared in which reviews of guideline implementation were commented upon and assigned a quality score (NHS99). Recently, the Netherlands Health Research and Development Council issued a report entitled: Effective Implementation: Theories and Strategies. Reviews of the factors limiting and facilitating implementation and current theories were incorporated and discussed here (ZON00) These two ‘reviews of reviews’ are important for this report, because here the Committee is not concerned with the effect of this or that recommendation on this or that area of medical practice, but with the general question about the motivation of medical professionals for their professional decisions and their way of dealing with guidelines.

Seven reviews, to some extent updates of previous publications, are specifically devoted to the implementation of guidelines (Dav97, EHC94, Gri94, Lom91, Tho98, Wen98, Wor97). Together they examine several hundred reasonably to well designed studies taken from the last 25 years. The studies cover a large number of subsectors and medical professional groups, with a marked over-representation of American experiences. Globally, the effect of guidelines is measured in two ways: by indicators of the activities of medical professionals and by measures of patient outcomes. The first method is the most widely used, although change in professional behaviour is naturally not an aim in itself but a means of achieving an improvement in care provision.

The studies are highly heterogeneous and the results no less so. Some doctors show little interest in the recommendations in guidelines, others sometimes follow the recommendations or part(s) of them, whilst still others strictly adhere to them. One of the reviews mentioned strikingly illustrates the heterogeneity (Gri94). Twenty-three studies are considered here, with a total of 143 recommendations on 70 different partial aspects of medical practice. On average the recommendations appear to have been followed in 55% of the decisions. The variation about the mean ranged from almost 0% to 100%. Effects of the use of guidelines on patients have been much less studied; research shows a positive effect in a minority (Gro99b).

The course of the implementation process appears to be affected by a varying complex of determinants for different practice situations. Some determinants relate to the conclusiveness of the evidence contained in the guideline or to the straightforwardness or complexity of the recommendations formulated. Others relate to the possible involvement of non-medical factors, such as financial interests, time invested in the change of practice, organizational or structural provision or patient co-operation.

Guideline implementation strategies are often viewed in conjunction with strategies for guideline development and dissemination. As yet, little thorough research has been devoted to the effectiveness of these diverse strategies. However, some indicative comments may be made about factors that increase the likelihood of adhering to guideline recommendations (Ber98, Gri93, Gro99b, NHS99). An important factor in the usability of a guideline concerns the persons involved in its development. The more users, or their opinion leaders, have been able to exert an influence, the more the application of guidelines appears to have a favourable outcome. The same holds true if greater allowance is made for local circumstances. Externally imposed recommendations or those that ignore local practice are rapidly considered less relevant.

Giving guidelines a ‘made to measure’ element clearly seems to benefit their dissemination. Interactive forms of information provision and training in which guideline users can incorporate their experiential knowledge appear to be relatively successful, whereas the passive dissemination of journals or other publications cuts almost no ice.

For actual implementation — which in the end must be apparent from changes in practice — most is to be expected from a mix of strategies.

The main conclusion is that no single approach provides success under all circumstances. Potential new obstacles will have to be detected at every turn. This diagnostic phase is a precondition for being able to choose an effective mix of activities tailored to the situation and the context at hand. Elements that have proved valuable are local consensus and feedback procedures and aides-mémoire that can be accessed via a computer for the treatment of a specific patient.

2.1.2 *Dutch experiences*

The Netherlands has seen two major national programmes for guideline development: that of the Netherlands General Practitioners Association (NHG) and that of the Quality Institute for Health care (CBO) — specifically for medical specialists, nurses and paramedics (Kis97). In addition, a number of other organizations, such as hospitals, advisory boards and professional associations have undertaken activities that might fall under the term ‘guideline development’. The need to develop strategies to successfully implement the outcomes of these different activities was also pointed out at an early stage in the Netherlands (Gro90).

Despite increasing interest in implementation strategies, until now few results from empirical research into the implementation of guidelines are available. Relatively much is known about the effect of guidelines on general practitioners’ decisions. According to a study in 1994 among 15 general practitioners with more than 23,000 patient contacts between them, the influencing of professional practice by guidelines does not automatically coincide with a positive effect in patients (Sch94). Thus no improvement in high blood pressure or indicators of diabetes was demonstrated. Recently, the final report of another extensive study among general practitioners conducted by the Quality Research Working Party was published (Spi99). In a representative group of 200 general practitioners, an investigation was undertaken to establish how far they followed NHG standards in their work. More than 70,000 medical activities or decisions were considered for assessment. On average, the recommendations appear to have been followed in 72% of cases. Of these, more than 65% involved recommendations in the standards to perform certain actions and almost 80% recommendations not to perform certain activities. There was however a large variation both between general practitioners — some reliably followed the recommendations, others almost not at all — and between standards. The high score in the non-performance of specific treatments is striking. The Committee finds these figures very encouraging. In any event they compare favourably with the international picture outlined in the previous paragraph.

Little systematic research has been done with respect to the implementation of specialist guidelines. In most cases there has been an ‘in-house’ investigation into the use of certain guidelines (Koe96). There then appears to be a mix of similar limiting and facilitating factors to those mentioned previously. There are no indications that the picture for the Netherlands differs from that presented by the international literature (Kis97).

2.2 Support other than via guidelines

Although the emphasis in the request for advice lies on guidelines, it is useful to devote some comments to the efficacy of other methods and techniques that can play a role in supporting medical practice. The aforementioned ZON report and the National Health Service (NHS) review publication also discuss results of research into different activities, for instance in the areas of information and of computer assisted control and feedback. As with guidelines the effectiveness appears to differ markedly. Under certain circumstances almost all the activities show some positive effect, but so far no single one appears as a panacea (NHS99, ZON00). Developments here are however not at a standstill. Thus, for instance, an electronic system has been developed at the Transmural & Diagnostics Centre in Maastricht, the GRIF reminder system, in order to give the general practitioner direct feedback when requesting supplementary diagnostic examinations (Bin00). The system issues a warning if insufficient data have been entered or if the working hypothesis or the reason for the request have not been completed. The system is developed to obtain better conformity with existing guidelines on supplementary diagnostic examinations. It is still in its test phase. Developments in the field of electronic patient records appear to offer good possibilities for checking the results of one’s own actions interactively against general epidemiological data (Gar98a).

A similar message of differences in effectiveness comes across in the area of activities in the field of continuing medical education (CME). According to the extensive reviews, certain individual activities, such as working with *opinion leaders* and the use of patient-specific information systems, can often positively influence doctors’ actions and regularly show a favourable effect on patients. Other activities, such as audits and the passive dissemination of information material, rarely appear to achieve anything. Here again, a mix of activities in most cases offers greater prospects of success. Passive forms of continuing education, such as conferences, workshops and lectures, have little effect on medical practice. Conversely, more interactive modalities, in which a clear appeal is made to participants’ own input, do appear capable of producing changes in practice, particularly when participants work together in small groups with colleagues. A familiar environment is a precondition for vocalizing concerns about a particular way of working. Internationally, the term continuing professional development (CPD) is coming into fashion (Pec00). CPD does not only refer to continuing scientific education, but also to training in the field of management, co-operation and social skills.

Various authors argue for a greater input of modern educational theories, such as the problem-based approach, and theories on professional socialization (Abr99, Mau99, Pec00). They find that insights from these disciplines should be introduced into medical educational programmes which must be more tailored to daily practice than is often now the case and which — this is essential — remain open to incorporate local or regional care patterns. The effectiveness of such programmes, however, has as yet been insufficiently evaluated to comment on their educational value for care practice.

EBM deserves separate attention. A few years ago individual doctors highlighted the fact that the best conceivable practice consisted of a mix of clinical expertise and insights from the best conceivable scientific research, which could be used to underpin clinical decisions that were adapted to the wishes and values of the patient (Sac97). They appealed for a change in the training of doctors, which should be based less on authority and the transmission of knowledge, and more on the development of skills to use insights from corroborated scientific research. EBM is intended to reduce the gap between knowledge and practice and to influence care practice directly. The key issue is that professionals need to be aware of the necessity to underpin their actions in practice as much as possible. This requires not only tracking down knowledge that is available in (summaries of) the scientific literature, but also developing skills to 'translate' this knowledge in making decisions with respect to individual patients (Gre97, Wel00). The key concepts

EBM can be seen to be described in the literature as an impoverishment of care provision through the emphasis on codification and formalization (Cha97, Ged97). However, for the pioneers and their successors it is the adequate professional reaction to universally expressed concerns for the underpinning and justification of practice, with optimising care practice as its focal point. At the same time, it is clear that the EBM approach requires fundamental changes in education and research policy and that it must be associated with the widespread use of information technology to facilitate the search for data.. This requires efforts that will not yield visible results in the near future (Gar98).

2.3 The importance of theoretical broadening

In the literature of the last few years, increasing attention has clearly been devoted to the viewpoint that implementation processes can be divided into various phases. Various barriers are associated with these phases, which can be overcome by specific activities.

Thus according to a recently published review, at least seven sorts of obstacles may be distinguished (Cab99):

- people are not aware of the existence of a guideline
- people know that there is a guideline, but are insufficiently acquainted with its content
- people do not agree with the contents of specific recommendations
- people consider themselves insufficiently capable of following the recommendations
- people have little trust in the outcome
- people find it difficult to break away from ingrained habits
- people see themselves confronted with external difficulties, such as patient preferences and insufficient facilities.

By systematically examining these aspects, it is possible to detect problems that are typical of a practice situation in order to eliminate or reduce them subsequently through specific interventions. Some investigators have developed this stepwise approach to the individual aspects further (Dav97, Gro97, Mou99, NHS99). They devise a cyclical procedure:

- make a strategic plan with interim aims
- examine how far the aims are achieved by the implementation of the staged plan
- introduce any changes in keeping with the findings.

Yet again it boils down to finding the exact diagnosis in the practice situation and adapting implementation activities accordingly. These investigators also advocate the broadening of the implementation perspective because it is apparent from previous research that practice is not only influenced by the state of medical science. Cultural aspects, characteristics of the discipline, training programs and context-specific factors play a role in everyday practice as well. The same holds for the organizational setting, financial factors and opinions about the allocation of time and energy between the different aspects of medical practice. The investigators call for the application of insights from the social, education and management sciences. Thus, it may be better understood how professionals think and act, both as individuals and as actors within organized networks.

The Committee concurs with these arguments. Broadening the theoretical basis appears to be necessary because it is apparent now that there is no clear one-to-one relationship between specific theories and concrete implementation strategies (ZON00).

This survey of the current scientific literature draws the Committee to its conclusion that the available information about the implementation of guidelines and other forms of synthesized knowledge does not provide a coherent picture. However it is clear that if implementation is to succeed, then as a rule no simple strategy will suffice. According to scientific analyses, it is once again a matter of finding an appropriate mix of strategic instruments. Further research will be needed to reveal the mix that will be most successful for each situation.

Implementation of new insights — whether or not in the form of guidelines — is not an aim in itself. It serves to optimize patient care. To that end it is an important, but not an absolute precondition. Bearing in mind the optimization aim, the Committee wishes to discuss a number of other topics that are of major importance for the quality of care and which precisely at this moment leave their mark on the care process.

Chapter 3

Guidelines and professional practice

As remarked previously, guidelines are essential instruments for underpinning the care process. However, their application is seldom a matter of just pressing a button. Skilful application of guidelines always requires familiarity with the subject in question.

In this chapter the Committee briefly examines the different phases which characterize the development of guidelines. Authors of guidelines have gradually found that 'effectiveness' of medical care is multidimensional and that it involves a normative concept. Medical interventions often have different effects in the shorter or longer term and the assessment of the effectiveness depends on the value attached to each of the effects concerned. This means that the wishes and values of patients themselves can be of fundamental importance in assessing effectiveness.

The Committee then examines some facets of the —mostly tacitly implied — characteristic of professional experiential knowledge. It discusses briefly the predictiveness of different types of data, how professionals think and reason and the lines along which continuing professional development can run.

3.1 The development of guidelines

Originally guidelines often came about through a relatively non-transparent consensus procedure based heavily on the opinion of experts. These first generation guidelines are currently, for the most part, known as *opinion based*. With the advent of *evidence based medicine,* the creation of guidelines became a more scientific affair since methods such as meta-analyses and systematic *reviews* became increasingly available for organizing large quantities of data, among others through the Cochrane Collaboration.

In the second generation, *evidence based,* guidelines, scientific data are central. Scientific data alone, however, rarely lead to unambiguous recommendations for practice. Guidelines also inevitably contain non-scientific considerations. At present, particular attention is being devoted to the conclusiveness of the epidemiological information used and to the explication of underlying considerations and assumptions (Day98, Kis97, KMNMG00).

It is apparent that different groups can assign different values to the same scientific data in the light of their intended goals. In the Netherlands, a recent example is the NHG Osteoporosis standard (Cro99). To the opinion of a specialist the Standard does not serve patient interests, while a general practitioner considers that the recommendations do justice to the average patient. This controversy is partly attributable to the lack of hard evidence on the benefit of certain interventions, which the Health Council's report 'Prevention of osteoporosis-related factors' has also pointed out (GR98), and partly to differences between patient groups that practitioners see in their practice. Insufficient evidence inevitably results in differences of opinion on the most desirable treatment. Similar differences have been described for rheumatoid arthritis and for CVA (Bos97).

An example from abroad is also illustrative here. Cardiologists from Toronto proved very hesitant in following American and Canadian guidelines for hormone replacement therapy in female cardiac patients (Gro99a). With good reason, according to one commentator: the guidelines were not based on results of randomized studies. The first results of randomized study in this field appeared in 1998 and it then became clear that a positive effect could in fact not be demonstrated.

There are also examples of guidelines which have been readily adopted. In the Netherlands, a well-known example is the guideline for acute ear inflammation (Gro99b). When research convincingly demonstrated that paracentesis did not yield a better result than non-intervention, within two years almost no more ears were pierced. In the United States, Harvard Hospital's anaesthesia guidelines found universal acceptance within two years of their publication, as the evidence provided was so convincing (Mil98). A certain amount of reticence in following guidelines may be justified. Analyses in various countries reveal that at present too many guidelines fail to stand up to criticism (Gro99b). Fortunately, increasing attention is being paid to the assessment of the quality of guidelines. In the United Kingdom, a methodological instrument has been corroborated for assessing the quality of guidelines. This involves aspects such as: how systematic and structured the guideline formulation was, its scientific content and the context for which it is intended and the ease with which the guideline was introduced and applied (Clu99). In the wake of this, a European Biomed project is now underway in which an attempt is being made to develop an assessment instrument for European guidelines. In this considerable emphasis is being placed on the assessment of the goal and scope of the guideline, the involvement of interested parties and a careful and clear formulation of the recommendations. Furthermore, a justification of the nature of the data on which the recommendations are based as well as the application possibilities, are included in the assessment (ZON00). In the third-generation guidelines currently under development, the aims have been extended. Means are being sought to incorporate data other than medical scientific findings, such as patient values and cost components.

The inclusion of cost components in guidelines remains, however, problematical. The results of cost-effectiveness calculations appear very sensitive to the assumptions used (KNMG00). Around the world, doctors appear to have difficulty in accepting a definition of ‘appropriate care’ in which financial arguments play a clear role. There is a tension between patient interests and costs that is difficult to eliminate (Day98). The Committee’s opinion is that aspects of efficiency must take second place in the development of guidelines. First and foremost guidelines serve to underpin professional interventions in care practice. The principal interested parties are care providers and their patients. In establishing guidelines, professionals — where possible in co-operation with patients — must take the lead.

3.2 Different types of data

Doctors are obliged by their professional oath to help their patients to the best of their ability, in other words according to the best medical insights. Viewed in this light, the implementation of new findings, or in other words EBM, is a fundamental characteristic of medical practice.

With the advent of EBM at the end of the 1980s, a discussion flared up about the tension between ‘casuistics’ and ‘statistics’ (Cha97). The initially strong emphasis on clinical and epidemiological knowledge — preferably obtained via RCTs — as the *best evidence* and the hierarchic approach to different types of information were the basis of this discussion. Put simply, the problem is: to what extent does a specific patient resemble the average patient in clinical research?

During the past few years, various parties have referred to the limitations of generic epidemiological information whenever specific clinical decisions are at stake (Kno97, Log96, Nay95, Ton99, Van98, Wel00). The beneficial effect of some systematically studied medical interventions may appear minor, albeit that patients say they have benefited from them, as benefit and risk are very closely aligned with one another. Another problem is that clinical research must soon be abstracted from patient preferences. These preferences, however, should be in the forefront in daily practice, certainly at the present time. Both points make it clear that clinical epidemiological data does not always provide clear-cut answers.

Further to this, there is the criticism expressed by epidemiologists themselves that epidemiological studies, meta-analyses and guidelines do not always contain a clear definition of their study subject or may well have introduced classifications whose value for care practice is dubious (Mie98). Nevertheless, good epidemiological information does in fact offer an interpretative framework for the assessment of specific cases.

At present EBM — and rightly so in the opinion of the Committee — is more broadly defined than at the time of its appearance more than ten years ago. In the current view, it involves the application of epidemiological data, while taking into account what professionals themselves consider significant, such as pathophysiological knowledge, clinical experience and patient preferences. The use of epidemiological evidence — whether or not encapsulated in guidelines — always requires considerations — whether or not in co-operation with the patient — that are tailored to a specific situation. In other words, clinical practice always involves the ability to establish a significant relationship between different types of data, making context-specific associations between ‘knowing how’ and ‘knowing that’. This is the essence of professional knowledge and expertise.

3.3 Professional knowledge and expertise

Applying generic knowledge to specific situations is a professional skill which is developed ‘on the job’ (Era94). It involves both the use of explicit knowledge obtained from manuals, scientific literature, data banks and the like, and implicit ‘experiential knowledge’ built up over the course of time in different practice situations and from countless patient contacts. The ability to establish meaningful relationships between the two is a skill that takes time to acquire, as it requires at every instance a sharp eye for detail and a good assessment of the significance of different types of data.

Epidemiological knowledge has the advantage of offering means of comparison between more or less related clinical situations, but at the cost — as has already been said — of being abstracted from a larger or smaller collection of patient-specific characteristics and from location-specific circumstances. Being able to ‘translate’ from the generic to the specific is the core characteristic of an individual’s professional knowledge.

When the subject of ‘translation’ arises, it is mainly in very vague terms. Even so, the reasoning process of medical professionals, especially the diagnostic process, has for a long time now enjoyed considerable interest. In a nutshell, developments have proceeded from the study by Elstein and colleagues which yielded the so-called hypothetical deductive model (Els78), via the study of the function of the long-term and short-term memory in medical problem solving, to the question of how medical professionals take decisions in their daily work (Pat96). Research in the first two phases was principally undertaken ‘under laboratory conditions’. Above all, this provided information about the manner in which ‘school knowledge’ is organized in the memory, about reasoning strategies, pattern recognition and domain-specific definitions of knowledge and expertise. These findings have made a considerable contribution to understanding the manner in which, and the conditions under which, professional knowledge and expertise are acquired (Abr99). This research has recently been extended to the workplace and has been dubbed research into the ‘working world of practice’. Here, in addition to professional socialization and educational theories, philosophical concepts about the type of knowledge that is involved in medical practice also play an important role. Research done in this area is more qualitative than quantitative in nature and extensive use is made for example of anthropological and ethnographic research methods (Pat96).

Although opinions about the exact course of medical professional reasoning and decision-making processes differ, a general characterization is nonetheless possible (Ora93). Firstly, medical problems are often poorly structured problems. Taking decisions is difficult and alternatives seldom present themselves in a clear way. In addition, different treatment options can counteract one another. In the second place, decisions must often be taken in the light of contradictory or incomplete information. Sometimes the problem is complicated by the patient’s rapidly changing situation. This means, thirdly, that a chosen sequence of interventions must often be revised. This entails the difficulty of not always being able to clearly establish whether the observed effects after a specific intervention are in fact the consequences of the intervention or whether they still derive from the underlying health problem. Fourthly, professionals from different disciplines are generally involved in the case of difficult medical problems, not all of whom necessarily share the same opinion about the interventions to be performed. It is preferable that all of those involved subscribe to a decision made which requires deliberation, persuasion and convincing. And finally there is always the pressure of time.

Medical professionals feel most at home with deterministic lines of argument based on pathophysiological insights and personal experience (Tan94). This means they will try to attribute significance to a specific situation by bringing out the underlying relationship between factors, which in their knowledge and experience determine the patient’s condition. Some philosophers consider that the reasoning and decision-making of medical professionals is not far removed from the ‘art of interpretation’ which assumes a considerable place in the humanities (Ber91, War86, Wul90). Probabilistic information appears to be used mainly to avoid risky interventions. In other words, the generic and probabilistic has more of a limiting function, while the specific above all acts as a compass (Tan94).

3.4 The learning professional

The need for a fruitful synthesis between pathophysiological reasoning and the incorporation of epidemiological data is being mentioned more often these days. At the same time the difficulties to bring about the appropriate integration of heterogeneous data are well recognized. In various recently published articles, a more structural approach to what is often loosely described as ‘translation’ has been advocated. These articles argue for fostering the argumentative skills of doctors (Dic98, Gre97, Hor98). This involves an orderly classification, discussion and evaluation of different categories of data using insights from argumentation theory (Tou76). Such patterns of reasoning should not be viewed as a new cookbook which in a manner of speaking adds other recipes to the guidelines, but more as an aid for dealing with different types of medical data, uncertainties therein, patient preferences and peripheral organizational conditions. As the Committee noted previously, this involves EBM in the broad sense attributed to it by many at the moment.

Whenever new scientific data become available, a discussion about the status of the evidence will arise. Behind this lies the question of where codified information is helpful and where professionals above all must draw on experience. The constant search for the best available information for optimising patient care brings into discussion the concept of the “learning professional”. Learning by professionals is not an independent activity, but part of their care practice. Learning not only means that one’s personal knowledge is supplemented by something ‘from outside’; it is just as much a matter of reassessing one’s own experience under the influence of new information. Modifying professional knowledge is thus difficult, because this also in fact requires something like the ‘deconstruction’ and ‘deroutinization’ of established experience to make way for the incorporation, the implementation, of new insights. Findings from evaluation research into continuing medical education, which indicate that changes in behaviour can be effected via interactive modalities in which a clear appeal is made to participants’ own input, fit in well here.

Learning by professionals also means, in the view of the Committee, that they must examine their own practice through ‘epidemiological spectacles’ so to say, and consider their own observations and experience *systematically*. The term *systematic* implies that drawing conclusions from daily practice data must fulfil the relevant statistical requirements. Experience as a source of information then evolves into more than just the sum of different observations in time and space. Medical information technology is an important tool to this end. As a result of the markedly improved automation possibilities, professionals can increasingly establish and evaluate their own practice data, for example using the electronic patient record. Recording and search systems are becoming constantly more user-friendly and are catering more and more for practical requirements in everyday practice (Bin00, Gar98a, Hun98). Systematically acquired practice knowledge constitutes an essential supplement to the ‘external’ knowledge from RCTs. The Committee holds that professional associations and the government must promote and facilitate this research into everyday practice during the coming years.

Chapter 4

Quality of care processes in organizations

The previous chapter centred around the individual professional with his knowledge and expertise. In this chapter, the Committee examines the position of professionals in organized networks. Over the last few years a development may be observed towards an increasing interconnectedness of care practices. ‘Care processes’ and ‘care chains’ involving professionals from different disciplines and different practices are becoming more the rule than the exception. The government is also promoting the development of larger care networks. An example of this is the emergence of transmural care.

4.1 Networks

Professionals in health care increasingly have to participate in networks in which, apart from representing the interests of their own patients, they are actors amidst other actors. So they face a variety of demands. Professional expertise and competence remain the core components of their care practice, but social skills and a co-operative attitude are now also issues. Optimization of the care process may, for instance, require logistical changes or changes in responsibilities. *Intensive care* (IC) treatment can serve as an example here (Kla99). In the past, various specialists used to work in this department without there being clarity about the ultimate responsibility. Co-operation was principally a matter of how individuals perceived it. Nowadays, hospitals often appoint an intensive care specialist as head of the IC. Of a totally different nature, but also to be classed under the term ‘networks’, is the increasingly formalized involvement of specialists in management. Under the flag of ‘management participation’, professional practice is increasingly becoming an integrated part of hospital practice.

General practitioners are increasingly more often organizing themselves in general practitioner groups within which they differentiate by specific areas, for example diabetes, COPD or mental problems. Underpinned by government policy, the National Association of General Practitioners (LHV) and the Dutch College of General Practitioners (NHG) are currently developing a way of care practice in which the practice nurse will assume an important position, including the periodic monitoring of patients and preventive activities.

Rapid advances in information technology can further eliminate traditional practice management (Kla00). At present patients requiring highly specialized care are referred to specialists at specific locations. Transfer of specific knowledge also often occurs via personal consultancies. Medical information technology possibilities, however, will further extend and facilitate the exchange of knowledge. Specific knowledge will become available at a variety of locations, and networks of knowledge and care will become increasingly more important.

4.2 Total quality management

The development towards greater organized networks has to be viewed in conjunction with the increasing attention being paid to improvements in the quality of the *process side* of care provision. As a result, organization and management concepts have also become important for health care. Berwick, for example, introduced a concept from business, *total quality management*, into health care (Ber89). He was motivated by the dissatisfaction of many workers in the American health care sector with the then prevailing concepts of management in care institutions. In his provocative article, the “Bad Apple Theory”, Berwick describes how managers using the pretence of quality improvement tend to explicitly or implicitly propagate the idea of ‘the rotten apple in the barrel’ by principally attributing the deficiencies in the quality of care provision to a lack of dedication by employees. Their way to improve quality of care is to institute all sorts of control instruments based on measurable parameters, ignoring the fact that important aspects of care provision, such as offering support, providing comfort and bonding with patients, cannot easily be measured. With the introduction of total quality management into health care, Berwick also pleaded for the integration of different aspects of care processes overstepping the boundaries of disciplines and departments. The idea is basically that in striving for good outcomes not only individual activities and decisions count but that the course of a care process throughout the entire organization is equally important. Thus the interaction between the various aspects of a care process is also a determining factor in quality. Such an integral approach requires major contributions from all those involved in terms of co-operation, consideration, agreement. This is one cornerstone. The other is the strongly initiating and facilitating role of management: foremost is that managers position themselves as ‘leaders’ of change and co-operation. In health care, such matters as a ‘patient-oriented view’, ‘involvement in and respect for professional practice’ and ‘continuous and systematic monitoring of practice processes, are central (Ber95, Blu98, Laf89, Sche00). Or as some say: leadership in health care is about convincing and persuading more than about controlling; about inspiring more than about exercising power; about bringing together groups and parts of the organization more than about dictating rules; about negotiating more than about pressuring (Min99).

During the past ten years, total quality management as a concept has certainly influenced quality of care strategies in health care institutions. Although implementing the concept as a whole throughout the entire organization is difficult, there has often been success in partially introducing aspects of it (Wal97). However, critical comments also need to be made. These basically boil down to the fact that quality projects initiated by management too often are merely organizational and carry too little consideration for individual expertise. Up till now the control-related aspects of quality thinking and the drive to change internal structures in the hope of reducing tensions between management and professionals appear to have had the upper hand (Cas98, Meu97). In a systematic review of the literature, no clear evidence could be found for any positive effects of total quality management on actual care provision, whether in terms of health outcomes or in experienced health benefits (Sho98). Others point to the fact that measuring outcomes of non-medical activities in patients is always difficult. They emphasize that the success or failure of total quality management is to a large extent related to ‘leadership’ (Blu98, Min99, Wal97).

4.3 The learning organization

In the business sector a change in opinions about tensions between management and professionals is more apparent now than a few years ago. One argues that it is too simplistic to describe these tensions as unavoidable. Concepts such as ‘knowledge-intensive organizations’ and ‘knowledge networks’ testify to this changing view of the relationship between professionals and organization (Weg97). No longer is contrast the central issue, but the question how the production, dissemination and application of knowledge can be promoted in order to achieve *common* goals. This endeavour is well described under the term ‘learning organization’. The term was introduced more than twenty years ago by people like Argyris and Schön (Arg79). Insights from psychology and sociology that on the one hand throw light on the characteristics of professional knowledge and expertise, on learning by professionals, and on their ambitions and loyalty, yet on the other hand emphasize among managers, above all leadership and belief in the quality of the professionals are important points of reference here. This concept is now also beginning to gain acceptance in health care (Dav00, Gar99).

The concept of the ‘learning organization’ generally refers to a group of people, most of whom have decided to pursue the same verifiable ideal or goal together (Weg97). The central idea is that in an organization, all employees, each at their own level, have knowledge which can benefit the organization as a whole. Mobilizing this knowledge is the core task of an organization’s leadership. The organization as a whole benefits from a climate in which the mobilized knowledge is systematically propagated, while ingrained habits and methods of working are brought up for discussion and new methods of working are learnt.

The concept of the ‘learning organization’ in this sense fits in well with the view that EBM rests on an uninterrupted professional learning process. The so-called Breakthrough model may be seen as a specific crystallization of this learning process. The model has demonstrated its success in the United States (Kil98) and in the meanwhile has also been adopted in Sweden, Norway and England. Under the name DOORBRAAK-program the Quality Institute for Health care CBO is instituting this method of working in the Netherlands.

Central in this model stands the care *process*. Professional practice is regarded as the motor for the optimization of this process. The ever present gap between available knowledge and daily practice is taken as a starting point. At the same time examples, *best practices*, are known, showing that the implementation of certain new ways of professional practice have resulted in improvements in the care process. From these *best practices*, experts distil principles which can be adopted by professionals themselves and adapted to local circumstances. Results from implementation research may be recognized in this approach. It is not simply a matter of gratuitously copying what has previously been discovered, but of *re*discovering, equipped with a suitable set of instruments, the possibilities for improving the care process in one’s own organization. If various care institutions, supported methodologically in this way, undertake the same care process at the same time, this has a stimulating effect because advances and results can be exchanged in the interim. This approach is also suitable to incorporate guidelines into local care processes. Implementation research showed the importance of allowing room for local variations and for certain aspects which are relevant to daily practice.

A second aspect which this concept caters for is that of countering the so-called *not-invented-here* syndrome. Professionals are sensitive to possibilities of bringing their own experience to a project.

A third — but certainly no less important — aspect is that the central positioning of the care process obliges co-operation between different groups of professionals. Professionals themselves begin to see that working solo conveys the impression of being out of date. Even more so they see that they are important actors in the organization of new forms of patient care. That was the reason for the Annals of Internal Medicine beginning a series, in 1998, under the title: *Physicians as leaders in improving health care* (Ber98). In a number of articles, professionals gained assistance from different perspectives that provided a better insight into the key elements of co-operation, into the manner in which they could promote shared interests, into the manner in which organizational processes are run and organizations are incorporated in larger networks (Cle98, Nol98, Rei98).

The ‘learning organization’ stands or falls by co-operation. What counts here, is not only the recognition that people with a different background and function have relevant knowledge and insights, but also that group dynamics are essential in order to come to a shared opinion on the nature, severity and scope of a problem and subsequently to tackle the questions and challenges that result (Gro97). An illustration here is the development of multidisciplinary guidelines and transmural agreements. This is a learning process ‘par excellence’, as is apparent from the evaluation of the first National Transmural Agreement ‘Asthma’ in children (Hul99). The initiative lied with the NHG and the Dutch Association for Paediatric Medicine (NKV). The Agreement is based on the NHG standard for the treatment of children with this disorder and on the consensus of the Paediatric Lung Diseases Section of the NKV. Both groups value the initiative and consider it a good starting point for reaching regional working agreements. However, they are also of the opinion that a number of obstacles still need to be overcome. This relates among others to the question of who is responsible when and for what. The difference in opinion about the competence of the general practitioner is striking. According to paediatricians, general practitioners are not in a good position to treat children with serious exacerbations, whereas the general practitioners themselves see no problem here. According to researchers, the explanation must be sought partly in the differences between the patient populations which general practitioners and paediatrics see.

Another example are the revised guidelines for the diagnosis, treatment and prevention of complications following diabetes (NDF/CBO98). In this, the Netherlands Diabetes Federation worked together with the Quality Institute for Health care CBO. In the meanwhile, the Social Health care Research and Development Foundation (STOOM) has taken the initiative to draw up a co-operative guideline with the NHG for the care of patients with dementia and for patients with pressure sore ulcers (verbal communication). The Committee finds such developments of great importance. They point to the fact that professionals realize the importance of co-operation not only with colleagues but also with patients.

Co-operation has primarily to do with social interactions. Findings from implementation research which indicate the importance of communication with peers and of interactive forms of continuing professional development point to social interaction as an important connecting link between professionals. The Committee believes that the insights from disciplines that have made social interaction and knowledge development in organizations their field of study should be assessed as to their potential contribution to health care. These could help, for example, in the development of skills necessary for good professional co-operation across the boundaries of one's own discipline or department, or outside the walls of one's own organization.

Chapter 5

Patient input

Optimizing the care process, the central theme of this report, is not possible without the input of patients themselves. In policy matters, explicit consideration of patient involvement is generally expressed in terms such as ‘customized care’, ‘greater patient participation’ and ‘inversion of the care process’. There is also the growing realization among health care professionals that patients can and must play an important role in formulating what is good and effective care and in achieving the desired changes in the care process. The search for opportunities to include possibilities other than medical scientific data in the guidelines reflects this view.

5.1 The patient’s opinion

Until now, the involvement of patients in the care process has principally been formalized in medical disciplinary law, patient legislation and complaint procedures. The ultimate measure of the application of scientific and experiential knowledge however are the outcomes of patient care. Patients these days are more vocal and knowledgeable. They can better formulate their ideas and thoughts about illness and the experience of illness, and can better indicate their preferences and priorities. Above all they influence their own health: the effectiveness of the care provided depends also on their behaviour (Gro99b).

Patient’s satisfaction with the care provided is generally seen as an important criterion of the quality of care. To date, satisfaction has been measured primarily by questionnaires based on criteria which, according to a recent review, do not always reflect what patients really find important (Cle98). Items such as eating, parking facilities, a nice environment, available ‘extras’ (and such like) are often extensively researched, but in most studies little attention is paid to topics such as good consultation, involvement in decision-making and respectful treatment. In addition, the current operationalization of the concept of ‘satisfaction’ still includes the existing expectations of investigators. In the same review it is apparent that patients themselves draw a clear distinction between ‘material’ matters and the ‘quality of care provided’. However, a complication is that the perception of quality of care varies markedly (Cle98). Patients may be satisfied with care of insufficient quality and dissatisfied with care of demonstrably good quality. Patient groups also appear to differ in how they rank matters of importance with respect to the quality of care.

The conclusion is twofold. The most important factor is that measuring the experiences of patients is much more complex than measuring consumer experiences in the market sector because a much larger range of conditions must be included in the evaluation. The other conclusion is that little or no trace of the patient information obtained is to be found in decisions that lie outside the immediate doctor-patient relationship.

The emphasis on the patient’s position has led to creative innovations, such as interactive forms of information provision on video or CD-ROM, educational programmes to learn how to cope with chronic disorders, including for patients’ partners, methods for self-diagnosis and self-treatment, informative websites on the Internet and so on (Gro99b). Consultation with patient panels and systematic surveys of patients’ requirements prior to specific treatment are now among the customary methods. It remains unclear as to what extent all of these matters ultimately make a demonstrable contribution to the quality of care. Thorough research into the value of this is still in its infancy (Wen98).

There is more clarity about the effects of a consultation style in which systematic attention is given to increasing the role of patients in taking decisions about their own course of treatment and care. Various randomized studies demonstrate that involvement in decision-making can lead to more favourable health results (Gua98, O’Co99, Ric98). However, these results should be regarded with some caution. The picture is far from homogeneous. For example, the decisions that seriously ill patients make between prolonging life and the side-effects of aggressive treatment with any subsequent restrictions, reveal much more variation during the disease process than was once assumed. Patients also tend to change their mind about their personal ‘costs and benefits’ during treatment of a serious disease such as cancer within a relatively short time (Tse95, Tse98).

Communication about the treatment of choice is also not always equally obvious, and patients and doctors may think differently about it. For instance, it is usually assumed that older women will accept the mutilation of a breast amputation more readily than younger women and that radiotherapy is stressful for them. To check this a study was set up with 50 women over 70 years of age and diagnosed with breast cancer for the first time (San96). After extensive and repeated information, the choice of treatment was left to them. Three quarters of the women opted for a breast-sparing operation with adjuvant radiotherapy. They tolerated the radiation well. After 21 months follow-up, this group of women appeared on average to be doing as well as younger women in the control group. Another example is a study into the kind of life-saving interventions one would want to undergo — Here patients and doctors formed the study group — in the event of a suddenly deteriorating situation. Seriously ill patients appeared more often to want resuscitation than their doctors thought and would choose for themselves, whilst they more often refused artificial feeding and fluids (Sch93). In both these studies the investigators suggest that doctors assess their patients' preferences in the light of what they themselves would want.

The importance of involving patients in formulating what constitutes good care is to the Committee's opinion undisputed. All the more so because it is becoming increasingly clear that being motivated and involved in one's own treatment is a precondition for an improvement in health status (Gro99b). Ideally, guidelines, apart from being scientifically sound, should also reflect patients' preferences. Actually, the diversity of preferences will probably be great. This complicates the definition and operationalization of parameters and criteria reflecting the preferences and values of the patients themselves. How this can best be pursued is still far from clear. Also the question as to how these criteria can subsequently be incorporated in guidelines and whether this would have to apply to all guidelines or to specific categories of guidelines is still unanswered. The Committee points out that a large and important field of research is lying fallow here. However, progress has also been made, as the example of the co-operation between the Dutch Diabetes Federation and the Quality Institute for Health care CBO in establishing the previously mentioned diabetes guidelines shows.

In accordance with the aforementioned, the Committee argues for an additional route to realize patient input. If guidelines are to be ultimately developed in which patients 're-cognize' themselves, then their inclusion at an early stage of the research, namely when formulating the study design, is also important. The *Association for Patient-Oriented Research* has recently been set up in the United States. The reason was the atrophy manifested in patient-oriented research as a result of the heavy emphasis on basic biomedical research (Hir99), which in its turn follows from the way research is being financed. Study designs generated at the bedside are given insufficient consideration for financing, and research into what patients themselves consider to be important outcomes of research accordingly is not a growth area.

5.2 Partnership

‘Partnership’ is a new term for the involvement of patients in care provision (Cou99). ‘Partnership’ has superseded ‘being a consumer’ as a guide for policy decisions in health care in the United Kingdom, according to the author of the editorial which introduces a special edition of the British Medical Journal on patient participation. In almost all the articles, the conclusion is that the involvement of patients in care provision is highly desirable, but that at present very little is known about effective ways to express this involvement in the many different aspects in which it is at stake. David Sackett, the founder of *evidence based medicine*, started a new series in May 2000 titled: ‘Why randomized controlled trials fail but needn’t’ (Sac00). Problems and pitfalls in the inclusion of patients in scientific research will play an important role in this series. But attention will also be given to the ways in which doctors and patients can jointly weigh up patients’ potential participation in trials by investigating whether the proposed research design— as well as collecting reliable medical data — will also provide data which the patients concerned find valuable.

The Committee endorses this progress towards greater patient involvement. If it is ultimately to materialize in all its diversity in optimizing patient care, then research into defining and formulating parameters and criteria reflecting the wishes and values of the patients must now be given greater attention.

Chapter 6

Conclusion

In the previous chapters, the Committee discussed issues that are important for the quality of care provision: professional knowledge and expertise, the increasing need for co-operation through the interconnectedness of care practices and the progress of increasingly vocal and better informed patients. In this concluding chapter, it presents its opinions with particular reference to the second subject in the request for advice.

The request for advice is essentially focused on the inquiry into possibilities for closing the gap between knowledge and practice by means of guidelines. Knowledge is above all understood to refer to results from patient-oriented scientific research. In doing so the request is closely aligned with MTA policy thinking. It makes sense in this concluding chapter to once again clarify some assumptions associated herewith. The limits of this approach will then surface and the importance of the broadening of the approach to implementation underlined.

A first point to mention is the particular nature of the knowledge obtained from clinical epidemiological studies that are often directed towards the stochastic relationships between treatments and outcomes in terms of life duration and health. Secondly, a specific idea of the line professionals should take underlies the request for advice. Professionals are expected to apply scientific data that have been obtained in a methodologically correct manner, carefully arranged and packaged in guidelines, as a matter of routine in their everyday practice. However, this appears not to be a self evident process. In the third place, there is the image that professional practice takes place as it were in a confined, fairly static world of its own.

In its report the Committee points to the fact that guidelines are more than just mere ‘packages’ for scientific research data. Incorporating scientific data into guidelines cannot be done without making judgements as to what has been adequately studied and what is regarded to be relevant in the light of intended aims. Moreover, opinions on how to weigh advantages and disadvantages up against one another in order to achieve recommendations always play a role. The fact that the implementation of guidelines reveals a very mixed picture, is a direct result of the aforementioned judgements — as research shows. The results also make it clear that day to day practice is very complex and is influenced by a number of factors outside the area of medical scientific knowledge. These are important reasons for attempting to define in the third generation guidelines — more so than is now the case in the second generation guidelines — the aims of the guideline writers and to explicate the underlying assumptions and choices made, so that these can be differentiated from scientific data. Arguments in the literature for a broadening of the analysis of the implementation problem are very much in agreement with this. Various researchers point here to the need to draw on insights from the social, education and management sciences. The Committee shares this view that a broadening of the theoretical basis now appears to be necessary.

Implementation of new scientific insights, however essential, is not the final aim. It is a means for ensuring good patient care. Good patient care necessitates attention for other topical developments as well.

Professionals in health care are currently confronted with both scientific and social dynamics. In the request for advice the central feature is the question of how care providers can best be induced to put into practice knowledge generated elsewhere, whether or not encapsulated in guidelines. The Committee favours another route. It considers *evidence based medicine* (EBM) as an attitude towards professional practice of importance in optimizing the care process. EBM in its present form is a practical approach that tries to integrate pathophysiological reasoning, clinical experience and patient preferences with findings from valid scientific research. Professionals are thus addressed in two ways: underpinning care practice with the best available evidence and participating in a continuous learning process. The essence of professional knowledge is the ability to establish a significant relationship between different types of data, whereby context-specific associations can be made between ‘knowing how’ and ‘knowing that’. The Committee terms this process ‘translation’. This approach includes the concept that good practice is always a dialogue: systematically stocktaking, analysing and codifying experiential knowledge is a necessary supplement to the knowledge emanating externally from *trials*.

Where social dynamics are concerned, the Committee points firstly to the increasing interconnectedness of care practices and, secondly, to the fact that patients are becoming increasingly more vocal and better informed. The former entails that professionals operate more and more in larger organized networks. In addition to being the representatives of their own patients' interests, they are also actors amidst other actors. This means that the *process side* assumes an important place in the care process effecting the content and the quality of care provision. This development implies that management concepts are also of importance for health care. A key concept here is 'interaction and co-operation'. Learning to work together does not fall within the domain of medical and biological knowledge development. Insights from other disciplines, for example social sciences and management science, are valuable to help here.

Contemporary society also sees patient perspective increasingly assuming centre stage. Patients are becoming better informed about medical matters and find it increasingly easier to express their values and preferences. Modern means of communication will increase these developments. Rightly, they want a greater involvement in formulating what constitutes good care. It is becoming clear that this is particularly important because above all patients themselves exercise an influence on their health and the effectiveness of the care provided depends partly on their behaviour.

Taking into account the developments discussed, one sees how the scientific aspect is embedded in a societal and dynamic approach. The central question shifts from guideline implementation to optimization of patient care. The Committee realizes that it is arguing for a reorientation of the implementation question as formulated in the request for advice. It is not yet possible to indicate which of the aforementioned areas should receive the most attention right now, because results of empirical research into the question which insights from the social, education and management sciences hold value for health care are still, by and large, lacking.

The Hague, 20 July 2000,
for the Committee

(signed)

JH Stegeman, secretary	Dr TED van der Grinten, chairman

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Annexes

Annex

A

The request for advice

On 4 January 1999, the Minister for Health, Welfare and Sport wrote to the Chairman of the Health Council of the Netherlands (reference CSZ/ZT-9819842):

The speed with which new scientific insights and results of Medical Technology Assessment are currently becoming available and the fact that all sorts of care processes and care systems are becoming increasingly more complicated has brought with it a number of problems which ultimately boils down to the question of how to close the gap between knowledge and practice. One way of achieving something here is to systematize and synthesize (new) scientific insights in a form applicable to everyday practice. In this respect reference is principally made to guidelines. (Other terms are standards, consensus agreements, protocols, and treatment regimens). Although guidelines cannot be established to the same extent for all care problems, they are currently available for a considerable part of first- and second-line care. In theory guidelines represent a good vehicle for aligning everyday practice with new scientific insights. However, guidelines often appear to influence everyday practice too slowly or insufficiently. Reference is then made to defective implementation.

In the past, very considerable attention has been devoted to the development of guidelines. Implementation as a separate focus of attention for research and policy, however, is a very recent activity in the Netherlands. In the Progress Report on Medical Technology Assessment of April 1997 it was announced that the government wished to bolster this stage in the MTA process. In the meanwhile, research has increased the insight into factors limiting or facilitating the implementation of guidelines. For example, it is known that the development of guidelines will have little or no effect on practice if no supplementary implementation activities are developed. Potential users must be constantly confronted with the existence and content of guidelines.

While the research that has been undertaken to date throws light on the indicators associated with defective or successful implementation, in general it provides little in the way of explanation for this. This is probably related to the fact that up until now little process information has been collected. At the same time it must be noted that there is still insufficient known about the way in which scientific knowledge at this time is integrated in the professional practice of doctors, psychotherapists, psychologists, paramedics and nurses. Likewise, it is not clear to what extent existing intramural, extramural and transmural structures lend themselves to the successful implementation of guidelines.

We are still to a large extent groping in the dark in seeking to answer questions such as:

- which factors influence the process of implementation of new scientific insights and to what extent can they be influenced
- what are the most fruitful approaches for interpreting the process of dissemination and implementation.

I request the Council to issue an advisory report on the present state of science in relation to the matter of the implementation of knowledge, by which at the same time is meant guidelines. As is known, this field is engaged in profiling the subject scientifically and I would be grateful to receive the Council’s view on the possibility of influencing factors that are relevant to the improvement of implementation, including in the area of mental health care. Information which helps bridge the gap between knowledge and practice over a broad spectrum of care is important for policy formation. I consider it of particular importance in this respect that consideration is given at the same time to how specific approaches can contribute to implementing a greater adherence to the interdisciplinary method of working in practice through the development of guidelines.

The Minister for Public Health, Welfare and Sport,
(Signed) E Borst-Eilers

Annex

B

The Committee

- TED van der Grinten, *Chairman*
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- J Balen, *Advisor*
  Health Research Council, The Hague
- PMM Bossuyt
  Professor of clinical epidemiology; University Medical Centre, Amsterdam
- HFJM Crebolder
  Professor of general practitioner medicine; University of Maastricht
- RPTM Grol
  Professor of quality of care; University of Nijmegen/University of Maastricht
- JP Holm
  Professor of gynaecology and obstetrics; University Hospital Groningen
- AJA Kaasenbrood
  Medical practitioner, psychiatrist, Psychiatric Hospital Wolfheze
- NS Klazinga
  Professor of social medicine; University Medical Centre, Amsterdam
- A Mol
  Professor of political philosophy; Twente University, Enschede
- JH Mulder, *Advisor*
  Ministry of Public Health, Welfare and Sport, The Hague
- WMLCM Schellekens
  Executive Director Quality Institute for Healthcare CBO, Utrecht

- AJJA Scherpbier
  Educational Institute, University of Maastricht
- P Schnabel
  Executive Director Social and Cultural Planning Office, The Hague
- MCDP Weggeman
  Professor of management science; Technical University of Eindhoven
- JH Stegeman, *Secretary*
  Health Council of the Netherlands, The Hague

Secretarial support: Mrs M Javanmardi
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