

CHRONIC DISEASE MANAGEMENT A NATIONAL STRATEGY

Disease Management Programmes and
Self-Management Support

2007

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1 Introduction

A report called "Chronic Conditions. Patient, Health Care and Community" was published by the National Board of Health in 2005¹. The purpose of this report was to describe the options and assumptions for an improved response to chronic diseases. Due to the emergence of increasingly efficient and costly treatment options, an ageing population and the ensuing increase in the number of people affected by chronic diseases and problems recognised in the care of chronic conditions it is necessary to identify the options for better care in connection with chronic conditions. During the analysis of the problems related to chronic conditions and the identification of possible solutions, the Chronic Care Model² has proven to offer an appropriate framework. The model combines the knowledge available on the value of the individual elements in a multifactor programme.

Chronic diseases have one or more of the following characteristics: they are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, or may be expected to require a long period of supervision, observation or care³. This definition includes both somatic and mental disorders.

"Chronic Conditions. Patient, Health Care and Community" describes a

number of problems concerning the commitment of society and the health service to citizens with chronic diseases. As a result of these problems the course of the disease often deteriorates and complications occur, which results in the need for hospitalisation and resource-intensive treatment. By appropriate organisation of the effort and by consistent utilisation of evidence-based guidelines it is possible to influence the course of the disease so that part of such health services is not required.

The report points out that patients' options of actively managing their health condition and maintaining a life in their own home should be especially emphasised. Consequently, an overall strategy describing organisational, professional and incentive assumptions for an efficient response to chronic diseases should focus in particular on strengthening patients' self-care and on the primary health-care sector.

Thus, the National Board of Health's recommendations focus on the organisation and provision of health care and the options of strengthened and supported self-management. Disease management programmes tailored to Danish health care and an action plan for better supported self-management, self-monitoring and self-treatment are the tools described in reports in Danish. This publication summarises those reports.

2 A Generic Model for Disease Management Programmes

- 1 The conclusions and recommendations of this report have been published in English. http://www.sst.dk/publ/Publ2005/PLAN/Kronikere/Kr_sygd_patient_sundhedsv_en.pdf
- 2 www.improvingchroniccare.org
- 3 Dictionary of Health Services Management, 2nd ed.

The purpose of a generic model for disease management programmes is to provide an overall framework for the content of such programmes adapted to the organisational conditions of the Danish health service.

The generic model describes the combined interdisciplinary, intersectorial and coordinated effort for a specific chronic condition. It ensures the use of evidence-based recommendations, a precise description of the distribution of tasks and the coordination and communication between all the parties involved.

It is important to ensure that the effort for patients with chronic diseases is organised appropriately at both the patient level and the organisational level. The goal is to ensure consistence between different efforts, to ensure that the health professionals and the patients involved have a uniform, common objective, that the staff already have or are acquiring the necessary qualifications, and to ensure that each care element gives the clinically best achievable results.

Many studies have shown a generally positive effect of disease management programmes for chronic diseases⁴. In general, patient satisfaction, patient compliance and control of the diseases have improved. To a lesser extent they show more effective utilisation of resources. Disease management programmes can be organised in different ways using different interventions⁵.

The disease management programme aims for a high-quality care and patient safety as well as appropriate utilisation of resources throughout the programme. The purpose is a systematic and proactive effort preventing progression of the disease, acute episodes and complications with built-in, ongoing monitoring of the quality of the programme.

The aim is to develop national disease management programmes, but local detailing/specification is necessary in connection with the actual organisation and distribution of tasks and the implementation of the disease management programme.

The following elements are part of the generic model that may form the framework of the development of specific national programmes:

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- 4 Ofman JJ, Badamgarav E, Henning JM, Knight K, Gano AD, Jr, Levan RK, et al.: Does disease management improve clinical and economic outcomes in patients with chronic diseases? A systematic review. *Am.J.Med.* 2004 Aug 1;117(3):182-192.
 - 5 Weingarten SR, Henning JM, Badamgarav E, Knight K, Hasselblad V, Gano A, Jr, et al. Interventions used in disease management programmes for patients with chronic illness - which ones work? Meta-analysis of published reports. *BMJ* 2002 Oct 26;325(7370):925.

2.1 Defining the group of patients

The patient group of the disease management programme must be defined, and the patients identified and registered.

This implies:

- Identifying the diagnosis that cause a person to be comprised by the programme.
- Describing how to register the diagnosis and how to collect and use the registration.

Objective:

- To diagnose persons with chronic diseases as early as possible in the course of the disease.
- To register the diagnoses of everyone diagnosed with the disease in question whether by a doctor in the primary health care sector or the hospital sector.
- To register all the patient's contacts with GPs, the municipal health service and the specialised health service concerning the relevant chronic disease.

Specification:

The disease management programme should specify:

1. The diagnoses causing a person to be comprised by the disease management programme.
2. The disease classification to be applied when registering diagnoses.
3. How and where to register diagnoses, who is responsible for the registration and how to collect and use data.

2.2 Care

The relevant treatment for the disease concerned should be described in evidence-based clinical guidelines.

This implies:

- Drawing up care recommendations for the chronic disease concerned.
- Describing relevant care based on clinical guidelines, including diagnostics and early detection, treatment, rehabilitation, follow-up and support for self-care.

Objective:

To ensure the use of evidence-based care recommendations for patients with a chronic disease.

Specification:

The disease management programme implies that the effort of the GPs, the municipal health service and the specialised health service should follow evidence-based clinical guidelines and provide guidelines for

- a. diagnostics, including early detection
- b. assessment of sequelae and comorbidity
- c. treatment and rehabilitation
- d. self-management support
- e. follow-up considering the degree of severity of the disease and the need for regular control

2.3 Self-management support

The disease management programme should contain a description of the contribution of an active correlation between the health service and patients to the mobilisation and strengthening of patients' self-care. The central elements are:

- Self-monitoring and self-treatment may be important elements of patients' self-care. This option should be used systematically.
- Patient education may qualify patients for an active approach to chronic conditions, their consequences and treatment.
- Targeted programmes for frail and vulnerable patient and population bases that are unable to actively assume responsibility.
- Appropriate medication and treatment instructions.
- Electronic patient records and clinical information systems as shared tools for patients and therapists.

Objective:

To help patients to perform self-management that is crucial for the course and consequences of the disease.

Specification:

To enable individual patients to mobilise their resources optimally, the health service must actively support this. Patients with chronic diseases must arrange for their own everyday

treatment and follow the medication intake plan and conditions such as diet, physical activity, smoking, etc. In the case of some diseases it is possible for patients themselves to monitor symptoms or measurable parameters of importance for the course and treatment of the disease. In these circumstances, some patients are able to make adjustments to both pharmacological and non-pharmacological treatments themselves.

2.3.1 Active self-monitoring and self-treatment

Self-monitoring means the patient's own measuring of disease parameters. They may include biological parameters measured using devices operated by the patients themselves or registration of symptoms or functional level. Self-treatment implies that based on this monitoring patients make independent or instructed decisions about their treatment.

The past decades have seen a technological development of measuring equipment that patients use for self-monitoring of objectively measurable parameters associated with the treatment of the disease in question. This includes equipment to measure blood glucose, blood pressure, respiration capacity and blood coagulation as well as electronic weights, etc. In addition to a general understanding of the changing patient role, this

development has resulted in some use of self-monitoring and patient-managed medication intake based on the patient's own measuring results.

In the case of some diseases, self-monitoring and patient-managed medication intake have gained general acceptance as being necessary and valuable. This applies first of all to type 1 diabetes, where the patient's own frequent blood glucose measurements are regarded as a necessary basis for the continuous adjustment of blood glucose control⁶. A similar approach leading to improved quality of life and improved treatment is technically possible in connection with a number of other conditions. This possibility is only utilised to a limited extent. It would be advisable to speed up the development towards active cooperation between patients and the health service, which would also lead to improved treatment quality and utilisation of resources.

Literature on objective self-monitoring using well-defined measuring equipment in connection with long-term anticoagulant therapy, asthma, type 2 diabetes and cardiac insufficiency has been systematically reviewed (National Board of Health 2006). It confirms that in connection with those conditions there is evidence that benefits can be obtained in the form of improved disease status and disease

control, reduced use of health services, improved emotional well-being and improved self-management. As regards all four analysed conditions there is relatively substantial evidence that self-monitoring and self-treatment lead to improved treatment results. Especially for long-term anticoagulant therapy there is good documentary evidence of the effect and of the appropriate organisation of the effort. A survey of the use of self-monitoring and self-treatment in Danish hospitals showed considerable variations, as self-monitoring is only used to a limited and varying extent in connection with diabetes, asthma, heart insufficiency and anticoagulant therapy. Instruction in self-treatment also varies considerably⁷. Thus, there is great potential for improvement through formalised initiatives that would contribute to increased dissemination of self-monitoring and self-management of medication. Concern regarding issues of responsibility and concern that self-monitoring and self-management of medication may lead to increased medicalisation, as well as scepticism as to patients' ability to handle their treatment may be contributory

reasons why this concept is not more widespread.

2.3.1.1 Anticoagulant therapy

Self-treatment in connection with long-term anticoagulant therapy (medical treatment reducing the risk of thrombosis by decreasing blood coagulability) is a well-documented example of self-treatment. The effect of self-treatment and how it may be organised has been documented.

International Self-Monitoring Association for Oral Anticoagulation (ISMAA) has drawn up a set of self-treatment principles that can be applied to other diseases⁸. They establish the following preconditions for recommending self-monitoring and self-treatment:

- The treatment results should be as good as or better than for conventional treatment.
- The quality of life should be affected favourably.
- Self-treatment should be cost-effective.
- It should be possible to identify the patients who are capable of self-treatment.

6 Daneman D: Type 1 diabetes. *Lancet* 2006; 367:847-858.

7 Patienten med kronisk sygdom. Sundhedsstyrelsen. 2007.

8 Ansell J, Jacobson A, Levy J, Völler H, Hasemkam JM: Guidelines for implementation of patient self-testing and patient self-management of oral anticoagulation. International consensus guidelines prepared by International Self-Monitoring Association for Oral Anticoagulation. *Int.J.Cardiology* 2005;99:37-45

- The technology (measuring devices) should be reliable.
- Guidelines should be established for education of both patients and the health professionals that are to educate patients in self-treatment.
- Continuous monitoring and quality surveillance of the activity should be established.

There is consensus in ISMAA that a considerable proportion of patients who need long-term anticoagulation therapy will be capable of self-treatment when they have completed a structured education programme.

The technology available enables patients to reliably measure the treatment effect and to adjust their medication dosage accordingly. The analytical measuring devices are user-friendly and reliable. As patients are able to take measurements more frequently than in connection with conventional treatments, treatment complications such as bleeding or thrombosis are significantly reduced. It is estimated that the treatment is more cost-effective than conventional treatment and increases the quality of life considerably by making patients independent of frequent contacts with the health service.

Selection for self-treatment is made on the basis of a subjective assessment of

the patient's medicine monitoring and dosage capacity.

It would be desirable, however, to qualify the selection of patients for self-treatment on the basis of objective criteria.

2.3.1.1.1 Generalisation in terms of other diseases

There is evidence that a large group of patients are capable of self-treatment of their disease and that this improves their quality of life. Based on the results of self-managed anticoagulant therapy and practical experience from self-monitoring of blood glucose in cases of type 1 diabetes, systematic use of the self-monitoring option in connection with chronic diseases is recommended wherever possible.

There is evidence of the value of this approach in connection with diseases such as asthma, heart insufficiency and type 1 and 2 diabetes, etc. Stronger focus on this is likely to inspire research that may lead to similar results in connection with other diseases. The development of tele-medicine will open possibilities for new ways to organise and support self-treatment. For example, electronic reporting of self-monitoring results to a GP or other health-care provider will open possibilities for the provision of individual or automated instruction on the Internet using computer software.

2.3.1.1.2 Quality assurance

The implementation of self-treatment should include continuous quality assurance with suitable indicators and monitoring of the implementation rate. For both blood glucose and blood coagulability measurements, patients can take their own measurements with a certainty and accuracy that is close to or as good as what is achieved in laboratory measurements.

Thus, patient measurements can be part of the continuous monitoring in addition to laboratory measurements. This assumes that the programme includes a description of the continuous quality assurance of devices and treatment results.

2.3.1.1.3 Economy

Self-monitoring and self-treatment presuppose organisational adjustments, training of staff, purchasing of devices, etc., and thereby resources. No specific health-economic analyses of self-monitoring and self-treatment are available. However, there is substantial evidence of improved quality of life, e.g. in connection with diabetes and anticoagulant therapy. This leads to a reduced complication rate and a delay or prevention of late complications in connection with the disease. There are good indications that self-managed anticoagulant therapy is cost-effective as it significantly reduces the need for hospitalisation due to cerebral

haemorrhage or thrombosis. A similar effect is to be expected for diabetes and other diseases.

2.3.1.1.4 Liability

Uncertainty about liability issues may be one of the reasons for the slow dissemination of self-treatment. However, under Danish law the same liability applies in this connection as in other situations of patient medication self-management where the prescribing doctor is also responsible for the treatment.

The doctor is responsible for indication, contraindications and assessment of the risk of adverse events and interaction with other medicine. The doctor must ensure that the patient who is to self-manage the treatment, has been instructed in the planning of the treatment, and that agreements are made about the necessary controls to avoid complications in connection with the medicine in question. It must be assessed and checked whether the patient is able to use the relevant devices/measuring equipment and to handle self-monitoring and self-treatment, including during the future course when further development of the disease or increasing age may influence the patient's self-treatment capacity. In those circumstances, the patient must give his/her informed consent to treatment with the drugs prescribed, including to self-monitoring and self-treatment.

If these preconditions are met, the doctor is not responsible if the patient acts against the instructions provided, nor for the patient's self-monitoring or self-control.

2.3.1.1.5 Conclusion

There is great potential for improving self-management for some of the chronic diseases by utilising self-monitoring and self-treatment. However, not all patients will benefit from this approach as a severe impact on the state of health or the lack of physical or mental capacity and knowledge of the disease may be obstructive factors. Patients who are able to make use of it will profit considerably by a better quality of treatment and life. At the same time resources will be made available that can be used to improve measures for patients who are incapable of self-treatment. Systematic utilisation of the options of self-treatment for more diseases would require organisational adjustments and a redistribution of resources. Consequently, it would imply a political/administrative decision and deliberate management measures. In return, we expect improved quality of treatment, better overall utilisation of resources and modified and improved interaction between patients in active self-treatment and the health service.

2.3.2 Patient education

Patient education includes structured courses. This implies an organisational framework, the use of effective and suitable educational methods and ongoing evaluation of the effect of the education. An overall patient education programme will include elements of both general and disease-specific education.

Objective:

To strengthen patients' ability to live with their disease and providing appropriate self-management.

Specification:

Planning of *disease-specific patient education* is aimed at patients with a specific chronic disease with a view to patients acquiring knowledge about the specific disease, its treatment and the effect of prevention and rehabilitation. The education may also include self-monitoring and self-treatment.

Planning of *general patient education* for patients with chronic diseases across diagnoses with a view to patients acquiring qualifications to handle/master the problems of living with a chronic disease, regardless of diagnosis. The

Stanford chronic disease self-management programme has been pilot tested in Denmark with a positive result and thereafter widely implemented in health care under a national license.

2.3.3 Frail and vulnerable patients

Development of programmes for particularly vulnerable patient and population groups to support their self-care capacity is required, including:

- patients who, due to severe illness, several concurrent diseases requiring treatment, disabilities, etc. and possibly a weak personal network, are highly dependent on health-care and/or social services;
- patients who, due to weak personal resources and a poor or different understanding of their disease, social or cultural circumstances, are incapable of proper behaviour and self-care.

Objective:

To reduce health disparities and inappropriate use of resources through an intensified and targeted effort for groups and individuals with particular needs.

Specification:

These vulnerable groups can be identified in different ways. For example, patients at high risk of recurring acute hospitalisation can be identified through register data, and it is also possible to identify groups and geographical areas with a particular risk profile. In some of the particularly vulnerable patients there may, based on an individual assessment, be an indication for the establishment of a special support function in the form of a case manager for a period or continuously.

2.4 Organising the care

Overall care organisation should be established.

This implies:

- Defining care pathway responsibility and describing the distribution of tasks.
- Laying down stratification criteria in order to planning a graded care.

Objective:

To ensure appropriate organisation of the overall effort for patients with chronic diseases.

Specification:

The health service should be organised to meet the particular needs for a coordinated, continuous interdisciplinary effort. It is recommended that first priority in the effort for patients with chronic diseases should be given to general practice and the municipal

health service while ensuring interaction and coordination with the specialised level. The patient's health status and individual needs should always determine the level of specific measures.

2.5 Distribution of tasks

The disease management programme should determine and describe the distribution of responsibilities and tasks based on the following principles:

1. It should be done based on the qualifications and technologies required to perform the specific tasks at a professionally qualified level.
2. Patient participation in monitoring, treatment and rehabilitation should be incorporated throughout the programme.
3. The programme should take into account considerations of organisation and resources.
4. National recommendations for the location of treatment should be followed.

Objective:

To ensure patients with a chronic disease high-quality care adapted to their needs and guaranteeing effective utilisation of resources.

Specification:

This implies relevant treatment, a staff with the necessary professional qualifications and appropriate organisation and coordination across professional groups and sectors.

The Danish Health Act determines the regional and municipal responsibility in the health-care area. However, there is considerable scope for variation within the framework of the Act in terms of the actual organisation of the effort.

2.5.1 Stratification

Stratification is a tool that can be used to allocate groups of patients for the treatment, rehabilitation and follow-up from which they derive most benefit and which ensure appropriate utilisation of resources.

Objective:

To ensure that patients are treated at the right health service level and that the treatment meets their needs throughout the course of the disease.

Specification:

A patient population with a specific chronic disease is often described by way of a stratification pyramid where patients are divided into groups according to the severity of the disease and the need for action (Figure 1). The stratification pyramid can be used as a tool to plan and dimension the care for a specific chronic disease.

In the Danish health service with easy access to general practice, stratification is already common in connection with the GP's role as a gatekeeper for the specialised health service. GPs make referrals to the specialised health service if more intensive and/or specialised measures are needed, but

explicit criteria for this only exist in exceptional cases. On the other hand, disease management programme stratification contains explicit criteria across sectors and professional groups.

2.5.1.1 Stratification criteria

The programme should establish stratification criteria with a view to planning a graded effort. The criteria should have prognostic significance and determine the care patients need.

Selection of stratification criteria should take into account the risk of complications and the patient's overall state, including the intensity and complexity of the disease, co-morbidity and the patient's self-management capacity.

Furthermore, the criteria should, to the widest possible extent, be based on evidence, and existing national criteria should be included in the stratification.

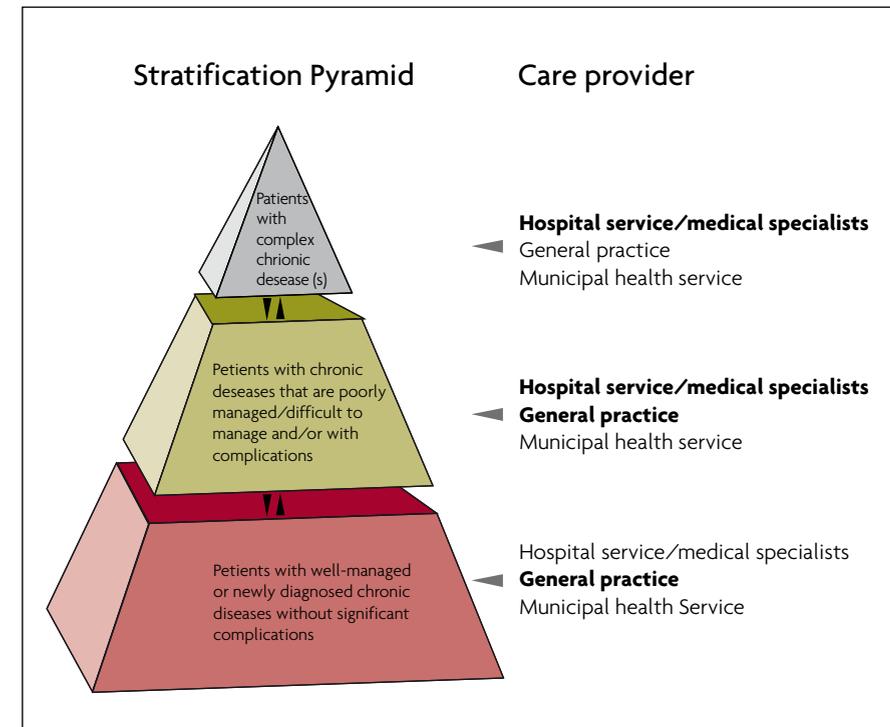
2.5.1.2 Practical application of stratification

We have limited experience with the application of stratification in Denmark. Hence, the disease management programme recommendations for the

practical application of stratification should be seen as part of a development process requiring testing, gaining and incorporating practical experience of using this tool. Persons allocated to a disease management programme on the basis of diagnosis registration should be stratified at the most appropriate level of treatment, rehabilitation and follow-up. This implies an assessment on the basis of the specified stratification criteria with the outcome determining the level of specialisation and the most appropriate intensity of treatment for the patient concerned. Patients should be involved in the specific considerations on which the stratification level decision is based. To facilitate the actual organisation of care, the disease management programme should contain overall guidelines determining the players who will be responsible for the care at different stratification levels. The following principles should be applied when determining this:

- For patients with a well-managed or newly diagnosed chronic disease without significant complications, treatment should be handled by GPs and the municipal health service.
- For patients with a chronic disease that is poorly managed/difficult to manage and/or with complications, treatment should be handled jointly by GPs, the municipal health service and the specialised health service (the hospital service and/or medical specialists).
- For patients with a complex chronic disease, the greater part of treatment should be handled by the specialised health service (the hospital service and/or medical specialists). Rehabilitation and self-management support should be handled in cooperation with GPs and the municipal health service.

The principle is outlined in Figure 1:



The disease management programme should describe how to register individual patient stratification and how to collect and apply stratification data. The stratification responsibility lies mainly with the GP who has the principal contact with the patient, and in principle the stratification can take place in both general practice and the hospital service. As far as possible, there should be consensus among the players involved about the stratification. Stratification is a dynamic rather than a final tool as the state of the

patient may improve, stabilise or deteriorate.

2.6 Coordination and cooperation

It is proposed that the tasks and responsibility of all the players involved to ensure a coherent and coordinated effort should be described in health agreements between regions and municipalities.

National legislation determines the framework of such agreements the pur-

pose of which is to remove any doubt about the distribution of responsibility for the provision of specific services or the cooperation and coordination between the players. As regards the handling of special functions such as the coordination of disease management programmes at the regional level it is important for the agreement to specify and describe the associated tasks and responsibilities.

The health agreements should also describe how to ensure coherent care regardless of the number of contacts, players or the nature of the effort needed. Coherence with the social authorities should also be included in the agreement.

2.6.1 Coordinators

It is recommended that all patients with a chronic disease should have a coordinator who is responsible for:

- coordinating the overall care
- evaluating the patient's health on an ongoing basis
- ensuring systematic follow-up and proactivity
- adhering to treatment targets

Objective:

To ensure and adhere to a systematic, coordinating and proactive effort.

Specification:

The coordinator is assumed to be familiar with each patient, to be available and to have in-depth knowledge of the health service and other relevant players. In general, this function should be handled in general practice. Some patients only have sporadic contacts with general practice for periods of time during the course of their disease. During these periods it is particularly important that the GP should be informed on an ongoing basis in accordance with the agreements of the parties on the exchange of information. For example, this may apply to a patient with a chronic disease whose treatment is primarily handled at the specialised level. During such periods the responsibility for regular evaluation of the patient's health, systematic follow-up and progressive, proactive measures as well as support for adherence to targets in relation to the chronic disease naturally lies with the specialised out-patients' clinic. Another case in point is a patient with a well-managed chronic disease whose treatment is handled by the municipal health service for periods of time. Here, part of the systematic follow-up and support for adherence to targets in relation to the chronic disease would naturally lie with the municipal health service.

2.6.2 Case manager

Some patients need support in addition to the support of the coordinator, relatives or other players involved in the care pathway. Increased support for the completion of and adherence to treatment and rehabilitation by attaching a case manager is recommended.

Objective:

To ensure intensified, customised support for patients with severe and complex needs.

Specification:

The offer of intensified support from a case manager is given on the basis of an individual assessment when the patient needs increased support for complex conditions in connection

with treatment, rehabilitation, self-management and social issues, etc. It is important that patients with such needs are identified and that the support is targeted and customised with a view to improving the treatment and quality of life of each patient while keeping resource consumption at an appropriate level.

The disease management programme should specify:

1. Criteria for referral for case management
2. How to ensure that relevant patients are offered supplementary intensified support through a case manager.

Case management should be initiated by the coordinator or according to agreement with the team responsible for treatment of the patient with the chronic disease in question.

Tasks performed by a case manager in cooperation with the patient and relatives, as required, based on the patient's needs

- Contributing to the coordinated, interdisciplinary, intersectorial effort across diseases, including both acute and stable phases of the disease.
- Supporting the patient's completion of and adherence to treatment and rehabilitation.
- Supporting the patient's options of self-management.
- Ensuring follow-up and adjustment of initiatives.
- Actively communicating with relevant parts of the health service when the patient is going to or has switched between sectors or different health-care providers.

Example of criteria for referral to case management

- The complexity of the disease and/or several concurrent chronic diseases requiring treatment makes it difficult to complete and adhere to treatment.
- The patient has been identified as particularly vulnerable and needs support for the self-management options, e.g. because of the patient's poor self-management capacity due to weak personal and social resources or inadequate understanding of his/her disease.

Case managers can be attached to the hospital service, general practice or the municipal health service. Specific experience in appropriate planning

of course coordination for particular groups of patients in Denmark is required.

2.7 Quality monitoring

Standards and indicators for monitoring the quality and effect of the programme should be established, and monitoring should be performed across the staff groups, institutions and sectors of the health service.

Objective:

To monitor the disease management programme from a patient, clinical and organisational perspective.

Specification:

In case of diseases included in the Danish Quality Model accreditation programme, the existing standards and indicators should be applied. In case of diseases that are not included, monitoring should be performed according to a template corresponding to the Danish Quality Model template so that it can be adapted concurrently with the development of the quality model.

The disease management programme should specify:

1. the standards and associated indicators of the quality of the programme to be monitored as a minimum
2. how to register, collect, analyse and communicate data
3. the person(s) responsible for the monitoring.

2.8 Implementation of disease management programmes

An implementation plan should be included in the disease management programme.

This implies:

- specification of the person(s) responsible for the implementation process
- an implementation schedule
- specification of the planned implementation measures and tools.

Objective:

To support the uniform implementation of disease management programmes.

Specification:

The implementation of disease man-

agement programmes implies careful planning of treatment and organisation based on interdisciplinary teams wherever possible. Cooperation in individual organisations and between sectors is important for the quality of the overall effort.

In addition, the implementation should be supported by both financial and non-financial incentives such as staff participation, ongoing evaluation and the use of internal and external reporting of quality data, including patient satisfaction, and active patient participation in programme recommendations. The Chronic Care Model describes a series of best practices stating methods and actions that encourage the implementation of clinical know-how embedded in the disease management programme. Thus, the model illustrates some practical approaches and tools to support the implementation of disease management programmes.

Active management involvement and commitment as well as the availability of the necessary professional and economic resources are important factors. In the development and implementation phase it is necessary to assess the need for extra resources for local adaptation of the disease management programme, training of staff and development of IT systems.

2.8.1 Coordination of disease management programmes at the regional level

An implementation plan should be included in the disease management programme.

This implies:

- specification of the person(s) responsible for the implementation process
- an implementation schedule
- specification of the planned implementation measures and tools.

Objective:

To form the basis of the decisions of the region and municipalities concerning disease management programmes.

Specification:

The regional coordinator should monitor the implementation, development and follow-up on disease management programmes in the region and municipalities and ensure cooperation with the relevant health-care authorities of the region and municipalities. As the basis for this work, the regional coordinator must have access to population data, the existence of risk factors, the occurrence of specific chronic diseases, the pattern of health service consumption, financial data and any existing national disease management programmes.

2.9 Evaluation and revision of disease management programmes

A plan for the evaluation and follow-up on the content of disease management programmes and for updating, evaluation and revision should be drawn up. It should specify who is responsible for evaluation and follow-up.

Objective:

To ensure ongoing evaluation, updating and revision of disease management programmes.

Specification:

Implementing a disease management programme for a specific chronic disease would provide new experience concerning increased patient participation, the use of stratification tools and changing the organisation of treatment.

In step with the continuous development of medical technology this experience should be collected and used to develop and update disease management programmes on an ongoing basis.

3 Disease management programme for diabetes

In step with the development of the generic model adapted to the particular conditions of the Danish health service the principles thereof have been applied to develop a disease management programme for diabetes. The purpose is to achieve a systematic and proactive high quality care preventing progression of the disease, acute episodes and complications with built-in, ongoing monitoring of the quality of the programme. A large number of national, regional and local cooperation initiatives have already been launched in the diabetes area, including:

- a national action plan from 2003
- a national steering group
- a national quality database

Diabetes is part of the systematic quality development in general practice, in the National Indicator Project and in the Danish Quality Model.

Thus, the biggest challenge in the development of the disease management programme and its subsequent implementation is to ensure that these initiatives are connected in a specific organisation.

Consequently, the goal is to ensure coherence between individual elements of the programme, to ensure that health professionals and the patient involved adhere to a common objective throughout the programme

and that each element of an individual programme yields the best achievable results.

The diabetes programme should be seen as the first version of a national disease management programme for diabetes and the first example of a disease-specific national disease management programme based on the generic model. The diabetes programme is based on the following components:

- a) Definition of the group of patients
- b) Determination and description of treatment
- c) Organisation of the care
- d) Quality monitoring
- e) Implementation plan
- f) Evaluation and follow-up

The specific organisation, the content of health agreements between regions and municipalities and the plan for the regional/local effort should take place in the region concerned.

3.1 Patient group

The programme includes all adults, children and pregnant persons diagnosed with type 1 or type 2 diabetes. To ensure a systematic effort and monitoring of the effort, the diagnoses of everyone diagnosed with diabetes should be registered.

The goal is for doctors and other relevant professional groups in both the primary sector and the hospital sector to register all contacts concerning diabetes, and to register the diagnoses of all persons with diabetes.

3.2 Early detection

The programme comprises only persons who have been diagnosed with diabetes. However, early detection, particularly of persons with type 2 diabetes, is an important element of an intensified effort in the diabetes area. It is estimated that close to 200,000 Danes have type 2 diabetes without knowing it, and that nearly half the patients recently diagnosed with diabetes already have one or more late complications. Persons of other ethnic backgrounds are a particular challenge due to a very high incidence of type 2 diabetes in this population base.

It is recommended that guidelines on early detection of persons with diabetes should be integrated in the relevant guidelines for diagnosing, treatment and rehabilitation of diabetes. A memorandum concerning detection and diagnosing type 2 diabetes was prepared by an interdisciplinary, intersectorial working group in 2004. It contains the following recommendations:

1. Recommendations for clinical case-finding with a description of the clinical symptoms that should trigger type 2 diabetes testing in both general practice and the rest of the health service.
2. Recommendations of when tests for undetected type 2 diabetes should be a mandatory, integral part of the examination programme for patients with other diseases, e.g. ischaemic heart disease.
3. Recommendations for intensified detection among high-risk individuals.

3.3 Diagnosis and contact registration

All persons with diabetes should be registered whether they are diagnosed by GPs, medical specialists or in the hospital sector.

All contacts with GPs, the municipal health service and the specialised health service concerning the person's diabetes should be registered.

3.3.1 Diagnosis and contact registration in the hospital service

The following ICD-10 diagnosis codes⁹ are used in connection with diagnosis and contact registration in the hospital service:

E10.0 – E10.9: Diabetes, insulin-dependent

E11.0 – E11.9: Diabetes, non-insulin-dependent

E13.0 – E13.9: Diabetes, other type

E14.0 – E14.9: Unspecified diabetes

Data from diagnosis and contact registration in the hospital service are collected in the Danish National Patient Registry.

3.3.2 Diagnosis and contact registration in general practice

General practice registration applies the extended Danish ICPC code system¹⁰ code T90: Diabetes/diabetes mellitus.

Data from diagnosis and contact registration in general practice are collected in the Danish General Practice Database (Dansk Almenmedicinsk Database).

3.3.3 Diagnosis and contact registration in the municipal health service

Extension of the existing system for diagnosis and contact registration in municipalities is recommended to allow it to support systematic registration and collection of data in the municipal health service.

3.4 Guidelines

A large number of local/regional clinical guidelines are available for measures concerning persons with diabetes. Among the purposes for the disease management programme for diabetes is to contribute to a more uniform treatment of patients with diabetes based on common updated, evidence-based clinical guidelines. The following national or nationwide clinical guidelines for diabetes have been published after the year 2000.

3.4.1 Nationwide Danish clinical guidelines

In 2003, the Danish Centre for Evaluation and Health Technology Assessment under the National Board of Health published a report on type 2 diabetes, health technology assessment of screening, diagnostics and treatment (*“Type 2-diabetes. Medicinsk teknologivurdering af screening, diagnostik og behandling”*).

In 2004, an interdisciplinary working group under the National Diabetes Steering Group prepared a report on good care pathways and late complications (*“Det gode patientforløb samt senkomplikationer”*) concerning type 2 diabetes patients. The report contains both clinical decision support,

proposals concerning increased late complication screening measures and proposals for organisational changes.

In 2004, DSAM, the Danish College of General Practitioners, published clinical, evidence-based guidelines on type 2 diabetes in general practice (*“Type 2-diabetes i almen praksis – En evidensbaseret vejledning”*). This was followed by patient guidelines for type 2 diabetes prepared in a collaboration between DSAM and the Danish Diabetes Association. The Danish Endocrine Society and the Danish Society of Nephrology together prepared a report on good care pathways for patients with diabetic nephropathy (*“Det gode patientforløb for patienter med diabetisk nefropati”*)

In 2005, The Danish Society of Diabetes Nurses (Fagligt selskab for Diabetessygeplejersker) under the Danish Nurses' Organization updated its clinical insulin injection guidelines for adults with diabetes mellitus (*“Kliniske retningslinier for injektion af insulin til voksne med diabetes mellitus”*) in 2006.

The Danish Association of Clinical Dieticians (Foreningen af Kliniske Diætister) has prepared national evidence-based 'framework plans' for dietetic treatment of type 1 and type 2 diabetes.

It has not been possible to identify specific Danish nationwide clinical diabetes guidelines for other relevant professional groups (cardiologists, ophthalmologists, chiropodists, physiotherapists). In addition to the above guidelines for health professionals, a number of patient guidelines have been published by the Danish Diabetes Association, among others.

The most recent nationwide clinical guidelines for type 1 diabetes were published by the National Board of Health in 1994.

The Danish national guidelines identified above were prepared by interdisciplinary working groups or with the participation of different professional groups, but they are not intersectorial, and they do not describe measures across general practice, the municipal health service and the specialised health service. A number of international guideline organisations and professional societies prepare clinical guidelines in the diabetes area, which are used as input to the clinical effort in Denmark.

It is assessed that there is a need for nationwide interdisciplinary, intersectorial clinical guidelines for diabetes in the following areas:

9 ICD10: International Classification of Disease 10th edition (WHO)

10 Extended Danish ICPC: International Classification of Primary Care (convertible into ICD10 code). For more information, go to www.dak-e.dk

- Heart diseases
- Treatment of foot ulcers
- Type 1 diabetes
- Patient education
- Support and advice on lifestyle and behavioural changes
- Mental co-morbidity
- Mental mastering, including support for 'vulnerable patients'.

3.5 Guideline requirements

3.5.1 Newly diagnosed patients

Patients diagnosed with diabetes should all be screened for complications. The severity of the disease should be assessed and a follow-up plan should be prepared. The initial stratification should take place at a competent level.

At the time of diagnosis, a structured patient education programme should be planned to inform the patient and enable him/her to make conscious choices. A structured patient education programme may include the following themes, among others: the nature of the disease, how to live with diabetes, diet, physical activity, smoking, metabolic regulation, medical treatment of hyperglycaemia, intercurrent diseases, chiropody, diabetic late complications, pregnancy, social circumstances and travel. Relatives may be involved in the patient education.

Individual assessments should be made in the initial phase to determine whether referral of the patient to an ophthalmologist or individual dietetic treatment, support for a change of lifestyle, and self-management, physical exercise and chiropody is required.

On completing the initial phase, the patient should switch to regular follow-up based on planned and annual visits to the doctor.

3.5.2 Regular follow-up

Individually agreed regular visits and a comprehensive annual visit to the doctor are the nucleus of the follow-up on persons with diabetes. The programme includes:

Planned visits 2-4 times a year

- HbA1c, BT and weight check. In cases of microalbuminuria they also involve urine testing.
- Review of blood glucose measurements at home, if relevant
- Interview about living with diabetes, including self-management, psycho-social aspects and the possibility of involving close relatives, networks, etc.
- Interview about dietary, exercise and smoking habits with a view to ensuring insight and ability to make conscious choices
- Interview about the medical treatment and need to make adjustments to it or to the individual treatment targets

- Identifying need for further patient education
- Individual risk assessment (stratification) and identifying individual treatment targets.
- Drawing up/adjusting an overall treatment plan in collaboration with the patient

Annual visit

In addition to the above, the annual visit should include:

- Deciding on the need for eye screening: fundus photo and eye examination by an ophthalmologist every second year (more frequently in case of pronounced retinal changes and in case of pregnancy)
- Chiropody examination: pedal pulse, malalignments, callosities, pressure marks or manifest foot ulcers, monofilament or vibration sense examination. Assessment of the need for referral to a chiropodist and ulcer centre/diabetes out-patients' clinic
- Assessment of symptoms of autonomic neuropathy, e.g. sexual dysfunction, gastroparesis, etc.
- Examination for diabetic renal disease: urine albumin-creatinine ratio or twenty-four hour urine-albumin, s-creatinine

- Examination for cardiovascular disease: symptoms and clinical signs of ischaemic heart, brain or peripheral vascular disease. Screening for cardiovascular risk factors: total cholesterol, HDL and LDL cholesterol and triglycerides
- Ensuring the patient gets relevant reimbursements (e.g. for medicine, test equipment, diet)
- Setting treatment targets and drawing up a treatment plan.

The purpose of the annual visit and the planned visits is to detect early signs of diabetic sequelae and to check and adjust the treatment of hyperglycaemia and other risk factors for diabetic sequelae.

In addition, the need for referral to other regional or municipal services should be determined at each visit. This might include intensified patient education with a view to improved self-management or consultations with a case manager or a psychologist for patients with particular problems in relation to the disease.

3.6 Support for self-management

According to the disease management programme for chronic diseases the programme should contain a description of the contribution of an active correlation between the health service

and patients to methods of and support for self-management through:

- general and specific patient education that contributes to the generation of knowledge, skills and attitudes in persons with a chronic disease
- pharmacological and non-pharmacological self-monitoring and self-treatment
- programmes for particularly vulnerable patient and population bases
- treatment and rehabilitation
- knowledge sharing between healthcare providers and patients

As regards diabetes, there is a lack of formalised nationwide initiatives and/or programmes in all the above areas. There is evidence of or consensus on the benefits and intents in several of those areas, e.g. for self-monitoring of blood glucose and specific patient education. Furthermore, written patient guidelines are available, prepared by the professional societies and the Danish Diabetes Association on the basis of clinical guidelines or professional consensus.

3.6.1 Intensified patient education

Some patients with diabetes that is poorly managed or difficult to manage may need intensified patient education provided individually or to groups of patients. The teacher may be a nurse or dietician with specialist knowledge

about diabetes. Referrals to intensified patient education should be made by the doctor who is responsible for treatment of the patient's diabetes.

3.6.2 Vulnerable patients

There is a need to develop education programmes for particularly exposed or vulnerable patient and population bases to support their self-management capacity. Vulnerable patients are defined as:

- patients who, due to severe illness, several concurrent diseases requiring treatment, disabilities, etc. and possibly a weak personal network, are highly dependent on health and/or social services;
- patients who, due to weak personal resources and a poor or different understanding of their disease, social or cultural circumstances, are incapable of proper behaviour and self-care.

It may be relevant to offer specific education programmes to ethnic groups.

3.7 Organising the programme

A wide range of players in the primary health sector (GPs, medical specialists and the municipal health service) and in the hospital sector are involved in the treatment of patients with diabetes. The Danish Health Act determines responsibility for a number of specific areas.

However, there is considerable scope for variation within the framework of the Act in terms of the actual organisation of the programme in individual regions or municipalities and, to some extent, across sectors.

The disease management programme for diabetes must be regarded as the basis for regional or local planning. When planning the effort it should be ensured the services described in the programme can be offered to persons with diabetes in the geographical area covered by the disease management programme; that the medical professionals have the necessary qualifications; that the programme is planned as a graded effort appropriately organised and coordinated across professional groups and sectors.

3.8 Graded care

A population of patients with diabetes can be described by way of a stratification pyramid that divides patients into groups according to their different needs (Figure 1, page 19).

Correct stratification ensures that each patient gets the treatment corresponding to the complexity of the disease and the patient's personal circumstances and individual needs.

3.8.1 Stratification criteria for persons with diabetes

The choice of stratification criteria should take into account:

1. The degree of severity and complications, etc. of the disease.
2. Any co-morbidity and sequelae of the disease.
3. The patient's self-management capacity.

To ensure that each person with diabetes is always given the appropriate level of treatment, the stratification should be dynamic, as the state of the patient may improve, stabilise or deteriorate. The first assessment of the most appropriate level of treatment for each patient should be made immediately upon diagnosis, and then on a regular basis, as a minimum in connection with the annual visit.

The first version of the stratification criteria were drawn up by the General Medical Quality Project (Det Almenmedicinske Kvalitetsprojekt – DAK) in cooperation with the Good Medical Department (Den Gode Medicinske Afdeling – DGMA). They have been tested and evaluated in general practice in a number of regions since 2006. The criteria should reflect the three levels of the chronic disease management pyramid where level 1 comprises patients with well-managed diabetes without significant complications; level 2 comprises patients whose diabetes is poorly managed or difficult to manage

or with complications; level 3 comprises patients with complex diabetes or several complex chronic diseases.

Allocation to level 1 requires all the criteria for level 1 to be met. Allocation

to level 2 requires neither the criteria for level 1 nor level 3 to be met. If a required criterion is not met, the patient should generally be allocated to level 2.

Allocation to level 3 requires only one criterion to be met.

Table 1. Stratification criteria for diabetes patients developed under the cooperation project between DAK and DGMA

Criterion	Level 1 Persons with well-managed diabetes without complications	Level 2 Persons at high risk of/with beginning complications	Level 3 Persons with complex diabetes or several complex chronic diseases
Glycaemic control after intervention:	HbA1c < 7% (0.07)		HbA1c > 9% (0.09) despite 6 months' attempt at optimised treatment
Blood pressure mmHg	< 130/80		> 160/90 despite 6 months' attempt at optimised treatment
Metabolic problems in connection with treatment	No	Severe insulin resistance	Tendency to serious or unexpected occurrences of hypoglycaemia. Highly fluctuating blood glucose.
Cardiovascular disease/large vessel disease	No present cardiovascular disease	Present cardiovascular disease	
The diabetic foot	No	Signs of neuropathy or arterial insufficiency	Foot ulcer/gangrene/Charcot foot
Nephropathy	Normal	Microalbuminuria	Macroalbuminuria/nephropathy
Retinopathy	Normal or stable simplex retinopathy	Any progression of the degree of retinopathy	Macular oedema or proliferative retinopathy

These criteria describe the intensity, complexity and sequelae of the disease, but not co-morbidity (e.g. mental disorder or chronic obstructive pulmonary disease (COPD)).

The patient's self-management capacity and several other criteria of the generic disease management programme are not covered by the above stratification criteria. These criteria need to be further developed. The current stratification criteria are being tested and evaluated in general practice which is why it would be expedient to postpone the reassessment and expansion of the stratification criteria for diabetes patients until testing has been completed.

3.8.2 Practical application of the stratification criteria

Several health-care services require the same qualifications regardless of whether the services are aimed at patients at level 1, 2 or 3. In cases of diabetes that is complex and difficult to manage, qualifications at specialist level are required.

The following principles should be followed when determining the local/regional effort:

- For *patients with well-managed or newly diagnosed type 2 diabetes without significant complications*, treatment should generally be handled by GPs or the municipal health service. Patients with newly detected type 1 diabetes should be referred immediately to a diabetes clinic.
- For *patients with diabetes that is poorly managed/difficult to manage and/or with complications*, treatment should be handled jointly by GPs, the municipal health service and the specialised health service (the hospital service and/or medical specialists).
- For patients with complex diabetes or several complex chronic diseases the greater part of treatment is handled by the specialised health service.
- Rehabilitation and self-management support are handled in cooperation with general practices and the municipal health service.

3.8.3 Current national organisational requirements

For certain patient groups and types of complications the National Board of Health medical specialty guidelines concerning national and university hospital service functions specify where they should be treated. It is stipulated that:

- Patients with type 1 diabetes should be offered checkups at diabetes out-patients' clinics according to their individual needs.
- Pregnant women with insulin-dependent diabetes should be referred to the university departments of gynaecology/obstetrics at Copenhagen University Hospital, Odense University Hospital, Aarhus University Hospital and at Aalborg Hospital. According to specific agreement with the university department, checkups can take place at a local hospital offering basic treatment.
- Patients with diabetes that is difficult to manage, including patients with pronounced insulin resistance and insulin allergy, should be referred to the university departments of endocrinology at Copenhagen University Hospital, Herlev Hospital, Odense University Hospital, Aarhus University Hospital and Aalborg Hospital.
- Complex diagnostics and treatment of vitreo-retinal diseases, including in connection with diabetes mellitus: the university departments of ophthalmology at Copenhagen University Hospital, Herlev Hospital, Odense University Hospital, Aarhus University Hospital and Aalborg Hospital.

- Severe cases of diabetes mellitus in children: the university departments of paediatrics at Glostrup Hospital, Odense University Hospital and Aarhus University Hospital (Skejby Hospital). These provisions are to be revised in 2007.

3.9 Coordination and cooperation

3.9.1 Coordinating functions

Coordinators

It is recommended that all patients with diabetes should have a coordinator who is responsible for:

- coordinating overall care
- evaluating the patient's health on an ongoing basis
- ensuring systematic follow-up and proactivity
- contributing to adherence to treatment targets

In general, this function should be handled by GPs. Some patients only have sporadic contact with GPs for periods of time during the course of their disease. In case of complex diabetes where treatment is primarily handled at the specialised level, responsibility will naturally lie with the medical specialists.

Case managers

Some patients need particular support. Offering such patients increased support to complete and adhere to their treatment and rehabilitation through the attachment of a case manager is recommended. The objective is to ensure intensified, customised support for patients with severe, complex needs.

Referral to a case manager should be made by the coordinator or the team responsible for the treatment of the diabetes patient.

3.9.2 Health agreements between regions and municipalities

The purpose of the health agreements is to remove any doubt about the distribution of responsibility for the provision of specific services or the cooperation and coordination between the players i.e. region and local level. The tasks, qualifications and responsibilities of all the players involved to ensure a coherent and coordinated care programme should be described in health agreements between the regions and municipalities. Representatives of all the players involved should participate in the drawing up of these agreements that form the basis for the implementation of the recommendations made in the national disease management programme and for the distribution of tasks between the players in the region and the primary sector.

As regards the handling of special functions such as case management and coordination of disease management programmes at the regional level it is particularly important for the health agreement to specify and describe the tasks and responsibilities. The agreements may also outline explicit requirements for the qualifications of the various players and any plans for further education.

3.9.3 Supportive information technology

In 2006, the National Board of Health published a report prepared by MEDIQ on the possibilities of IT support for disease management programmes for diabetes.

The report demonstrates the following potential benefits in connection with supportive information technology:

- Easy access to necessary data exchange between the various health-care providers.
- Shared data basis across the various health-care providers (information sharing).
- Better overview of the overall status of individual care pathways, e.g. by visualising key data.
- Access to decision support.
- Support for systematic follow-up on diabetes patients by way of annual visits and planned visits.

The report emphasises potential IT support for self-management by way of:

- Calendar function concerning visits to the doctor
- Registration of self monitoring by way of glucose measurements
- Decision support and reminders in connection with blood glucose regulation
- Electronic diabetes diary
- Quality monitoring, research and development.

3.9.4 Quality monitoring

Monitoring of the quality of the programme should include both clinical

results, organisational factors and patient experience of the programme, and the standards and indicators that form part of the Danish Quality Model should be applied. In addition, a number of nationwide monitoring initiatives in the diabetes area were in operation or planned at the end of 2006: the National Diabetes Register, the National Indicator Project, the Danish Diabetes Database, the Danish Quality Model for the Health Service and the Danish General Practice Database.

The following indicator areas are used:

Indicator area	National Diabetes Register ¹	National Indicator Project (NIP) ²	Danish Diabetes Database ³ (*)	Danish Quality Model ⁴	General Practice Database ⁵
Prevalence	■				■
Incidence	■				■
Mortality	■				
Metabolic or glycaemic regulation		■	■	■	■
Hypertension		■	■	■	■
Lipids		■	■	■	■
Albuminuria		■	■	■	■
Retinopathy		■	■	■	■
Neuropathy (chiroscopy examination)		■	■	■	■
Nephropathy (age 0-18)			■		
Severe hypoglycaemia (age 0-18)			■		
Ketoacidosis (age 0-18)			■		
Ophthalmologic treatment			■		
Prevalence of blindness			■		
Written, updated guidelines				■	
Audit reports				■	
Quality improvements				■	
Action plans in case of quality defects				■	
Individual treatment targets					■
Lifestyle interview					■

3.9.4.1 National Diabetes Register

The National Diabetes Register of the National Board of Health provides an overview of diabetes incidence and prevalence in the total population. The register is made up of the National Patient Register and the National Health Insurance Register and, in time, data from the Register of Medicinal Product Statistics.

3.9.4.2 National Indicator Project (NIP)

Since 2004, diabetes has formed part of the National Indicator Project (NIP). It collects data concerning six indicators.

3.9.4.3 Danish Diabetes Database

As part of the national diabetes action plan of November 2003, a common national diabetes database, the Danish Diabetes Database (DDD), is to be developed. It is the intention to merge data on diabetes in adults (NIP), childhood diabetes (Danish Register for Childhood Diabetes (DIA-REG B & U) and diabetic eye complications (DiaBase) into one national clinical quality database.

3.9.4.4 Danish General Practice Database

In connection with the introduction of a general practice diabetes programme, the DAK project (the General Medical Quality Project) in cooperation with the Research Unit

for General Practice at the University of Southern Denmark has developed a software product for automatic data collection on the treatment of patients in general practice. The collected data describe the diabetes patient base on the basis of a number of indicators and the stratification data of individual patients.

3.9.4.5 Danish Quality Model for the Health Service

The Danish Quality Model (DDKM) for the Health Service is a joint quality development and accreditation system for the Danish health service based on a common set of standards and indicators.

Diabetes has been selected as one of the disease-specific themes/areas, and standards and indicators were developed in 2006. In the course of 2007 the standards should be implemented at all public Danish hospitals and in a number of municipalities, and in 2008 it should be measured whether the institutions meet the new quality targets.

3.9.4.6 Proposals for further monitoring initiatives

It is recommended that, in future, the existing nationwide monitoring initiatives should collect data that will contribute to the monitoring of specific recommendations in this disease management programme.

Consequently, indicators should be developed for:

- the roles of coordinator and case manager
- patient education
- self-management
- patients' experience of quality/patient satisfaction
- implementation of disease management programmes

In addition, quality monitoring of the municipal health service effort should be ensured. Some areas may only be fit for local/regional monitoring and evaluation. This may be performed by auditing care pathways, evaluating and revising cooperation agreements, analysing procedures, evaluating local/regional further education initiatives, etc.

3.9.5 Implementation of the disease management programme

Successful implementation requires a good organisational culture, management commitment, resource allocation, professional and financial incentives, staff participation, regular evaluation and use of quality data.

A regional coordinator should be responsible for the implementation, development and follow-up on disease management programmes in regions and municipalities. At the same time the coordinator may contribute to ensuring that the programme activities involve the relevant health-care councils and other regional and municipal health-care authorities.

9.10 Evaluation and revision of disease management programmes

The need for updating and revision of the national disease management programme should be determined on a regular basis. The disease management programme for diabetes is the first example of a national disease management programme. An evaluation of the implementation and applicability of the programme is therefore proposed as input for updating and revision of the programme.