Position Paper

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Diabetes in Europe: role and contribution of Primary Care

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Introduction

Diabetes is a chronic condition associated with multiple late complications, reduced life expectancy[1] and a marked limitation in the quality of life[2]. Mortality among people with diabetes is about twice as that in the normal population and life expectancy is about five to ten years shorter. The disease, its complications and late onset consequences cause a dramatic burden for health systems[3-5].

This position paper focuses on the pivotal role of Primary Care in the management of people with diabetes mellitus and targets policymakers in the European Union and its member states. We argue the need for a concerted approach to define how programs to manage diabetes mellitus should be designed, developed, implemented and evaluated to ensure the highest level of quality care delivery across the different European healthcare systems.

1 Definition and classification of diabetes mellitus :

Diabetes mellitus is a group of endocrine disorders characterised by hyperglycaemia as a consequence of disturbed secretion or function of insulin. Chronic hyperglycaemia in diabetic subjects is associated with long term complications and decreased functioning of several organs and tissues, especially the heart and blood vessels, the eyes, kidneys and the nervous system.

The following four types of diabetes can be classified[6 7] :

1. Type 1 diabetes: disordered insulin secretion due to destruction of the beta-cells in the pancreas with mostly absolute deficiency of insulin. A special form with slowly developing deficiency of insulin secretion is known as latent autoimmune diabetes of adults (LADA).
2. Type 2 diabetes: disorder of insulin effects (insulin resistance) with relative deficiency of insulin (typically a disorder of glucose dependent insulin secretion).
3. Other specific types of diabetes: these are caused by diseases of the exocrine pancreas or other endocrine organs or might develop due to pharmacological causes, genetic defects or syndromes or infections.
4. Gestational diabetes: this type develops for the first time during pregnancy as a disorder of glucose tolerance.

Diabetes mellitus is diagnosed primarily by measurements of elevated fasting glucose values

on at least two different days in plasma or full blood. Quality assurance of tests is an absolute requirement. Devices designed for self measurements by patients are not accepted to establish the diagnosis[6]. In suspected clinical situations and in case of contradictory results, the diagnosis is based on the oral glucose tolerance test. An impaired fasting glucose and an impaired glucose tolerance (together known as prediabetes) have been defined with their specific lower and upper limits and are considered the early forms in the development of diabetes[7] . The determination of glycosylated haemoglobin (HbA 1c) alone is currently not suited for making the diagnosis and is used exclusively for monitoring of long term care and for aiding decisions on management[6 7].

While type 1 diabetes with its typical symptoms and acute onset is usually diagnosed quite early, the diagnosis of type 2 diabetes usually is preceded by a longer symptom free interval. However, insulin resistance and a disorder of insulin secretion does exist in these patients long before the disease becomes manifest, which very often already at this time leads to an increased risk of stroke, myocardial infarction and peripheral arterial disease[7]. Measures for prevention and early recognition of type 2 diabetes are therefore of prime importance.

2 Epidemiology

Type 1 diabetes only accounts for 5 to 15 percent of all diabetic patients. Type 2 diabetes is the most common form of the disease and accounts for approximately 90 percent of all people suffering from diabetes. Usually, type 2 diabetes is diagnosed after the age of 35 years; however, over the last few years, there has been an increase in prevalence of type 2 diabetes among adolescents[8]. Furthermore, evidence suggests that there is a high proportion of people with undiagnosed diabetes[9 10]

The impact of diabetes on health in Europe can hardly be underestimated. Unfortunately, sources of data on diabetes and data collection are different. In 2003, however, the International Diabetes Federation estimated that about 48 million people in Europe suffer from diabetes. This corresponds to a prevalence of 7.8%, which is expected to rise to 9.1% by 2025. By 2025 the direct cost of diabetes is expected to represent between 7% and 13% of the total health expenditure[4] .

Diabetes has a dramatic impact on mortality, morbidity, daily functioning[11] and quality of life: diabetes patients have 3- 4 times as much risk to die from cardiovascular diseases. Diabetes is still the most common cause of blindness at working age, one of the most common causes of kidney failure and the most common cause of leg amputation[5 12].

3 Reasons for concern and central questions

There is ample evidence that the typical long term relationship between patients with chronic conditions and their GP / Family Physician with multiple consultations and health checks over time offer a very good opportunity to assess risk factors or early suspicious symptoms and to identify patients with increased risk for developing diabetes or another chronic disease[13] Although the quality of diabetes care in many healthcare systems is gradually improving, this holds for a part of the patient population only[14-19]. Furthermore, besides the high proportion of people with undiagnosed diabetes, there is still a wide variation in quality of care, with rates of recommended care processes to be unacceptably low in some health care settings[19-24]

What are the reasons for that variation in the quality of care? What lessons can be learned ? What are our recommendations in order to improve diabetes care in Europe ?

4 Methodology and process

To improve diabetes care in Europe the position paper 2006[25] has put forward arguments for the chronic care model[26 27] as a conceptual basis and its foundation routed in primary care has been underlined. The following general principles have been summarized:

① ***Patients should be active and empowered partners in diabetes care***

② ***Diabetes care should be provided by an interdisciplinary team***

③ ***Quality monitoring is a prerequisite for efficient diabetes management***

④ ***Information and communication technology are crucial to facilitate integrated diabetes care***

⑤ ***Prevention and early detection of diabetes require more attention***

Based on these conclusions the current position paper aims to provide some more specific recommendations. A survey was conducted in the fall of 2007 via a network of participating GPs, experts and specialists in the field of diabetes. They were recruited via Wonca network organizations and their partners in the field of diabetes (table 1, annex). Reports from 15 countries were received. A workshop was organized in Vienna in December 2007 with the following participants: *Luk Van Eygen-Belgium, Domingo Orozco-Spain , Rurik Imre-Hungary, Hakan Yaman- Turkey, Susanne Pusarnig-Austria, Astrid Knopp-Austria and Manfred Maier-Austria.* At the workshop, the reports received from different countries were

discussed and the draft version of the position paper was reviewed. As a result, the lessons learned and conclusions drawn were formulated and included in the position paper. Several calls for comments to the subsequent draft versions resulted in a lively discussion via internet and additional contributions or suggestions by colleagues (table 1) could be included in the final version of this position paper.

5 Experiences and practices

Background information relevant for diabetes care from 15 European countries – most of it unpublished in the scientific literature - could be collected by our survey (table 2, annex). In addition, the scientific literature was searched accordingly. Some key issues are summarized below.

5.1. National strategies for Diabetes care:

Based on available data many countries lack a national strategy for diabetes care. Such a strategy, however, apparently supports the quality of care provided and the outcome of diabetes care achieved.

As can be seen from table 2, only six countries have a national strategy for diabetes care in place. In Romania, a new comprehensive protocol for diabetes care was offered to doctors and patients in 2007. In Hungary, a program exists, but it is hardly implemented[28]. And in seven countries there is no national strategy at all. In the UK, a National Service Framework was published in 2001 with the aim of improving the quality of care of people with diabetes and of reducing variations in care[29].

Furthermore, only Spain[30 31], France, Slovenia, Lithuania and the Netherlands have implemented a disease registry for patients with the disease. Registers might be implemented only at the secondary level (Slovenia) or only in some regions (Denmark[32], the Netherlands[33], UK[34]), or only for patients taking part in a structured disease management program (Germany, Austria); in France, registration is incomplete, the same seems to be true for Romania.

Similarly, only Finland, Slovenia, Turkey[35], Lithuania and the Netherlands[36] have some form of screening program in place. In Austria, Belgium and the UK, there is opportunistic screening [6]; in all other countries, apparently, there is no national screening program for people at risk for developing diabetes or for people so far undiagnosed with the disease.

5.2. Care providers:

If the responsibility for the management of diabetes care is not allocated to a predefined level of care or a predefined group of health professionals, outcome appears to be unsatisfactory. A well developed Primary Health Care system, where people with diabetes type 2 are managed, appears to be a good foundation for better outcomes. Vocational training and status for GPs, however, are different across Europe and specific training in diabetes care for GPs has only recently been introduced in some countries.

Across the nations surveyed medical care for people with diabetes is provided by both General Practitioners (GPs) and specialists. Although the majority of people with type 2 diabetes are managed in Primary Care by GPs in France, Finland, Belgium, Spain, Lithuania, Denmark, Switzerland, Austria and in the Netherlands, responsibility for patients is not always clearly defined. In the Netherlands, shared diabetes care has been implemented to a large extend with well-defined guidelines for referral from primary care to hospital-based care. General Practitioners, specialists/ diabetologists and diabetes nurses work together in regional networks. In the UK, majority of people are cared for in primary care[37]; however, there has recently been a shift in reducing the proportion of people being cared for in secondary care and instead new intermediate care models are now being implemented in a community setting[38]. In all other countries patients are cared for primarily by specialists at specified institutions or at the secondary level in a hospital.

Even among countries which have implemented a structured program for the care of people with diabetes, clear allocation of responsibility for the coordination of care exists only in Hungary, Lithuania, Denmark, the Netherlands and the UK. In all other countries with a structured care program, responsibility for coordinating care and managing patients seems to be left to market forces between GPs and internists.

Vocational training to become a Specialist in Primary Care or specific training of GPs to care for patients with diabetes differ across Europe. Specific training in some way or another exists in the majority of countries: in Spain specialty training for general practice was introduced already in 1982; in other countries specific training for GPs to improve the care of people with diabetes has been introduced during the last few years , mostly in relation to a structured program for screening or care (Austria, Germany;[39 40], UK[38]).

5.3. Patient involvement and support for self- management:

In order to improve care and outcome of people with diabetes, active participation of well informed patients, their commitment, their sense of responsibility and their motivation for adequate self-management appear to be necessary. Based on their long lasting relationship with their patients and on the knowledge of their individual psycho-social background, GPs are in a perfect position to support and foster patient involvement.

While providers are experts in the medical field of diabetes, people with diabetes themselves are experts in the field of living with diabetes[41]. It seems logical to make use of that expertise and activate it to improve care and outcome. As GPs are in a very good position to understand that decisions made by individual patients – especially outside of hospitals in the community setting[42] - are influenced more by their own personal beliefs of diabetes than by medical concepts, joint agreements between patient and coordinating physician on diagnostic procedures and treatment options are necessary. Thereby, individual risks and patient's preferences have to be taken into account[43], owing to the patient centeredness of Primary Care[44]. This implies active patient participation and commitment- i.e patient-empowerment. Although these strategies have been implemented already, these have so far proven to be effective on a rather small scale only.[45-47]

Apparently, the potential of patient empowerment has been recognized recently. In 10 out of 15 countries some form of patient empowerment such as a structured education program has been implemented and the need for picking up responsibility for one´s own health has been emphasized (table 2).

5.4. Quality of care provided:

Though diabetes guidelines exist in almost all countries across Europe, the level of adherence to these guidelines is unknown or unsatisfactory. The quality of care provided is unknown or unsatisfactory in most countries, mainly due to the lack of reliable data.

Overall, very little is known about the quality of care provided to people with diabetes in Europe. In particular, reliable and valid data, which can be used for assessment and evaluation of outcomes, are not available in most countries. An exception is the Netherlands; based on available data (table 3) it can be concluded that outcome of care is known and can be judged

to be good[21 33 48-51]. Also in the UK, the quality of care was good[52]; however, it has improved further since the introduction of a pay for performance contract in 2004[53]. In all other countries the outcome is believed to be either unsatisfactory[54 55] or possibly acceptable.

Surprisingly, national guidelines believed to be a prerequisite for quality care exist in all but two countries (Switzerland and Germany). These have been implemented dating back as early as 1989 (Netherlands); the majority of guidelines are said to be evidence based and are updated more or less regularly. Ministries of Health, specialists, general practitioners or an interdisciplinary group of professionals are mainly responsible for the development of these guidelines. From the available data it seems clear that the development of guidelines by the ministry or by specialists does not support adherence among Primary Care Physicians. In contrast, adherence to guidelines, which have been developed by General Practitioners and specialists together, appears to be better[33].

5.5. Context of care provision:

The context of where and how diabetes care is provided appears to be important. A framework with gate keeping, a list system for patients and structured programs accompanied by financial incentives seems to be supportive for adherence and good outcomes.

Finland, Spain, Slovenia, Lithuania, Denmark, the UK and the Netherlands have health care systems with gate keeping and a patient list in place (table 2). In countries like Germany, Belgium, Hungary or France gate keeping is either voluntary or implemented at the regional level only.

Most countries provide care for people with diabetes at the community level or are at least encouraging community based care (Turkey). In Romania, Slovenia, Turkey and in Hungary care at least in part is provided at specialized clinics or institutions, for example in Romania for diabetic patients on insulin therapy.

During the last 10-15 years 10 countries have implemented some form of structured program for the care of diabetic patients[39 56]. Seven of them have supported implementation or continuation of the program by financial incentives for the care provider, the patient or both[57]. Among them are the Netherlands and UK with good outcomes in diabetes care[21 33 48-51 53] or countries which have good data[54] or which have moderate to good adherence to guidelines[33].

5.6. Monitoring, feedback and research:

Many countries lack quality monitoring or systematic research of the diabetes care provided. This may cause insufficient information and feedback at the political level.

Among the 15 countries surveyed only Finland, the UK and the Netherlands have a quality monitoring system in place at the primary care level. Other countries have implemented quality monitoring either at the regional level or in secondary care or within a structured disease management program [39 56].

The majority of countries show some research activities at the Primary Care level. In Europe, however, only the UK, Denmark and the Netherlands have a strong international research record[52 58]; so far, little or no research is done in Austria, Switzerland, Romania or France. It is not the aim of this paper to identify the reasons for this difference in research activities. It is common knowledge, however, that an appropriate infrastructure and funding situation for research would help to bridge the gap between process and outcome of health services provided and health policy[59 60].

6 Lessons learned

From the country reports provided (table 2 and 3) and from the literature it can be concluded:

1. Care of people with diabetes is differently organized across Europe. The level and degree of organisation varies widely and apparently depends on both the status of the health care system and the level of professional involvement.
2. Official data on the prevalence of diabetes vary widely (1.8-10%); sources of data and data collection are different. As a consequence, prevalence or incidence data are hardly comparable.
3. In almost all countries, diabetes is believed to be underdiagnosed and the prevalence of type 2 diabetes is believed to be underestimated.
4. In most countries, the quality of care is unknown but perceived to be unsatisfactory.
5. In most countries, the acceptance/adherence to guidelines is unknown and seems to be unsatisfactory. The development of guidelines alone or their simple availability does not necessarily improve quality of care for patients with diabetes.
6. Countries which have a monitoring system and are registering patients with diabetes have a better quality of care than countries without such a register.
7. Countries with a tradition of research in Primary Care have much better information and data on quality of diabetes care than countries without that tradition.

Positive highlights of this survey have also been identified: In many countries

- there is a trend towards Disease Management Programmes / structured programmes for care of people with diabetes
- specific guidelines for managing people with diabetes have been developed with primary care input in most countries
- there is a trend towards patient empowerment, emphasizing patient-centred medical care
- specific training to become a GP or to train GPs specifically for the care of people with diabetes is developing in some countries
- there is a trend to recognize GPs as coordinators of structured care programmes

Some negative highlights were also found: In many countries

- there is a lack of reliable epidemiological data
- there is a lack of data for outcome measures or of data on the quality of care
- there is a lack of research at the level of Primary Care
- adherence to guidelines is not known
- structured screening or prevention programmes are scarce

It should be kept in mind that data about adherence to guidelines and about the quality of care from the hospital-based diabetes care across almost all European countries also hardly exist.

7 Recommendations

Based on the information and data collected or available, the current position paper extends the evidence summarized in 2006[25] and provides further recommendations to improve the quality of care for diabetic patients:

General recommendation:

To improve the quality of diabetes care and to develop a sound and sustainable evidence base for decisions in health policy regarding diabetes care, we strongly recommend

- ***to recognize the importance of a well developed Primary Care work force in this endeavour and***
- ***to promote and strengthen Primary Care***
    - by increasing education and training,
    - by providing a supportive environment for care provision and research at the primary care level including the allocation of research funds
    - by developing methods for collection of routine data and monitoring and
    - by positioning Primary Care at the centre of health care systems in Europe.

Specific recommendations:

1. ***An interdisciplinary team of professionals should agree on common goals and on a national strategy for the care of patients with diabetes.***
2. ***Initiatives aiming to improve the quality of care must be evidence based and should be developed by an interdisciplinary team including all parties involved in order to facilitate implementation and adherence.***
3. ***Programs should be implemented, conducted, coordinated, adapted to individual patients and evaluated at the community level by trained Primary Care physicians (and their teams).***
4. ***Systematic education or training should be offered to care providers and patients.***
5. ***Comprehensive registers for patients with diabetes should be established and maintained as standardized source of reliable information.***
6. ***Implementation of initiatives to improve the quality of care and outcome should be supported by incentives for providers and patients.***

8 Conclusions

The different stages of developments in the organisation of diabetes care in Europe illustrate the transition process European health systems are going through. They were designed in the middle of the 20th century to deal mainly with acute diseases, but due to the progress of medicine and the ageing of the European population, the focus has shifted towards chronic disease management. Diabetes care is one of the fields where the implementation of these changes has reached the furthest so far. Important choices have to be made, which don't affect diabetes care only, but also the overall health care organisation. In 2006 we strongly plead for a diabetes care model rooted in Primary Care[25]. Primary Care offers holistic, comprehensive and continuing care to the diabetes patient in a personalized and efficient way[61]. Evidence has clearly shown that well structured Primary Care can provide high quality diabetes care[13 21 33 36 48-51 53 55 62].

It is clear that at present many health care and primary care systems in Europe have been unable to take up this task. In addition to global payment systems, patients' listing and a gatekeeper role for the general practitioner[25] we recommend

- development of strategies and national guidelines by all players involved,
- provision of incentives to improve adherence to such guidelines in primary care,

- coordination of structured programs at the community level and adaptation to individual patients by a well developed Primary Care workforce
- registration of patients,
- education of patients and training of professionals and regular evaluation of such programmes through health services research projects.

So far, there is no evidence available to recommend population based screening programmes. Therefore, screening programs for impaired glucose tolerance among high risk individuals which are considered in some countries[63] should be a focus for research before implementing them on a population level.

These proposed reforms will not only have their impact on diabetes care, but will strengthen the position of Primary Care within each health care system and make the future implementation of other Disease Management Programmes for chronic conditions in Primary Care easier. ***We strongly believe, therefore, that the lessons learned and recommendations listed for the disease entity "diabetes mellitus" most likely will be very similar for other chronic conditions as well***.

Therefore, the debate on the diabetes care organisation, its consensual development and harmonization, its efficient implementation and systematic evaluation at the national level reflects the fundamental choices the European health care systems, professionals and consumers have to make at the beginning of the 21st century in the face of the demographic developments.

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Annex:

Table 1: Participating colleagues and their nationality

Austria (AT) – Astrid Knopp, Susanne Pusarnig, Manfred Maier
Belgium (BE) - Luk van Eygen, Patricia Sunaert, Johan Wens
Denmark (DK)– Torsten Lauritzen
Finland (FI)– Liisa Hiltunen
France (FR) – Patrick Chevallier, Jean-Pierre Lebeau
Germany (DE) – Harald Abholz. Erika Baum, Günther Egidi, Michael Kochen
Hungary (HU)– Imre Rurik
Lithuania (LT)– Leonas Valius
Netherlands (NL) – Henk van Dam, Frans van der Horst, Wim de Grauw, Guy Rutten
Rumania (RO) – Dan Pletea
Slovenia (SI)– Janko Kersnik
Spain (ES) – Domingo Orozco, Fernando Alvarez-Guisasola, Xavier Cos
Switzerland (CH) – Niklaus Egli, Christoph Hollenstein, Bruno Kissling
Turkey (TR) - Hakan Yaman
United Kingdom (UK) – Kamlesh Khunti

Table 2- background information collected by the survey

	AT	CH	RO	FR	FI	UK	ES	SI
Prevalence, %	5*	4	1.8	2.1	9.6	3.7	10	3 (4)
Status of PC • gate keeping • list system	No	No (volunt.)	No	No (volunt.)	Yes	Yes Yes	Yes	Yes
Structured program/DMP • Date of implementation • Coordinated by • Financial incentives	Yes 2007 GP/Int. Yes	No	No	No	Yes 2003 Int./nurses no	Yes GP Yes	Yes 2004 GP/Int. Variable	Yes 1995 GP/Int. No
Natl. disease registry	No	No	(yes)	Yes	No	No	Yes	Yes
National guidelines • date of implementation • developed by • evidence based • adherence	Yes 2005 Interdisc. Yes ?	No	Yes 2005 GP's Yes ?	Yes 1999 interdisc. Yes low	Yes 1997 Multidisc. Yes high	Yes 2004 Multidisc Yes High	Yes 2000 GP's (Yes) ?	Yes 2007 Spec. Yes high
Specific training for (participating) GP's**	Yes	No	Yes	No	Yes	Yes	Yes	Yes
Patient empowerment	Yes	Yes	(Yes)	Yes	Yes	Yes	Yes	Yes
Outcome of diabetes care • data • guesses	Not known - Unsatis.	Not known - acceptable	Not known - Unsatis	Not known - Unsatis	Not known partly Unsatis	Yes Yes -	Not known Some Unsatis	Not known - Acceptable ?
Quality monitoring in PC	No	No	?	No	Yes	Yes	Part.	No
Research at PC-level	Little	Little	Little	Little	Some	Few	Some	some
National Strategy	No	No	(Yes)	No	Yes	Yes	Yes	Yes

* prescription data, undetected cases estimated

** specialty training to become a GP or
Specific training for GP's participating in a program

MOH-ministry of health

Country abbreviations see table 1

Table 2- cont.

	TR	HU	BE	DE	LT	DK	NL
Prevalence, %	3,4 -7,2	± 5	3,3	> 6,9	2-4,2	3,8	3,8
Status of PC • gate keeping • list system	 2009 2009	 No Yes	 No Part.	 No Part.	 Yes Yes	 Yes Yes	 Yes Yes
Structured program/DMP • Date of implementation • Coordinated by • Financial incentives	No	occasional 1997 GP None	Yes 1988 Spec. Yes	Yes 2004 GP/Spec. Yes	Yes 2006 GP Yes	Yes 2007 GP Yes	Yes 1989 GP Yes
Natl. disease registry	No	No	No	DMP	Yes	Yes	Yes
National guidelines • date of implementation • developed by • evidence based • Updated • adherence	Yes 2003 MOH/interdisc. Part. Yes unknown	Yes 2005 Spec. Yes Yes Moderate	Yes 2005 GP´s/Spec. Yes Yes unknown	Yes 2002 Spec. No No unknown	Yes 2002 MOH Part. Yes moderate	Yes 1991 GP's Yes Yes moderate	Yes 1989 GP´s/Spec. Yes Yes good
Specific training for (participating) GP's**	Sporadically	Yes	No	Yes	No	Yes	Yes
Patient empowerment	Yes	Not in PHC	Yes	Yes	?	No	Yes
Outcome of diabetes care • data • guesses	Not known unknown unknown	Not known - Unsatisf.	Not known Some Acceptable	Not known Some	Known Some Unsatisf.	known Yes	Known Yes good
Quality monitoring in PC	No	No	No, in sec. care	Within DMP	No	Yes	yes
Research at PC-level	Some	Some	Some	Little	Some	Yes	Yes
National Strategy	No	Yes	No	No	Yes	Yes	Yes

Table 3. Results of routine diabetes care in general practices without support of special diabetes services achieved in a good structured primary health care system

OUTCOME	**Study 1[48] (1999) N=594**	**Study 2[49] (2000) N=1641**	**Study 3[50] (2000) N=1084**	**Study 4[33] (2003) N=1640**	**Study 5[21] (2004) N=7893**	**Study 6[51] (2005) N=309**
HbA1c (%)	7.1 (1.5)	7.1 (1.7)	7.5(1.3)	7.1 (1.1)	7.0 (1.3)	7.0
RR systolic (mmHg)	150 (20)	148 (21)	162 (26)	146 (19)	149 (21)	138
RR diastolic (mmHg)	82 (9)	84 (11)	87 (12)	83 (9)	83 (11	76
Cholesterol (mmol/l	5.4 (1.1)	5.8 (1.2)	5.7 (1.1)	5.2 (1.0)	5.2 (1.1)	-
BMI	29.2 (5.1)	28.7 (5.2)	28.9 (4.8)	29.4 (5.5)	-	29.0