October 2011

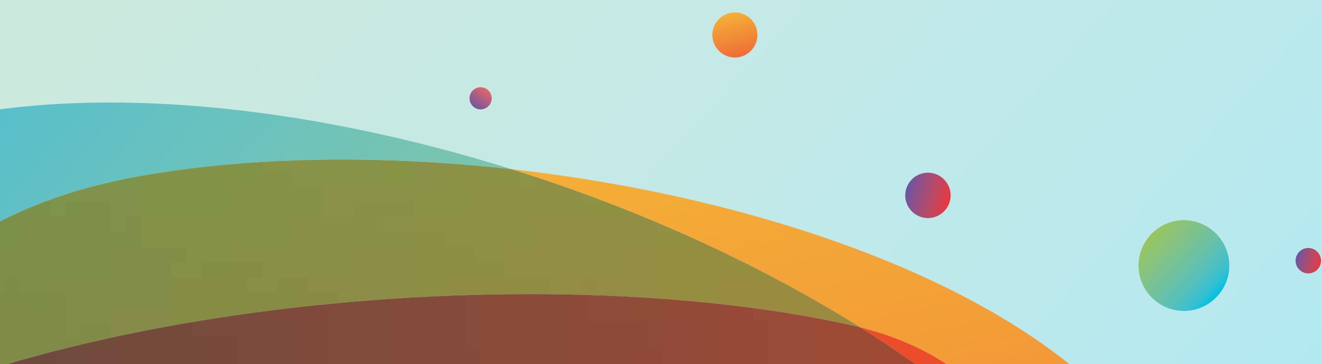
Applying a holistic view to diabetes management and care in Europe

a think-piece

Note: This document has been written by Dr Suzanne Wait of SHW Health Ltd, with full financial support from Bristol-Myers Squibb and AstraZeneca. The contents of this document are the result of desk research and stakeholder interviews.

We would like to express our thanks to Professor Johan Wens, Adrian Sanders, Baroness Sarah Ludford, Sophie Peresson and the entire Board of the International Diabetes Federation-Europe for providing guidance on initial drafts of this document.

This document is intended as a starting point for discussion and we hope that it will prove useful to you and to your organisation. We would welcome any comments or feedback that you may have – please contact Suzanne at suzanne@shwhealth.co.uk



Contents

Foreword 4

I. The Starting Point: Diabetes in all its Complexity 6

The chronic disease epidemic of the 21st century 6
A complex chronic condition that evolves over time 7
Diabetes care carries its own inherent complexities 9
A changing external environment for diabetes and its care 9
Diabetes policy: clear unmet needs 10

II. Shifting the Debate: A Holistic Vision for Diabetes Management and Policy 12

Pillar 1: Treatment and management focused beyond glycaemic control 14
Zooming in: Diabetes and the UN High Level Meeting on Non Communicable Diseases 14
Zooming in: The importance of hypoglycaemia 15
Zooming in: Addressing mental health issues in patients with diabetes 16
Avenues for change 17

Pillar 2: A patient-centred approach to care and management 18
Zooming in: Goals of treatment for patients and physicians 18
Zooming in: The National Service Framework for Diabetes in the UK 19
Zooming in: A national programme focused on improving the quality of life of people with diabetes – Sophia in France 20
Zooming in: The Innovative Care for Chronic Conditions Framework 20
Avenues for change 21

Pillar 3: Long-term planning for diabetes as a chronic condition 22
Zooming in: Women and diabetes 22
Zooming in: The Global Monitoring of Quality of Diabetes Care 23
Zooming in: DIAMAP – the Road Map for Diabetes Research in Europe 24
Avenues for change 25

Concluding Thoughts 26

References 27

Foreword

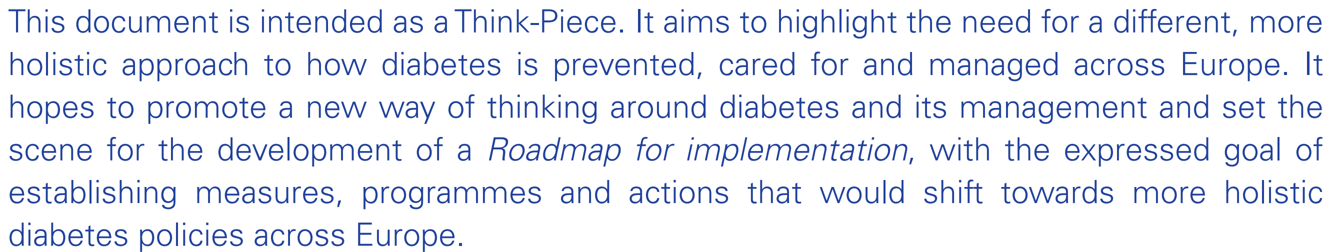
For patients with diabetes, diabetes is a 365-day-a-year condition that they have to manage with often limited support from the time-constrained health professionals responsible for their care. Many patients only see a health professional perhaps once a year for a short consultation. The advice patients receive is often centred solely on blood glucose control, which is like telling an aspiring golfer to enter the 'Open' with just one club.

The patient journey in diabetes is thus a lonely and challenging one. There is a lack of accessible, comprehensive and continuing education that could help many people with diabetes manage their condition more effectively. Education is needed that would assist patients to concentrate beyond simplistic blood glucose control in the management of their diabetes. This education would have to cover the changes to the body or lifestyle that come with age or environmental factors. These changes need to be understood in terms of how they affect the patient's control and what support he or she requires across a range of disciplines.

Over the past decade, significant strides have been made in Europe and globally to raise awareness of the challenges posed by diabetes and advocate for better prevention, management and care for people with diabetes. For example, in 2006 Members of the European Parliament (MEPs) joined efforts in a written declaration on diabetes, which served as a springboard for a number of important policy initiatives, culminating recently in the launch of the report by the European Coalition for Diabetes, in partnership with the EU Diabetes Working Group, 'Delivering for Diabetes in Europe'.* Some consistent themes run through existing policy documents and advocacy materials: diabetes is unique, as care is not episodic but chronic. The psychological, cultural, social and biological aspects to care are as central to the successful management of diabetes as are the strictly clinical facets of the condition. And most importantly, individual patient needs must be at the core of every aspect of prevention and care if one is to achieve successful outcomes.

Yet despite these considerable initiatives, diabetes still does not receive the political attention it deserves. There remains a huge gap between what should be done and what actually happens in practice. Many leaders and policy-makers have spoken about a 'holistic' vision for diabetes in the past, however this new way of managing, planning for and treating diabetes has yet to become a daily reality for people affected with diabetes across Europe.

* A full copy of the report can be found at http://www.ecdiabetes.eu/documents/TheGrandChallenge-conference-book-08Dec10.pdf



This document is intended as a Think-Piece. It aims to highlight the need for a different, more holistic approach to how diabetes is prevented, cared for and managed across Europe. It hopes to promote a new way of thinking around diabetes and its management and set the scene for the development of a *Roadmap for implementation*, with the expressed goal of establishing measures, programmes and actions that would shift towards more holistic diabetes policies across Europe.

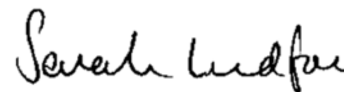
This Think-Piece is targeted at everyone concerned with diabetes, be they patients, carers, clinicians, advocacy groups, policy-makers or politicians. Our call to action, however, is really aimed at politicians at the national and EU levels: without political will and the resources to follow, nothing will change and no evolution in the direction needed can be expected. Thus although responsibility for changing the way we address diabetes is joint, impetus and resources must come from government.

The prevalence of diabetes is growing exponentially. We would urge all governments to ensure that, as we face growing budgetary pressures and strive to reform our health care systems, we do not forget the needs of people living with diabetes and we ensure that, embedded in all reforms, a truly patient-centric model of care can be achieved and maintained.

It is our sincere hope that this Think-Piece will start not just a debate but create a pathway to change in all European countries.

Adrian Sanders,
MP and UK Chair of the
All Party Parliamentary Group
for Diabetes

Johan Wens, MD, PhD
University of Antwerp and
Chairman of Primary Care
Diabetes Europe (PCDE)



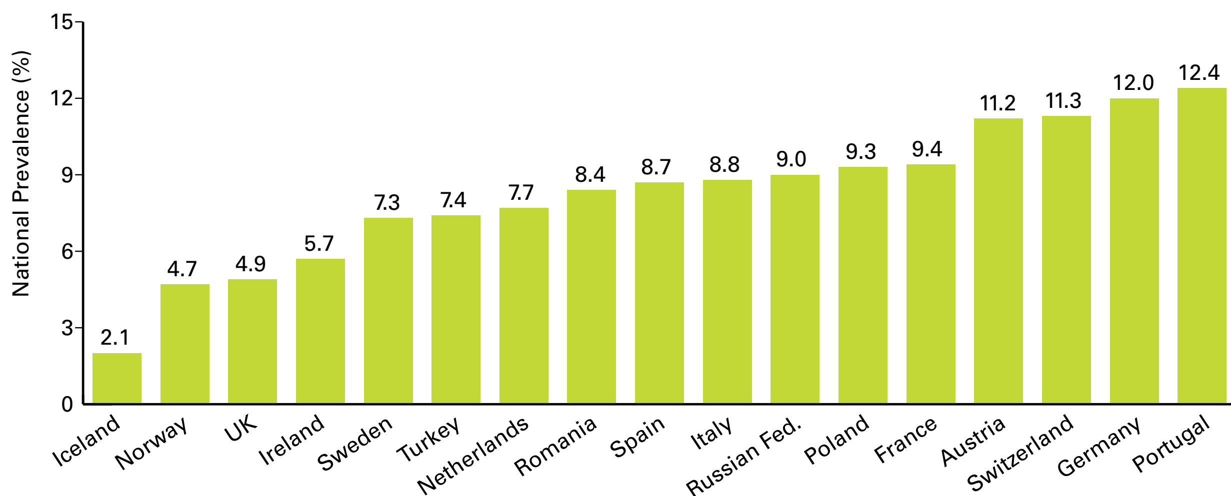
Baroness Sarah Ludford,
MEP and Co-chair of the
EU Diabetes Working Group

I. The Starting Point: Diabetes in all its complexity

The chronic disease epidemic of the 21st century

Diabetes has been described by the World Health Organisation as the chronic disease epidemic of the 21st Century. In the EU, over 31 million people currently live with diabetes.[1] Within Europe, diabetes accounts for over 630,000 deaths per year and it affects approximately 8.5% of the population aged 20-79 years (*see Figure 1*). By 2030, it is predicted that 1 in 10 Europeans will have diabetes. Approximately 90% of diabetes cases are type 2 diabetes, with the remainder being type 1.

Figure 1:
Prevalence of diabetes (type 2, 20-79 years) in selected European countries (2010)[2]



The costs associated with diabetes are considerable and are expected to grow exponentially if better prevention and treatment are not achieved. The cost of diabetes was estimated at 75 billion Euros in 2010 and it is anticipated that this figure may reach 87 billion Euros by 2030.[3] Although rates vary by country, diabetes accounts for up to 10-15% of total health expenditure.[4] But the burden of diabetes is not confined to the health care system. Individuals with diabetes may be restricted in their ability to work due to their condition, thus resulting in a huge social loss in terms of productivity. Caregivers must give up time to accompany family members to medical appointments and provide care within the home, at a huge cost to them in terms of time, lost productivity, quality of life and often, their own health as well. And most importantly, diabetes has a tremendous impact on the quality of life of those it affects, and this impact grows exponentially with the appearance of complications.

A complex chronic condition that evolves over time

One of the inherent challenges to the management of diabetes is that it is a complex chronic condition which evolves over time. From a public health perspective, diabetes shares many risk factors (high blood pressure, obesity and smoking) with other chronic conditions such as cancer or cardiovascular disease. It also presents with co-morbidities, such as hypertension, which need to be managed alongside glucose control.

Diabetes is also associated with the development of specific long-term organ damage (complications), which include eye damage (retinopathy) leading to potential blindness, kidney damage (nephropathy) with a risk of progression to renal failure requiring dialysis and kidney transplantation, nerve damage (neuropathy) with a risk of foot ulcers and amputation. In addition, sexual dysfunction is a common complaint amongst people with diabetes.[5] People with diabetes are also at greater risk of developing cardiovascular, cerebrovascular, and peripheral artery disease[6] (see **Table 1**).

Mortality increases several-fold and costs are 3-5 fold higher when complications are present.[7, 8, 9] The presence of complications has also been found to be the most important factor predicting poorer quality of life in patients with type 2 diabetes.[10]

> **"Preventing and reducing the severity of complications is the key to improving patients' quality of life."**
>
> (Koopmanschapf *et al*, 2002)

Table 1: **Complications of diabetes**

Cardiovascular disease

- Up to 30% of people with type 2 diabetes are at risk of cardiovascular disease within 10 years. This is a 2- to 4-times greater risk than in those without diabetes.[11]
- Women with diabetes have a five times greater risk for heart disease than women without diabetes.[12]
- The risk of stroke is twice greater in people with diabetes in the first five years after diagnosis compared to individuals without diabetes.[13]
- Up to 75% of people with diabetes die of cardiovascular disease (CVD).[14]

Lower limb amputations

- Rates of foot amputations are rising amongst people with diabetes.[15]
- Currently, between 1-4% of diabetic patients in Europe have to undergo foot amputation.[16]
- Amputation rates vary significantly across Europe and have been shown to reach up to 6.6%.[17]

Diabetic neuropathy (nerve damage)

- 60% to 70% of patients with diabetes develop neuropathy.[18]
- Chronic painful neuropathy affects approximately 1 in 6 people with diabetes, as compared to 1 in 20 in the general population.[19]

Nephropathy (kidney damage) and end-stage renal disease

- Between 10-20% of diabetic patients die of kidney failure.[20]
- A significant proportion of patients with diabetes will need dialysis and, eventually, kidney transplantation.
- Diabetes remains the most common cause of end-stage renal disease.[21]

Diabetic retinopathy

- Diabetes is the leading cause of blindness in people aged 30-49 years old.[22, 23]
- Prevalence of diabetic retinopathy among type 2 diabetics ranges from 10-65% depending on study design.[24, 25]
- After 20 years of disease, nearly all patients with type 1 diabetes and 60% of those with type 2 diabetes are affected by damage of small blood vessels in the retina.[26]

Diabetes care carries its own inherent complexities

The complexity of diabetes, its impact on patient quality of life and the importance of preventing complications as early as possible have significant implications for how diabetes needs to be managed. Like many other chronic conditions, diabetes is mostly managed in the community. However, patients are responsible for monitoring their glucose at home, as well as constantly adapting their diet and physical exercise. Patient care is divided between specialists and general practitioners or family physicians (not to mention diabetes nurses and other health care professionals such as pharmacists and dieticians, when they are available). The respective roles of these different health professionals vary over the course of the disease, and depending on the health care system and resources available.

All of these factors lend themselves to a 'network of care' approach to diabetes, in which active case management by a dedicated professional who is working in true partnership with the patient and his or her family is critical. Within the constraints of existing health care systems, however, the execution of such a model of care is often far from perfect. In fact, the viability of existing models of diabetes care is threatened by current health care reforms in many European countries, as resources are cut and staffing shortages are likely to occur.

Notwithstanding these pressures, it is imperative that health care systems always strive to adopt patient-centred models of care for diabetes management if they wish to optimise patient outcomes over time. Active patient involvement in all aspects of prevention and care is critical to achieving successful outcomes. Put differently, diabetes calls for a patient-centred approach, where the needs of each individual person with diabetes are the starting point of every intervention.

A changing external environment for diabetes and its care

Added to the complexity inherent to diabetes are pressures facing the external environment within which diabetes management is evolving. Demographic shifts, including the ageing of the population and migration within and into the EU, are changing the composition of the diabetic population. Health care systems are under constant financial pressure and health care reforms are bound to change roles and impact service delivery to diabetes patients. The challenge is to ensure that diabetes policies, the programmes put in place and the models of care built to deliver services, are not compromised in their ability to serve patient needs within the dynamic context of their surrounding health care environment.

> **"People living with diabetes should be empowered to enhance their personal control over the day-to-day management of their condition in a way that enables them to experience the best possible quality of life."**
>
> (EU Diabetes Working Group, 2006)

Diabetes policy: clear unmet needs

Despite a number of important initiatives in EU policy on diabetes, there remain a significant number of important unmet needs. Diabetes stakeholders have been calling for an EU Council Resolution on diabetes since the signing of the St Vincent Declaration in 1989. Only 13 out of the 27 EU member states have national plans on diabetes in place.* At the EU and national levels, diabetes is still not accorded the importance or sense of urgency that its prevalence warrants when compared to other chronic conditions – and this despite considerable efforts by the EU Diabetes Working Group, the European Coalition for Diabetes and other leading diabetes groups and stakeholders. Stark inequalities exist across the EU in terms of prevention, diagnosis and control of diabetes. And most importantly, diabetes still does not have a cure and outcomes for patients remain unsatisfactory.

Thus the message to be delivered must be clear: **we cannot afford to become complacent**. The following figures speak for themselves:

- Up to 50% of diabetes cases are undiagnosed.[27]
- An even smaller proportion of those receive care.
- The proportion which actually has active prevention of complications – the main cost driver for diabetes – is even smaller.
- The delay to diagnosis is as long as 7 years even in very advanced clinical settings.[28, 29]
- At least one third of people with type 2 diabetes managed in primary care do not meet targets for glycaemic control or cardiovascular control.[30]

What needs to change? It is important to build upon what has already been achieved. Yet at the same time, new approaches to policy, clinical practice and care are needed that **address diabetes in all its complexity**. It is time to shift the debate and adopt a more holistic vision of diabetes. This was recently articulated by the European Coalition for Diabetes at the European Parliament:

> **“The responsibility of the healthcare community is to build an understanding cross-sectorally of the need to prevent chronic metabolic diseases, especially diabetes, and to be pioneers in practical implementation. A holistic approach is necessary taking into account public health, social environmental determinants, a realistic view of care structures and population migration and improved communication between all stakeholders.”**
>
> (European Coalition for Diabetes, 2010)

The purpose of this document is to propose an agenda for paving a Roadmap for Implementation of a holistic vision for diabetes across the EU. The topics described in the subsequent section are far from exhaustive, but instead are intended as a starting point for further discussions and debate across different EU countries.

* According to the 2008 edition of IDF Europe and FEND's policy audit "Diabetes - The Policy Puzzle: Is Europe Making Progress?" (accessible here: http://www.idf.org/regions/europe/publications/diabetes-policy-audit), these were: Austria, Cyprus, Czech Republic, Denmark, Finland, Lithuania, Netherlands, Poland, Portugal, Romania, Slovakia, Spain and United Kingdom. Bulgaria, Germany, Ireland, Italy, Lithuania, Malta and Slovenia indicated their intention in 2008 to introduce a national plan in the near future.

Starting Point

Key Messages

- Diabetes is a life-threatening condition which carries a high risk of mortality. It constitutes a major public health threat and the burden it poses on society is considerable and is growing exponentially.

- Diabetes is a complex chronic condition which evolves over time. It presents with co-morbidities that need to be managed alongside glucose control, its risk factors are common to other diseases and its complications are serious diseases that bring significant morbidity and mortality and have considerable impact on individuals' quality of life.

- This complexity has important implications for how diabetes needs to be managed: a patient-centred approach is critical, with recognition of the impact of diabetes on individuals' quality of life, and a holistic perspective on treatment goals and outcomes.

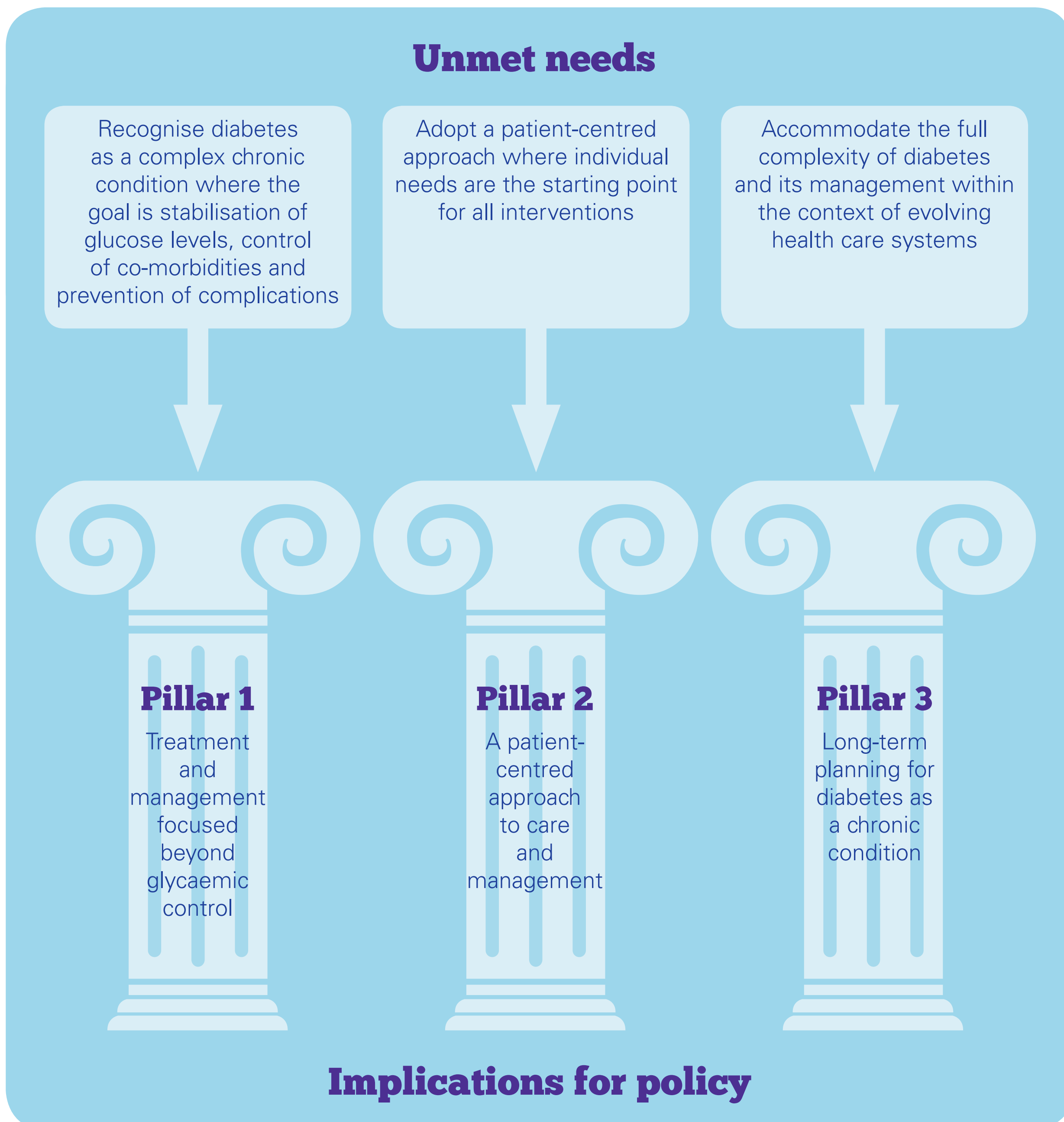
- Diabetes has risen on the policy agenda in recent decades, however challenges remain and awareness still remains inadequate.

- **Despite numerous initiatives to contain diabetes and broad recognition of its epidemic nature, there remain clear unmet needs in terms of patient management, policy and practice across Europe.**

II. Shifting the debate:

A Holistic Vision for Diabetes Management and Policy

The following diagram illustrates the three central pillars proposed as the foundation for a holistic vision for diabetes management and policy. It should be underlined that the first pillar – treatment and management of diabetes beyond glucose control – is pivotal and without this being achieved at the clinical level, the other two pillars, which rely mostly on political action, cannot be realised.



The following sections will address each of these areas in more detail, focusing on selected topics within each of these pillars.

Treatment and management focused beyond glycaemic control

Key topics:

- Management of preventable risk factors as part of the overall preventive approach to cardiovascular disease (CVD) and other non-communicable diseases (NCDs)
- A balanced approach between prevention and treatment
- Focus beyond glucose control on the early prevention and treatment of complications
- Mental health problems amongst people with diabetes.

Management of preventable risk factors (smoking, obesity, lack of physical exercise, diet) as part of the overall preventive approach to CVD and other non-communicable diseases (NCDs)

Diabetes shares many risk factors with other non-communicable diseases such as heart disease. Thus efforts should be made to remove existing silos between prevention efforts, campaigns and policies targeting different NCDs. In the spirit of the WHO 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Non-communicable Diseases,[31] **a concerted approach is recommended** to encourage individuals to adopt healthy lifestyles with benefits across a number of NCDs.

Diabetes and the UN High Level Meeting on Non Communicable Diseases

On 13 May 2010, the United Nations General Assembly passed a resolution on non-communicable diseases (NCDs), calling for the first UN Summit on Non Communicable Diseases, which took place in September 2011. Although focused primarily on poor- and middle-income countries, the Summit objectives apply globally, as their aim is to 'create a sustained global movement against premature death and preventable morbidity and disability from NCDs, mainly heart disease, stroke, cancer, diabetes and chronic respiratory disease'[32]. Some of the challenges raised include the integration of surveillance of NCDs into national information systems, successful mechanisms for engaging non-health sectors in prevention initiatives and strengthening health care systems to deliver more effective care.[33]

The Summit led to a Political Declaration on NCDs, which was unanimously adopted by global leaders on 19 September 2011. It recognises that 'the global burden and threat of NCDs constitutes one of the major challenges for development in the twenty-first century, which undermines social and economic development throughout the world.'

The full declaration may be found at:
http://www.un.org/ga/search/view_doc.asp?symbol=A%2F66%2FL.1&Lang=E

Further interesting developments related to the Summit are:

- The NCD Alliance, an umbrella organisation representing the joint interests of cardiovascular disease, diabetes, cancer and respiratory disease, has been working with the World Economic Forum to develop 'the business case for diabetes' and cost the NCD Global Plan.
- The International Diabetes Federation (IDF) is working on a Global Diabetes Plan as well as a Diabetes Care Model, which may serve as a blueprint for national initiatives.

Further information at: www.idf.org

A balanced approach between prevention and treatment

There is a common, if sometimes unspoken, perception that preventing diabetes is all about modifying behaviour. It is, of course, true that healthier lifestyles and prevention of modifiable risk factors are essential to help prevent the onset of (type 2) diabetes. However, other factors, be they biological, environmental or genetic, also contribute to the rise of diabetes. Moreover, this needed **focus on prevention should not come at the expense of investment in treatment and management** pathways for individuals already affected by diabetes. This balance needs to be better reflected in policies on diabetes across the EU.

Focus beyond glucose control on the early prevention and treatment of co-morbidities and complications

Therapeutic advances have improved outcomes for patients with diabetes, however diabetes still has no cure and too many patients remain uncontrolled despite the propensity of glucose-lowering medication. There is a tendency to focus on immediate glucose control and take a short-term view of diabetes management. Education and training of all physicians involved in diabetes care, particularly GPs and family physicians, is critical if one wishes to shift the focus of treatment beyond glucose control. It is also important to recognise that guidelines for diabetes management are not followed as much as they should be and therapeutic nihilism is a real risk with many diabetes patients.

Significant gaps remain in our knowledge as to how to prevent and treat the complications arising from diabetes. Clinical efforts must be targeted at the prevention and management of complications from the onset. The costs of complications increase linearly from the time of diagnosis. Thus early detection of diabetes coupled with secondary prevention of complications and patient empowerment would not only confer significant health benefits but also reduce the costs of diabetes as well.[34]

Diabetes is accompanied by a number of co-morbidities, including high blood pressure and hypoglycaemia. Hypoglycaemia is a particular problem as it may occur as a consequence of treatment and may result in reduced treatment adherence on the part of patients.

The importance of hypoglycaemia

The significance of hypoglycaemia to the overall well-being of patients with diabetes was highlighted in the PANORAMA Pan-European study, the largest observational study on type 2 diabetes patients. The study found that patients who had a severe, or more than one non-severe, episode of hypoglycaemia reported a much more negative impact of diabetes on their quality of life, less satisfaction with treatment and greater fear of hypoglycaemia than patients who had not had any experience of hypoglycaemia. The implication is that patients who are worried about future hypoglycaemic episodes may be less compliant with their medication and may thus avoid aiming for optimal glycaemic control, thus increasing their risk of long-term complications.[35] Clearly, finding a balanced approach with thorough communication with the patient is key to achieve optimal outcomes.

> **EU member states should develop disease management plans derived from evidence-based treatment guidelines which aim to prevent diabetes-related complications and co-morbidities and expand management from blood glucose control to a comprehensive cardiovascular strategy.**

(European Coalition for Diabetes, 2010)

Mental health problems amongst people with diabetes

Studies suggest that patients with diabetes are 2 to 4 times more likely to develop depression than people without the disease. Recent studies suggest that up to 18% of patients with Type 2 diabetes are affected by depressive disorders,[36] and this figure increases to 26% if one considers lesser forms of depression.[37, 38] Depression is thought to exacerbate non-compliance to medication[39] and is associated with higher rates of complications,[40, 41] greater functional disability, reduced work productivity, and lower quality of life, as well as overall mortality.[42, 43] Yet mental health issues are unlikely to be on the radar of most treating physicians when faced with a diabetes patient. **Targeted training of all health and social care professionals involved in the care of patients with diabetes, as well as people with diabetes themselves, is clearly needed** to reduce the risks associated with this important co-morbidity.

Addressing mental health issues in patients with diabetes

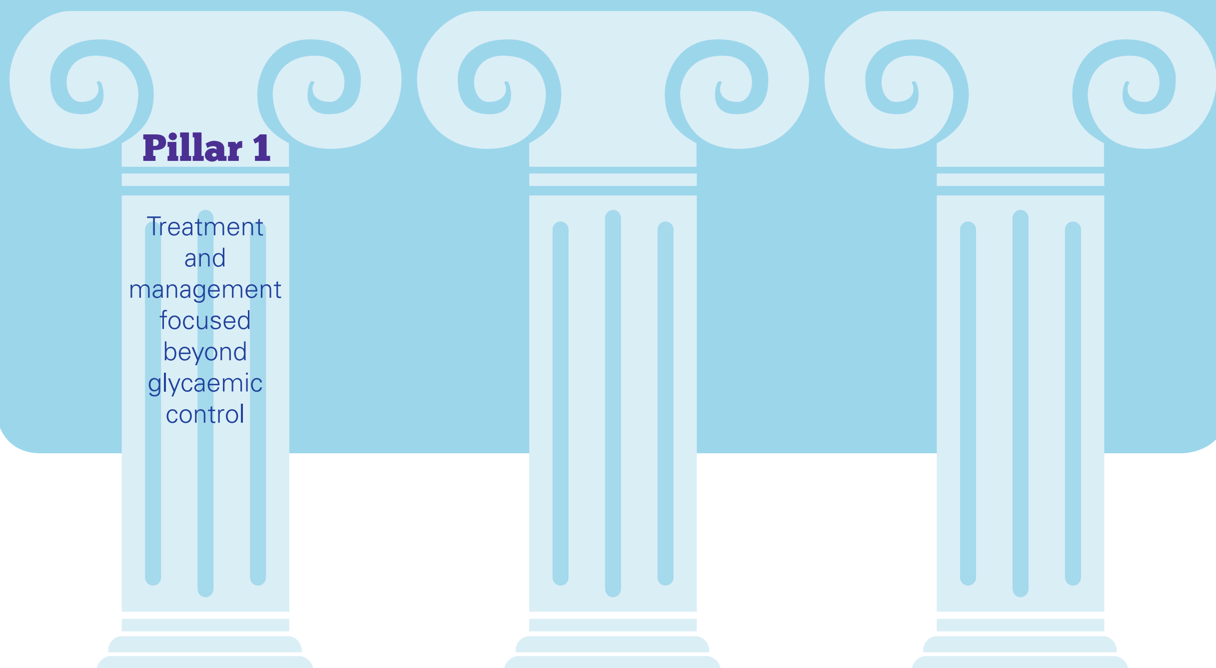
In 2011, the European Psychiatric Association, supported by the European Association for the Study of Diabetes and the European Society of Cardiology, published a consensus statement aimed at raising awareness of the need to screen for and treat cardiovascular risk factors and diabetes in patients with severe mental illness.[44] This Consensus builds on the work done by the *Mental and Physical Health Platform* in 2009.[45] The proposals made by both groups could equally apply in reverse and be aimed at improving awareness, prevention and treatment of mental health problems in diabetic patients. Some of the salient issues that affect both patient populations are:

- The importance of shared care between mental health and diabetic care teams
- Need to increase awareness among psychiatrists, diabetologists and primary care physicians of the links between mental health and diabetes and the need to screen and accurately diagnose depression particularly in patients with diabetes
- Risks of discrimination and stigma for people suffering from diabetes, akin to (and often cumulated with) the stigma associated with mental health disorders
- Need to reform primary care models to facilitate the diagnosis and management of symptoms of depression in persons with diabetes
- Importance of multidisciplinary teams to address the mental health and diabetic needs in patients suffering from both conditions

Pillar 1

Avenues for change

- A concerted approach is needed in prevention to encourage individuals to adopt healthy lifestyles with benefits across a number of non-communicable diseases, including diabetes.
- The focus on prevention in diabetes policy should not come at the expense of investment in treatment and management pathways for individuals already affected by diabetes.
- Clinical efforts should be targeted at the prevention and management of complications and co-morbidities from the onset and not focus merely on immediate glucose control.
- Targeted training of all health and social care professionals involved in the care of patients with diabetes, as well as people with diabetes themselves, is needed to raise awareness of the risks of mental health problems and other co-morbidities.



A patient-centred approach to care and management

Key topics:

- These are not mere patients, they are people living with diabetes
- The importance of patient-doctor communication
- Integrated models of care focused on patient needs
- The importance of quality of life as a key outcome of diabetes care
- Adapting models of care to the external environment

These are not mere patients, they are people living with diabetes

The management of diabetes is a long-term journey in which the person with diabetes, his or her family and the professionals involved in providing care must be engaged in **a continuous dialogue about treatment goals, possibilities for prevention, the impact of treatment on the individual's well-being, and the evolution of the condition.** The person with diabetes is not simply sick with diabetes, he or she **lives with diabetes:** every aspect of his or her life is affected. Thus the success of this 'journey' hinges on how well-equipped each individual is to tackle diabetes, and on how effective and reciprocal the communication is between the doctor/nurse and the patient. Patients need to be accompanied throughout this journey with the appropriate balance of information, counselling and support. Unfortunately, this is often where the health care system fails patients and their families – indeed this weakness is not unique to diabetes but has been evidenced with other chronic conditions as well.

The importance of patient-doctor communication

It is not surprising that all policy documents on diabetes call for a patient-centred approach to diabetes care. Enacting this, however, depends less on processes and policies in place than on the individuals involved in each patient-physician dynamic: there is a constant need for **more training and education of patients and physicians** to help build and maintain effective communication throughout the course of the disease.

Goals of treatment for patients and physicians

Health care professionals and people with diabetes may have different perspectives on goals of treatment

Healthcare professional (HCP):

- Achieving **blood glucose control** (HbA_{1c} level)
- Avoidance of:
  - Diabetes complications (micro- and macrovascular)
  - Hyperglycaemia and symptoms
  - Hypoglycaemia
  - Weight gain

Person with diabetes:

- **QoL** and achieving **blood glucose control** (HbA_{1c} level)
- Avoidance of:
  - Inconvenient and inflexible treatment
  - Hyperglycaemia and symptoms
  - Hypoglycaemia
  - Weight gain
  - Side effects of treatment

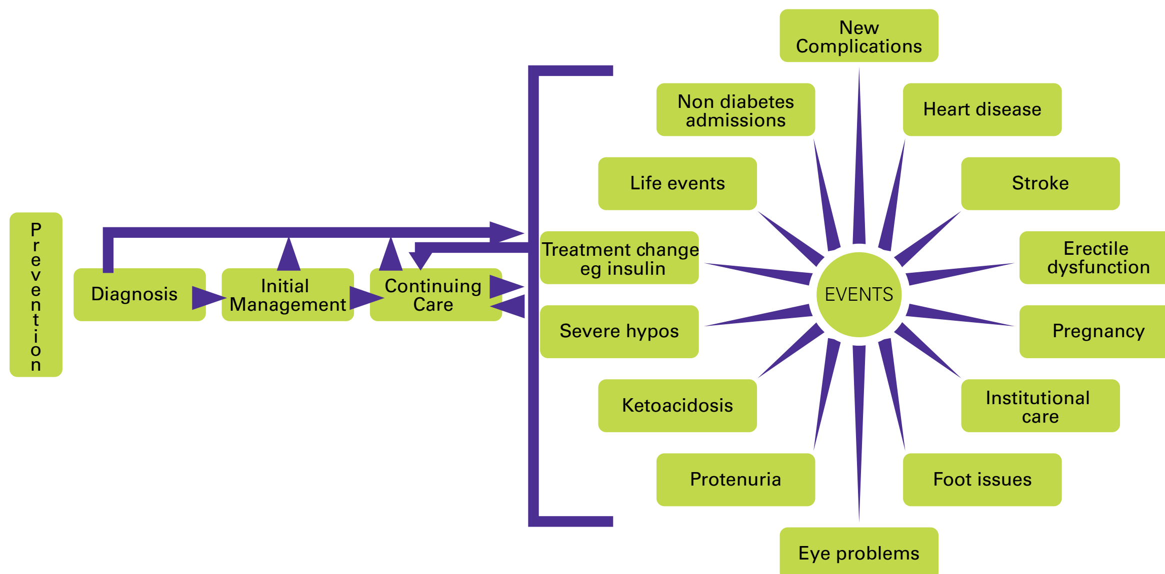
Adapted from Snoek FJ. Int J Obes Metab Disord. 2000;24 (Suppl. 3): S12-S20.

Integrated models of care focused on patient needs

People with diabetes come into contact with all parts of the health care system, from GPs to intensive care units. As they incur complications and resulting disability, their care may also require involvement from social services in the community. Thus **diabetes care must be integrated across all of these services**. That way, the person with diabetes can be sure to receive continuous care within a well-organised system or network where every professional involved in his or her care is aware of his or her needs and how his actions fit into the patient's overall care pathway. The choice of the person with diabetes must always be respected, such that **care planning is a joint partnership activity** regularly undertaken between the physician or care provider (eg. diabetic nurse) and the patient with involvement of his family as appropriate.[46] Care planning and management must also be seen as dynamic processes that evolve around the changing needs of the patient and events that trigger the need for targeted interventions.

The National Service Framework for Diabetes in the UK[47]

The NSF for Diabetes in the UK provides a helpful depiction of the series of interventions encompassed in the journey of a patient with diabetes. The salient point from the diagram below is that this journey of care evolves over time and that interventions delivered to patients must at once be responsive to events as they occur as well as preventive to minimise morbidity for the individual.



The importance of quality of life as a key outcome of diabetes care

Because people live with diabetes, prevention and treatment pervade their home life, their work, and their leisure time. Thus care must be patient-centred and tailored to individual patient needs at that time. Diabetes has been shown to have significant impact on individuals' quality of life. **Minimising negative impacts on quality of life must thus constitute one of the foremost goals of care** and continuous 'quality of life checks' should be done, not necessarily through formal instruments but through open dialogue between the treating physician and patients and proactive case management.

A national programme focused on improving the quality of life of people with diabetes – Sophia in France

Sophia was first launched on a pilot basis in 2008 and will be extended to cover all districts by 2013.

Sophia is a French, government-led programme aimed at preventing complications from diabetes and improving the quality of life of patients. It is part of a concerted action led by the government in partnership with patient associations and health care professionals which is focused on improving the quality of life of patients suffering from diabetes and other chronic conditions.

Patients are invited to enrol on a volunteer basis into a programme of personalised case management by a trained nurse who is based at the main national sickness fund (CNAMTS). Nurses are in regular contact with patients in order to help them cope with diabetes in their daily lives and support them through lifestyle changes such as diet or exercise. They also provide a link to the treating physician.

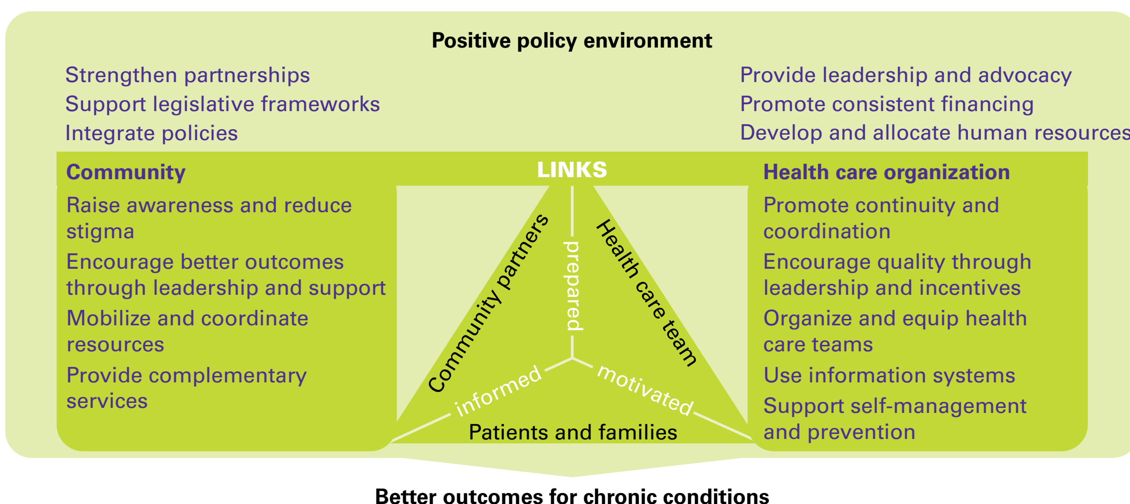
In March 2011, 15,300 treating physicians and 103,000 patients were enrolled in Sophia. Patients have a 'carnet de santé' (individual case notes) that they are responsible for, and they also have access to a dedicated website where they can find information and keep track of their progress. The first results of this programme are overwhelmingly positive, in terms of patient satisfaction, adherence to treatment, and improved prevention of complications.

Adapting models of care to the external environment

As our health care systems face chronic budget cuts and their architecture is in constant flux, it is challenging to advance 'ideal' models of care for diabetes. Flexibility allowing for changes in the external environment must be built into the design of any such models of care. At the same time, it is an important policy message that **for models of care to work, they need to be given a supportive environment** that may contribute to its sustainability and feasibility – for example, through appropriate resourcing. This supportive environment goes beyond the confines of the health care system, and includes, for example, the workplace and education settings in which people with diabetes may be subject to stigma or discrimination on account of their disease and their need to monitor their glucose 'in public' and take certain medications. Ensuring that the rights of people with diabetes are respected and that all risks of systemic discrimination are eliminated must be a key goal within all areas of social policy.

The Innovative Care for Chronic Conditions Framework[48]

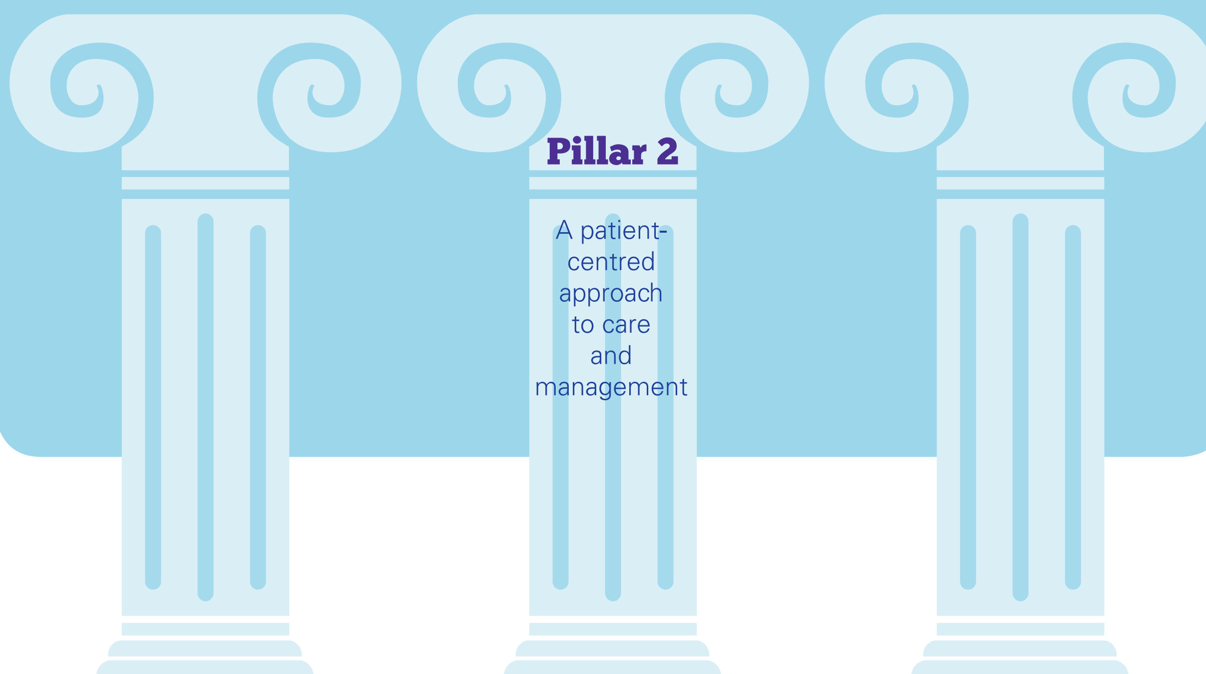
The Innovative Care for Chronic Conditions Framework may provide a helpful tool for devising models of care and understanding the interplay between patient needs, their community, the health care system and the overall policy environment.



Pillar 2

Avenues for change

- Diabetes management must involve a continuous dialogue about treatment goals, possibilities for prevention, the impact of treatment on the individual's well-being, and the evolution of the condition.
- In all policies and programmes, it is critical to recognise that the person with diabetes is not simply sick with diabetes, he or she lives with diabetes.
- Maintenance of individuals' quality of life must constitute one of the foremost goals of care.
- Effective communication between the patient and his or her care team is critical throughout the entire course of the disease.
- Integrated diabetes care must be favoured in all models of care for diabetes management.
- Within these models of care, the choice of the person with diabetes must always be respected, such that care planning is a joint partnership activity.
- For models of care to work, they need to be given a supportive environment that may contribute to its sustainability and feasibility – for example, through appropriate resourcing.



Long-term planning for diabetes as a chronic condition.

Key topics:

- Recognising diversity in the diabetes population
- Need for appropriate and meaningful quality indicators
- Embedding quality standards into clinical care
- Guiding the future of therapeutic innovation

Recognising diversity in the diabetes population

The **changing demographics of diabetes** need to be taken into account in all policies and programmes targeting diabetes. With the ageing of the population, the proportion of older diabetics is growing and their particular needs must be taken into consideration. For example, complications of diabetes may exacerbate existing disability and co-morbidities in some older people and limit their ability to maintain independence in their own homes. Diabetes is also more prevalent amongst certain ethnic groups and their cultural, linguistic and other needs (for example, attitudes to diet and exercise) must be taken into consideration. Migration both within the EU and into the EU is also increasing. A number of studies have suggested that migrants may be at greater risk of developing diabetes than non-migrants (Carballo *et al*, 2006).[49] Finally, complications of diabetes differ by gender, calling for a *gender-sensitive approach* to diabetes care.

To be successful, health promotion and prevention programmes must be **appropriate for the different groups they target, and be age-, gender- and culturally specific**. These same principles should ideally also apply to all aspects of diabetes care.

Women and diabetes

There has been increasing attention to the growing prevalence of diabetes in women in the developing world. In more developed economies, it is fair to say that there is less recognition for the particular challenges and issues faced by women with diabetes:

- Women with diabetes have worse coronary heart disease (CHD) mortality than men with diabetes, possibly on account of poorer blood pressure control.[50]
- Some of the risk factors for diabetes, including obesity, unhealthy nutrition and lower educational attainment, are more prominent in women, rendering them at greater risk of developing diabetes.[51]
- Some of the barriers to appropriate care seen in women with cardiovascular disease may also be applicable to women at risk of diabetes.[52] For example, women, particularly those involved in caring for children or older relatives, tend to neglect their own health needs due to their focus on their dependents. As a result, symptoms may go unnoticed and diagnosis of conditions such as heart disease or diabetes may be delayed.
- Women may receive less optimal treatment than men, for example for blood pressure, which is an important co-morbidity of diabetes.[53]

Need for appropriate indicators of the quality of care

As we encourage the building of diabetes plans and national strategies to tackle diabetes, it is important to build in measures that allow us to **measure 'how well we are doing'**. To do so, we need to be confident that the indicators we are using are meaningful, in that they measure what is important and not just what is easily measurable. Given the importance of avoiding complications in diabetes care for example, it is important that **quality indicators reflect longer-term outcomes of diabetes care** such as the prevention and management of complications, and not just immediate glucose control.

The Global Monitoring of Quality of Diabetes Care

The Diabetes Quality Improvement Project is a US-based research initiative aimed at developing a set of indicators to measure the quality of diabetes care. These indicators were subsequently adapted for use by the Organisation for Economic Cooperation and Development (OECD) and are now included in their Health Care Quality Indicators (HCQI) Project. There are currently 9 indicators for diabetes, four of which represent complications. However, making international comparisons of these indicators is complicated by the fact that data are not necessarily comparable across countries and information systems, nor are the raw data actually available in many countries. For example, standard definitions of diabetes complications do not exist (eg. the definition of neuropathy varies from one system to another). There is thus a clear need for standardisation of datasets across different countries as well as of the sampling methodologies to determine diabetic patient populations for whom data are collected.[54]

Embedding quality standards into clinical practice

If we wish for the quality of care that patients receive to change, it is important to ensure that individual clinicians are encouraged – or even incentivised – to **deliver high-quality diabetes care**. A number of countries, in particular the UK with their Quality Outcomes Framework (QOF) and France with the Contrat d'amelioration des pratiques individuelles (CAPI) system, explicitly tie remuneration of physicians to the attainment of a number of treatment and prevention goals for diabetes patients.*

Results from CAPI suggest that overall patient outcomes have improved since the introduction of the scheme.

* For example, one of the CAPI indicators is that >65% of diabetic patients must have had an eye care consultation, a detailed eye exam or a retinography every year.

Guiding the future of therapeutic innovation

Another important facet to planning for diabetes involves the prioritisation of research towards therapies and interventions that offer the most promise for patient care. The diabetes medicines landscape is a crowded one, yet there remain significant unmet clinical needs which still need to be addressed by truly innovative and effective agents. Increasing pressure on pharmaceutical budgets worldwide means that payers are very resistant to new medicines unless they can demonstrate a clear value to the patient and society at large, with substantial benefits over existing agents. Within this context, and considering the sobering fact that up to 50% of diabetes patients are poorly controlled, it is essential that we **define innovation in diabetes care based on outcomes that matter to patients**.

Within this context, more cooperation is needed between industry, the research community and regulators (health authorities, regulatory agencies and payers) to ensure better consistency and understanding of the meaning of value and innovation in the development of new therapeutic interventions for people with diabetes. Such collaboration can only be of benefit to patients, and also to all parties involved as they may help focus efforts in research and development on priority areas. It may also enable a more constructive and earlier dialogue between industry, health authorities and regulators and, as a result, lead to **better congruence between research priorities, fundings decisions and drug development.**

DIAMAP – the Road Map for Diabetes Research in Europe[55]

DIAMAP (the Road Map for Diabetes Research in Europe) is a multi-partner initiative borne from the recognition that 'the challenge of curing diabetes and preventing its onset will only be met through increased research'. It aims to chart the future of diabetes research in Europe focused on the needs of persons with diabetes. A 2010 report was issued in order to chart a series of recommendations to guide investment in diabetes research in years to come.

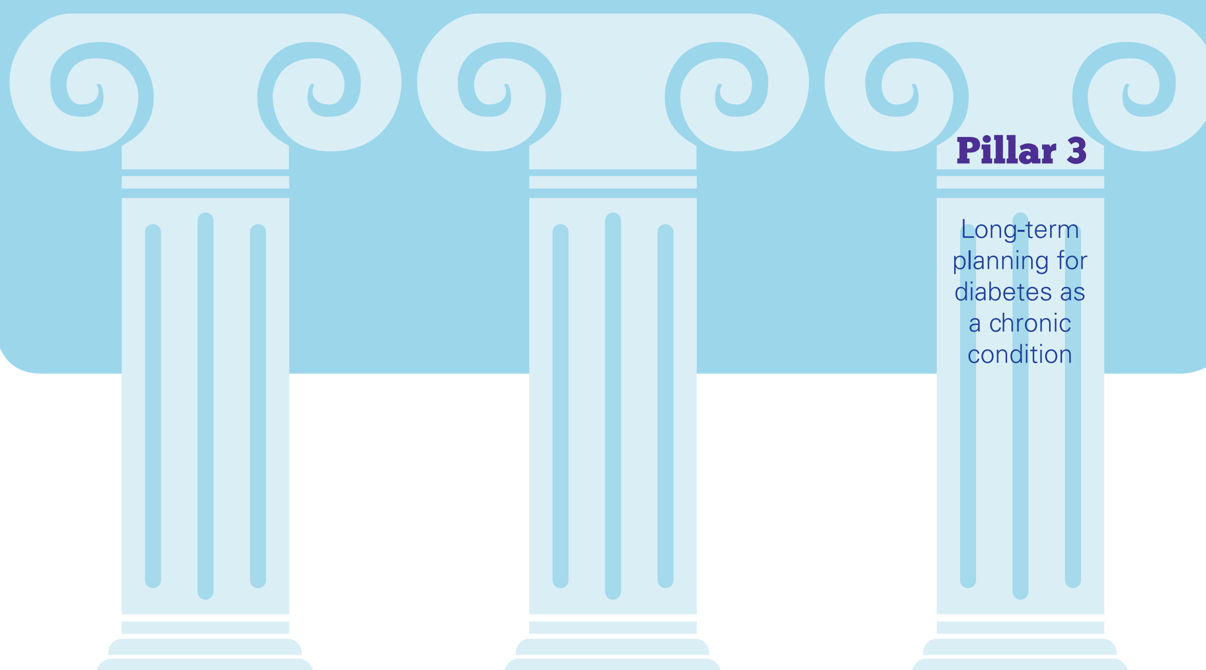
For example, Goals 1.4 and 1.5 of DIAMAP are, respectively, to 'develop approaches to the prevention of complications of type 2 diabetes and '*develop novel personalised diabetes treatment strategies through studying the aetiology and prediction of complications.*' A strategic map to direct research efforts towards these goals is provided. Some of the strategic directions recommended include:

- Develop methods for defining high-risk type 2 diabetes subgroups
- Develop economic models of the impact of public health interventions on complications of type 2 diabetes
- Define appropriate balance between high-risk and population approaches to the prevention of type 2 diabetes complications.

Pillar 3

Avenues for change

- The changing demographics of diabetes need to be taken into account in all policies and programmes targeting diabetes.
- To be successful, health promotion and prevention programmes must be appropriate for the different groups they target, and be age-, gender- and culturally specific.
- As we encourage the building of diabetes plans and national strategies to tackle diabetes, it is important to build in measures that allow us to measure how well we are doing using quality indicators that reflect longer-term outcomes of diabetes care such as the prevention and management of complications, and not just immediate glucose control.
- We must ensure that individual clinicians are encouraged – or even incentivised – to deliver high-quality diabetes care.
- More cooperation and earlier dialogue is needed between industry, the research community and regulators (health authorities, regulatory agencies and payers) to ensure better consistency and understanding of the meaning of value and innovation in the development of new therapeutic interventions for people with diabetes.
- Innovation should be defined based on outcomes that matter to patients and society at large.



This Think-Piece has outlined some of the issues surrounding the management of people with diabetes in Europe. It has made the case that there remain significant areas of unmet need in diabetes policy both at national and EU levels. We have highlighted the inherent complexity of diabetes and its management and proposed that such complexity requires a holistic approach if we want to reduce the burden of diabetes on our societies and improve the well-being of patients and their families.

We propose that this holistic approach rests on 3 central pillars: clinical efforts must go beyond glucose control, patient needs must be at the core of all programmes and activities and long-term planning is needed for diabetes as a chronic condition. Achieving the goals set out for each of these pillars requires a concerted approach involving all stakeholders. However, the starting point for all action must come from national governments both in terms of political will and dedicated resources.

This Think-Piece is intended as a starting point, an outline for future debate and discussion and a possible Table of Contents for a Roadmap for Implementation to be drafted. The topics addressed within this Think-Piece are illustrative rather than complete, however they bring to light some of the key challenges we face in trying to make a difference and do things differently for people with diabetes in Europe in the years to come.

Change is possible, however it can only be achieved through concerted actions and initiatives that bring all stakeholders around the table in a rich, multidisciplinary dialogue.

References

1 International Diabetes Federation Atlas (2009). Fourth edition. www.diabetesatlas.com/book/export/html.50 (accessed 7 Sept 2011).
2 The International Diabetes Federation (ibid).
3 International Diabetes Federation (2009), ibid.
4 Lindstrom J. et al. *Horm Metab* Res 2010 Apr; 42 Suppl 1:S37-55. Epub 2010 Apr 13.
5 Rydén *et al*, 2007. Guidelines on diabetes, pre-diabetes, and cardiovascular diseases: full text. The Task Force on Diabetes and Cardiovascular Diseases of the European Society of Cardiology (ESC) and of the European Association for the Study of Diabetes (EASD). *Eur Heart J*. 2007;9 (Suppl C): C3-C74.
6 Alberti K, et al. International Diabetes Federation: a consensus on Type 2 diabetes prevention. *Diabet Med*. 2007;24:451-63.
7 Nichols GA, Brown JB. The impact of cardiovascular disease on medical care costs in subjects with and without type 2 diabetes. *Diabetes Care* 2002; 25: 482-6.
8 Williams R, Van Gaal L, Lucioni C. Assessing the impact of complications on the costs of type II diabetes. *Diabetologica* 2002; 45: S13-17.
9 Martin S, Schramm W, Schneider B, et al. Epidemiology of complications and total treatment costs from diagnosis of type 2 diabetes in Germany (ROSSO 4). *Exp Clin Endocrinol Diabetes* 2007; 115(8): 495-501.
10 Koopmanschap M, the CODE-2 Advisory Board. Coping with type 2 diabetes: the patient perspective. *Diabetologica* 2002; S18-22.
11 American Diabetes Association 2005. National diabetes fact sheet.
12 Hillier TA, Pedula KL. Complications in young adults with early-onset type 2 diabetes: losing the relative protection of youth. *Diabetes Care* 2003; 26: 2999-3005.
13 Jeerakathil T, Johnson JA, Simpson SH *et al*. Short-term risk of stroke is doubled in persons with newly treated type 2 diabetes compared with persons without diabetes: a population based cohort study. *Stroke* 2007; 38(6): 1739-43.
14 Rydén et al, 2007 (ibid)
15 Bloomgarden ZT. American Diabetes Association 60th Scientific Sessions 2000: the diabetic foot. *Diabetes Care* 2001; 24: 946-51.
16 IDF Diabetes e-Atlas, 2006, 2nd edition.
17 van Battum P et al. Differences in minor amputation rate in diabetic foot disease throughout Europe are in part explained by differences in disease severity at presentation. *Diabet Med* 2011 Feb;28(2):199-205
18 American Diabetes Association, 2005 (ibid)
19 Daousi C *et al*. Chronic painful neuropathy in an urban community: a controlled comparison of people with and without diabetes. *Diabetic Medicine* 2004; 21(9): 976-82.
20 WHO, Diabetes Fact Sheet no 312, Sept 2006.
21 Department of Health (2007). *Improving diabetes services: the NSF four years on*. http://www.bipsolutions.com/docstore/pdf/16198.pdf (accessed 7 Sept 2011).
22 Younis N, Broadbent DM, Harding SP, Vora JP. Incidence of sight-threatening retinopathy in type 1 diabetes in a systematic screening programme. *Diabet Med* 2003; 20: 758-765.
23 Klein BEK. Overview of epidemiologic studies of diabetic retinopathy. *Ophthalmic Epidemiol* 2007; 14: 179-83.
24 IDF 2009 (ibid)
25 van Dieren S, Beulens JW, van der Schouw YT, Grobbee DE, Neal B. The global burden of diabetes and its complications: an emerging pandemic. *Eur J Cardiovasc Prev Rehabil* 2010 May;17 Suppl 1:S3-8. Review.
26 EUDIP group, European Union Diabetes Indicators Project. Establishment of indicators monitoring diabetes mellitus and its morbidity. Final report 2002
27 IDF and FEND. Diabetes. *The Policy Puzzle: is Europe making progress?* 1st edition (2005).
28 Harris MI, Klein R, Welborn TA, Kneiuman et al. Onset of NIDDM occurs at least 4-7 years before clinical diagnosis. *Diabetes Care* 1992; 21: 1414-31.
29 Samuels TA, Cohen D, Brancati FL, Coresh J, Kao, WHL. Delayed diagnosis of incident type 2 diabetes mellitus in the ARIC study. *Am J Managed Care* 2006; 12: 717-24.
30 Shah BR, Hux JE, Laupacis A, Zinman B, et al. Clinical inertia in response to inadequate glycemic control: do specialists differ from primary care physicians? *Diab Care* 2005; 28: 600-6.
31 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Non-Communicable Diseases (NCDs): prevent and control cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. World Health Organisation: Geneva (2008).
Weblink: http://whqlibdoc.who.int/publications/2009/9789241597418_eng.pdf
32 The Lancet NCD Action Group and the NCD Alliance. Priority actions for the non-communicable disease crisis. The Lancet published online April 6, 2011.
33 Alwan A. Raising the priority accorded to diabetes in global health and development: a promising response...Editorial. *Int J Diabetes Mellitus* 2010; 2: 139-40.
34 FEND and IDF-E. Diabetes – the Policy Puzzle: Is Europe Making Progress? 2nd edition, 2008.
Weblink: http://www.idf.org/webdata/docs/EU-diabetes-policy-audit-2008.pdf
35 Bradley C, Eschwege E, de Pablos-Velasco, *et al*. The PANORAMA Pan-European Study: Impact of severe and non-severe hypoglycaemia on quality of life and other patient-reported outcomes in patients with type 2 diabetes. [Abstract no. A-10-1900]. *Diabetologia* 2010: 53 (Suppl 1): 1-556. Presented at the 46th Annual European Association for the Study of Diabetes (EASD) Meeting, Sept 2010, Stockholm, Sweden.
36 Katon W *et al*. Diabetes and poor disease control: Is comorbid depression associated with poor medication adherence or lack of treatment intensification? *Psychosom Medicine* 2009; 71: 965.
37 Anderson RJ, Freedland KE, Clouse RE & Lustman PJ. (2001). The prevalence of co-morbid depression in adults with diabetes. *Diabetes Care*, 6, 1069-1078.
38 Petrak F, Herpertz S. Treatment of depression in diabetes: an update. *Curr Opin Psychiatry* 2009; 22(2): 211-217.
39 IDF Diabetes Atlas, www.diabetesatlas.org/content/diabetes-and-depression
40 Rustad JK, Musselman DL, Nemeroff CB. The relationship of depression and diabetes: pathophysiological and treatment implications. *Psychoneuroendocrinology* 2011, ePrint accessed April 2011.
41 De Groot M, Anderson R, Freedman KE *et al*. Association of depression and diabetes complications: a meta-analysis. Psychosom Med 2001; 63: 619-30.
42 Egede LE, Nietert PJ, Zheng D. Depression and all-cause and coronary heart disease mortality among adults with and without diabetes. *Diabetes Care* 2005; 28: 1339-45.
43 Le TK, Able SL, Lage MJ. Resource use among patients with diabetes, diabetic neuropathy, or diabetes with depression. Cost eff Resour Alloc 2006; 4: 18.
44 De Hert M, Dekker JM, Wood D, Kahl KG, Holt RIG, Möller H-J. Cardiovascular disease and diabetes in people with severe mental illness position statement from the European Psychiatric Association (EPA), supported by the European Association for the Study of Diabetes (EASD) and the European Society of Cardiology (ESC). *European Psychiatry* (2009), 24(6): 412-24.
45 *The Mental and Physical Health Charter*. Bridging the gap between mental and physical health (2009).
http://ec.europa.eu/health/mental_health/eu_compass/policy_recommendations_declarations/mh_charter_action_en.pdf
46 Diabetes UK, Primary Care Diabetes Society, and others. Joint Position Statement. Integrated care in the reforming NHS – ensuring access to high quality care for all people with diabetes
December 2007. http://www.diabetologists.org.uk/Shared_Documents/notice_board/joint_statement_v4.pdf
47 Department of Health (2003) *National Service Framework for Diabetes: Delivery Strategy*
48 Singh D, WHO Observatory 2008. The Innovative Care for Chronic Conditions Framework.
49 Carballo M. And Schiek F. Migration and diabetes: the emerging challenge. *Diabetes Voice* 2006; 51, issue 2: 31-33.
50 Duggirala MK, Cuddihy RM, Cuddihy MT, Nyman MA, Naessens JM, Pankratz VS. Women with diabetes have poorer control of blood pressure than men. *J Womens Health (Larchmt)* 2005 Jun;14(5):418-23.
51 Parodi CT and Barcelo A. Social injustice and unmet needs: women and diabetes in the Americas. DiabetesVoice May 2009; Vol 54, Special issue.
52 *A Healthy Heart for European Women*. European Heart Network, European Health Management Organisation, and Bristol-Myers Squibb: http://www.ehnheart.org/files/HealthyHeart%20(final)-155331A.pdf
53 Duggirala MK, Cuddihy RM, Nyman MA, Naessens JM, Pankratz VS. Women with diabetes have poorer control of blood pressure than men. *J Women's Health (Larchmt)*, 2005; 14(5): 418-23.
54 http://www.diabetesatlas.org/book/export/html/35
55 DIAMAP. Road Map for Diabetes Research in Europe. Road Map Report Summary, Sept 2010. Supported by the European Commission (FP7), coordinated by EURADIA. www.diamap.eu