BELGIAN DIABETES FORUM

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Diabetes in Belgium

White Paper

September 2020

Dear reader,

Diabetes is the most common and non-communicable chronic disease of our modern world, and it is still spreading. The disease is a leading contributor to health and social care costs. It has an increasing impact on the health of the Belgian population and the lives of so many individuals and their families. Diabetes affects lives in a permanent way and kills slowly, sometimes invisibly. The recent COVID-19 pandemic also illustrated how the diabetic population is more prone to complications induced by new sanitary threats compared with the rest of the population.

We want to emphasise that the quality of diabetes care in Belgium is very high. The authorities have already taken several good initiatives so that diabetic patients are now assured of high-quality care and guidance. However, the sustained and rapid growth of the number of people suffering from diabetes, as well as the increase in the number of complications related to this pathology, requires that the level of awareness of this chronic disease be urgently raised to a real national health priority.

The Belgian Diabetes Forum (*BEDF*) was set up in the autumn of 2019 by multiple actors working to curb or treat diabetes. A thorough analysis was conducted to identify what is going well, what is lacking and what can be improved in the treatment of diabetes. Based on this analysis, the Forum's mission is to identify the main improvements to be made in the treatment of diabetes and the prevention of its complications. More information about the BEDF can also be found on www.belgiandiabetesforum.be.

The first part of our work consisted of conducting a significant number of interviews over the previous months with diabetes stakeholders, which enabled us to write this White Paper.

This White Paper presents a brief but powerful list of recommendations rather than give an exhaustive overview to help prioritise future policy actions and raise awareness among policy makers on how to fill the identified gaps and align prevention, care and lifestyle initiatives in a cost-effective way.

In order to optimise this project, the BEDF has collected reactions, comments and suggestions to the observations, shortcomings and proposals set out in this Paper from a large number of stakeholders.

After this consultation period, we updated the White Paper. In addition, we have formulated specific policy recommendations to support the BEDF's future outreach to decision makers. These will provide us with a compass for policy guidance to policy-makers.

We hope you find this White Paper interesting.

On behalf of the Belgian Diabetes Forum,

Prof. Dr. Frank Nobels,

Chairman

Introduction

The number of people living with diabetes is increasing sharply worldwide, driven in particular by the obesity epidemic that is associated with an increased risk of type 2 diabetes. According to the WHO's 2016 World Report on Diabetes, the number of people with diabetes worldwide increased from 108 million to 422 million between 1980 and 2014 and is estimated to have reached 463 million in 2019[1]. During the same period, the prevalence of the disease increased from 4.7% to 8.5%. Diabetes caused 1.6 million deaths worldwide in 2015, almost half of which were among people under 70 years of age.

In Belgium, the figures for diabetes are limited and incomplete. It is therefore impossible to determine the exact number of people suffering from diabetes, as there is no systematic registration of those who are diagnosed. According to Sciensano[2], one in ten adults in Belgium has diabetes, and this percentage rises to 27% among people aged 65 and over. In addition, 5% of the adult population has elevated glucose levels that could increase their risk of developing diabetes at a later stage.

Specific attention needs to go to people living with type 1 diabetes, a disease that is not associated with obesity. They represent approximately 5% of the people living with diabetes. The number of people with type 1 diabetes hover around 40,000, including more than 3.000 children and adolescents.

All in all, nearly **1 million people in Belgium** suffer from hyperglycaemia (prediabetes and diabetes), meaning they do or should benefit from the prevention and treatment of diabetes and its complications.

In addition to the suffering for patients and their families, the pathology entails significant costs. In total, healthcare costs related to diabetes accounted for **5.82 billion euros** of expenditure in the Belgian social security system in 2018[3]. Despite exact monitoring, it would seem that most of this budget is related to the management of complications caused by diabetes, while only 6% accounts for the drug cost for the treatment of diabetes and its co-morbidities.

The quality of care for diabetes patients in Belgium is already at a high level. Several good initiatives have been taken in recent years and these efforts are set to continue. We face many challenges. Better diabetes prevention and care and a higher level of well-being for people living with diabetes are possible. These improvements involve the development of more specific approaches to the different population categories affected by diabetes: children affected by type 1 diabetes, adolescents at risk of developing type 2 diabetes, the elderly who are living longer than before with this disease, pregnant women who suffer from gestational diabetes and its consequences after pregnancy.

An essential prerequisite for containing the diabetes epidemic is support for **widespread, coherent and ambitious policies aimed at improving everyone's lifestyle**, thus preventing obesity and type 2 diabetes and preventing onset of complications of diabetes overall. This implies improving the quality of our food, adopting an active lifestyle and fighting sedentariness, but also stopping risky habits such as excessive alcohol consumption or tobacco use. A lot of fragmented initiatives already exist but they lack the necessary ambition to allow us to tackle the existing challenges.

This healthy lifestyle – which helps to fight other widespread diseases as well – should not be limited to people who are considered as being directly "at risk". Learning about a healthy lifestyle from a young age can help prevent many diseases. And since we influence each other lifestyles, we all have the power to stimulate others in our

[1] IDF, Diabetes Atlas, 2019.
[2] J. Van der Heyden, D. Nguyen, F. Renard, A.Scohy, "Enquête de santé par examen belge", November 2019, Sciensano.
[3] Total social security expenditure for health care in 2018: €25.7 billion. Diabetes-related expenditure accounted for more than 1/5th of this total figure.

family, work or public environment to adopt healthier lifestyles. **The responsibility for changing our lifestyle is a shared responsibility**.

This also means the fight against diabetes is and cannot be the responsibility of public health actors only: we can only do better if the same objective is shared among all areas of public and private action (creating a healthy and safe environment, sporting facilities, regulation of food industry, etc). Responding to this imperative therefore goes well beyond the ambition of this document. It is nonetheless essential.

Diabetes in a nutshell

Diabetes is a chronic disease that occurs when the pancreas does not produce enough insulin or when the body does not properly react to the insulin it produces. Insulin is a hormone that regulates blood sugar levels. If blood sugar level is not properly regulated, there is a risk of hyperglycaemia (a high concentration of sugar in the blood) which, over time, can lead to serious disturbances in the body's organs.

There are several types of diabetes, of which two types (type 1 and type 2) are the most common. Type 1 diabetes is linked to insufficient/absent insulin production by the pancreas. It is caused by an auto-immune destruction of the insulin producing beta cells of the pancreas. Type 2 diabetes is the most prevalent type of diabetes and is related to the inability of the body's cells to respond fully to insulin (insulin resistance) in combination with inadequate production of insulin. There is a strong link with smoking, overweight and obesity, sedentary lifestyle, increasing age, as well as with ethnicity and family history. Gestational diabetes occurs in pregnancy, putting the mother and child at risk of complications. Mothers have a very high risk of developing type 2 diabetes after pregnancy. In addition, there are several other causes of diabetes that make up about 5% of the total.

The consequences of diabetes are serious. It increases the risk of cardiovascular diseases, foot ulcers or infections, damage to the retina leading to blindness, is the main cause of kidney failure (progressive destruction of the kidneys) and as a consequence significantly shortens life expectancy. These complications are associated with significant personal, direct (medical) and indirect (economic) costs.

Recommendation #1 – A future-proof data policy

"We have a very large amount of health data, from medical files, pharmacists, health funds... but we do so little with it. We obviously have to respect privacy, but this should not prevent us from integrating data and learning from it: what are the needs, what works, what doesn't and what needs to be adjusted? Without the right data, we are implementing policy by guesswork."

We do not know how many people suffer from diabetes in Belgium.

Our health system needs a paradigm shift when it comes to considering costs. Currently, decisions tend to focus on direct costs, whereas direct and indirect benefits inside and outside the diabetes budget are not (sufficiently) considered, and a long-term vision is lacking.

One of the (main) reasons for this is that there is no **diabetes data policy** in Belgium. While we have a lot of data, we do not have centralised data on people who are affected by the disease. The available data are neither integrated nor used to identify the evolution and health needs, even less so to assess the impact of policy changes. The collection and use of epidemiological data is required to support policy-making work, facilitate a better management of diabetes and health budgets and evaluate existing and new measures. The use of health and diabetes (big) data is an efficient solution to avoid wasting budget and resources, because it would facilitate the measurement of the medium- and long-term impact of decisions (such as decisions related to changes in reimbursement policies).

At the same time, lifestyle habits are strongly correlated with type 2 diabetes and have an impact on the management of diabetes in general. Meanwhile, lifestyle habits are strongly correlated with socio-economic living standards. The integration of socio-demographic data and health data makes it possible to identify those people who are likely to become diabetic with some precision, in addition to those who are more at risk of developing complications. This is all the more important since at least one diabetic in three is unaware that he or she suffers from this pathology and that complications develop as early as this prediabetes phase.

Finally, it is crucial that all of these data, that are related to individual situations and linked to privacy, benefit from adequate and high protection, both in terms of access and in terms of the use that can be made of them.

RECOMMENDATIONS

- Present the advantages and gains linked to the adoption of an **exhaustive registration** of the diabetic population and of those suffering from glycaemic disorders (but who are not aware of it) to political and health decision-makers, in order to accurately identify the evolution and consequences of this epidemic in the population and improve the answers to this chronic disease, among others to promote more efficient reimbursement policies.
- Map existing **registration systems** of diabetes in Belgium, retain what works well and, if necessary, create more efficient registration systems to enable a comprehensive mapping of the incidence and prevalence of diabetes in Belgium.

- Accelerate the development of **a sustainable model and platform for the use of health and diabetes data** in Belgium, resulting in an Electronic Health Record[4] focused on patients, supporting healthcare providers to ensure accurate encoding and correct use of data.
- Integrate existing databases and registries managed by health administrations and health funds. Give intermediary health actors, and in particular health funds, the **responsibility** to actively participate in the data collection process and the proactive linking of existing databases.
- Develop and use **statistical tools and artificial intelligence algorithms**, on the basis of socio-demographic data, allowing for the timely identification of people at risk to offer them accompanying measures to reduce the risk of developing diabetes. Also use these tools to identify patients who are at high risk of complications more quickly, while ensuring regular global monitoring.
- Ensure the absolute **protection** of the personal data collected in order to avoid any commercial or lucrative use leading to forms of discrimination against people with glycaemic disorders, in particular with regard to employment or insurance.

Recommendation #2 – Invest in prevention, screening and early detection

"At the age of 56, I was hospitalised due to a heart attack. They told me then that this had something to do with diabetes, but I didn't even know I had it. Too bad I didn't know that sooner, because then I might have been able to prevent the heart attack from happening, right?"

1 in 3 people with diabetes are unaware that they suffer from it.

Although there is no exact figure for people living with diabetes in Belgium, we know that the **prevalence** of diabetes in the population is rising constantly. Type 2 diabetes, as a chronic and silent disease, is all too often detected by chance. The International Diabetes Federation estimates that one in three people in the world who have diabetes are unaware that they suffer from diabetes. According to the WHO, this figure could rise to one in two people by 2030.

Prevention, screening and early detection of type 2 diabetes have the potential to prevent or delay the devastating complications of the disease. The measures for preventing type 2 diabetes are generally similar to those for preventing obesity and cardiovascular diseases. International initiatives have had clear results. Belgium has several initiatives around awareness, prevention and early detection of type 2 diabetes, but they are small-scale for the most part.

Prevention and early detection of type 1 diabetes require a completely different approach, aimed at detection of genetic and immunologic parameters and trying to halt autoimmune reaction with (experimental) pharmacological approaches. This is still in the preclinical experimental domain. The Belgian Diabetes Register has developed extensive and internationally-renowned expertise in this field.

[4] Referring to the conclusions of the Health Working Group's Report contributing to the Pact for strategic investments, Sept. 2018.

RECOMMENDATIONS

- List easily accessible outreach and screening initiatives and evaluate what works and what does not.
- Support and coordinate **awareness campaigns** targeting the general population and health actors in the broadest sense about the risk factors for type 2 diabetes (in particular on the importance of quitting smoking, healthy eating and physical exercise) and the crucial importance of prevention and early diagnosis, and develop a specific and adapted approach for the populations that are most at risk.
- Develop prevention and awareness initiatives based on raising the attention and increasing the involvement of patients that are potentially at-risk.
- Optimise and coordinate **initiatives for cross-disease prevention and screening** (cardiovascular, obesity, diabetes) to improve the general diagnosis rate for diabetes.
- Promote **cooperation** to offer support to and encourage people at risk to be screened, among others by including patient associations, insurance companies, (mutual) health funds, pharmacies, occupational health services, …
- Provide clear guidelines for caregivers on screening tools for assessing diabetes risks and on strategies to prevent diabetes in high-risks persons.
- Dedicate special attention to prevention and early detection of type 1 diabetes, through detection of genetic and immunologic parameters.
- Involve professional groups that can play an important role in prevention and screening, such as pharmacists, occupational physicians, nurses, podiatrists, physical therapists, etc.

Recommendation #3 – Keep improving diabetes care

"At some point, the medication for my sugar control was no longer effective. My GP referred me to a specialist. I had to inject medication once a week. A care pathway was agreed upon so that a nurse could visit me at home to assist me with this. But she also gave me a lot of practical information about diet and exercise for blood sugar control. It was very strange to hear this for the first time after having diabetes for 11 years."

Diabetes care is **complex**:

20% of the population fails to achieve glycaemic control.

- It is multifactorial: lifestyle, blood glucose, cardiovascular risk factors, early detection and treatment of complications should be taken into account.
- It focuses on targets such as body weight, blood glucose, HbA1c, blood pressure, lipids, …
- It requires a holistic approach considering the comorbidities and the social and psychological situation of the person with diabetes.
- It requires empowerment of people with diabetes to teach them to take responsibility for managing their own health.

As no caregiver can provide all aspects of care, this requires a multidisciplinary approach with structured collaboration between different caregivers. At the same time, diabetes care should be organised in a flexible way, enabling caregivers to differentiate care and tailor it to the needs of different patients.

Care that integrates all these aspects is called **integrated care**.

People with type 1 diabetes need elaborate multidisciplinary care from the onset of the disease, that involves the use of technology. For people with type 2 diabetes the complexity of care usually increases with longer diabetes duration.

Belgium has created many excellent care systems to provide high quality multidisciplinary care for people with diabetes. The system of diabetes conventions allows for the flexible and integrated management of complex cases for people with type 1 diabetes and for people with advanced type 2 diabetes or other types of diabetes that require complex care. The **IQED** (initiative for the promotion of quality and epidemiology of diabetes mellitus) quality assurance systems monitor quality and facilitates improvement if necessary. The monitoring indicates that very high-quality care is provided, that is ranked among the best international practices.

The system of **diabetes care pathways** combines primary and specialised care for people living with type 2 diabetes who switch to more complex treatments. Quality monitoring shows that this is an effective way of caring for these patients, promoting collaboration between primary and secondary carers, again ranking among the best international practices.

Unfortunately, for type 2 diabetes these systems of integrated care only start at a later stage of the disease. The so-called **'precare trajectory'** tries to provide integrated care to people in the early stages of type 2 diabetes, with a focus on education/empowerment. However, much of the support (education) is limited to a subgroup of diabetics (≤69y + BMI >30 and/or hypertension). It is not properly implemented in routine clinical practice, leaving many people with early-stage type 2 diabetes without adequate support at a time when they need it. Finally, the transition from the "precare trajectory" to the actual care pathway must become more fluid.

The future has many challenges in store. Over the last years, tremendous pharmacological and technological advances were made in the treatment of diabetes. It is expected that there also will be significant advances in the coming years. Selecting those innovations that really improve care will be the main challenge.

RECOMMENDATIONS

- Map all existing initiatives that allow access to care for people with diabetes.
- Maintain the existing excellent integrated care systems (diabetes conventions, diabetes care pathways).
- Identify roadblocks in the systems that promote access to care for people with diabetes.
- Propose paths to further improve existing integrated treatments systems. Ensure easy access and smooth transition between the different systems.
- Extend integrated care to all people living with diabetes, from the diagnosis onwards, and identify which actors can contribute to it.

- Make lifestyle education activities an essential part of all care pathways.
- Monitor the effectiveness of the care provided in terms of three dimensions: quality of care, quality of life of people living with diabetes at the physical and mental level (such as PREM and PROM[5]) and treatment costs.
- Introduce testing ground concepts to test innovations in patient support and select those that result in significant and cost-effective progress.
- Intensify both fundamental and applied **research** efforts, as well as collaboration between research centres, in order to better identify the multiple aspects of this condition and to develop treatments that can be adapted to each person's situation and strengthen his or her autonomy. Dedicate specific attention to research aimed at halting the auto-immunity reaction in case of type 1 diabetes.

Recommendation #4 – Develop a child-friendly approach

"My daughter was diagnosed with type 1 diabetes at the age of seven. It was a terrible shock for the whole family. Luckily, we were very well supervised as part of the paediatric convention, and they even came to the school several times to give explanations. It is not always easy for the teachers, but they do a wonderful job. Next year, she will go on a vacation camp that is organised by the Diabetes Association. It will be great for her to be able to play with children of her own age! »

In the prevention and treatment of diabetes, children and adolescents require special attention. Supporting families with a child with type 1 diabetes requires a global approach. A healthy lifestyle aimed at preventing type 2 diabetes later in life is not easy for these age groups but is crucial nonetheless.

More than 90% of children with diabetes suffer from type 1 diabetes. Specific attention must be devoted to them, based on their life context.

The majority of patients in this group have type 1 diabetes. The impact of this disease on children, adolescents and their immediate entourage is significant. The socio-economic vulnerability of the family in question often determines the proper follow-up of treatment and is a key factor to be taken into account. The large number of active care providers involved in the treatment of the child makes it all the more relevant to ensure full communication of data between care providers and the availability of uniform treatment plans for both type 1 and type 2 diabetes.

To avoid type 2 diabetes later in life, the top priority, however, is to teach children (and their parents) a healthy lifestyle and a rational multidisciplinary approach to obese children and adolescents.

RECOMMENDATIONS

- Develop a **comprehensive approach to healthy eating** and adequate physical activity. These initiatives must also facilitate the active participation of parents and the active role of the child's entourage (school, day-cares, extracurricular activities...).

[5] Patient-Reported Outcome Measures (PROM) and Patient-Reported Experience Measures (PREM) are measures that probe patients' perceptions of their care. These PROMs and PREMs provide a range of information about how patients perceive their own health status or experience the care process. As these data are reported directly by the patient without being interpreted by a doctor or other caregiver, they make it possible to understand what is really important to the care recipient (source: KCE).

- Develop tools to ensure that the **child's background** is properly taken into account in the implementation of prevention and awareness-raising programmes as well as treatment. These factors (socio-economic level, mother tongue, family situation...) require a tailor-made approach.

- Facilitate the **uniform and digital recording of data** and the consistent implementation of treatment plans that can be consulted by all stakeholders involved in the multidisciplinary approach to the care of children with type 1 diabetes and the treatment of childhood obesity.

- Create a legal framework to **help those who work with children with type 1 diabetes** (teachers, educators, vacation counsellors, etc.) with blood glucose testing, insulin injection and glucagon administration if necessary.

Recommendation #5 – Strengthen the prevention of complications

"I've suffered a very serious foot wound. I was afraid that I would lose my leg, just like my father. In the diabetic foot clinic they finally ended up removing part of my foot, which was needed to close the wound. I am tremendously grateful to these people. I now have to wear special shoes inside and outside. The health fund only reimburses one pair every two years. I paid for the other pair out of my own pocket. But what about all those people who can't afford it?"

Prevention of complications is crucial in the treatment of diabetes. Easy access to all necessary care is therefore needed to keep living a life that is as normal as possible and achieve both primary and secondary prevention.

The largest share of diabetes-related health expenditure is related to complications.

While a lot of means and efforts are dedicated to treating the complications of diabetes (foot, eyes, kidneys or other), more attention is needed to **prevent** these complications from happening and reoccurring after successful treatment. Awareness should be raised among people with diabetes, their families and the population as a whole, but also among caregivers and all other actors in the care system.

In total, diabetes-related healthcare **expenditure** by the government social security system accounted for 5.82 billion euros in 2018[6]. It is estimated that a large part of this budget is related to the management of complications caused by diabetes, while only 6% is related to the cost of drugs for the treatment of diabetes and its co-morbidities.

RECOMMENDATIONS

- Identify the **frequency** of diabetes-related complications and the **costs** this entails. This will help to **raise awareness** of the effects of diabetes on the life of people with diabetes and on the health system in terms of manpower and budget. This will also provide arguments to support **budget shifts** towards better prevention of complications.

[6] Total social security expenditure for health care amounted to 25.7 billion euros in 2018, accounting for more than one fifth of total healthcare expenditure in other words.

- Identify roadblocks in access to care for the prevention and treatment of diabetes complications, including reimbursement of care.
- Increase screening to **detect complications** at an early stage (such as microalbuminuria, creatinine, eye exam, foot exam) and strengthen the connection between general practitioners and other front-line and specialised providers, particularly in the pre-care trajectory phase.
- Analyse **education and prevention activities** for a healthy lifestyle for diabetic people or people suffering from glycaemic disorders (fasting) in order to improve their effectiveness and targeting.
- Improve secondary prevention strategies, especially for cardiovascular complications and diabetic foot.
- Identify the areas where the number of people at risk is proportionately high, in order to ensure full **geographical coverage** of secondary prevention policies and activities across the entire territory, and set up **pilot projects** at the local level in areas that are particularly affected by diabetes in order to measure the impact of very intensive and close monitoring programmes.
- Develop and make available **new mobile applications** or features aimed at assessing the evolution of the pathology to patients, ensuring their ease of use (through, for example, a dashboard) and encourage the adoption of good physical practices, as well as the adoption and maintenance of healthy eating habits.

Recommendation #6 – Organise for real teamwork in care

"I've recently entered such a diabetes care pathway. I'm happy about this, because now I can also go to a nurse and a dietician, who give me lots of information and explain things. The only annoying thing is that these people know almost nothing about my file. You would think that they would be able to check which pills I take, or that they know my blood pressure and my cholesterol, but every visit they ask me the same things".

Patients with diabetes depend on the care of **several caregivers** (general practitioner, diabetologist, nurse, physiotherapist, pharmacist, dietician, diabetes educator, podiatrist, ophthalmologist…), as well as on the help of non-medical professionals.

Caregivers are very well trained but are not yet acting as a real team.

It is therefore essential that these professionals act in a **coordinated** manner, deliver consistent messages to the patient and communicate effectively with each other. In situations where different caregivers work in the same environment, such as in the diabetes convention centres, this can be more easily achieved. The challenge is greater in primary care where the different actors do not usually work in the same practice and consequently do not all have access to the same medical files.

Overall, e-health has made great strides in recent years, but there is still a long way to go to achieve a uniform electronic medical record that can be easily accessed by patients and all relevant healthcare providers, each within their own area of expertise and with respect for privacy.

RECOMMENDATIONS

- List all successful multidisciplinary initiatives and **expand the best practices** to inspire other professionals in the field.
- Develop initiatives that strengthen **network collaboration** between healthcare actors, particularly in primary care and between primary and secondary care, in order to foster mutual knowledge of each other's services and develop trust between the healthcare providers involved in the treatment of diabetes in its various forms.
- Ensure that all health care professionals deliver **consistent and easy to understand messages** to people with diabetes.
- Accelerate the adoption and performance of the **global medical record**, by integrating it in an e-Health application that can be accessed by all members of the treatment team, not just physicians but also paramedics and even administrative staff, each within the framework of their own mission. This would help to improve communication between outpatient and hospital staff and ensure a better follow-up, in particular after the treatment of a specific condition deriving from the diabetic situation.
- Improve **continuous training** (including distance learning) of medical staff. This must make it possible to align the knowledge of all actors with new solutions, offering the most effective treatments for the management of the disease and the reduction of risk behaviour. Recommendations should also be adapted to the person's socio-cultural background and the use of empowering techniques should be supported. Special attention to gestational diabetes is also necessary when training medical and paramedical personnel in the context of pregnancy and preparation for childbirth.

Recommendation #7 – Enable people living with diabetes to remain dedicated to their treatment

"I often tell my doctor that it's all easy when you're sitting on the other side of the desk, but I get up every day with diabetes. I have to choose what I put in my shopping cart in the supermarket, think about what's on my plate at the restaurant, stay strong when my friends tell me 'it won't hurt this once'...'. But what bothers me the most is all the time wasted in waiting rooms, going to the doctor again because a prescription has expired, doing all kinds of paperwork ...".

Although the health system and the social environment play a crucial role for diabetes patients, ultimately the burden of the illness is borne by the patient him/herself.

A segmented and prescriptive model does not empower patients who need constant focus and discipline.

Treatment compliance is anything but easy, as diabetes often suddenly forces those who suffer from it to make radical and permanent changes, sometimes without the appropriate help and education that are required. In the end, the patients with the highest level of autonomy seem to cope better.

A mainly **segmented and prescriptive** model (with separate phases of lifestyle advice – medication – control & follow-up) is no longer tailored to the current challenges of this epidemic.

It is therefore essential that patients are really empowered, that they are given the appropriate tools to make it easier for them to comply with their treatment. In this respect, raising the global autonomy level of diabetes patients is the way forward.

RECOMMENDATIONS

- Take stock of known hurdles, such as the administrative burden patients face, and identify other hurdles in diabetes treatment compliance.
- Promote a **more equal relationship model** between the patient and healthcare professionals. Such a model requires a combination of a medical and motivational approach, by which the patient is not only encouraged but also enabled to understand and observe his or her treatment in the best possible way.
- Invest in research and in the implementation of research regarding the **long-term contribution of technology** to improve treatment compliance for all.
- Invest in research and research translation for user-friendly technologies that can improve **treatment in the long term.**
- The development of **telemedicine** should facilitate increased access to consultations, the development of targeted support and ensure treatment compliance (taking into account each patient's situation).
- Make **treatment compliance assistance programmes accessible** for all patients, regardless of the follow-up system (convention, care pathway or other) and age (including 70+).
- Beyond individual approaches, provide a structural framework to facilitate the development of programmes aiming at **training patients** through therapeutic educational groups and setting up peer groups to support each other.

Recommendation #8 – Minimise legal and social obstacles

"I got married last year. We want to buy a house now, but the insurance company is causing problems. Although my diabetes has been well controlled for years, they are charging me a substantial additional premium for my outstanding balance insurance. This is not normal."

Living with a chronic disease such as diabetes is a daily struggle. Patients need to continuously focus on treatment compliance and on avoiding or coping with complications while trying to live an active and normal life. In addition to this, people with diabetic must overcome additional hurdles in daily life.

Insurers still refuse diabetes patients or ask higher premiums.

This means that the patient's personal and family life is not only impacted due to the discipline that is required to balance blood sugar levels. **Additional difficulties** appear as a secondary consequence of living with the disease:

some jobs are not accessible for diabetes patients; women with diabetes who want to have children need perfect discipline and close and continuous monitoring; insurance coverage is denied in lots of situations because of a "pre-existing condition", leading to higher costs for services that are usually covered for other people, insurance companies still use obsolete statistics to calculate exaggerated insurance premiums… More generally, there is still a taboo on disclosing the existence of the chronic illness out of fear for negative consequences.

RECOMMENDATION

- Identify problems of integration and discrimination in society on the basis of different types of diabetes.
- Address the issue of discrimination of people with diabetes with all relevant actors (employers federations, insurance industry, UNIA…) and develop awareness campaigns showing how people living with diabetes can live a normal life and can continue to go about their activities.
- Communicate the already excellent level of care for diabetes patients in Belgium to the public to help remove the social stigma. In addition, all improvements recommended in this White Paper will contribute to better prevention, care and compliance. Communication should also focus on quick wins and longer-term efforts and effects of current and future diabetes policies.
- Raise awareness of the systemic aspect of the illness and its consequences by setting up targeted programmes and communication campaigns for families, HR Managers, teachers, the insurance industry...

Recommendation #9 – Make care (more) accessible for everyone

"As a doctor, I treat a lot of people of foreign origin. They don't usually talk openly about diabetes, although it is much more common in this population group. Informing them properly about the disease continues to be difficult; sometimes they just wait far too long before seeking help. But we keep trying to improve our communication with all patients."

Some ethnocultural minorities are 6 times more vulnerable to diabetes than the general population

Access to healthy lifestyles and adequate use of health resources is strongly correlated with the population's socio-economic standard of living. At the same time, certain ethnocultural minorities are more affected (up to a factor of 6) and therefore require much closer attention. Health illiteracy creates a distance between certain population groups and health professionals and makes treatment monitoring and compliance more challenging, especially because some people do not believe in the diagnosis that was established or the proposed solutions.

RECOMMENDATIONS

- Develop **communication actions adapted to the social and cultural characteristics of the target audiences** in order to help actors in contact with at-risk populations and invisible patients to raise awareness on the subject and to enable them to direct people concerned or at risk to specialised actors. This includes actions targeted at general practitioners and pharmacists, who are frontline actors and trusted advisors for many socially vulnerable people.
- Value and reinforce **local multidisciplinary initiatives and networks** in neighbourhoods or municipalities where the population at risk rate is high, in order to set up preventive actions to ease the burden for the medical actors in its educational actions. At the same time, the Forum suggests reinforcing the **integration of socio-cultural associations** within **local multidisciplinary networks** in order to strengthen their action in the field in terms of the adoption of healthy lifestyles and to encourage patients from ethnocultural minorities to follow their treatment in its different aspects.
- Make sure all health professionals systematically **adapt dietary advice, lifestyle and treatment compliance education** to social conditions and cultural habits.
- Improve **screening** and aftercare of (potential) complications, including through close follow-up with people suffering from medical illiteracy or who experience difficulties securing their livelihood.
- Make sure the best **technological and digital health solutions** are available for everyone, accompanied by educational measures and follow up.

Annex: Methodology

Building common ground with all the diabetes stakeholders in Belgium is at the heart of the mission of the Belgian Diabetes Forum. The basis for this White Paper was developed by collecting experiences and ideas from the bottom up from people living with diabetes or working in the diabetes sector and, in doing so, the entire diabetes landscape has been covered.

More specifically, we conducted an extensive 'field research' effort. We did this by individually interviewing a large group of persons to get a good idea of their experiences, especially on what is going well, what is missing and what can be improved in diabetes prevention and care in Belgium.

This round of interviews started in the autumn of 2019. To date, we have conducted in-depth discussions with people with different backgrounds:

- Patient associations and patients;
- Diabetes specialists and academics;
- GPs and doctors' associations;
- Payers (health funds and NIHDI);
- Hospitals or hospital associations;
- Paramedical professions (nurses, dieticians, podiatrists) and their associations;
- Pharmacists' associations;
- Unions and employers' associations;
- Administration and public institutions (FPS, Sciensano);
- Diabetes industry.

Their valuable input is summarised in this White Paper, reflecting the multi-stakeholder approach that the Belgian Diabetes Forum stands for. This White Paper was then presented to people who are confronted with diabetes, either personally or in their professional practice, with a view to being further validated or finetuned. Following this consultation, an exchange of viewpoints took place with interested parties before the texts were updated. In parallel, the White Paper will be transformed into a policy-oriented document proposing concrete actions.