



**International
Diabetes Federation**
Europe



INTEGRATING DIABETES EVIDENCE INTO PRACTICE: CHALLENGES AND OPPORTUNITIES TO BRIDGE THE GAPS



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About the International Diabetes Federation Europe (IDF Europe)

IDF Europe is the European chapter of the International Diabetes Federation (IDF). We are an umbrella organization representing 70 national diabetes organisations in 47 countries across Europe. We are a diverse and inclusive multicultural network of national diabetes associations, representing both people living with diabetes and healthcare professionals.

More info at www.idf-europe.org

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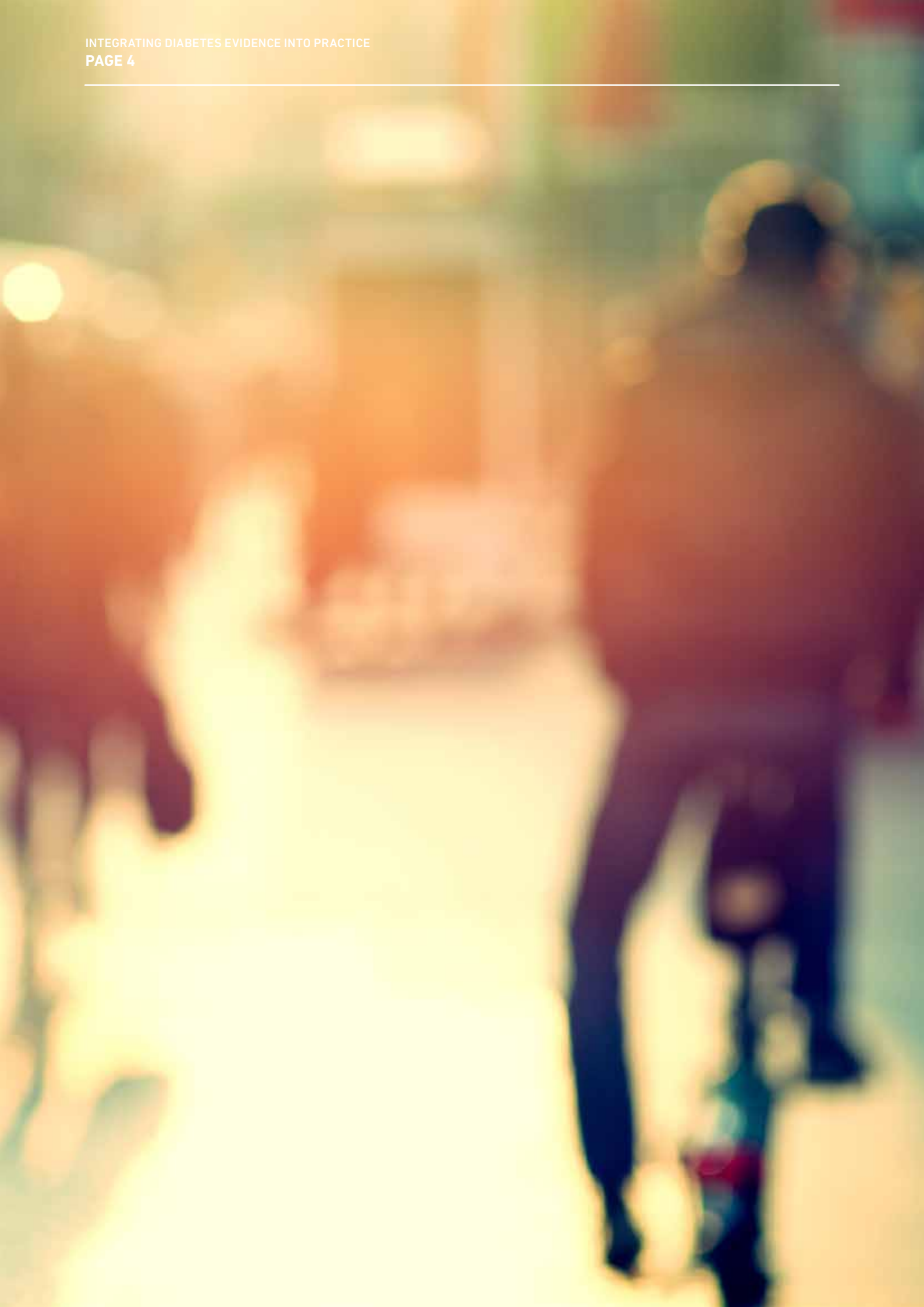
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Foreword

Integrating diabetes evidence into practice: challenges and opportunities to bridge the gaps

Diabetes presents a significant burden in Europe; the IDF Diabetes Atlas 2017 estimates that it affects 58 million people and costs a staggering 145 billion euros annually.

Every day, new evidence is produced to improve the prevention and treatment of diabetes. However, the pace at which this new evidence is implemented into practice and has an impact on healthcare systems, healthcare professionals and persons living with diabetes, can be slow. To align with the IDF mission to promote diabetes prevention, care and a cure for diabetes, IDF Europe is working to produce evidence to support effective advocacy efforts at European and country-wide levels, positioning IDF Europe as a key partner for European health researchers and policy makers.

This report defines the current landscape in relation to diabetes in Europe and identifies barriers and solutions for implementing diabetes evidence into practice. We have described the current evidence, and have sought the perspectives of IDF Europe member organisations and people with diabetes. We have also analysed social media platforms to identify common diabetes-related topics and key issues for people living with diabetes. We wanted to identify and understand the barriers at all levels, including why diabetes is still not a priority in many countries, why recommended care models are not adopted and why adherence to therapy is still too low.

The findings of this report have identified a number of key barriers to implementing diabetes evidence into practice, including problems with (or lack of) national diabetes programmes and registries, and inappropriate formulation of diabetes guidelines. For people with diabetes, common barriers related to adherence, education and lack of empowerment. Overall, we identified that involvement and communication between policy makers, healthcare professionals and people with diabetes needs to be better.

We have made recommendations for improving implementation of evidence at both micro and macro levels. In 2018, we intend to work with key stakeholders to further refine these recommendations, making sure that we put people with diabetes at the forefront in our efforts to address diabetes burden, improve health-related outcomes and ultimately improve quality of life.

Prof Kamlesh Khunti,
Chair of the Editorial Committee;

Prof Sehnaz Karadeniz,
Chair of IDF Europe;

Dr Niti Pall,
Chair-Elect of IDF Europe



Executive Summary



This report, “Integrating diabetes evidence into practice: challenges and opportunities to bridge the gaps”, identifies the local and European-wide challenges of implementing diabetes evidence into practice and makes recommendations based on the findings. Diabetes presents a significant health and economic burden across Europe, affecting 58 million people and costing 145 billion euros per annum. There is an urgent need to identify ways in which implementation of evidence can be improved.

The findings of this report are presented from three distinct perspectives: healthcare system; healthcare professional; and person living with diabetes. The report draws on data from: the published literature; a survey of International Diabetes Federation Europe (IDF Europe) member organisations across 38 responding countries; and social media. In analyzing all these sources we received technical support from IBM. We have focused on current practice, challenges for implementing evidence into practice, and ways in which implementation may be facilitated.

Key findings

Healthcare systems

From a healthcare system perspective, IDF Europe member organisations reported that the most common barriers to implementing diabetes evidence into practice related to: problems with national diabetes programmes/strategies (structure, implementation, monitoring, evaluation); problems with national diabetes registries (their use or structure); lack of effective involvement from healthcare professionals and persons with diabetes; and ineffective or uneven distribution of resources.

Despite the World Health Organization (WHO) and IDF recommending the development and implementation of national diabetes programmes since the 1990s, only 22 (58%) IDF European countries were implementing national diabetes programmes. Similarly, only 15 countries (39%) had national diabetes registers.

While all of the countries had national diabetes guidelines or diabetes clinical protocols, their implementation and monitoring was fragmented across the regions. Stakeholders were not always aware of the guidance and only a few countries had well-developed systems in place to develop clinical guidelines. IDF Europe member organisations considered that European countries had fair access to medication and healthcare services but perceived that access to medicine and medical devices was uneven and co-payments (from patients) contributed to increased non-adherence to recommended treatments. Cost, availability and lack of supplies were the most frequently cited problems from low-income country respondents.

Healthcare professionals

The most common barriers identified in the IDF Europe member organisation survey for healthcare professionals were poorly supported and implemented prevention programmes (primary, secondary or tertiary), limited consultation time, ineffective communication between healthcare professionals, and lack of integrated facilities and/or medical teams. Barriers reported in the literature included treatment costs, patient reluctance to use insulin, medication burden, and fear of complications.

Other barriers reported for healthcare professionals included inappropriate formulation of diabetes guidelines and implementation strategies, therapeutic inertia and inadequate contextual support.

Both the literature and IDF Europe survey suggested that healthcare professionals were not fully implementing existing clinical diabetes guidelines: 35% of respondents reported that implementation of the guidance was monitored and only 25% reported that the impact of the offered health service was evaluated. Only four countries in the IDF Europe member organisation questionnaire reported that patients and families were regularly offered diabetes education on important therapeutic factors, such as physical activity, diet, metabolic control, adherence and foot hygiene. Nearly 75% of countries did not recommend continuing education to patients or family members.

Persons living with diabetes

Responses from the IDF Europe survey indicated that the most common barriers to achieving optimal health for persons with diabetes were poor adherence to medication or lifestyle change, limited patient/family skills to properly manage diabetes, lack of/poor empowerment of persons with diabetes and poor family education.

Adherence was the most important component of diabetes management identified. Review evidence generally showed low adherence to medication (less than 20% in some studies). Adherence to lifestyle change appeared to be somewhat higher. Half (50%) of study participants reported that they made dietary changes, and between 17% and 70% of participants across studies reported that they adhered to physical activity recommendations.

The most frequently discussed themes on social media in relation to diabetes were support, education and access to care or medication ('accessibility'). The most common negative sentiments related to support, education and costs for both type 1 and type 2 diabetes. Education also featured highly (it was the second most common theme) in the open responses from IDF Europe organisations.

Conclusions

This report has demonstrated that there are substantial European-wide challenges in the implementation of evidence-based practice for healthcare systems, healthcare professionals and persons living with diabetes. Recommendations for overcoming these challenges are outlined below.

- Implementation of diabetes evidence should be tailored to local circumstances.
- Effective human, financial and material resource management strategies are needed to improve the delivery of healthcare systems and patient outcomes, and reduce therapeutic inertia.
- Prioritisation should be given to the education of healthcare professionals and persons living with diabetes to maximise the impact of government investment.
- Appropriate prevention strategies are vital to reduce the incidence of diabetes.
- More effective tools for managing behavioural change need to be developed.
- All stakeholders (policy makers, healthcare professionals, healthcare/commercial organisations and providers, and persons with diabetes) should be actively involved in policy initiatives targeted at addressing diabetes burden and improving quality of life.





1

Introduction

Diabetes is a non-communicable disease that occurs when the pancreas does not produce insulin or cannot produce insulin effectively. Insulin is needed by the body because it enables glucose to be extracted from the blood stream to pass into cells and produce energy.

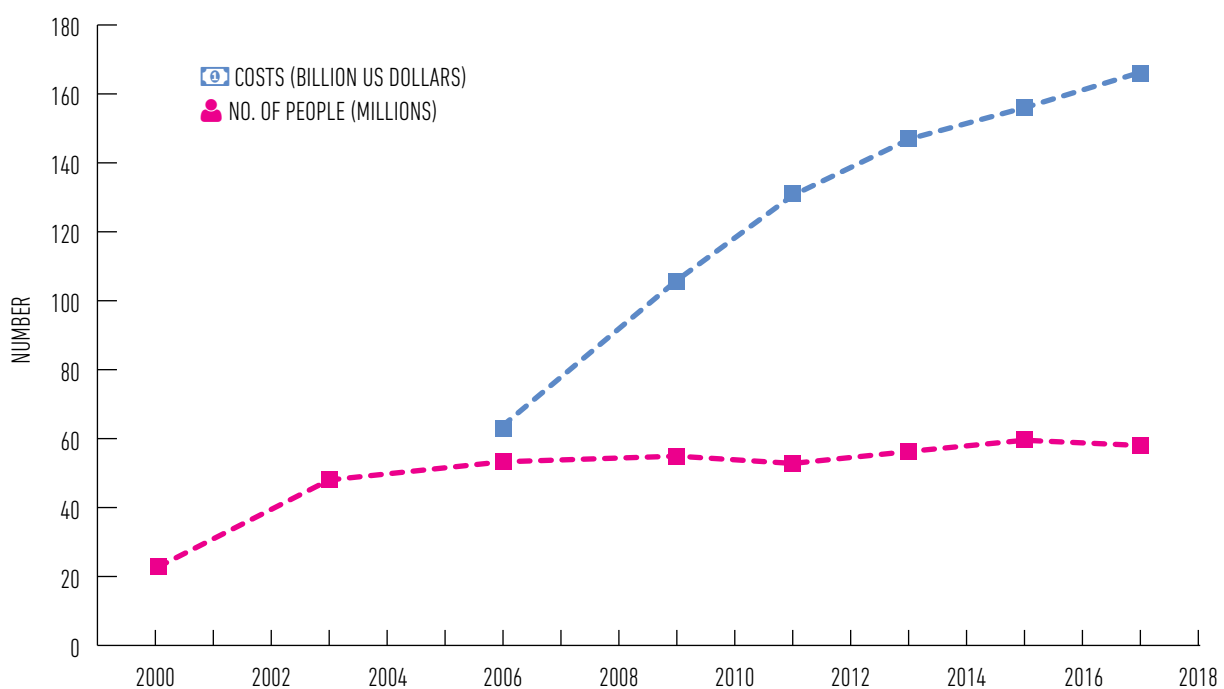
1.1. Background and existing evidence

Diabetes presents a significant health and economic burden across Europe, affecting an estimated 58 million people and costing 145 billion euros per annum. (Figure 1)^{4,6,10,14,19,28,39,52} Its prevalence is expected to rise even further in the future as a result of rising obesity and increased unhealthy lifestyles, such as poor diet, physical inactivity and sedentary behaviour. There is an urgent need to identify ways in which implementation of evidence can be improved to help to prevent or delay the onset of diabetes and to improve outcomes for those who already have diabetes.

This report, “Integrating diabetes evidence into practice: challenges and opportunities to bridge the gaps”, identifies the local and European-wide challenges of implementing diabetes evidence into practice and makes recommendations based on the findings.

The findings of this report are presented from three distinct perspectives: the healthcare system; healthcare professional; and person living with diabetes. The report draws on data from three sources: the published literature; a survey of IDF Europe member organisations; and social media analytics. In analysing all these sources we received technical support from IBM. We have focused on current practice, challenges for implementing evidence into practice, and ways in which implementation may be facilitated.

Figure 1: Burden of diabetes in Europe (estimates from IDF Diabetes Atlas 2000-2017)



1.2. Aims and objectives

The aim of this report is to:

- determine current practice in relation to diabetes prevention, treatment and management across Europe;
- identify barriers to implementing diabetes evidence into practice across Europe;
- identify ways in which implementation of diabetes evidence into practice can be improved.

2

Study Design and Methods

The report draws on data from: the published literature; a survey of International Diabetes Federation Europe (IDF Europe) member organisations across 38 countries; and social media.

2.1. Evidence from the literature

Evidence from the literature was summarised by conducting a focused narrative review of published review articles (i.e. 'review of reviews') to identify and map scientific evidence on non-adherence patterns in the implementation of diabetes-related evidence into practice. National policy initiatives, diabetes and non-communicable disease strategies, and guidelines for managing diabetes in European countries were also targeted to identify barriers and also opportunities to increase effectiveness of the investment made by national governments.

We focused on:

- diabetes management and healthcare systems in Europe;
- barriers/solutions to adherence to diabetes guidelines for healthcare professionals;
- barriers/solutions to adherence to recommended treatments (medication, diet, lifestyle) for people with diabetes.

The review was reported in accordance with the Preferred Reporting Items for Systematic review and Meta-Analysis Protocol (PRISMA-P).¹⁵

2.1.1. Sources of information

We searched electronic bibliographic databases MEDLINE (Ovid interface), EMBASE (Ovid interface), Web of Science and the Cochrane Library for relevant publications.

For the grey literature, we manually searched documents published by United Nations (UN), IDF, WHO, Organization for Security and Co-operation in Europe (OSCE), European Association for the Study of Diabetes (EASD), National Health Service (NHS) and National Institute for Health and Care Excellence (NICE).

We also searched other diabetes-related European organisations, projects or consortia (the Alliance for European Diabetes Research [EURADIA], Foundation of European Nurses in Diabetes (FEND), Primary Care Diabetes Europe (PCDE), CHRODIS, European Policy Action Network on Diabetes [ExPAND] and the Health Consumer Powerhouse).

2.1.2. Search strategy

Electronic bibliographic databases were searched using medical subject headings (MeSH) and free-text words relating to the themes of this review (**Box 1** and **Box 2**). Truncation and Boolean operators were incorporated into the search strategy to allow for differences in terms and spellings.

Box 1: Search terms used for literature search of barriers/solutions to adherence to diabetes guidelines for healthcare professionals

```
((diabetes AND (guideline OR best practice) AND (implementation OR adherence OR compliance OR knowledge translation) AND (barrier OR solution OR intervention))))
```

Box 2: Search terms used for literature search of barriers/solutions to adherence to recommended treatments for people with diabetes

```
(diabetes AND patients AND (treatment OR lifestyle OR diet OR physical activity) AND (adherence OR compliance OR barriers OR solution OR intervention))
```

For the grey literature, we searched for information on the current situation with regard to diabetes in the WHO European countries. We also looked for recommended diabetes management tools for healthcare systems, and their development, implementation, monitoring and evaluation. We further searched for identified barriers and potential solutions to improve services for people with diabetes and help to contain the diabetes epidemic.

2.1.3. Eligibility criteria

Inclusion criteria

- Published studies, reviews and systematic reviews (including grey literature).
- Studies focusing on:
 - diabetes management and healthcare systems in Europe (grey literature);
 - barriers/solutions to adherence to diabetes guidelines for healthcare professionals (see **Box 1**);
 - barriers/solutions to adherence to recommended treatments (medication, diet, lifestyle) for people with diabetes (see **Box 2**)
- Studies published from 2000 onwards owing to changes in the guidelines in response to the Diabetes Control and Complications Trial (DCCT) and United Kingdom Prospective Diabetes Study (UKPDS), and development of new treatment regimes.
- Population-based and clinical-based studies, including paediatric and transition care and populations with type 1 or type 2 diabetes;
- Studies published in the English language.

Exclusion criteria

- Studies where the majority of participants had gestational diabetes;
- Studies where conclusions and recommendations drawn from the study were not relevant to this report (e.g. protocols, measurement systems, comparisons between different research tools);
- Studies on pre-diabetes or primary prevention interventions;
- Studies limited to economic analyses;
- Conference proceedings, non-peer-reviewed papers, opinion pieces, commentaries and case reports.

2.1.4. Data management, screening and selection

All search results were uploaded to the reference management software, Mendeley, where they were screened.

Initial screening comprised manual searches through the title, abstract and subject headings of the citations in accordance with the eligibility criteria. Next, full-text

articles were retrieved and manually screened by two reviewers. Discrepancies between the reviewers were resolved by discussing the papers, with members of the Editorial Committee adjudicating any unresolved disagreements.

2.1.5. Data extraction

The following data were extracted for this evidence review.

- publication details:
 - author(s) names;
 - year of publication;
 - country of study;
 - date of publication;
 - place of publication.
- study design:
 - systematic review;
 - review of reviews;
 - international studies.
- summary of conclusions.
- recommendations.

2.1.6. Data analysis and synthesis

Data analysis and synthesis was done manually and with the support offered by the Watson Explorer software (provided by IBM). Data were synthesised into four themes:

- a description of the current situation in Europe with regard to diabetes-related guidelines;
- identified barriers and potential solutions for adherence to existing guidelines by healthcare professionals;
- identified barriers and potential solutions for adherence to recommended treatments by persons living with diabetes;
- recommendations from international studies drawn from international publications (grey literature) to address issues related to public policies of management of healthcare systems.

2.2. Survey of IDF Europe member organisations

A survey of IDF Europe member organisations was conducted between June and August 2017. Member organisations comprise healthcare professionals (doctors, nurses and educators), people with diabetes and their relatives, and mixed constituencies (both healthcare professionals and people with diabetes). All 70 IDF Europe member organizations were invited to fill in the online or offline questionnaires, according to their constituency.

2.2.1. Questionnaires

Two separate questionnaires were developed for health care professionals and people with diabetes to capture their different motivations and perspectives. See Appendix 1 and 2 for a copy of the questionnaires for healthcare professionals and persons with diabetes respectively.

2.2.2. Response rate

We received 56 responses from the IDF Europe member organisations, representing 38 countries (81% of the countries represented in IDF Europe). Where member organisations were from mixed constituencies, we have incorporated both healthcare professional and individual perspectives.

2.2.3. Process of identifying barriers and solutions in IDF Europe survey

The analysis of the responses to the questionnaires was done manually and with the technical support provided by IBM. A Delphi process was followed for identifying barriers to implementing diabetes evidence into practice. This involved summarising the top 10 most common barriers identified by IDF Europe member organisations in relation to three themes: healthcare system; healthcare professional; and person living with diabetes. For the first round of the Delphi process, respondents were provided with the top 10 barriers and asked to rate them in order of relevance. The top six were then selected for the second round of the Delphi process whereby four barriers were identified and summarised.

2.3. Social media analytics

Over the last few years, strong diabetes communities have emerged on various online platforms. As a result, social media has become an important source of information on diabetes-related issues. People with diabetes are sharing their lived experiences of their condition, raising awareness and problems, seeking advice, and supporting others. These data are important because they enable comparisons between individual views of people living with diabetes in the community and feedback provided by national institutions or IDF Europe member organisations.

As well as focusing on the main aims of this report, the objectives of this programme of work were:

- to determine whether data and information circulated in social media overlapped with information collected from IDF Europe member organisations;
- to determine when and where diabetes-related topics were discussed;
- to identify the main diabetes-related barriers and issues for people living with diabetes;

- to determine the utility of using social media information to support and improve IDF Europe activities; and
- to determine whether there were any differences in discussions around different non-communicable diseases on social media platforms.

2.3.1. Software

IBM Watson Analytics for Social Media was used for the analysis of diabetes-themed social media data. This software allows the user to search for topics and themes of interest on social media. Searches can be tailored to various parameters (timeline, language, sources) and relationships and patterns in the data are identified. Preconfigured visualisations are used to display the nuance of social media conversations, with dashboards to highlight themes, topics, sources, geography, active and influential authors. The software also provides information on the sentiment of comments or expressions used (positive, negative, neutral or ambivalent). For example, the comment "I love my insulin pump but I hate infusion sets" would be identified as both positive and negative.

2.3.2. Search restrictions

All comments posted in the English language were considered, including from geographical locations outside Europe. We limited the timeframe for the posts to the period April 2017 to July 2017 to identify the most current topics of discussion. We also restricted to posts related to the persons living with diabetes. We compared the incidence of diabetes-related posts with posts relating to other selected non-communicable diseases, based on their burden.

2.3.3. Data sources

Social media platforms explored were: Twitter; Facebook; blogs (e.g. Blogger, WordPress, blogs on websites); videos (e.g. YouTube, Dailymotion); forums; reviews; and news.

2.3.4. Selection of topic and themes

Tables 1, 2 and 3 show the three models used for the analysis. The first model involved IDF Europe and the IBM team identifying diabetes-related topics and themes (**Table 1**). The second model involved identifying themes for the main diabetes-related barriers and issues for people with diabetes (**Table 2**). The final model involved identifying topics and themes for diabetes and other selected non-communicable diseases (based on their prevalence and burden) on social media to determine whether there were any differences in the incidence of posts and how users discussed these diseases on social media (**Table 3**). For each of the models, the most significant and relevant keywords were identified (around 2 000 were used). The software identified the most frequently discussed diabetes-related topics.

Table 1: First model: diabetes-related topics and themes

Topics	Themes
Type 1 diabetes Type 2 diabetes	Advocacy Awareness Barrier Blood sugar Complications Diabetes Food Guidelines Holiday Interventions Medical devices Medication Risk factors Support Transport

Table 2: Second model: barriers related to diabetes

Topics	Themes
Diabetes	Access to care Accessibility Diabetes cost Discrimination Education Support

Table 3: Third model: comparison with other common non-communicable diseases

Topics	Themes
Breast cancer Chronic obstructive pulmonary disease Dementia Diabetes Ischaemic heart disease Stroke	Accessibility Cost Education Lifestyle Prevention Risk of death Support Treatment

3 Results

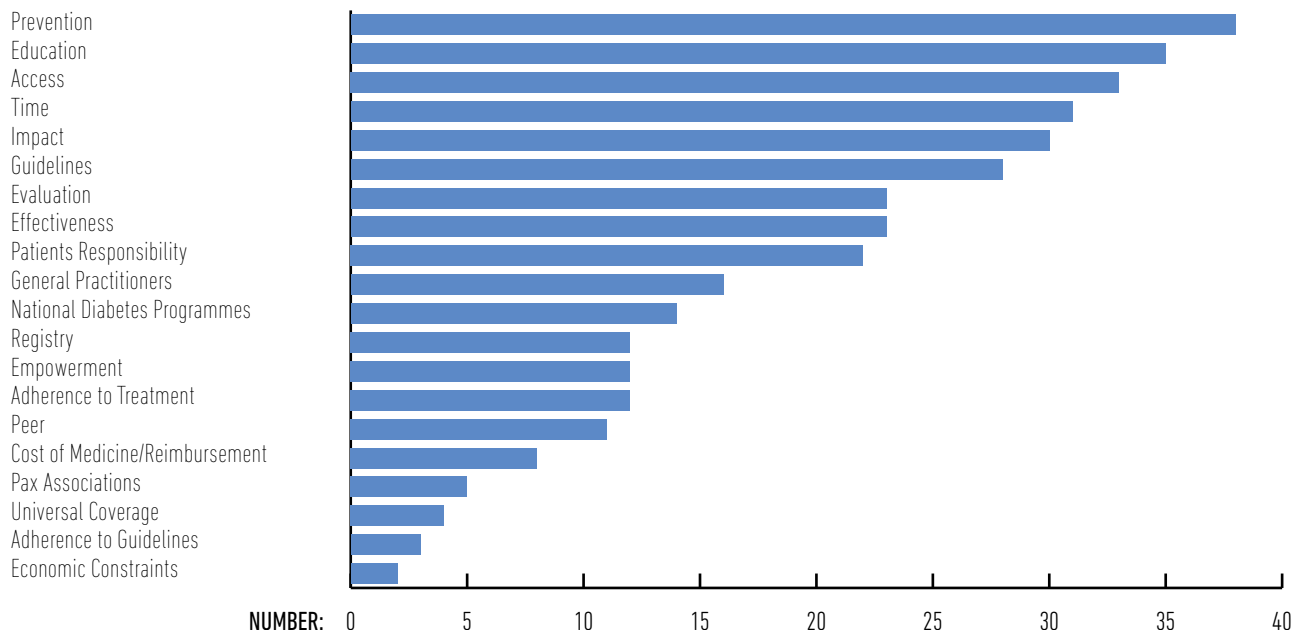
3.1. Evidence review

3.1.1. Diabetes management and healthcare systems

The manual searches revealed 52 publications that addressed diabetes-related topics. The 20 topics of highest frequency are shown in **Figure 2**.

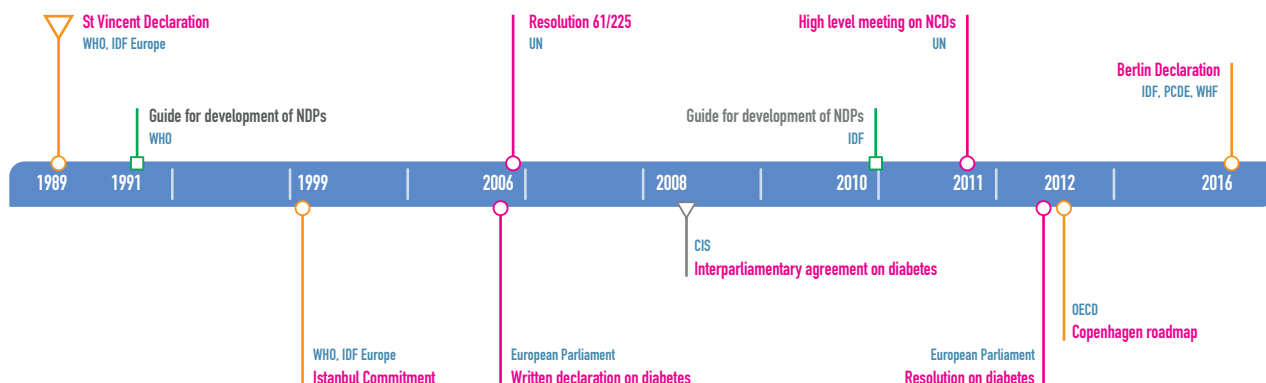
Subsequent to the St Vincent Declaration,¹ it has been recommended that countries adopt plans for the prevention, identification and treatment of diabetes. It is also stated that general goals and targets can be achieved by actively working with people with diabetes, their friends, families, work colleagues and relevant organisations. Both the WHO (1991)² and IDF (2010)¹⁶ have provided guidance for establishing, implementing, monitoring and evaluating national diabetes programmes (NDPs) and strategies so that national and international consistency can be achieved.

Figure 2: The 20 diabetes-related topics of highest frequency in the manual search of grey literature



Similar tools are recognised and recommended by the European Parliament (Written Declaration in 2006⁸: national diabetes plans) and the UN (resolution 61/225: national policies for prevention, treatment and care of diabetes⁹). In 2012, the Resolution of the European Union (EU) Parliament²² called on the member states to develop diabetes management programmes, based on best practice and evidence-based treatment guidelines, to support patients in obtaining and sustaining the skills needed to enable competent life-long self-management (**Figure 3**).

Figure 3: Diabetes policy initiatives and guidance in Europe

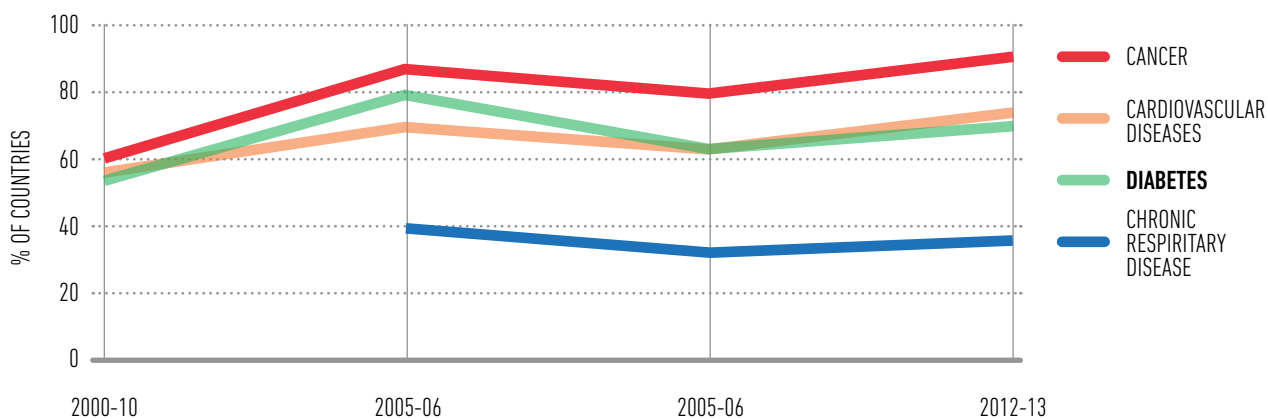


The current situation

The current situation with regard to the presence and use of recommended diabetes management strategies, such as national diabetes programmes and national diabetes registries, is presented in three dedicated publications^{18,32,44} that studied countries in the WHO European Region or European Union.

In 2014, a total of 29 out of 47 countries in the WHO European region implemented a national policy, strategy or action plan that either addressed diabetes specifically or as part of a wider strategy for non-communicable diseases. A further 10 countries did not have such a plan but announced one in the near future.³²

Figure 4: Reported³¹ percentage of countries in the WHO European region having a specific national policy, strategy or action plan for preventing and controlling major diseases



A separate study in the European Union found that seven of the 22 countries that responded to the survey had no formal national diabetes programme. Two countries had concluded a previous national diabetes programme and not (yet) developed a follow-up programme and, in one country, the national diabetes programme had been succeeded by a new national strategy and the implementation of 'Diabetes Care Standards'. In two other countries, diabetes was included as part of an overall strategy targeting non-communicable diseases more broadly. Three countries reported not having a specific national diabetes programme but pointed to national diabetes disease management programmes (DMPs) to address diabetes via several disease-specific and non-specific measures.⁴⁴

Figure 5: Reported³¹ percentage of countries in the European Region with specific national policies, plans or strategies for preventing or controlling major diseases and risk factors and their stage of implementation 2012-2013

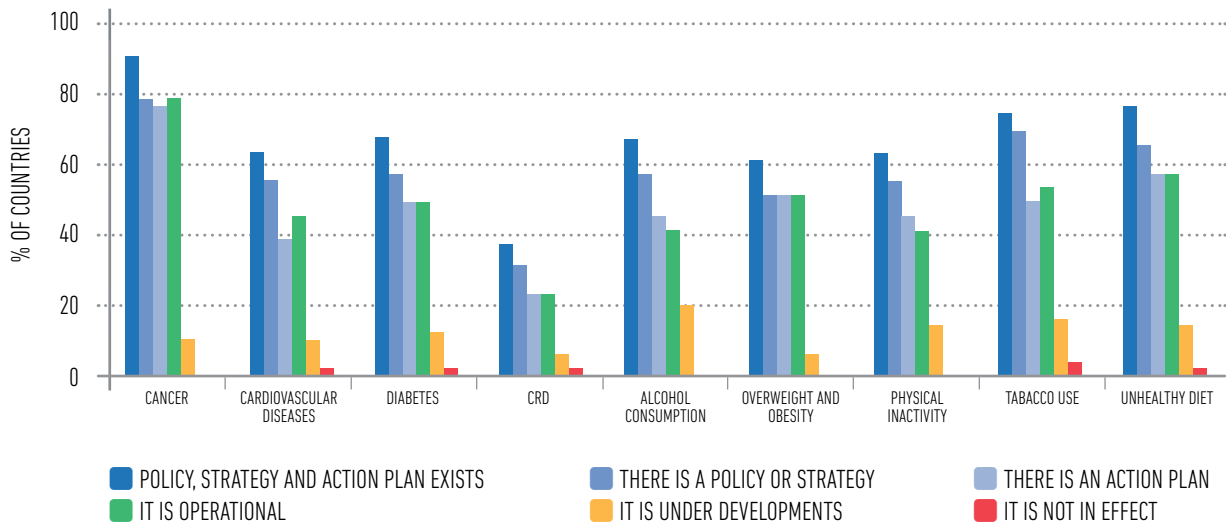
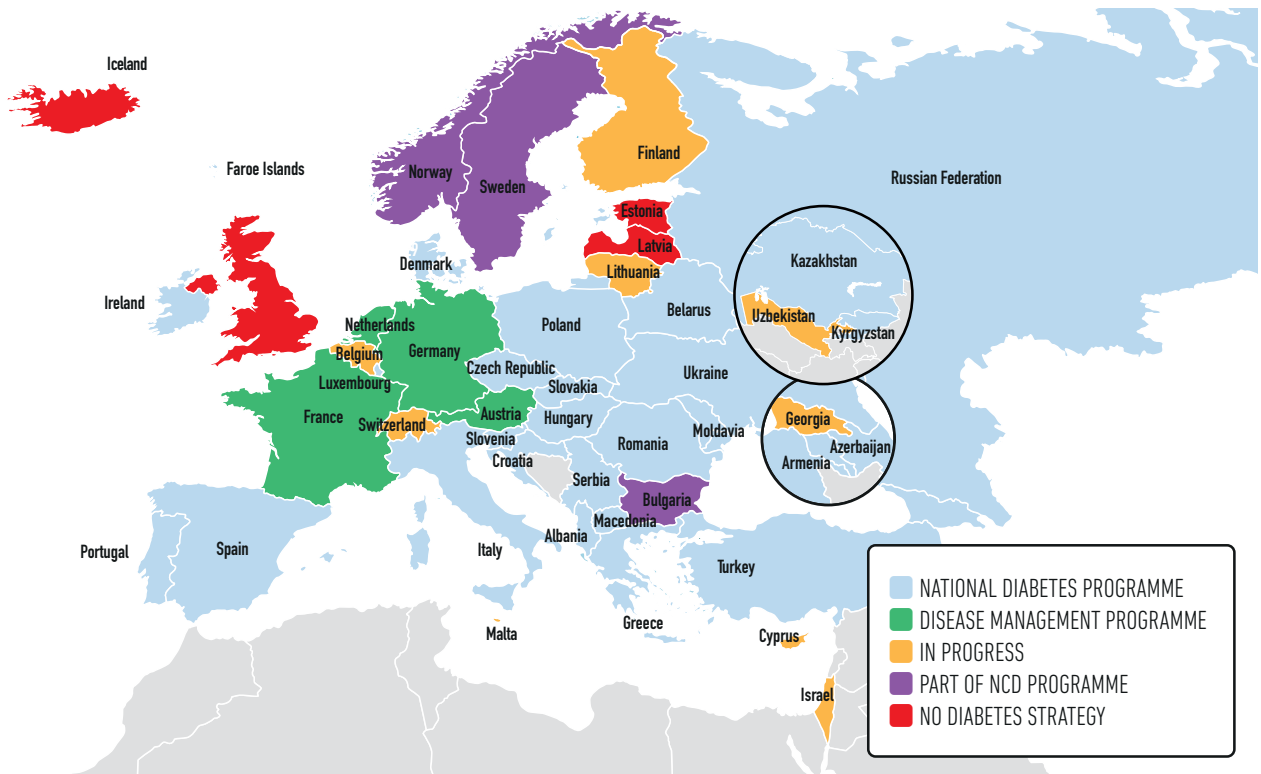


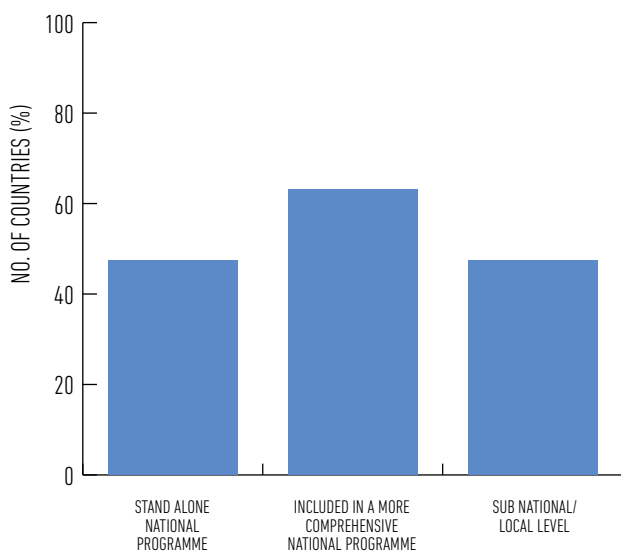
Figure 6 shows the WHO European region and the status of national diabetes programmes/strategies within individual countries. The majority of countries had a diabetes or non-communicable disease strategy in place and many of the countries also had prevention policies in relation to lifestyle risk factors for diabetes (obesity/overweight, healthy eating, physical activity, smoking and harmful use of alcohol).

Figure 6: National diabetes programmes/strategies in WHO European region



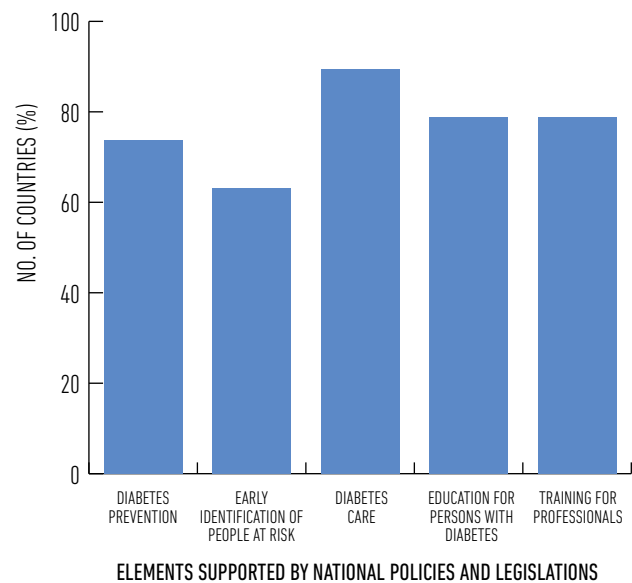
The structure of the national diabetes programmes or strategies varied widely across European Union countries (Figure 7). Most of the plans covered type 1 and type 2 diabetes and, in some cases, gestational diabetes. Only 11 of the European countries reported that their diabetes strategies accounted for individual differences, preferences and cultural diversity.⁴⁴ Not all of the programmes included references to prevention activities (primary, secondary or tertiary) or therapeutic education. There was a lack of coherence between programmes, thereby disadvantaging some groups at risk. For example, diabetes screening programmes targeted at those at risk of cardiovascular disease may miss young women with gestational diabetes and overweight young people, which is particularly concerning given the increasing prevalence rates of type 2 diabetes in children and adolescents.¹⁸

Figure 7: Support for different elements of national policies and legislations across the European Union⁴⁴



In the EU countries that participated, the identification of high-risk individuals and prevention of the onset of diabetes in these individuals was a common feature of the national diabetes programmes, although about one-third of countries with national diabetes programmes did not include early detection of diabetes in high risk populations.⁴⁴ Almost universally, the European countries employed mechanisms for diabetes prevention: primary prevention policies and campaigns targeting obesity and overweight, promoting healthy eating, physical activity, smoking cessation or tackling harmful use of alcohol were reported in more than 95% of European countries.³² Prevention remains poorly funded as only nine countries reported having a budget for prevention policies and campaigns.

Figure 8: Reported⁴⁰ percentage of countries in the WHO European region having diabetes policies with specific prevention targets



Education for people with diabetes and their families is recognised as a major component of controlling the condition. Educational programmes were developed in Europe as early as the late 1970s. Despite this, relatively few countries had included structured education in their national diabetes programmes: 15 out of 19 participating countries in the European Union reported having education programmes for people with diabetes (Figure 8). A few countries (16%) reported that they had a stand-alone education programme, while 37% reported to have education programmes as part of their national diabetes programmes.⁴⁰

In the European countries, only five included monitoring and surveillance of their national diabetes programmes.⁴⁴ Among the IDF Europe countries, gathering reliable information on monitoring and implementation of national plans for diabetes in Europe was generally problematic. Among the 31 national health authorities that were asked about monitoring and evaluation components covered in their plans, only 22 were able to provide any information. Similarly, only one country reported that its national plan included all the key elements of a strong evaluation system.³²

Another recommended management tool is the diabetes register. In line with the objectives of the WHO Non-Communicable Disease Action Plan 2013–2020,²⁹ diabetes registries may help to strengthen national capacity to collect, analyse and use representative data on the burden and trends of diabetes and its key risk factors.⁴⁵

All countries in the WHO European region have civil or vital statistics registration systems and all national health information systems routinely collect mortality data. Almost all of the countries are able to separate the data by age (100%) and gender (98%) and a further 74% can separate the data into civil registries by sociodemographic characteristics.²¹ However, these general registration systems are unable to consistently provide information on monitoring and managing diabetes as there is limited data available nationally and diabetes registries are not established in all countries.³⁸

Although the rise in diabetes burden throughout Europe is undisputed, the lack of comparable data makes it difficult to quantify this rise at both national and European levels. National diabetes registers play a key role in monitoring the status of the epidemic, as well as ensuring good-quality care. Although there has been an absolute increase in the number of countries with some kind of diabetes register – from 23 in 2011 to 30 in 2014 (out of 47 countries) – more than 83% were considered by stakeholders to be incomplete. Similarly, the availability of data for specific populations was generally low, e.g. only seven countries reported collecting data on pregnant women within their registries.³²

The need to recognise organisations for people with diabetes as legitimate partners in developing public policies is also recommended in a number of international publications: empowerment of citizens and communities is an essential part of the WHO NCD Action Plan 2013–2020.²⁹ Although many countries reported that they had established partnerships with non-governmental, community-based and civil society organisations, there had been no increase since 2010.³¹ A people-centred approach that seeks to improve the entire diabetes pathway requires a coordinated system involving primary, secondary, tertiary and social care sectors, with the individual at the centre. This will need patient empowerment through activities driven by civil society and patient organisations.²¹ National diabetes associations and service user organisations from at least five of the European Union countries were seen to have played an important role in the development and approval of national diabetes prevention programmes.⁴⁴

There was very little information with regard to patient recognition and empowerment across the European countries or participation in the process of policy development. The term empowerment was included in many of the principal documents^{23, 24, 32, 35} but none of the European studies offered further information on what this meant for people with diabetes (or other non-communicable diseases).

Barriers for diabetes management and healthcare systems

Among the key barriers identified was the need for countries to move towards a more comprehensive, multi-sectoral approach to diabetes, and for putting in place effective mechanisms for the implementation, monitoring and evaluation of national diabetes plans. In some countries, building technological capacity was indicated so that management tools such as diabetes registers could be developed effectively.⁴⁴

Another key challenge identified was that there is a lack of consensus between European countries (in both the European Union and WHO European regions) with regard to definitions, data collection methods and data reporting, which makes it difficult to determine country-specific diabetes burden.⁴⁴ Similarly, the type and scope of data collected in diabetes registries and the potential for data linkage varies between countries which makes it difficult to investigate overall quality of care.²⁰ Additionally, although empowerment is recognised as being a major contributor to improving health outcomes, there are no agreed indicators for measuring this among people living with diabetes.

Potential solutions for diabetes management and healthcare systems

The reviewed literature suggested a number of solutions to increase the effectiveness of diabetes-related public policies and to improve the management of health systems in controlling the diabetes epidemic:

- multiple stakeholder involvement;^{35,40,42,44,45}
- participation of representatives of people with diabetes and those who care for them;^{20,25,35,40,41,44,45}
- use of dedicated resources;⁴⁴
- improved management of the available resources;^{25,35,41,44}
- use of appropriate data collection systems;^{21,37,44}
- incorporating education and training for people with diabetes and their families in the diabetes guidelines and protocols;^{25,35,40,42}
- use of appropriate incentive systems to promote performance;^{21,35}
- support for dedicated research programmes and promotion of new technologies (including information technology);³⁵
- inclusion of prevention activities in diabetes strategies and support for their implementation.^{35,40,42,45}

Disease registries were also highlighted as being important facilitators for managing national diabetes programmes by enabling systematic monitoring and evaluation to inform future policy developments and driving change.⁴⁴ Registers have also allowed the use of predictive tools and indicators to monitor disease complications and the health of people with diabetes.³⁷

A framework for action to assist countries in formulating their response to non-communicable diseases exists that builds on already established strategies and actions while encouraging them to assess and refine existing approaches. It is guided by **five key messages**: the importance of prevention throughout life; the value of health-supporting environments; the need for health services to be fit-for-purpose; the empowerment of people as active partners in promoting health and managing disease; and the crucial role of government in building inter-sectoral policy and facilitating access.¹³

3.1.2. Adherence to existing guidelines by healthcare professionals

A total of 253 articles were identified in the search of the literature. After screening the titles, 169 articles were selected and downloaded for further screening. A total of 156 articles were considered relevant for this review: 35 reported on the current situation with regard to adherence to diabetes-related guidelines by healthcare professionals; 43 identified barriers; and 51 suggested potential solutions (i.e. interventions or recommendations).

In the European Union, 10 of 28 countries are considered to have well-established guidelines and six are identified as making progress in this regard. Randomised controlled trials comparing the use of guidelines against usual care have shown a significant improvement in patients' health status, but not in glycaemic control in relation to type 2 diabetes.²⁵

The current situation

Studies around the world have demonstrated that adherence to existing diabetes-related guidelines differs significantly by country, region and type of healthcare service provided (i.e. general practice or specialised care) (Table 4). The level of adherence to national diabetes guidelines is suboptimal at best in many of the European countries.

Table 4: Adherence to diabetes guidelines by country/region and type of healthcare service

Country/region	Type of healthcare service	Level of adherence	Topic	References
United States	General practice, specialist care	6%	Primary prevention	236
Austria	Specialist care	70%		124, 139, 142, 151, 192, 203, 253
China		52%		
Puerto Rico		Not achieved		
United Kingdom		Low		
United States		Not followed		
Canada	General practice, specialist care	Good	Guidelines adherence, reaching targets and tertiary prevention	55, 56, 57, 60, 69, 75, 98, 101, 105, 126, 131, 161, 183, 186, 188, 192, 194, 207, 216, 228, 232
Europe		53.6%		
France		Not consistently followed		
The Netherlands		Not optimal		
Italy		Good level of reception		
Japan		Less than required		
Korea		Unsatisfactory		
Luxembourg		0.6%, 45%		
Puerto Rico		2.2%, 7%		
Saudi Arabia		Suboptimal		
Spain		An important gap, degree of compliance is mostly low		
Sweden		Deficient		
Turkey		Suboptimal		
United Kingdom		49%		
United States		33%, <50%, 48%		
Austria	General practice, specialist care	Increased	Guidelines implementation	58, 60, 110, 115, 179, 254
Bosnia & Herzegovina		72% – 82%		
Hong Kong		Relatively good		
Kuwait		17%		
Norway		A high degree		
United States		Relatively high		
Canada	Specialist care	Not receiving quality care	Youths and young adults with type 2 diabetes	63
United Kingdom	General practice	42%	Patients informed according to guidelines	124

General adherence to guidelines

Overall, adherence to guidelines was variable. In the United States, data from a large cohort of patients with acute coronary syndrome demonstrated gaps in adherence to guideline-directed therapy (USA).²¹⁷ Gaps were also observed in diabetes-related knowledge and decision making among practising physicians⁸⁹ and between clinical guidelines and glycaemic control in inpatients with diabetes (Spain).¹⁰¹ Similarly, other studies found that physicians' adherence to guidelines was suboptimal (Saudi Arabia, the Netherlands, Turkey),^{55,56,187,215} particularly in nursing homes (Sweden).¹⁸²

In China, 83% of surveyed physicians were at least 'aware' of the existence of diabetes guidelines in relation to standards of care for type 2 diabetes; level of awareness was related to hospital grade, speciality, geographical location, professional rank and participating in training programmes.¹⁴² In Norway and Italy, guidelines were generally received and followed well.^{178,193} and in Hong Kong, adoption of guidelines was relatively high among primary care physicians.²⁵² In Canada, adherence to guidelines for type 2 diabetes management was generally good and could be improved with more training.⁵⁷ Similar findings were found in relation to chronic care in Austria.¹¹⁰

Adherence to prevention strategies

Studies on prevention found that only 6% of primary care physicians were able to identify 11 prediabetes risk factors that would prompt them to screen patients under the American Diabetes Association (ADA) guidelines (USA).²³⁴ The degree of compliance with the process indicators for screening chronic complications of type 2 diabetes was mostly low (Spain).⁷⁵

Adherence to investigations

Only 49% of requests for glycated haemoglobin (HbA1c) conformed to guidance; 21% were too early and 30% were too late. Under-requesting was more common in primary care, in female patients, younger patients, and in patients with generally poorer control (UK).⁹⁸ For Medicaid-only beneficiaries with diabetes, 78% lacked glycosylated haemoglobin tests, 62% lacked low-density lipoprotein cholesterol tests, and 50% lacked eye exams. Quality of care was suboptimal, with non-adherence varying by condition (USA).¹⁸⁴

Adherence to recommended investigations was generally unsatisfactory, particularly with regard to eye examinations, testing low density lipoprotein (LDL) cholesterol, and setting target goals. Guideline adherence was positively related to better prognosis (Korea).¹⁸⁵ Poor adherence to guidelines was observed in the UK (<2 diabetes-related physician visits and HbA1c tests/year)⁶² and Luxembourg where a large

percentage of patients were not provided with a systematic annual follow-up between 2000 and 2006.²⁰⁶ A study conducted in the United States based on real-world data from a large type 2 diabetes patient population found that adherence to ADA guidelines for HbA1c testing frequency and drug treatment modifications was extremely low.¹⁶¹ Despite HbA1c being defined as the gold standard for glucose control, it was not universally measured, with more physicians indicating routine use of glucose before fasting and glucose non-fasting (China).¹⁴²

Adherence to diabetes retinopathy screening guidelines was also low; it was estimated that more than half of patients failed to receive necessary screening (USA).¹⁰⁵ Screening for retinopathy and nephropathy was less frequent than required, despite favourable conditions for access to healthcare in Japan.²³¹ In France, general practitioners did not consistently follow guidelines for type 2 diabetes, but the intervention of family medicine teams helped to improve HbA1c levels.⁹⁴ Quality variations of care extended to people with diabetes have been noted in individual family medicine teams (Bosnia & Herzegovina).¹¹⁵

Adherence to therapy

Just over half (52%) of physicians indicated the use of oral anti-diabetic (OAD) drugs as monotherapy, in line with recommended guidance. However, OAD use varied considerably between different regions and city tiers (China).¹⁴² People at high risk of diabetes were not informed of their risk status, as recommended by NICE guidelines (UK).¹²⁴ Adherence to NICE guidance for initiating and continuing GLP-1 receptor agonists was similarly low (UK).¹³⁹ Seventy per cent of new initiators of oral hypoglycaemic treatment in Austria received metformin as recommended by international guidelines.²⁵¹ Overall adherence to prescribing diabetes guidelines was 77.7%. Significantly higher prescribing adherence was found in the secondary care facilities (82.4% compared with primary care 72.5%). Nineteen criteria out of 43 achieved an adherence >80% in secondary care compared with ten criteria in primary care (Kuwait).⁵⁸

Achievement of recommended targets

Target achievements for intermediate outcome measures were generally low, with only 53.6% having HbA1c levels of 7% (Europe).²²⁷ A substantial proportion of adults with diabetes did not achieve ADA recommendations on selected preventive practices and treatment goals (Puerto Rico).¹⁹¹ Overall adherence to the 2013 blood cholesterol guidelines was 33%; this measure can be used as a baseline assessment of current adherence with the guidelines (USA).¹³¹ The proportion of patients reaching stricter treatment targets is consistent with the results of earlier Norwegian surveys (Norway).¹⁷⁸ Non-optimal achievement of target goals for HbA1c, blood pressure and body mass index was prevalent (Kuwait).⁵⁸

Barriers to adherence to guidelines

Several studies indicated that the implementation of developed and supported national diabetes guidelines had positive outcomes.^{20,40,51,107,139,161} The most frequently mentioned barriers were: inadequate contextual support for implementation; therapeutic inertia; poor communication and dissemination strategies; inappropriate formulation of the guidelines (e.g. without proper reference to the evidence base); and unworkable recommended approaches (**Table 5**). The studies also indicated that knowledge/awareness of diabetes guidelines needed to be accompanied by adequate support (professional, resources, organisational/structural). Even where guidelines were implemented, non-clinical support was needed to help reach the intended outcomes.

Table 5. Barriers to diabetes guideline adherence

Barriers to diabetes guideline adherence	References
Inappropriate formulation of diabetes guidelines, discrepancies	98, 137, 182, 206, 213
Use of inappropriate references or approaches	84, 130, 164
Poor communication and dissemination strategies	110, 117, 130, 140, 168, 193
Uneven implementation (geographical or institutional)	150, 193
Inadequate contextual support for implementation (limited resources)	68, 70, 111, 130, 150, 157, 159, 190, 212, 225, 226, 251
Lack of education of healthcare professionals	62, 227
Therapeutic inertia	69, 70, 78, 188, 193, 203, 222, 227, 235, 238
Treatment or implementation costs	134, 209, 230
Lack of education of persons with diabetes	67, 110, 209

Guideline-specific factors, such as rigor of development, clarity and presentation, were found to affect providers' trust in and adherence to guidelines (USA).¹⁸¹ Similarly, implementation of guidelines was noted to be influenced by their validity, reliability, applicability and effectiveness of dissemination, as well as factors specific to healthcare systems, such as trained human and financial resources, infrastructure, policy and organisational set up (USA).¹⁸⁸

In Indonesia, it was observed that type 2 guidelines did not necessarily lead to adoption of adherence to recommendations that were important for outcomes and quality of care.²⁴⁹ Clinical practice guidelines were perceived to be more useful if they contained more detail on care protocols, specific skills and competencies, especially for people expected to be less able to effectively self-care (worldwide).¹⁵⁹ It remains challenging to derive robust new quality indicators from clinical guidelines in the absence of established systems for routine structured recording in clinical care (UK).²¹²

In people with multimorbidity, current guideline recommendations rapidly cumulate to drive polypharmacy, without providing guidance on how best to prioritise recommendations for individuals in whom treatment burden will sometimes be overwhelming (UK).¹³⁷ In France, a paradigm shift was recommended to manage complex patients with multimorbidity.⁸⁴ Other barriers included treatment costs (USA),²⁰⁸ limited resources and organisational factors, including the availability of information technology and protocols to better structure diabetes care, lack of personal continuity of care and limited continuing education opportunities for healthcare professionals (worldwide).⁹²

For healthcare providers, the main barriers to implementing diabetes guidelines were concerns about patients' ability to follow more complicated regimens and physicians' own inexperience with insulin and progression algorithms (worldwide)¹⁹⁵ or lack of knowledge (Austria).¹¹⁰ Clinics with the highest relational climate (i.e. shared vision and relationships) were 25 per cent more likely to provide guideline-compliant care than those with the lowest relational climate. Among insulin-dependent veterans with diabetes, this effect was twice as large (USA).²²⁴

Therapeutic inertia was another factor identified as potentially further increasing the gap between general practice and specialised care (the Netherlands).¹⁸⁷ Therapeutic inertia and poor knowledge by many physicians played an important role in delaying diabetes control (Brazil)¹⁹² and failure to achieve targets in type 2 diabetes (Spain).²³³ Therapeutic inertia is often the consequence of a discrepancy between the technical rationality of evidence-based medicine and the modes of reasoning of physicians practised in 'real-life', which is marked by uncertainty and risk (France).²⁰⁵ Four relevant reasons for not following American Association of Clinical Endocrinologists guidelines were physician-related: (i) "metformin monotherapy is sufficient to improve glycaemic control"; (ii) "monotherapy is easier to handle than dual therapy"; (iii) "I believe that monotherapy and changes in lifestyle are enough for hyperglycaemia control"; and (iv) "I recommend monotherapy before considering dual therapy" (USA).²⁰²

Physicians appear to have concerns about initiating treatment when diabetes is first diagnosed, particularly with newer diagnostic guidelines. This can be either positive, because they understand the importance of emphasising lifestyle modification, or negative, because of scepticism about the value of such treatment at relatively modest levels of hyperglycaemia, despite evidence from epidemiologic studies and randomised controlled trials that such treatment is appropriate (USA).⁷⁸ General practitioners were more inclined to control blood glucose levels than blood pressure or cholesterol levels. Inertia in response to poorly controlled high blood pressure was less common if nurses assisted general practitioners (the Netherlands).²³⁶ Therapeutic inertia may be caused by an overestimation of the care provided, perception by the clinician that glycaemic control is improving or that the patient is not compliant with diet and exercise, lack of proper clinical training or the absence of focus on achieving patients' therapeutic goals (USA).²²⁶ Evidence suggests that the clinical and organisational context may be particularly important in reinforcing therapeutic inertia, notably the increasingly severe time constraints for diagnosis and management of multiple morbidities, consideration of complex guidelines and assessment of cost and appreciation of patient concerns, all of which may hamper prioritisation of the important issue of under-treatment (Canada).²⁰⁰

Patient-related barriers restricting healthcare professionals' adherence to guidelines included lack of awareness (Austria),¹¹⁰ treatment costs and reluctance to use insulin (USA).²⁰⁸ These barriers were influenced by treatment side effects, complex treatment regimens, needle anxiety, poor patient education, and the absence of an adequate patient care plan (USA).²⁰⁹

Solutions for adherence to guidelines

The main solutions identified for increasing adherence to national diabetes guidelines (**Table 6**) were:

- formulation of tailored guidelines that take account of local circumstances (structure, organisation and resources);
- coordination with non-clinical providers to support implementation of dissemination strategies;
- development of defined and comprehensive dissemination strategies;
- use of digital technology (electronic databases, records, mobile apps, etc.);
- education and support for healthcare professionals to implement the guidelines;
- provision of information resources for people with diabetes; and
- monitoring the implementation of the guidelines and evaluating their impact.

Table 6: Barriers and solutions identified from the literature with regard to adherence to national diabetes guidelines

Potential solutions	Barriers addressed	References
<ul style="list-style-type: none"> Involve family physicians, other care providers and people with diabetes in the design and development of best practice guidelines. Develop programmes targeting both providers and persons with diabetes with consideration of patient-related characteristics (e.g. age, ethnicity). Policy reform addressing modifiable risk factors Standardisation of inpatient diabetes management. 	Inappropriate formulation of diabetes guidelines.	67, 185, 243
<ul style="list-style-type: none"> Cooperation with healthcare providers and regional commissioners. Discussions about adherence before prescribing multiple drugs. 	Unworkable recommended approaches.	117, 224, 239
<ul style="list-style-type: none"> Development of guideline implementation strategies. Use the individuals with expertise in implementation. 	Uneven implementation (geographical or institutional)	111, 122
<ul style="list-style-type: none"> Use of SMS (short message service) support strategies. Support in the development of clinical informatics. Use of telemonitoring. Use of commercially available certified Electronic Health Records. Use of web-based registries. Linkage of diabetes registries with other available medical registries. 	Poor communication and dissemination strategies	67, 83, 106, 116, 169, 178, 200, 218, 256
<ul style="list-style-type: none"> Promotion of participation in group practices. Use of nurse-led type 2 diabetes consultations. Use of General Practice Management Plans. Provision of training for pharmacists to support implementation. Linkage of healthcare agencies with academia. Use of collaborative care approaches. Provision of training for medical administrators to support implementation. Use of telephone coaching. Use of managed care approaches. Use of integrated care programmes. Integration of diabetes care in community programmes. Use of collaborative inter-professional practice. Use of care plans. Use of nurse-led programmes. Accompany information technology tools with shared professional values. 	Inadequate contextual support for implementation (limited resources)	54, 88, 103, 119, 123, 125, 144, 145, 152, 166, 170, 177, 205, 241, 240, 249
<ul style="list-style-type: none"> Provision of support in the development of clinician competencies. Development and implementation of educational programmes for family practitioners. Increasing the rate of physicians' participation rate in training programmes. Use of web-based interactive education programmes. Prioritisation of healthcare professional education, training and competency. Use of educational programmes. Application of clinical audits. Use of validated assessment tools. 	Lack of education of healthcare professionals	58, 74, 83, 135, 156, 178, 216, 221

Potential solutions	Barriers addressed	References
<ul style="list-style-type: none"> • Use of incentive payments or performance pay. • Use of therapeutic education to increase participation for people with diabetes in the treatment process. 	Monitor and evaluate impact of the guidelines	121
<ul style="list-style-type: none"> • Development educational and training strategies. • Development of easy-to-use guidelines for persons with diabetes. • Development and implementation of structured educational strategies. • Inclusion of self-management resources in the guidelines. 	Therapeutic inertia	132, 217, 247
<ul style="list-style-type: none"> • Development educational and training strategies. • Development of easy-to-use guidelines for persons with diabetes. • Development and implementation of structured educational strategies. • Inclusion of self-management resources in the guidelines. 	Lack of person with diabetes' education	89, 102, 146, 184, 193, 217, 243

As highlighted in the table, most of the suggested solutions address inadequate contextual support for implementation and ineffective use of limited resources, communication and dissemination strategies (including better use of existing information technology), and proper support for healthcare professionals and persons with diabetes.

3.1.3. Adherence to recommended treatments for people with diabetes

The literature search yielded a total of 2330 articles. After screening the titles, 148 articles were selected and downloaded for assessment, and 81 articles were considered relevant for this review. Twelve of the articles reported on the current situation with regard to persons with diabetes' adherence to recommended treatments (medication, lifestyle, diet, physical activity, alcohol and tobacco usage, etc.), 37 identified barriers, and 51 suggested potential interventions or recommendations to increase adherence to recommended treatments.

The current situation

Non-adherence to recommended treatments is one of the main reasons for poor outcomes in controlling diabetes. Recommended treatments cover a number of components, including adherence to medication, self-monitoring and management, regular check-ups, and lifestyle changes (diet, physical activity, etc.). However, there is a relatively small amount of literature on adherence levels in people with diabetes.

Table 7: Reported adherence to recommended treatments by persons with diabetes

Country/region	Level of adherence	Topic	References
The Netherlands	Suboptimal	Treatment adherence	138, 153, 245
United States	69%, 75%		
World-wide	Suboptimal		
Europe	10%	Poor control	149
Finland	22%	Monitoring of glucose levels	5, 147, 234
United States	26% (children), 40% (adults)33%		
Finland	58%	Incorrect doses	138
United States	31%	Intentional omission of doses	197
Romania	40% eye, 57% lipids, 31% feet, 42% renal	Compliance with recommended check-ups	51, 248
United States	66% eye, 88% lipids, 68% HbA1c		
Australia	40%	Compliance with recommended diet	162, 248, 254
Finland	48%		
United States	52%–60%		
Canada	37%	Compliance with recommended physical activity	5, 167, 202
China	42% adults		
United Kingdom	35%		
United States	39%, 25% youth		

General adherence to recommended treatments

The literature available suggests that most people with diabetes are unprepared at their consultation visit. While shared decision-making was generally applied at consultation visits, people with diabetes were relatively passive collaborators with healthcare providers taking responsibility for healthcare decisions (the Netherlands).²⁴³ People with diabetes who were perceived to be healthy (i.e. younger, new to diabetes treatments, and on fewer additional medications) may be at risk of non-adherence.(USA)¹⁵³ Adherence to prescribed self-monitoring of glucose levels in blood and insulin administration varied widely between studies (**Table 7**). Similarly, adherence to prescribed dietary and physical activity requirements was variable, between 25%–60% across studies and countries.

Adherence to blood glucose control

Adherence to prescribed self-monitoring of blood glucose levels varied widely, depending on the frequency or aspect assessed in the studies. Although most patients reported some level of blood glucose monitoring, 60% of those with type 1 diabetes and 67% of those with type 2 diabetes reported practising self-monitoring of blood glucose less frequently than recommended by the ADA (USA).¹⁴⁷ It is estimated that poor control affects 1 in 10 of the population (UK).¹⁴⁹ Only 26% of children reported monitoring glucose levels as recommended (3–4 times daily), compared with approximately 40% of adults with type 1 diabetes.⁵

Adherence to recommended medication

Medication adherence, persistence and discontinuation rates were suboptimal in patients with type 2 diabetes prescribed oral antihyperglycaemic agents (USA)¹³⁸ and 58% administered incorrect doses of insulin.⁵

Adherence to recommended lifestyle changes

Over half of the participants reported assessing both the content and amount of food that they ate daily (48%) while 14% of the respondents did not evaluate their food at all. In the United States, only about half (52%) followed a meal plan.⁵ Among adults with diabetes, 39% reported they were physically active compared with 58% of those without diabetes. Based on ADA (2007) and Department of Health and Human Services (DHHS, 2008) guidelines, only 25% and 42% respectively of older adults with diabetes were found to meet recommendations for total physical activity. Adults with diabetes were 31% to 34% less likely to participate in physical activity at recommended levels and 13% to 19% less likely to be physically active than those without diabetes.⁸³

Adherence to recommended investigations

Overall, 95% of the participants reported having their blood pressure checked at all or most visits, 88% had lipid levels measured, 83% had kidney function tested, 68% underwent HbA1c testing, and 66% underwent an eye examination, in accordance with ADA recommendations (USA).²⁴⁶ In Romania, only 40% attended the recommended eye check-ups, 57% tested the lipid levels, 31% had their feet examined and 42% tested the condition of their renal function.^{43,107}

Barriers to adherence to recommended treatments

A number of studies in the literature explored barriers to adherence to recommended treatments (**Table 8**). The most common barriers related to side effects, inadequate resources, and lack of education about diabetes or poor health literacy.

In general, more complex treatment regimens negatively affected adherence: these included frequency of self-care behaviour (i.e. how often the person follows the required behaviour) and frequency of dosing (i.e. once-daily doses generally have increased adherence). Duration of disease also generally had a negative relationship with adherence, with longer durations equating to decreased adherence. Similarly, both the quality of the relationship between patients and care providers and social support were found to be associated with adherence.⁵

Table 8: Barriers to adherence to recommended treatments by people with diabetes

Barriers to adherence to recommended treatment	References
General lack of adherence to treatment	129, 167, 181, 223
Commitment / refusal to adhere to treatment	68, 82, 87, 149, 181, 211
Cultural barriers, perception of therapies	61, 92, 174, 171, 227
Inadequate resources (lower income, cost of treatment, co-payments)	25, 61, 82, 92, 113, 129, 171, 174, 189, 198, 248, 258
Side effects (including weight gain, invasive delivery, hypoglycaemia, pain)	66, 92, 129, 149, 162, 196, 198, 210, 211, 227, 258
Social or family issues	5, 82, 90, 92, 149, 160, 185, 258
Interference with professional or daily routines	72, 113, 149, 198, 211, 227
Lack of information, knowledge and skills (lack of education, poor health literacy)	61, 66, 94, 82, 68, 113, 129, 149, 162, 171, 210, 211
Polypharmacy	5, 66, 113, 137, 198, 210, 233
Poor medical or social support/guidance	137, 201
Poor or misled communication with HCPs	5, 82, 201
Burnout, treatment fatigue	5, 66, 94, 113, 201
Emotional or psychological issues	82, 90, 201, 113, 165, 167, 229, 233, 258
Safety issues	113

Solutions for adherence to recommended treatments

Interventions to improve adherence suggested by WHO⁵ for people with diabetes include family preparedness and structured education programmes (Table 9). From the healthcare professional perspective, there should be support for more patient-focused care, including better assessment of psychosocial needs, continuous monitoring, re-assessment of recommended treatments and simplification of regimens (where possible and appropriate). Healthcare professionals should also receive training on adherence.

Table 9: Interventions to improve adherence⁵

Diabetes	Factors affecting adherence	Interventions to improve adherence
Socioeconomic-related factors	<ul style="list-style-type: none"> ⊖ Cost of care ⊖ Patients aged 25+ years (adherence to physical activity) ⊖ Older adolescents (insulin administration) ⊖ Older adolescents (self-monitoring of blood glucose) ⊖ Male (adherence to diet) ⊖ Female (adherence to physical activity) ⊖ Environmental high-risk situations ⊕ Aged <25 years (adherence to physical activity) ⊕ Younger adolescents (insulin administration) ⊕ Younger adolescents (self-monitoring of blood glucose) ⊕ Female (adherence to diet) ⊕ Male (adherence to physical activity) ⊕ Social support 	<ul style="list-style-type: none"> • Mobilisation of community-based organisations • Assessment of social needs • Family preparedness
Healthcare team/system-related factors	<ul style="list-style-type: none"> ⊖ Poor relationship between patient and physician 	<ul style="list-style-type: none"> • Multidisciplinary care • Training of healthcare professionals on adherence • Identification of treatment goals and development of strategies to meet them • Continuing education • Continuous monitoring and re-assessment of treatment • Systems interventions: health insurance for nutrition therapy • Telephone reminders to patients • Chronic care models
Condition-related factors	<ul style="list-style-type: none"> ⊖ Depression ⊖ Duration of disease 	<ul style="list-style-type: none"> • Education on use of medicines
Therapy-related factors	<ul style="list-style-type: none"> ⊖ Complexity of treatment ⊕ Less frequent dose ⊕ Monotherapy with simple dosing schedules ⊕ Frequency of self-care behaviour 	<ul style="list-style-type: none"> • Patient self-management • Simplification of regimens • Education on use of medicines
Patient-related factors	<ul style="list-style-type: none"> ⊖ Depression ⊖ Stress and emotional problems ⊖ Alcohol abuse ⊕ Positive self-esteem/self-efficacy 	<ul style="list-style-type: none"> • Behavioural and motivational interventions • Assessment of psychological needs

⊕ factors having a positive effect on adherence; ⊖ factors having a negative effect on adherence

Several potential solutions to increase people with diabetes' adherence to the recommended treatments were identified in the reviewed literature (**Table 10**), which should be specially tailored to local needs and circumstances. The most frequently cited interventions related to: the use of structured educational and peer support programmes; provision of emotional, psychological and social support; frequent interaction and communication with healthcare professionals; use of modern treatments, medical devices and information technologies; and less complex treatment regimens/patterns.

Table 10: Potential solutions to increase adherence to recommended treatments by persons with diabetes

Potential solutions	Barriers addressed	References
Active involvement from person with diabetes / participatory processes	Interference with professional or daily routines.	174, 219
Provision of emotional and psychological support	Emotional distress, depression	81, 160, 174, 191, 199, 215
Frequent and improved interaction / communication between people with diabetes and healthcare professionals	Increase health literacy, education, report side effects	133, 174, 201, 211, 233
Adoption of modern information technologies	Increase health literacy, education, report side effects, improved health monitoring,	61, 76, 91, 93, 104, 113, 141, 237, 250
Participation in structured education and peer support programmes	Increase health literacy, education, report side effects, improved self-management, increase PWDs confidence,	79, 85, 94, 96, 107, 210, 214, 215, 227, 233, 237, 242
Social and community support	Address non-clinical issues	61, 113, 148, 176, 202, 252
Clinical settings, multidisciplinary teams, less complex treatments	General rate of adherence to recommended treatments	66, 113, 180, 233
Use of modern medication and medical devices (pens, continuous glucose monitors, insulin pumps, etc.)	General rate of adherence to recommended treatments	85, 100, 127, 223
Encouragement of self-management or patient empowerment	General rate of adherence to recommended treatments, decrease costs and visits to the HCPs	85, 96, 118, 219, 227
Lobbying for lower co-payment schemes	Decrease financial burden and Increase general adherence	92, 141
Provision of more support adapted to the needs of the population	Increase general adherence	93, 158, 195, 233, 253, 255
Increased healthcare professional training and support	Increase general adherence	76, 86
Promotion / adoption of healthy lifestyles	Improved therapeutic outcomes	96, 220, 227

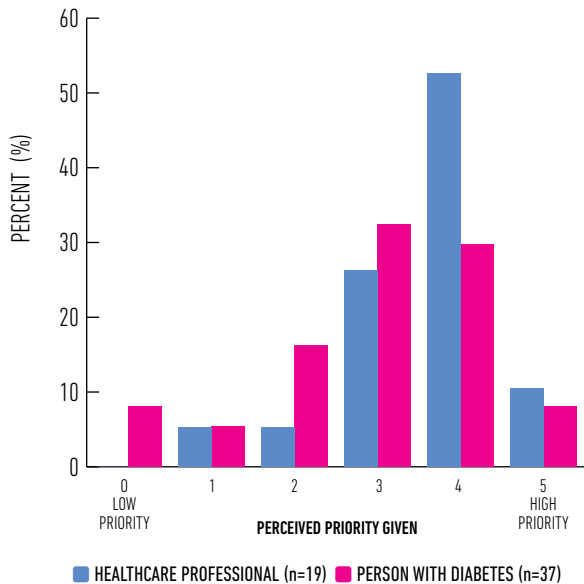
3.2. Survey of IDF Europe member organisations

In the below section, we have reported on the percentage responses of IDF Europe member organisations to key questions on the IDF Europe survey. As discussed in section 2.2.1, questions differed for healthcare professionals and people with diabetes, but have been presented together where possible. (Appendix 1 and 2)

3.2.1. Responses related to policy/healthcare systems

Respondents were asked if they considered diabetes to be a national priority in their own country. Responses from healthcare professional organisations (n=19) and persons with diabetes (n=37) are shown in Figure 9.

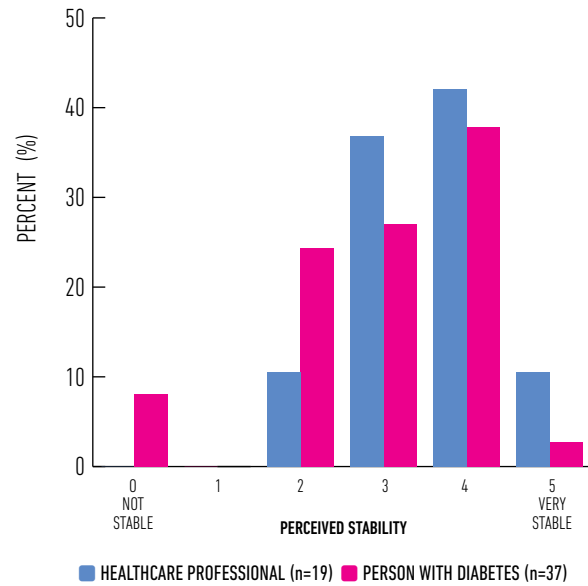
Figure 9: IDF Europe member organisations' perception of whether diabetes is considered a national priority



Generally, respondents considered diabetes to be of medium priority. On a scale of 0 (for low priority) to 5 (high priority), healthcare professionals gave an average (mean) rating of 3.6 compared with persons with diabetes who were less optimistic giving an average rating of 2.9. Similarly, three organisations representing people with diabetes (8%) perceived diabetes to be low priority in their respective countries.

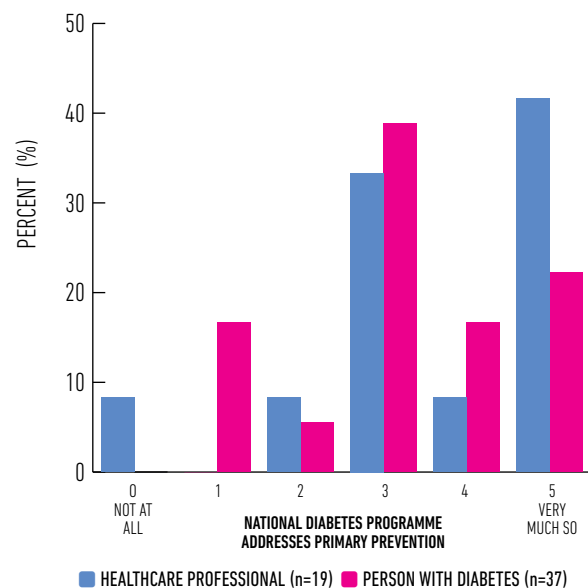
When asked for their perceptions on the stability of the healthcare policy environment, healthcare professionals and persons with diabetes also gave a moderate response, with healthcare professionals again giving a more optimistic rating (average 3.5 compared with 2.9 on a scale of 0 (not stable) to 5 (very stable)). As before, three organisations for people with diabetes (8%) felt that the healthcare policy environment was not stable (Figure 10).

Figure 10: IDF Europe member organisations' perceptions on the stability of the health policy environment



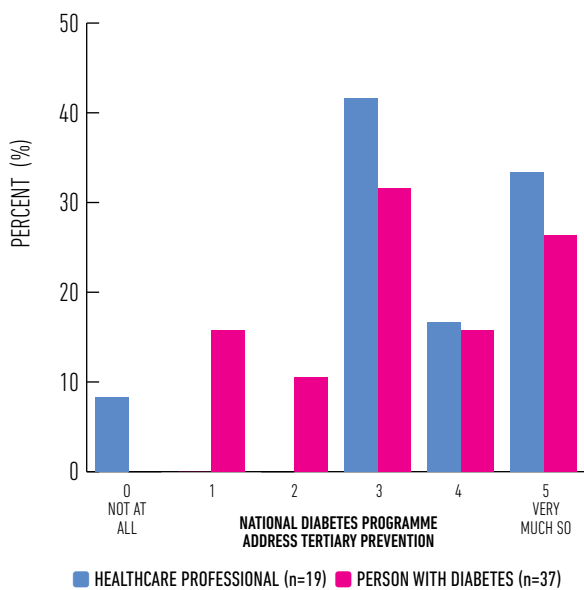
Twenty-two of the European countries (that are represented in IDF Europe by 30 organisations) had a national diabetes programme or national strategy for diabetes: six were in Eastern Europe, six in central Europe and 10 in Western Europe. The target population for these programmes varied: 10 included the general population, 19 included populations 'at risk' of developing diabetes, 22 included persons with type 2 diabetes and 17 included persons with gestational diabetes. Thirteen of the 22 countries (59%) monitored the implementation of the programmes or strategies and the same number (n=13; 59%) evaluated their impact.

Figure 11: IDF Europe member organisations' perceptions on whether their country's national diabetes prevention programme addresses primary prevention



In those countries that implemented national diabetes programmes or strategies, both healthcare professionals and people with diabetes gave a moderate-to-high rating for whether they addressed primary prevention (Figure 11; average rating 3.6 for healthcare professionals and 3.2 for people with diabetes on a scale of 0 for not at all to 5 for very much so).

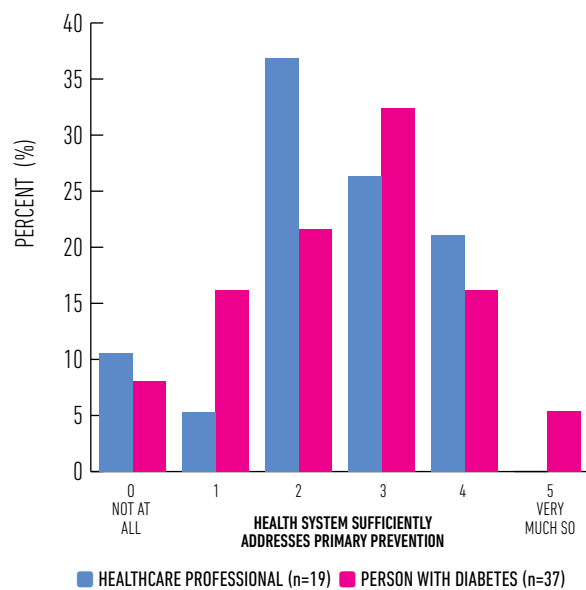
Figure 12: IDF Europe member organisations’ perceptions on whether their country’s national diabetes prevention programme addresses tertiary prevention



Similar responses were revealed for perception of whether national diabetes programmes addressed tertiary prevention (late diabetes complications). The average rating was 3.6 for healthcare professionals and 3.2 for people with diabetes on a scale of 0 for not at all to 5 for very much so (Figure 12).

Of the 22 national programmes or strategies, 16 included monitoring data (e.g. on prevalence, incidence, geographical distribution and complication rates) and 14 included specific targets for reducing prevalence, incidence and complications. At least two national programmes or strategies did not meet the minimum requirements to qualify as diabetes management tools, as set out by the IDF and WHO publications.^{2,16}

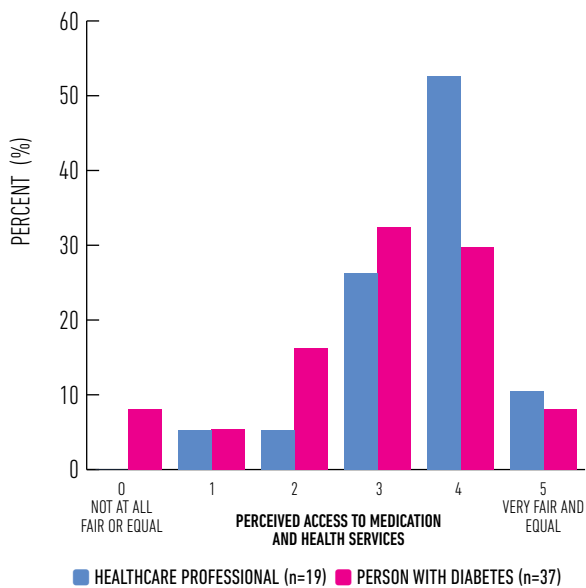
Figure 13: IDF Europe member organisations’ perceptions on whether their health system/registry addresses primary prevention



A total of 15 countries (39%) had a national diabetes system or registry in their particular country; 13 of these countries used these systems to produce periodic reports. However, in two of these countries, the system was not well-documented because different organisations from the same country reported this differently. People with diabetes reported having access to the registry in only three of the 15 countries (one-third). At least six countries did not make information from their registries available to members of the public. Organisations of healthcare professionals and people with diabetes gave a range of views as to whether their national health system sufficiently addressed primary prevention (Figure 13), giving a moderate response overall to this question (average rating of 2.4 for healthcare professional organisations and 2.5 for people with diabetes organisations).

Prevention of tertiary care (late complications) was perceived to be better addressed by the health systems, but average ratings remained moderate (2.9 for healthcare professional organisations and 2.5 for people with diabetes).

Figure 14: IDF Europe member organisations' perceptions on whether their healthcare system offers fair and equal access to medication and health services



Healthcare professionals and people with diabetes were generally positive when asked whether access to medication and health services was fair and equal, giving an average rating of 3.5 and 3.2 respectively, on a scale of 0 (not at all fair and equal) to 5 (very fair and equal). However, four organisations for people with diabetes (11%) and one healthcare professional organisation (5%) gave a low rating (1 or 2) in this category (Figure 14).

We also calculated weighted averages for the above responses using the ratio of the adult population with diabetes in each respective country to the total diabetes population in all countries. Weighted averages were slightly higher (i.e. more positive) than the non-weighted responses, but the distributions were similar.

Similarly, both organisations for healthcare professionals and persons with diabetes had similar perceptions on the shared responsibility of improving diabetes care. Healthcare professionals attributed 36% of responsibility to healthcare professionals, 29% to persons with diabetes and 35% to politicians/governments; people with diabetes cited very similar proportions (36%, 28% and 36% respectively).

3.2.2. Responses related to healthcare professionals

Of the 19 respondents representing IDF Europe health professional member organisations, five (26%) stipulated that they used international guidelines and recommendations, 12 (63%) used nationally developed guidelines and two (11%) used guidelines that had been developed locally. Most of the guidelines

referred to recommendations from IDF, European Association for the Study of Diabetes (ESAD), National Institute for Health and Care Excellence (NICE) or the American Diabetes Association (ADA). Fifteen of these respondents reported that, where national activities were guided by international recommendations, these were adapted to local needs and circumstances.

Five (26%) of the country's guidelines were reviewed and updated (where necessary) every two years; six (32%) were reviewed every three years and the remaining eight (42%) were reviewed every five years. All of the respondents reported that any changes in diabetes best practice recommendations were rapidly communicated locally. However, as 74% of guidelines were reviewed and updated every three years or longer, there is likely to be a delay in the adoption of recent evidence into everyday practice. There is a balance between resources involved in adapting recommendations, allowing time for evidence to be replicated and validated, and rapidly responding to evidence that affects health outcomes, which warrants further investigation.

Figure 15: IDF Europe healthcare professional member organisations' perspectives on their ability to implement evidence and influence change

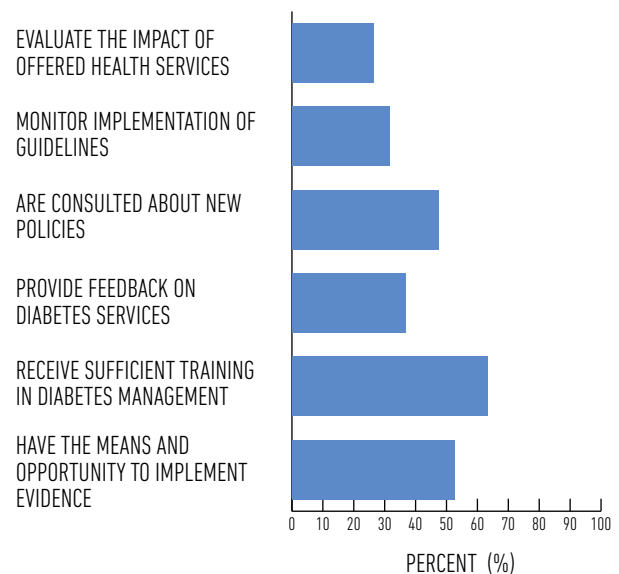


Figure 15 shows the healthcare professionals' perceptions on their ability to implement evidence and influence change. Just over half (n=10; 53%) respondents perceived that healthcare professionals in their countries had the means and opportunity to implement the latest evidence locally. The most common methods to share latest evidence or guidelines were presentations (32%), training sessions (28%), manuals (12%), information sheets (12%) and webinars (9%). Just under half (n=9; 47%) of countries

indicated that their professional bodies offered full support and resources for implementing the latest evidence or guidelines, but national guidelines were largely considered to be implemented successfully (average rating 3.3).

Twelve respondents (63%) felt that healthcare professionals received sufficient training in diabetes management. Eighteen (95%) indicated that therapeutic education was offered (4 on a regular basis and 14 from 'time to time').

In terms of input given by healthcare professionals on national policies, seven respondents (37%) reported that healthcare professionals were asked to provide feedback on diabetes services provided in their own countries and nine (47%) reported that they were consulted when new diabetes policies were developed. However, only seven (32%) reported that implementation of guidelines was monitored and five (26%) reported that the impact of health services were evaluated in some way.

Figure 16: Perspectives of IDF Europe member organisations for people with diabetes on healthcare professionals and their own ability to effect change

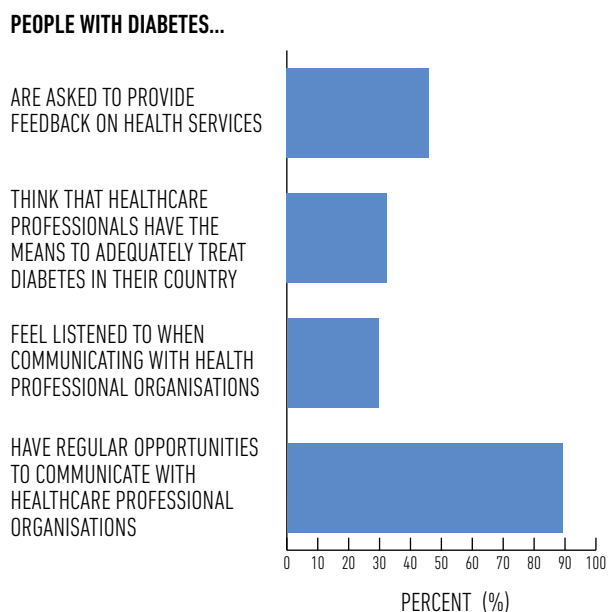


Figure 16 summarises the views of the 37 IDF Europe member organisations representing people with diabetes in relation to healthcare professionals and their organisations. Although many (n=33; 89%) were given opportunities to communicate with healthcare professional organisations, few (n=12; 30%) felt that they were listened to and less than half (n=17; 47%) were asked to provide feedback on the health services offered. Similarly, only one-third (n=12; 33%) of respondents perceived that healthcare professionals had the means to adequately treat diabetes in their respective countries.

3.2.3. Responses related to persons with diabetes

Overall, organisations for people with diabetes had a relatively low opinion about health systems addressing the needs of people with diabetes (average rating 2.7). Only eight of the 36 respondents (22%) considered that therapeutic education was adequate in their respective countries compared with 12 (32%) who felt that it was not adequate.

Figure 17: IDF Europe member organisations' perceptions on whether people with diabetes assume responsibility for managing their own condition

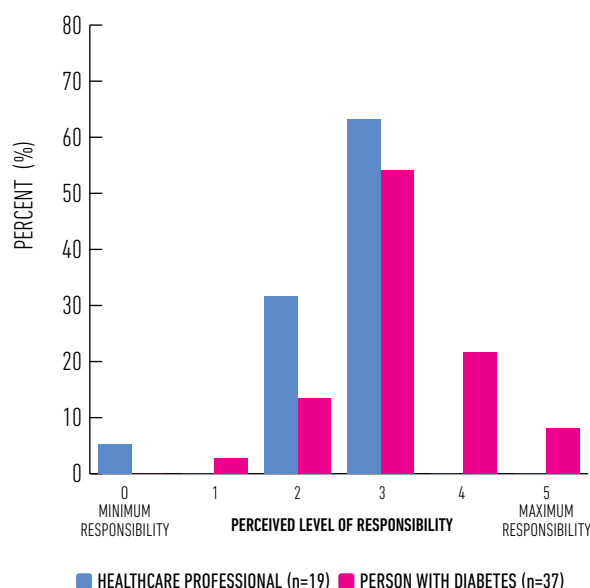
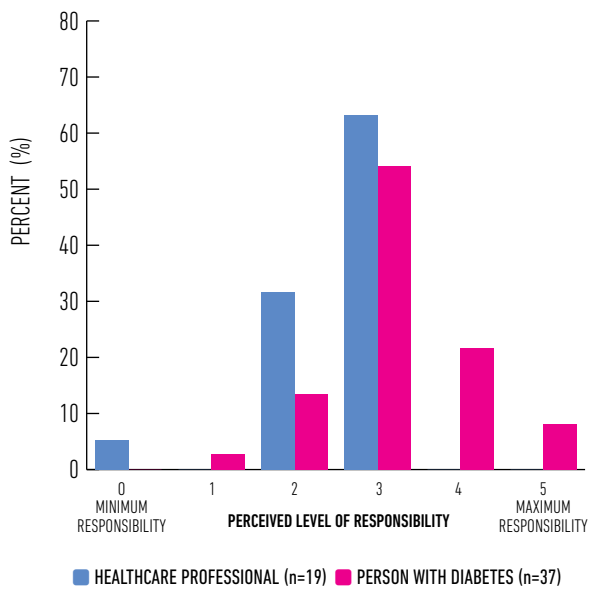


Figure 17 shows the member organisations' perceptions on whether the individuals take responsibility for their own diabetes. Healthcare professionals perceived that people with diabetes took moderate responsibility for managing their condition, giving an average (mean) rating of 2.5 (where 0 was no responsibility and 5 was high responsibility). None of the healthcare professionals gave a high rating (4 or 5) for this question. People with diabetes generally felt that they were more responsible for managing their condition, giving an average rating of 3.5.

Figure 18: IDF Europe member organisations' perceptions on whether self-management is encouraged in their country



Healthcare professionals and persons with diabetes had similar perceptions when asked whether self-management was encouraged in their country, giving an average rating of 3.1 and 3.0 respectively on a scale of 0 (for no encouragement) to 5 (high encouragement) (Figure 18).

Of interest, in five (13%) of the respondents' countries, people with diabetes need to pay for their own diabetes-related healthcare services, including laboratory tests, medicines and medical devices. Similarly, 24 countries (63%) need to pay for special diets and 12 (32%) for other medical supplies.

Almost two-thirds (n=24; 65%) in the organisations for people with diabetes indicated that they were consulted when new diabetes policies were developed. Similarly, 14 (38%) of these respondents felt that they had a sufficiently large 'voice' to affect public policies, compared with only two (11%) of the healthcare professional organisations.

3.2.4. Barriers and solutions for implementing evidence into practice

Appendix 3 shows the top 10 barriers identified by IDF Europe member organisations. The six barriers (seven for the healthcare professionals) after the first round of the Delphi process are shown in Appendix 4. The top four barriers identified after the second round of the Delphi process by theme are outlined below.

Policy-related barriers

- Problems with national diabetes programmes/ strategies (structure, implementation, monitoring, evaluation).
- Problems with national diabetes registries (their use or structure).
- Lack of effective involvement from healthcare professionals and persons with diabetes in the development of new public policies.
- Ineffective or uneven distribution of resources (healthcare professionals, general practitioners, facilities, funds).

Barriers related to healthcare professionals

- Poorly supported and implemented prevention programmes (primary, secondary, tertiary).
- Limited time for consultations.
- Ineffective communication between healthcare professionals.
- Lack of integrated facilities and/or medical teams.

Barriers related to persons living with diabetes

- Poor adherence to medication or lifestyle change.
- Limited patient/family skills to properly manage diabetes.
- Lack of/poor empowerment of person with diabetes.
- Poor family education.

Open responses to the questionnaires provided additional insight into perceived barriers and are shown in full in Appendix 5. The most frequent phrase in relation to public policies was 'national diabetes programme', with the open responses referring to lack of funding, effective use of the programmes for diabetes management and the need to address prevention. For the management of health systems, 'access' was most frequently cited in relation to medicines, services, education, prevention, medical devices, modern treatments and testing.

Similarly, for healthcare professionals, education and training were most frequently mentioned for healthy lifestyles, families and the general population. The open responses referred less to people with diabetes, but 'awareness', 'adherence' (or compliance) and 'empowerment' were mentioned.

Further analysis of the free text responses to identify influential factors on primary or tertiary prevention revealed a moderate correlation between healthcare systems that addressed diabetes prevention and efforts to encourage self-management or adherence to therapies. Similarly, where moderate effort was made to encourage self-management or adherence to therapies, a correlation was found between healthcare systems that addressed diabetes prevention and

knowledge and skills among healthcare professionals. Overall, this suggests that the country’s focus on prevention is influenced by its own personal investment in self-management/adherence to therapies and capacity building of healthcare professionals.

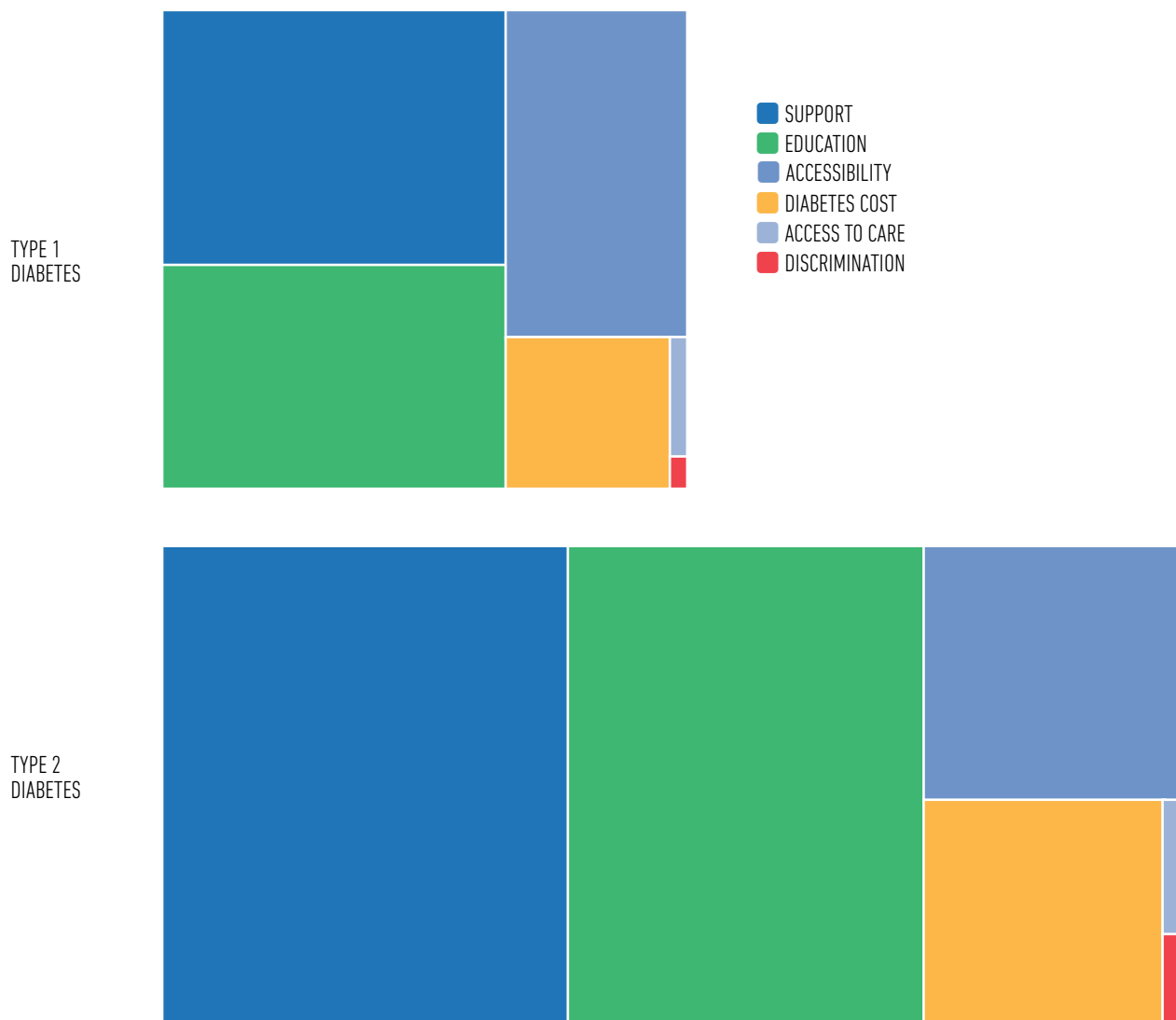
Of the potential solutions to implementing diabetes evidence into practice offered, the respondents considered improved health education to people with diabetes as being most relevant (89%), followed by improved training for healthcare professionals (85%), better use of technology (67%) and better treatments (49%).

3.3. Social media analytics

A total of 28,970 sites/posts from a variety of social media sources were identified and considered in relation to diabetes-related topics and themes (Model 1; Table 1) and barriers related to diabetes (Model 2; Table 2). For the comparison of other selected non-communicable diseases (Model 3; Table 3), 123,387 sites/posts from different social media sources were considered. Findings from each of the models are shown below.

Figure 19: Themes mentioned by topic

THEME MENTIONS BY TOPIC



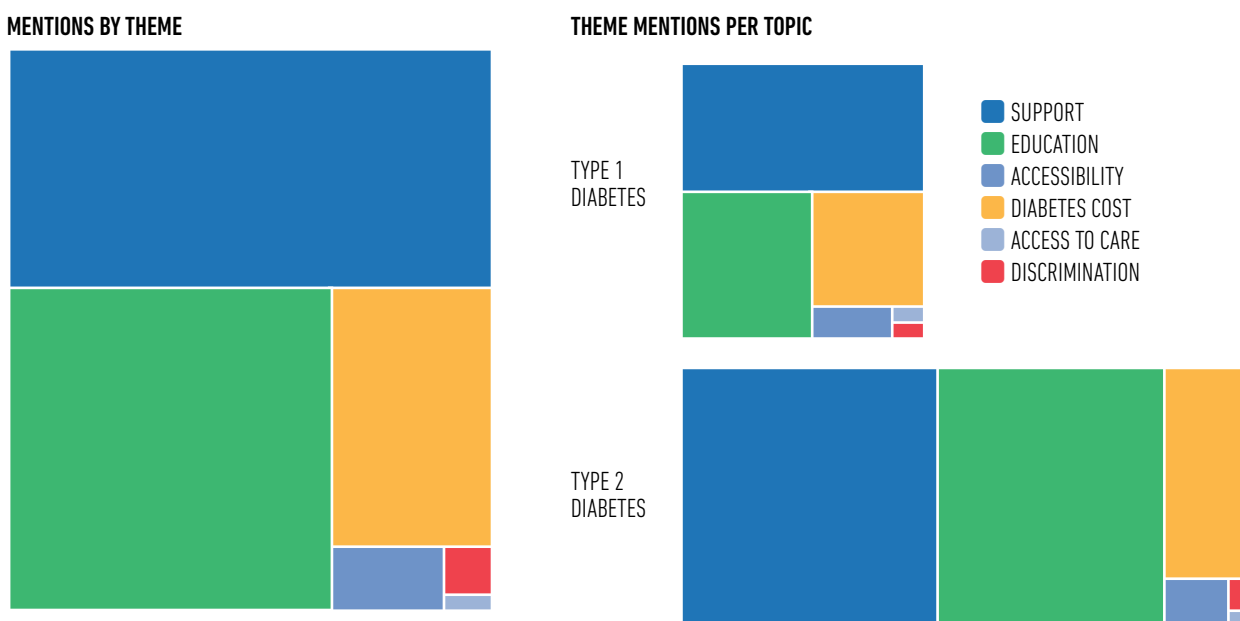
3.3.1. Diabetes-related topics and themes (Model 1)

The most commonly discussed themes on social media were support, education and accessibility (Figure 19). It is noteworthy that education also featured highly (i.e. was the second most common theme) in the open answers given by IDF Europe member organisations.

3.3.2. Barriers related to diabetes (Model 2)

To identify perceived barriers to adequate diabetes control, posts with 'negative sentiments' were selected. The most common themes in relation to negative sentiments were support, education, diabetes cost, and accessibility (Figure 20). Particularly common posts related to: high costs of health care and medication; purchase of non-prescription medication or lower cost medication; education workshops, camps, events or programmes; access to medication, assistance or care; affordable treatment; patient support groups; diabetes self-management; transition in diabetes care; diabetes education and prevention; and psychological and social problems.

Figure 20: Themes mentioned by topic, filtered by 'negative sentiment'



3.3.3. Comparison with other non-communicable diseases (Model 3)

The highest incidence of posts for non-communicable diseases related to diabetes. There were almost four times as many posts for diabetes compared with other non-communicable diseases (Figure 19). The most frequent diabetes-related topic was 'lifestyle improvement', whereas for all of the other conditions, the most frequent topic was 'fear of death'.

Figure 21: Mentions by theme and frequency of themes mentioned in all posts, filtered by non-communicable disease

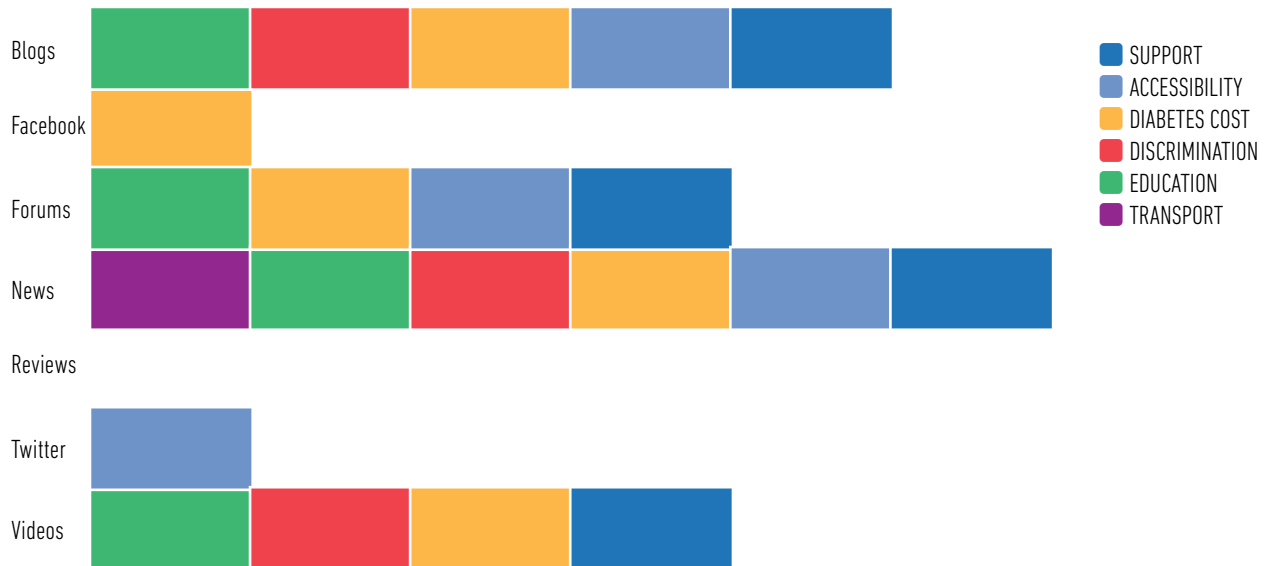
WHAT IS THE BREAKDOWN OF SOURCES AND THEMES - Filtered by Source



Figure 22 shows the topics by source of social media post. The most frequent posts were from videos (e.g. YouTube, Dailymotion). Diabetes was the most frequently mentioned topic in all of the social media sources, with the exception of Twitter and Reviews where stroke was most frequently mentioned.

Figure 22: Topics by source of social media post

WHAT IS THE BREAKDOWN OF SOURCES AND THEMES - Filtered by Source and Sentiment



4 Discussion

Overall, our findings have revealed significant European-wide barriers to integrating diabetes evidence into practice. They also suggest that analysis of social media platforms can provide useful insights into diabetes care and management.

Since the early 1990s and subsequent to the St Vincent declaration, WHO and IDF have recommended the development and implementation of national diabetes programmes and registries as a means of monitoring and managing diabetes. Some 25 years later, only 22 countries (out of 38 that responded to the questionnaire) have adopted such a strategy. The adoption of a national diabetes programme is not triggered by the level of prevalence³² and according to our own study the level of diabetes related DALY is not correlated with the existence of such a strategy. A more effective tool for improving health outcomes appears to be the use of national diabetes registries (or other similar recording mechanisms). However, the review of the literature showed that collection of data is inconsistent, making comparisons between countries difficult. A constant focus of prevention throughout life, the provision of health-supporting environments, the design of health services to fit local needs, the empowerment of people as active partners in promoting health and managing disease, and the crucial role of government in building inter-sectoral policy and facilitating access need to be constantly considered when developing and adopting public policies addressing diabetes.

One of the key findings of this study is the perceived lack of input on diabetes-related healthcare policy initiatives from healthcare professionals and people with diabetes. Less than half of healthcare professional organisations were asked to participate in the development of diabetes-related policies. Although this proportion was higher for organisations for people with diabetes (two-thirds reported participation), the organisations themselves perceived that they had very little power to actually influence policy change. Similarly, the relationship between IDF Europe healthcare professional member organisations and organisations for people with diabetes was still relatively constrained in many countries.

While the concept of patient empowerment has been developed and promoted in the diabetes community for more than two decades, actual reinforcement and recognition at healthcare professional and policy level is still very low. While diabetes is clearly important to the public, as demonstrated by its dominance in social media (where it was discussed almost four times as often as any other non-communicable disease), people with diabetes do not appear to have a strong voice in many of the European countries. Similarly, review evidence showed that adherence to recommended treatment by people with diabetes was generally poor (less than 20% in some studies). Cost, family, community and social issues need to be addressed as they have a high impact on adherence to recommended treatments. Moving forward, we highlight the importance of closer cooperation between IDF Europe member organisations for health care professionals and people with diabetes to promote adherence to recommended treatments, support for peers, families and schools, and training and awareness campaigns.

In terms of adherence to diabetes guidelines, we found that not all of the countries were fully implementing existing practice guidance and that improvements could be made in relation to their monitoring and evaluation. As most of the responsibility for managing diabetes and related co-morbidities is assumed by general practitioners, it is important that guidelines and management instruments are better adapted to their needs and that they are involved in the process. The majority of national guidelines were updated every 3–5 years, which is likely to hinder the rapid implementation of new discoveries and evidence. There is a balance between the cost of producing annual guidelines, the speed at which new evidence is implemented and ensuring that the evidence is safe and effective, but there may be scope for updating guidelines more rapidly where necessary. Similarly, certain approaches such as nurse-led and community-led diabetes programmes,

use of trained pharmacists, encouragement of self-management (patient empowerment) and use of modern technologies to monitor diabetes indicators may offer solutions to improving diabetes outcomes and healthcare professionals' adherence to guidelines. Ultimately, efficient adoption and implementation of prevention strategies is the only way in which diabetes incidence can be reduced.

From the healthcare professional perspective, both cost containment and cost compensation policies hindered the adoption of new lines of treatment. IDF Europe member organisations for both healthcare professionals and people with diabetes indicated that access to medicines or medical devices was uneven and the co-payment system (which is not proportionate to the economic situation of the country) also contributed to increased non-adherence to recommended treatments. This is largely supported by the discussions on social media where common negative sentiments related to high costs of diabetes medicines and healthcare, purchasing non-prescription medicines and affordable treatments. It was also recognised that most of the systems were under-resourced, not only financially, but also in terms of personnel, equipment and facilities. It is important that the improvement, promotion and support for continuous education and training of diabetes specialists and general practitioners are prioritised.

4.1. Limitations

Respondents to the IDF Europe survey were representative of IDF Europe member organisations. However, this meant that countries with organisations for both healthcare professionals and people with diabetes could contribute twice to the survey and had a stronger voice. We have minimised this by separating the views of organisations for healthcare professionals and people with diabetes. Moreover, in countries with federal structures (e.g. Russia, Germany and United Kingdom), we may not have captured some of the differences as a result of local legislations.

For the social media analysis, owing to resource limitations, we were only able to consider comments posted in the English language and we did not restrict to those in Europe only. We also only considered posts from the perspective of people with diabetes and did not consider healthcare professionals or other stakeholders in the analysis. In addition, we limited the timeframe of the posts to the period April 2017 to July 2017. As information on social media typically has a short life span, this allowed us to explore immediate issues, needs and concerns.

4.2. Conclusions

We have demonstrated that there are substantial European-wide challenges in the implementation of evidence-based practice for healthcare systems, healthcare professionals and persons living with diabetes. Recommendations for overcoming these challenges are outlined below

- Implementation of diabetes evidence should be tailored to local circumstances.
- Effective human, financial and material resource management strategies are needed to improve the delivery of healthcare systems and patient outcomes, and reduce therapeutic inertia.
- Prioritisation should be given to the education of healthcare professionals and persons living with diabetes to maximise the impact of government investment.
- Appropriate prevention strategies are vital to reduce the incidence of diabetes.
- More effective tools for managing behavioural change need to be developed.
- All stakeholders (policy makers, healthcare professionals, healthcare/commercial organisations and providers, and persons with diabetes) should be actively involved in policy initiatives targeted at addressing diabetes burden and improving quality of life.

IDF Europe will continue to work with the Member Associations and other stakeholders to further refine these recommendations, making sure that people with diabetes are at the forefront in their efforts to address diabetes burden, improve health-related outcomes and ultimately improve quality of life. The IDF Europe Member Associations are invited to share their own experience and to suggest effective means to reach improvements in more effectively addressing diabetes.

5

References and
Bibliography

References and bibliography from no 53 to 256 may be downloaded from:
www.idf.org/europe/publications-and-resources

1. The St Vincent Declaration; World Health Organization Europe, International Diabetes Federation Europe; 1989
2. Guide for development of National Programme for a Diabetes Mellitus; World Health Organization; 1991
3. The Istanbul Commitment ; World Health Organization Europe, International Diabetes Federation Europe; 1999
4. IDF Diabetes Atlas, 1st edition; International Diabetes Federation ; 2000
5. Adherence To Long-Term Therapies: Evidence for action; World Health Organization; 2003
6. IDF Diabetes Atlas, 2nd edition; International Diabetes Federation ; 2003
7. Diabetes Action Now; World Health Organization, International Diabetes Federation; 2004
8. Written Declaration on Diabetes; European Parliament; 2006
9. UN Resolution 61/225; United Nations Organization; 2006
10. IDF Diabetes Atlas, 3th edition; International Diabetes Federation ; 2006
11. International Charter Of Rights And Responsibilities of People with Diabetes; International Diabetes Federation; 2007
12. Improving access, responding to patients A 'how-to' guide for GP practices; National Health Service; 2009
13. Gaining health Analysis of policy development in European countries for tackling noncommunicable diseases; World Health Organization Europe; 2009
14. IDF Diabetes Atlas, 4th edition; International Diabetes Federation ; 2009
15. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group ; Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.; BMJ 2009;339:b2535, doi: 10.1136/bmj.b2535; 2009
16. A Guide to National Diabetes Programmes; International Diabetes Federation; 2010
17. Global Diabetes Plan 2011-2021; International Diabetes Federation ; 2011
18. Screening for diabetes in EU Member States; Foundation of European Nurses in Diabetes, International Diabetes Federation Europe; 2011
19. IDF Diabetes Atlas, 5th edition; International Diabetes Federation ; 2011
20. The diabetes epidemic and its impact on Europe; Organisation for Economic Co-operation and Development , Danish Diabetes Association, Novo Nordisk; 2012
21. Prevention and Control of Noncommunicable Diseases: Guidelines for primary health care in low-resource settings; World Health Organization; 2012
22. EP Resolution on Diabetes; European Parliament; 2012
23. Action Plan for implementation of the European Strategy for the Prevention and Control of Noncommunicable Diseases 2012 – 2016 ; World Health Organization Europe; 2012
24. Copenhagen Roadmap; Organisation for Economic Co-operation and Development , Danish Diabetes Association, Novo Nordisk; 2012
25. Health at a Glance Europe 2012; Organisation for Economic Cooperation and Development and the European Commission; 2012
26. Clinical guidelines for chronic conditions in the European Union; European Observatory on Health Systems and Policies; 2013
27. Access To Quality Medicines And Medical Devices For Diabetes Care In Europe; International Diabetes Federation Europe; 2013
28. IDF Diabetes Atlas, 6th edition; International Diabetes Federation ; 2013
29. Global Action Plan for the prevention and control of noncommunicable diseases 2013–2020; World Health Organization ; 2013
30. Health at a Glance: Europe 2014; Organisation for Economic Co-operation and Development and the European Commission; 2014
31. Prevention and control of noncommunicable diseases in the European Region: a progress report; World Health Organization Europe; 2014
32. Diabetes In Europe Policy Puzzle The State We Are In; EURADIA, Foundation of European Nurses in Diabetes, International Diabetes Federation Europe, Primary Care Diabetes Europe; 2014
33. Euro Diabetes Index; Health Consumer Powerhouse; 2014
34. Global Diabetes Scorecard Tracking Progress For Action; International Diabetes Federation ; 2014
35. The ExPAND Policy Toolkit on Diabetes; The European Policy Action Network on Diabetes; 2014
36. Integrated surveillance of Noncommunicable diseases; European Parliament, World Health Organization Europe; 2015

37. European Best Information through Regional Outcomes in Diabetes ; A shared evidence-based diabetes information system; 2015
38. SWOT Analysis Final Report; SWOT Analysis Final Report; 2015
39. IDF Diabetes Atlas, 7th edition; International Diabetes Federation ; 2015
40. Diabetes: a case study on strengthening health care for people with chronic diseases; Survey on practices for prevention and management of diabetes; JA-CHRODIS Work Package 7; 2016
41. Diabetes: a case study on strengthening health care for people with chronic diseases; Recommendations to improve early detection, preventive interventions, and the quality of care for people with diabetes. Definition and agreement on a common minimum set of indicators; JA-CHRODIS Work Package 7; 2016
42. Euro Health Consumer Index 2016; Health Consumer Powerhouse; 2016
43. Access to Medicines and Supplies for People with Diabetes A GLOBAL SURVEY ON PATIENTS' AND HEALTH PROFESSIONALS' PERSPECTIVE; International Diabetes Federation; 2016
44. National Diabetes Plans in Europe What lessons are there for the prevention and control of chronic diseases in Europe?; Joint Action CHRODIS; 2016
45. Global Report On Diabetes; World Health Organization; 2016
46. The Diabetic Retinopathy Barometer Report Global Findings; International Federation on Ageing, International Federation for the Prevention of Blindness, International Diabetes Federation, Bayer; 2016
47. Health at a Glance: Europe 2016 STATE OF HEALTH IN THE EU CYCLE; Organisation for Economic Co-operation and Development , European Commission; 2016
48. The Berlin Declaration A collective ambition for policy change to drive early action in type 2 diabetes; International Diabetes Federation, Primary Care Diabetes Europe, World Hart Federation, AstraZeneca; 2016
49. Patient – Reported Indicators Survey; Organisation for Economic Co-operation and Development ; 2016
50. Early Action Global Diabetes Policy Forum ; International Diabetes Federation, Primary Care Diabetes Europe, World Hart Federation, AstraZeneca; 2017
51. Romanian White Chart of Diabetes 2016; Romanian Federation of Diabetes Associations; 2017
52. IDF Diabetes Atlas, 8th edition; International Diabetes Federation ; 2017

References and bibliography from no 53 to 256 may be downloaded from www.idf.org/europe/publications-and-resources

Appendix 1



**International
Diabetes Federation
Europe**

Questionnaire for IDF Europe members, as representatives of healthcare professionals

IDF Europe is producing a publication to assess the translation of diabetes evidence and recommended best practice into real-life care. We are investigating the gaps which prevent optimal diabetes care being implemented from the perspective of persons with diabetes and health care professionals. Following our review of the literature investigating the gaps and barriers to care, we will also consider some of the solutions to these shortfalls. This work will be published for the benefit of persons with diabetes, diabetes organisations, health care professionals and policy makers.

We are kindly asking our 70 member associations to fill-in this questionnaire, which should take approximately 20-30 minutes to complete. The deadline for responses is 30th June 2017. This questionnaire has been specifically designed for diabetes associations that represent persons with diabetes.

For any administrative or technical queries, please contact Ms Lauren Quinn at Lauren.Quinn@idf-europe.org

Thank you very much for your valuable time and contribution to this important work. The results from this survey questionnaire will inform future IDF Europe policy work and publications, which will help all of us in Europe advocate for positive change based on evidence.

With kind regards from the Editorial Committee.
IDF Europe

1. Please choose from the drop down list your country and organization:

Policy related topics

2. Is diabetes considered a national priority in your country? (Think in terms of visibility, perceived social and economic threat that diabetes poses)
[0=not a priority, ... 5= a top priority]

0 1 2 3 4 5

3. Please justify your answer:

4. Diabetes health policies are stable enough, with continued prioritisation despite changes in governance [0=not very stable, 5= very stable]

0 1 2 3 4 5

5. Is there a National Diabetes Plan or Strategy in your country? (if the answer is NO, please go to question no 22)

Yes No I do not know

6. What is the name of this National Diabetes Plan (NDP)?

7. Please provide a link to website for the NDP:

8. Date NDP was first introduced:

9. Expected NDP completion date (if applicable):

10. Leading institution responsible for the development/implementation of this NDP?

11. Funding support for this NDP:

[Please select all that apply]

Government

I do not know

Other

12. Level of implementation:

NDP was developed but not yet implemented

NDP not fully implemented at national level

NDP implemented

I do not know

13. Target groups included in the NDP?

[Please select all that apply]

General population

People at high risk of diabetes

People with type one diabetes

People with type two diabetes

Women with gestational diabetes

I do not know

Other

14. Is the implementation of the NDP or of the diabetes health policies monitored?

No

I do not know

Yes (please specify who does it)

15. Is the impact of the NDP (or of the diabetes health policies) evaluated periodically?

- Yes
 No
 I do not know

16. How frequently is the NDP evaluated?

17. Who is responsible for the evaluation of the NDP?

18. The NDP sufficiently addresses primary prevention of diabetes
[0= strongly disagree 5=strongly agree]

- 0 1 2 3 4 5

19. The NDP sufficiently addresses prevention of diabetes late complications
[0=strongly disagree 5= strongly agree]

- 0 1 2 3 4 5

20. Does the NDP include current diabetes figures (incidence, prevalence, territorial distribution, complication rates, etc.)?

- Yes No I do not know

21. Does the NDP outline the targets for improvement of these figures?

- Yes No I do not know

22. Is there a national diabetes registry, to record patient outcomes, in your country? [If the answer is NO, please proceed to question no 25]

- No
 Yes (no link available)

Yes (please provide the link)

23. To whom is the information in the diabetes registry accessible?

[Please select all that apply]

- Persons living with diabetes
 Registered health professionals
 I do not know

Other

24. Is the information from this registry used to produce periodic reports regarding the status of diabetes in your country?

- No
 Yes (no link available)

I do not know

Yes (please provide a link)

25. The health system in your country sufficiently addresses prevention of diabetes (primary prevention)? [0=strongly disagree ... 5= strongly agree]

- 0
 1
 2
 3
 4
 5
 I do not know

26. The health system in your country sufficiently addresses prevention of complications that can arise from diabetes e.g. heart disease, kidney disease, neuropathy, retinopathy [0=strongly disagree ... 5= strongly agree]

- 0
 1
 2
 3
 4
 5
 I do not know

27. The health system in your country provides fair and equal access to medication and health services to all people living with diabetes [0=strongly disagree ... 5=strongly agree]

- 0
 1
 2
 3
 4
 5
 I do not know

28. Who do you consider to be responsible for improving diabetes care:
[Please select all that apply]

- Health professionals
 Persons living with diabetes
 Politicians/Government
 Other

29. What are the priority improvements that need implementing to address prevention and treatment of diabetes in your country?

Health professionals topics

30. What diabetes guidelines are predominantly used by health care professionals in your country?

International guidelines and recommendations

National guidelines

Local guidelines

Other

31. To what extent do national or local guidelines significantly differ from international guidelines or recommendations (e.g. ADA, EASD, IDF)?

[0=they differ very much 5= they do not differ at all]

0

1

2

3

4

5

I do not know

32. Please outline the major reasons for these differences? [Please specify if the differences are related to local or national guidelines]

33. Are diabetes guidelines adapted to fit the local environment (with regards to culture, economic situation, professional background, etc.)?

Yes No

34. How frequently are national or local guidelines updated in your country?

Every year

Every 2 years

Every 3 years

Every 5 years

Other

35. Please provide a link to the latest version:

36. Are changes to diabetes best practice, recommendations or guidelines communicated and disseminated to health care professionals appropriately?

Yes

No

I do not know

37. By what means, how often?

38. What proportion of health care professionals engage with these dissemination opportunities?

39. Is e-learning a popular tool for training health care professionals in your country?

- Yes No I do not know

40. Would e-learning be a good way of disseminating changes to diabetes guidelines?

- Yes No

41. Do you consider that the diabetes health professionals have the means and opportunities to be up to date with the latest practices, studies, recommendations or guidelines?

- Yes Sometimes No

42. Do professional bodies provide tools for the implementation of new practice guidelines ?
[Please select all that apply]

training sessions

info sheets

manuals

presentations

webinars

Other

43. Do health professionals in your country have the support and resources to apply the existing diabetes guidelines?

- Yes Partially No

44. To what extent are current diabetes guidelines implemented by health care professionals in your country?

[0= not at all implemented ... 5=fully implemented]

- 0 1 2 3 4 5

45. Do health care professionals keep sufficiently up to date with changes in best practice diabetes care and guidelines?

- Yes No I do not know

46. Is there adequate training for health care professionals to manage diabetes in your country?

- Yes No I do not know

47. Is therapeutic education offered regularly to persons with diabetes and their families?

- Yes From time to time No

48. In your country, what forms of education would better equip persons with diabetes to self-manage their condition? E.g. group work, health care professional led, peer support, lectures, webinars, online resources

49. Are diabetes health care professionals asked for feedback regarding the diabetes services provided in your country?

Yes No

50. Do people with diabetes the following care check-ups and how frequently?
[Please select all that apply]

	No	Every 3 months	Every 6 months	Every year	Other
Foot examination (neuropathy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eye screening (retinopathy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kidney checks (nephropathy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiovascular disease risk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

51. What proportion of patients with diabetes related complications are managed by diabetes specialists rather than in a general practice or primary care setting?

52. Is there a system of monitoring the implementation of diabetes guidelines?

Yes No

53. Are diabetes health services evaluated in your country?

Yes No I do not know

54. How often and by whom?

55. Are diabetes health professionals consulted when diabetes health policies are developed?

Yes Sometimes No

56. What is the priority for improving diabetes care in your country?

Persons living with diabetes topics

57. Are there opportunities for diabetes health professionals and persons living with diabetes to discuss, debate on the status of diabetes in your country?

- Yes No

58. How frequently does your organisation support organisations specifically for persons with diabetes (include fundraising, education etc)?

- weekly
 fortnightly
 monthly
 quarterly
 biannually
 annually

59. Do persons with diabetes have the power and the voice to influence diabetes healthcare policies in your country?

- Yes Sometimes No

60. In your country, to what extent are mobile apps used by persons with diabetes to help them selfmanage their condition?

[0=not used at all 5=used to a great extent]

- 0 1 2 3 4 5

61. In your country, to what extent do individuals assume responsibility for their diabetes?

[0=to no extent 5= to a great extent]

- 0 1 2 3 4 5

62. In your country is enough done to encourage persons living with diabetes to selfmanage and adhere to diabetes therapies? [0= not enough, ... 5=more than enough]

- 0 1 2 3 4 5

63. Do people with diabetes need to pay for the following diabetes care services:
 [Please select all that apply]

	Yes	For some	No
Diabetes-related medical services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes-related laboratory tests (e.g. blood tests, HbA1c, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes-related medicines or medical devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Special diets (e.g. gluten free)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other recommendations from health care professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

64. Please denote what in your opinion are the barriers that impact on the healthcare you receive:

[Please select all that apply]

- General lack of knowledge and skills amongst health care professionals
- Time limitations during routing consultations
- Lack of incentives amongst healthcare staff
- Lack of information amongst healthcare staff
- Lack of information amongst patients
- Resistance of patients to changes
- Service not evenly implemented
- No barriers
- I do not know
- Other

65. Of these, which would be the greatest barrier to optimizing diabetes care in your country?

66. Please denote the solutions that could improve the healthcare that you receive
[Please select all that apply]

- Better treatments
- Improved health education for patients
- Improved training for health care professionals
- Better utilisation of technology for e-health
- I do not know
- Other

67. Of these, which would be the most effective solution to optimizing diabetes care in your country?

68. What would facilitate improved participation of the people with diabetes in your country, in the work of the medical professionals and the health authorities?

You have completed this questionnaire

Thank you for your precious time and valuable input!

We will advise you when the results of the survey are analyzed.

Appendix 2



**International
Diabetes Federation
Europe**

Questionnaire for IDF Europe members, as representatives of persons with diabetes

IDF Europe is producing a publication to assess the translation of diabetes evidence and recommended best practice into real-life care. We are investigating the gaps which prevent optimal diabetes care being implemented from the perspective of persons with diabetes and health care professionals. Following our review of the literature investigating the gaps and barriers to care, we will also consider some of the solutions to these shortfalls. This work will be published for the benefit of persons with diabetes, diabetes organisations, health care professionals and policy makers.

We are kindly asking our 70 member associations to fill-in this questionnaire, which should take approximately 20-30 minutes to complete. The deadline for responses is 30th June 2017. This questionnaire has been specifically designed for diabetes associations that represent persons with diabetes.

For any administrative or technical queries, please contact Ms Lauren Quinn at Lauren.Quinn@idf-europe.org

Thank you very much for your valuable time and contribution to this important work. The results from this survey questionnaire will inform future IDF Europe policy work and publications, which will help all of us in Europe advocate for positive change based on evidence.

With kind regards from the Editorial Committee.
IDF Europe

1. Please choose from the drop down list your country and organization:

Policy related topics

2. Is diabetes considered a national priority in your country? (Think in terms of visibility, perceived social and economic threat that diabetes poses)
[0=not a priority, ... 5= a top priority]

0 1 2 3 4 5

3. Please justify your answer:

4. Diabetes health policies are stable enough, with continued prioritisation despite changes in governance [0=not very stable, 5= very stable]

0 1 2 3 4 5

5. Is there a National Diabetes Plan or Strategy in your country? (if the answer is NO, please go to question no 22)

Yes No I do not know

6. What is the name of this National Diabetes Plan (NDP)?

7. Please provide a link to website for the NDP:

8. Date NDP was first introduced:

9. Expected NDP completion date (if applicable):

10. Leading institution responsible for the development/implementation of this NDP?

11. Funding support for this NDP:
[Please select all that apply]

Government

I do not know

Other

12. Level of implementation:

NDP was developed but not yet implemented

NDP not fully implemented at national level

NDP implemented

I do not know

13. Target groups included in the NDP?

[Please select all that apply]

General population

People at high risk of diabetes

People with type one diabetes

People with type two diabetes

Women with gestational diabetes

I do not know

Other

14. Is the implementation of the NDP or of the diabetes health policies monitored?

- No
- I do not know
- Yes (please specify who does it)

15. Is the impact of the NDP (or of the diabetes health policies) evaluated periodically?

- Yes
- No

16. How frequently is the NDP evaluated?

17. Who is responsible for the evaluation of the NDP?

18. The NDP sufficiently addresses primary prevention of diabetes
[0= strongly disagree 5=strongly agree]

- 0
- 1
- 2
- 3
- 4
- 5

19. The NDP sufficiently addresses secondary prevention of diabetes
[0=strongly disagree 5= strongly agree]

- 0
- 1
- 2
- 3
- 4
- 5

20. Does the NDP include current diabetes figures (incidence, prevalence, territorial distribution, complication rates, etc.)?

- Yes
- No
- I do not know

21. Does the NDP outline the targets for improvement of these figures?

- Yes
- No
- I do not know

22. Is there a national diabetes registry, to record patient outcomes, in your country ? [If the answer is NO, please proceed to question no 25]

- No
- Yes (no link available)
- Yes (please provide the link)

23. To whom is the information in the diabetes registry accessible?
[Please select all that apply]

- Persons living with diabetes
- Registered health professionals
- I do not know
- Other

24. Is the information from this registry used to produce periodic reports regarding the status of diabetes in your country?

- No
 Yes (no link available)
 I do not know
 Yes (please provide a link)

25. The health system in your country sufficiently addresses prevention of diabetes (primary prevention)? [0=strongly disagree ... 5= strongly agree]

- 0 1 2 3 4 5

26. The health system in your country sufficiently addresses prevention of complications that can arise from diabetes e.g. heart disease, kidney disease, neuropathy, retinopathy [0=strongly disagree ... 5= strongly agree]

- 0 1 2 3 4 5

27. The health system in your country provides fair and equal access to medication and health services to all people living with diabetes [0=strongly disagree ... 5=strongly agree]

- 0 1 2 3 4 5

28. Who do you consider to be responsible for improving diabetes care:
[Please select all that apply]

- Health professionals
 Persons living with diabetes
 Politicians/Government
 Other

29. What are the priority improvements that need implementing to address prevention and treatment of diabetes in your country?

Health professionals topics

30. Are there opportunities for representatives of the persons with diabetes to engage in discussions/ debates with health care professionals about diabetes care in your country?

- Yes No

31. Do you feel that the patients' voice is listened to in such discussions/debates?

- Yes Sometimes No

32. In your opinion, do medical professionals have the resources to adequately treat persons living with diabetes in your country?

- Yes Maybe No I do not know

33. Are advances and improvements in diabetes care disseminated to your organization?

- Yes No

34. Current diabetes guidelines reflect the care persons with diabetes receive
[0=strongly disagree 5=strongly agree]

- 0 1 2 3 4 5

35. Are the persons with diabetes asked to offer feedback regarding the diabetes services provided in your country?

- Yes No I do not know

36. Do people with diabetes the following care check-ups and how frequently?
[Please select all that apply]

	No	Every 3 months	Every 6 months	Every year	Other
Foot examination (neuropathy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eye screening (retinopathy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kidney checks (nephropathy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiovascular disease risk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. How could communication and discussions be improved between your organization and health care professionals?

Persons living with diabetes topics

38. How do persons living with diabetes keep up to date with the most recent developments and advances in diabetes care?
[Please select all that apply]

- Internet
- Newsletters/publications
- Local health professionals
- Congresses/Conferences
- Other

39. In your country, what forms of education would better equip persons with diabetes to self-manage their condition? (e.g. group work, health care professional led, peer support, lectures, webinars, online resources)

40. Do you feel there is adequate therapeutic education for persons living with diabetes?

Yes

I do not know

No (please explain)

41. In your country, to what extent are mobile apps used by persons with diabetes to help them self-manage their condition?

[0=not much 5=very often]

0 1 2 3 4 5

42. In your country, do persons with diabetes receive guidance around mobile apps or health technology from health care professionals?

Yes

In some facilities

No

I do not know

43. To what extent do you agree that the healthcare system in your country address the needs of persons living with diabetes?

[0=strongly disagree ... 5=strongly agree]

0 1 2 3 4 5

44. To what extent do you agree that persons with diabetes are satisfied with their diabetes care in your country?

[0=strongly disagree ... 5=strongly agree]

0 1 2 3 4 5

45. Does your organization offer training for the persons with diabetes in non-clinical topics (e.g. social protection, employment, academic studies, moral or psychologic support, etc.)?

Yes

No

46. In your country, do persons living with diabetes assume responsibility for managing their condition? [0=Strongly disagree ... 5=Strongly agree]

0 1 2 3 4 5

47. In your country, is enough done to encourage persons with diabetes to self-manage and adhere to diabetes therapies?

[0=strongly disagree 5=strongly agree]

0 1 2 3 4 5

48. Do you feel that the voice of the persons with diabetes, is able to influence public policy making?

Yes

Sometimes

No

49. Do people with diabetes need to pay for the following diabetes care services:
 [Please select all that apply]

	Yes	For some	No
Diabetes-related medical services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes-related laboratory tests (e.g. blood tests, HbA1c, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes-related medicines or medical devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Special diets (e.g. gluten free)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other recommendations from health care professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

50. Does your organization contribute to producing evidence regarding the situation of diabetes in your country (satisfaction studies, adherence studies, quality of services, access to medication or medical services, etc.)?

Yes No

51. Is your organization consulted when new policies regarding diabetes are outlined?

Yes Sometimes No

52. What would enable your organization to have more influence and facilitate improved diabetes care?

53. Please denote what in your opinion are the barriers that impact on the healthcare you receive:

[Please select all that apply]

- General lack of knowledge and skills amongst health care professionals
- Time limitations during routing consultations
- Lack of incentives amongst healthcare staff
- Lack of information amongst healthcare staff
- Lack of information amongst patients
- Resistance of patients to changes
- Service not evenly implemented
- No barriers
- I do not know
- Other

54. Of these, which would be the greatest barrier to optimizing diabetes care in your country?

55. Please denote the solutions that could improve the healthcare that you receive

[Please select all that apply]

- Better treatments
- Improved health education for patients
- Improved training for health care professionals
- Better utilisation of technology for e-health
- I do not know
- Other

56. Of these, which would be the most effective solution to optimizing diabetes care in your country?

You have completed this questionnaire

Thank you for your precious time and valuable input!

We will advise you when the results of the survey are analyzed.

Appendix 3

IDF Europe is producing a publication to assess the translation of diabetes guidelines and recommended best practice into real-life care.

Following the responses to our first surveys, we would like to consolidate the identified barriers and to look for potential solutions by a two stage Delphi process. We are kindly asking you to dedicate about 15 minutes and fill in this survey.

We encourage you to ask any questions if at any point you have difficulty understanding the questionnaire.

We kindly ask for the questionnaire to be completed by as soon as possible, before 15 September, 2017.

For any administrative or technical queries, please contact Mr Cristian Andriciu at candriciu@gmail.com

Thank you very much for your valuable time and contribution to this important work.

With kind regards from the Editorial Committee.
IDF Europe

Please choose from the drop down list your country and organization:

Policy / health system related barriers

2. Lack of, improper structure, ineffective implementation, uneven monitoring or evaluation of National Diabetes Programmes or strategies [1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

3. Limited or uneven access to medicines, medical devices, health services, therapeutic education or peer support [1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

4. Ineffective use or uneven distribution of limited resources (diabetes health professionals, general practitioners, facilities, funds) [1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

5. Lack of or ineffective cost containment policies (pricing, level of compensation) [1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

6. Lack of, poorly implemented or not adapted diabetes guidelines - to address PWD needs, to match local environments or available level of funding

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

7. Ineffective management of health care programmes (limited monitoring, limited evaluation or limited development processes)

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

8. Uneven implementation / distribution of diabetes related health services

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

9. Lack of, improper structure or ineffective use of **diabetes registries**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

10. Limited involvement of health professionals and PWD representatives in the process of developing new public policies

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

11. Lack of official encouragement for patient empowerment

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

Health care professionals related barriers

12. Lack or limited training or supportive instruments for general practitioners managing PWDs

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

13. Uneven treatment patterns and care services offered to PWDs

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

14. Poorly supported and implemented prevention programmes (primary, secondary or tertiary)
[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

15. Limited time for consultations

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

16. Ineffective communication between health care professionals

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

17. Lack or uneven collaboration between health specialists, academia, and general practitioners

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

18. Lack or too few **interventions outside medical facilities** (schools, workplaces, families) for prevention and to address the complexity of living with diabetes

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

19. Limited numbers of **integrated facilities** or medical teams

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

20. Limited use of available or **new technologies** (including IT)

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

21. Incomplete **adherence** to existing diabetes guidelines

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

Persons living with diabetes barriers

22. Lack or insufficient basic knowledge of the persons with diabetes regarding diabetes and its late complications

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

23. Lack of skills to properly manage diabetes (PWDs or their families)

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

24. Poor adherence to recommended treatments or lifestyle changes

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

25. Lack or poor education of the families of the persons with diabetes

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

26. Lack or poor empowerment of the persons with diabetes

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

27. Lack of integration / unity / cooperation of PWD organizations

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

28. Poor communication of the PWD representatives with the health professionals' groups

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

29. Lack of or insufficient peer support

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

30. Weak or ineffective public voice of PWD organizations

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10

31. Limited human and financial resources for the PWD organizations
[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9
 10
-

Appendix 4



**International
Diabetes Federation
Europe**

Following the responses to our first stage of the Delphi process we are kindly asking you to dedicate about 10 minutes and fill in this survey. You may offer scores between "1=not important" to "10=very important" to any of the listed barriers that received the highest scores in the first stage. We have indicated the average score received by each barrier as well the score you have offered in the first stage.

We encourage you to contact us if at any point you have questions about the publication or about the Delphi process.

We kindly ask for the questionnaire to be completed by as soon as possible, **before 30 September, 2017**.

For any administrative or technical queries, please contact Mr Cristian Andricuc at candricuc@gmail.com

Thank you very much for your valuable time and contribution to this important work.

With kind regards from the Editorial Committee.
IDF Europe

Please choose from the drop down list your country and organization:

SECTION 1 - Policy / health system related barriers

Q2. (2.) Lack of, improper structure, ineffective implementation, uneven monitoring or evaluation of **National Diabetes Programmes** or strategies

You have previously marked this barrier with The average score is **8.13**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q3. (11.) Lack of official encouragement for **patient empowerment**

You have previously marked this barrier with The average score is **7.60**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q4 (9.) Lack of, improper structure or ineffective use of **diabetes registries**

You have previously marked this barrier with The average score is **7.43**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q5 (4.) Ineffective use or uneven distribution of **limited resources** (diabetes health professionals, general practitioners, facilities, funds)

You have previously marked this barrier with The average score is **7.33**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q6 (8.) **Uneven implementation** / distribution of diabetes related health services

You have previously marked this barrier with The average score is **7.33**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

Q7 (10.) Limited **involvement of health professionals and PWD** representatives in the process of developing new public policies

You have previously marked this barrier with The average score is **7.30**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

- END OF SECTION 1 -

SECTION 2 - Health care professionals related barriers

Q8 (14.) Poorly supported and implemented **prevention programmes** (primary, secondary or tertiary)

You have previously marked this barrier with The average score is **8.50**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

Q9 (15.) Limited **time** for consultations

You have previously marked this barrier with The average score is **8.23**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

Q10 (16.) Ineffective **communication** between health care professionals

You have previously marked this barrier with The average score is **7.90**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

Q11 (18.) Lack or too few **interventions outside medical facilities** (schools, workplaces, families) for prevention and to address the complexity of living with diabetes

You have previously marked this barrier with The average score is **7.87**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

Q12 (20.) Limited use of available or **new technologies** (including IT)

You have previously marked this barrier with The average score is **7.53**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

Q13 (12.) Lack or limited **training or supportive instruments** for general practitioners managing persons with diabetes (PWDs)

You have previously marked this barrier with The average score is **7.47**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

Q14 (19.) Limited numbers of **integrated facilities** or medical teams

You have previously marked this barrier with The average score is **7.47**

[1=not important, ... 10= very important]

- 1 2 3 4 5 6 7 8 9 10

- END OF SECTION 2 -

SECTION 3 - Barriers related to persons living with diabetes

Q15 (23.) Lack of **skills** to properly manage diabetes (PWDs or their families)

You have marked this barrier with The average score is **8.27**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q16 (24.) Poor **adherence** to recommended treatments or lifestyle changes

You have previously marked this barrier with The average score is **8.20**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q17 (25.) Lack or poor **education** of the families of the persons with diabetes

You have previously marked this barrier with The average score is **8.17**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q18 (31.) Limited human and financial **resources** for the PWD organizations

You have previously marked this barrier with The average score is **8.10**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q19 (22.) Lack or insufficient **basic knowledge** of the persons with diabetes regarding diabetes and its late complications

You have previously marked this barrier with The average score is **7.90**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

Q20 (26.) Lack or poor **empowerment** of the persons with diabetes

You have previously marked this barrier with The average score is **7.90**

[1=not important, ... 10= very important]

1 2 3 4 5 6 7 8 9 10

- END OF SECTION 3 -

Thank you for your precious time and valuable input!
We will advise you when the results of the survey are analyzed.

Appendix 5

Health policies, guidelines		
plan/programme	21	NDP, funding of, planned intervention, for diabetes management, GDM planning, advocacy, prevention, autonomy
policy	4	development, realistic, makers
school	4	policies for, interventions in
family	3	education for, policies for, information for
cost	2	of medicines, compensated

34

System management		
access/ availability of	21	medicine, services, equal, education, prevention, selfmanagement, medical devices, new technologies, medical devices, modern treatments, medical protocols, personnel, dieticians, tests
resources, funds/funding	20	financial, human, organization, limited/stretched, increase of, sustainable, lack of
guide(line)	15	for HCP, for self management, adherence/compliance to, development of to fit the real needs, adapted, international, national, regional, not considering costs and cost effectiveness
management/control	14	diabetes, self management, skills/knowledge for, quality means for, motivation for selfcontrol, plans for, of PWDs
implementation	14	of policies, equal/even, of technologies, of restrictions, of services, of NDP
support	8	of PWD suggestions, from Governments, from policy makers, for healthy lifestyles, for self management, for therapeutic education
primary care / general practitioners /family doctors	8	structure/organization of, involvement, knowledge of diabetes for, regular managing PWDs, cooperation with specialists
awareness	6	of the public, of the type 2 PWDs, about risk factors
registry	5	for diabetes persons, national
tests/lab analysis	3	compensation for, availability of, increased access to
incentives	3	lack of, for HCP
structure	3	prevention, primary care
evaluation	3	of interventions, of health systems
outcomes/results	3	of health services, patient

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Medical professionals		
education/training/ knowledge/ information/ skill	123	about healthy lifestyles, therapeutic, for PWD, for HCP, for families, for general population, sector (involvement of the), continuous, camps, vitally important, funding for, (involvement of the) Ministry of, equity in delivery, standard, reinforcement of, for GPs, equity, campaigns, training programmes, sharing of, funding of
treatment/care	63	knowledge about, collaborative, over/under, uniformity, self treatment, education for, improved, access to, resources/funding for, protocols for, guidelines for, of complication, of diabetes, availability, integrated, investment, improvement, professionals, systems, quality of, adequate, implementation of, foot, primary

prevention/ early diagnosis/detection/ screening	38	programmes, structured, access to, of type 2, of complications, a plan for, primary, secondary, tertiary, effectiveness of, of risk groups, of diabetes, of complications, for prediabetes, for diabetes, for GDM, for complications
time	21	limitations
complication	12	screening for, avoiding/preventing, early diagnosis of, treatment for, prevalence of
lifestyle	7	guidance for, healthy, collaborative interventions, modification of
support	6	of PWD suggestions, for healthy lifestyles, for self management, for therapeutic education,
communication	6	between specialities, as means to educate/inform, PWD & HCP
collaboration	5	for lifestyle interventions, social and medical, PWD & HCP
monitoring	5	of patients, self monitoring
intervention	4	in schools, in workplaces, for decrease overweight and obesity, evaluate
integration	4	of specialists' centers and universities, of different levels of assistance, of PWD organizations, of care
school	4	policies for, interventions in
family	3	education for, policies for, information for
implementation	2	education programmes, advanced IT technologies
empowerment	2	of PWDs, support for,

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PWDs		
awareness	6	of the public, of the type 2 PWDs, about risk factors
adherence/ compliance	3	PWD recommended treatment
family	2	education for, information for
empowerment	2	of PWDs, support for,
integration	1	of PWD organizations
communication	1	PWD & HCP
support	1	peer
collaboration	1	PWD & HCP
skill	1	lack of PWD skills
implementation	1	of peer support

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