



International  
Diabetes Federation  
Europe

# Living in COVID Times:

Experiences from People living with Diabetes

April 2021

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### Steering Committee

Dr Lauren Quinn, Academic Clinical Fellow and Specialty Registrar, Diabetes and Endocrinology; Dr Niti Pall, IDF Europe Chair; Prof Nebojsa Lalic, IDF Europe Chair Elect, President, Dr Jose-Manuel Boavida, IDF Europe Board Member; Prof Kostas Makrilakis, IDF Europe Board Member; Prof Tatjana Milenkovic, IDF Europe Board Member; Mrs Stella de Sabata, IDF Europe Board Member; Mrs Elisabeth Dupont, IDF Europe Regional Manager; Ms Sabine Dupont, IDF Europe Senior Consultant

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Cyprus Diabetic Association
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- FAND - Associazione Italiana Diabetici
- Associazione Medici Diabetologi
- Societa Italiana di Diabetologia
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Kazakhstan/Association of Doctors-  
Endocrinologists of Kazakhstan
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Kyrgyzstan
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### Writing team

Cristian Andriciu, Senior Consultant  
Elisabeth Dupont, IDF Europe Regional Manager  
Sabine Dupont, IDF Europe Senior Consultant

### Editing

Lisa Dolan, IDF Europe Communications Coordinator

### Layout

Lisa Dolan, IDF Europe Communications Coordinator  
Maartje Roskams, IDF Europe Youth Coordinator

## Contents

### Table of Figures

I.	Executive summary .....	8
II.	Introduction and rationale .....	9
III.	The COVID-19 context .....	9
III.1	What is COVID-19? .....	9
III.2	COVID-19's spread in Europe .....	10
III.3	Governments' responses.....	11
III.4	Challenges in implementing the actions/policies.....	13
III.4.1	Challenges in preventing transmission.....	13
III.4.2	Challenges in ensuring sufficient physical infrastructure and workforce capacity of medical units.....	13
III.4.3	Challenges in ensuring effective provision of current health services .....	14
III.5	COVID-19's impact on people living with diabetes .....	14
IV.	The IDF Europe survey .....	16
IV.1	Geographic coverage and dissemination .....	16
IV.2	The questionnaire .....	16
IV.3	Limitations.....	16
IV.4	Response rate.....	17
V.	Survey analysis .....	18
V.1	The responses of governments and health systems to the pandemic.....	18
V.1.1	Testing for COVID-19 .....	18
V.1.2	Effectiveness of the country's response in reducing the spread of COVID-19 for people living with diabetes .....	19
V.1.3	Effectiveness of protection measures when working .....	19
V.1.4	Guidance given for people living with diabetes .....	20
V.2	Living during COVID-19 .....	21
V.2.1	Diabetes management .....	21
V.2.2	Weight variations and activity levels.....	22
V.2.3	Blood glucose management .....	23
V.2.4	Hypoglycaemia & hyperglycaemia .....	24
V.2.5	Mental health .....	26
V.2.6	Financial concerns .....	28
V.3	Diabetes care during COVID .....	29
V.3.1	Access to medicines, supplies and technologies .....	29
V.4	Access to medical care .....	34
V.4.1	Access to diabetes related medical care .....	34



V.4.2	Access to non-diabetes related care .....	39
V.5	The shift to remote care.....	39
V.5.1	Availability and usage of remote consultations .....	39
V.5.2	Usage of technologies to support care and education.....	42
VI.	Conclusions.....	43
VII.	Recommendations.....	45
VIII.	Appendices .....	48
VIII.1	Appendix 1 – Respondents’ profile .....	48
VIII.2	Appendix 2 – Country abbreviations.....	49
VIII.3	Appendix 3 – The IDF Europe COVID-19 questionnaire .....	50
IX.	References .....	58

## Table of Figures

Figure III.2-1 – Evolution of the weekly number of infections in the EU, EEA and the UK between March and December 2020 .....	10
Figure III.2-2 – Evolution of the weekly number of infections in countries other than the EU, EEA and the UK between March and December 2020 .....	10
Figure III.3-1– The Oxford government response index for EU, EEA and the UK (part 1) .....	11
Figure III.3-2– The Oxford government response index for EU (part 2) .....	11
Figure III.3-3– The Oxford government response index for European countries other than the EU, EEA or UK .....	12
Figure III.3-4 – Percentage of COVID-19 cases out of the total population between March and December 2020 .....	12
Figure IV.4-1 – List of countries included in the analysis .....	17
Figure V.1-1 – Ease of testing for COVID-19 .....	18
Figure V.1-2 – Reasons for having a COVID-19 test .....	18
Figure V.1-3 – Effectiveness of government measures to reduce the spread of COVID-19 to PwD .....	19
Figure V.1-4 – Protection measures at the workplace to lower the risk of COVID-19 .....	19
Figure V.1-5 – Guidance given to PwD during COVID-19 .....	20
Figure V.1-6 – Requirements to better manage diabetes .....	20
Figure V.1-7 – Sources of information when receiving guidance .....	21
Figure V.1-8 – Proportion of respondents receiving guidance from diabetes associations, by country .....	21
Figure V.2-1 – Self-perceived ability to manage diabetes, before and during COVID-19 restrictions .....	22
Figure V.2-2 – Weight variations during COVID-19 .....	22
Figure V.2-3 – Physical activity variations during COVID-19 .....	22
Figure V.2-4 – Physical activity and weight variations during COVID-19, by country .....	23
Figure V.2-5 – Blood glucose testing frequency during COVID-19 .....	23
Figure V.2-6 – Blood glucose testing frequency, by country, during COVID-19 .....	23
Figure V.2-7 – Blood glucose readings variability, by country, during COVID-19, compared to before COVID-19 .....	24
Figure V.2-8 – Blood glucose testing frequency, by diabetes type .....	24
Figure V.2-9 – Blood glucose reading variability, by diabetes type, during COVID-19 .....	24
Figure V.2-10 – Hypoglycaemia, severe hypoglycaemia and hyperglycaemia – episodes registered during the pandemic .....	25
Figure V.2-11 – Frequency of hypoglycaemic events, by country .....	25
Figure V.2-12 – Frequency of hyperglycaemic events, by country .....	25
Figure V.2-13 – Anxiety levels during COVID-19 .....	26
Figure V.2-14 – Frequency of low mood episodes .....	26
Figure V.2-15 – PwD’s biggest worries during COVID-19 .....	26
Figure V.2-16 – PwD’s biggest worries during COVID-19, by country .....	27
Figure V.2-17 – Perception of the risk to become infected with COVID-19 and/or develop a serious form of the disease .....	28
Figure V.2-18 – Proportion of respondents experiencing financial concerns as a result of COVID-19 .....	28
Figure V.2-19 – Proportion of respondent experiencing financial concerns as a result of COVID-19, by country .....	28
Figure V.3-1 – Ease of access to diabetes medicines pre-COVID and during COVID-19 restrictions .....	29
Figure V.3-2 – Ease of access to diabetes medicines prior to and during COVID-19 restrictions, by country .....	29
Figure V.3-3 – Ease of access to diabetes supplies prior to and during COVID-19 .....	30
Figure V.3-4 – Ease of access to diabetes equipment prior to and during COVID-19 .....	30
Figure V.3-5 – Ease of access to diabetes supplies prior to and and during COVID-19, by country .....	30
Figure V.3-6 – Ease of access to diabetes equipment prior to and .....	30
Figure V.3-7 – Biggest barriers to accessing medicines, supplies and technologies, during COVID-19, by country .....	31
Figure V.3-8– Biggest barriers to accessing medicines, supplies and technologies during COVID-19, by country .....	32
Figure V.3-9 – PwD’s stockpiling of medicines/supplies, by country .....	32
Figure V.3-10 – PwD’s stockpiling of diabetes supplies and medicines during the pandemic .....	32
Figure V.3-11 – Proportion of PwD worried about potential shortages of medicines, supplies and technologies, during COVID-19 .....	33
Figure V.3-12 – PwD’s worries about potential shortages if medicines/supplies and technologies, during COVID-19, by country .....	33
Figure V.4-1 – Disruption in routine diabetes care during COVID-19 .....	34
Figure V.4-2 – Time delays in rescheduling appointments for routine diabetes care during COVID-19 .....	34
Figure V.4-3 – Time delays in rescheduling appointments for routine diabetes care during COVID-19 by country .....	35
Figure V.4-4 – Disruptions in appointments for the screening of diabetes complications during COVID-19 .....	35
Figure V.4-5 – Time delays in rescheduling appointments for the screening of diabetes complications during COVID-19 .....	35
Figure V.4-6 – Access to the multidisciplinary team, during COVID-19 .....	36
Figure V.4-7 – Biggest barriers to accessing diabetes care during COVID-19 .....	36

Figure V.4-8 – Perception of the effectiveness of outpatient care during COVID-19 .....	37
Figure V.4-9 – Perception of the effectiveness of outpatient care during COVID-19, by country .....	37
Figure V.4-10 – Proportion of respondents receiving advice from their healthcare team regarding diabetes management during COVID-19 and proportion contacted proactively .....	38
Figure V.4-11 – Proportion of respondents not receiving advice from their healthcare team.....	38
Figure V.4-12 – Proportion of respondents contacted proactively by healthcare team.....	38
Figure V.4-13 – Biggest barriers to non-diabetes-related care during COVID-19 .....	39
Figure V.5-1 – Rating of virtual diabetes consultations .....	39
Figure V.5-2 – Rating of virtual diabetes consultations, by country .....	40
Figure V.5-3 – Technology used to conduct virtual diabetes consultations during the pandemic .....	40
Figure V.5-4 – Proportion of respondents having attended virtual consultations prior to the pandemic.....	40
Figure V.5-5 – Proportion of respondents attending virtual consultations during the pandemic compared to proportion stating these were not available prior to the pandemic .....	41
Figure V.5-6 – Proportion of respondents considering attending virtual consultations in the future .....	41
Figure V.5-7 – Proportion of respondents considering attending virtual consultations as part of a mix in the future .....	42
Figure V.5-8 – Use of technologies to support diabetes management during the pandemic .....	42

## I. Executive summary

COVID-19 has had a detrimental impact on people living with diabetes. Not only does the virus itself have the potential to cause severe harm to people living with the condition, but the restrictions imposed by governments to contain its spread have also taken their toll. This has led to delays in the diagnosis of diabetes and/or its complications, adversely affected the ability of people living with diabetes to manage their condition and had a negative impact on their psychological health.

The “Living in COVID-19 times” report is based on a survey of 3,480 people living with diabetes across 32 countries in Europe conducted between August and October 2020. It primarily aims to understand how the COVID-19 crisis has affected the everyday life and well-being of people living with diabetes and their diabetes care. It also seeks to identify gaps and good practices in healthcare provision as well as to highlight some of the effective solutions that were implemented during the crisis to remedy the challenges posed by the new restrictions.

All proxy indicators of diabetes management, including changes in weight and physical activity, effectiveness of self-management, and fluctuations in blood sugar levels, suggest that survey respondents were less able to manage their diabetes well during COVID-19 than prior to the pandemic. More than 50% also reported a deterioration of their mental health, with more frequent incidences of low mood. Additionally, over 40% of participants reported being very or extremely more anxious during the pandemic.

While most respondents did not experience any major challenges in accessing medicines and supplies nor any financial concerns, this masked severe geographical inequalities. Difficulties in access as well as financial worries were especially marked in central and eastern European countries as well as in the south of Europe. By contrast, there were significant disruptions to people living with diabetes’ ability to access their diabetes and non-diabetes related care, reflecting the restrictions placed on face-to-face interaction imposed by

many countries. Many healthcare systems responded rapidly to the challenge and the period saw a huge rise in the number of virtual consultations and a move towards increased use of digital tools. However, the virtualisation of care relied quite heavily on older forms of communication such as telephone consultations rather than on newer technologies in the form of video calls and internet-based tools. This underlines the limited deployment of e-health across Europe pre-pandemic.

Fear of contamination was a greater barrier to accessing medication and technologies than the actual supply itself and it was also the most significant obstacle to accessing care. Where shortages of medicines/technologies/supplies occurred, they tended to concern primarily sensors and test strips, although some respondents also noted shortages or delays in getting supplies of insulin and metformin.

While the virtualisation of care was generally deemed to have been a success, more will need to be done to convince the 30% of respondents who remarked that they would not want virtual consultations in the future.

Although healthcare systems rallied together across Europe, the COVID-19 crisis has clearly brought to light, firstly their weaknesses and secondly, the necessity to reduce, and better manage, the burden of chronic diseases to shore up their resilience. This means not only accelerating the pace of innovation and digitalisation, but also re-thinking investment strategies to prevent the development of chronic disease, and engaging more meaningfully with people living with diabetes to understand and respond to their needs – for example, better therapeutic education and psychological support. This also means shifting towards a truly integrated and value-based model of care, which recognises the health outcomes that matter most to people living with the condition.



## II. Introduction and rationale

Since WHO declared COVID-19 a pandemic in March 2020<sup>1</sup>, governments around the world developed specific recommendations and imposed measures to limit the spread of the disease, decrease its burden on healthcare systems, and protect their population and their economies.

Diabetes was quickly identified as one of the major risk factors for developing severe forms of COVID-19, placing an unprecedented physical and psychological burden on people living with diabetes (PwD) in an attempt to protect themselves from the risk of infection. The restrictions imposed by governments in response to the crisis also had a severe impact on the ability of PwD to manage their routine care (through disruptions in access to care, medicines and supplies) and get adequately screened for potential complications. There were significant delays in new diagnoses taking place.

To better understand the experience of living with diabetes during the pandemic and the overall impact this had on their mental health, self-management and care, identify gaps in healthcare provision across Europe as well as good practices developed during the crisis, IDF Europe conducted a survey on the impact COVID-19 had on PwD, based on their perceptions and experiences. The survey was conducted between August and October 2020, and, therefore, broadly reflects PwD's experience of the first wave of the pandemic across Europe – from the beginning of restrictions, through to a period widely characterised by severe lockdowns and restrictions on movements, and finally an easing of these restrictions.

## III. The COVID-19 context

### III.1 What is COVID-19?

The ongoing COVID-19 pandemic is caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). It was first identified in December 2019 in Wuhan, China. WHO declared the outbreak a Public Health Emergency of International Concern in January 2020 and a pandemic in March 2020.

The virus spreads mainly through close contact between individuals. Recommended preventive measures include social distancing, wearing a face mask in public, ventilation and air-filtering, hand washing, sneezing or coughing in one's elbow, disinfecting surfaces, and monitoring and self-isolation for people exposed or symptomatic.

Although some vaccines have now been approved and many more are being developed, at the time of the outbreak few therapeutic options existed to prevent or treat the most severe cases of the disease. Authorities worldwide responded by implementing travel restrictions, lockdowns, workplace hazard controls, and facility closures.

### III.2 COVID-19's spread in Europe

The pandemic has caused global social and economic disruption, including the largest global recession since the Great Depression<sup>ii</sup>. Misinformation has circulated through social media and mass media<sup>iii</sup>.

The evolution of the infections across Europe differed from country to country and the number of confirmed cases had three major peaks at the time of writing: one in spring and one in autumn 2020 and one in the first quarter of 2021.

According to WHO 45,877,941 confirmed cases and 980,586 deaths due to the COVID-19 were recorded in the WHO Europe Region by April 4, 2021.

The weekly evolution of the number people infected during 2020 is presented below (adjusted by the respective countries' populations).

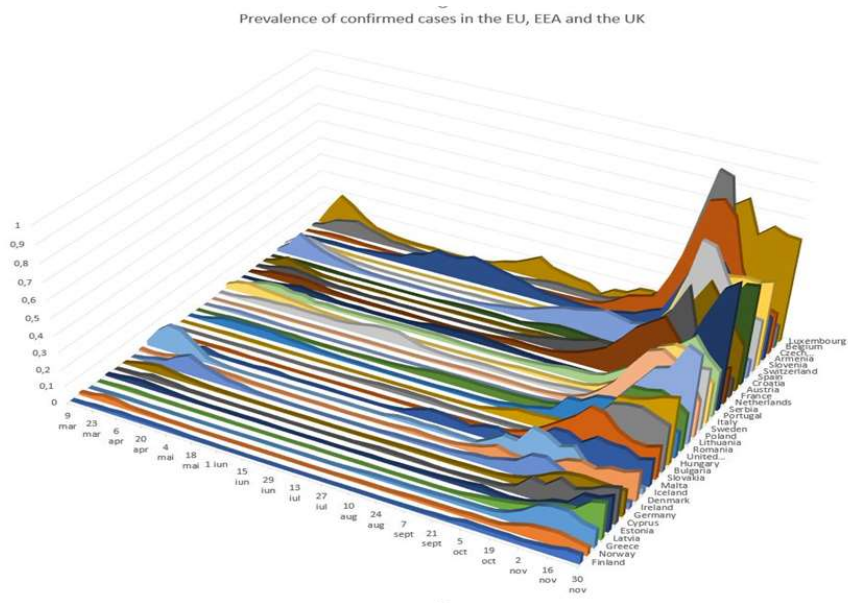


Figure III.2-1 – Evolution of the weekly number of infections in the EU, EEA and the UK between March and December 2020<sup>iv</sup>

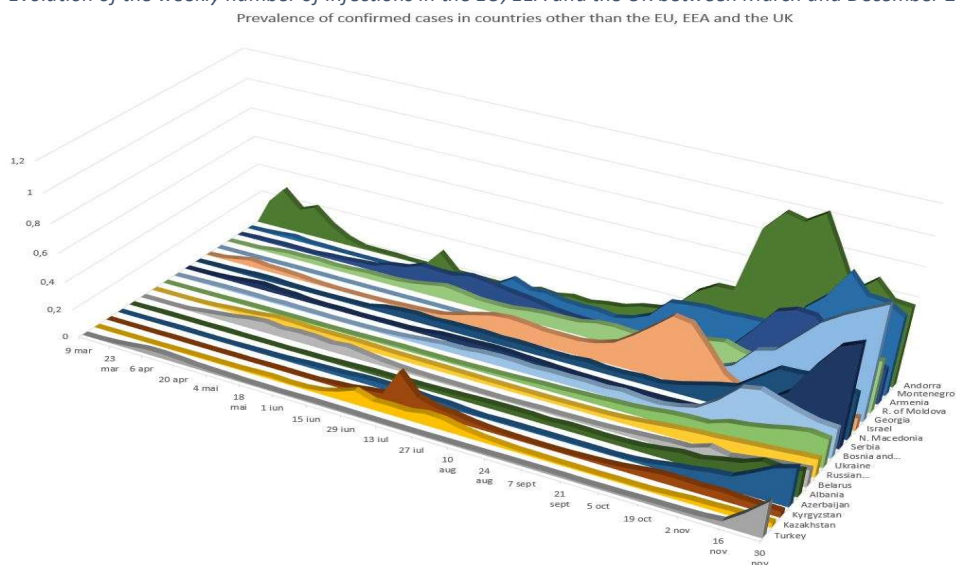


Figure III.2-2 – Evolution of the weekly number of infections in countries other than the EU, EEA and the UK between March and December 2020<sup>v</sup>

### III.3 Governments' responses

At different times and for different periods of time, local governments adopted measures to limit the spread of COVID-19, facilitate delivery of health services, and to support the economy. A record of these policies is held by WHO Europe, the European Commission and the European Observatory of Health Systems and Policies.<sup>vi</sup> The up-to-date description of the interventions taken by the governments may be accessed [here](#).<sup>vii</sup>

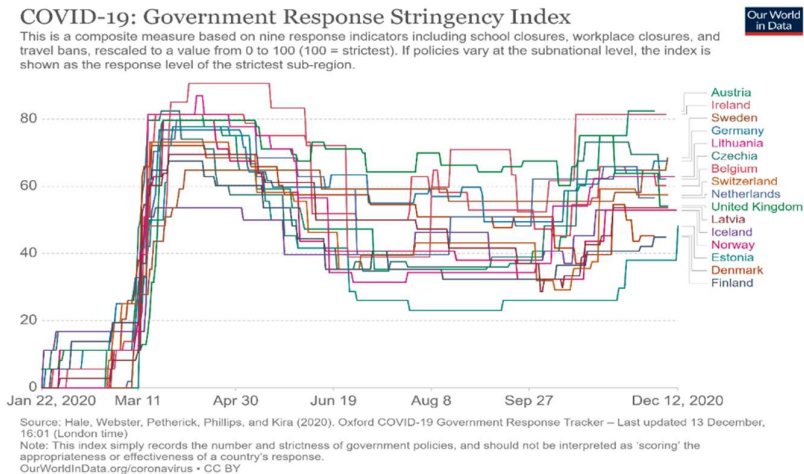


Figure III.3-1– The Oxford government response index for EU, EEA and the UK (part 1)

The University of Oxford (the Blavatnik School of Government) developed the Oxford COVID--19 Government Response Tracker (OxCGRT) that systematically collects information on several different common policy responses that governments have taken in response to the pandemic on 18 indicators. The Oxford index suggests that there was a more coordinated policy approach in the countries of the EU, EEA and the UK as opposed to the widespread approaches by the other European countries.

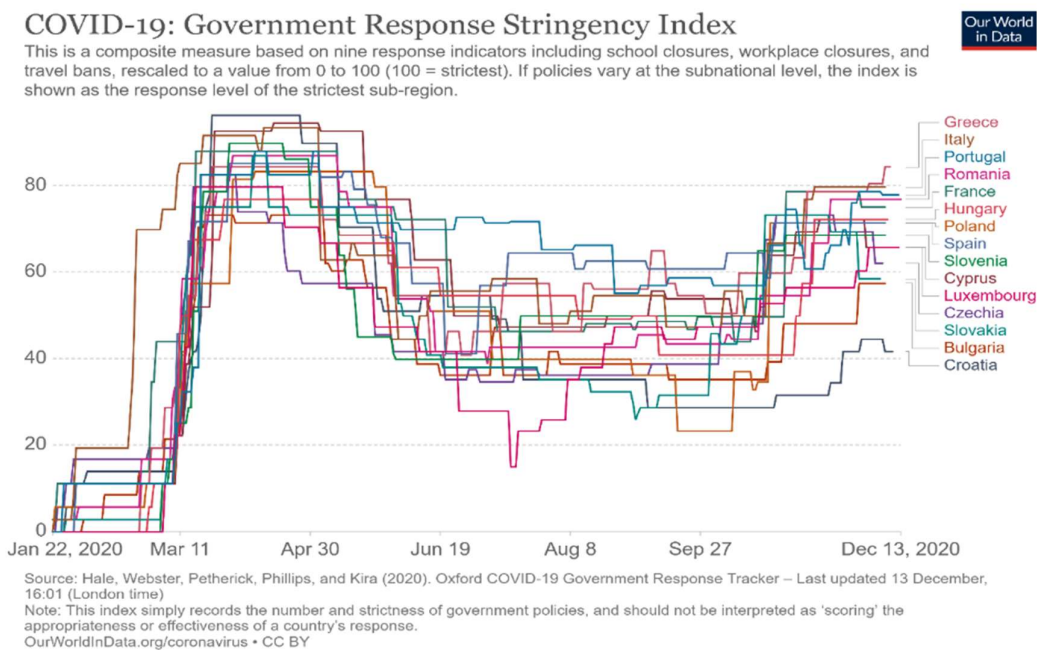
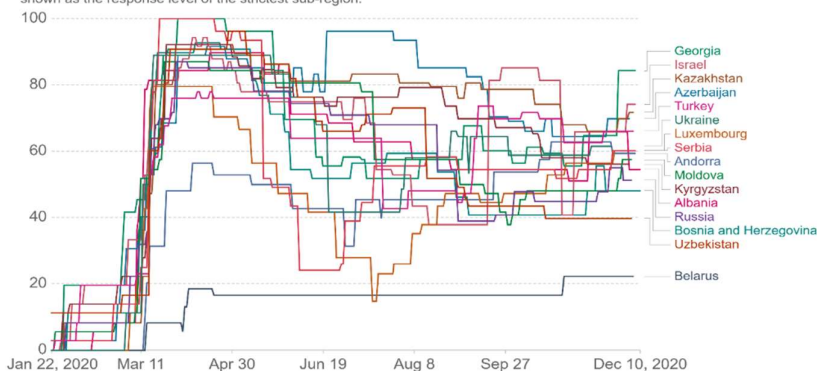


Figure III.3-2– The Oxford government response index for EU (part 2)

### COVID-19: Government Response Stringency Index

This is a composite measure based on nine response indicators including school closures, workplace closures, and travel bans, rescaled to a value from 0 to 100 (100 = strictest). If policies vary at the subnational level, the index is shown as the response level of the strictest sub-region.

Our World  
in Data



Source: Hale, Webster, Petherick, Phillips, and Kira (2020). Oxford COVID-19 Government Response Tracker – Last updated 10 December, 13:01 (London time)  
Note: This index simply records the number and strictness of government policies, and should not be interpreted as 'scoring' the appropriateness or effectiveness of a country's response.  
OurWorldInData.org/coronavirus - CC BY

The effectiveness of these policies may be generally assessed by the percentage of the weekly or accumulated cases out of the general population and it depends on timeliness, duration, content, enforcement, general population adherence as well as other cultural or economic factors. Over the period between March and December 2020 the number of people who tested positive for infection with COVID-19 represented between 0.2% (Uzbekistan) and 10.2% (Andorra) of the respective countries' populations.

Figure III.3-3– The Oxford government response index for European countries other than the EU, EEA or UK

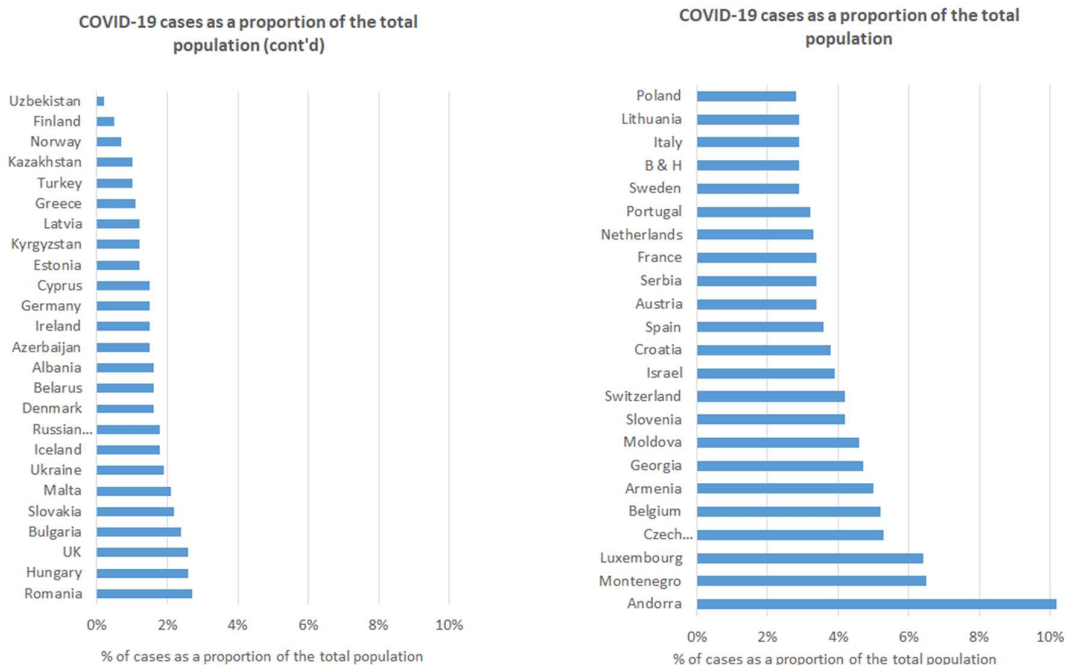


Figure III.3-4 – Percentage of COVID-19 cases out of the total population between March and December 2020<sup>viii</sup>

The European Commission has coordinated a common European response to the coronavirus outbreak. It has taken resolute action to reinforce the public health sectors and mitigate the socio-economic impact in the European Union. The Commission has taken actions and made recommendations across several areas: public health, travel, research and innovation, jobs and economy, crisis management and solidarity, digital solutions, emergency support, transportation and fighting disinformation.



As of April 2021, the European Commission had authorised six contracts with pharmaceutical companies (of which vaccines for two have yet to be approved by the European Medicines Agency) for the procurement of 2.6 billion doses of vaccines, and had concluded talks with two additional manufacturers for the supply of 260 million doses<sup>ix</sup>. In the same time the Russian Federation approved the use of an anti-COVID-19 vaccine (Sputnik V).<sup>x</sup>

### III.4 Challenges in implementing the actions/policies

#### III.4.1 Challenges in preventing transmission

Most countries were rather strict in addressing and enforcing measures to prevent the transmission of COVID-19 (according to the Oxford Government Response Stringency Index) during the first wave of COVID-19 infections. The second wave came in with higher numbers of affected people (Figures III.2.1 and III.2.2) but the level of response by governments was less strict (Figures III.3.1, III.3.2 and III.3.3).<sup>xi</sup>

Some of the challenges that exist in preventing transmission of the virus are:

- Populations' level of adherence to the regulations
- Inadequate skills or limited access to the internet, smart phones, tablets, computers etc. for teleworking, health consultations and/or shopping
- Distrust that the risk of COVID-19 infection is real
- Fatigue from adhering to the regulations
- Inability for some people and businesses to work and function remotely.

#### III.4.2 Challenges in ensuring sufficient physical infrastructure and workforce capacity of medical units

Facing a sharp increase in the number of people infected with COVID-19, medical systems needed to ensure that physical infrastructure was in place and a specialized workforce available. Transient measures were applied rapidly to ensure the physical infrastructure in new (tents, sports or concert halls, mobile units), or existing health units that were reshaped to cope with the new requirements and equipment. WHO Europe, the European Commission and the European Observatory on Health Systems and Policies worked together to collect information on how countries were responding to the crisis and WHO Europe provided guidance to strengthen the health systems' response<sup>xii</sup>.

Some of the challenges faced by health systems at the onset of the pandemic were the lack of:

- credible guidelines and verified treatments
- sufficient medical supplies
- trained personnel to handle infectious conditions
- adequate space and specific apparatus mainly for intensive care units (ICUs) and/or personal protective equipment (PPE)
- clear guidance in handling comorbidities in patients that contracted COVID-19

### III.4.3 Challenges in ensuring effective provision of current health services

Current health services had to be redesigned to cope with the decreased available space and personnel while continuing to deal with scheduled appointments, tests and/or operations. Non-COVID19 services had to continue operating while preventing the spread of the infection. This had to be done in the context of reduced resources, fewer face-to-face consultations and medical units that had become, or had the potential to become, clusters of COVID-19 cases.

### III.5 COVID-19's impact on people living with diabetes

From the early stage of the pandemic, many medical articles and status reports showed that diabetes was a key risk factor for severe forms of the disease in infected individuals. In the European Union (EU), European Economic Area (EEA) and United Kingdom (UK) over a one-week period (as an average for the month of December 2020), 6.5% of the total number of individuals registered with COVID-19 infection and under observation or care were living with diabetes and some 59% needed to be hospitalized, including close to 9% of whom were suffering from severe stages. Approximately 12.5% of the people with diabetes and COVID-19 infection died.<sup>xiii</sup>

The European Centre for Disease Control (ECDC) states that “underlying health conditions reported among adult patients with severe COVID-19 include hypertension, diabetes, cardiovascular disease, chronic respiratory disease, chronic kidney disease, immune compromised status, cancer, smoking and obesity. Pre-existing medical conditions have also been suggested as a risk factor for severe disease and ICU (Intensive Care Unit) admission in children and adolescents.”<sup>xiv</sup>

Medical studies published between May and October 2020 indicated that:

- Pre-existing diabetes does not present a higher risk of infection with COVID-19, compared with the risk in the general population<sup>xv, xvi, xvii</sup>
- Pre-existing poorly managed diabetes presents a greater risk of severe illness and in-hospital mortality in patients admitted with COVID-19<sup>xviii, xix, xx, xxi, xxii, xxiii, xxiv</sup>
- The COVID-19 pandemic also presents the risk of worsening the outcomes of diabetes treatment due to disruptions caused by the pandemic, including stress and changes to routine care, diet, and physical activity<sup>xxv</sup>
- PwD have COVID-19-specific worries related to their diabetes, which are associated with poorer psychosocial health. These worries should be addressed through support targeting the specific questions and needs of individuals living with diabetes as well as frequent updates on new knowledge regarding COVID-19 and diabetes.<sup>xxvi, xxvii</sup>
- Health services for PwD are affected by the presence of the pandemic due to lack of or limited medical appointments or reduced hospital attendance for diabetes emergencies.<sup>xxviii</sup>

Not becoming infected is the easiest prevention measure for PwD (as with the general population) and should keep them safe from becoming severely ill. The rate of adherence to the basic general recommendations greatly depends on health literacy levels and the information people receive in a timely fashion from trusted sources.

At the time of publishing, only some recommendations regarding the steps medical professionals should take when a person with diabetes tests positive for COVID-19 have been published.<sup>xxix</sup> There is currently no official guidance to prioritize these cases if they need in-patient treatment. Many healthcare professionals and PwD rely on the information shared by their own diabetes associations and/or IDF Europe. Many associations have organised webinars, issued guidelines, opened support hotlines, etc.

Few, if any, of the studies looking at the impact of COVID-19 on PwD have drawn on PwD's own experience of the COVID-19 epidemic. This was a key driver of this study, which aims to provide an analysis of this impact, based on PwD's needs, opinions and perspectives.

## IV. The IDF Europe survey

### IV.1 Geographic coverage and dissemination

In order to understand how the COVID-19 crisis has affected PwD, their everyday life and well-being, as well as their diabetes care, IDF Europe conducted a survey between August and October 2020. The survey was available in 22 languages and was promoted via the IDF Europe's social media channels, IDF Europe's Member Organisations (70 diabetes organizations in 44 European countries) and third-party channels (e.g., other NGOs and some corporate partners' websites).

### IV.2 The questionnaire

The questionnaire, presented in [Appendix 3](#), included 75 questions addressing information about the respondents, COVID-19 testing and treatment, diabetes management and access to medication and medical devices.

The study aimed to gather information about topics characterising the well-being of people with diabetes: some that are present in normal times and some that were induced by the pandemic crisis. The following indicators were used to analyse PwD's perceptions of the restrictions imposed prior to, during and after the pandemic.

- Access to specific medicines and medical devices
- Access to medical services (outpatient, inpatient or emergency) related to diabetes and its complications as well as to other situations that are not related to diabetes
- Use and acceptance of new ways of ensuring regular medical check-ups (telemedicine)
- Capacity to manage diabetes (weight control, physical activity, monitoring of the blood glucose levels, frequency and severity of acute events, psychological balance, recommended diet or regimen of life during the pandemic)

A number of additional factors were highlighted by measures brought in to prevent or restrict face-to-face interactions:

- Severity of the pandemic
- Access to reliable, trusted, clear and proactive guidance in managing diabetes and preventing infection
- Testing and treatment services received for COVID-19
- Effectiveness of the containment measures taken by the governments

### IV.3 Limitations

The questionnaire was available in 22 languages either online or in printed form. The ability of people with limited access to internet to participate might have been limited. The actual reach of the study may also have reflected the communication activities or strengths of local partner organisations as well as the extent of their own work in relation to COVID-19 and/or time availability to promote the survey. Some countries had similar national surveys that were conducted simultaneously which might also have limited the participation.

As different countries applied different measures to contain the spread of the COVID-19 infection at different moments, for different lengths of time and to different degrees, the actual responses offer a composite impression of the impact of the anti-COVID-19 measures.



Medical services improved continuously throughout the period that the survey was conducted (clarifications regarding treatments, availability of specific tests, availability of specific medication, personal protective equipment (PPE) adapted for the pandemic, etc.) and more options became available within the span of the study which are, thus, not reflected in the questionnaire.

#### IV.4 Response rate

Responses were obtained from 3,566 PwD or their relatives/carers from 49 European countries – with at least one respondent in every country. For the purpose of presenting a representative analysis across Europe, and to account for the uneven distribution of responses across countries, responses were weighted based on the size of the population living with diabetes in each European country. Countries with low response rates were removed from the analysis. The final number of responses included in the study was 3,480 across 32 countries. A more detailed country-level analysis is provided in this report for 18 countries with more than 50 responses each. Individual country profiles have also been developed.

Albania	Finland	Latvia	Portugal
Austria	France	Lithuania	Romania
Belgium	Germany	Luxembourg	Serbia
Bosnia & Herzegovina	Greece	Malta	Slovenia
Bulgaria	Ireland	Netherlands	Spain
Croatia	Italy	North Macedonia	Sweden
Cyprus	Kazakhstan	Norway	Switzerland
Czech Republic	Kyrgyzstan	Poland	UK

Figure IV.4-1 – List of countries included in the analysis

## V. Survey analysis

### V.1 The responses of governments and health systems to the pandemic

Respondents were asked to give their opinion on their government’s handling of the pandemic, including their perception of the measures implemented to prevent the spread of COVID-19, the guidance given, as well as the ease of testing for COVID-19. They were also asked to comment on the recommendations that were made specifically with regard to PwD in relation to their health and general interactions during the crisis.

#### V.1.1 Testing for COVID-19

Just under a quarter of all respondents were tested for COVID-19, primarily because they were displaying symptoms of infection. Two-thirds suggested that testing was easy or very easy, with under 10% reporting that it had been difficult or very difficult. Of the countries with at least 50 respondents to this question, only in Ireland did a greater number of respondents (15%) than the European average (9%) report that the testing had been difficult or very difficult.

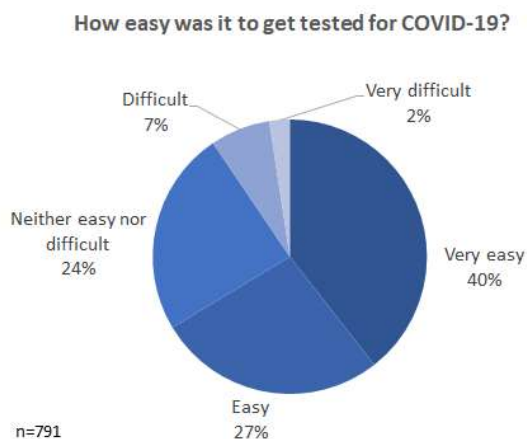


Figure V.1-1 – Ease of testing for COVID-19

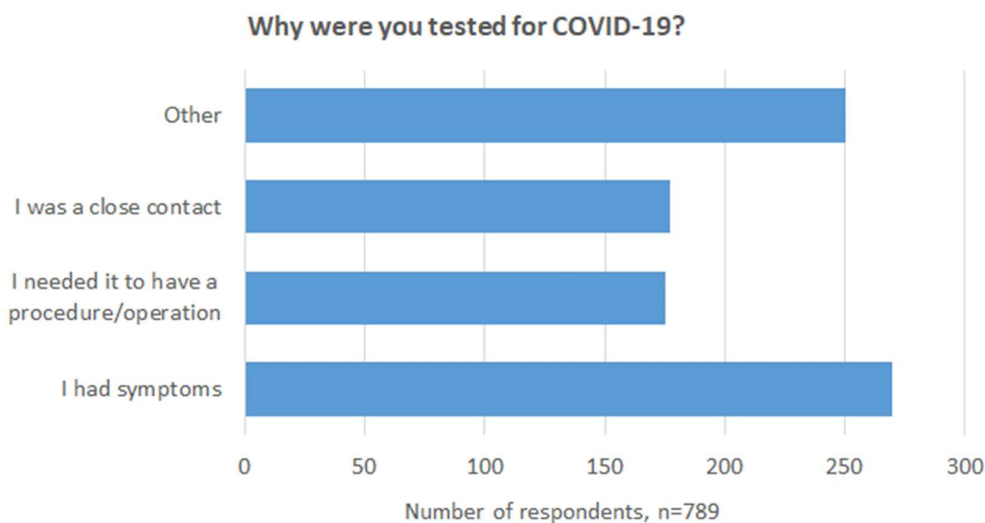


Figure V.1-2 – Reasons for having a COVID-19 test

### V.1.2 Effectiveness of the country’s response in reducing the spread of COVID-19 for people living with diabetes

Overall, PwD did not feel that their governments had been very successful in limiting the spread of COVID-19 to their communities. Just under a quarter of respondents across Europe believed that their government had been totally ineffective in this endeavour, and a further quarter, ineffective.

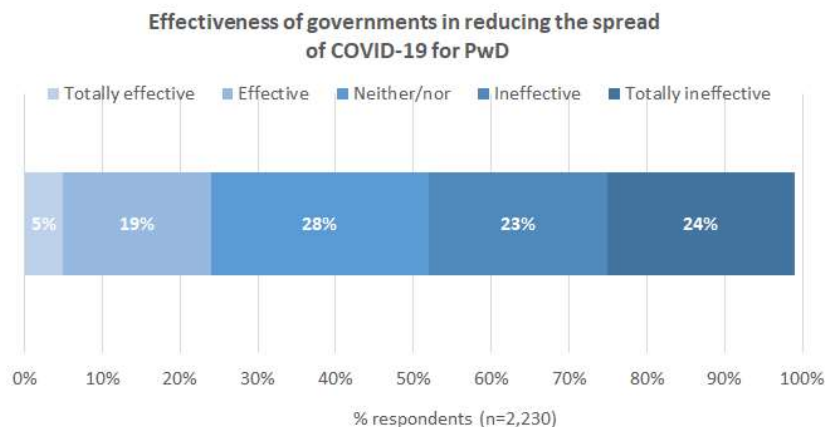


Figure V.1-3 – Effectiveness of government measures to reduce the spread of COVID-19 to PwD

### V.1.3 Effectiveness of protection measures when working

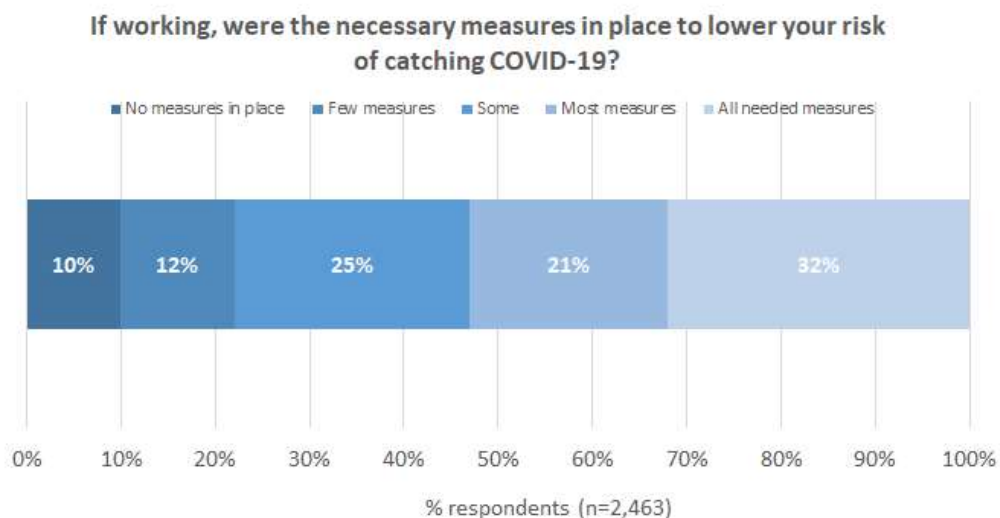
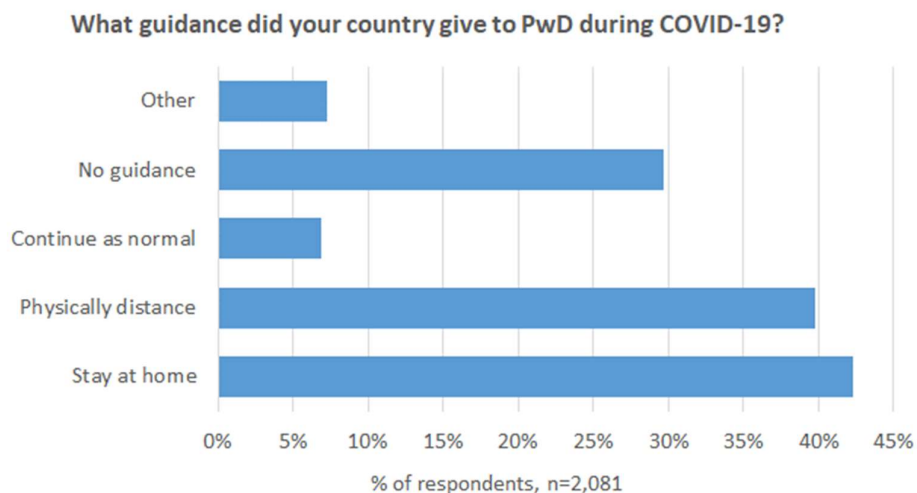


Figure V.1-4 – Protection measures at the workplace to lower the risk of COVID-19

More than half the respondents who had to go to their workplace during the pandemic reported that the measures taken by governments to limit the spread of COVID-19 generally, and specifically in the workplace, were, to a great extent, in place. This was the case in most countries, with the exceptions of the Czech Republic (48% considering that most or all measures were in place), Spain (44%), Finland (43%), North Macedonia (39%) and Greece (34%).

#### V.1.4 Guidance given for people living with diabetes



Guidance for PwD largely followed the guidelines for the general population. Just under one third of all respondents said that there was no specific guidance given to people living with diabetes.

Figure V.1-5 – Guidance given to PwD during COVID-19

Many respondents also commented, however, to the fact that even when specific guidance was given, it did not necessarily differentiate between different types of diabetes, or situations with regard to diabetes control – e.g. risk levels based on blood glucose measurements. Asked in a separate question what would have helped them manage their diabetes better, more than three quarters of respondents indicated more information and clearer recommendations for PwD.

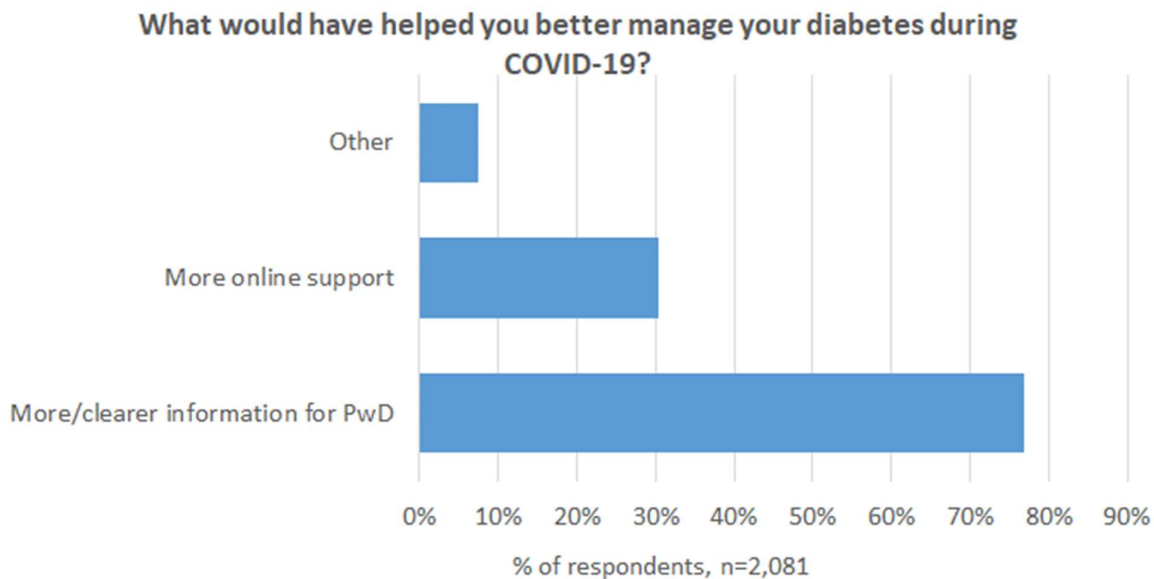


Figure V.1-6 – Requirements to better manage diabetes



Diabetes associations were a key channel of information for PwD, with more than one third of respondents citing them as a source, although unsurprisingly, government information was by far the single largest source of information via a number of information channels and materials. A large proportion of respondents in five countries in particular cited their diabetes association as a source of guidance – France, Spain, Portugal, Norway and Italy.

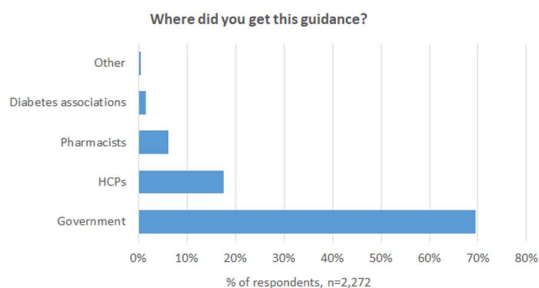


Figure V.1-7 – Sources of information when receiving guidance

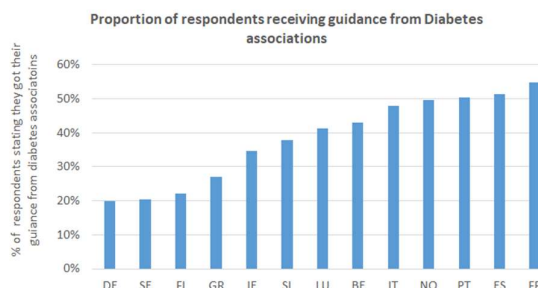


Figure V.1-8 – Proportion of respondents receiving guidance from diabetes associations, by country

## V.2 Living during COVID-19

In this section, respondents were asked to comment on their ability to manage their diabetes during the pandemic, as well as on a number of proxy indicators for diabetes management, such as physical activity levels, weight, low mood, etc.

### V.2.1 Diabetes management

The main prevention measures in place in most European countries during the pandemic included:

- Wearing a face mask in public spaces and covering both mouth and nose
- Working or learning from home, when possible
- Keeping a safe distance from the other people and avoiding crowded places
- Frequently washing or sanitizing hands

Additional measures included altered business hours (or the closure) of shops, other businesses, and pharmacies. In some cases, the measures led to delays in the supply of certain foods and medical supplies, increased time spent in virtual meetings, increased use of online tools for ordering food and/or other goods, obtaining medical advice and/or prescriptions and communicating with family and friends, and reduced income.

All of these had a negative effect on the ability of a number of PwD to manage their condition. The proportion of respondents who rated their ability to manage their diabetes as not effectively or not very effectively rose from more than 3% pre-COVID-19 to 11% during the COVID-19 crisis. Meanwhile, the proportion of people who rated their ability as being average rose from 22% to just under 28% in the same period.

There were only marginal differences in people’s ability to manage their diabetes prior to and during COVID-19, depending on the type of diabetes with which they live. There was a slightly greater increase in the proportion of people living with Type 2 Diabetes (T2D) compared to the proportion of people living with Type 1 Diabetes (T1D) reporting that they could not manage their diabetes effectively or very effectively during COVID-19, compared to pre-COVID-19.

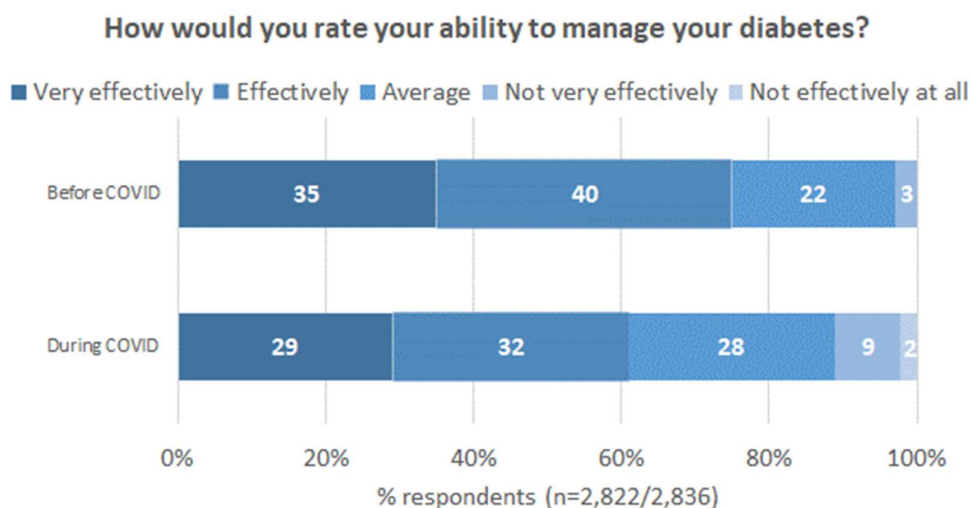


Figure V.2-1 – Self-perceived ability to manage diabetes, before and during COVID-19 restrictions

### V.2.2 Weight variations and activity levels

The restrictions imposed to contain COVID-19 and their consequences, notably limitations on movement, restricted availability of public transport, increased stress, altered food intake patterns, reduced social interactions, and working or learning from home, led to about one third of respondents gaining weight during the pandemic. More than half the respondents also reported being less active during the pandemic.

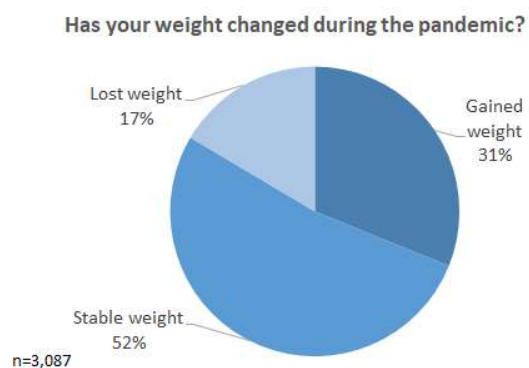


Figure V.2-2 – Weight variations during COVID-19

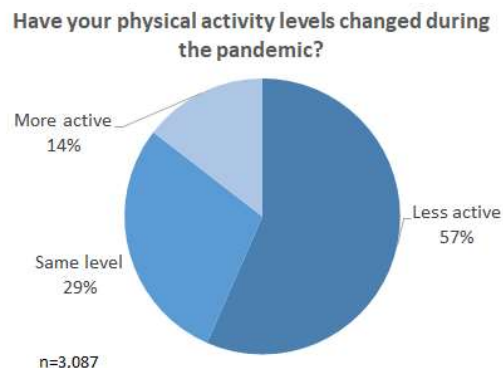


Figure V.2-3 – Physical activity variations during COVID-19

Within Europe, the situation was very contrasted. At one end of the scale in a few countries such as Romania, Spain and North Macedonia, more than 40% of respondents reported that they had put on weight and more than 70% stated that they had been less active. At the other end, less than 20% of Slovenian respondents reported gaining weight and less than 30% being less active.

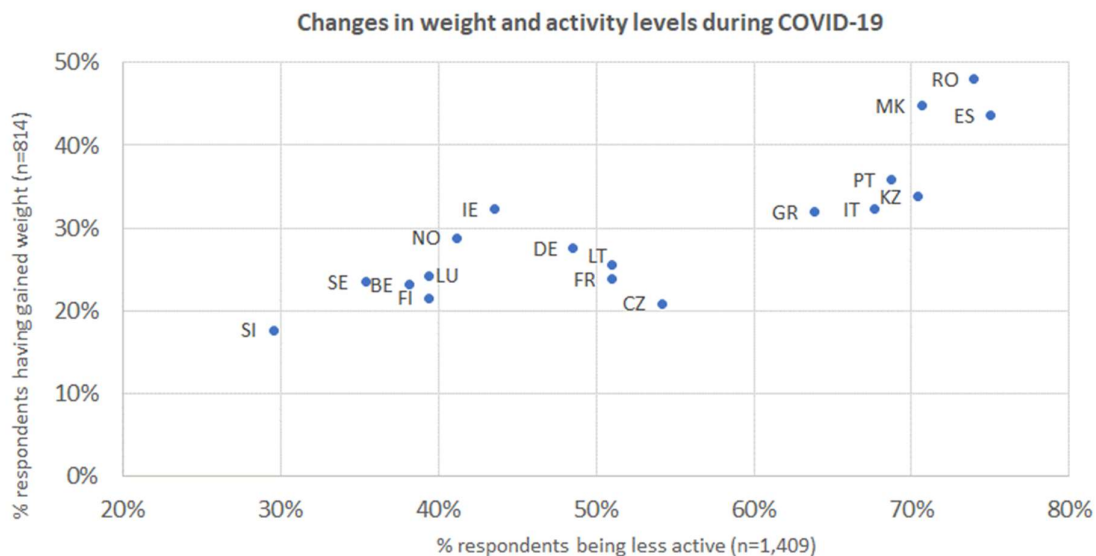


Figure V.2-4 – Physical activity and weight variations during COVID-19, by country

### V.2.3 Blood glucose management

About three-quarters of respondents kept the same frequency of testing of their blood sugar levels during the pandemic as they had done prior to it. A still significant proportion – one in five – actually increased the number of tests. Again, this proportion varied markedly across European countries, perhaps reflecting anxiety levels and the lockdown restrictions playing havoc with people’s usual diabetes management patterns.

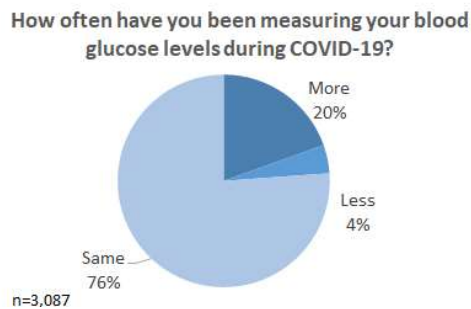


Figure V.2-5 – Blood glucose testing frequency during COVID-19

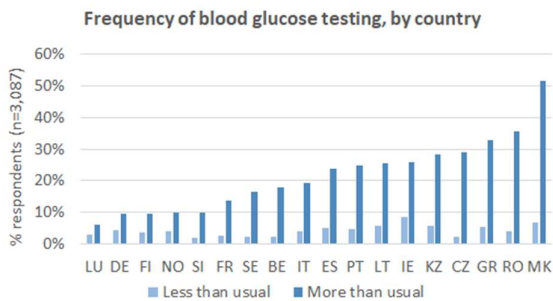


Figure V.2-6 – Blood glucose testing frequency, by country, during COVID-19

Some 30% of respondents reported their blood sugar levels to have been more variable than usual, while 55% reported the levels to have remained about the same as prior to the start of the pandemic. A further 15% of respondents stated that their levels had been more stable than before. Although this was not the case for all, respondents who tested more often also tended to have greater variability in their blood glucose levels.

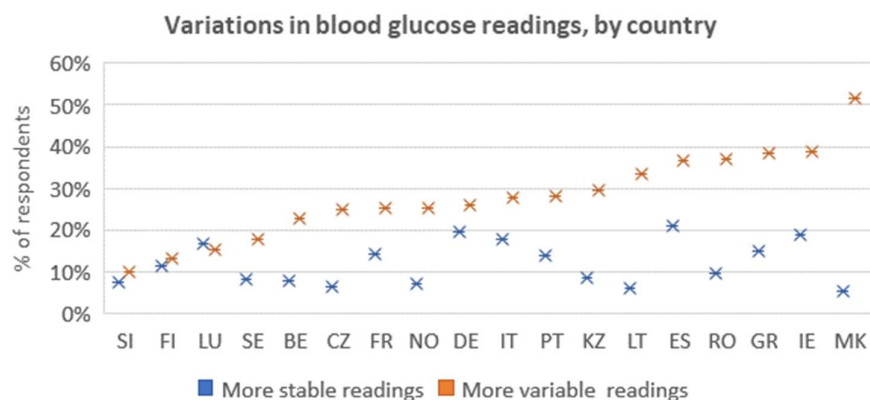


Figure V.2-7 – Blood glucose readings variability, by country, during COVID-19, compared to before COVID-19

Compared with people living with Type 2 diabetes, people living with Type 1 tended to increase the frequency of their blood glucose testing, and also reported more stable glucose levels during the pandemic compared to before.

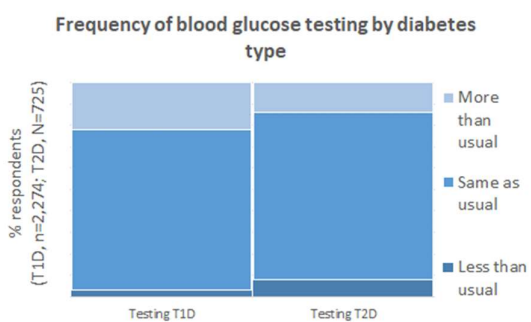


Figure V.2-8 – Blood glucose testing frequency, by diabetes type

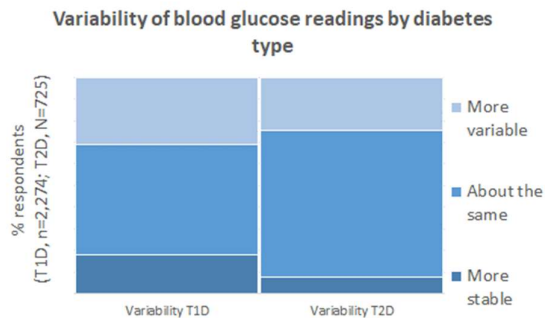


Figure V.2-9 – Blood glucose reading variability, by diabetes type, during COVID-19

### V.2.4 Hypoglycaemia & hyperglycaemia

Another indication of PwD’s ability to manage their condition during the pandemic was the number of hypoglycaemic and hyperglycaemic events that they experienced. More than 80% of respondents to the survey experienced at least one episode of hypoglycaemia. A similar proportion experienced at least one episode of hyperglycaemia, while more than one quarter reported experiencing at least one episode of severe hypoglycaemia.

Some 15% of respondents reported experiencing hypoglycaemia more often than usual, with some 25% experiencing hyperglycaemia more often. There were few differences for episodes of severe hypoglycaemia experienced prior to versus during the pandemic.

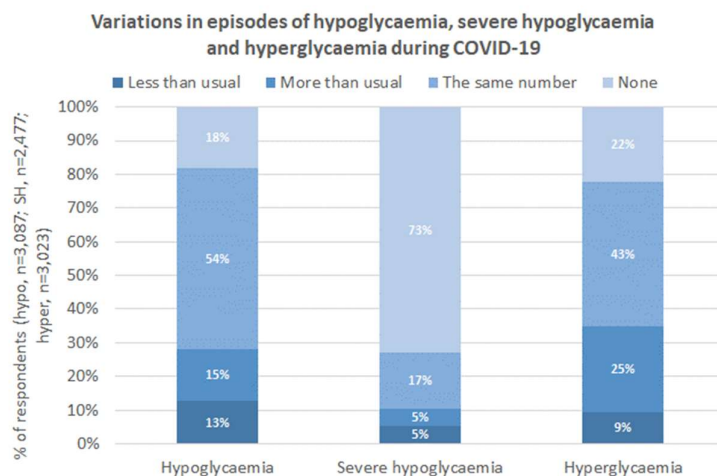


Figure V.2-10 – Hypoglycaemia, severe hypoglycaemia and hyperglycaemia – episodes registered during the pandemic

There was quite a large spread of responses on the frequency of hypoglycaemic and hyperglycaemic events, dependent on the country of residence. The low variations in Slovenia may be partly explained by the strong representation of people living with T2D from that country in the survey, who may experience fewer episodes of hypoglycaemia.

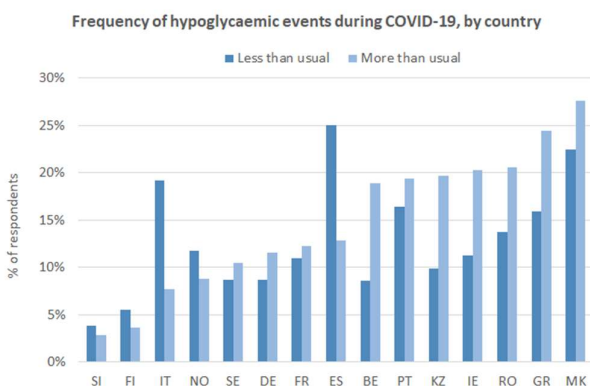


Figure V.2-11 – Frequency of hypoglycaemic events, by country

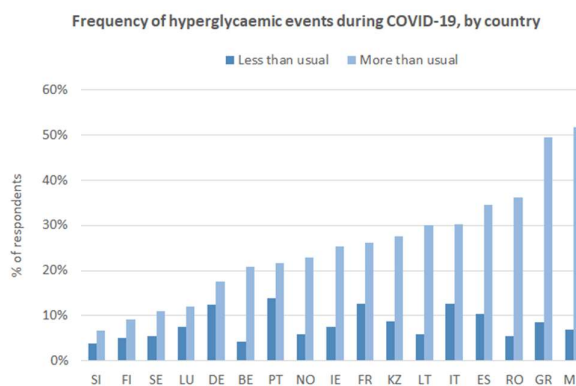


Figure V.2-12 – Frequency of hyperglycaemic events, by country



### V.2.5 Mental health

As a lifelong disease, requiring 24/7 management, diabetes represents a significant burden on the mental health of people living with the condition. The impact of COVID-19 on the mental health of PwD falls into two categories – the restrictions placed on movements, limitations on access to treatment, food etc. and limited social interactions, as well as the fear of developing a severe form of the disease.

During the pandemic, 43% of respondents felt slightly more or much more anxious than before, and more than half experienced an increase in the number of episodes of low mood.

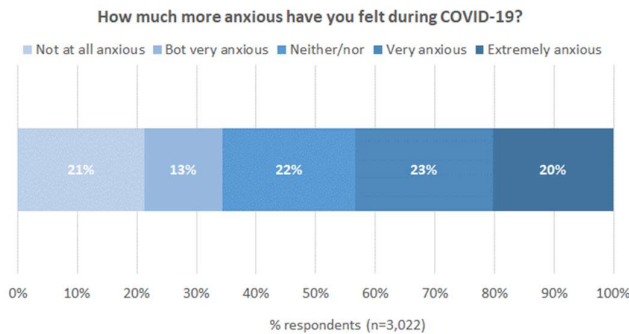


Figure V.2-13 – Anxiety levels during COVID-19

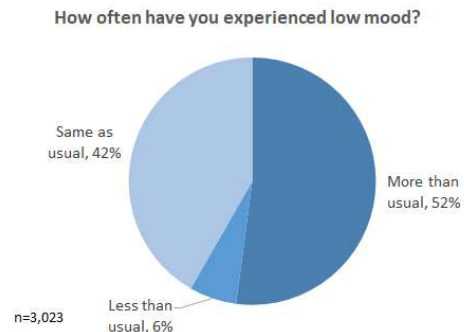


Figure V.2-14 – Frequency of low mood episodes

Deteriorating mental health was also specifically mentioned by just under one in five respondents as being one of their biggest worries during the pandemic. Catching the disease (38%) and developing a serious form of it (52%) were the single most commonly mentioned worries across all respondents ahead of not being able to access medication/supplies (25%) and worsening diabetes management (19%).

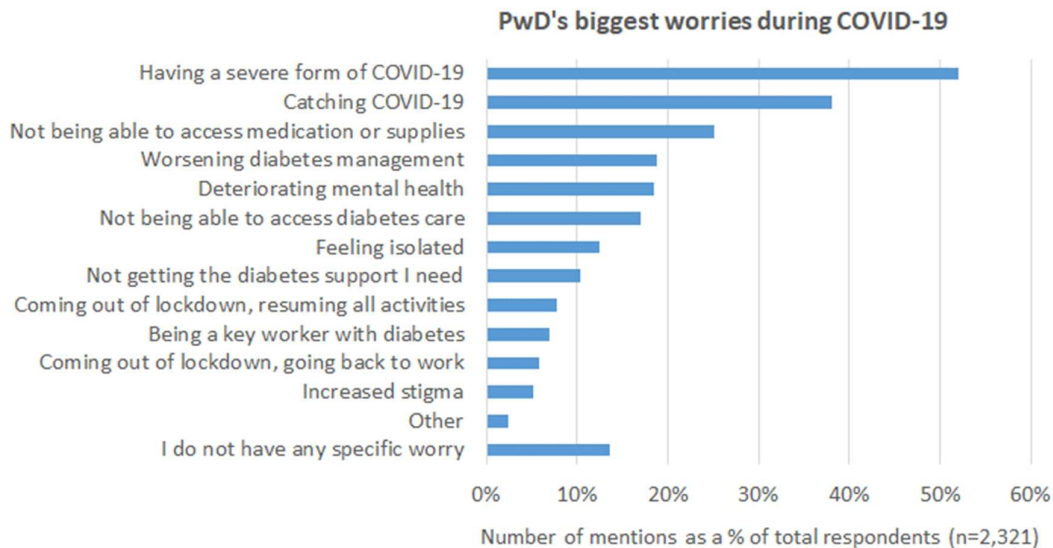


Figure V.2-15 – PwD's biggest worries during COVID-19

The most common worries for PwD during the pandemic varied by country. The most common answer in all countries except Kazakhstan (not being able to access medicines/ supplies) was either the fear of catching COVID-19 or the fear of developing a serious form of COVID-19. Excluding the two responses relating to catching/developing COVID-19, not being able to access medicines/supplies gained the most mentions in more than half the countries analysed in detail for this report.

**Single most mentioned worry by country (excluding fear of catching or developing a serious form of COVID-19)**

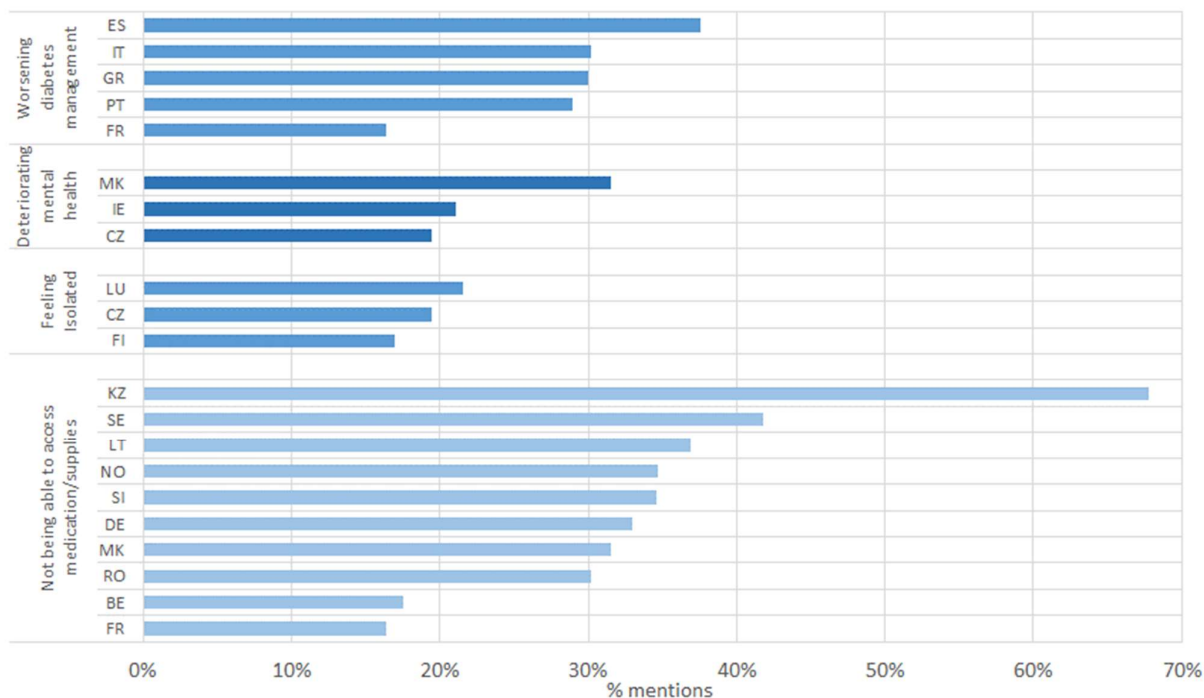


Figure V.2-16 – PwD’s biggest worries during COVID-19, by country  
NB – Number of responses to this question below 50 for CZ, KZ, MK and RO

With regard specifically to the risk of catching COVID-19 and developing a severe form of the disease, respondents were asked to rate whether they considered themselves at high risk. Some 46% considered themselves at high or very high risk of catching the disease, while 59% perceived the risk of developing a severe form of the condition as high or very high.

The risk of catching catch COVID-19 (countries with at least 50 answers to this question) was perceived to be especially high in Greece (44% of respondents) and Romania (37%). At the other end of the scale, the proportion of people believing the risk to be very high was particularly low in Germany and Norway (7% each) and Luxembourg (5%).

With regard to the risk of developing a serious form of the disease, the highest proportions of PwD (countries with at least 50 answers to this question) believing the risk to be very high were in Greece (43%), Romania (39%), Portugal (31%) and Ireland (24%). By comparison, only a small proportion of respondents believed the risk to be very high in Sweden (12%) and Germany (11%).

**Perception of risk of catching or developing a serious form of the disease**

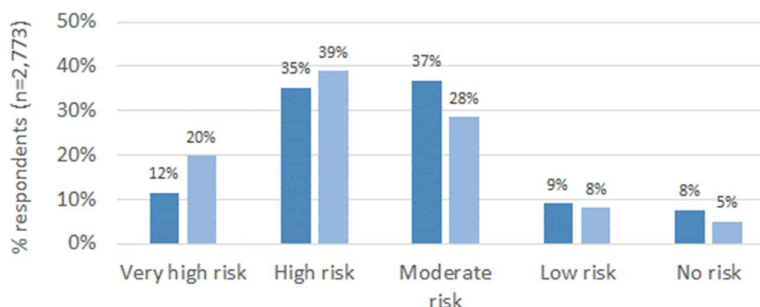


Figure V.2-17 – Perception of the risk to become infected with COVID-19 and/or develop a serious form of the disease

### V.2.6 Financial concerns

Financial sustainability represented a core issue for people living with diabetes, as a number of small or medium-sized businesses either reduced their activities or closed. Hotel Restaurant Catering (HORECA) enterprises that employ large numbers of individuals had to restructure and reduce personnel. Artists of all kinds have seen their shows, events or exhibitions cancelled. Organisers of public events had to reduce their staff and only very few managed to reshape their line of business. About a quarter of respondents experienced some financial concerns. This was very strongly marked in some central and eastern European countries as well as in the south of Europe.

**Have you experienced financial concerns as a result of the pandemic?**

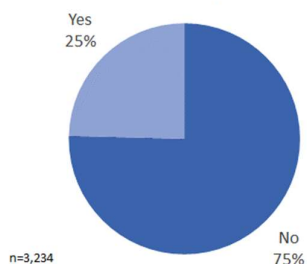


Figure V.2-18 – Proportion of respondents experiencing financial concerns as a result of COVID-19

**Proportion of respondents stating they had experienced financial concerns, by country**

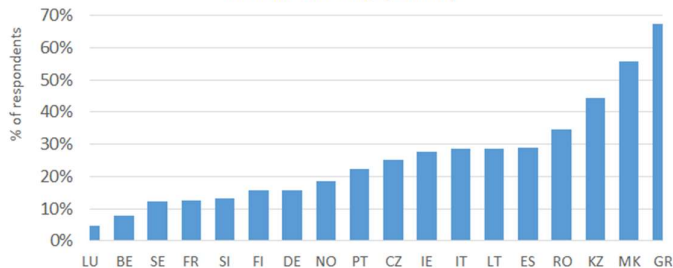


Figure V.2-19 – Proportion of respondent experiencing financial concerns as a result of COVID-19, by country

### V.3 Diabetes care during COVID

Respondents were asked to comment about the ease with which they were able to access their diabetes medicines, supplies and technologies during the pandemic as well as any barriers they faced.

#### V.3.1 Access to medicines, supplies and technologies

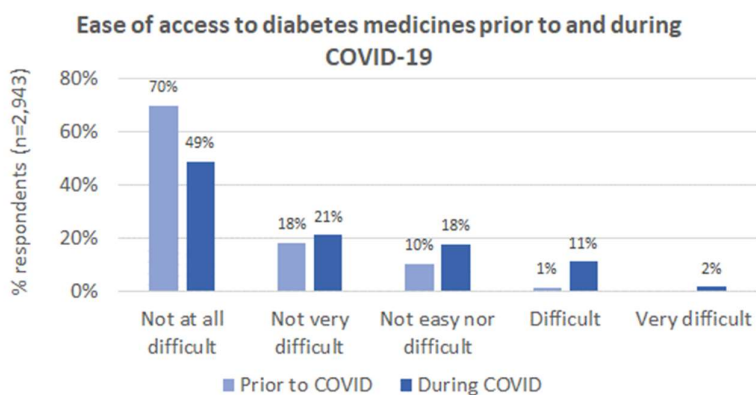


Figure V.3-1 – Ease of access to diabetes medicines pre-COVID and during COVID-19 restrictions

About half the respondents did not experience any difficulty in accessing their diabetes medicines, while one in five also rated their access as not very difficult. Still there was a significant increase in the proportion of PwD who felt that access to medicines had become difficult or extremely difficult during the crisis (from just 1% of respondents prior to the crisis to 13% during it).

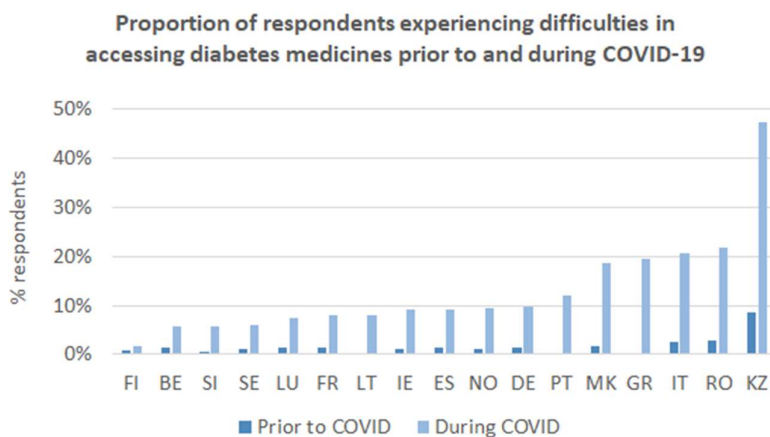


Figure V.3-2 – Ease of access to diabetes medicines prior to and during COVID-19 restrictions, by country

There were few differences in the experiences of respondents in accessing diabetes medication, based on whether respondents lived with T1D or T2D; instead, the variations were a greater reflection of the country of residence.

A greater number of respondents in most countries reported that accessing medicines was difficult or very difficult during COVID-19 in comparison to before the start of the pandemic. Of the countries under detailed review, Kazakhstan followed by Romania, Italy, Greece, North Macedonia and Portugal had the greatest proportion of respondents reporting access to medicines as being difficult or very difficult. In all other countries, less than 10% of all respondents experienced difficulties.

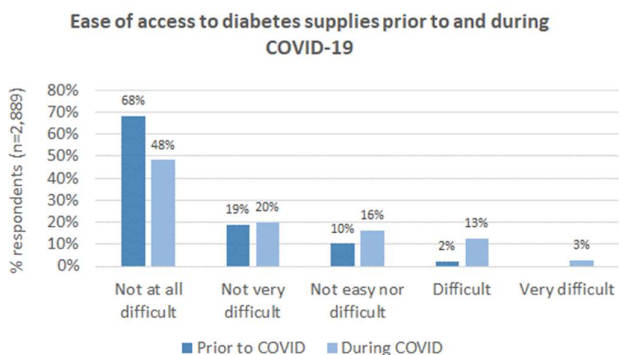


Figure V.3-3 – Ease of access to diabetes supplies prior to and during COVID-19

Difficulties experienced in accessing diabetes supplies and equipment showed a similar pattern – a marked fall in the number of people who did not record any difficulty, and, conversely, a five- to eight-fold increase in the number of people who stated that it had become difficult or extremely difficult to access supplies or equipment during the pandemic.

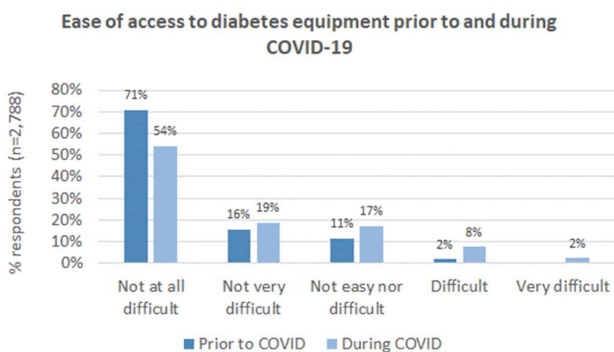


Figure V.3-4 – Ease of access to diabetes equipment prior to and during COVID-19

Geographically, a similar pattern to that of access to medicines emerged for diabetes supplies and equipment.

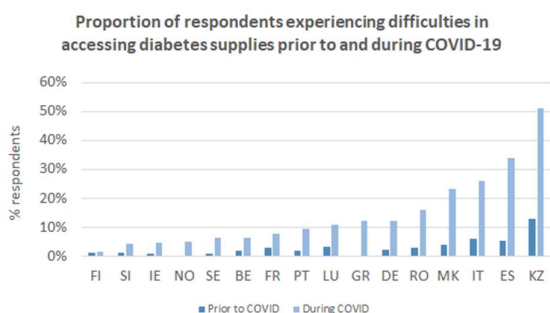


Figure V.3-5 – Ease of access to diabetes supplies prior to and during COVID-19, by country

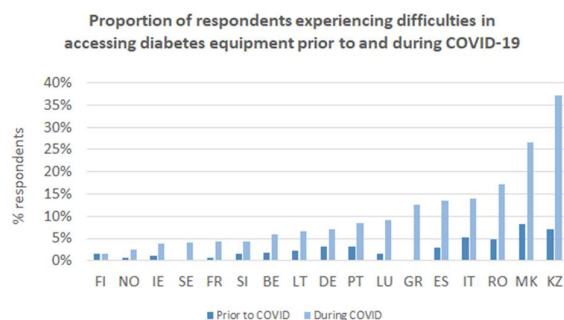


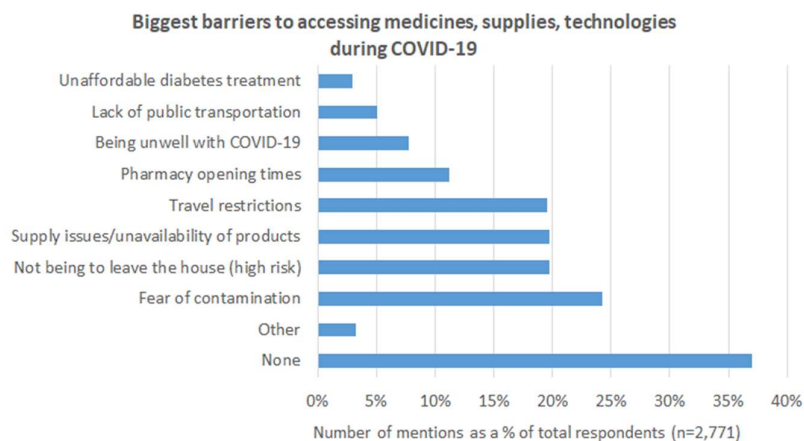
Figure V.3-6 – Ease of access to diabetes equipment prior to and during COVID-19, by country

NB – Number of responses for equipment in CZ, KZ, LT, MK, higher than 40

More than one third of respondents stated that they did not encounter any barriers in accessing their diabetes medication, supplies and technologies. For those that did, however, fear of contamination was the single most mentioned barrier, ahead of supply issues, not being able to leave the house due to being at high risk and travel restrictions.

Most difficulties in accessing medication were linked to shortages or delays in the delivery of the medicines prescribed, in particular insulin and metformin and challenges faced in getting prescriptions, often because of a lack of access to doctors and/or hospitals.

Supplies and equipment shortages and delays in deliveries affected a number of products, chief amongst which were sensors. In this case, shortages and delays were compounded by the fact that in several countries, these products are not available in country, but rather need to be ordered/delivered from abroad. Test strips, needles, catheters and infusion sets, as well as some models of insulin pumps were also mentioned by a few respondents.



*Figure V.3-7 – Biggest barriers to accessing medicines, supplies and technologies, during COVID-19, by country*  
 NB – Number of responses in CZ, KZ, LT, MK, higher than 40



Fear of contamination and being at high risk were the single most common barriers in the majority of countries under review, with travel restrictions posing a major problem in Slovenia, Italy, Greece, France and the Czech Republic.

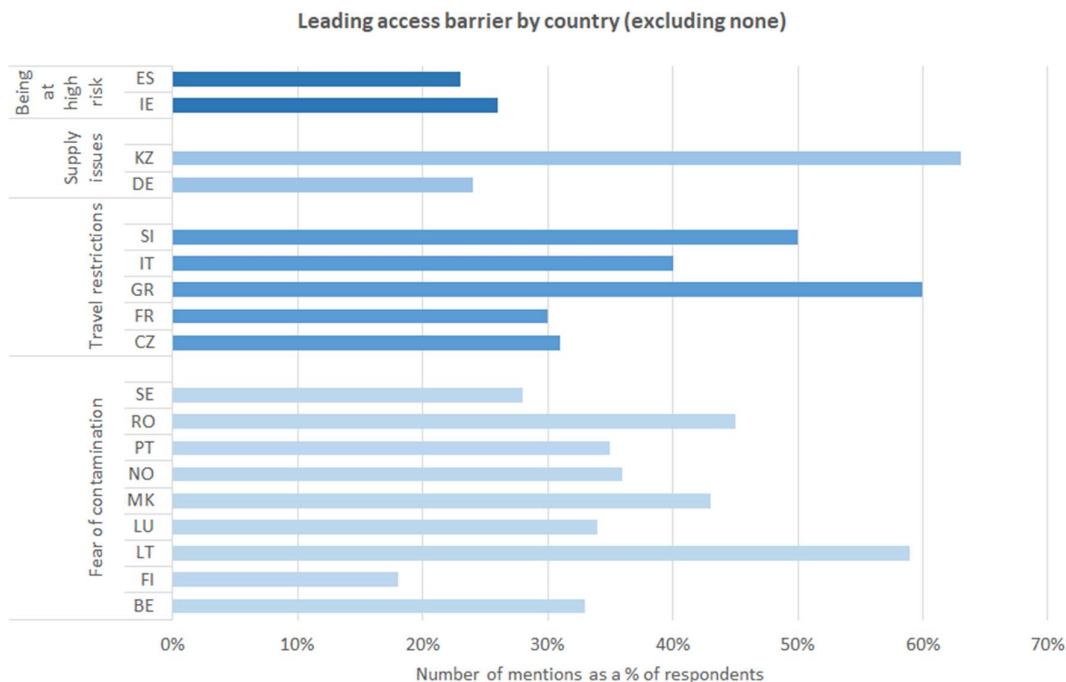


Figure V.3-8– Biggest barriers to accessing medicines, supplies and technologies during COVID-19, by country

As a result of reduced opening hours of pharmacies, restrictions on transportation and fear of shortages or temporary unavailability of needed medication and/or medical devices and supplies, just under one third of respondents stocked up on more medicines and supplies than was required. This was especially marked in some countries such as Greece, North Macedonia and Portugal.

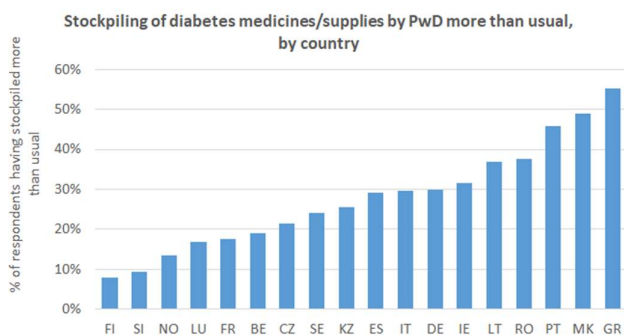


Figure V.3-9 – PwD’s stockpiling of medicines/supplies, by country

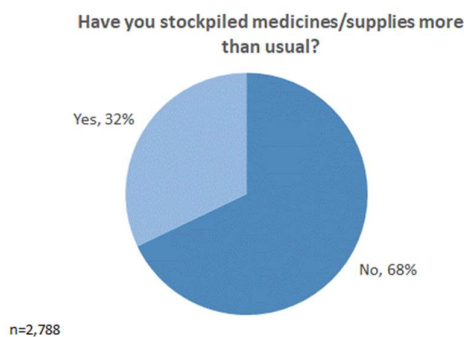


Figure V.3-10 – PwD’s stockpiling of diabetes supplies and medicines during the pandemic

A similar proportion of PwD to those who stockpiled medicines and supplies were very or extremely worried about accessing their prescribed medication and/or supplies and medical devices, whereas a quarter expressed no worry whatsoever.

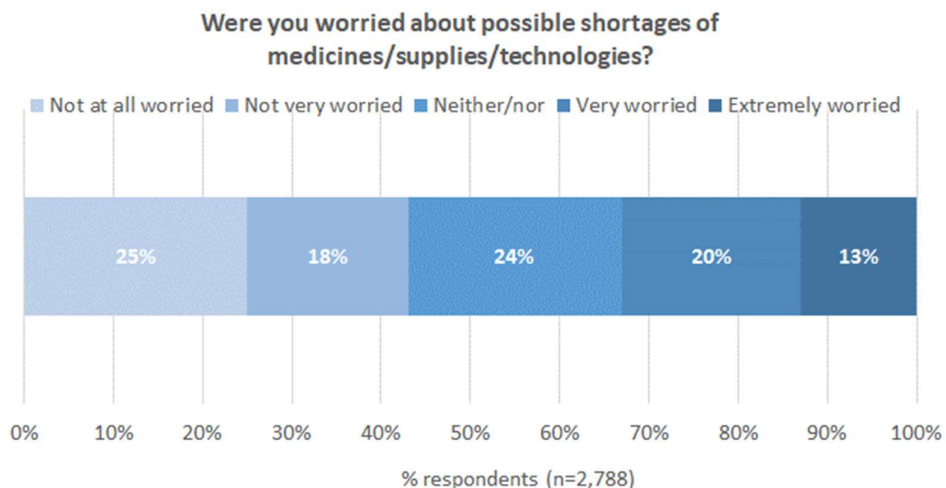


Figure V.3-11 – Proportion of PwD worried about potential shortages of medicines, supplies and technologies, during COVID-19

The fear of shortages was particularly felt by respondents in a few southern/eastern European countries.

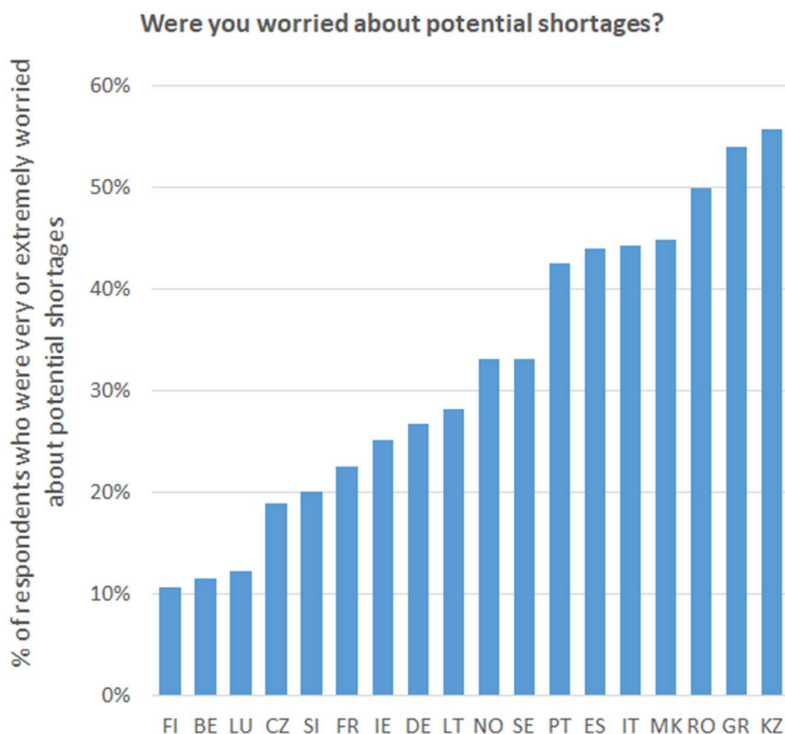


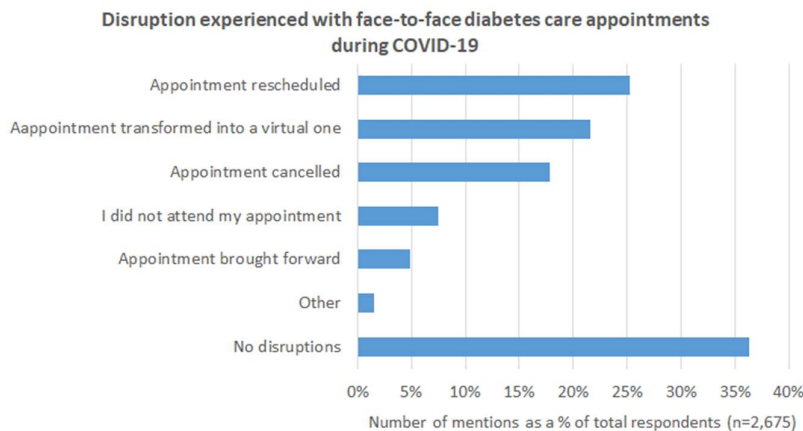
Figure V.3-12 – PwD's worries about potential shortages if medicines/supplies and technologies, during COVID-19, by country

## V.4 Access to medical care

Respondents were also asked to describe their ability to access routine diabetes care, screening for diabetes complications and non-diabetes-related care throughout the course of the pandemic.

### V.4.1 Access to diabetes related medical care

#### V.4.1.1 Routine diabetes care



Reflecting the restrictions put in place in many countries limiting in-person meetings as well as the general fear of contamination, the first period of the pandemic saw a vast increase in the number of consultations taking place virtually and in the number of consultations being cancelled or re-scheduled. While 36% of respondents did not experience any disruptions, a quarter saw their appointments rescheduled.

Figure V.4-1 – Disruption in routine diabetes care during COVID-19

More than one in five attended virtual consultations in place of a face-to-face appointments.

There were marked differences in the time that it took for appointments to be rescheduled. More than 40% of appointments were rescheduled within one month, whereas 34% of respondents had to wait for more than two months.

A high proportion of respondents in Italy and Ireland reported experiencing long delays in the rescheduling of their appointments. By contrast, more than half the respondents in Germany, Sweden, Lithuania and Romania had their

appointments rescheduled within one month. Figures have to be considered with caution, however, due to the small number of responses to this question.

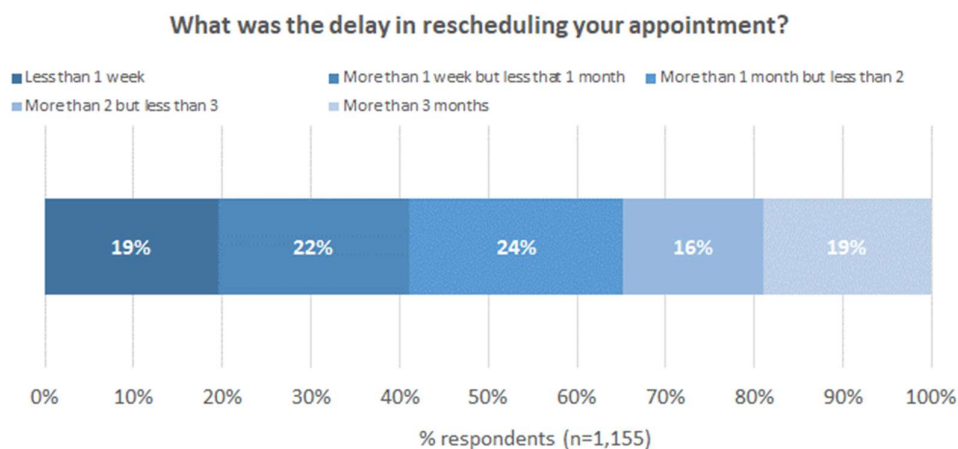


Figure V.4-2 – Time delays in rescheduling appointments for routine diabetes care during COVID-19

V.4.1.2 *Screening for complications*

Concerning disruptions to appointments for the screening of diabetes-related complications, more than half the respondents did not indicate any disruptions. Just under one in five respondents reported that their appointment had been rescheduled.

**Delays when rescheduling appointments, by country**

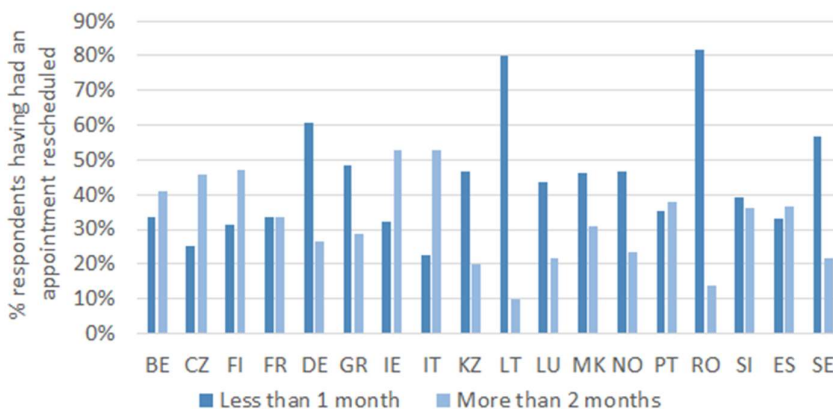
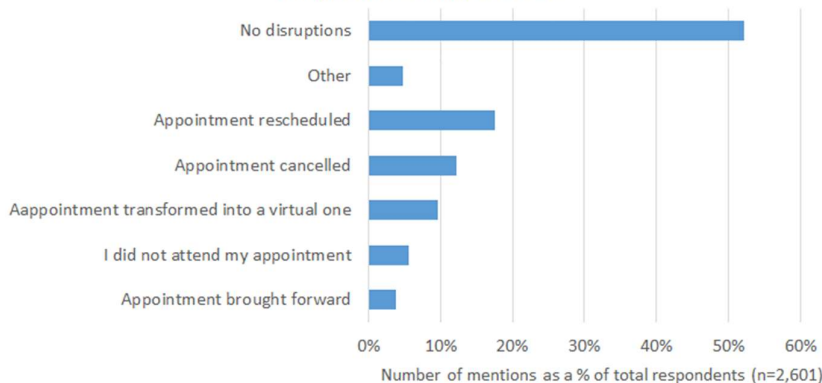


Figure V.4-3 – Time delays in rescheduling appointments for routine diabetes care during COVID-19 by country

**Disruption experienced with face-to-face appointments for diabetes complications during COVID-19**



It must be noted that part of the reason behind the lower levels of reported disruption to screening appointments may be due to the longer timeframe between such appointments. This means that over the time period of the survey, fewer appointments related to complications may have been due to take place. The majority of appointments were re-scheduled within a three-month period.

Figure V.4-4 – Disruptions in appointments for the screening of diabetes complications during COVID-19

**What was the delay in rescheduling your appointment for the screening of diabetes complications?**

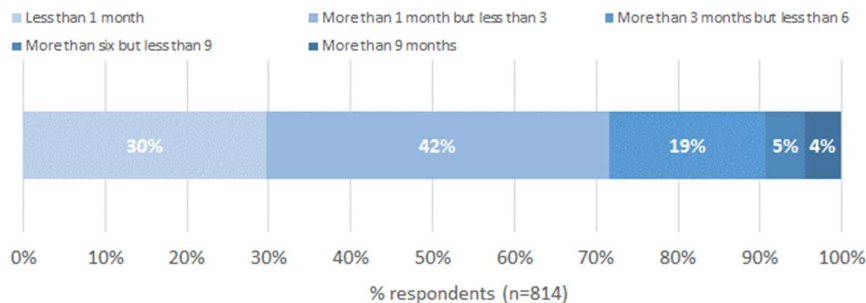
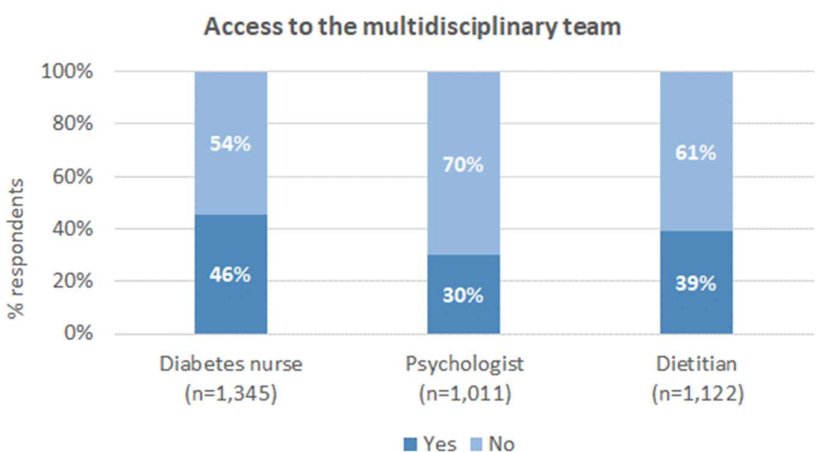


Figure V.4-5 – Time delays in rescheduling appointments for the screening of diabetes complications during COVID-19

### V.4.1.3 Access to the multidisciplinary team



Disruptions in access to the multidisciplinary team were also quite severe across Europe for PwD who normally have access to these professionals. More than 50% of respondents found themselves no longer able to access their diabetes nurse, increasing to 70% for psychologists.

Figure V.4-6 – Access to the multidisciplinary team, during COVID-19

### V.4.1.4 Barriers to access to care

As with access to diabetes medicines, supplies and technologies, fear of contamination was the greatest barrier to accessing diabetes care. This was experienced by 33% of respondents. Travel restrictions were the next most common barrier, with more than a quarter of respondents reporting challenges in this respect. While 38% of PwD who responded to this survey did not report any barriers, for 16% of respondents, there was simply no care available at all. The availability and ease of use of technological tools did not appear to represent much of a barrier to accessing diabetes care.

### Biggest barriers to accessing diabetes care during COVID-19

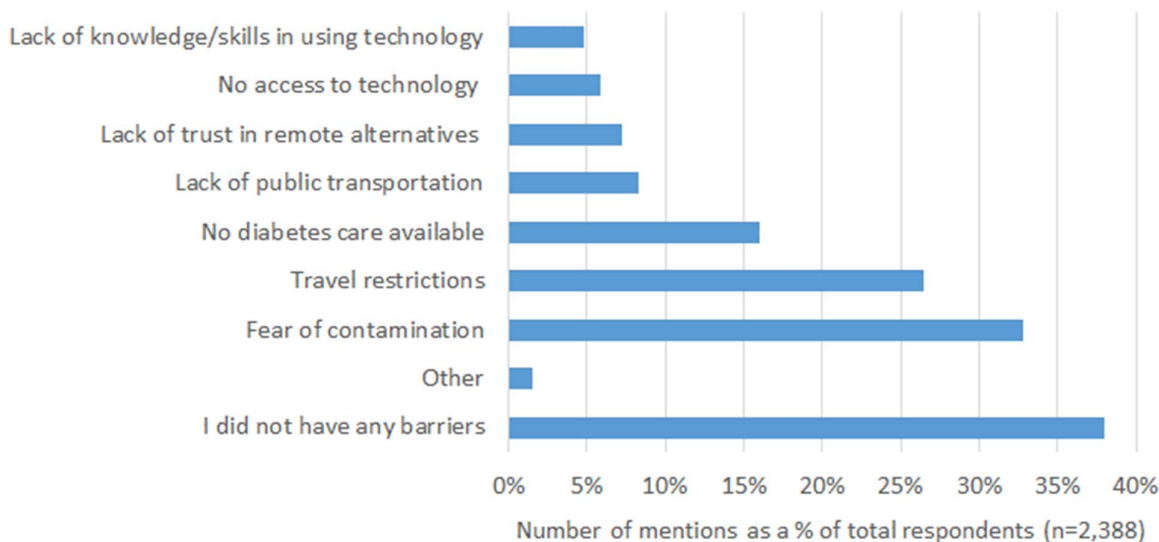


Figure V.4-7 – Biggest barriers to accessing diabetes care during COVID-19

V.4.1.5 *Effectiveness of care*

Ultimately, opinions were divided on the effectiveness of the diabetes care provided during the pandemic. One in five PwD felt it was totally ineffective and a similar proportion felt it had been very effective.

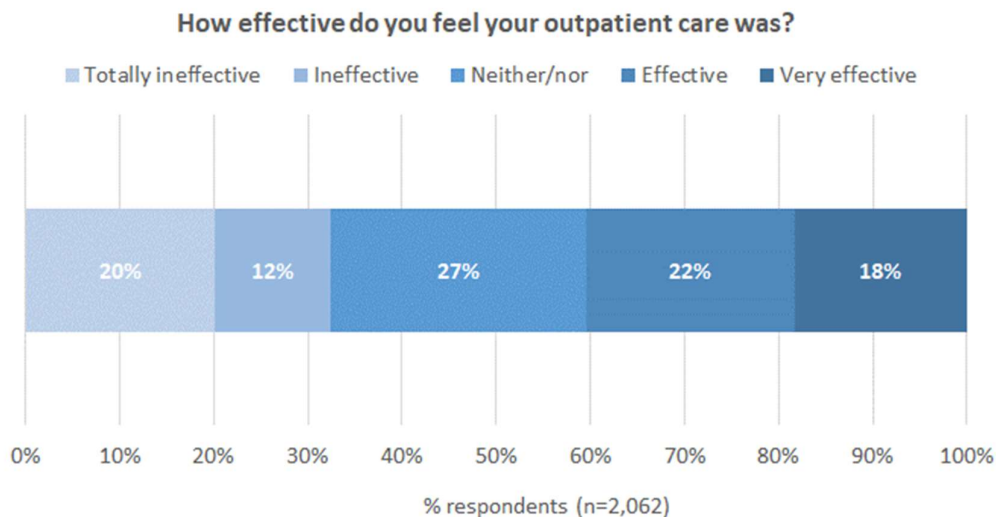


Figure V.4-8 – Perception of the effectiveness of outpatient care during COVID-19

Overall, there was quite a spread of opinions on the effectiveness of care throughout the pandemic, with a small proportion of respondents in countries such as France (20%) believing their care to have been ineffective or totally ineffective compared with 40% feeling the same in Italy, for example.

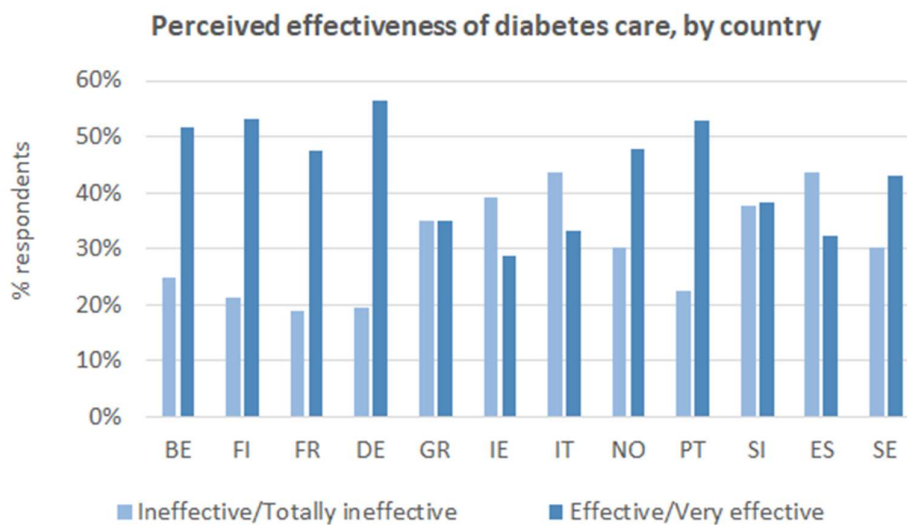


Figure V.4-9 – Perception of the effectiveness of outpatient care during COVID-19, by country



#### V.4.1.6 Contact with healthcare teams

Only about half the respondents across Europe were proactively contacted by their healthcare professionals regarding their diabetes care and only 41% received specific advice for managing their condition during the pandemic.

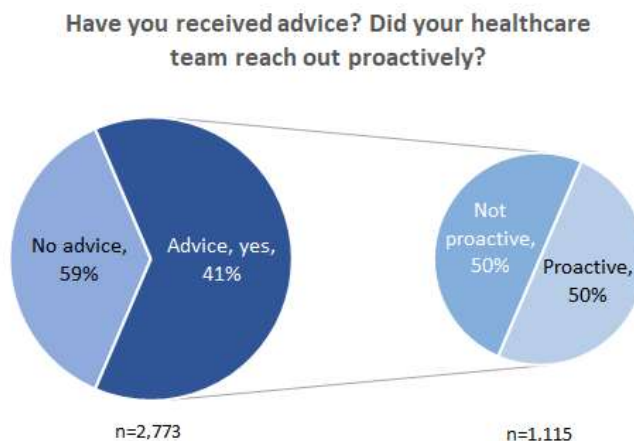


Figure V.4-10 – Proportion of respondents receiving advice from their healthcare team regarding diabetes management during COVID-19 and proportion contacted proactively

More than 50% of respondents reported having been contacted proactively in about half the countries under review. With the exception of four countries – Greece, Portugal, France and Ireland – more than 50% of respondents in each of the countries under review did not get advice specifically related to COVID-19.

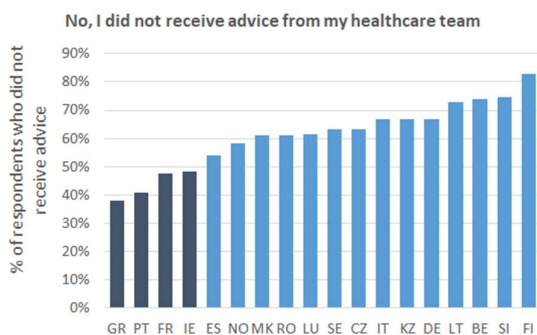


Figure V.4-11 – Proportion of respondents not receiving advice from their healthcare team

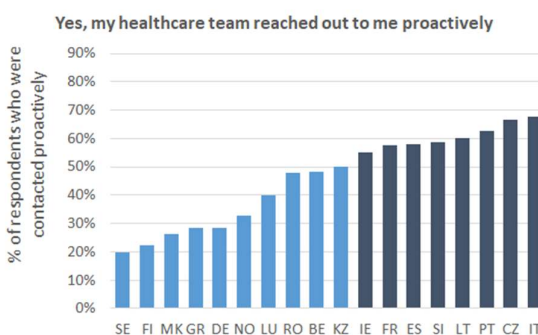


Figure V.4-12 – Proportion of respondents contacted proactively by healthcare team

#### V.4.1.7 Diabetes treatment while hospitalised

Just 1% (31) of all respondents had been hospitalised due to COVID-19. Just two of these respondents thought the management of their diabetes was poor or very poor; 17 reported it to be good or very good and 12 described it as average.

## V.4.2 Access to non-diabetes related care

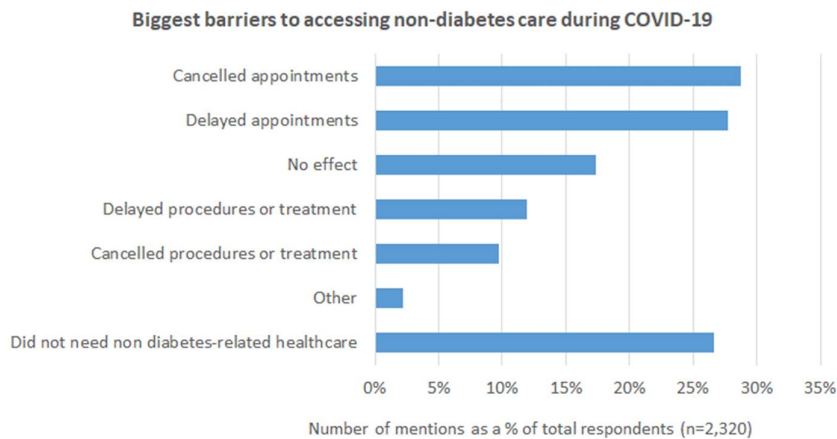


Figure V.4-13 – Biggest barriers to non-diabetes-related care during COVID-19

an unclear system for scheduling or accessing appointments, longer queues, longer delays in scheduling appointments, virtual vs. face-to-face consultations, or simply certain medical services becoming unavailable.

Over the period this survey was conducted, of the approximately three-quarters of respondents who needed to access non-diabetes related care, such as dentist visits, about 18% did not notice any disruption. Just under 30% had their appointments cancelled and/or delayed, with 12% having procedures and/or treatments delayed.

Some of the obstacles to accessing medical services for non-diabetes related care were

## V.5 The shift to remote care

### V.5.1 Availability and usage of remote consultations

One of the major consequences brought about by the epidemic was the need to maintain some continuity of care, despite the difficulty in holding traditional face-to-face consultations. Across Europe, about one third of respondents did not have diabetes consultations during the period under review (either because they did not have any planned, or they were rescheduled/cancelled). Meanwhile, one third had face-to-face consultations, and a further third had diabetes-related consultations held virtually.

Those virtual diabetes consultations were seen as being helpful or very helpful by close to 60%, while just over 18% of respondents did not find them helpful or at all helpful.

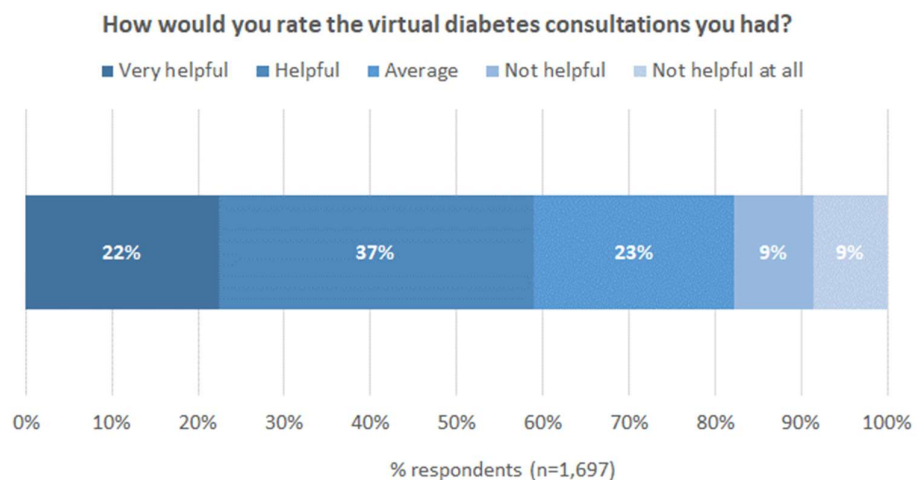
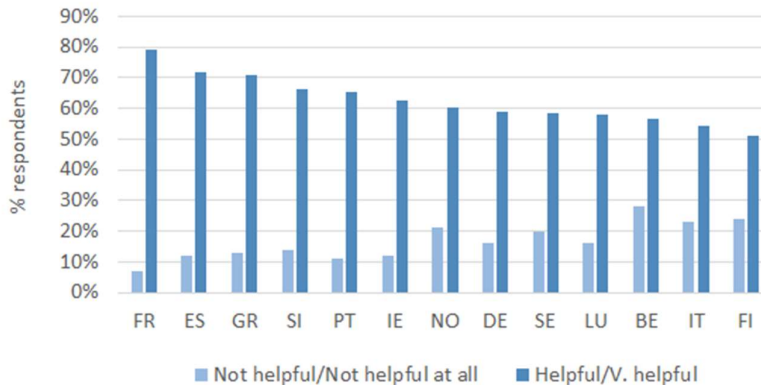


Figure V.5-1 – Rating of virtual diabetes consultations

**Helpfulness of virtual consultations, by country**

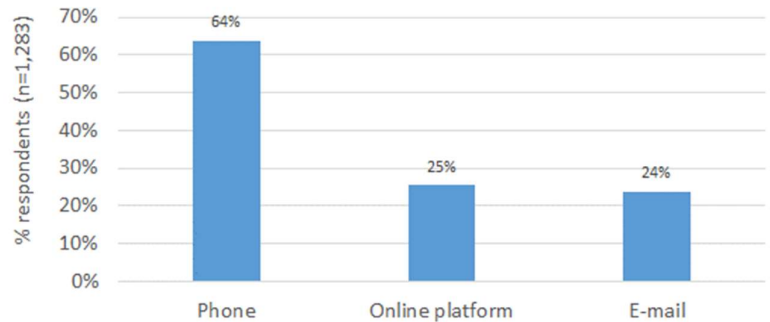


Of the countries with more than 50 responses to this question, respondents in France, Spain and Greece were amongst the most appreciative of virtual modes of consultation, with 70% or more of them rating them as helpful or very helpful.

Figure V.5-2 – Rating of virtual diabetes consultations, by country

Underlining the limited deployment of advanced telemedicine options in Europe, the vast majority of remote consultations did not take place through an online platform, but rather by phone. A number of respondents used a combination of tools. SMS and WhatsApp messaging were also used frequently, mostly to follow-up after appointments, remind people about appointments, or share prescriptions.

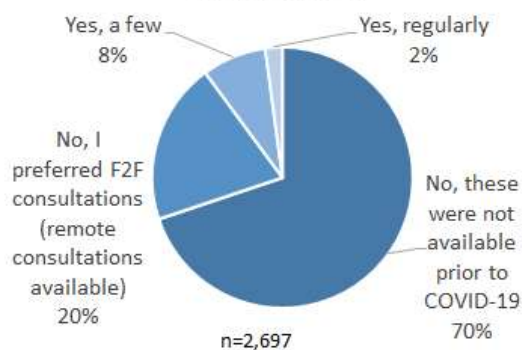
**What was the technology used to conduct remote consultations?**



French and Greek respondents were atypical in this regard, with close to 50% reporting they had used an online platform, nearly double the European average.

Figure V.5-3 – Technology used to conduct virtual diabetes consultations during the pandemic

**Had you attended virtual consultations prior to the pandemic?**



About 70% of the respondents indicated that prior to the start of the pandemic virtual consultations were not available. Face-to-face consultations were the preferred mode of consultation for one fifth of respondents, although remote consultations were available in their country. Only 2% used virtual consultations regularly.

Figure V.5-4 – Proportion of respondents having attended virtual consultations prior to the pandemic

The high number of respondents who attended virtual consultations during the pandemic when they were not available previously suggests that healthcare systems responded quite rapidly and extensively to the challenges posed by COVID-19. This appeared to be the case particularly in countries such as Ireland, Spain and Portugal.

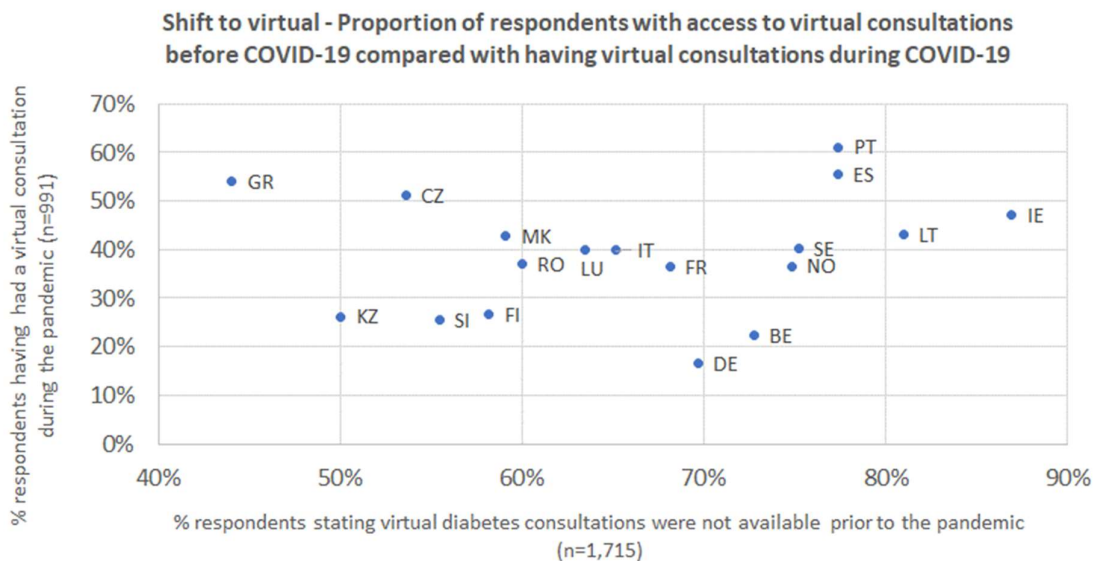


Figure V.5-5 – Proportion of respondents attending virtual consultations during the pandemic compared to proportion stating these were not available prior to the pandemic  
 NB – Number of responses in CZ, KZ, LT, MK, higher than 40; others higher than 60

Perhaps reflecting the fact that a majority of respondents across Europe had found remote consultations either useful or very useful, just under half of them declared that they would consider attending a mix of diabetes consultations in the future. About 25% suggested they would like to have as many of their diabetes consultations as possible held virtually, while a slightly larger proportion were not interested in this option.

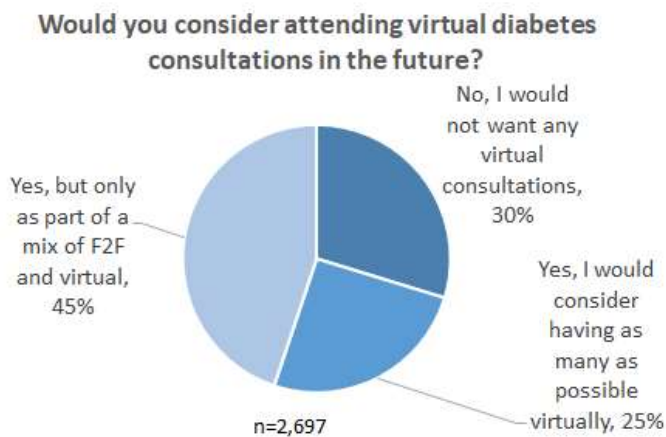


Figure V.5-6 – Proportion of respondents considering attending virtual consultations in the future

Portuguese respondents were the most enthusiastic when it came to having virtual consultations as a mix of virtual and face-to-face in the future. Conversely, respondents in Kazakhstan, France and North Macedonia expressed much more reluctance – well below the European average.

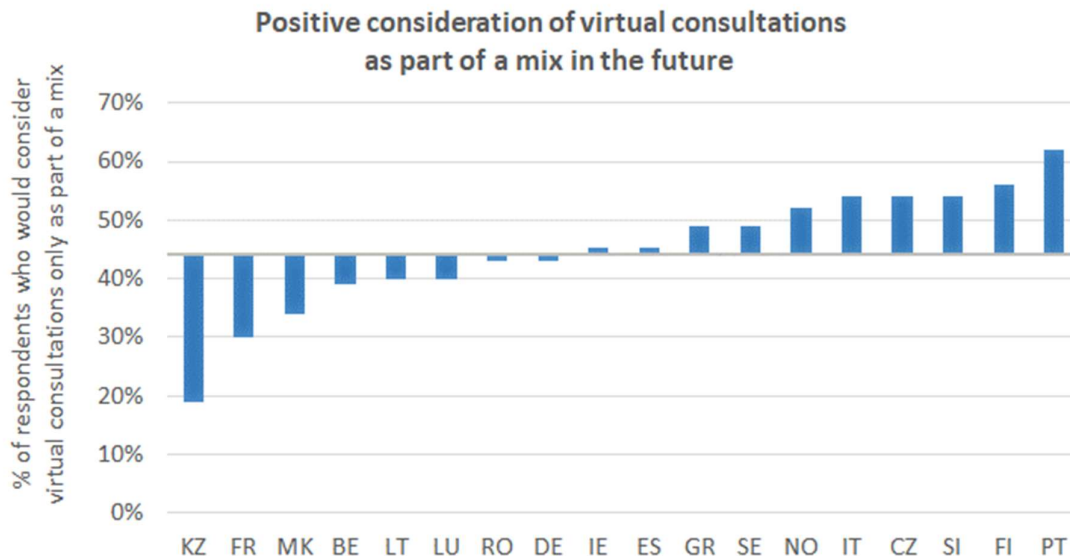


Figure V.5-7 – Proportion of respondents considering attending virtual consultations as part of a mix in the future  
NB – Number of responses in CZ, KZ, LT, MK, higher than 40; others higher than 60

### V.5.2 Usage of technologies to support care and education

About a quarter of respondents indicated that they did not use any technology, such as apps, social media or websites, to manage their diabetes. Of those that did, there was a sharp increase in the use of all tools to support diabetes management during the pandemic, with the use of social media showing the strongest increase.

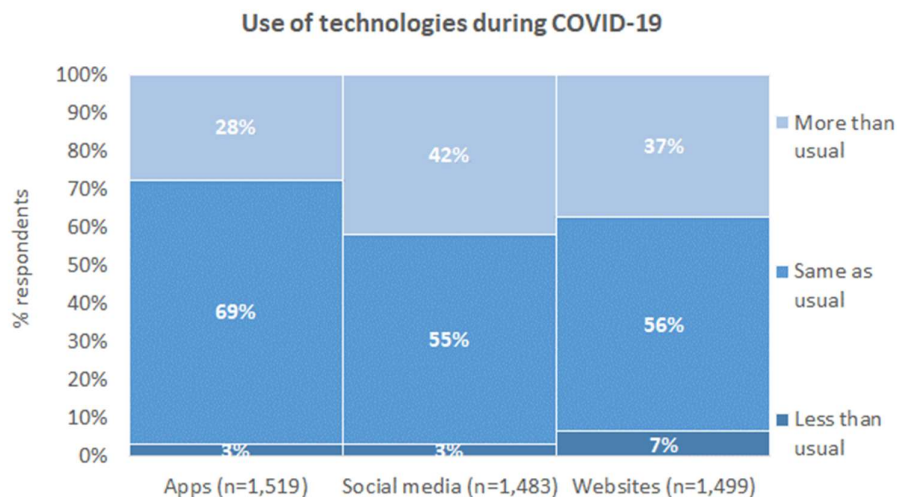


Figure V.5-8 – Use of technologies to support diabetes management during the pandemic

## VI. Conclusions

**The measures that were put in place to contain the spread of COVID-19 created havoc for many healthcare systems across Europe.** They found themselves forced to adapt their provision of health services, in the context of restrictions on face-to-face meetings and reduced availability of staff and/or resources. The disruption was particularly evident in countries where large numbers of COVID-19 cases caused resources to be diverted from other services to care for them. Such diversion of care often led to the interruption of screening programmes, cancelling planned operations, rescheduling appointments, etc.

**However, in many regions and countries, healthcare systems adapted remarkably rapidly** to offer a range of, often remote, services and options. The survey results clearly indicate that novel, and effective, approaches were developed and deployed across many countries. IDF Europe is currently identifying the good practices that were implemented in European countries during the pandemic for dissemination across its network.

**The anti-COVID-19 measures strongly constrained every aspect of people's daily diabetes management.** Diabetes management worsened for more than 10% of respondents, who stated that they were not able to manage their diabetes effectively during the pandemic. This was up from just 3% before it started. More than 30% of respondents gained weight and close to 60% were less active. Some 30% of respondents also reported their blood glucose levels to be more variable than before the start of the pandemic and 20% increased their number of blood glucose tests in order to adjust their regimen to the restrictions. There was also a marked increase in the number of hypoglycaemic and hyperglycaemic events experienced by PwD.

**The pandemic, and governments' subsequent responses to it, took a strong toll on the mental health of PwD.** This reflected the several challenges and uncertainties PwD faced during this

period, such as potential shortages in medication, medical supplies and goods; limited freedom of movement; fear of contracting the disease and the increased risk of developing severe forms of it; financial or job- and school-related concerns, etc. Some respondents felt reduced to the status of "patients", as opposed to being treated as an equal partner in their diabetes care, as had been the case prior to the pandemic. More than four in ten respondents felt more anxious than before and more than half experienced an increase in incidences of low mood.

**The guidance provided to PwD was inadequate to help them protect themselves against COVID-19 and manage their diabetes during the pandemic.** Studies and statistics suggested relatively early on that people living with diabetes are no more likely to catch COVID-19 than the rest of the population. Sub-optimal glucose levels, however, pose an increased risk for PwD of developing severe forms of the disease. While respondents across Europe appear to have generally understood these facts, there remained some confusion regarding the risk of catching COVID-19 and whether or not the likelihood of developing a severe form of the disease was a function of whichever type of diabetes they live with, or also depended on other health characteristics. This led to uncertainty about what appropriate protection and management measures would be appropriate. While respondents across Europe acknowledged that they had received guidance in this regard, they also commented that the guidance was not clear or strong enough to properly help them navigate the pandemic safely.

**The pandemic exacerbated many of the pre-existing inequalities in access to care and medicines. Access to diabetes care, medicines and supplies was disrupted across all European countries, but the severity and scope of the disruptions varied greatly by country.** More than half the respondents did not find it difficult or very difficult to access medication, supplies and



technologies during the pandemic but the proportion of PwD experiencing difficulties increased across the board to at least one in ten people. This was more marked in some southern, central and eastern European countries than in most western and northern nations.

**COVID-19 fostered an accelerated digitalisation and virtualisation of healthcare systems across Europe. There was rapid uptake in the use of telemedicine,** conducted via phone or online platforms. This was largely in response to access to many face-to-face appointments being cancelled and/or rescheduled. Altogether, some 35% of respondents to this survey benefited from virtual consultations for their diabetes care, and 60% of PwD rated them as useful or very useful. This compared with just 10% having experienced remote consultations prior to the pandemic.

**The shift to remote services will probably constitute a permanent change to healthcare**

**systems in Europe.** Only 30% of European respondents stated that they would not want to attend virtual consultations in the future. By contrast, 45% would consider them as part of a mix of remote and in-person consultations and a further 25% would like to have as many virtual appointments as possible.

**There is a serious risk that the true impact of the pandemic on health outcomes for PwD will only become apparent further down the line. Fear of contamination was the single most common barrier to accessing care and medicines across Europe during the pandemic, ahead of supply and availability issues.** This means that in addition to the number of people whose pre-planned screening appointments were delayed, many people opted not to seek care when they needed it and may be at higher risk of developing diabetes-related complications in the long term.

## VII. Recommendations

### Tackling the NCD challenge for more resilient health systems

The COVID-19 pandemic has brought to the fore the significant burden posed to health systems by non-communicable diseases (NCDs), including diabetes. It has also demonstrated the urgent need to tackle NCDs in order to bolster the resilience of healthcare systems as well as to ensure better preparedness for potential future health crises. Addressing diabetes and other NCDs requires concerted action across a number of areas:

#### 1. Improving the prevention of Type 2 diabetes and diabetes-related complications

Across Europe, 59 million people live with diabetes, a figure anticipated to rise to 66 million by 2030. One in 11 European citizens were living with diabetes in 2019, and diabetes-related expenditure stood at €148 billion. Complications accounted for 75% of the total cost of diabetes. Diabetes is a life-long condition, requiring 24/7 management and is a key risk factor for other NCDs such as cancer, cardiovascular disease, etc. **Reducing the incidence of Type 2 diabetes and diabetes-related complications can improve the quality of life of people who are at risk of developing diabetes, and those who are already living with the condition. Meanwhile, it will significantly reduce the financial burden that the disease places on healthcare systems. In turn, this will free up resources that can be reinvested into further strengthening these systems.** A healthier population, with fewer co-morbidities, may also be better prepared to face some future health threats.

This ambition can be achieved through investment strategies that focus on the prevention of diseases rather than their management. These include an array of policies and initiatives, including improving awareness of diabetes among the general population and healthcare professionals, tackling stigma and discrimination, creating health-

enabling environments, addressing the socio-economic determinants of health, and acting early through screening, improved diagnosis, and reduced therapeutic inertia.

#### 2. Accelerating the pace of innovation, virtualisation and digitalisation

The COVID-19 crisis has also highlighted not only the opportunities brought about by more innovative, virtual, and digitalised, care but also the feasibility of its implementation. Across Europe, a variety of new tools and approaches have become available, ranging from e-prescriptions through to frameworks codifying the use and options for the reimbursement of virtual consultations. More than one third of respondents to this survey benefited from virtual consultations during the pandemic, at least three times more than had ever experienced this type of care, prior to the crisis. Post-pandemic, **it is critical that an in-depth analysis of the implementation of these models be conducted to identify good practices and promote the exchange of information across all European countries.** It is also vital to ensure healthcare systems do not move backwards as we emerge from the pandemic, but rather build on their experience (by listening to the preferences and needs of PwD and other people living with NCDs) to further improve the effectiveness of care and prevention

In parallel to this, **more investment is required to further digitalise healthcare systems and build up robust data networks**, such as national diabetes registries (along with a strong governance framework). Within the EU in particular, national diabetes registries could become a critical component of a European Health Data Space.

Fostering the development of a common set of (diabetes-related) data, alongside a series of outcome measures, including outcomes that matter to PwD, would help design more effective prevention programmes, support the development of more evidence-based and personalized care, and help create better response mechanisms for future health crises.

A pre-requisite to ensuring such data become available and accessible to all would undoubtedly be improved digital, data and health literacy and more widespread access to new digital tools and technologies.

### **3. Engaging with, and supporting, European citizens, diabetes associations and civil society**

Firstly, **the reduced number of interactions between PwD and their healthcare teams, especially during the first COVID-19 wave, exemplified the expertise that PwD have in self-managing what is a hugely complex condition.** In addition to improving health outcomes, effective self-management has been demonstrated to be cost-effective. **Acknowledging this fact by ensuring that PwD are treated as equal partners in their care will greatly benefit healthcare systems through improved communication, faster and better diagnosis, reduced risks of complications etc. It is also critical that this expertise be further developed** by ensuring that all PwD have access to the required, and as much as possible, cutting-edge, self-management skills and therapeutic education throughout their life. Part of this includes broadening the provision of peer-to-peer support, which is critical for many PwD, as evidenced by the sharp increase in respondents' use of social media during the crisis.

**A second facet of this engagement is the recognition that as experts, PwD know better than anybody else what health outcomes matter most to them,** and what their unmet needs are. Engagement with PwD in designing and implementing new digital and virtual working methods and tools, identifying investment areas

for further research, implementing value-based care systems, **will help to ensure more effective care, improve health outcomes and reduce the financial and human cost of diabetes.**

**A third component of engagement is the closer collaboration between governments, health systems and representatives of PwD (diabetes associations and other civil society organisations).**

During the COVID-19, crisis, PwD were shown to be at high-risk of developing a serious form of the disease. Despite this, in many cases, little to no specific guidance was provided to them by governments and health systems on how to protect themselves and manage their condition. This void, however, was rapidly filled by diabetes associations across Europe, including IDF Europe, that worked to keep PwD informed on the latest developments regarding the disease and provide support. In addition to the work of its member associations, some of which was shared on its website, IDF Europe collated information from manufacturers on any potential supply issues, shared news of vaccine approvals and recommendations as well as advice on nutrition and physical activities, all of which is available on a dedicated [COVID-19 page](#).

**The engagement of diabetes associations, the agility with which they were able to provide support, and the expertise they shared with healthcare systems was invaluable.** Key to anticipating long-term challenges ahead of any future crises and also to supporting the transformation efforts of healthcare services, will be closer collaboration between governments and these organisations. A framework for collaboration could be developed between Ministries of Health and Diabetes Associations, which could then be activated from the onset of future health emergencies. However, ideally, would function even in non-crisis times to share expertise, represent the needs of PwD, etc.

#### 4. Reducing inequalities across and within Europe

The survey also demonstrated unacceptable inequalities in access to care, medicines and technologies across Europe, and in particular, brought to the fore the difficulties experienced by some PwD whose needs are not easily met in their own countries, or for whom diabetes care comes at a cost. There was a clear geographical divide across the continent with PwD in central/eastern parts more likely to experience difficulties. **More needs to be done at a national and pan-European level to ensure that all PwD across Europe can achieve the best possible health outcomes through adequate and affordable access to all the required medicines, technologies, supplies and care they need.** Some of the measures required to improve this access include greater transparency of procurement practices, the promotion of greater competition and product substitution

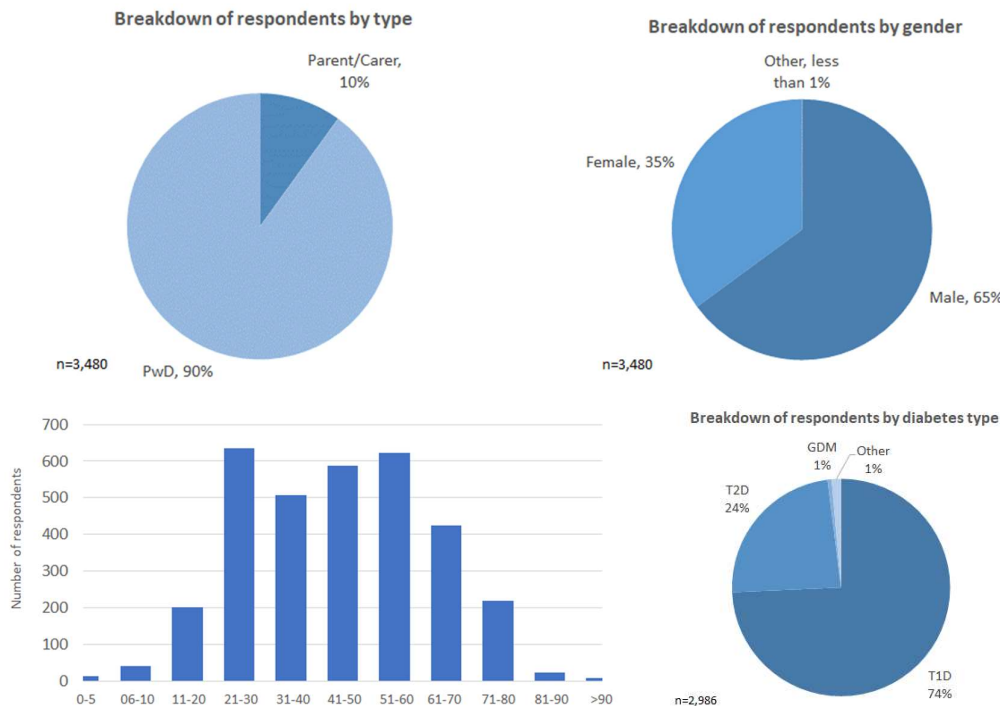
where appropriate and with the enlightened consent of PwD, and more collaboration between all stakeholders.

**Also contributing significantly to inequalities in access to healthcare and in health outcomes are the social determinants of health.** It is likely that the IDF Europe survey did not reach all population groups in every country, and this reflects yet another example of inequality. However, many other publications have documented the role that socio-economic factors played in the impact of COVID-19 on individual population groups, for example WHO Europe's report on [Health inequity and the effects of COVID-19](#). Post-pandemic, it will be important, to not just rebuild our society, but to ensure that we "rebuild fairer".

## VIII. Appendices

### VIII.1 Appendix 1 – Respondents’ profile

Some 90% of the respondents were people with diabetes and 10% parents/carers of people living with diabetes. About 65% of respondents were male, and three-quarters lived with Type 1 diabetes. There was a broad distribution across all age groups.



## VIII.2 Appendix 2 – Country abbreviations

The country abbreviations used in this report are based on the [International Standard Organisation's 3166 country codes classification](#). The most often used codes used in the report are presented below:

<b>Country</b>	<b>Code</b>
Belgium	BE
Czech Republic	CZ
Finland	FI
France	FR
Germany	DE
Greece	GR
Ireland	IE
Italy	IT
Kazakhstan	KZ
Lithuania	LT
Luxembourg	LU
North Macedonia	MK
Norway	NO
Portugal	PT
Romania	RO
Slovenia	SI
Spain	ES
Sweden	SE



### VIII.3 Appendix 3 – The IDF Europe COVID-19 questionnaire

## IDF Europe COVID-19 questionnaire

### How has COVID-19 impacted you and your diabetes?

#### Section 1: About yourself

1. Please specify whether you are answering the survey as a person with diabetes or as a carer/parent of a child with diabetes.

- I am a person living with diabetes  
 I am a parent/carer of a child living with diabetes

If you are a carer/parent of a child with diabetes, please answer all questions on her/his behalf (for example, for the question – what is your age, please enter your child’s age; for the question – what is your gender, enter your child’s gender, etc.)

2. How old are you? \_\_\_\_\_

3. What is your gender? Female  Male

4. In what country do you live? Choose an item.

5. How would you describe your employment status?  
 (if your **usual** place for work is **home**, then please choose “**usual**”, below)

	Prior to COVID-19	During COVID-19	Post-lockdown/as restrictions are being lifted (for those whose countries had a lockdown)
Employed – at usual place at work			
Employed – working from home			
Self-employed - at usual place at work			
Self-employed - working from home			
Unemployed			
Temporarily not working because of COVID-19 (but still employed)			
Temporarily not working (off sick with COVID-19)			
Housewife/househusband			
Retired			
Apprentice/trainee			
Student			
Other, please specify			

6. Have you had a test for COVID-19 (by test we mean a swab from the nose/throat)?  
 Yes  No

## Section 2: COVID-19 testing

**7. Why was your COVID-19 test (swab) done? Select all that apply**

- a.  I had symptoms of COVID-19
- b.  I needed it to have a planned procedure or operation
- c.  I had been in contact with someone who had COVID-19
- d. Other, please specify \_\_\_\_\_

**8. What were the results of the test?**

- e.  The test was positive for COVID-19
- f.  The test was negative for COVID-19
- g.  I am awaiting the results of the test

**9. How easy was of for you to get tested if you had symptoms of if you had been in contact with a person with COVID-19?**

- Very easy    Easy    Neither easy nor difficult    Difficult    Very difficult
- 

## Section 3: COVID-19 treatment:

**10. Have you stayed at home because of your diabetes during the COVID-19 pandemic, i.e. not leaving the house because you are at high risk?**

- Yes, all the time     Yes, most of the time     No

**11. Have you had to self-isolate?**

- Yes     No

**12. Have you been admitted in hospital for COVID-19?**

- Yes     No

**13. How would you rate the hospital management of your diabetes during the COVID-19 hospitalisation?**

- Very good     Good     Average     Poor     Very poor

**14. Have you needed intensive care for COVID-19 (hospitalised in an intensive care/high dependency unit)?**

- Yes     No

**15. Have you needed ventilation for COVID-19?**

- Yes     No

## Section 4: Living in COVID-19 times

**16. Are you a keyworker (as defined by your government as providing an essential service and therefore having to go to work)?**

- Yes     No

**17. Have you had financial concerns as a direct result of the COVID-19 pandemic?**

- Yes     No

**18. If working during the COVID-19 pandemic, do you feel that all necessary measures were put in place to lower your risk of catching COVID-19? (Please rate on a scale of 1-5, with 1 being none of the measures were in place to 5 all the necessary measures were taken)**

- 1     2     3     4     5

**19. Have you used personal protective equipment (PPE) during the COVID-19 pandemic, for example face masks or gloves, even if it was not compulsory to do so?**

- Yes, at home
- Yes, at work
- Yes, when leaving the house
- Never



**32. Do you have any diabetes-related complications? (select all that apply)**

- Diabetes eye disease (retinopathy or maculopathy)
- Diabetes foot disease
- Kidney disease
- Heart disease
- I do not have any diabetes complications
- Other (please specify) \_\_\_\_\_

**Section 6: Access to diabetes medication and/or supplies**

**33. What treatment do you take for your diabetes? (select all that apply)**

- Diet-controlled
- Oral medication only
- Oral medication and insulin
- Insulin only
- Other: please specify \_\_\_\_\_

**34. How do you take your insulin?**

- Syringe injections
- Insulin pen device(s)
- Insulin pump

**35. How have you been able to follow your diabetes regimen been during the COVID-19 pandemic, including blood glucose testing and taking your medication as prescribed?**

- More able than usual     Same as usual     Less able than usual

**36. How would you rate the difficulty you may have had accessing your diabetes medication before and during COVID-19? (on a scale of 1 to 5, with 1 being not at all difficult to 5 being extremely difficult)**

	1. Not at all difficult	2. Not very difficult	3. not easy nor difficult	4. Difficult	5. Very difficult
Prior to COVID-19					
During COVID-19					

**37. If you had any problems accessing your diabetes medication, please indicate which one(s)**

\_\_\_\_\_

**38. How would you rate the difficulty you may have had accessing your diabetes supplies before and during COVID-19? (on a scale of 1 to 5, with 1 being not at all difficult to 5 being extremely difficult)**

	1. Not at all difficult	2. Not very difficult	3. not easy nor difficult	4. Difficult	5. Very difficult
Prior to COVID-19					
During COVID-19					

**39. If you had any problems accessing your diabetes supplies, please indicate which one(s)**

\_\_\_\_\_

**40. How would you rate the difficulty you may have had accessing your diabetes equipment before and during COVID-19? (on a scale of 1 to 5, with 1 being not at all difficult to 5 being extremely difficult)**

	1. Not at all difficult	2. Not very difficult	3. not easy nor difficult	4. Difficult	5. Very difficult
Prior to COVID-19					
During COVID-19					

**41. If you had any problems accessing your diabetes devices/supplies, please indicate which one(s)**

\_\_\_\_\_

42. Even if you have not had any problems accessing diabetes/supplies/technologies, were you worried about possible shortages? (on a scale of 1-5 with 1 being not at all worried and 5 extremely worried)

- 1    2    3    4    5

43. Have you stockpiled more diabetes medication/equipment than usual?

- Yes    No

44. What have been the biggest barriers to accessing your diabetes medication /supplies /technologies during the COVID-19 pandemic? Select a maximum of 3 answers

- Pharmacy opening times  
 Travel restrictions  
 Lack of public transportation  
 Not being able to leave the house to go and get the medication, etc. because I am at high risk  
 Being unwell with COVID-19  
 Supply issues/unavailability of products  
 Being unable to afford diabetes treatments  
 Fear of contamination  
 None

### Section 7: Access to diabetes care:

45. As a person living with diabetes, do you consider yourself to be at high risk of catching COVID-19? (Please select the best option)

- Very high risk   High risk   Moderate risk   Low risk   No risk

46. As a person living with diabetes, do you consider yourself to be at higher risk of the severe form of COVID-19 (for example requiring intensive care and ventilation)

- Very high risk   High risk   Moderate risk   Low risk   No risk

47. During the COVID-19 pandemic, have you received advice from the health care professionals who normally look after your diabetes?

- Yes    No

48. Did he/she proactively reach out?

- Yes    No

49. Have you had any diabetes-related consultations during the COVID-19 pandemic?

- Yes, face to face    Yes, virtually (telephone, online)    No

50. How would you rate the virtual diabetes consultation you had?

- Very helpful   Helpful   Average   Not helpful   Not helpful at all

51. Have you had any other sorts of follow-up/checks? (e.g. text messages, WhatsApp, etc)

- Yes    No    Please specify which

52. Had you attended any virtual diabetes consultation prior to the COVID-19 pandemic?

- No, these were not available prior to COVID-19  
 No, I preferred to attend face-to-face consultations, although remote consultations were available  
 Yes, I attended a few  
 Yes, I attended them regularly

53. If you attended any virtual consultations during the COVID-19 pandemic, what was the technology used?

- I attended my diabetes consultations by phone  
 I attended my diabetes consultations via an online platform  
 I attended my diabetes consultations via e-mail  
 Other (please specify) \_\_\_\_\_

**54. Would you consider attending virtual diabetes consultations in the future?**

- Yes, I would consider having as many of my diabetes management consultations as possible virtually  
 Yes, I would consider it but only as part of a mix of face-to-face and virtual consultations  
 No, I would not want any virtual consultations in the future

**55. Has COVID-19 disrupted your appointment schedule of the daily management of diabetes care (regular appointments for checks)?**

- Appointment rescheduled  
 Appointment brought forward  
 Appointment cancelled by your care provider  
 Face-to-face appointment transformed into a virtual one  
 I did not attend my appointment  
 No disruptions  
 Other, please specify \_\_\_\_\_

**56. If your appointment was cancelled, has it been rescheduled?**

- Yes  No

**57. If your cancelled appointment has been rescheduled, what delay does it entail?**

- A delay of less than one week  
 A delay of more than one week but less than one month  
 A delay of more than one month but less than two months  
 A delay of more than two months but less than three months  
 A delay of more than three months

**58. Has COVID-19 disrupted your appointment schedule of the screening of diabetes complications?**

- Appointment rescheduled  
 Appointment brought forward  
 Appointment cancelled by your care provider  
 Face-to-face appointment transformed into a virtual one  
 I did not attend my appointment  
 No disruptions  
 Other, please specify \_\_\_\_\_

**59. If your appointment was cancelled, has it been rescheduled?**

- Yes  No

**60. If your cancelled appointment has been rescheduled, what delay does it entail?**

- A delay of less than one month  
 A delay of more than one month but less than three months  
 A delay of more than three months but less than six months  
 A delay of more than six months but less than nine months  
 A delay of more than nine months

**61. How would you rate the management of your diabetes complications because of any difficulties you may have encountered accessing diabetes care during COVID-19? (on a scale of 1 to 5, with "1" complications not having worsened at all to "5" complications having worsened a lot)**

- 1  2  3  4  5

**62. Were you able to access multidisciplinary team care, for example, your dietitian, psychologist, or specialist nurse?**

	Yes	No	Not applicable
I was able to access my diabetes nurse			
I was able to access my psychologist			
I was able to access my dietitian			



**63. How much have you used the following technologies/platforms to support your diabetes care during the COVID-19 pandemic**

	Frequency
Apps <input type="checkbox"/>	
Social media <input type="checkbox"/>	
Dedicated websites <input type="checkbox"/>	

**64. What have been the biggest barriers to accessing diabetes care during the COVID-19 pandemic?**

- Travel restrictions
- Lack of public transportation
- Fear of contamination
- Lack of trust in remote alternatives (such as virtual consultations)
- Lack of knowledge/skills in using technology for virtual consultations
- No access to technology allowing virtual consultations
- No diabetes care available
- I did not have any barriers
- Other (please specify) \_\_\_\_\_

**65. How effective do you feel your outpatient diabetes care was during the COVID-19 pandemic? (on a scale of 1-5, with "1" totally ineffective to "5" very effective)**

- 1     2     3     4     5

**66. How has the COVID-19 pandemic affected your non-diabetes healthcare (e.g. cancer screening, dentist visits)?**

- Delayed appointments
- Delayed procedures or treatment
- Cancelled appointments
- Cancelled procedures or treatment
- Not effect
- I did not have any need for non-diabetes related healthcare
- Other, please specify \_\_\_\_\_

**67. What are your biggest worries at present as a person with diabetes? Select a maximum of 3 answers.**

- Catching COVID-19
- Having a severe form of COVID-19
- Being a key worker with diabetes
- Not being able to access medication or supplies
- Not being able to access diabetes care
- Worsening diabetes management
- Not getting the diabetes support I need
- Feeling isolated
- Increased stigma
- Deteriorating mental health
- Coming out of lockdown, going back to work
- Coming out of lockdown, resuming all activities
- I do not have any specific worry
- Other, please specify \_\_\_\_\_

**68. What would have helped you manage your diabetes better during the COVID-19 pandemic?**

- More information and clearer recommendations for people living with diabetes
- More online virtual support
- Other, please specify \_\_\_\_\_

**69. What guidance did your country give specifically for people living with diabetes during the COVID 19 pandemic?**

- To stay at home and not leave the house
- To physically distance
- To continue as normal
- No guidance given
- Other, please specify \_\_\_\_\_

**70. Where did you get information about this guidance?**

- Government (media, posters, announcements, etc.)
- Healthcare provider
- Pharmacist
- Diabetes association
- Other (please specify) \_\_\_\_\_

**71. How effective do you think your country's response was in reducing the spread of COVID-19 for people living with diabetes? (on a scale of 1-5, with 1 being totally ineffective to 5 being extremely effective)**

- 1     2     3     4     5

**72. How effective do you think your country's response was in treating of COVID-19 for people living with diabetes? (on a scale of 1-5, with 1 being totally ineffective to 5 being extremely effective)**

- 1     2     3     4     5

**73. How clear do you think the guidance was for people with diabetes (on a scale of 1-5, with 1 being totally unclear to 5 being extremely clear)**

- 1     2     3     4     5

**74. As a person living with diabetes, what do you think could have been put in place to better support you during the COVID-19 pandemic?**

**75. Is there anything else you would like to add?**

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