Diabetes self-management and Social media: Experiences of children and young people in Kyrgyzstan

Report

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1. Background

Diabetes mellitus (DM) is an acute health and social challenge globally. According to the International Diabetes Federation (IDF) in 2021, 10.5% of the world's adult population (about 537 million people aged 20 to 79 years) suffered from Diabetes, and almost half of them were unaware of their disease. Forecasts published in The Lancet indicate that by 2050 this number could increase to almost 1.5 billion people. The financial burden on health systems is also increasing: in 2021, global diabetes-related costs amounted to US$966 billion, and are estimated to increase by another US$100 billion by 2045.

In the Kyrgyz Republic, the problem of diabetes also remains extremely urgent. As of 2023, there are 84,020 officially registered patients with diabetes in the country, which is 1.18% of population, although survey results show that over 7% of the population suffers from diabetes (STEPS, 2023).

Insulin expenditure reached 1.92% of the State health expenditure, while hemodialysis expenditure, which is needed mainly by patients with complications of diabetes, accounted for 6% of total health expenditure. Of the 2,604 patients undergoing hemodialysis, 95% began to need this treatment precisely due to the complicated course of diabetes.

In these conditions, it has become important to support self-monitoring of diabetes by patients, ensuring the availability of drugs and devices of self-monitoring blood glucose levels, as well as information support. These actions can not only improve the quality of life of people with diabetes, but also significantly reduce the economic burden on the healthcare system.In 2022, a multi-country study “Target product profile of non-invasive and minimally invasive glucose self-monitoring devices for low- and middle-income countries: a qualitative study in Kyrgyzstan, Mali, Peru, and Tanzania” was conducted, with the participation of Foundation for Innovative New Diagnostics (FIND), Addressing the Challenge and Constraints of Insulin Sources and Supply (ACCISS), and Health Action International (HAI). This marketing research aimed to study the opinions of consumers and healthcare professionals on the available and desired characteristics of self-monitoring devices.

This study focuses on the information needs of children and adolescents receiving insulin to achieve self-management and the role of social media in ensuring that self-management. Here, the term "self-management" refers to measures taken by patients and their relatives or caregivers to maintain the most important vital signs, primarily blood glucose levels, at a controlled and stable level. These measures include blood glucose self-measurement, insulin self-administration, healthy nutrition, physical activity, sleep, rest, and work. The term “self-management” might be interchangeable with terms such as “self-monitoring”.

In light of this, the following research questions are explored: What is the patients’ awareness about essential elements of diabetes self-management? How and to what extent effectively do potential sources of information on self-management tools function? Under what market conditions and social attitudes do patients practice the self-management and receive information on self-management tools? How does the access to information as well as the information itself need change as children with diabetes grow up? What is the role of social media in meeting the need of information to maintain self-management?

Aim and objectives

Aim: To explore information needs and self-management practices in diabetes patients, with focus on children and adolescents receiving insulin therapy.

Objectives:

1. Conduct a secondary review and analysis of the qualitative dataset collected in the form of transcribes as part of the original (marketing) study.

2. Synthesize the information to answer the research questions.
3. Develop recommendations for potential users of the research.

Methodology

In 2021, the multi-country qualitative study “Target product profile of non-invasive and minimally invasive glucose self-monitoring devices for low- and middle-income countries: a qualitative study in Kyrgyzstan, Mali, Peru, and Tanzania” was conducted in the named countries. The data was collected and recorded in audio files and then transcribed. Open-ended questions as part of semi-structured questionnaires were used to stimulate discussions.

In Kyrgyzstan, data was collected in Bishkek city and Chui region, focusing on the opinions of patients, parents/caregivers, and healthcare professionals. Open-ended questions that were asked during individual and group interviews explored daily experience of using self-management devices and the expected characteristics of glucose measuring devices, as well as revealing important issues around access to health services, information for self-monitoring, psychological and socio-economic issues.

The study in Kyrgyzstan included total 96 respondents who were part of 48 individual interviews and 48 focus group discussions. The 96 respondents comprised of five groups:

1. Medical workers who manage Diabetes - Family Doctors, Endocrinologists, nurses (n = 24).
2. Adult people living with Type I Diabetes (n=24)
3. Adult people living with Type II Diabetes (n=24)
4. Caregivers/parents of people living with type I diabetes (n=18).
5. Adolescents living with type I diabetes (n=6).

After the mentioned original (marketing) study, a secondary review of the collected data was conducted, in order to synthesize information on those aspects of daily self-management that had been collected in the interviews but did not represent a strong focus for the marketing research. The rationale behind this secondary review is that the data collection of the initial research was carried out in the first years immediately after the onset of the COVID-19 pandemic, in 2021 and 2022, and since then the country's health system has undergone some changes. In particular, there have been changes regarding the merging of Primary Health Care (PHC) organizations with Territorial hospitals to form the Centers for General Practitioners, in addition the MoH and the Mandatory Health Insurance Fund were merged, and the government has strengthened its role in providing medicines to the population.

For this study, the qualitative data subjected to secondary review and analysis using the MAXQDA program. The following *keywords* were used in MAXQDA to find relevant quotes and statements:

- glucose measurement, insulin, self-management, information, adaptation, access, diabetes school, growing up, social media.

The quotes extracted from the software were collected into information blocks, which became part of the information synthesis to answer the research questions.

Methodological limitations

1. The sample of patients in the original (marketing) study did not include patients with severe complications of diabetes. Although many of the interviewed patients had episodes of hypo- and hyperglycemia in the past, there were no patients who had recently or at the time of the interview been in the departments of septic surgery, cardiology, or ophthalmology.

2. All interviewed patients receive parenteral insulin. However, some respondents expressed opinions regarding all patients with diabetes, including patients who do not receive insulin.

3. The original (marketing) study did not interview any experts and government officials. Thus, this study, similar to the original study, does not aim to obtain a comprehensive picture of health policy and reforms, nor policy in the area of non-communicable diseases.

4. The interviewed patients, their parents/ caregivers, and healthcare workers represent the Chui region and Bishkek city. Therefore, individual situations described by respondents may not represent the full picture of Kyrgyzstan.

2. Self-measurement of blood glucose

Self-measurement of blood glucose is crucial in self-management of diabetes. Regular measurements help to avoid sharp fluctuations in glucose and reduce the risk of complications. The data obtained via self-measurement of blood glucose enables adjusting the treatment.

Until recently, a **conventional glucometer with test-strips** has been the main tool for self-measurement of blood glucose . In recent years, **continuous glucose monitoring systems** have become increasingly wide-spread and effective means of diabetes management. Certain tests, in particular glycated hemoglobin, can be performed in healthcare laboratories.

2.1 Conventional glucometers with test-strips

The procedure involves taking a drop of blood from a finger and placing it on a test-strip, which reacts with blood glucose and displays the result. The status with conventional glucometers is as follows:

1) According to monitoring of insulin access in Kyrgyzstan[1], about 74.3% of patients with type 1 diabetes use glucometers for self-monitoring. Patients receive devices from three sources: they buy them at pharmacies, receive them as humanitarian aid in healthcare organizations, and receive them as gifts from pharmaceutical companies.

2) Patients may face irregular supplies of test strips of certain brands or their absence in pharmacies. Patients have to spend a lot of resources and time to find the required consumables for self-monitoring.

> *"Sometimes in pharmacies I can't find test strips for the Finetest glucometer … Now it is no longer possible to find test strips from this company in any pharmacy. I usually go to the Central Pharmacy, they have them in stock", (Patient, 19 y.o.).*

In the absence of certain brands of test strips, patients have to buy new devices of other brands. The most frequently purchased brands of glucometers among the surveyed patients include: Finestest, Accu Chek Aktiv/Performa and Sattelit.

3) Cost of conventional glucometers is one of the significant challenges for patients. When test strips for the main glucometer become excessively expensive, patients often decide to use other brands, whose test strips are more affordable.

> *"We have several glucometers: Accu Chek which we bought ourselves, and Viva Chek which we were given at the dispensary [Endocrinology centre]. Now we use Accu Chek. We bought it for about 1,550 soms. But the test strips for it are expensive. Then, we bought Fine test. It costs 2,200 soms, but the test strips for it cost 750 soms. Test strips are needed more often, so it is most profitable to use this, (Patient's parent, 41 y.o.).*

4) Patients under the State Guarantee Program (SGP) are entitled to buy test strips in pharmacies at discounts, but this is hampered by limited information and a small number of pharmacies with contracted by the Mandatory Health Insurance Fund. Under the SGP, test strips can be purchased at pharmacies with discounts of up to 50%. Children under 18 are given prescriptions for purchase of 2,500 test strips per year, and adult insulin-requiring patients are given prescriptions for purchase of 800 pieces per year (MoH Order No. 279 dated June 1, 2024).

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[1] Ewen, Margaret, Molly Lepeska, David Beran, Aida Abdraimova, Karen Bonilla-Aguilar, Stéphane Besançon, Asel Dunganova, George Msengi, Moise Nguemeni, and Janeth Tenorio-Mucha. (2023) *Monitoring Access to Insulin (MAIn) tool: Evidence from people living with diabetes is crucial to policy development*. *(p. 1)*

The Directory of Medicines of the MHIF Additional Package[2] includes 11 brands of test strips that must be purchased at pharmacies with co-payment. Test strips sold at discounts can only be purchased at pharmacies that have MHIF contracts. However, the number of such pharmacies is limited and their range of products may have a limited number of brands of test strips.

> *"You know, I was once given a discounted prescription, but I couldn't find where to buy it. I went through a half of pharmacies in the city, that is, this system is very inconvenient: it's kind of there and kind of not there. This is a bit depressing, because it's easier to just buy what you need at the pharmacy. However, this discount would allow you to buy more tests", (FGD participant, patient).*

The process of issuing prescriptions for discounted dispensing of drugs and medical devices have remained unclear to many patients today. Many newly diagnosed patients with diabetes, most often type 2, do not even know about their entitlement[3] to receiving prescribed test strips and antidiabetic drugs. Only 28% of patients with diabetes buy test strips with co-payment[4]. Sometimes a patient is given prescriptions for discounted test strips for glucometers of certain brands, while the patient has a glucometer of a different brand.

> *"We are entitled to discounts on test strips, but I do not use them because I have a different glucometer. And the pharmacy that provides the discount simply does not have test strips for it", (Patient, 28 y.o.).*

2.2 Continuous glucose monitoring systems

Continuous glucose monitoring systems (CGMS, also referred to as Sensors) are devices that measure blood glucose levels in real time. They typically consist of a sensor that is inserted under the skin and a transmitter that sends data to a smartphone or a monitor. Sensors measure glucose levels in the interstitial fluid using sensors that are inserted under the skin and transmit data on current glucose levels to a receiver or mobile app, as well as data on trends and changes. CGMS provide the patient with more frequent and actual data on blood glucose levels in a minimally invasive manner.

> *"Before using Libra [CGMS "Libra"], we measured [glucose levels] 10-12 times a day with a glucometer. We measured before meals, after meals, sometimes between meals and when felt required. Now, sugar readings from the 24-hour monitoring are sent to my and my child's phones every 4 minutes. Now, along with using Libra, we check our blood sugar levels 3 times a day with a [conventional] glucometer", (Patient's parent, 44 y.o.).*

Frequent blood sugar measurements help patients feel more confident, and minimizing the number of finger pricks makes the blood sugar testing process more comfortable. The CGMS warns of glucose fluctuations and can notify of high or low blood sugar levels. Modern insulin pumps can integrate with the CGMS and automatically adjust insulin delivery depending on the blood sugar level. This further reduces the need for frequent manual measurements.

There are many different brands of CGMS registered in Kyrgyzstan, but the most popular among patients are Abbott Diabetes Care sensors. Despite the advantages over conventional glucometers, access to such

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[2] Names of test-strips: IME-DC PRINCE, iDia, iSafe Accu 2, GluNeo Lite, Fine test, AGM-2100, Accu-Chek, Selfy Check, CleverChek, Viva Chek, Care Sens

[3] Ewen, Margaret, Molly Lepeska, David Beran, Aida Abdraimova, Karen Bonilla-Aguilar, Stéphane Besançon, Asel Dunganova, George Msengi, Moise Nguemeni, and Janeth Tenorio-Mucha, (2023) *Monitoring Access to Insulin (MAIn) tool: Evidence from people living with diabetes is crucial to policy development*. (p. 12)

[4] Ewen, Margaret, Molly Lepeska, David Beran, Aida Abdraimova, Karen Bonilla-Aguilar, Stéphane Besançon, Asel Dunganova, George Msengi, Moise Nguemeni, and Janeth Tenorio-Mucha, (2023) *Monitoring Access to Insulin (MAIn) tool: Evidence from people living with diabetes is crucial to policy development*. (p. 9)

technologies remains quite limited in Kyrgyzstan. According to studies, only 22.9% of patients with type 1 diabetes use it[5].

Barriers for using CGMSs by patients in Kyrgyzstan

In pharmacies the CGMSs are not available for sale and patients have to order them through various companies, intermediaries or have them delivered from other countries, such as Kazakhstan, Russia, Turkey and China. This creates inconvenience in the use and availability of CGMSs. **Access to consumables, such as tapes, specialized patches and other necessary accessories, is also limited**.

> *"…we order sensors from Russia, every year I get stressed out that I cannot buy them freely here, that I cannot go to a pharmacy or a specialized store and buy it here, I have to find a more affordable option for myself, that is from Germany, Czech Republic, now Russia. These are about expectations, risks, plus additional shipping costs",(Patient's parent, 41 y.o.).*

High prices of sensors have been a significant obstacle for many patients. Prices for CGMSs often exceed budgets of average families. Many parents of children with diabetes reported they used their child's disability allowances to purchase sensors and consumables. Currently, the social allowances for a child under 18 y.o. with type 1 diabetes is 8,000 som. Adult patients without serious complications of diabetes qualify as Group III Disability under Government's Social Support programs and receive payments of app. 2,000 som[6]. Considering that the average market price of 2-week CGMS in Kyrgyzstan is 5,500 som, even disability payments for children are not enough to buy a full set of sensors for a month, not to mention adult patients.

Some patients find ways to extend the device service life via performing specific manipulations and restarting them for extra 7 to 13 days. In particular, they open the devices and replace the batteries with new ones, which can be dangerous (e.g. risk of battery explosion) and is often not recommended by the manufacturer. However, the need to save money and the desire to control blood sugar levels force people to take such risks.

The use of CGMS requires calibration with glucometers due to possible deviations in readings. This is because sensors may not always accurately reflect blood glucose levels, in particular under conditions of changing physiological factors such as hydration levels or skin temperature. Even with the widespread introduction of CGMS or similar innovative devices, it will not be possible to completely eliminate the use of conventional glucometers.

2.3 Blood glucose measurement in healthcare organizations

For PHC, there is a "Basic Package of Primary Health Care Services" which remains free for the entire registered population. Patients with diabetes belong to the preferential category and, therefore, they are entitled to a package of free services for the main disease at the outpatient and inpatient healthcare settings. Under the basic package, for patients with diabetes registered with the Family Medicine Center/Family Group Practitioners, upon a doctor's referral, the following services are provided free of charge, in Kyrgyzstan:

- Screening for Diabetes mellitus and Diabetes insipidus (detection of blood and urine glucose).
- Screening for early complications of Diabetes (detection of glycated hemoglobin levels once a year).
- Consultation with a doctor with the essential medical procedures.
- Detection of glucose in the blood serum and urine.
- Detection of glycated hemoglobin (once a year for patients with diabetes).

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[5] Ewen, Margaret, Molly Lepeska, David Beran, Aida Abdraimova, Karen Bonilla-Aguilar, Stéphane Besançon, Asel Dunganova, George Msengi, Moise Nguemeni, and Janeth Tenorio-Mucha, (2023) *Monitoring Access to Insulin (MAIn) tool: Evidence from people living with diabetes is crucial to policy development*. (p. 9)

[6] https://mlsp.gov.kg/ru/ezhemesyachnoe-posobie-litsam-ne-imeyushhim-prava-na-pensionnoe-obespechenie-sotsialnoe-posobie/

Public healthcare facilities experience periodic difficulties with performing the glycated hemoglobin test, which force referrals to private laboratories. However, in 2022 and 2023, the number of glycated hemoglobin tests tended to increase and amounted to 14,400,000 and 22,300,000 cases, respectively[7].

Blood and urine glucose testing is in high demand in healthcare facilities. It is particularly important for those patients with type 2 diabetes who are less committed to self-monitoring and do not have glucometers. In such cases, this test becomes one of the few methods for managing the disease and preventing its decompensation.

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[7] Health Policy Analysis Centre (2024), *Policy Brief: Provision of services under State Guarantees Program at PHC and access to glycated hemoglobin test for Diabetes patients*, Bishkek, Kyrgyzstan.

3. Self-administration of Insulin

3.1 Provision of insulin

Government programs and some NGOs provide diabetes patients with medications and consumables for self-management. According to Insulin Availability Monitoring in 2023, **91.1% of patients in Kyrgyzstan received insulin free of charge in healthcare organizations,** which ensures high access to insulin[8].

The Law of the Kyrgyz Republic "On Public Procurement" No. 27 dated 04.14.2022 provides that insulin is purchased centrally through tenders held by the Ministry of Health. According to the Chief Endocrinologist of MoH, until 2019, tenders had been held once every two years, then annually, and in the context of the COVID-19 pandemic, purchases increased to twice a year. According to MoH official data, **the budget for insulin has been constantly growing: from 120,000,000 som in 2019 to 266,000,000 som in 2024, which is due to growth of USD exchange rate and an increase in the number of patients.**

The MoH procurement rules provide that the requirement of insulin is determined based on data from previous years with 10% surplus to reflect the annual increase in morbidity. In 2023, changes were made to the insulin procurement process. The state enterprise “Kyrgyzpharmacia” was established, which is now responsible for procurement without tenders, using the direct negotiations method. According to Government requirements set forth in the Law of Public Procurement (No. 72 dated 03 April, 2015), medicines and other goods for healthcare must be purchased at the lowest price.

Since the start of its operation, the State Enterprise “Kyrgyzpharmacia” has purchased original insulins from Novo Nordisk, despite higher prices, which required a justification to the Cabinet of Ministers. That decision was made with account to requirements of patients and healthcare professionals who prefer original drugs, despite the availability of cheaper analogues. Thus, although the decision to purchase original insulin was more costly, it was justified in terms of patient satisfaction and clinical effectiveness.

According to the Department of Medicines and Medical Devices, over 50 types of insulin are registered in the country. The government purchases both analogue and biosimilar insulins that are used by children and adolescents, as well as genetically engineered insulins that are used by adult patients. There are short-acting (Actrapid), medium-acting (Protafan), ready-made mixtures (human insulin, Mixtard), ultra-short-acting (Novorapid, Apidra), long-acting (Lantus, Levemir) and ready-made mixtures (analog insulin, NovoMix). The Government also purchases insulin injection equipment: insulin syringes, pens and needles for syringe pens. Insulin syringes are dispensed to the patients who use genetically engineered insulins, at monthly basis in healthcare facilities. Most patients reuse the disposable syringes dispensed to them by the government due to the limited supply.

In Kyrgyzstan, there are only a few insulin suppliers at the moment. The Kyrgyz market is probably unattractive for them, since insulin distribution is centralized and carried out by the healthcare organizations. Insulin is available for sale in several large pharmacies in the capital city, while in the regions the patients, particularly those who use analog insulins, must look for alternative ways to purchase medicines. Most of these patients order analog insulins from neighboring countries, purchase them through intermediaries, or use social media platforms.

> *“It would be good if new medicines that are not yet available in Kyrgyzstan were accessible to our citizens. For example, they are indicated in the [clinical] protocols, but they are not sold in pharmacies. Some patients ask for more affordable medicines, longer-acting medicines that manage well the diabetes, but they do not have access to these medicines in pharmacies, nor there is information about these medicines”, (Doctor of the Family Medicine Center).*

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[8] Ewen, Margaret, Molly Lepeska, David Beran, Aida Abdraimova, Karen Bonilla-Aguilar, Stéphane Besançon, Asel Dunganova, George Msengi, Moise Nguemeni, and Janeth Tenorio-Mucha, (2023) *Monitoring Access to Insulin (MAIn) tool: Evidence from people living with diabetes is crucial to policy development (p. 2-3).*

3.2 Dispensing and distribution of insulins

Insulin is dispensed and distributed to patients at the FMCs/FGPs where the patient is registered. In Bishkek, insulin is distributed to patients by the Republican Endocrinology Center. In the healthcare organizations, the head nurse is responsible for dispensing insulin, while the endocrinologist or family doctor determines the type and amount of insulin. Patients receive insulin for one month. Usually in practice, up to 2-month supply is dispensed to patients, and when the insulin runs out, the patients receive a new supply. Insulins are not dispensed for longer periods.

In cases of limited access to insulin in the healthcare organizations, the medicines are primarily issued to children and patients with complications. One example of such restrictions occurred in 2022, when there were cases of interruptions in the supply of insulins in the country due to the military hostilities in Ukraine and fluctuations in the currency exchange rate. Some patients, in particular those using human insulin, were left without the essential medicines (in particular, Protafan).

> *"If more funds were allocated for insulins so as not to give children too much, but to have some in reserve, it would be great. Sometimes if a patient injects larger doses, for example, eats more carbohydrate-rich food, then he/she may not have enough insulin by the end of the month", (Doctor of the EC).*

When choosing between analog and genetically engineered insulins, **many health workers, including those with diabetes, preferred analog insulins**. Although there is no quantitative evidence in this study, the assessment of access to insulin in 2018 demonstrated that in Bishkek the specialists were convinced that analog insulins have a number of advantages over other classes of insulin[9]. In the regions, most doctors reported that many patients after 18 years of age switch to human insulin and they do not observe an increase in the number of complications or any deterioration in clinical indicators. The only difference is in the increase in frequency of injections. However, some interviewed patients reported it is the increase in the number of injections that makes the use of human insulin much more difficult.

> *"I also use analog insulins myself. I buy them because, unfortunately, the government can no longer provide adults with insulin analogs. And I buy analogs because the quality of life is better with analog insulins. I don't want to say that analogs are better and genetically engineered ones are worse. No! They are both good insulins, human ones. But the quality of life is much better with analogs… it is much better, it is simpler and easier to live with them", (Doctor of the National Center for Maternity and Child Care).*
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> *"To improve the quality of life, it is better for him [the patient] to use analog insulins," (Doctor of the Emergency Center).*

Insulin is distributed *to hospitals* in sufficient quantities, however, in some PHC facilities there are interruptions in the delivery of insulins and syringes. Among the possible reasons, respondents reported the lack of organization of transportation and provision of cold chain and untimely delivery of drugs.

> *"We, the hospital, are supplied insulins in sufficient quantities. But there are difficulties in obtaining insulin in clinics outside the city of Bishkek, because we have many children admitted from the regions and villages. When doctors refer patients to their district polyclinics to receive insulin, there is not enough insulin there", (Nurse from the National Center for Maternity and Child Care).*

Insurance status significantly affects access to insulin, since the lack of insurance creates financial barriers and makes it difficult to obtain medicines. Refusal of health insurance may point to patient's underestimation of the severity of the disease and lack of information about the benefits. The uninsured

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[9] Health Policy Analysis Centre (2018) "*Rapid assessment of insulin access and service provision for Diabetes patients in Kyrgyzstan"*. (p. 50)

pay most of the co-payment for hospitalization, and they do not receive discounts when buying test strips and glucose-lowering medicines in pharmacies.

> *"If they are uninsured or do not work, they cannot get discounted medicines and insulins. I recommend that they obtain insurance, buy a mandatory health insurance police, but they refuse because they have no money", (Doctor of the Family Medicine Center).*

3.3 Insulin administration devices

Insulins are administered in 3 ways: with insulin syringes, insulin pens, or with the help of automated insulin pumps. In Kyrgyzstan, insulin syringes are dispensed to those patients who use human insulins, at monthly basis and free of charge, in amount of 25-30 pieces. Most patients use disposable sterile syringes multiple times, and one insulin syringe is used from 2 to 4 times on average, which is not recommended[10]. Continuous insulin injection devices (pumps) are purchased and serviced entirely at the expense of patients. Pens are dispensed to newly diagnosed children with type 1 diabetes upon registration or during outpatient treatment; usually two pens are dispensed - for the administration of short-acting and long-acting insulin.

> *"Recently, even pen syringes are short in supply; they [patients] are only given disposable insulin syringes. First, they are inconvenient to use. Second, the child is afraid of a huge needle. Third, needles in the syringes are blunt and it is painful to pierce the skin with them. The problem is observed only with the distribution of syringe pens, because a child should be given 2 pieces for short and extended types of insulin. Parents have to buy these themselves for 2,000-3,000 som, although they should be given for free in their clinics or in the Endocrinology centres", (Nurse of the National Center for Maternity and Child Care).*

Needles for syringe pens are dispensed to healthcare facilities upon request of patients. **Government purchases of needles for syringe pens should become more responsive to user needs.**

> *"... children, due to the peculiarities of their bodies, that is thinner subcutaneous fat, thin skin, require smaller needles. Providing these children with very short needles can be quite difficult. Basically, the government purchases needles for insulin syringe pens measuring 6-8 millimeters, while children need smaller needles for convenience. Parents have to buy these needles themselves. We give everything else to children free of charge, including insulin, syringes, needles and syringe pens", (Doctor at the National Center for Maternity and Child Care).*

3.4 Access to insulins after patients reach the age of 18

Although in the country there is fairly wide access to insulin, there is one important aspect that makes it difficult for some groups of patients with diabetes to obtain the required types of insulin. After reaching the age of 18, the access to insulin for young diabetes patients changes. According to the updated Order of MoH # 748 dated 07.08.2019, ***analog insulins*** **should be dispensed to patients up to the age of 29**. However, the government cannot provide all of these types of insulin. Thus, in practice, it turns out that already **upon reaching the age of 18, patients are forced to switch to using *human insulin***.

> *"…previously, the government purchased a much larger number of different types of insulin. Now the government does not provide such a large choice of insulins. Also, **insulins are often purchased by those patients who have reached the age of 18** but previously received analog insulins. These analog insulins are very expensive and the government cannot cover the entire need", (Doctor at Endocrinology centre).*

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[10] Ewen, Margaret, Molly Lepeska, David Beran, Aida Abdraimova, Karen Bonilla-Aguilar, Stéphane Besançon, Asel Dunganova, George Msengi, Moise Nguemeni, and Janeth Tenorio-Mucha, (2023) *Monitoring Access to Insulin (MAIn) tool: Evidence from people living with diabetes is crucial to policy development (p. 16-17).*

The 2018 Rapid Assessment of Access to Insulin[11] also identified this problem, but at that time the analog insulins were often only dispensed to children up to age of 14. About 30% of patients noted that they only received analog insulin up to age of 14 at that time.

> "When distributing these insulins to patients aged 18 to 29, **preference is given to those who have developed complications or who use pumps** [insulin delivery devices]", (*Doctor at Endocrinology centre*).

At the moment, there are improvements observed in the supply of children under 18 with analog insulins. The number of available drugs has increased, which has had a positive impact on quality of life of young patients.

Limited access to analog insulins reduces the quality of treatment in young patients who use insulin pumps. Many pumps are used only with ultra-short-acting analog insulins, so when switching to genetically engineered insulins the patients have to give up using pumps and lose the benefits of using these devices.

> *"I used to use analog insulins; at that time they were free and were dispensed at the Endocrinology centre to people over 18 years old. And now I would also really like to use them, but they are very expensive, over 100 USD per month is spent for buying it. I had difficulties switching from analog to regular, genetically engineered insulins. First, after analog insulins, the genetically engineered insulins begin to work worse ... Second, it was financially difficult for me to buy them, and test strips, sensors, the amounts to spend were already much higher. Due to all these, I decided to use genetically engineered insulins, which are given out free of charge……the insulin pump can only be used with analog insulins, so when they stopped giving them out free of charge, it was already financially difficult for me to use it", (Patient, 35 y.o.).*

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[11] Health Policy Analysis Centre(2018) *"Rapid assessment of insulin access and service provision for Diabetes patients in Kyrgyzstan"*. (p. 49-50)

4. Psychosocial aspects of self-management in children and adolescents

4.1 Difficulties in accepting the diagnosis

Children and adolescents

After the diagnosis of diabetes and the start of insulin therapy, a child's life changes dramatically. The child and his family face emotional and psychological difficulties in accepting the diabetes diagnosis. Daily insulin injections, regular sugar measurements and diet make them feel "not like everyone else".

The age at which diabetes is diagnosed plays an important role in accepting the diagnosis and mastering self-management skills. Younger children perceive changes less consciously. For them, injection procedures gradually become part of the routine, over time they get used to them, perceiving them as a normal part of life. Parents at this stage play a key role, via fully controlling the treatment process and teaching the child the essential skills.

> *Age of 6 years is the time of an unconscious person, so my diabetes is my norm. I am not very worried. When sugar levels jump, I am worried. But I try to cope with it, (Patient, 17 y.o.).*

Teenagers

Adolescents face more serious emotional and social difficulties. They often rebel against regular injections and dietary restrictions, while the need to run procedures at school or in public causes them shame and discomfort.

In addition, adolescence is associated with hormonal changes that can make it more difficult to control glucose levels, making them less predictable. This creates additional difficulties and can cause irritation, increasing the risk of refusing treatment and worsening adherence to self-control. At this stage, it is important to involve not only medical specialists, but also psychologists, support from family and the environment to help the adolescent cope with emotional difficulties and accept a new lifestyle.

> *In the first year, I did not want to accept this disease at all. I did not want to believe that I had diabetes, that I needed to constantly inject insulin. I understood that my life would change, that I would need to rebuild my future for diabetes. I saw that other children could eat everything, do anything, but I couldn't eat what I really wanted because of 'sugar'. A year later, I thought that thanks to a healthy lifestyle, my health would be stronger, (Patient, 17 y.o.).*

Parents

Parents, having found out the diagnosis, often face emotional shock, guilt and anxiety for the child's health. Such parents experience fear of possible complications and uncertainty of the future, not knowing how to cope with the new reality. Constant monitoring of glucose levels, regular injections and the need to follow medical recommendations become a heavy burden, causing chronic stress and fatigue. In some cases, this leads to the fact that all the attention of parents is focused exclusively on the disease, displacing other life aspects of the child and family.

> *At that very moment when I learned about diabetes, I was shocked. Since I knew nothing about diabetes, I was worried about how long and how my child would live. When she was asleep, I would go up to see if she was breathing, how she was feeling. Also, when I gave her food, I was afraid of how the body would react. I was afraid to give too much food or, on the contrary, leave her hungry. Gradually, I got used to it, (Patient's mother, 45 y.o.).*

Such a focus on the disease can disrupt family dynamics, causing conflicts, misunderstandings and tension in relationships with the child. Some parents can become overly controlling, which causes protest in children, particularly adolescents, and worsens their psychological state. In other cases, parents, feeling burnout, can experience emotional detachment, which reduces the quality of support the child needs.

> *At the start, parents are in limbo for long time. First, they begin to blame themselves, ask questions about what they had done wrong and why exactly their child was diagnosed with diabetes. Sometimes* ***parents reach such a level of introspection that they begin to search and think about who is to blame, whose heredity or relatives influenced this. Some parents develop depression against this background****, (Doctor at National Center for Maternal and Child Care).*

Mothers of children receiving insulin therapy have the hardest time, since they are often forced to devote themselves entirely to caring about the child. Until adolescence, mothers take care of their children, performing the necessary daily procedures.

> *… I myself became constantly attached to my child. I even got a job in the same kindergarten specifically to be nearby, give her food, and inject insulin. She is still too young to do anything herself. Of course, I could work somewhere else, but then who would look after my child? (Patient's mother, 28 y.o.).*

Looking after and caring for the diabetes child takes up most of their lives, taking away the opportunity to find jobs and pursue careers. As a result, in most cases, the entire burden of providing for the family falls on the father’s shoulders.

> *I often hear them complain that they have no one to leave a sick child with, no stranger knows how to inject insulin and how to check glucose, so they sit only with the child all the time, do not work. I feel most sorry for mothers: they have a sick child and they still have another baby in their arms, and everyone needs care, attention, and control; mothers are simply torn apart, (Doctor of the National Center for Maternal and Child Care).*

In addition to the feeling of guilt and anxiety that parents’ experience after the child’s diagnosis, they do not always receive sympathy and support from loved ones. Often, instead of compassion and help, parents face reproaches and accusations.

> *My biological mother at some point began to accuse me that my child had diabetes. I was in a terrible state, since my biological mother did not support, did not calm me down at that moment, (Patient’s mother, 45 y.o.).*

Unfortunately, not all mothers receive support from their husbands. Some husbands are reported to blame their wives for their child having diabetes. One mother says she was accused of "driving out" her child by giving her too much workload and, therefore, she got sick. When a parent, usually a mother, is accused from all sides of a child's illness, it becomes very difficult psychologically. This feeling of guilt and loneliness aggravates the stress and makes an already difficult situation even more unbearable.

4.2 Social difficulties

In such families, schools and other places where people are aware of diabetes, the attitude towards children receiving insulin is quite supportive. Many peers, teachers, relatives treat patients with understanding and are ready to help, for example to help in controlling glucose levels, via reminding them of the need to take insulin or eat during classes.

> *Today, everything is much calmer, people perceive diabetes normally. Earlier sometimes people would ask if it could be contagious, ask what you do, what injections, whether it is drugs and so on, but now it is much easier,(Patient).*

However, some people still show caution or even a negative attitude towards children who receive insulin. Often this happens due to a lack of information or existing stereotypes.

> *I have a case when a parent made a scandal at school when he found out that a child with diabetes was studying in his child's class. He thought that it was a contagious disease. As a doctor, I was invited to the school, I had a conversation with the parents, explained that there was no danger to others, (Doctor).*

Some children and their parents have to hide from others that they or their children have diabetes. Fear of condemnation makes them hide the need for self-management and medical procedures. As a result, they face risks of serious complications associated with failure to comply with basic self-management measures.

> *When a child is in children's environment may also be ashamed of injecting insulin. There have been cases when children secretly and in a hurry injected insulin incorrectly, as a result their blood glucose levels rose or fell. Children are often embarrassed by their peers; they inject insulin incorrectly or do not inject at all and hide their diagnosis, (Nurse, 25 y.o.).*

Myths and stereotypes

Successful self-management in people with diabetes is significantly affected by the myths and stereotypes that prevail in society, and they are fueled by a lack of information. Myths are false beliefs, and stereotypes are fixed and simplified ideas about a group of people or things.

Many people know about diabetes, but do not always understand the difference between type 1 and type 2 diabetes. Type 1 diabetes is often perceived as a disease of children and young people, while type 2 diabetes is associated with older people and obesity. However, not everyone is aware that type 2 diabetes can also occur in young people, in particular if there are risk factors. In turn, older people, with damage to the pancreas, can develop type 1 diabetes.

There are various myths and stereotypes about diabetes in society that interfere with correct perception and management of the disease. Among the most common myths about diabetes, we have identified three - the myth that diabetes is contagious (communicable), the myth that sugar consumption directly causes diabetes, and the myth that diabetes is hereditary.

The contagiousness myth can lead to discrimination and social isolation of a child with diabetes. It is worth noting that diabetes is a non-communicable disease that is not transmitted by airborne droplets, physical contact, coughing, sneezing, or shaking hands.

Some may mistakenly believe that diabetes is caused solely by consuming large amounts of sugar. Type 1 diabetes is an autoimmune disease, and therefore consuming sugar or other foods does not affect the risk of developing type 1 diabetes. Although consuming large amounts of sugar can contribute to obesity and other adverse factors that can also increase the risk of type 2 diabetes, sugar consumption alone does not directly cause diabetes. Because of the existing stereotypes about sugar, people living with diabetes feel pressured or judged, believing that the disease is a consequence of their habits, although this is not the case, in particular for type 1 diabetes.

The myth that diabetes is hereditary is due to misunderstanding of the nature of type 1 diabetes and associated to possible undesirable consequences for family life and reproductive health. Although type 1 diabetes has a genetic component, this does not mean that the disease is necessarily inherited. The risk of inheriting type 1 diabetes is indeed higher in children of parents with this type of diabetes, but the probability is still relatively small. In addition to genetics, the development of diabetes is influenced by such factors as autoimmune processes, viral infections and environmental features that are not directly related to genetics.

Today, the myth of the heritability of diabetes and the fear that a woman with diabetes will not be able to have healthy children is rare, but, unfortunately, it still taking place. Pressure from society, families and outdated knowledge about the disease can be strong barriers to starting a family. According to one of the doctors at the City Endocrinology Center, there have been cases when the parents of the bride or groom demanded the engagement to be broken if one of the partners had type 1 diabetes, out of concern for the health of the children.

Healthcare workers and psychologists

The way healthcare professionals communicate the diagnosis, provide information, and establish contact determines the extent to which the patient and their loved ones can accept the new condition and adapt to changes in life. Doctors and nurses also help patients and their families understand the nature of the disease, the importance of self-management, and the possible risks of not treating it. At this point, they act not only as informants, but also as emotional support, alleviating fear of the disease. A clear, accessible explanation of the next steps - from insulin therapy to lifestyle changes - reduces anxiety and creates the basis for a trusting relationship between the patient and the healthcare team.

In real life, healthcare professionals help diabetes patients learn basic self-management skills, but the influence of healthcare professionals on the patient's daily life, behavioral habits, and perception of the disease is usually limited to visits and consultations. In addition, not all healthcare professionals have the opportunity to regularly support the psychological state of patients. This complicates ongoing interaction and motivation for self-management. Most patients and their parents noted the importance of support to be provided by professional psychologists in the healthcare organizations.

> *Parents do not understand what diabetes is and often leave their children alone with their disease, believing that they are already adults, they already know a lot, they have attended the Diabetes School and understand everything. However, children are children, even at 18-20 years old. Here you need to find some kind of line so as not to overdo it; thus, such patients need psychological help. We have absolutely no such psychologists. Doctors themselves cannot be psychologists, give false hope, or deliberately worsen their mood. Also, our endocrinologists are not trained in how to provide psychological support,(Doctor at Endocrinological centre).*

Including the psychological support in the care system is one of effective tools to avoid excessive medicalization of care for patients with chronic diseases such as diabetes. It is important to realize that disease management is not only taking medications or following a regimen, but also working with emotions, motivation and cognitive attitudes. This helps to develop a conscious attitude towards treatment and self-control.

> *...now I feel that I need psychological support and work with a psychologist again because my leg was amputated, I had 3 operations in a very short time. I am going through this hard, (Patient, 41 y.o.).*

Self-management at public settings

Patients with type 1 diabetes have to take measurements in public settings, to manage their condition and avoid complications such as hypoglycemia or hyperglycemia. Many patients may be embarrassed to measure glucose levels in public places. Some people around them may not know that measuring sugar levels is a standard medical procedure, and not something unusual or worrisome.

> *There are fool people, and there are those who perceive diabetes inadequately. For example, when you go to a café or sit in a public place and you urgently need to inject insulin, there are people who stare at you, do not understand what I am injecting. They are surprised what kind of injections are and what they are for. Among them, there are people who cannot be explained what insulin and diabetes in general are. Many people think that diabetes is contagious, (Patient, 17 y.o.).*

In Kyrgyzstan, public settings such as restaurants, parks, shopping centers and schools have nearly no convenient conditions for taking blood measurements. It is difficult for patients to find a clean, private place to work with a glucometer and inject insulin. In crowded places or transport, it is difficult to concentrate on the procedure, which increases the risk of errors.

Also, in public settings it is not always possible to maintain the required level of hygiene during the procedure. This can be a challenge, especially if the patient does not have the opportunity to wash their hands before measuring or to handle the devices in clean conditions.

> *I still prefer to find some private corner to take measurements. Then in public places, on the street, in parks, it is not always possible to wash your hands, you have to measure with dirty hands, which distorts the results, (Patient, 18 y.o.).*

However, as practice shows, due to the lack of specially created conditions for the essential manipulations, many patients manage to adapt to measurements and injections in public places. More and more patients with type 1 diabetes report they do not experience any discomfort or embarrassment when taking measurements at school, on public transport, at work, on the street and other places.

> *There are no difficulties, I am not embarrassed by others. I do not bother about measuring glucose, but I feel more comfortable giving an insulin injection in a secluded place. I usually look for some kind of toilet. I can check my glucose in a cafe under the table, on my knees, after all, I prick it, blood comes out and people do not particularly like to look at it (laughs). I do not see any point in limiting myself in this regard, (Patient, 24 y.o.).*

Many young patients with type 1 diabetes demonstrate a high level of adaptation to the physical and psychological aspects of blood glucose self-measurement and insulin self-administration in public places. Thanks to the development of technology, support from society and their own awareness of the importance of these procedures, they confidently manage their disease without significant discomfort.

> *... I have no problems with measuring in public places. I can do it even in a minibus. And I basically don't care what people are watching and what they are thinking about themselves. As for those who are embarrassed to do it, it's the problem in the people themselves. Because those around them deeply, deeply don't care who does what, (Patient, 17 y.o.).*

Self-management at pre-school and school institutions

Public educational institutions are not always ready to accept children with diabetes. One of the main reasons we identified was the unwillingness of the administration to take responsibility for health and condition of a sick child during their stay at school.

> *I warned her that she now has diabetes. The school principal immediately refused to enroll us. The child is already emotionally stressed, and now they don't want to accept her into school. She said that they had had a child in elementary school with diabetes and there were many problems associated with his illness. But at 7-8-9 years old, a child cannot regulate his glucose independently, he needs help. And my daughter was 13 years old, she knows everything herself, (Patient's mother, 62 y.o.).*

Children with diabetes often face negative reactions from classmates, such as ridicule, bullying and rejection. Such situations can become a barrier to the implementation of essential self-monitoring procedures by the children.

> *My classmates did not accept my new status at all, I was an outcast in the class. They said I was contagious and other unpleasant things. I had to change schools. At the new school, my classmates were very supportive, but the class teacher started saying: "I don't need a sick child in the class. She's nothing but trouble", (Patient, 17 y.o.).*

The lack of constantly accessible and fully equipped medical rooms deprives children of safe and comfortable conditions for measuring blood glucose and injecting insulin. In most schools, the available medical rooms are only accessible during certain shifts, and the rest of time the rooms are closed. In such conditions, children have to look for other places to carry out the essential procedures.

Often children go to the toilet where they measure glucose or inject insulin in the toilet cubicle. **This can be inconvenient and unsafe, given the possible sanitary risks and the lack of support in case of unforeseen situations.** The need to hide their actions from peers or teachers can increase the feeling of isolation and stress in children.

However, with the growing overall awareness of diabetes, the attitude of peers and teachers in educational institutions is often open and supportive.

> *Some class teachers know about children with diabetes and treat them well, such was the case with my little sister. My cousin also got diabetes. She does not experience such problems at school, on the contrary, teachers try to help and guide her, (Nurse, 25 y.o.).*

Some initiatives, such as training medical and teaching staff on the basics of diabetic care, as well as developing public awareness programs on diabetes, have already begun to gain momentum. Parents of children receiving insulin therapy can receive information and support from doctors, diabetes centers and individual enthusiasts who strive to improve the quality of life of these families.

> *… a few years ago, there was a large social project -* ***Kindergarten for diabetes children****. It really worked and helped children adapt well to the social environment. It is still functioning, but it is quite difficult to gather preschool children from all over the city in one place, (Pediatric endocrinologist, 57 y.o.).*

4.3 Financial expenditures and self-management

We identified four significant expenditure items for patients and their families: a) purchasing test strips, b) purchasing insulin (except for those who receive insulin for free), c) treating comorbidities, and d) healthy eating. Financial constraints negatively affect adherence to healthy diet and limit physical activity.

> *We want him to attend various training clubs so that he doesn't have free time for gadgets, but due to financial difficulties, we can't do everything. We can't even enroll him in a swimming pool. A membership there costs over 4,000 with a trainer and therapeutic exercise, (Patient's mother, 41 y.o.).*

5. Information on self-management

This section evaluates *sources of information* on diabetes self-management and the processes of providing information materials, consultations, trainings and other forms of information.

5.1 What do healthcare organizations do?

Healthcare organizations and MoH subordinate institutions conduct information work on diabetes. The main types of information are consultations for patients, trainings and distribution of information and educational materials on diabetes prevention and treatment. Information is also needed for laboratory tests, drug management and to ensure other types of activities.

There are not enough endocrinologists in the regions, to the extent that often family doctors are employed as endocrinologists. In some facilities, health workers are mainly at senior age. Therapists and endocrinologists work in the FMC, but these specialists only provide care to adults. In Bishkek, the FMC/FGPs only treat patients with type 2 diabetes who receive oral insulins. And there are a lot of type 2 patients. One endocrinologist reported an FMC serving 1,300 diabetes patients, which according to the doctor seems considerable.

Children with newly diagnosed diabetes and children receiving treatment from all over Kyrgyzstan have to travel to Bishkek due to a shortage of pediatric endocrinologists. The Endocrinology Center is very busy. There are 100 to 200 patient visits per day, ***mainly to receive insulin.*** Due to large number of patients, the Endocrinology Center has an appointment booking system. The waiting time for an appointment with a doctor can be 7-10 days. This is inconvenient for those who need an urgent consultation. The Endocrinology Center admits out of turn the patients who feel unwell. The Endocrinology Center also believes that a psychologist and a nutritionist would strengthen the work.

Doctors and nurses at FMCs and FGPs need more training on diabetes. Additional education on diabetes management is available at the Kyrgyz State Medical Institute of Continuing Education and Retraining. When it is not possible to undergo a formal Additional Education on diabetes, doctors learn from their colleagues.

> *More training on diabetes should be provided to family doctors. You asked about insulin, I know nothing at all. We also need to hold conferences and provide training for patients. Our patients know nothing at all, and we also don't have time to sit and tell them everything in detail, (FGP doctor).*

NGOs, pharmaceutical companies, and international organizations play an important role in improving and maintaining the knowledge of medical workers.

> *...the visit of the President of the International Diabetes Federation, Maria Alba, had a very big impact, she told a lot of interesting things and opened my eyes to many things, (Pediatrician at the National Center for Maternity and Child Care, 61 y.o.).*

Doctors have become more wary of gestational diabetes in pregnant women, its detection and diagnosis are improving. According to the Chief Endocrinologist, due to the fact that gestational diabetes manifests itself only during pregnancy, **there are no clear statistics on the incidence of gestational diabetes in the country.**

> *I also had gestational diabetes. Then I had a late diagnosis, although I am a doctor myself, I was either lazy or felt hot and did not go to the doctor with this problem. When I started having more obvious symptoms, I connected everything and started to sound the alarm. Previously, doctors did not have such a thing that all pregnant women measured their blood glucose, it was not accepted then. Now they pay attention to this and make diagnosis faster, (Endocrinologist at the National Center for Maternity and Child Care, 49 y.o.).*

5.2 What do Diabetes Schools do?

Diabetes Schools (further referred DS) operate within some healthcare organizations. The MoH's intention to establish DS in the maximum number of healthcare facilities was not successful, as a result DS actually operate in some tertiary healthcare organizations - the National Center for Maternity and Child Care, the Bishkek Endocrinology Center, secondary healthcare organizations such as general hospitals, and individual Family Medicine Centers/Family Group Practices. Diabetes Schools are crucial in teaching patients and their families how to effectively treat and control diabetes. Completing it is an important part of treatment, especially for patients with type 1 diabetes and their families.

To evaluate DS, it is interesting to consider the international experience of similar structures. For example, in the UK there is a national educational program for diabetes patients DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed). Completing such programs is mandatory for patients to gain access to treatment and support. DESMOND is mandatory for patients with type 2 diabetes, while for patients with type 1 diabetes there are separate programs, such as DAFNE (Dose Adjustment for Normal Eating).

In Kyrgyzstan, patients undergoing DS is more of a recommendation. However, doctors strongly recommend patients to attend such programs, as these improve the quality of life and help to better cope with the disease. The ***Diabetes Schools teach patients basic self-management skills***: in particular, patients learn how to control blood glucose, insulin administration, calculate carbohydrate balance, and other skills. At DS, patients receive information on how to develop and follow individual treatment plans, including nutrition, physical activity, medication regimen, and insulin therapy. All calculations are individual and require a special approach from doctors, the patients themselves, and family members.

> *Even I, being a teacher at the Diabetes School, say that everything I explain is the basics. Everything that concerns each child must be selected individually. The same insulin can be taken differently by each organism... The approach to insulin is very subtle; unfortunately, not all doctors understand this, (Patient's mother, 45 y.o.).*

The training course consists of 8 lessons, which can be divided or adjusted depending on how the material is absorbed by patients and their parents. All family members can attend the lessons at the Diabetes School. Patients who have just learned about their diagnosis may find it difficult to perceive well all the information delivered at the School of Diabetes. Therefore, much attention is paid to training family members so they can better support their family members with diabetes. At the Diabetes School, they teach first aid skills for hypoglycemia, patient support for following doctor's recommendations, and how to create and maintain a favorable environment for self-management.

> *The School only provides the basics, because there is simply no point in giving too much information in the state you [patient] are in there. The brain does not absorb this information, this knowledge. They provide such a base so that when you get home you more or less know what to do. And you learn all the details and nitty gritties, different variations on your own, (Patient, 41 y.o.).*

Overall, the effects of Diabetes Schools are well recognized. Patients with newly diagnosed diabetes have higher interest in the Diabetes School, because they face the need to quickly acquire new knowledge and adapt to a new reality. There is a separate group for them, where they are taught basic knowledge and practical skills necessary at the early stages of self-management. For more experienced patients, there is an advanced group, where they refresh their existing knowledge, and gain new knowledge.

> *We have noticed that over the past 2-3 years, the number of sick children who are admitted with ketoacidosis has decreased by several times. We believe this is only due to training at the Diabetes School. That is, patients began to understand how to live with their condition, how to control and treat it, (Pediatrician, 61 y.o.).*

The Diabetes School provides a lot of knowledge and skills for healthcare workers themselves. The importance of the Diabetes School is so high that there are enthusiastic doctors who learn from senior doctors and from their own experience in order to work in these schools.

> *With my working schedule, I did not manage to get to additional training at the KSMICER. The last time we had a training on Sensors [Continuous Glucose Monitoring Device] and Pumps [insulin administration device], but I did not get there. I completed training at our Diabetes School, and learned everything else in practice, read magazines and books, talked to other people. When we first start work, the Diabetes School conducts training for new medical staff, (Nurse, 25 y.o.).*

However, there are patients and relatives who are not always able to attend the scheduled classes. Not everyone is comfortable with the working time, because the classes are held only on certain days and at a certain time.

Recently, the volume and format of classes have had to be changed, due to the increased number of patients. **In conditions of overloaded healthcare facilities, the quality of individual approach deteriorates, and patients are often forced to look for alternative sources of information.**

> *When newly diagnosed patients are concerned, then I used to work with them completely individually, but now, due to sharp increase in the number of newly diagnosed children, I am not able to conduct individual classes, (Endocrinologist, 49 y.o.).*

The lack of educational materials limits the possibility of conducting practical classes. In schools where there are no handouts, such as modern glucometers, insulin syringes and demonstration models, or they are outdated, it is difficult to introduce innovative teaching methods that could increase patient involvement.

> *... the materials are not always available. When they are, I hand them out, when they are not, I tell them verbally. Recently, we have been handing out materials without fail: the girls [nurses] have printed out self-monitoring diaries, beautiful and colorful, brochures on insulin, on the technique of its administration, on calculating bread units and using a glucometer, (Endocrinologist, 49 y.o.).*

There is a shortage of trained specialists in the functioning Diabetes Schools. Due to the shortage of personnel, the workload of existing instructors increases, which leads to a reduction in the time devoted to each patient and complicates the individual approach to training.

> *We actually had a Diabetes School in the clinic. A very experienced nurse, who herself suffered from diabetes, was trained. She informed our patients very well, taught them diabetes management, all the basics of disease control. Unfortunately, she was made redundant, and the Diabetes School was closed. I have been working without this nurse for a month now, during which time I have had 27 newly diagnosed patients with diabetes. In a 20-minute appointment, I physically do not have time to tell them everything about disease management, I do not have time to train them. I think this is a huge problem for patients, (Endocrinologist, 51 y.o.).*

Doctors do not have enough time to train patients. Healthcare workers are in favor of creating more Diabetes Schools. In such a situation, a more active involvement of nurses in the patient training process is proposed as an appropriate solution.

> *Diabetes Schools have been opened all over the country, of course, but there are very few of them. There is also a shortage of training personnel. At the moment, our state and international projects are working to delegate the functions of training in Diabetes Schools to nurses, (Endocrinologist, 49 y.o.).*

Indeed, where the Diabetes School and attending physicians cannot cover individual issues that arise for patients and relatives, informal consultations from nurses take place. And this is another source of information and consultation for patients that needs further development and bringing to order.

> *... if I personally know something, I have a conversation with them, because there are parents who cannot speak openly with the doctor. Since nurses work 24 hours a day, I spend a lot of time with them. If a patient with newly diagnosed diabetes is admitted on my shift, then most likely I will explain to them everything that I know. Since I work 24 hours a day, 24 hours a day, and spend almost 24 hours with the patient, it is easier for me to find a common language with them and tell them about things that they cannot ask their attending physician, (Nurse, 25 y.o.).*

5.3 Social media

Since the early 2000s, when the Internet and social media became accessible to a wide range of people, online communities began to appear all over the world, which became an important source of communication and support for people with different interests and problems. These communities helped people unite by interests, share experiences, receive advice and help, and find emotional support in difficult times. This trend has become particularly significant for those facing chronic diseases such as diabetes, where participation in such groups helps to receive useful information and motivates to better control their health. And the role of social networks as a source of information is growing.

At the global level, forums and websites such as Diabetes Daily[12] or Children with Diabetes[13] are well known, where parents of children with diabetes unite to discuss treatment methods, share advice and support each other. With the development of mobile applications and messengers such as WhatsApp, Facebook, Telegram, Viber and others, communication has become faster and more convenient. This has made it possible to create small local or international groups where participants can instantly exchange information. **Type 1 diabetes patients in Kyrgyzstan are also involved in international groups and communities, taking part in online groups and staying in touch with people who have similar experiences.**

> *... there is a Russian group called "Type 1 Diabetes", which I am a member of. The group is closed and not so easy to join. ... There are a lot of outstanding professors in this group, they share very useful and necessary information. The most important thing is that a psychologist works there on Skype, it is all free for group members, (Patient, 41 y.o.).*

The authors of the study "Social Media in the Management of Obesity and Diabetes: An Underutilised Population Educational Tool" (2024)[14] claim that chats and forums on social networks improved patients' understanding of their disease. Among the specific effects of social media, scientists highlighted the improvement of patients' skills in calculating carbohydrate balance. Now, with the help of instant messaging, blogs, and forums, patients can easily discuss insulin-to-carbohydrate ratios and insulin dosages for certain foods with people around the world. Additionally, apps like MySugr, Digibete, myDesmond, and GDm-Health provide patients with resources they can use in their free time to educate themselves and better manage their diabetes.

“Patients’ Use of Social Media for Diabetes Self-Care: Systematic Review” by Elnaggar et al. (2020)[15] noted that social media platforms provide social support by offering practical options to *facilitate self-care and emotional support* for those living with chronic diseases, which is preferred by patients, except when information about prescription medications is needed. Facebook groups were found to be the most useful tool as they provide a multi-functional platform for accessing content, sharing skills, monitoring progress, and organizing online and live groups. Additionally, these groups can be a useful tool for patients and their caregivers to obtain information about blood glucose monitoring devices and receive technological

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[12] https://www.diabetesdaily.com/

[13] https://childrenwithdiabetes.com/forums-and-research/

[14] https://pmc.ncbi.nlm.nih.gov/articles/PMC11096135/

[15] https://pmc.ncbi.nlm.nih.gov/articles/PMC7210496/

assistance. Active participation in blogs has been shown to be associated with a higher sense of responsibility and provides patients with more opportunities to learn about their disease. However, the review continues, **prior to encouraging widespread use of social media as a communication tool for patients and their families, healthcare professionals should assess their control and possible risks, and integrate this communication into the patient's medical record.**

There are already quite a lot of studies globally about the impact of social media on self-monitoring in diabetes. We will analyze social media in Kyrgyzstan using the example of *WhatsApp groups of parents of children with type 1 diabetes*. In general, in Kyrgyzstan, joining WhatsApp groups has recently become almost the most common communication tool.

> *And there is [WhatsApp group] "Diamamochki" who know more about diabetes than doctors, they will chew everything up and explain. It is very useful to communicate with them, as you get a lot of information, (Patient's mother, 41 y.o.).*

The history of emergence of groups of parents of diabetes children in Kyrgyzstan is closely related to development of technology and the need in social support and experience exchange among people with chronic diseases. These groups emerged as a response to challenges faced by families raising children with diabetes, and due to the need in support that healthcare organizations cannot readily provide.

Despite the existence of medical resources, many parents feel a lack of comprehensive information about everyday life with diabetes, especially regarding blood glucose management in children, insulin therapy adjustments, and other aspects of living with type 1 diabetes. *Doctors' visits and visits to doctors are often one-time, while diabetes requires constant monitoring.* Parents seek answers to questions about specific situations (school, sports, holidays) and face the need in consultations outside medical institutions' working hours.

For many parents, the diagnosis of diabetes in their child becomes a strong emotional shock. They begin to seek support from those who are facing similar problems. Communities, namely groups of parents of children with type 1 diabetes, have *become a place to share experiences and gain understanding*. The feeling that a person is not alone in their journey plays an important role in accepting the diagnosis and forming a positive attitude towards diabetes management.

We have highlighted several **<u>key functions that WhatsApp groups of parents of children with diabetes in Kyrgyzstan perform:</u>**

1) **Participation in information campaigns to raise awareness and promote patients' rights.** Parents and children take part in campaigns aimed at raising awareness about diabetes, breaking myths and stereotypes, and forming tolerant and supportive attitudes towards children with diabetes.
2) **Exchange of practical advice.** In WhatsApp groups, parents share practical advice on self-management of children, talk about proven methods for monitoring blood glucose, proper nutrition and physical activity, and other aspects of self-management.

> *We have a group in Bishkek for parents whose children have diabetes. We can always go there, ask questions, and get answers. Many have more experience than us, so they give us practical and useful advice. In this group, there are children who are sick [at the age of] 17-18. Their parents write how and what to do. When newcomers join the group, we all help each other, (Patient's mother, 45 y.o.).*

3) **Resolving urgent issues.** In case of urgent issues or problems related to the self-management process, parents can quickly get advice from other group members, which can be particularly important in critical situations, such as hypoglycemia.

4) **Access to information about novel medical products, technologies, and medications.** Group members actively share news about novel devices, e.g. glucometers, insulin pumps, or continuous glucose monitoring systems. The latest medical recommendations and changes in treatment regimens

and nutrition are also discussed. Discussing novel devices and technologies in groups helps to more quickly introduce them into everyday self-management practice, which improves the quality of life of patients. Parents, using the knowledge gained, can more effectively monitor their children's blood glucose levels, preventing complications such as hypo- or hyperglycemia, etc.

5) **Emotional support.** Parents in these groups share their experiences, fears, and joys, finding understanding and sympathy from those who are going through the same experiences. This helps to cope with the emotional difficulties associated with caring for a child with diabetes.

5.3.1 COVID -19 and Social media

Social media for health have gained a renewed drive in the early stages of the COVID-19 pandemic. With travel and social interactions restricted, working remotely, online, and via social media became **the new norm**. Fear of complications, lack of information, and frequent changes in health recommendations during the early stages of the pandemic not only affected businesses, but also led to a significantly increased activity in online health communities, including support groups for people with chronic diseases.

The COVID-19 pandemic has exposed weak points in the coordination of health authorities. Limited access to healthcare and resources has forced many groups, including parents of children with diabetes, to seek alternative ways to receive information and support. Social media has become a platform for people to coordinate efforts, share experiences, and help each other. These online communities have often responded faster than traditional healthcare structures, providing up-to-date information and advice on managing diabetes during the pandemic.

It is worth mentioning here that the **interviewed healthcare workers have noted an increase in the incidence of diabetes and its complications in Kyrgyzstan, and they see a connection between this increase and the COVID-19 pandemic.**

> *... we noticed that during the [COVID-19] pandemic and after the pandemic, the incidence rate also increased, and complications worsened. I have been working in the Endocrinology department for 5 years, but I have not seen this before, (Nurse, 25 y.o.).*

Of course, a direct cause-and-effect relationship between COVID-19 and the development of diabetes has not yet been reliably established. Therefore, these observations of individual health workers interviewed should be considered only unverified hypotheses. However, there is evidence that the cytokine storm in COVID-19, the body's systemic response, as well as local reactions of the pancreas should be considered significant factors that, in addition to damaging all body systems, can also directly damage pancreatic cells, including cells that produce the hormone insulin[16].

5.3.2 Social media and growing of children with diabetes

Rational and targeted use of social media by doctors and healthcare organizations can lead to greater receptivity of parents to their doctors' recommendations. The Ministry of Health and professional associations could be leaders in setting the agenda, content, clinical and practical guidelines.

To illustrate, we consider the growing up of children with type 1 diabetes and the need to adjust the dosage. The interviewed doctors point out the difficulty of explaining this need to some parents. This is facilitated by the fact that some parents and children miss injections or visits to the doctor or have fears and misconceptions about the effects of adjustments, in particular increasing the insulin dose, on the growing child.

> *Many parents are afraid to increase the dose. Even if they see that the dose used is insufficient and the level is high. They think that if the dosage increases, it is harmful for the child, the child*

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[16] Abramczyk U, Nowaczyński M, Słomczyński A, Wojnicz P, Zatyka P, Kuzan A. Consequences of COVID-19 for the Pancreas. Int J Mol Sci. 2022 Jan 13;23(2):864. doi: 10.3390/ijms23020864. PMID: 35055050; PMCID: PMC8776154.

> *will be dependent throughout the life. Many parents hope that their child can recover forever and live without insulin, so they do not want him/her be used to it. For example, I had a case: the child has constant [condition of] hyperglycemia; I tried to persuade the child's mother for a long time to increase the dose by 1 unit - she was categorically against it, (Doctor, FGD participant).*

Those patients who resort to the Internet and social media for information and consultations have less friction with their doctors on specific aspects of self-management. It seems that doctors should embrace using such concepts as "influencer" and "blogger" in social media to their advantage.

> *... again, I learned a lot from applications, watched somewhere, read somewhere. I watched some bloggers who suffer from diabetes. I learned from bloggers that the more is weight, the higher the insulin dosage becomes, and much more. That is, I anyway rely more on the Internet, (Patient, 24 y.o.).*

As discussed in Section 3.4 "Access to insulin after patients reach age of 18", after reaching the age of 18, children with type 1 diabetes on insulin therapy in Kyrgyzstan essentially stop receiving free insulin analogues from healthcare organizations and are offered to continue receiving for free the human insulin. Most patients prefer to continue using insulin analogues and, therefore, after access to free insulin analogues ceases, they face a dilemma: to receive human insulin for free from the healthcare organizations or to buy insulin analogues with their own money.

It is for this reason that many patients choose to buy insulin analogues with their own money. The availability of analogue insulins on the pharmaceutical market is limited. These patients have to spend a lot of money to buy insulin analogues, which often have to be imported from abroad. Most often from Kazakhstan, Russia, Turkey. This forces them to unite in groups, share information, help each other overcome administrative, regulatory and logistical barriers.

Although social media provide a useful platform for sharing experiences and mutual support among people with diabetes, the role of health authorities, namely the Ministry of Health, professional associations, and nursing associations, remains crucial. These agencies are in position to provide reliable information, and competent consultations. Healthcare institutions have the necessary resources and expertise to support patients, prevent complications, and develop scientific approaches to diabetes treatment. Ideally, social media and healthcare organizations should work in tandem to improve the quality of life of patients. Patients are presumably safer when healthcare professionals are more engaged in contents posed at social media platforms.

We have found that **one of the important characteristics of social media initiatives for children receiving insulin is their sustainability in the long term**. In fact, the generation of patients whose parents once organized WhatsApp groups or other social media as a communication tool has already grown up or is leaving adolescence. They are largely able to independently conduct daily self-management. Social media have comparatively better sustainability due to the fact that after specific parent leaders of these platforms leave, others will take the lead. This fundamentally distinguishes social media from other forms of mutual assistance of parents, such as public unions or associations, a number of which had been founded by parents and then ceased to function after their children with diabetes grew up.

6. Novel technologies for Diabetes self-management in Kyrgyzstan

The new clinical protocols in Kyrgyzstan contain information on the use of novel technologies, such as insulin pumps and sensors. Doctors are trained in their use. However, it is not yet clear what problems of the healthcare system in the field of diabetes should be solved by using the novel devices, what difficulties may arise when used by patients themselves and what solutions are available for these difficulties, what characteristics users expect, and how to ensure wide access to them. This section attempts to answer some of these questions.

6.1 What kind of patient issues can novel technologies solve?

According to respondents, the ideal devices for blood glucose measurement and insulin administration should have the following features:

- Make blood glucose measurement less traumatic.
- Eliminate the need in test strips.
- Store measurements in the device's memory.
- Remote access to measurement data.
- Reliability of measurements.
- Balance between continuous measurements and measurements on demand.
- Affordability.
- Physical access.
- Should be simple, i.e. both children and adults can use them.
- Measurements should be carried out on different biological media, not only on blood.

6.2 High prices of novel devices

All novel devices - sensors, pumps and the like - are quite expensive. Consumables for these devices are also expensive. How do patients and families adapt to the high cost?

One way is to alternate more expensive sensors with a regular glucometer. This approach also allows the patient to monitor the accuracy of sensor measurements by comparing them with measurements from a conventional glucometer. Moreover, many patients believe that the **reliability of glucose measurements by non-invasive methods should be confirmed by invasive methods, i.e. conventional glucometers.**

> *Not everyone agrees with the glucometer readings - they are considered a relative indicator, since this is not venous blood. As a doctor, I still adhere to the opinion that **the most accurate is a laboratory blood test for glucose,** (Doctor at Family Medicine Center, 38 y.o.).*

Another way is that patients who use a device for continuous blood glucose monitoring, which is designed for 14-day use, extend the operation of the device for another period, that is, for extra 14 days. However, such manipulations often lead to the display of distorted measurement results.

For patients with type 2 diabetes, some of the advantages of the novel devices are not essential. For example, continuous measurement, including at night during sleep, is not necessarily recommended for patients with type 2 diabetes, while it is important for patients with type 1 diabetes, especially in children. In this regard, health policy makers and healthcare managers should prioritize patients with type 1 diabetes and children.

To fully utilize all the advantages of novel technologies, it is best for patients to use sensors and pumps together. This will maximize self-management, and therefore improve the quality of life.

6.3 How to ease the access to novel technologies in the market?

In general, respondents are pessimistic about the government's willingness and readiness to purchase novel devices for blood glucose self-measurement and insulin self-administration. However, the interviewed doctors and patients suggested different approaches to solving the procurement issues: some considered certain social groups as priority, others considered value of focusing on analog insulins, and others suggested revising the approaches and mechanisms for purchasing insulins and glucometers.

> *We need to include [the purchase of novel devices] in the State Guarantees Program [SGP], and then patients would receive the devices, (Endocrinologist, 65 y.o.).*
>
> *Elderly patients with diabetes are very vulnerable. I think the government should seriously address this issue, (GP, 38 y.o.).*

Several healthcare workers **suggested introducing a shared payment for new devices between the government and patients, i.e. introducing co-payment.**

> *...the government provides such a device, and the patient pays a third or half of the cost of the device. Providing the device completely free of charge will not do any good. And if the patient paid half of the cost of the device and then spends n-th amount on consumables every month, he will use this device more diligently. He will be motivated to control his glucose level and achieve compensation, (Pediatric endocrinologist, 57 y.o.).*

Other respondents went further: they *suggested using co-payment to solve the issue of availability of analog insulins*.

> *Although genetically engineered medicines are purchased for all patients, half or part of these funds should be used to purchase analog medicines so that our patients could buy analog insulin at the pharmacy for at least half the amount.* ***Then there would be no surplus of genetically engineered insulins and more people would have a choice of insulin type.***

Currently, test strips are prescribed to patients with a 50% discount under the Additional Program of the Mandatory Health Insurance Fund. The amount of out-of-pocket expenditures for the purchase of 50 pieces is between 600 to 1,200 som, depending on the type of glucometer.

NGOs, donor organizations are mentioned as potential sources of resources to improve access to novel devices, in addition to the government.

> *We also have various NGOs [non-governmental organizations] that often help with the provision of such medical devices. Perhaps these devices will be of interest to them.*

7. Discussion

The study shows the social, psychological and organizational aspects of self-management in children and adolescents with diabetes receiving insulin therapy. Using the example of children and adolescents with diabetes, an attempt was made to identify and describe the links between information sources, information processes, and self-management in the context of Kyrgyzstan's health system.

The health system of the Kyrgyz Republic has been making enormous efforts to create conditions for patients with diabetes to exercise self-management, via providing easy access to free insulin, glucometers, preferential terms for purchase of test strips, creation of specialized Diabetes Schools and other measures. These efforts are taking place in the context of general restrictions (financial, personnel, information and organizational) in the health system, which result in specific restrictions on patient access to self-management tools and information on self-monitoring.

For example, information sessions in Diabetes Schools in healthcare facilities have proven to be quite effective in teaching patients, their families, and even nurses basic knowledge and skills. However, in the context of widespread use of social media by patients and their relatives as a source of information, the Diabetes Schools have limited application. In addition, these healthcare units have not yet become widespread in the regions, and they lack trained personnel and training materials, which further limits their ability to "keep up". Thus, *healthcare organizations are in the greatest need to improve the information component of self-management.*

In general, children with diabetes are sensitive to the pain of skin injections and the complexity of procedures. However, they perceive the need for self-management procedures more easily than adolescents. Young children perceive changes in life unconsciously and, over time, self-management becomes normal for them, a kind of routine.

For children, adolescents, and young people with diabetes in general, there are still difficulties in social functioning. This is shown by the example of how social attitudes and stereotypes work when entering school, insulin injections in public settings, and marriage among young people.

Compared to children, it is more difficult for parents to accept and care for the disease, adapt to an unusual way of life, find a job, and cope with social prejudices. Difficulties in finding a job exacerbate the difficult financial situation in families with a child who suffers from diabetes and takes insulin.

Healthcare workers and health authorities are unable to solve most of the described socio-economic and everyday difficulties. Doctors and nurses cannot effectively solve psychological difficulties in patients and their families. Obviously, many of these problems should be solved with the participation of other sectors of public administration: social assistance, education, economic development, business, non-profit organizations, media, etc. The participation of all this diversity of actors and parties in solving social and everyday issues of self-management can be facilitated by the development of social media and other Internet resources. This study did not find any negative experiences of diabetes patients when using Social media; however, a closer engagement of government and non-government agencies would be a good deterrent of bullying, mobbing, excluding individuals due to their disease.

There are three reasons for the growing importance of social media: i) staffing and infrastructure constraints in public healthcare organizations, ii) the increased use of social media due to the COVID-19 pandemic, and iii) initiatives by parents of children receiving insulin. WhatsApp groups of parents have proven to be the most prominent representation of social media in providing information on self-management. The latter circumstance was found in Kyrgyzstan and possibly can be relevant to other countries, especially in the Central Asian region.

One of the applications of social media has been the exchange of information on the availability of self-management tools on the market. After reaching the age of 18, patients face a number of difficulties in accessing insulin, primarily due to the preference for analog insulins, which they receive free of charge from the government during childhood and adolescence. Despite the entitlement to receive this type of insulin until the age of 29, there are cases when after the age of 18 these patients receive for free the human insulins, and not analog insulins. Many patients and parents perceive analog insulins as more comfortable to take and comparatively better tolerated. Although the proportion of such patients is unknown, there is no doubt that many patients with this preference continue to take analog insulins after the age of 18. Due to the extremely limited availability of such insulins on the local pharmaceutical market, such patients are forced to resort to importing analog insulins from abroad.

Another significant fact is that currently some patients directly buy insulin through Internet resources and do not consider visits to the doctor as something essential. Moreover, it was found that the main motive of patients for visiting monthly consultations is to receive insulin through state guarantees. Thus, the access to insulin is almost the main gateway for improving patient self-management and improving exchange of information.

In Kyrgyzstan, the most common and functional form of social media turned out to be WhatsApp groups, and the main motive for creating such groups is mutual assistance in purchasing devices for blood glucose measurement and insulin therapy. Unfortunately, elements of self-management that are not related to technology, namely healthy eating, physical activity, work and leisure regimes, and others, remain outside the focus of users of the Kyrgyz social media sector.

In international practice and literature, there are practically no significant and measurable effects of social media on the quality of self-management, and in Kyrgyzstan the potential of social media is not fully utilized. However, with the growth of blood glucose measurement and insulin administration technologies and the limited role of the government in providing novel technologies, social media activity in Kyrgyzstan will continue to grow. Therefore, regulators and other stakeholders should pay attention to the potentials of social media and begin to more actively engage in its development as a tool for interaction with patients, the pharmaceutical industry, and other parties.

8. Recommendations

1) **Diabetes Schools are recommended to allocate more financial support, provide up-to-date teaching aids and training materials.** This will improve the motivation of both participants and the specialists themselves.

2) **Nurses should conduct more training and allocate more functions for teaching patients with diabetes.** In conditions of limited access to Diabetes Schools in healthcare organizations and staffing difficulties, nurses have already become one of the sources of information and counseling for patients with diabetes.

3) **Programs to support diabetes patients should be intersectoral in nature**. Examples of parents creating inclusive kindergartens, public associations and social media for children with diabetes and closing these institutions after these children grow up indicate that many psychosocial difficulties cannot be solved only with the participation of the Ministry of Health and professional associations. This step requires coordinated efforts from the government, educational institutions, social support agencies, NGOs, and the private sector.

4) **Health authorities and professional associations are encouraged to become more actively engage in social media as a tool for interaction with patients, the pharmaceutical industry, and other parties.** Leadership by the Ministry of Health and professional associations in shaping the agenda and content in social media will be one of the mechanisms for improving self-management.

5) To influence social media content on self-management, **health authorities are encouraged to work in partnership with participants in the entire social media architecture.** The Ministry of Health, professional associations, and educational institutions can better adapt their capabilities by closely interacting with bloggers, influencers, and social media groups.

6) **Social media can become a reliable source of information and a tool for collecting data on various patient characteristics, i.e. insulin and glucometer users, healthy eating habits, and other attributes of proper self-management.** The results of using social media can contribute to improving the implementation of digital patient registration, drug and medical device tracking, e-procurement, and a number of other ongoing reforms.

7) **Conduct additional research on patient preferences for different classes of insulin - biosimilars, analogs, and genetically engineered.** Such research would make it possible to make insulin procurement more responsive to insulin preferences and needs.

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