Country Report – Ukraine

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Following the IDF Europe Board's decision regarding the country reports for some of our member associations, I travelled to Ukraine in March 2010 in order to perform the interviews necessary for the present country report. The report notes the status of the services offered for the **people with diabetes (PWD)** in Ukraine, the status, and achievements of the **Ukrainian Diabetes Federation (UDF),** as well as the more general relationship between the four major stakeholders in the area of diabetes: the persons with diabetes (PWD), the medical professionals, the public health institutions and the private medical services and pharmaceutical providers.

Ukraine has a population of about 45.7 million and the official data state that the prevalence of diabetes in Ukraine is 2.5% % (1,133,922 people are registered with diagnosed diabetes). The Diabetes Atlas (2009) indicates for Ukraine an estimated prevalence of 9.6% [for the population between 20 to 79 years old] which is in great discrepancy with the figures registered by the health system (2.5%) but is closer to the results of local studies (8.7%).

The country statistics reported by WHO do not include diabetes as a major risk factor the public health. No statistical data or research results are registered by WHO.

Ensuring health care for the population is, officially, one of the key functions of the state set out in the 1996 Ukrainian Constitution, with Article 49 stating that "the state creates conditions for effective medical services accessible to all citizens". The formal health care system is supervised by the state, and as in other former Soviet republics, lines of accountability are fragmented. In theory, the national Ministry of Health has responsibility for health policy. In practice, its influence is limited as it only directly manages a few specialized facilities. Most health care is delivered in facilities owned and managed at regional and district level, and funded by the respective tiers of government from allocations provided by the Ministry of Finance or raised locally. In practice, therefore, the scope of the national Ministry of Health is confined to issuing guidance and norms and to matters of national health policy.

There is one diabetes organization registered with IDF: the Ukrainian Diabetes Federation (UDF). A second organization, the International Diabetes Association of Ukraine applied for the IDF membership but it did not yet receive membership. There is also registered a third republican organization, the Ukrainian Diabetes Union, which at the time of the visit was inactive.

The UDF was established in 1993. It is a mixed organization bringing together health professionals and lay persons. The organization has a federative structure and its members are local organizations from 25 locations. These members are independent legal entities. According to the Ukrainian law UDF is a "republican" organization. It has an advisory and coordinator role for its members and it represents the interests of the members and the general population affected by diabetes (not necessary members of the association) at republican level. Its activities are performed with the support of volunteers and a limited number of hired staff. It does not have a regular publication or a web site.

The four stakeholders

During all the interviews, the relationships between all the stakeholders were highlighted.

There are several PWD associations registered in Ukraine. Most of them are registered with one or both of the diabetes federations: the UDF and the International Diabetes Association of Ukraine. In most cases the local organizations are independently registered. The involvement and participation of the youth in the associative life is considered to be problematic as the interest of the young adults with diabetes is to secure the start of a professional career or for establishing a new family. Still, in all the organizations met there were young adults performing executive functions within the organizations on a regular basis.

As most of the issues related to diabetes are going round the issue of insulin (what is available, what is compensated by the health system) most of the organizations were started due to the insulin issues when the quality was improper and the distribution was irregular. Besides local lobby, the local organizations are offering direct services to their members. Material support is well regarded as well as news regarding the latest in diabetes research. Relative small numbers of associations are currently using the internet to gather relevant information for their members.

Most of the focus is on peer support and education, social support for the members who have a more difficult situation, cooperate and complement the medical act, offer certain events for the children or elderly. The services are driven by the needs highlighted by the members.

At present the registration process was simplified to the level that in one small town there are registered more than 70 non governmental organizations. Organizations learned rather quickly to develop projects and to apply for funding with international donors. In Brodi the local organization has about 60 registered members representing some 500 persons with diabetes in the area.

Membership fees are very modest (3UAH/year ~ 30EURO cents).

Local organizations are more flexible in cooperating and finding support in the local governments or businesses. Schools are also more open to cooperate for a proper monitoring of the children with diabetes.

Organizations may choose to rent an office – outpatient institutions are some of the best choices as the rent might be lower and the office is closer to the patient flux. The level of the office rent is about 200UAH (~18.7 EUR) per month for a 10 sqm office in a small town up to 50 USD (~38.5 EUR) per month in Kiev. The officials do not help here. Each organization has a bank account.

Local organizations have an organizational structure similar to the central federations: are coordinated by a volunteer group of people who is elected regularly; individuals are elected to perform audit or monitoring of financial activities; there are no limits in the number of terms to be accomplished by any person. Strategic decisions and executive responsibilities are staying with the same people (the board of management). Local

organizations have a yearly plan adjusted every month according to the needs; the yearly plan is done by the organization's board and also follow the plan of the national organizations; activities are not followed by budgets in the yearly activity plan; activities are budgeted on a case by case basis. Organizations may receive support from both pharmaceutical and non-pharmaceutical companies. In some cases local administration even if it did not directly helped the activities of the local associations, endorsed them with a support letter that allowed the associations raise funds from local businesses. One organization is using its regular printing (a diabetes review) to generate income for the association. There is belief that the governments should support more the activities of the civil society (project funding or unrestricted grants). Cost recovery is used in several places as a normal procedure (as opposed to another attitude inherited by post soviet countries, where everything should be offered for free to the members).

One of the problems raised by the PWD organizations is the fact that the politicians are changing so often (12 Ministers of Health in 20 years). When asked about their wishes, most focused on the lack of support from the government, quality of treatment, and stability of the medication. Associations feel that they were left by the professionals to deal with education of the PWD.

All the organizations are cooperating with the local health specialists. All of the organizations know about the World Diabetes Day.

The problems revealed by the PWD associations are related to the fact that diabetes is not accepted on the priority list of the health officials, and prevention is not yet seriously taken by the health officials and professionals.

Besides the PWD associations there is also a professional association of the endocrinologists which is not affiliated with IDF. There is also a professional association of paediatric endocrinologists affiliated to ISPAD. Professional associations, as the competing PWD associations, do not share very much their resources or activities: the ophthalmology specialists treating mainly diabetes retinopathy complained that their point of view is not considered by their colleagues working in diabetes. There is also an association of the nurses which is less active and not represented at the level of the Coordinating Council of the Ministry of Health.

PWD reported that the medical act does not represent a problem, as all the medical services are covered by the state. The quality of the medication, limited access to quality injection instruments, the limited access to oral medication and self monitoring devices and consumables, ineffective training (mostly done by associations with limited professional support), fluctuations in the supply of the core medication, over politicized environment (in one place the blue circle could not be displayed as blue is the colour of the opposition party) are only some of the issues mentioned by the PWD.

Life with diabetes is difficult mainly because the condition becomes obvious when secondary complications are already present. The recommendations of the doctors are in certain cases not connected to what is to be found on the market, or to what is happening in the places of work. Non medical support is not currently offered to the newly diagnosed. In some places legal advice is offered for free by local organizations but few really trust that they can find their justice in the court of law. Some organizations are offering peer support but without the use of trained specialists.

Children attend the courses in the regular schools. Certain issues were reported in larger cities, due to the lack of cooperation between the teachers and parents (teachers refusing to assume responsibility for monitoring insulin dependent children). In smaller cities no such situation was reported – teachers accepted to be trained in basic procedures and also accepted to allow children with diabetes to eat or test their blood sugar level if needed. In the schools with medical personnel (nurses) there is no problem is letting the children visit the medical cabinet to either check their blood sugar levels or to have a shot of insulin. In such cases nurses, teachers and parent cooperate via the mobile telephones. Colleagues and friends are aware of the condition and also they are told how to react in case of a hypoglycaemia episode. Children and youngsters have to cope with the general perception that "self injecting is related to drug addiction". Children and youngsters with diabetes are included in programmes where participants without diabetes are present as well.

Young families are supported by peers. There is a trend to invest more in the families that decide to have children, so that the health of the families and of the children will not be jeopardised. In regions there are hospitals or outpatient units that specialized in pregnancy monitoring and child delivery for women with diabetes. In one case a woman spent six month for balancing and treatment during her pregnancy.

Most of the children with diabetes are registered as "invalids" to receive some social financial support from the government. The amount of support (67-200 UAH ~6.3-19 EUR) may contribute to insuring a better management of diabetes (for example for buying extra test strips, as the government offers only one strip a day for free). After the age of 18, the invalidity is granted only if there are recorded real disabilities due to late complications or other causes.

Active persons might choose not to disclose the fact they have diabetes as they might lose their job or they might be limited in exercising their profession (like not being allowed to travel abroad or to receive a driving license).

Persons with type 2 are complaining about the fact that they have to pay for the medication, glucometers and the test strips if they choose to manage their diabetes.
In some places urine tests are used more extensively as they are less expensive. Alternative medication (like herb teas) or general healthy supplements (vitamins, minerals, etc.) are frequently used to help with the treatment and psychological balance of the PWD.
Analogue insulins are less used in the regions. Prescription of analogue insulins is not properly regulated, but, being more expensive than the rest of the products paperwork has to be filed. Candidates may be persons with bad control of their diabetes and without hypoglycemia episodes. For type 2 insulin analogues (long acting) are recommended if the person uses more than 50IU, presents secondary complications or has a complex to manage condition.

Persons using insulin need to visit the doctor once a month to receive the prescriptions. People are looking for a treatment milder than injections, with less aggressiveness (like a shot a day) or painless glucose testing. In several places people asked about the effectiveness of the stem cells procedures: in Ukraine there are two large enterprises (one private and foreign, and one public) offering stem cell treatment to "cure or improve diabetes".

People expect to receive credible information regarding proper management of diabetes, pay less for laboratory tests (one HbA1 test may cost half of a monthly pension), effective training programmes for self monitoring/ self management, receiving psychological support, having access to rehabilitation programmes and camps, more relaxed employment condition (less discrimination for the PWD, equal opportunities), increased access to authorities, improved social protection, more information about the rights and how individuals can pursue justice.

In some regions education programmes started 20 years ago, in others much later.

People would like to have access to more test strips as they are appreciating the impact of the self monitoring. Certain regions are offering support for students and pregnant women to access test strips and better control their condition.

Insulin dependent PWD would like to be able to receive their medical prescriptions once every three months not every month. Visiting the doctor interferes with the work or school.

In Ukraine the PWD are managed by several medical professionals: family doctors, therapists, paediatricians, and endocrinologists most of them from public institutions.

The main professional issue is that even if there is a lot of pressure to move the responsibility of managing the regular type 2 from the specialist to the family doctor, the level of knowledge is very limited (only eight hours of diabetes during the medical university cannot offer the needed knowledge to properly manage type 2 patients). Under the National Diabetes Programme there is a schedule to train the family doctors in recognizing the symptoms of diabetes and to perform the daily management but this schedule is hampered by the lack of funds, human resources and motivation of the doctors to assume this new responsibility. Efforts are done by the Academy of Science to compensate this lack of professionals and a new training unit was establish to allow post graduate education for the doctors willing to increase their knowledge in diabetes.

The career track of a medical doctor who wants to become a specialist in endocrinology presumes that after the graduation of the medical school the candidate will take two years specialization in internal medicine with a special training in endocrinology for extra three months. Another way is to go directly from the medical school into endocrinology residency. At the end of the speciality stage there is organized an exam and positions may be either offered by the health system or the person may find its own positions in clinics with endocrinology departments.

The level of salary is low and endocrinologists are not motivated from this point of view to continue their professional career in this domain.

A specialist in an outpatient unit in a rather small town may see about 30 patients per day.

Doctors are hoping to see diabetes centres equipped with the necessary tolls for properly treating diabetes and its complications; more funds for insulin; governmental support for oral medication; increased funding for self monitoring; education facilities in the outpatient units; in the territory there are still issues with the quality and

regularity of provision of the diabetes medication, limited access to podiatry facilities, limited access to advise regarding safely having children (families with diabetes), lack of enough trained nurses, lack of diabetes schools outside cities. Without specific guidelines pregnant women with diabetes may be treated only with short acting insulins (even if in 4 to 6 shots a day).

There is a constant concern regarding the late detection of type 2 (usually after the onset of secondary complications) and low level of compliance of the type 2 patients (less than 58% follow the recommendations of the doctors), PWD do not assume the responsibility of managing their condition, the time to convey the needed information is too little, the motivation to follow the doctors' recommendations is low as it is the awareness of the seriousness of diabetes. Self control should be better supported for children and made accessible for adults. Prevention programmes should address a larger pool of population including young children. Active screening should be also supported by the National Diabetes Programme mainly in the population that is more and more prone to develop diabetes due to the major changes in lifestyle. Effective measures should be taken in the area of lifestyle changes (fighting bad habits), increasing physical activities and along with these, proper education of the medical professionals (mainly the family doctors and therapists) and exposure to international forums and congresses. It is interesting to see that even if there is a certain self satisfaction with the way diabetes is addressed, certain new inputs seem to be not known to specialists. A training session offered by colleagues from Moscow with core elements of diabetes education and management was well received in 2009.

The ophthalmologists mentioned that there is no professional occasion where to share the points of view with colleagues from other specialities. A high number of patients are referred for treatment in stages when the damage is already done.

Doctors recognize more and more the importance of a good doctor-patient relationship and the need for psychological support especially for the newly diagnosed.

There are improvements to be made in corroborating the efforts for diabetes prevention (primary and secondary) with the control of incidence of CVD and lipid control. The understanding of the correlations between these complex mechanisms is still out of the reach of the generalists (family doctors and therapists).

There is an Association of Endocrinologists which brings together the specialists from the main education and research health units in Ukraine. The Association is consulted by officials on a non regular basis. For the new version of the National Diabetes Programme (2009-2013), the council of the professional association was offered along with the council of the PWD associations. The Association looks to restart the BlackSeaDiab activities as a potential resource for solutions in transition societies.
The Association of Paediatric Endocrinologists has a project implemented for many years where specialists (endocrinologists, ophthalmologists and nurses) travel with a mobile unit in the territory to thoroughly examine children with diabetes and complications. The mobile team also performs prevention activities with children and youngsters. For the next years the specialists have a project to improve the compliance rate of children via education sessions delivered in sanatoria (free of charge). The paediatricians will also develop a hand book for teachers in classes where children with diabetes go. These recommendations are developed with the support of the PWD associations (UDF).

Nurses have limited responsibilities in the medical act. They perform mostly the bureaucratic activities as well as certain medical procedures. In certain locations nurses are requested to deliver the education sessions without any clinical responsibilities. Dieticians and educators are not included in the diabetes teams. For the future there is the intention that the education activities for the PWD should be performed mainly by trained nurses.

The professional associations supported the efforts of the PWD associations to have children treated with quality medication.

Public health authorities

The Ministry of Health is considering prevention and control of diabetes as one of its priorities. The new National Diabetes Programme, developed with the input of the officials, professionals and patient organizations will increase the activities in the area of primary and secondary prevention while also addressing the level of compensation for diabetes oral drugs. The NDP was allocated a budget of 2.5 billion UAH (~236 million EUR). The programme develops the idea of prevention cabinets for eye and foot complications. The investments will be mostly in information technology, education (of the professionals and patients) and laboratory equipment. All the outpatient units have received glucometers and test strips (consumables). Glucose testing devices are also included in the standard set used by the family doctors. Non Communicable Diseases are approached as a package and prevention will address more than one condition at a time (similar to the health determinants' approach of the EU Commission).

Health Centres were established across the country, and they will be more and more involved in health education and health promotion including healthier lifestyles.

The prevention and public health programme includes financial incentives for healthy lifestyles, anti smoking campaigns, decrease of the number of harmful advertisements, regular check up's of the citizen, sport centres for all. Family doctors will have performance indicators and the successful ones will receive incentives.

The health authorities are listening more often to the professional and patient groups. There is established an advisory body (Union of Patient Organizations) representing patient organizations with a consultative function to the Ministry. The Union is represented at the level of the coordination council of the Ministry, headed by the deputy Minister of Health.

In 2010, there were enough funds to secure the needed amount of insulins. Each region will have its own programmes for patient education. The programmes will have separate tracks for type 1 and type 2 diabetes and will promote the idea of patient responsibility and self management so that the average level of compensation of the persons with diabetes will improve.

As mentioned above, it is budgeted to include in the list of compensated medication the core oral medication for type 2.

The officials have also to solve a delicate political problem: there are at least two Ukrainian pharmaceutical companies producing insulins – and quite a strong reaction from the public regarding the quality and consistency of the locally produced insulins.

Except for the licensing programmes, there is little cooperation with the private companies offering medication or health services.

The private companies offer limited health services and most of the pharmaceutical products for the public health system and for the general population. The medical services for diabetes are limited to some outpatient cabinets and laboratory tests. In Odessa the Filatov Institute established a private company that is in the proximity of the institute and that uses some of the best practitioners. The private enterprise is offering better hotel, catering and laboratory services.

On the insulin market there are present Novo, Aventis, Eli Lilly, Bioton and an Indian company. There are two Ukrainian companies producing insulins: Farmak and Indar. Their products are mostly prescribed to adults and elderly.

For the self monitoring products there are Roche, Abbott, Johnson & Johnson, Bionime along with other Russian and Japanese products.
Farmak has an agreement with Eli Lilly to bottle human insulins produced by Eli Lilly. The insulins are registered under a local brand name.

Indar started as a public owned company (71%) with the purpose to secure the needed amounts of insulin. They started in 1999 with monocomponent insulin (based on pig insulin and using Ukrainian technology) and in 2003 they registered their first genetically recombined insulin. The aim of the company is to become a provider of all needed medication and aparata for treating diabetes (insulins, oral medication, delivery systems, glucose testing materials and education).

Local companies complained that certain doctors may receive incentives if they prescribe certain brands of medication.

As the political environment is in continuous development, the rules and regulations have little weight. The public procurements are paid rather late. There is little control and regulation on the market.

Representatives of foreign companies mentioned that they market the mid level products. The top products might be offered for clinical research. Besides the marketing and technical support the pharmaceutical companies are involved in the support for professionals and PWD education programmes.

Registration of a new medical product may take up to six months. Some products may be requested to withstand clinical trials in Ukraine.

The actual import and distribution of any foreign medical product is done by local entrepreneurs.

Pharmaceutical companies offer funding for NGO activities. As they cooperate with all the lay and professional organizations on the market these companies also have a good knowledge of the activities and impact of the NGOs. They are the primary

financial supporters for the participation of Ukrainian specialists to local and international congresses and meetings. Many of the education materials are printed by Novo or Indar. The Conversation Maps will be distributed and managed by Farmak. It is interesting to see that the initiative to invest in education and collateral areas, not only in pharmaceutical products, was assumed by a local company with a lot of enthusiasm and it seems that the results can be seen in the way the company products are received on the market.

Private companies feel that there is still a lot to do to change the attitude of the doctors working with chronic diseases (improve communication skills) along with professional skills needed for a correct treatment of the condition, patient education is also seen as a key element to addressing diabetes.

The health services provided to the PWD

Country statistics

Ukraine reports to have 1,133,922 persons affected by diabetes (2.5%). Out of this, 92% have type 2 diabetes. Still the statistic results regarding diabetes are not considered to be public information (not shared with the public). The Governmental bodies are the ones responsible to collect the data from the territory. In local research activities it was revealed that the actual number of persons with undiagnosed diabetes might be up to 2.5 times higher than the known numbers. The distribution is not uniform across the country (Western regions have lower than average levels of prevalence). For type 1 diabetes the prevalence might fluctuate between 0.17 to 0.38%. Life expectancy for a person with type 1 is about 40 years.

For type 1 the major complications are angiopathy of the lower extremities (92%), nephropathy (24%) and retinopathy (21%). In a hospital with republican expertise the average level of HbA1c is 8.6% (and improvement from 10.5% some years ago). In the early 1990 there was registered an increase of the incidence rate for type 1 with 7% per year.

The main causes of death for cases directly attributed to diabetes are renal failure (69%), ischaemic heart disease (9%), ketoacidosis (6%) and hypoglycaemia (3%).

Specialists report that about 10% of the registered PWD can keep their HbA1c under 7%, 10% are managing their HbA1c between 7 and 8% and the rest have values over 8%. It is also reported that only about 15% of the known persons with diabetes test their levels of HbA1c and out of these only 2.5% are well compensated (in 2007).

It is estimated that more than 80% of all the persons with diabetes for more than five years have major secondary complications.

About 7.8% of the persons with type 2 diabetes are treated with insulin.

The Diabetes Atlas (2009) indicates for Ukraine an estimated prevalence of 9.6% which is in great discrepancy with the figures registered by the health system (2.5%) but is closer to the results of local studies (8.7%).

For Ukraine WHO does not list diabetes as a major topic for concern or a risk factor.

Health system data

The country has a five year national programme for diabetes (this is the second national programme, the first being implemented in 1999-2007). It mainly addresses the governmental support for insulin treatment and health services for people with diabetes. Primary and secondary prevention and control are also included in the programme.

There a little data regarding the number of medical professionals working in the diabetes speciality (about 1200 endocrinologists taking care of any endocrinological case, including diabetes) and how are they distributed in the territory. As in all post Soviet countries diabetes is not recognized as a separate speciality. To compensate that and the lack of relevant education during the university studies (only eight hours are dedicated to diabetes), the National Academy of Science established a postgraduate course for medical doctors interested in enhancing their knowledge in diabetes.

Diabetes may be diagnosed and treated by endocrinologists (children and adults) or internists, family doctors and therapists (adults).

There is a tendency to move the responsibility of managing type 2 diabetes to the family doctors.

Nurses have limited responsibilities and diabetes nurses are not recognized as a separate speciality. There is no special training for the diabetes nurses. Sometimes they are involved in the education process. Nutritionists or dieticians are rarely employed and if they are, they are shared with many other conditions. The functions of educators, nutritionists and dieticians are assumed in most cases by the endocrinologists.

Access to health services

Access to treatment for people with diabetes is theoretically free of charge (see above). The geographic coverage of the country is also good. The facilities visited have the main instruments to assess the condition of the PWD. Usually, the more complex cases are referred to the higher levels where both the laboratory facilities and the health professionals can correctly assess the cases and offer the proper solutions. Where the funding is not enough (like in the city policlinics) the current monitoring of diabetes might be done with the contribution of the PWD who support the cost of the test strips from their pockets.

Theoretically each of the 27 regions should have endocrinologists in its regional and district units. But not all the positions are filled with specialists (endocrinologists), so in certain locations professional advice may be offered only in other centres.

Considering the registered figures, there is one endocrinologist for every 1000 PWD.

Since 2004, paediatric diabetes teams travel to the regions to offer on-site consultation for the more complex cases.

There are national protocols for examination and treatment of both type 1 and type 2 diabetes.

Public screening activities are performed either within certain research programmes or during awareness campaigns supported by the industry and PWD associations. Considering the involved costs, such campaigns are not frequent. Epidemiology studies are also rather few (for the last 10 years there is no such published study regarding diabetes) and in most cases the studies are addressing limited populations. A number of public health activities are run by the Ministry of Health including public campaigns on nutrition and diabetes. The PWD associations are organizing awareness campaigns mainly close to either local events or to the World Diabetes Day.

The onset of diabetes may be recognized by the paediatricians, family doctors /general practitioners or by in-patient doctors.

Children (under 18) are referred to paediatric hospitals with endocrinology departments. Once a youngster turns 18, it cannot use any of the paediatric services and has to attend only adult health service.

The adults might be referred to an endocrinologist by general practitioners or internists or following the results of lab tests usually done for other conditions. The diagnostic is established by an endocrinologist who also prescribes the treatment. In most of the cases, the treatment adjustment is done in the outpatient units. The regular management of diabetes is done by therapists if the treatment is with oral medication. All insulin patients are managed by endocrinologists. If insulin therapy is needed, the person will spend up to two weeks in an endocrinology ward. PWD with type 2 have access to free health services but receive no compensation for the cost of the diabetes oral medication (when released from the hospitals).

At city levels there are outpatient units (polyclinics) which also provide inpatient services for patients with chronic conditions (including diabetes). PWD may stay up to 10 days and have their condition stabilized. In these units there are only limited laboratory facilities (basic tests). Patients are also screened for secondary complications.

Private medical practices are limited in Ukraine and most of them focus on outpatient diagnosis and management. Private laboratories for diabetes have better equipment and a more stable supply of consumables. In some cases highly regarded public institutions establish private units with the same profile and staff but on commercial basis, so that they can provide better services for the patients asking for a better return for their money.

PWD with secondary complications are referred to the respective specialists. In most cases specialist cabinets are also located in the same hospital or policlinic.

Laser treatment for diabetic retinopathy is currently offered in several locations. The Eye Institute in Odessa reported having records for more than 6000 persons with diabetes retinopathy. The UDF is raising funds to acquire a fundus camera: a sign that public services are still behind the needs of the population. Podiatry is not recognized as a separate speciality and it does not have a recognized track for education. The job may be performed by either a trained endocrinologist or a knowledgeable surgeon.

HbA1c tests may be performed in the oblast capitals. The test is not compensated by the government and it may cost as much as 6-7 EUR. Microalbuminurea tests are regularly used.

In the outpatient units a specialist might see as many as 25 – 30 patients a day. In paediatric endocrinology wards the proportion of diabetes cases is about 50%, and in the adults' wards the proportion of diabetes is higher. The standard duration of a visit to the endocrinology specialists is 12 minutes and for a podiatry session 20 minutes.

According to the protocols, once a year each PWD should be checked for any late complications (nephrology, neuropathy, cardiovascular condition). If needed the specialists may recommend more frequent check-ups. Children are recommended more often check-ups.

Blood glucose level may be tested in most of the district facilities and their cost is covered by the outpatient clinic or by patients. Children are expected to test their HbA1c level every three months. The tests in the hospitals (inpatient) are supported by the hospitals. For the adults the tests are less often.

The general treatment scheme for type 1 in children is intensive (several shots of insulin a day, with a combination of rapid and long acting insulins). The duration of the stay in the hospital is regularly up to two weeks, depending on the complexity of the case. In the last years the professionals with the support from the associations managed to insure that children are receiving trusted brands of insulin and modern means of insulin administration. For adults the treatment for type 1 is in general intensive but there are still places where the treatment consists of two shots of insulin per day. Very few are treated with insulin pumps as the government does not compensate the costs. For type 2 the treatment is in about 15% of cases with insulin (or a combination of insulin and oral medication). Most of the oral medication is available (with the exception of the DPP4 inhibitors) on the market, but none is supported by the government.

For persons using the health services there are certain grievance mechanisms involving letters, articles in the press and publications, rallies or legal suites.

Access to medication

Through the National Diabetes Programme insulin is insured for free to all the persons needing it. About 80% of the funds are from the national budget and the rest is filled in by the local authorities. A prescription system for insulin was adopted in 2009. There is no compensation for oral medication. When first designed the NDP indicated that the central government will provide the funds for the insulins and the local governments should provide for oral medication and self monitoring. Due to the non coordination between the planed and actual needs, the local money went to supplement the insulin budget.

At the time of the visit there was indicated that 4% of the produced insulin is animal insulin.

The country moved from a centralized procurement of the compensated quantities of insulin to decentralized procurement supported for less corruption and increased

flexibility. In Ukraine it is offered a large range of insulins. The country has two pharmaceutical producers for insulin: one (Farmak) with a franchise from Lilly (it is bottling Lilly produced human insulins) and the other one (Indar) is producing mono component and human insulins in its own facilities (one smaller facility is based in Kiev and a second, larger one, in Lviv). Several foreign companies are present and distribute diabetes products on the Ukrainian market: Novo Nordisk, Eli Lilly, Sanofi Aventis, Bioton, Servier, Hoechst, Berlin Chemie, Roche, Lifescan (J&J), Bionime, and Abbott.

Since 2004 all children are provided via the Diabetes Programme with trusted quality insulins (theoretically whatever type is needed should be supported by the system). Some 50 children (<6 years old) are using insulin pumps. The health system does not support any of the costs for the use of the insulin pumps.

For adults with type 1 and type 2 the most used insulins are the locally produced ones.

The paediatric endocrinology department in Kiev has three CGMS. The systems are used for up to six days. The consumables are supported by the hospital budget. It is intended that every regional hospital should have at least one CGMS.

The specialists are not sure that the insulin distribution systems (based mostly on private companies) are ensuring the cold chain in a proper mode.

Insulins can be procured in pharmacies without a medical prescription. There is the intention to impose the sell of insulins only based on medical prescription. At present the system is not unified, as patients may receive prescriptions from both public and private doctors.

The main political problem is if the system should use only the locally produced insulins (tempting for the government) or a combination of imported and locally produced. The issue is mainly related to the uncertainty of the quality of the local products (Indar) as the raw materials used in the process may vary widely and may also include very unreliable sources. On this topic the two main federations have different points of view: UDF (who had for about ten years a president hired by a governmental institution) is for a mixed system (foreign and local products), while the IDAU is supporting the use of only imported products. The private or national laboratories do not have the needed technical equipment to guarantee that the products in discussion are of acceptable quality or not. To bypass this, Indar is using a parallel system of testing its products (to the regular laboratory tests) by using in vivo testing on mice.

Some local governments supplement the local health budgets so that to insure the purchase of extra test strips, basic oral medication or for the means of administration.

Availability of free oral medication is dependent in most of the cases by the amount of the local administration contribution to the health budgets. If the contribution is more generous, more expensive or modern medicine may be available for the PWD. The regular oral medication includes Diabeton (Gliclazide, regarded as expensive), Maninil, Siofor (Metformin) and Glibenclamide.

Blood glucose testing materials (at the level of 350-400 strips a year) are offered with 100% compensation for all children. Several brands are present on the market.

Glucagon kits are registered and included on the compensation list.

Access to training

Diabetes education is offered in most cases in the specialized ward of endocrinology of the polyclinics and hospitals. Training in hospitals is offered mostly for type 1 PWD and in the training the outpatient units is mostly for type 2 PWD. Training is done based on several versions of curriculum. In some of the units delivering training nurses are the ones directly involved, atop of their regular duties. In the paediatric hospitals medical doctors are taking the lead with help from the certain nurses. The injecting techniques or the glucose testing might be taught with the help of the nurses. Diet is part of the curriculum. Follow up education sessions may be offered in the regional or district facilities.

Endocrinology paediatric departments have self control cabinets where children and their parent can learn about self-monitoring and self management. These cabinets are staffed with both doctors and nurses.

The therapeutic education is not formally recognized and it is not properly compensated. Dieticians were not mentioned in any of the facilities visited.

All the PWD associations offer diabetes support and training even if the facilities might not meet international standards. Peer group support is also offered with the help of volunteers (there are no specially trained educators for peer groups). Commercial companies supplement some of the professional and PWD training but only with limited interventions (limited both in topic coverage and geographically). For delivery they use the services of recognized endocrinologists.

Health units have sometimes specially designated spaces for patient education. The process is usually a small group one. In some places a computer based education system is offered even if there is less acceptance of the impact of the method. Even if the training sessions do not specifically assess the changes in the skills of the students, the medical professionals are looking for the improvements in the overall parameters (like HbA1c levels) of the students.

At the moment of the visit several institutions and organizations were supporting the idea of a united curriculum and a system of certification for schools and educators. They are also looking for any outside support (existing materials, experience, testing systems, follow up systems) including from IDF.

Collateral topics (family or social life, school, work, legal advice, marriage, etc.) may be addressed during the discussion sessions offered by the PWD associations but there is no structured approach.

There is no unified track record of a PWD, regarding the sessions attended and the health results (impact of the training sessions).

The pharmaceutical companies deliver education modules mostly for the medical professionals. The education sessions offered by the pharmaceutical companies are hosted outside the health units.

The National Registry for Diabetes

In March 2009 the government adopted a law for the National Registry and the system of reimbursement of the diabetes related health services. There are some systems of registering the persons with diabetes, but no united one. One of the systems is based in the Endocrinology Centre and has some 544,000 records (in 2008 there were reported some 90,000 entries). There is no indication how often this database is updated and who enters the data. Also there was little indication on how the reports are used for the public health planning exercise. Paediatric clinics have their own system of recording the evolution of their patients. Still, a National Diabetes Registry is an objective to be accomplished.

Outcomes

The visit was conducted in a stressed period of the country, immediately after the Presidential elections and while the UDF and its counterpart, IDAU, were in a vivid dispute regarding the access of IDAU in IDF.

Both organizations were announced about my intention to visit Ukraine and my interest to learn more about each of the organizations. IDAU was offered at least one day, but they chose to use only a few hours. There was an intention to discuss with both the organizations the possibility of uniting the diabetes movement in Ukraine, but the meeting soon slipped into a confrontation. My main message to both the organizations was that they should find the means to work and live with each other; that nobody from outside will be a good judge for their problems and that the diabetes movement needs unity not wasting efforts.

If in the private meeting representatives of UDF were more balanced (bringing the arguments of unity and common targets) in the common meeting the discussion moved to who was first organization established and who did more for the persons with diabetes in the country. In the same time if in a regular meeting several persons from the room would speak up, in the presence of their counterparts only the leaders spoke – which is another indication that the dispute is also based on personality basis. In the meeting at the IDAU there was an open question about what should they do to push UDF out of the IDF. With all the efforts the two leaderships could not come to common grounds and the topic of the condition of the two organizations is postponed indefinite.

According to the local legislation UDF is registered as a republican organization (with members in more than half of the country's regions) while IDAU was established by only four organizations (three from Ukraine and one from Russia). Each organization evolved from one structure to another, from one town to another, from one membership and target to another so that it becomes very complicated to understand the history of each one of them and where their disputes are coming from.

If one can find both organizations in certain activities beneficial for the whole population affected by diabetes (like the redesign of the National Diabetes Programme, or the need to unify the prescription system for insulins) there are other areas where little can justify the actions: the fight of IDAU for decentralizing the insulin procurement process or the investment of IDAU to track how pharmaceutical companies are reimbursed by the health system.

It is reported that following the country visit in March, the third republican association started operating again.

Conclusions

The country faces the major drawbacks of the post Soviet development while being one of the most unstructured one. The health system is obligated to function mostly in the governmental system. The average condition did not evolve as quickly as expected and the country is still fighting between two directions: East or West?

The basic principles of the health system have changed little since independence. It maintains financial and economic mechanisms that stimulate further expansion of capacity while creating new problems through the substantial mismatch between state guarantees of universal, unlimited access to free health care and the actual availability of health care funding. This has been further complicated by failure to apply effective means of cost-containment or to increase efficiency, except for measures to reduce oversupply of hospital beds and health care staff. This complex interplay of factors along with the difficult economic situation has resulted in a drastic reduction in the quality of, and accessibility to, health care, with unofficial payments and other forms of health service charging having become widespread.

With all these the recent achievements in the area of diabetes are bringing good hope to all the citizens affected: a second National Diabetes Programme was launched, type 2 will come into focus as well, most of the essential medication can be found on the Ukrainian market, the politicians have the intention to invest in the right direction (making the health service more effective) and bringing therapeutic education in the first lines of action. The existing "good solutions" cannot still answer the situation of individuals who cannot fully live their lives due to their health condition.

The Ukrainian organizations received very good support from the time they were established and they found their own ways of acting and influencing the governments. They found ways of supporting their projects and developing their membership. Unfortunately, personal issues are preventing the two main organizations in joining efforts for the benefit of the people with diabetes.

List of annexes

Annex 1 – List of sources and references
Annex 2 – Schedule of the visits
Annex 3 – Pictures and maps