Economic Evaluation of Epilepsy in Russia
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Introduction

The final report of the project is aimed at rationalization of medical financing and problem solving in managing the quality of life for people living with epilepsy.

International company IRS Group is a young and purposeful team of people whose social duty is to develop and improve the quality of life.

Regularly our company publishes reports of independent studies on a not-for-profit basis.

The present report is a result of stand-alone research which is important for decision-making at all levels: from patients to profile agencies.

The Economic Evaluation of Epilepsy in Russia report presents the cost calculation of epilepsy diagnosis and treatment, federal budget expenditures and potential GDP losses in the Russian Federation. It includes the review of medical devices (domestic and international markets) for tracking of a patient status and prevention of epileptic seizures.

The data revealed are intended for interested individuals and companies as well as organizations subordinate to the Ministry of Health, Ministry of Industry and Trade, Ministry of Finance and Economic Development (Russia).
Recommendations

1. To develop the availability of medical and social assistance in remote regions including specialized diagnostics and telemedicine services.

2. To devote special attention to supporting patients and their relatives due to the high incidence rates among children and prevalence among employable population.

3. To develop the Epileptology education programs.

4. To pay special attention to partial epilepsy for increasing the total cost-efficiency.

5. To decrease the cost of medications for diagnosis and therapy of partial epilepsy.

6. To integrate domestic medical devices for control of physiologic status of people with epilepsy.

7. To monitor the statistics of epilepsy incidence and prevalence after domestic medical devices are integrated.
Statistics

Epilepsy is a group of neurological disorders characterized by epileptic seizures. Epileptic seizures are episodes that can vary from brief and nearly undetectable to long periods of convulsive shaking.

Epilepsy leads to decrease of patients’ quality of life. But the caring attitude of patients with epilepsy to their condition, close attention of the public health system and adequate social and economic policies can improve the diagnostics and therapy of epilepsy.

Epilepsy prevalence rate in Russia is growing with the average annual CA-GR$_{5(2012-2016)}$ (Compound Annual Growth Rate) increase of 1.23% (2012-2016). Only one region, the Far Eastern Federal District shows a negative dynamics of -0.71%.

According to the epilepsy prevalence data, children in the Russian Federation are most affected by the disease. The prevalence rates per 100,000 population is 71.0 for children, 24.3 for working-age adults, and 13.9 for elderly people.

However, despite high disease prevalence among children, working-age adults are the most affected group: prevalence rate amounts to 55% working-age vs 31% children. Higher adult rate is explained by chronic nature of epilepsy.

Average epilepsy incidence among children is 3 times higher than among adults.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of People</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>348,811</td>
</tr>
<tr>
<td>2013</td>
<td>351,845</td>
</tr>
<tr>
<td>2014</td>
<td>350,338</td>
</tr>
<tr>
<td>2015</td>
<td>355,868</td>
</tr>
<tr>
<td>2016</td>
<td>370,773</td>
</tr>
</tbody>
</table>

In 2012, there were 348,811 people with epilepsy, in 2013, the number increased to 351,845. In 2014, it decreased to 350,338. In 2015, it increased again to 355,868, and in 2016, it increased further to 370,773. The changes are indicated by arrows: +3034, -1507, +5530, +14,905.
Prevalence of epilepsy in Russia, total statistics. 2016

Epilepsy prevalence rates among children are the highest in Krasnoyarsk Krai, the Chukotka Autonomous Okrug, Kaliningrad Oblast, the Mari El and Chuvashia republics, the Nenets and Yamalo-Nenets autonomous okrugs, Karelia, Arkhangelsk Oblast and Yakutia.

Prevalence of epilepsy among working-age adults

Data for working-age adults shows very similar pattern with lower prevalence, except the Chechen Republic that has pretty high rate for this group.
Prevalence of epilepsy among elderly people

The majority of elderly people suffering from this condition are estimated to reside in Yakutia, Kamchatka Krai, Magadan Oblast, Nenets Autonomous Okrug and also in the Republic of Ingushetia and the Chechen Republic, North Caucasus.

Climate zones in the Russian Federation

Surprisingly, there is a co-relation between the prevalence of epilepsy and climate zones in the Russian Federation. Climate zoning is determined by the latitude, and in the Russian Federation climate zones mostly match 20th, 40th, 60th and 80th meridians.

Zone II

Very similar to the Zone I

-10 °C ... +25 °C

Zone I

Warm regions of Russia

-9.5 °C ... +30 °C

Zone III

Winter significantly colder, low windy

-20...-18 °C ... +16...+20 °C

Zone IV and «Specific»

Regions are lower of Polar Circle

Harsh climate, lack of sunlight, windy – less 1.5 m/s.

-41 °C ... 0 °C

The highest child disease prevalence of 92.3 is observed in climate zone IV

Data analysis shows no significant differences across climate zones, however, the morbidity rates are the highest in climate zone IV
The vast majority of epileptic population is concentrated in Volga, Central and Siberian federal districts. Distributions among age groups are similar across federal regions.

And as working-age adults are the most economically active group and represent the majority of potential workforce, the social and economic aspects of epilepsy are of extreme importance. Please see more insights below.

It is worth mentioning that epilepsy has mortality rates of 918 cases, officially registered in 2016, which, in our opinion, does not reflect real situation.
Availability of Neurological Care

Russia has a decent number of neurologists per 100,000 population: an average of 18.8 (CAGR -0.21%), with max of 22.1 in Northwestern Federal District and min of 16.5 in South Federal District. This figure is higher compared to European countries, where same metric varies from the highest of 10.0-16.5 in Lithuania, Latvia, Estonia and Bulgaria, to the lowest of 2.7 in Great Britain, or 1.8 in Ireland, and low 3% growth of specialists has been a tendency over the past decade. However, direct comparison is not correct due to significant differences in patient routing systems and doctor’s functions. In Europe it is common that general practitioner provides neurological care.

Specialists’ professional enhancement is crucial for epilepsy treatment services. Currently, there are only 23 organizations in the Russian Federation authorized to provide professional enhancement services in only 5 federal districts out of 11.

Two main providers of low-residency programs (approximately 972 contact hours) are the Pirogov Russian National Research Medical University (RNRMU) and the Krasnoyarsk State Medical University. Tuition fees vary between 80 and 570 Rubles.

### Professional Enhancement Courses

<table>
<thead>
<tr>
<th>Federal District</th>
<th>Educational Institutions</th>
<th>Average Cost (Rubles)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Central Federal District</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voronezh Oblast</td>
<td>×1</td>
<td>166,67 P</td>
</tr>
<tr>
<td>Moscow City</td>
<td>×10</td>
<td>569,81 P</td>
</tr>
<tr>
<td>Kursk Oblast</td>
<td>×1</td>
<td>166,67 P</td>
</tr>
<tr>
<td><strong>Volga Federal District</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Republic of Tatarstan</td>
<td>×2</td>
<td>131,94 P</td>
</tr>
<tr>
<td>Samara Oblast</td>
<td>×2</td>
<td>115,33 P</td>
</tr>
<tr>
<td><strong>Siberian Federal District</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irkutsk Oblast</td>
<td>×1</td>
<td>194,44 P</td>
</tr>
<tr>
<td>Krasnoyarsk Krai</td>
<td>×1</td>
<td>80,56 P</td>
</tr>
<tr>
<td>Novosibirsk Oblast</td>
<td>×1</td>
<td>208,33 P</td>
</tr>
<tr>
<td><strong>South Federal District</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rostov Oblast</td>
<td>×1</td>
<td>129,31 P</td>
</tr>
</tbody>
</table>

And just 25% of those organizations provide specialized training in children’s epileptology.

Professional enhancement courses are available in full-time and low-residency formats: 1026 contact hours for full-time, 2016 contact hours for low-residency programs. Full-time courses are available in 52.1% of regions, low-residency programs available in 39.1% of regions. Course tuition can be covered by the State and/or Federal Compulsory Medical Insurance Fund in all regions.
Conclusions

High prevalence rates among children in Zone IV can be considered as a stimulus to conduct additional epidemiological studies of children’s epilepsy, however it is good to keep in mind that correlation does not mean causation. At the same time, this knowledge is significant for organizing the public health system in general and providing broader access to health care in remote regions of Russia, including popularization of telemedicine services for patients and their relatives.

High incidence among working-age and elderly adults is also observed in regions of Zone IV, but possibility to arrange the specialized Epileptology education is limited by the almost complete lack of relevant organizations, so doctors have to travel to other regions.

These issues directly show that more attention should be paid to the financing of telemedicine, especially for “problem” regions. It is also vital to launch the specific Federal training programs for neurologists and to expand their geographical reach.

Notes

Prevalence calculations are based on 2011-2016 data analysis.

Unit of labor input (ULI) is an equivalent 36 hours (reference model European Credit Transfer System, ECTS).

http://appsso.eurostat.ec.europa.eu/hui/submitViewTableAction.do

edu.rasminzdrav.ru
Economic Aftermaths of Epilepsy

To calculate the economic aftermaths, we used DALY (Disability-Adjusted Life Year) metric, developed by Harvard University for the World Bank and widely used by public health institutions, including WHO.

It has been used to calculate the burden of disease and economic consequences. For a disease or health condition DALY metric is calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for people living with the health condition or its consequences.

DALY does not take the population density into account. Thus, direct comparison of absolute metric values between different regions within the Russian Federation, or between the Russian Federation and other countries is incorrect. For these purposes, DALY per 100,000 population is a proper metric to use:

**DALY in developed countries**

205–308 per 100,000 population

**DALY in Russian Federation**

183 per 100,000 population

\[
\text{DALY} = (N \cdot L_D) + (I \cdot DW \cdot L_R)
\]

- **YLL** expected average Years of Life Lost
- **YLD** expected average Years Lost due to Disability
- **N** number of deaths
- **L_D** standard life expectancy at age of death in years
- **I** number of incident cases
- **DW** disability weight
- **L_R** average duration of the case until remission or death (years)

Comparison of statistics data on prevalence of epilepsy types, percentage of deaths in different age groups, and the severity of the disease (according to WHO) allowed to calculate that for every region DALY is formed from generalized epilepsy (91.9%) and partial epilepsy (8.1%).
According to the calculations made, the most challenging territories that have highest DALY values among the employable population (per 100,000 population), are the major part of the Northwestern Federal District (in particular 483.9 — Nenets Autonomous Okrug), partially the Volga and the Siberian Federal Districts (in particular 336.0 — Perm Krai, 381.0 — the Tyva Republic), the Far Eastern Federal District (with the highest record in Russia 637.0 — the Sakha Republic), the North Caucasus Federal District (with the highest 283.6 — the Chechen Republic), and other regions of this district (120 — 130).

More favorable situation is in the Central and the South Federal Districts with the lowest DALY rates in Russia: 70–80 (e.g. Kursk, Ryazan, Tambov, Volgograd regions and others).
DALY in Russia increases by 3-4K years annually due to epilepsy.

According to estimates, Russian working-age adult citizens who are epileptics, combined, will “lose” more than 268K years of their life due to disability and/or premature death in 2018.

GDP loss in Russia

GDP loss is defined as the potential GDP volume, underproduced due to premature death and/or disability of epileptic population.

GDP losses per region in the Russian Federation were estimated using WHO recommended formula:

\[
\text{GDP}_{\text{loss}} = \text{DALY} \times \text{GDP}_{\text{pc}}
\]

- \(\text{GDP}_{\text{loss}}\): expected GDP loss
- \(\text{GDP}_{\text{pc}}\): GDP per capita
GDP loss per federal districts in Russia

It is expected that in 2018 the following regions will face the greatest GDP losses due to epilepsy prevalence: Moscow (241 million USD), Kharaty-Mansi Autonomous Okrug (93 million USD), Saint Petersburg, and the republics of Tatarstan and Sakha (70 to 80 million USD each).

Of total underproduced GDP, one forth accounts for the Central Federal District, and one fifth – for Volga and Ural federal districts each.
Conclusions

Comparison of calculated DALY rates per 100,000 population and statistic data on the prevalence of epilepsy (per 100,000 persons) shows that more “problematic” regions are in Zone IV (Nenets Autonomous Okrug, the Sakha Republic). It supports the need to pay more attention to the regions of Zone IV and it can serve as an incentive for additional epidemiological, social and economic research.

GDP loss depends on GDP per capita. The city of Moscow is the leader in this list (expected loss – 241 million USD in 2018).

However, the value of DALY per 100,000 people for the capital of Russia ranks 66th out of 83 subjects of the Russian Federation. The similar situation can be seen in St. Petersburg, the Republic of Tatarstan and other regions.

This means we cannot only focus at the regions of Zone IV.

Notes

Salomon JA et al., Lancet, 2013
Moseyko E. E., 2013
Cost Calculation of Epilepsy Diagnosis and Treatment

Conclusions were made that the financial losses are greater for partial type epilepsy at the diagnosis and therapy selection phase, while the remission phase is cheaper.
Epilepsy diagnosis and treatment costs

Epilepsy treatment in 2018 was estimated to cost approximately 1.1 billion dollars.

Almost 25% of the estimated amounts will be spend in Volga Federal Region, but not because of higher disease prevalence, but due to higher medical facilities tariffs for this region.

Taking into account the disease prevalence by region, costs per patient are the highest in Moscow, and the lowest in Chukotka Autonomous Okrug.

But for generalized epilepsy, diagnosis is way cheaper compared to the remission phase. Treatment of epilepsy with general type seizures is approximately half as expensive as the partial type epilepsy.

The same estimates show that costs per patient are the highest in Chukotka Autonomous Okrug, Nenets Autono-
GDP losses calculation background

New epilepsy classification 2017

Epilepsy diagnosis and treatment cost estimates were calculated based on the new standard for epilepsy classifications, introduced at the International Epilepsy Congress (September 2-6, 2017, Barcelona, Spain) by Dr. Ingrid E. Scheffer (Australia), the lead of the International League Against Epilepsy disease classification research group.

New standard divides seizures into partial and generalized, and specifies healthcare practices to treat each of them.

Calculations do not take into account such etiological characteristics as structural, genetic, infectious roots, etc.

Costs of epilepsy diagnosis and treatment (per region and for the whole country) were calculated based on the Russian Federal State Statistics Service reports on prevalence of generalized and partial seizure cases in the federal subjects.

Cost of activities under tariff agreements 2018

Tariffs for medical measures in the Russian subjects were taken from the Tariff agreements approved by the territorial funds of Compulsory Medical Insurance for 2018.

Cost calculated for 1-year-long treatment

Frequency of diagnosis, treatment and control procedures, list of medications and course medication doses per patient calculations are based on the Epilepsy Treatment General Medical Services Standards, established by Ministry of Health of the Russian Federation.

Standards include the following procedures: medical specialists office visits, examination, consultation, supervision, laboratory and instrumental tests; nursing care and supervision; drug-free methods of prevention, treatment and medical rehabilitation.

Prices based on List of Vital and Essential Drugs for Medical Use 2017

The total cost of medication course is based on prices stated in the List of Vital and Essential Drugs in 2017, approved by Russian Federation Government Decree № 2885-r as of December 28, 2016.
Conclusions

The program of medical care standards for patients with epilepsy is balanced: 91.9% of GDP loss accounts for general type of epilepsy and 90% of drugs are in the List of Vital and Essential Drugs. On the other side, it is necessary to pay attention to the partial type of epilepsy to optimize the total costs.

Analysis of medical tariffs in Russian regions (taken from the Tariff agreements approved by the territorial funds of the Compulsory Medical Insurance for 2018) showed that medication expenses amount to 65% of all costs.

Thus, the reduction of the cost of drugs for partial epilepsy will have the greatest influence on total cost reduction.
Medications in Cost Structure per Patient in Russia

The program of medical care standards for patients with epilepsy is balanced: 91.9% of GDP loss accounts for general epilepsy and 90% of drugs are in the List of Vital and Essential Drugs.
Currently, there is a number of therapeutic devices designed for people with epilepsy. Important to note, that none of them can cure epilepsy, but rather are designed to detect seizures and prevent serious health risks.

In clinical practice, the golden standard for detecting epileptic seizures is the measurement of electroencephalogram (EEG) in conjunction with video monitoring. However, such technique can be performed mainly in clinical settings and requires additional training.

Therefore, more user-friendly and commercially available seizure detecting devices have been developed. For the purpose of this report, advanced methods such as near infrared spectroscopy (NIRS), EEG, and other recently developed and complex methods will not be reviewed, but rather only commercially available and user-friendly devices will be outlined.

Seizure detecting systems are designed to detect ongoing seizures and provide clinicians with data useful for the management of epilepsy. Moreover, they serve a useful tool for parents and caregivers of people with epilepsy, as those systems provide sense of security and control over unexpected nature of seizures.

Currently, a number of different seizure detecting systems are available on the market. These include:

- Mattress devices/ movement sensors
- Watch devices/ accelerometers
- Camera/ video/ infrared devices
- HR analysis systems
- Sounds analysis systems
Mattress monitors are designed to detect seizures that occur during sleep. Usually they include a pressure sensor mat placed under the sheet or mattress of a person to detect abnormal movement or absence of movement. In case of a seizure, an alarm sound system will warn a caregiver or a parent.

Those devises are useful for preventing SUDEP for patients with generalized tonic-clonic seizures (GTCs), while unsupervised in bed at night. Some studies showed that mattress devices are capable of detecting up to 62.5% of seizures (47).

However, the system has a very poor predictive value of 3.3% and a very high false positive value of 99.8% (47). Additionally, mattress detection systems usually have certain weight restrictions and are limited to the area, where a person is sleeping.

Those systems are useful for parents and caregivers of children and young adults with epilepsy as they provide peace of mind to parents who are concerned that their child may have a seizure while sleeping without them knowing.

The most popular commercially available mattress systems are the Emfit movement monitor (Emfit Ltd., Finland) and Medpage MP5 (Medpage Ltd.). The price range of such system can vary depending on the additional features. Some devices have also connection to Pager systems, which allows to automatically call the ambulance or medical assistant.

<table>
<thead>
<tr>
<th>Advantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Detecting GTCs during sleep</td>
</tr>
<tr>
<td>Preventing SUDEP</td>
</tr>
<tr>
<td>Sense of control for parents and caregivers</td>
</tr>
<tr>
<td>Price</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>High false positive rate</td>
</tr>
<tr>
<td>Weight restrictions</td>
</tr>
<tr>
<td>Limited to sleeping area</td>
</tr>
<tr>
<td>Detect only seizures with rhythmic movements</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Price range</th>
</tr>
</thead>
<tbody>
<tr>
<td>$700–1300</td>
</tr>
</tbody>
</table>
Watch devices and accelerometers

Watch devices, bracelets, hand patches and other external wearable devices are probably the most popular and commercially available devices.

Despite the variability, most of them work the same by detecting changes in velocity and direction with a “3-D accelerometers”. These systems are capable of detecting motor seizures, such as tonic-clonic or myoclonic seizures. Similar to mattress devices, the system can alert a caregiver in case of the seizure via the alarm system or sms/phone call etc.

There are a lot wearable devices available on the market. The price can vary from 140$ to 1500$ depending on the complexity of the devices.

For example, the SmartWatch (Smart Monitor, Inc) is a device that can be worn both on the wrist and ankle and include a specially designed seizure detecting algorithm. Thus, SmartWatch also includes daily activity and sleeping tracker. Collected data can be then used by a practitioner for therapy adjustment.

Another example are watch Embrace (Empatica Inc.), one of the first watch that received FDA approval for use in neurology. Comparing to other similar devices, Embrace uses the technology of measuring electrodermal activity that captures changes in skin conductance resulting from the sympathetic nervous system activity. The price for such watch is around 250$. Additionally user will have to pay around 20$ per month for app subscription.

A major advantage of using such system is that it allows caregivers or parents to distantly monitor health a person, who has epilepsy. Thus, it excludes the necessity of being constantly with a patient, provide sense of a security and control over seizures and allows caregivers and parents to live normal everyday life.

**Advantages**

- User-friendly
- Connection to other smartphones
- Up to 90% seizure detection
- Alert system for caregivers
- Data collection

**Disadvantages**

- Only ongoing seizures
- High false-positive rate
- Price
- Detect only seizures with motor component

**Price range**

$140–1500
Different models have been developed to capture seizures using video monitoring. Those devices usually include a variety of capturing elements, such as cameras, infrared cameras (for night detection), microphones, elements that analyze speed and duration, rotation of movement, temperature in the room etc.

Those models are primarily used to detect focal, hypermotor, myoclonic, and clonic seizures. Motion trajectory methods are based on the path of moving objects through space over time. Some of them also use marker-based system with spatio-temporal interest points system to detect myoclonic seizures with a higher sensitivity and specificity.

However, those systems can be uncomfortable over time as they require to constantly wear the marker. Marker-free systems can detect only seizures with a large motor component, as well as they are limited to the area covered by the video recording device.

Despite that, video detection devices are popular among parents with small children who have epilepsy. They are also useful for caregivers to monitor their older parents. The recording can be monitored through a mobile phone and in case of seizure detection, the system will alert a caregiver or a parent. Some devices also allow distance access to the camera, which is a useful feature for parents.

Most popular commercial example is SAMi (Hipass Design LLC). During sleep, audio-video information from a remote infrared video camera is sent to an app running on an iOS device such as an iPhone or iPod Touch. The SAMi app records and analyzes the video for unusual activity. The basic camera is available for 400$, while a full pack kit can be purchased for 950$.

### Advantages
- Useful for parents with small children with epilepsy
- High level of sensitivity (70%-100%)
- Can be monitored through phone
- Price
- Simple to use

### Disadvantages
- Limited to the cover area
- Can’t detect if a patient is covered (by the blanket)
- Can’t detect seizures that do not involve movements that occur during a tonic-clonic seizure

### Price range
- $50-$950
Conclusion

According to the Federal State Statistics Service of Russia (Rossstat), epilepsy is a serious burden that affects more than 370 thousand Russian citizens.

The stable annual growth of epilepsy prevalence is a message to pay special attention to this condition, especially due to the fact that morbidity rates are three times higher among children than in other age groups. However, adult employable population is most affected by the disease that poses a substantial impact not only in social and demographic spheres, but the country’s economy as well. Moreover, figures may vary across the country and are inconsistent with the federal funding.

For instance, in 2018 alone, Russia is expected to underproduce up to 1.8 billion USD of GDP, with the Central Federal District accounting for one forth and the Volga and the Ural Federal Districts – for one fifth each. But the disease burden is the heaviest for the Nenets Autonomous Okrug, the Republic of Karelia and the Republic of Sakha, which are outside the above mentioned territories. Average costs per patient for the Compulsory Medical Insurance Fund are the highest in the Chukotka Autonomous Okrug, Ryazan Oblast, Rostov Oblast and others. The medical care standards program is only capable of covering 30% of expenses for people living with partial epilepsy.
Specialized medical devices are a helping hand for those who suffer from epilepsy. They cannot cure the disease, but more importantly they can prevent serious health risks associated with seizures. We think that integrating such devices in everyday use would positively influence the prevalence rates.

The main objective of this report was to outline the current social, demographic and economic status of epilepsy morbidity in Russia and to make the readers familiar with the most challenging issues in this field as well as ways to address them. This report is made for not-for-profit purposes and is intended not only for individuals and companies, but also for institutions subordinate to relevant governmental agencies.