

Difference in framing the policy issue of child oncology in Russia and in the Netherlands

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Chapter 1. Introduction

The present work deals with policy on child healthcare in the field of cancer detection and treatment in the Russian Federation. Relatively little research has been done in this sphere. Most research papers describe the child healthcare provision in the USA or represent the cross-cultural system comparison among countries of the European Union.

Lennard Kohler gives two major reasons as to why child healthcare is a field of paramount importance: children represent a considerable group of the population and children can also be described as a vulnerable group in society. Thus, it is duty of the society to take care of the fulfilment of children's rights and satisfaction of their needs¹. Besides, it is important to remember that the Convention of the Rights of the Child adopted by the United Nations in 1989 declared «the right of the child to the employment of the highest attainable standard of health²». That is why child healthcare was chosen as a field of study for present research.

The incidence of cancer is increasing nowadays. This class of diseases is affecting people irrespective of their age, social status or nationality, though the risk of some types of cancer increases with age. According to the statistics of the World Health Organisation cancer is responsible for more than 13% of all deaths in 2005³. Though danger of cancer is less for children, more than 166,000 new cases of cancer among children under 15 are being diagnosed each year in the world. Annually approximately 80,000 children die from this disease.

The situation with treatment of children with cancer has a dualistic character. On the one hand, in the well-developed countries the death rate is relatively low. For example, in such countries as USA, UK, Germany or the Netherlands the survival rate is high – more than 7 out of 10 children. On the other hand, less developed countries face huge problems⁴. For instance, in India, cancer results in the deaths of 8 out of 10 children⁵. Thus we can name inequality in access to modern methods of treatment as one of the reasons for high mortality rate in some parts of the world. The situation with child cancer treatment also depends on the political situation in the country and the organisation of decision-making in healthcare and its funding. In this work these factors are described using examples of Russian Federation and the Netherlands.

Cancer is not a new disease, such as AIDS for example. First notions about it can be traced back to Ancient Egypt around 1600 B.C. However, until the end of the 19th century this disease was considered incurable: though surgical operations were done, they provided poor results due to restricted knowledge and unsatisfactory hygienic conditions. Despite the long history of attempts to find a cure for cancer, it was not found. Nowadays treatment of cancer consists of several methods that can be used either separately or combined: surgery, radiation therapy, chemotherapy, immunotherapy, and hormonal therapy and angiogenesis inhibitors. The

¹ Kohler, L. (1998). "Child public health: A new basis for child health workers." *Eur J Public Health* 8(3): 253-255.

² Article 24:1, Convention of the rights of the child. New York: UNICEF/ United Nation's Centre for Human Rights, 1989

³ Cancer fact sheet (2009). Retrieved April 05, 2009 from WHO official web site. Web site: <http://www.who.int/mediacentre/factsheets/fs297/en/>

⁴ Children in developing world bear the burden of cancer (2003). Retrieved April 07, 2009 from Cancer research UK web site. Web site: <http://info.cancerresearchuk.org/news/archive/pressreleases/2003/february/39505>

⁵ Annually 15,000 new patients, only 20% benefit from the treatment. Childhood cancer (2008). Retrieved from Cancer patients AID association web site. Web site: <http://www.cpaaindia.org/activities/childhood.htm>

treatment depends on the type of cancer, stage and prognosis and can consist of different combinations of the above mentioned methods⁶.

During the preliminary research it was found out that child oncology in the Russian Federation is facing considerable difficulties. Malignant neoplasm in Russia is second most common reason for child mortality for over 10 years. The problem is being manifested by the representatives of the medical community, charity organisations and parents of the sick children. However, little is being done to improve the situation on the state level. For some reason, the fact that child oncology is facing considerable difficulties is being denied by the Russian authorities. In this work, the present state of affairs will be investigated and attempts to explain the actions of the authorities will be made.

The behaviour of the representatives of Russian federal authorities will be analysed through the combination of several theories about framing of the policy issues. To conduct a comparative cross-cultural study the combination of Cultural theory and Model of Policy belief system, which derives from Advocacy Coalition Framework, will be used. As a result, we would be able to detect the differences in the general approach to the agenda and priority setting in child cancer treatment, which can result from the cultural differences and historical background.

The data for the analysis was collected through Internet and personal interviews. The major statistical data was found on the official web-sites of the public organisations of statistics in Russian Federation and in the Netherlands. Information about the beliefs held by different stakeholders was derived from the official statements, newspaper articles and personal interviews.

First, in the present work, child cancer detection and treatment process would include all aspects that influence the amount and quality of treatment provided. This includes legislation on the matter, existence of the federal/regional institutions that provide specialized help and research. The division of jurisdiction among different levels of organizations will be studied, as well as existence and amount of civil society organizations, special associations and projects supported by the government. Also, the financial side of the question will be analyzed: how much funds are allocated in the sphere, where do they come from, do they have national or international origin.

Second, it is also important to impose age limitation of the patients. According to *The United Nations Convention on the Rights of the Child* a child is "every human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier⁷." However, the statistical data for Russian Federation showed different age groups for different criteria: child mortality is calculated for children 0-9 years old, while cancer cases are calculated for children 0-15 years old and the hospital cases are collected for the ages 0-18 years old. For the Dutch system of Healthcare children are the ones 0-15 years old. For this reason, in the present research children will be defined as those from 0 to 15 years old.

⁶ Sala A., P. P. R. D. B. (2004). "Children, cancer, and nutrition - A dynamic triangle in review." *Cancer* **100**(4): 677-687.

⁷ (1990). Convention on the Rights of the Child. U. Nations.

The thesis is going to have the following **structure**. First, a description of the systems of healthcare provision in both the Russian Federation the Netherlands. This will be followed by a description of the situation in the sphere of child oncology in both countries. Using the information on the state of affairs in the Russian Federation and in the Netherlands the problem framework would be formulated in more details. We would then move on to describe the theoretical framework that will be used in the analysis. After that, policy beliefs about the topic will be discussed using the Cultural theory and the Model of policy belief system (adopted from Advocacy coalition framework) to detect the main differences in the frames used in organisation of child cancer treatment. Analysis of policy beliefs will be connected with frames and beliefs about the child oncology treatment. For comparison on this level, the policy beliefs on child oncology will be detected on two levels:

1. Policy beliefs on organisation of child oncology in the Russian Federation,
2. Policy beliefs on organisation of child oncology in the Netherlands.

After description and analysis of differences in framing the child oncology, an explanation of the present state of affairs will be given and an attempt to give some recommendations will be made. As a result, the hypothesis that cultural beliefs influence the organisation of child oncology help and priority setting in child healthcare in Russia and can be reason of the appearing problems, will be challenged. Some directions for changes in the system of child oncology in Russia in order to improve the effectiveness will be provided.

Chapter 2. Description of situation in the field of child oncology

In order to describe the situation in child oncology in Russia and the Netherlands first general facts on the state of affairs in the system of healthcare in both countries will be provided. After that description of child oncology will be started by giving facts about the importance of the problem: incidence of child cancer, the mortality rate and other facts. This will be followed by an overview of problems, which child oncology is facing in each country. Based on this information about current situation in both countries the research question will be formed and discussed in more details.

2.1. Russian Federation

2.1.1. System of healthcare in Russian Federation

Main principles of the Russian healthcare system are stated in the Basis of Legislation of Russian Federation on the Protection of the Citizens' health⁸. They are:

1. Protection of human and civil rights in the field of healthcare;
2. Priority of the preventive methods in the field of healthcare;
3. Accessibility of the medical-social help,
4. Social security of the citizens in the case of loss of health⁹.

To give a proper description of the healthcare system several aspects need to be covered: decision-making process, financial system and labour division.

According to the Law of Russian Federation # 5487-1, adopted 22 July 1993, "On the basis of the legislation of Russian Federation in the protection of citizens' health", the system of healthcare, for both adults and children, is divided in 3 main parts: Federal state, municipal and private systems of healthcare¹⁰.

The decision-making power in the field of healthcare depends on the amount of rights and responsibilities the actor has. Federal authorities are responsible for such activities as:

- general state policy in the sphere of healthcare;
- definition of the percentage of expenditures for health care within the federal budget;
- elaboration of a fiscal policy (including tax exemptions, duties and other payments to the budget) in relation to health protection;
- establishment of medical care quality standards and control over compliance with them;
- development and approval of a basic program of compulsory health insurance and establishment of tariffs for its premiums;
- defining benefits for certain population groups receiving medical-social care and pharmaceutical supplies;
- establishment of procedures for licensing of medical and pharmaceutical activity¹¹.

The sphere of responsibility of regional authorities includes:

⁸Article 1.1, Federal Law of Russian Federation, # 30 FL, 02.03.1998

⁹ Article 2, Federal Law of Russian Federation, # 30 FL, 02.03.1998

¹⁰ Article 12, Federal Law of Russian Federation, # 30 FL, 02.03.1998

¹¹ Holm-Hansen, J. (2009). Family Medicine in Russia. Swedish reform support evaluated. Nordberg A.S.: 77.

- development and allocation of the regional budgets;
- technical supply for the health care facilities under the ownership of the region¹².

The municipal (rayon) field of action is the most limited one and includes:

- organization, maintenance and development of municipal health care facilities;
- development of the local budget for health care expenditures¹³.

As it can be seen from the division of the rights and responsibilities, in Russian Federation federal level has the most power over the decision-making in the field of healthcare. In general system in this respect is characterised by high level of bureaucracy.

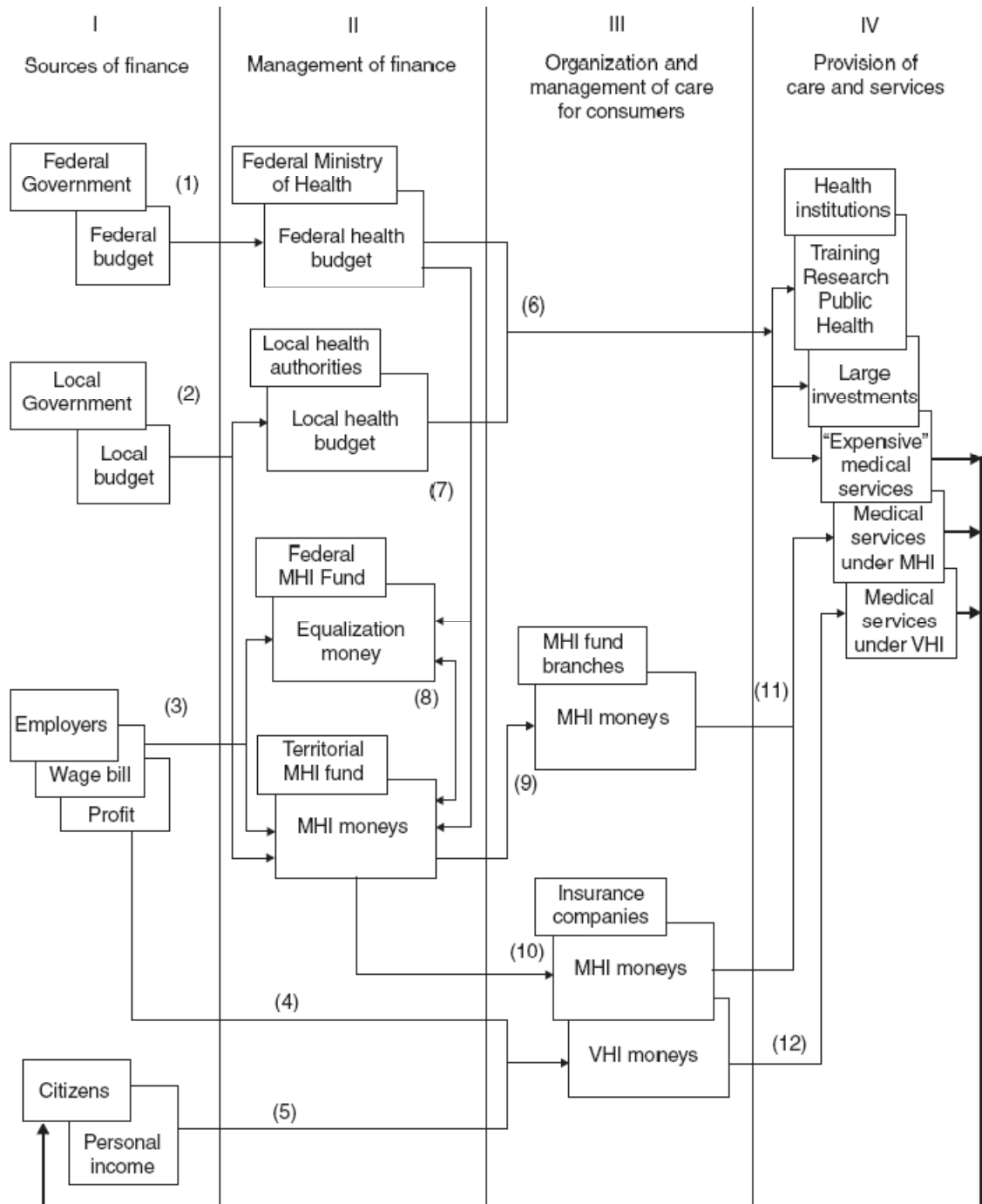
Insurance character of medical care in Russian Federation was established in 1993, when in addition to the budgetary system of Healthcare the System of Compulsory Health Insurance was created. As the result of that budgetary-insurance model of financing the system of healthcare was adopted in Russian Federation. Starting from 1998 Program of Governmental Guarantees to the citizens of Russian Federation in the sphere of provision of free healthcare is adopted annually by Government of Russian Federation.

Financing of the child healthcare is done in the same way as all the others spheres of healthcare in Russian Federation. There are 4 main sources of finance in the system: Federal Budget, Local Budget, Employers and Citizens' personal income. These are main sources of funds for the system; however, among the incomes may also be incomes from bonds, bank credits, charity etc. The system of finances in healthcare in Russian Federation is reflected in the Figure 1.

¹² Tragakes, E. and S. Lessof (2003). Healthcare system in Tradition. Russian Federation. E. Tragakes. Copenhagen, European Observatory on Health Systems and Policies. 5.

¹³ Ibid.

Figure 1. Representation of Health Insurance legislation in Russian Federation since the reform in 1993, (Chernichovsky and Potapchik 1999).



Fund of Compulsory medical insurance in divided in 2 levels: federal and territorial. On the December 2007 in Russian Federation, there were 85 territorial funds of compulsory medical insurance. Incomes of these funds in accordance with Statute of the Federal Fund of compulsory medical insurance mainly consist of taxes paid by the employers. It is important to note that money from the citizens and employers are spent only on the provision of medical services (including salary of the medical workers).

The structure of expenditures of the budgetary system of the Russian Federation on the healthcare and sport can be reflected through the following table:

Table 1. Expenditures in Russian Federation on healthcare and sport (www.gks.ru)

	% of GDP			
	1995	2000	2005	2006 ¹⁴
The total budget of the Russian Federation	2,9	2,1	3,7	3,6
including:				
Federal budget	0,3	0,2	0,4	0,6
the budgets of state extra-budgetary funds	0,3	0,4
consolidated budgets of subjects of Russian Federation ¹⁵	2,6	1,9	2,1	2,3
budgets of the territorial state extra budgetary funds	1,2	1,2

According to the American Journal of Public Health the contemporary Russian medical care is developing dual system: the old state system, facing chronic underfunding, and a second, poorly understood, and loosely regulated system of better equipped and staffed private practices available only to those with the cash to pay the doctor's bill.¹⁶ A number of scientists point out the complexity of the system of finances. None of the budgets is situated in open access. A strong hierarchical structure of the financial relations in the sphere of healthcare in general and child healthcare in particular can be observed.

Next step of description of the system will be the analysis of labour division within the system of healthcare in Russia. In general 5 functions of healthcare can be observed in Russian Federation: preventive care, primary, secondary healthcare, rehabilitation and long-lasting care for chronically ill or handicapped people. Through this division of labour all groups of society are covered: healthy, not totally healthy, sick, recovering and those, who need constant care.

Functional division of labour in the Healthcare system in Russia is supported by the division of labour among the institutions. Despite the fact that there are 5 functions of the healthcare institutions in Russia we can observe only 4 echelons of specialists providing healthcare services. These echelons can be represented by the following scheme:

¹⁴ In 2006, GDP of Russian Federation was 760,6 trillion Euros.

¹⁵ Only for technical supply.

¹⁶ Barr, D. A. and M. G. Field (1996). "The current state of health care in the former Soviet Union: implications for health care policy and reform." *Am J Public Health* **86**(3): 307-312.

Table 3. Division of child healthcare institutions by the nature of care provided,
adopted from (Boot J.M. and Knapen 2001)

	1st echelon	2nd echelon	3rd echelon	4th echelon
Nature of care	General, not specialized	Specialised	General and specialised	Specialised
Accessibility	Free	After referral to 1st	After referral to the 1st or 2nd echelon	After referral to 2nd echelon
Location regarded to target group	In the centre of the target group	In the centre of target group	At a distance, but not big one	CAN be at a distance
The way care is provided	In at-home situation: extramural, ambulatory	In at-home situation: extramural, ambulatory	Ambulatory, intramural, polyclinic, clinical	CAN be intramural Substitute of home situation

1st echelon of care includes general practitioners in polyclinics and nurses at school. These specialists provide preventive care (vaccination) and primary care in case of minor illness as well as rehabilitation services. The access to these institutions is free; citizens should just make appointment either by phone or personally. These specialists are situated in schools, polyclinics and feldsher-midwife stations in rural areas. Usual standard is approximately 1 polyclinic or feldsher-midwife station per 2 200 children¹⁷.

2nd echelon of healthcare institutions includes specialised care, which is provided on the extramural basis. This kind of care is provided by the specialists in the polyclinics. Patients can refer to these specialists only after referral to the representatives of the 1st echelon. This category includes physiotherapists, massagers, manual therapy and specialists in different spheres (heart, brain, eyes etc.). Wide range of healthcare services can be obtained in polyclinics without the need for an overnight stay. These institutions provide primary and partially secondary help. Some specialists are also responsible for control over the rehabilitation care provided to the patients after surgical operations.

Third echelon of institutions represents specialised care, which is provided in cases when special procedures are needed: diagnostics, tests or surgeries. This echelon consists of general hospitals. The patients are able to refer to these institutions only after referral to either general practitioners or to the specialists in the polyclinics. Patients are transferred to the hospitals in case the previous echelons of the medical care cannot provide adequate treatment. Institutions of the 3rd echelon are providing secondary care, first rehabilitation care and in some cases long-lasting care.

¹⁷ This number is derived from the total number of children in Russian Federation and total number of institutions of the 1st echelon.

Forth echelon is the most specialised one; it includes institutions that are providing treatment to the certain illnesses, for instance, hearth diseases, cancer or care for the handicapped people. Patient can be referred to these institutions only after referral to the specialists of the 2nd echelon. The care is provided on the intramural bases as in general hospitals. These institutions provide long-lasing care, secondary care and rehabilitation.

As it can be seen from the descriptions of the healthcare organisation in Russia, the division of labour exists even among the representatives of the specialised care. However, the more specialised care is needed for the patient the harder it is obtained. This happens because the number of institutions is decreasing: polyclinic and rural feldser-midwife stations are the most common institutions, then come general hospitals, that are situated in all rayon centres (in the middle-sized and large cities), specialised hospitals are situated only in the largest cities in Russia and are not easily accessible for all patients. According to the national statistic in 2007 on the territory of Russian Federation there were 9 620 organizations that provide medical help¹⁸. The high level of corruption in the field of healthcare is the common knowledge, however little information can be found about it in official sources. Citizens explain the need for bribing doctors by stating that doctors have little salaries and after «presents» the quality of care will be improved.

To sum up, we can state that the Russian system of child healthcare and healthcare in general is in troublesome situation nowadays, despite the statements of authorities on constant reforms and improvements. It can be characterised by high control of the Government, complex bureaucratic administration and low level of empowerment of medical specialists or patients.

2.1.2. General statistic on cancer diseases among children

Before discussing the system of the healthcare services provision for the children diagnosed with cancer, it is important to understand the field of the policy actions, i.e. to see the scale of problem in Russia. In general it can be observed that the number of children in the country was decreasing¹⁹, from 42 138 000 in 1990 to 29 020 000 in 2006²⁰. Due to the decrease of the number of children in the country the number of mortalities from cancer diseases also decreased from 3 161 in 1990 to 1 364 in 2006.

Despite the decrease of mortality rate, the number of the cases of the first diagnosis of cancer among children 0-14 years old (irrespective of the type of cancer) increased from 59 700 cases in 2000 to 80 200 cases in 2007. The timeline of the child cancer diagnosis can be found in Appendix 2. The numbers of cases per 100 000 children would be more representative in this respect. According to the Federal Bureau of Statistics²² in 2000 it was observed that 8,7 children out of 100 000 had been diagnosed with cancer, while in 2006 already 13 children from 100 000

¹⁸ The numbers are for adult and children healthcare due to the limitations of the access to information

¹⁹ **Ошибка! Источник ссылки не найден.**

²⁰ The general population of Russian Federation decreased from 147 million people in 1990 to 142,2 million people in 2007.

²¹ Such decrease in the number of children is explained by several facts. First and foremost, it is the so called «baby boom» of 1980s – 1987, secondly it is the economic and political crisis of 1990s, which followed. The largest decrease in the number of new-born children was registered in 1992 – 1994.

²² Statistics on Children (2006). Retrieved May 07, 2009 from The Federal Bureau of Statistics of Russian Federation official web site: <http://www.gks.ru/>

were diagnosed for the first time. In comparison in the U.S.A. in 2006 only 6,6 children out of 100 000 were diagnosed with cancer²³.

According to the Federal Bureau of Statistic of Russian Federation cancer is the second reason for child mortality in Russia by the number of deaths of children 0-15 years old. Unfortunately due to the difference in the statistical formats the data on the number of deaths of children 0-18 is impossible to find. First most common reason for child mortality in Russian Federation is external reasons of death, such as traffic accidents, poisoning, murders, etc. These factors are responsible for 5 429 mortalities among children below 16 years old, it is 26 mortalities per 100 000 children. Cancer is the reason of 982 mortalities in 2006, which makes 4,7 deaths from cancer among 100 000 children. Third most common reason for child mortality in Russia are infection diseases, which resulted in 930 child deaths, which makes 4,45 mortalities per 100 000 children. After that come illnesses of blood circulation, digestion and some other diseases²⁴.

The remarkable fact that only in 23,6% cases the diagnosis of cancer was made at I or II stages, while in 76,6% of cases cancer was diagnosed on already III and IV stages²⁵. The international practice shows that the earlier cancer is diagnosed, the better the chances for survival are. According to the research conducted by N. N. Blokhin Cancer Research Centre of Russian of Academy of Medical Science, 65% of cases late cancer diagnosis of cancer among children appear due to the fact that doctors fail to make necessary tests, in 17% of cases it is fault of parents and 18% of cases were objectively difficult to diagnose²⁶.

Most of the cancer cases in Russia are connected with brain tumours – 26% of total amount of cases. Second most common type of cancer is leukaemia (blood cancer), next comes lymphosarcoma and sarcoma of soft tissues²⁷. According to American Cancer Society, this situation is typical for most countries. In the world leukaemia (blood cell cancers) and cancers of the brain and central nervous system are among the 12 major types of childhood cancers. Together they account for more than half of the new cases²⁸.

Thus we can see that situation with child oncology in Russian Federation needs changes. Unlike the external causes of child mortality, this issue can be addressed on the national level.

²³ Centres for Disease Control and Prevention. National Centre for Health Statistics. Health Data Interactive (2008). Retrieved May 03, 2009 from Department of Health and Human Services official web site. Web site:

www.cdc.gov/nchs/hdi.htm.

²⁴ Appendix 2

²⁵ In general cancer is divided in IV stages, which differ by the chances for better recovery. First one is considered to be the most curable, while the fourth one is very hard to treat.

²⁶ Durnov, L. A. (2003). Modern aspects of child oncology help in Russian Federation, N.N. Blokhin Cancer Research Centre of Russian of Academy of Medical Science.

²⁷

Appendix 4

²⁸ American_Cancer_Society (2007). Cancer Facts and Figures. Atlanta, American Cancer Society.

2.1.3. Main problems of child oncology in Russia

Unfortunately nowadays there is a number of serious problems in the system of child oncology help, which resulted in 1 290 mortalities among children under 14 in Russia in 2006²⁹. In general they may be categorized in 3 main groups:

1. Problems connected with ineffective organisation of healthcare,
2. Problems, resulting from the lack of funds and medicaments,
3. Problems, resulting from the difference of standards of treatment.

Most problems appear due to the not effective division of labour and funds among the healthcare institutions in the sphere of child oncology³⁰. According to the Russian legislature, regional departments of healthcare have the right to identify the number of quotas³¹ (operations, high-tech treatment and hospital beds) necessary for their region for the year³². In reality it is impossible to predict how many new cases of which disease are going to appear each year and how many children are going to need high-teach medical help. This results in the situation when children from some regions are not able to receive the needed polio-chemical, radio therapy or bone marrow transplantation. This kind of treatment is done in the limited amount of centres around Russia mostly situated in big cities such as Moscow, St. Petersburg or Novosibirsk. However, the number of quotas in such centres is limited. There are situations when children, who started their treatment during one year, are not able to continue it in the following year due to lack of «quotas»³³. To illustrate it real life story will be presented.

²⁹ Appendix 3

³⁰ Durnov, L. A. and T. A. Sharoev (2004) "Children oncology: stages of development, successes and problems." **Doctor Volume**, DOI:

³¹ Quota is the complex of operations in some field, which is needed to treat one person with particular disease for a year

³² Act of Ministry of Healthcare of Russian Federation, # 786n, 29.12.2008

³³ Press-release of Press Conference Problems of Child oncology in Russian Federation: role of Government, business and civil society, (2008). Retrieved May 06, 2009 from Medlinks official web site. Web site: <http://www.medlinks.ru/article.php?sid=32811>

In October 2008 10 year old Tatyana started to lose her eye sight. MRI was done in the city hospital and showed Germinal cell tumour of the brain. After that the girl was sent to Moscow Oncology centre because this kind of tumour could not be treated in the city hospital. On the October 9th Tatyana was hospitalised in the department of naira-oncology in Solncevo (Moscow region), where she started the course of chemical therapy that lasted till the end of December. After that she was sent to the Russian Scientific Centre of Roentgen-radiology. After the request of the head of the paediatric department of the Centre, Ministry of Health provided a quota for high-techs medical help for Tatyana with a starting date 19th December 2008. The date of hospitalisation was set on the 19th of January (after New Year holidays). However, when Tatyana and her parents came to the centre in January, they found out that quota was no longer valid because the order of quota provision was changed from January 1st 2009. As the result there were no quotas available for the region Tanya was coming from. Right now Tanya needs 6,000 Euros for the radio therapy. Several charity organisations are collecting money for this child.

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that in most cases the disease is found too late on the terminal stages. Russia is a big country, however number of institutions, where cancer can be diagnosed and treated is limited, thus not all children that need urgent help or diagnostics can obtain it. This is pointed out in several articles about the problems of child oncology in Russian Federation³⁴.

Second group of problems results from the lack of both financial and medical funds. The financial issue was tackled above, thus it is important to highlight the medical side of the problem. As an example it is possible to name so called «orphan drugs». These are the drugs that

³⁴ Mentkevich, L. D. C. (1997). "Pediatric Hematology/Oncology in Russia." Pediatric Hematology and Oncology **14**(2): 103 - 107.

are unauthorized in Russia, but vitally important for the children with oncology illnesses³⁵. European Commission defines orphan drugs as medicinal products intended for the diagnosis, prevention or treatment of life threatening or very serious diseases affecting less than five in 10 000 persons in the Community³⁶. In Russia the problem of these drugs is very urgent in the sphere of oncology in general. Because the «orphan drugs» are also usually not registered in the national registry of the drugs, this makes it even more difficult for patients to get them. Due to the special legal status these drugs are also not on the list of the medications provided for free. Most of the times medications are brought unofficially from other countries and paid for from the family budget. Taxes result in additional costs (which are 30% of the price of the drug).

Right now in Russian Federation the procedure of importing any drugs even for personal use is very complicated and the legislative system is not friendly towards the registration of new medications. Thus the climate makes it not profitable for pharmaceuticals to introduce new drugs on the Russian market in case it is not a popular drug. This problem is actively discussed on the online medical forums of Russian oncologists³⁷. Some examples are provided.

Dmitry, 5 years old. Since the age of 3 the boy was suffering from epilepsy. During the screening nothing bothering was discovered. However after one of the attacks Dmitry began to have difficulties in opening one eye and moving left arm and leg. He was sent to the regional hospital for screening, which showed brain cancer of the IV stage (terminal). Soon after that an operation was done, however after the operation the condition of the child was still very bad: ability to move left part of the body did not come back. The second operation was needed. Unfortunately the regional hospital did not have quota for the second operation, thus a charity complain was launched by joint efforts of several charity associations such as International Association of Haematologists AdVita and Regional Association «Children and Parents against Cancer».

Money was collected, however operation was not successful and additional treatment was needed. On the 22nd of April 2006 one of the medications needed for the rehabilitation disappeared from the pharmacies of the city because the firm that was responsible for the delivery of this medication had legal difficulties in prolonging the licence. The drug appeared again only 2,5 weeks later, but still there were difficulties in receiving free medication, so the money started to be collected again by the charity organisations.

³⁵ Henkel, J. (1999). "Orphan Drug Law Matures into Medical Mainstay." *FDA Consumer magazine* 33(3).

³⁶ Orphan drugs strategy (2000). Retrieved May 07, 2009 from European Commission official web site. Web site: http://ec.europa.eu/health/ph_threats/non_com/rare_6_en.htm

³⁷ Press conference on child oncology (2008). Retrieved June 02, 2009 from Medlinks official web site. Web site: <http://www.medlinks.ru/article.php?sid=32742>

The CEO of the hospital where Dmitry was situated and directors of several pharmacies started negotiation process with the CEO of the Pharmaceutical firm and in the beginning of May the medication was delivered to Dmitry for free. However in the middle of May the free access to medication disappeared again and the NGOs took part in providing medication.

The further treatment could not be provided by the regional hospital, thus Dmitry was moved to the central hospital of St. Petersburg, where he had the third operation, which was financed by the National Charity Fund. Unfortunately Dmitry could not recover after the operation, the child died on the February 8, 2007.

The third urgent problem in child oncology in Russia is considered to be difference in the standards of treatment. This includes the difference between Russian standards of treatment and the European ones, as well as differences in treatment provision depending on the region of Russia. By standard of treatment the level of equipments of the hospitals, their accessibility for the patients and variety of procedures available is considered. This situation is occurring due to the limited number of specialized centres in the sphere of child oncology and constant under financing. Right now on the Federal level there are only 9 specialized centres, which also vary by the number of beds from N. N. Blokhin Child Cancer Research Centre of Russian Academy of Medical Science with 150 beds to Research institute of haematology of Novosibirsk with only 12 beds. In general in Russia there are 46 medical institutions with at least 10 beds which are designed to provide examination of children with tumours as well as treatment. The number of beds is also unequal in different regions; this however is also connected with the child population in the region. In the most densely populated region – Central region there are 365 beds for children with oncology illnesses, while the child population is 7,4 million³⁸. In the Far East region there are only 80 beds, while population is 2 080 thousand.

The difference between Russian and European quality of care and cure differs from hospital to hospital from region to region. There are general standards of treatment that should be provided for children with cancer adopted in both countries. The analysis of these guidelines is not included in the present research, however, it is important to point out that while in the Netherlands guidelines are adopted by the Medical community, the guidelines in Russian Federation are formulated on the Governmental level. Thus we can observe the high level of intervention of the Government in the healthcare field. The other point that should be mentioned is that in Russia the palliative care for the children on the terminal stages of cancer is not present; there is not a single hospice for such children. In comparison, in the Netherlands there are 4 hospices that provide terminal care and respite care for children. Within these hospices there are a total of 39 beds³⁹. Also there are 4 consultant teams in hospitals and 2 homecare teams. In Russia doctors and general practitioners at the hospitals and polyclinics do not have enough knowledge on pain management and supportive therapy. This fact can be explained by the

³⁸ Year 2000

³⁹ Kuin, A., Courtens, A. M., van Zuijlen, L., van der Linden, B., and van der Wal, G. (2004). "Palliative care consultation in the Netherlands: a nationwide evaluation study." *Journal of Pain and Symptom Management* 27(1): 53-60.

priority setting in the healthcare, which pays more attention to the kids that can be cured than to those that cannot be cured. The priorities of the Russian system of child healthcare will be discussed later in this work.

Summing up the information about Russian healthcare system and the state of affairs in the child cancer treatment, we can say, that although high intervention of the government both in administration of healthcare and treatment provision can be observed, the system is characterised by international scientists as over bureaucratic, complicated and not efficient.

2.2. The Netherlands

2.2.1. System of healthcare in the Netherlands

The main principles of the Dutch healthcare system can be derived from the Article 22 of the Constitution of the Netherlands. In this article Governments takes responsibility to protect the citizens of the country against any health risks. The exact citation is the following: «the Government shall take measures to promote public health»⁴⁰. Based on this citation the two basic rights of the Dutch citizens can be derived:

- The right of health protection and promotion;
- The right of health care⁴¹.

The right of health protection and promotion refers to the general measures of organisation of public health both in individual and collective sense. The right for health care constitutes the necessity to ensure accessibility (financial and physical) of the institutions of public health and control over their effectiveness and efficiency.

The general principles of Dutch healthcare are similar to the ones of Russian Federation, however Dutch healthcare policy field has several distinguishing characteristics:

1. Relatively strong autonomy of the health professionals and private delivery of treatments;
2. Decentralised and autonomous regulation in different sectors of healthcare executed by several types of stakeholders including the Autonomous Governing Bodies (ZBOS, Zelfstandige Bestuursorganen). The role of centralised government in this respect is mostly to control and adjustment over demand and supply in the Healthcare field.

In the field of decision-making process Dutch system has focus on the self-regulation of the healthcare providers. The specialists are believed to have more knowledge about the field and thus more competent. The government is seen more as protector and observer.

The main objectives of the Dutch system of healthcare go in line with the objectives listed by the OECD and they are:

1. Adequacy and equity of access to healthcare for all citizens, to some extent, based on solidarity between poor and rich, sick and healthy and young and old;
2. Macro-economic efficiency, expressed in terms of an acceptable level of spending, as related to national resources;
3. Micro-economic efficiency aiming at the achieving good health outcomes and patient satisfaction at acceptable costs⁴².

In the Netherlands, as in the most healthcare systems, the division of labour among the healthcare institutions is used. The division is made by the functions of institutions: preventive, curative or aftercare. This is done for several reasons: increase of efficiency, better division of

⁴⁰ Constitution of the Netherlands

⁴¹ Vos, P. (2002). Legislation and Consultative Bodies - Relation between Political and Participative Democracy. Health and Healthcare in the Netherlands. A Critical Self-assessment of Dutch Experts in Medical and Health Sciences. E. Rooij (van), Kodner L.D, Rijsemus T and S. G. Maarssen, Elsevier Gezondheidszorg: 301-309.

⁴² OECD (1994). The Reform of Healthcare. A review of 17 OECD Countries. Health Policy Studies O. f. E. C. a. D. (OECD). Paris. 5.

personnel involved and not to increase risk of healthy or cured patients to receive new disease from the already sick ones, in case of infectious diseases.

The medical institutions in the Netherlands can be divided into 3 echelons, representing different levels of the treatment and care provided to the patients. The most basic level includes general practitioners that are examining the patients, and deciding about the seriousness of the illness. General practitioners have the right to send the patients further to the 2nd and 3rd echelon.

2nd echelon represents the institutions that are providing specialised intramural, clinical or polyclinic care. These are the centres spread around the country. *Kempenhaeghe epilepsiecentrum (poli)kliniek* situated near Eindhoven can be a good example of the institutions of the 2nd echelon. In this clinic epilepsy and sleeping problems are addresses. The patients are referred to the centre either by their General practitioner or by the Epilepsy polyclinics that are situated in 9 different cities around the country.

Such polyclinics together with the general hospitals form the 3rd echelon of the healthcare providing institutions. Most hospitals and facilities providing specialised care in the Netherlands are owned and managed by the non-profit religious or charitable organisations, while General practitioners are mostly private entrepreneurs. However the tendency in the last years is for the General practitioners to unite in joint practices⁴³. The division of health care and services provided by different institutions in the Netherlands are shown in the following scheme⁴⁴:

Table 4. Division of child healthcare institutions in the Netherlands by the nature of care provided (Boot J.M. and Knapen 2001)

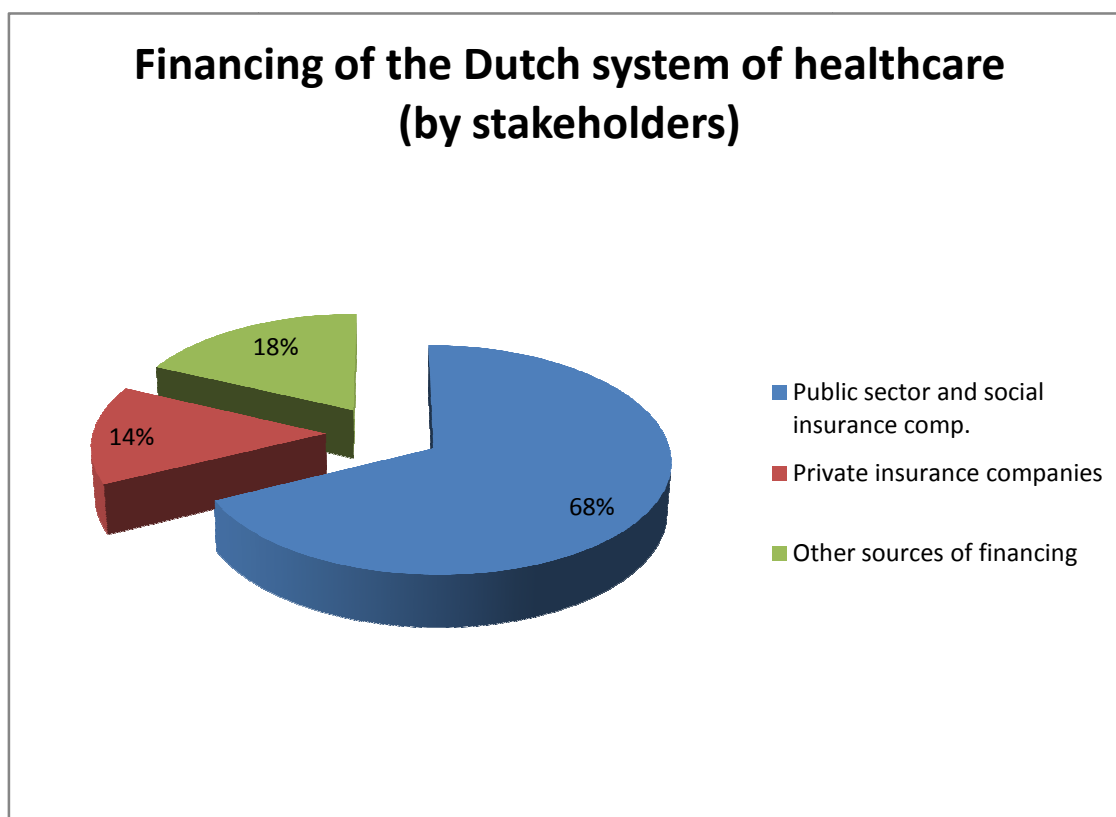
	1st echelon	2nd echelon	3rd echelon
Nature of care	General, not specialized	Specialised	General and specialised
Accessibility	Free	After referral to 1st or 3rd echelon	After referral to 1st or 2nd echelon
Location regarded to target group	In the centre of the target group	At a distance from target group	CAN be at a distance
The way care is provided	In at-home situation: extramural, ambulatory	Ambulatory, intramural, polyclinic, clinical	CAN be intramural Substitute of home situation

⁴³ Borst-Eilers, E. (2002). Health Policy in the Netherlands - A Balance between Containment and Expansion. Health and Healthcare in the Netherlands. A Critical Self-assessment of Dutch Experts in Medical and Health Sciences. E. Rooij (van), Kodner L.D, Rijsemus T and S. G. Maarssen, Elsevier Gezondheidszorg: 17-22.

⁴⁴ Boot J.M. and M. H. J. M. Knapen (2001). Handboek Nederlandse gezondheidszorg. Schiedam, Het Spectrum B.V.

In the Netherlands we can see the balanced system of private and public financing of the healthcare. In 2004 the total costs of healthcare in the Netherlands were equal to the 12,8% of Gross Domestic Product of the country that year. According to the CBS Nederland public means of financing the healthcare system together with social insurance companies constitute 68% of all finances received by the Dutch healthcare system. 16% is being received from the private insurance companies and 18% from the other sources (EU, international grants etc.).

Figure 2. Structure of Financing of Healthcare in the Netherlands (CBS Nederlands, <http://statline.cbs.nl/StatWeb>)



The structure of funding of the healthcare system also determines the weights of the stakeholders in the decision-making process in the sphere. Most of the healthcare services such as hospital care, dental care or the visits to the General practitioners are paid either from social or private health insurers. However some services such as treatment of mentally or physically disabled, nursing at home and some others are financed through the Exceptional Medical Expenses Act (AWBZ Algemene Wet Bijzondere Ziektekosten). AWBZ is believed to be the act which insures the provision of long-lasting care and coverage of other severe health risks, which cannot be covered by the private insurers. Through this act the government of the Netherlands insures that the adequate healthcare is provided to all the citizens, thus the principle of equity is fulfilled. Government is also taking part in organisation of the Healthcare provision through financing the subsidies aimed to increase the frequency of the intramural cooperation of different institutions. These subsidies also encourage the healthcare institutions to set up new organisational arrangements geared toward changing consumer demands⁴⁵. However the

⁴⁵ Borst-Eilers, E. (2002). Health Policy in the Netherlands - A Balance between Containment and Expansion. Health and Healthcare in the Netherlands. A Critical Self-assessment of Dutch Experts in Medical and Health Sciences. E. Rooij (van), Kodner L.D, Rijsemus T and S. G. Maarsse, Elsevier Gezondheidszorg: 17-22.

Government tends to restrict its role in the provision of the general healthcare services and gives autonomy to the medical specialists and administrators.

To sum up we can say, that Dutch system of healthcare provision in general and child oncology in particular, provides more freedom for the Medical community for self-regulation. Role of government is restricted and market of healthcare services exists.

2.2.2. General statistic on cancer diseases among children

In general the number of children in the Netherlands is quite stable. While in 1990 there were 3 313 218 children the amount of children in 2006 is just slightly different – 3 384 745. The number of the cases of the first diagnosis of cancer, registered in Paediatric cancer hospitals in 2007, was 530 (children from 0 to 15), plus 70-100 new cases of children 15-18 years old, that are treated in adult hospitals. That brings us to the number 600 – 630 each year⁴⁶.

According to the Centraal Bureau Statistiek (CBS) cancer is the major reason for child mortality in the Netherlands⁴⁷ among children 0-9 years old and second most common reason of death among children 0-15 years old⁴⁸. Unfortunately due to the difference in the statistical formats the data on the number of deaths of children 0-18 is impossible to find. Cancer in 2007 is a reason of 85 child deaths. The most common reason of death among children 0-15 years old in the Netherlands external causes of death (traffic accidents, injury, poisoning, homicide etc). External causes were reason for 105 child mortality in 2007. Second most common reason is cancer or neoplasm. Third most common reason of deaths among children 0-15 years old are diseases of nervous system, they resulted in 59 deaths. The fourth place with a big scale difference is occupied by diseases of blood circulation, which caused 29 mortalities⁴⁹. If we calculate the percentage of deaths from cancer for 100 000 children, we would see that it is just 2,5 deaths per 100 000 children. This number is considerably lower than the one in Russian Federation, where cancer is the cause of 4,7 mortalities among 100 000 children. It is worth mentioning that the child mortality from neoplasm in the Netherlands was constantly decreasing since 1990, from 118 to 85 cases.

According to the medical statistics in the Netherlands like in Russian Federation Leukaemia (blood cancer) and tumours of the central nervous system are the most common types of cancer among children⁵⁰. Leukaemia is responsible for 25% of cancer cases; tumours of the central nervous system (brain) are at the second place and constitute 20% of cases. Third comes lymph node cancer (Hodgkin's lymphoma and non-Hodgkin's lymphoma) with 11% followed by bone tumours 7% of cases and tumours of the soft parts 7%. Wilms-tumour (and other kidney tumours) and neuroblastoma are even less common with 5% each of cancer diagnosis in children below 15 years old. The least common cancer types in the Netherlands are germ cell tumours and retinoblastoma, which are responsible only for 3% of all cases of child cancer each⁵¹. The

⁴⁶ Pieters, P. R. (2009). Interview on child cancer treatment in the Netherlands. Rotterdam.

⁴⁷ The prenatal reasons are excluded

⁴⁸ Numbers provided for 2007.

⁴⁹ General facts about Netherlands (2007). Retrieved May 15, 2009 from CBS official web site. Web site: <http://www.cbs.nl/en-GB/menu/cijfers/default.htm>

⁵⁰ Appendix 1

⁵¹ Kinderen en kanker (2008). Retrieved June 01, 2009 from KWF Kanker official web site. Web site: <http://www.kwfkankerbestrijding.nl/index.jsp?objectid=15837>

statistics in the Netherlands are in line with the world tendencies on the division of cancer cases, which were identified by American Cancer Society⁵².

As we can see the division of mortality reasons in the Netherlands is similar to the one in Russian Federation. However the number of deaths per 100 000 children differs considerably, which underlines the problems of child oncology in Russia.

2.2.3. Main problems of child oncology in the Netherlands

Now let us discuss the situation in the areas, which were shown as problematic in Russian Federation. They were:

1. Problems connected with ineffective organisation of healthcare,
2. Problems, resulting from the lack of funds and medicaments,
3. Problems, resulting from the difference of standards of treatment.

One of the reasons of ineffectiveness of the organisation of child oncology in Russia is the lack of hospitals, which are providing the treatment and their unequal distribution. In the Netherlands right now there are 5 Paediatric Oncology Hospitals (in Groningen, Nijmegen, Rotterdam and 2 in Amsterdam) and 2 Child Centres of Neurogenic Stem Cell Transplantation (in Utrecht and Leiden). The number of oncology cases appearing each year is approximately 530⁵³, it means that annually there is around 100 patients per centre. Taking into consideration the size of the country, the number of centres and their position covers all necessities in the sphere.

The problems with financing the treatment are avoided by the usage of the different system of health insurance, with private insurance companies providing the payment directly to the hospital without involvement of the government. The annual budget per one child with oncology diseases is around 100 thousand Euros⁵⁴, which is totally covered by the insurance.

There is as well the problem of so called "orphan drugs". In the Netherlands there is a list of orphan drugs. These drugs are called "orphan" in Europe in general and in the Netherlands in particular, because the pharmaceutical industry has little interest, under normal market conditions, in developing and marketing products intended for only a small number of patients suffering from very rare conditions⁵⁵. On the European level some steps were taken to improve the situation. In 2000 the EU Orphan regulation was adopted. This regulation sets up the criteria to designate orphan drugs and provides the list of incentives to encourage research and development of the drug intended to treat rare diseases. The steps include such measures as 10-year market exclusivity, protocol assistance, and access to the Centralised Procedure for Marketing Authorisation. However, still some of the effective drugs are not registered in the Netherlands, thus even though doctors know that the drug is effective they cannot prescribe it. But if there is any possibility to buy these drugs, in case they are vitally important and cannot be substituted, the money is provided by the treating hospital⁵⁶.

⁵² American_Cancer_Society (2007). Cancer Facts and Figures. Atlanta, American Cancer Society.

⁵³ Only children from 0 to 15 are treated in the Child Oncology Hospitals

⁵⁴ Only direct costs, excluding the price of the building, electricity e.t.c

⁵⁵ Orphan drugs strategy (2000). Retrieved May 07, 2009 from European Commission official web site. Web site: http://ec.europa.eu/health/ph_threats/non_com/rare_6_en.htm

⁵⁶ Henkel, J. (1999). "Orphan Drug Law Matures into Medical Mainstay." *FDA Consumer magazine* 33(3).

The problem with the inequality in the access to healthcare does not exist in the Netherlands. The country is small enough so every patient can travel to any Oncology centre within 3,5 hours. In most cases the Oncology Centre that is the closest one to the patient's house is selected, however if parents are not satisfied with the treatment in the Centre, the patient can be transported freely to any other. In vast majority of cases the treatment starts to be provided to the young patient within 24 hours after diagnosis was proven. No queues exist in child oncology in the Netherlands unlike the situation in adult oncology.

In the Netherlands the importance of child palliative care is understood. In the country there are 4 hospices that provide care for the children that have no hope for being cured. Right now in the country in general a lot of research is being done on the improvement of the palliative care for the terminally ill. The research and the hospices themselves are funded through several ways: by General practitioners, by the NGOs and by national and international research grants.

Despite the stable situation in the provision of the child cancer treatment in the Netherlands, there is always room for improvement. Right now the survival rate of the children is around 75%⁵⁷, thus more fundamental research is necessary to increase the survival rate and decrease the relevant risk of death for the small patients. The other direction for changes is connected to the cost-effectiveness and cost-efficiency of child oncology. In the Netherlands right now there are 5 Paediatric Oncology Hospitals and 2 Child Centres of Neurogenic Stem Cell Transplantation. In this sphere in the Netherlands there are 330 medical workers involved, including 45 paediatric oncologists, 3 surgeons, 3 neuro-surgeons, and around 280 – 300 nurses⁵⁸. The fact that these specialists are working for different centres results in additional costs. Costs also occur at the phase of learning new procedures and protocols of illness treatment. Cost reduction is one of the main problems right now in the sphere. The plan of the Dutch Child Oncology Group (DCOG) is to unite all Child oncology help in one Centre, which will be either part of the Adult Oncology Centre or a Child University Hospital. More details about the project will be given in the Chapter which deals with beliefs of different actors on child oncology in the Netherlands.

Based on the presented information we can consider Dutch system of child oncology to be more developed than in Russian. The mortality rate is considerably lower than one in Russian Federation. However systems are considerably different in two countries. In the Netherlands more freedom is given to the Medical community and patients are more empowered. Based on this information the research questions will be formulated and the research design will be defined.

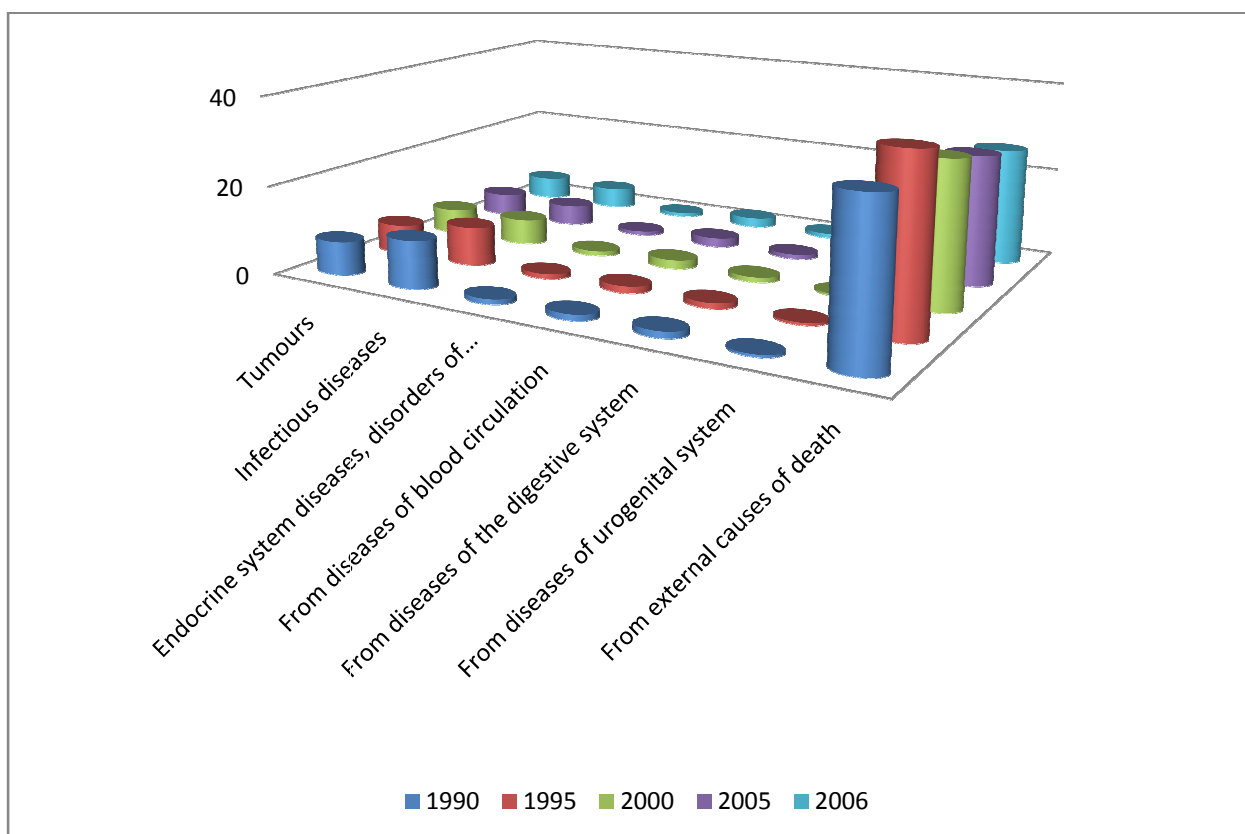
⁵⁷ Pieters, P. R. (2009). Interview on child cancer treatment in the Netherlands. Rotterdam.

⁵⁸ Information provided in Full-time workers

2.3. Problem framework

In the first part of the present chapter it has been found out that in the Russian Federation child cancer is the second most common reason of child mortalities in the country. The researchers observe the constant increase in the number of cases of cancer among children. However, little attention is paid to the problems child oncology. According to the information received from the online governmental and medical resources, child oncology was not included in the National Project Healthcare initiated by the President of the Russian Federation in 2006. Besides, nothing is said about the child cancer treatment improvement in the other National Program Children of Russia, which started in 2007. On the other hand, prophylactics of diseases and preventive medicine in all spheres were called the main priority of the National Project Healthcare. As the result the increase of the salaries of general paediatricians was observed in 2007-2008, while child oncologists lost their federal bonus, which resulted in the loss of 15% of the salary. According to the data presented during the press Conference Problems of Child Oncology, which took place in May 2008, the average salary of child oncologists was 10 000 rouble per month, which is around 300 Euros.

Figure 3. Causes of child mortality in Russia, 1990 – 2006, (www.gks.ru).



We can also find numerous statements about children with cancer in difficult situation because their parents cannot afford treatment and medication, or there are no beds in the cancer centres etc. More than 50 different charity organisations that help to find funds for child cancer treatment exist on the territory of the Russian Federation.

Medical community and representatives of the Federal Authorities in the field of healthcare state that most problems in the child healthcare derive from ineffective planning and little attention, which in turn results in lack of financial funds provided. It is worth mentioning

that the Netherlands spends more money on healthcare in general (percentage of Gross Domestic Product). In 2006 3,6% of GDP were spent in Russia for healthcare and sport facilities, while in the Netherlands 6,1% of GDP was spent. Some additional statistics on the % of GDP spent on the Healthcare in some countries around the world can be found in Appendix 5. As we can see the amount of money spent on the healthcare in Russia is lower than majority of the European countries, excluding the former Soviet republics. The funds spent on the healthcare in general are reflected, and child oncology is among the fields that receive the least attention and thus less funds. However, the budget of the Russian Federation was in surplus last several years, money were put in the Stabilisation Fund and Fund of Future Generations, where it was just stored. Instead money could have been spent on the development of child healthcare in general and child oncology in particular. So the explanation of the present financial situation is not a satisfactory one.

In the Netherlands, child cancer is also on the main child mortality reasons; the percentage of kids dying from it is considerably lower. Child oncology provides treatment which is successful in 70 to 75% of child cancer cases. Little charity is done through direct money transaction for treatment provision.

So the origins of the problems of child oncology in Russia and in the Netherlands are different. While in Russia most problems are connected with the lack of attention paid to child oncology, which results in cuts of federal funds, in the Netherlands community is struggling to make it more cost-efficient and effective. In the Russian Federation it is government's responsibility to plan the healthcare provision for the citizens. Often people not qualified enough are involved in the planning of funds provision for healthcare sphere. This results in the unpredictable and dangerous situation for the patients, delays in treatment, which can lead to lethal consequences. In the Netherlands it is possible to provide care for all children with cancer. But the treatment provided is costly, thus the possibilities to decrease the cost of treatment are being searched for.

If such problematic situation occurs the rational decision-maker would be expected to act in one of the 3 directions: prevention, treatment and facilitation of the negative consequences. In the case of child oncology these 3 fields are: development of the diagnostic methods, improvement of treatment by investing in further research and development of the palliative care for the sick children. Then why so little is done in the field of child oncology in the Russian Federation despite the constant complaints about system ineffectiveness and lack of funds from both medical specialists and patients.

Can the situation be explained through not enough attention paid by the state authorities to the statistical data, or is it the result of the different priority settings by different stakeholders within one system? The reasons for non-acting of the Russian government will be researched upon. It is possible that weak position of some stakeholders and their inability to influence the policy process is described by the cultural beliefs about the system of child healthcare in general and child oncology as part of it. Then the hypothesis that cultural beliefs are influencing the decision-making process in the policy field in Russia will be challenged. To prove that these beliefs differ from system to system the cross-country comparison between Dutch and Russian beliefs will be made.

Chapter 3. Theoretical framework

3.1. Background and research design

The present research will be done from the point of view of interpretative policy analysis. This approach takes into consideration the meanings in public policy, which consist of values, beliefs and feelings the actors have about the policy issue are also shown through the policy artefacts such as language, objects, acts and so on. There is always a difference in the public policy sphere between what actors think, what they say and what they are actually doing. However to understand better the true meanings the issue has for the actors not only beliefs should be observed, but the objects and artefacts as well⁵⁹.

The main focus of the research is the differences in framing of the policy issues by different actors and the possibility that such differences result in problems in implementation of policy decisions. Thus the attention will be drawn to the framing theory and the way agenda setting is connected with the policy implementation artefacts and policy objects.

The research of policy beliefs will be based on the two main theories.

- Cultural theory
- Advocacy coalition framework

These theories will be used to detect the differences in policy approach to the child cancer treatment in different countries and by different stakeholders. First, the central stakeholders in each country will be detected through stakeholder analysis. Then after combination of the theories named above we would be able to detect the prevailing views on the child cancer treatment held by different groups of stakeholders. Based on this analysis we would be able to say how different the Russian vision and the frame used in the Netherlands are. It will be also possible to detect some common features in the frames used by the two parties.

3.2. Framing

The idea of thinking in terms of frames appeared in the field of public policy in 1970s and 1980s. It was used to provide a «discourse» of the public policy analysis. Frames are believed to be different ways of formulating, structuring and viewing the problems by different stakeholders. Frames are tools to construct the boundary around the reality that is viewed similarly by a group of actors or a community⁶⁰.

Frame was defined by Marvin Minsky in 1978 as «a particular way of representing knowledge»⁶¹, later W. Gamson introduced the term «packaging», which defines a special type

⁵⁹ Yanow, D., Ed. (2000). Conducting interpretative policy analysis. Sage University Papers Series on qualitative research methods. Thousand Oaks, CA: Sage.

⁶⁰ Parsons, W. (2002). "From Muddling Through to Muddling Up - Evidence Based Policy Making and the Modernisation of British Government." Public Policy and Administration 17(3): 43-60.

⁶¹ Rein, M., & Schön, D. (1993). Reframing Policy Discourse. In F. Fischer & J. Forester (Eds.), *The Argumentative Turn in Policy Analysis and Planning* (pp. 145-147). Durham: Duke University Press.

of framing – «the process by which a central organizing idea, a frame, is embodied in a policy position that is then expressed through such condensing symbols as metaphors and slogans»⁶².

One of the major works on the topic of reframing in public policy is *Reframing* by Schon and Rein, published in 1993. The idea of rationality was stated there. According to their vision rationality is not the prerogative of the state and experts to decide about what is rational, but government together with «lay» people, who may have different perspective, «frame».

In the works of Baldwin and Kohler it is possible to find the common hypothesis that there were several different frames in healthcare in Europe in general and in child healthcare in particular. They argue that because of the shift of frames the priorities in the national policy-making were changing over time. For example in the book *Disease and democracy* by Baldwin⁶³ provides vision of different approaches to treatment of people with AIDS. The author states that in the beginning HIV positive people were seen by the policy-makers as trouble-makers, representatives of the marginal parts of society that were potentially dangerous for the common wealth. Thus often sick people were forced to receive treatment and the process of treatment could be violating their rights. However, the more the illness spread the more liberal approaches started to be used by policy-makers. More attention started to be paid to the prevention of the illness and making people responsible not only for their own health, but also for the state of health of others⁶⁴. Nowadays, according to Lennart Kohler healthcare is in the stage when preliminary concern is search for new knowledge and reassertion of such principles, that were used in the past, as prevention, protection and promotion⁶⁵. In the work of Baldwin we can find a proof of ability of policy-makers to shape the policy issues.

Gusfield⁶⁶ (Gusfield 1981) was the one who tried to construct the theory that combined the framing of policy problems and the cultural dimension. He provided the structure of policy problems. Using the example of the problem of drunk drivers in the U.S.A. Gusfield showed that each problem can be characterised by the following elements:

- Problem ownership or who is the one defining the problem situation;
- Causality or what causes and consequences of the situation are publicly exposed;
- Accountability or who is the one responsible for solving the problem⁶⁷.

However Gusfield's study can be appreciated for providing concept of the problem, however his work is based on only one real life example: drinking-driving problem in only one of the regions of U.S.A. Sometime after Gusfield's work the cultural theory became popular.

⁶² Rein, M., & Schön, D. (1993). *Reframing Policy Discourse*. In F. Fischer & J. Forester (Eds.), *The Argumentative Turn in Policy Analysis and Planning* (pp. 150-166). Durham: Duke University Press.

⁶³ Baldwin, P. (2005). *Disease and Democracy: the industrialized world faces AIDS*. Berkeley and Los Angeles, University of California Press.

⁶⁴ Ibid.

⁶⁵ Kohler, L. (1998). "Child public health: A new basis for child health workers." *Eur J Public Health* 8(3): 253-255.

⁶⁶ Gusfield, J. (1981). *The Culture of public problems: drinking-driving and the symbolic order*. Chicago and London, The University of Chicago Press.

⁶⁷ Ibid.

3.3. Agenda setting

3.3.1. Cultural theory

Mary Douglas was the one who formulated the cultural theory in 1992. She was developing the theory of risk perception, which is based on the belief that people belonging to some cultures are prepared to take higher risks with their lives and those of others, than in other cultures. M. Douglas explains it not through psychological reasons, but through the influence of the community and the cultural aspects. This was applied in such works as «Risk and blame: Essays in cultural theory» by Mary Douglas⁶⁸ and «The self as risk taker: a cultural theory of contagion in relation to AIDS» by Mary Douglas and Marcel Calvez⁶⁹.

In the work of R. Hoppe⁷⁰ two approaches to cultural theory are mentioned: attitudinal and inclusive. Attitudinal approach sees culture as solely mental product, while inclusive approach precepts culture as combination of types of social relations, cultural bias and behavioural strategy⁷¹. In the present work the inclusive vision of culture will be applied.

In her works Mary Douglas identifies four categories of cultures that can have influence on the policy-making process. They are: Network market, hierarchy, egalitarianism and zero-network. Before moving to the next theory that is going to be used in the present research let us define quickly main features of these cultures.

Network market (Individualists culture) is characterized by high value of functional and strategic rationality combined with many possibilities for negotiation. The structure of systems in such cultures can be described as a strategic alliance emerging around common agendas or mutual advantage, which is acting through collective actions. There is low dependance from the group, members of the culture project institutional domains of the market on the social network relations. Systems in such cultures are not stable structures established by high authorities, but they tend to change according to the needs and demands of the actors⁷². In the system not all stakeholders have valuable resources and thus not all stakeholders have equal power in the decision-making process. In the networking culture, however, the number of actors is not restricted by the access to the political power; there is diversity of participants in the policy-making process. In the Network market independent policy-makers express "concerns" about "threats", which have to be avoided, rather than talk about goals, which need to be reached⁷³. As policy instruments such policy-makers prefer incremental changes.

Hierarchical culture also gives high values to the functional rationality, but also underlines an importance of analytic rationality as well. The structure of systems in such cultures can be described like a well-defined division of power, authority and responsibility among actors, represented by standardized procedures. The advances bureaucracy is of high value as the best way of organizing the processes in the system. The main idea is that division of labour

⁶⁸ Douglas, M. (1994). *Risk and blame: essays in cultural theory*, Routledge.

⁶⁹ Mary Douglas, M. C. (1990). "The self as risk taker: a cultural theory of contagion in relation to AIDS." *The Sociological Review* 38(3): 445-464.

⁷⁰ Hoppe, R. (2002). "Cultures of Public Policy Problems." *Journal of Comparative Policy Analysis* 4: 305-326.

⁷¹ Ibid.

⁷² Aaron, W. (1987). "Choosing Preferences by Constructing Institutions: A Cultural Theory of Preference Formation." *The American Political Science Review* 81(1): 4-21.

⁷³ Hoppe, R. (2002). "Cultures of Public Policy Problems." *Journal of Comparative Policy Analysis* 4: 305-326.

among experts in different fields will produce better results in analyzing situations, in short: all problems should be structured before solutions start to be worked upon. Decision-making process is concentrated at the top of the hierarchy. Policy-makers in such culture prefer to structure any problem by breaking it into solvable pieces. Any problem is visioned more from the interventionist perspective and government is believed to be the one in control over the situation⁷⁴.

Egalitarian culture (Enclavists) states that rationality is a communicative process, i.e. it is a matter of communication and persuasion. The structure of the systems in such culture can be described like an existence through a long-lasting cooperation or\and conflict between two parties: «us» and «them» and equal opportunities and responsibilities of actors within the system. These systems are usually closed ones; all issues are solved by the actors within the system without help from outside. Goals are put for the community and all resources are united in order to reach that goal. Policy issues are framed as problems of redistributive justice and fairness within the group. Policy-makers in such culture prefer to be seen as defenders of the weak.

Last category of cultures is **zero-networking (isolates, fatalists)**. In such culture gambling rationality is used. Actors believe themselves to be outcasts. Systems in such culture simply do not exist due to the belief that any decision-making is senseless and actors are reluctant to impose any definitive framing on a problem. The main goal of supporters of such culture is surviving. There are two main visions of the policy-field by the fatalists:

- either total anarchy and absence of any control, people need to fight for their own survival and nobody is going to help to improve the situation;
- or tyranny in the field. Everything is run by somebody's evil tyrannical will. That is why lay people can do nothing to improve the situation.

To sum up the cultures can be described as conservative hierarchy, egalitarian, competitive individualism and back water isolates or fatalists. According to R. Hoppe the following most can be applied for the cultures. individualists: «Let's make things better», Hierarchists: «Structure it!», enclavists: «It's not fair!», isolates: «Surviving without resistance!»⁷⁵.

After a short description of main cultures proposed by Mary Douglas, it is important to state that it is hard to find pure representatives of these cultures. We can speak about predominance of one culture over the other in the system though.

3.3.2. Model of policy belief systems

For the present work only part of the Advocacy coalition framework, which is connected with the different levels of policy beliefs, is going to be used. All information relevant to the topic would be divided into parts in accordance with its level of generalization: deep core beliefs, policy core beliefs, secondary beliefs.

⁷⁴ Ibid.

⁷⁵ Hoppe, R. (2010). *The Governance of Problems. Puzzling, Powering, and Participation*. Bristol, The Policy Press (in press).

Deep core beliefs involve the most general beliefs about the surrounding world; they reflect the norms and values of the person, group or society in general. Such beliefs tend to be stable and have only incremental changes through time. To change them a considerable internal or external shock is needed⁷⁶. However these deep beliefs may have a strong influence on the type of policy used to tackle certain problems. Despite the fact that core beliefs have strong influence on the choice of the policy actions, they are not going to be studied in this work, because they are general and universal.

Policy core beliefs concern more the values and beliefs of the agents about the policy field. Such beliefs can be called applications of deep core beliefs to the field of action⁷⁷. Such policy beliefs correspond with deep core beliefs; as they are influenced by the latter. Policy core beliefs require considerable efforts and shocks to be changed⁷⁸. Definition of the problem, identification of social groups that welfare is more important, basic choices of instruments can be considered as policy core beliefs⁷⁹(R.Schlaepfer 2001). Combined with public memory they define what kind of policy will be adopted and agreed on. For example, in Baldwin's book *Disease and Democracy*, the difference of policies towards AIDS epidemic depending on the historical background of fighting other epidemics is described because that influenced the policy beliefs of agents in extreme situation of fighting against AIDS⁸⁰. Thus we can see that policy core beliefs are reflection of frames used in policy decision-making. It is also true, that frames and beliefs about the policy issue differ in different social groups and the beliefs of the most influential one are reflected in the national policy.

The third level of generalization is secondary beliefs. These beliefs are narrow and concern administrative rules, budgetary allocations, statutory interpretation and revision, program performance and seriousness of the problem⁸¹. It is argued that all beliefs show decreasing resistance to external changes, secondary beliefs are easier to change than deep core beliefs⁸², thus they become reason of negotiations and objects of political process.

In the present work, policy beliefs on child cancer treatment will be analysed. For the analysis we would use the table which combines different cultural models described by M. Douglas and different levels of policy beliefs. Subdivisions of the policy core beliefs are adopted from the work of Schlaepfer, C. E. R. (2001). "The advocacy coalition framework: application to the policy process for the development of forest certification in Sweden"⁸³". In the article the policy beliefs of coalitions in the sphere of forest legislation are analysed. Schlaepfer distinguishes the following components of core policy beliefs:

⁷⁶ Sabatier, P. A. and C. M. Weible (2007). *The Advocacy Coalition Framework: Innovations and Clarifications*, Westview press.

⁷⁷ Ibid.

⁷⁸ Ibid.

⁷⁹ R.Schlaepfer, C. E. (2001). "The advocacy coalition framework: application to the policy process for the development of forest certification in Sweden." *Journal of European Public Policy* 8(4): 642-661(20).

⁸⁰ Baldwin, P. (2005). *Disease and Democracy: the industrialized world faces AIDS*. Berkley and Los Angeles, University of California Press.

⁸¹ R.Schlaepfer, C. E. (2001). "The advocacy coalition framework: application to the policy process for the development of forest certification in Sweden." *Journal of European Public Policy* 8(4): 642-661(20).

⁸² K"ubler, D. (2001). "Understanding policy change with the advocacy coalition framework: an application to Swiss drug policy." Ibid.: 623-641.

⁸³ Elliott, C. and R. Schlaepfer (2001). "The advocacy coalition framework: application to the policy process for the development of forest certification in Sweden." Ibid.: 642-661(20).

1. Definition of the problem;
2. Identification of social groups whose welfare is most critical;
3. Orientation on substantive policy conflicts;
4. Basic choices concerning policy instruments;
5. Desirability of participation by various segments of society;
6. Ability of society to solve problems in this policy area.

The secondary believes Schlaepfer analyses through comparison of the following points:

1. Decisions concerning administrative rules, budgetary allocations, statutory interpretation and revision;
2. Information concerning programme performance, seriousness of the problem etc.

To conduct the analysis the characteristic features of different cultures should be distinguished. Thus the table will be used. Horizontally different cultures will be presented and vertically the subdivisions of policy core beliefs will be put. On the crossing of cultural system and policy core beliefs sub point the expectations about the situation can be found.

However for the present analysis not all the points defined by Schalaepfer will be used. In the policy core beliefs definition of problem given by different stakeholders will be discussed in the first place. The way the problem is presented by different stakeholders will give us the mapping of the stakeholder groups holding different cultural beliefs. Next, identification of social groups whose welfare is most crucial in the sphere of child healthcare will be done. This will help us to map the priorities both in general child healthcare and child oncology. After that the description of desirable policy instruments will be provided. And the final point of analysis in the policy core beliefs will be desirability of participation of different segments of society as reflection of the limitations on participation of stakeholders.

As a result we can observe the different traits that can possibly be found in different systems of healthcare, depending on the cultural model dominating in the country.

Table 5. Main assumptions about beliefs in different culture (about child cancer treatment)

Policy core beliefs⁸⁴	Network Market	Hierarchy
1. Definition of the problem 2. Identification of social groups whose welfare is most critical 3. Basic choices concerning policy instruments 4. Desirability of participation by various segments of society	1. We need to cooperate in order to make treatment of cancer more effective 2. Representatives of all interest groups, that possess knowledge 3. Preference for incentives and communication tools 4. More public participation is necessary. For example NGOs should have opportunity to advise the decision-makers.	1. We need to make some research in order for government to decide which model of treatment is better 2. Children, because it is their interests that should be protected 3. Preference for more use of regulatory tools 4. Governmental agencies are the ones, who should have final say in what happens in the country, but the public can still be informed
Secondary beliefs		
1. Decisions concerning administrative rules, budgetary allocations, statutory interpretation and revision	1. Legislation should be constantly revised, knowledge is constantly changing, budget – depending on the result	1. Legislation provides adequate basis for healthcare system, budget articles stable

⁸⁴ Ibid.

Policy core beliefs ⁸⁵	Egalitarianism	Zero-Network
<p>1. Definition of the problem</p> <p>2. Identification of social groups whose welfare is most critical</p> <p>3. Basic choices concerning policy instruments</p> <p>4. Desirability of participation by various segments of society</p>	<p>1. We need to modify our system, which is now better than the others in order to increase equality</p> <p>2. All «our» people are equal, equal access for everybody even if we are all equally poor.</p> <p>3. Unite in small local units to solve local problems. Together we can solve it.</p> <p>4. All members of community should participate in reaching effective system, but only those from the community</p>	<p>1. Healthcare is not working, but there is nothing we can do about it</p> <p>2. Only individual, do not care about others</p> <p>3. Nothing, policy cannot solve anything. So people need to try to solve their own problems themselves.</p> <p>4. Everybody that wants can participate, but nobody is interested. People accept their own fate.</p>
Secondary beliefs		
<p>1. Decisions concerning administrative rules, budgetary allocations, statutory interpretation and revision</p>	<p>1. Legislation should first and foremost ensure equal access to healthcare for members of community. Budget should cover inequalities.</p>	<p>1. Legislation is provided by the high authorities. We cannot influence neither it, nor budget.</p>

⁸⁵ Schlaepfer, C. E. R. (2001). "The advocacy coalition framework: application to the policy process for the development of forest certification in Sweden." Journal of European Public Policy 8(4): 642-661(20).

Chapter 4. Policy beliefs about child oncology

A first step towards accomplishing the proposed research would be stakeholders' detection and mapping. This is needed to specify the actors, whose beliefs are actually influencing the situation, but it will also help in empirical detection of patterns of interaction and possibilities for conflicts⁸⁶. «Stakeholder analysis can be defined as an approach for understanding a system by identifying the key actors or stakeholders in the system, and assessing their respective interest in that system⁸⁷».

The changed definition of stakeholders provided by Freeman is going to be the basic one: «A stakeholder in an organization is (by definition) any group or individual who can affect or is affected by the achievement of the organization's objectives»⁸⁸. A stakeholder in policy process is any group or individual who can affect or is affected by the decision-making and policy implementation process.

In the present work the theory presented by Ronald K. Mitchell et.al⁸⁹ will be used to define the main stakeholders in the sphere of child cancer treatment. According to this theory, stakeholders may be categorized by three major attributes:

1. Power to influence the policy process
2. Legitimacy of the stakeholder's relation to the process
3. Urgency of stakeholder's claims

According to the possession of these attributes all stakeholders are divided in 8 categories:

1. Definitive stakeholders – possess all three attributes,
2. Dominant stakeholders – possess power and legitimacy,
3. Dependent stakeholders can be categorized by legitimacy and urgency,
4. Dangerous stakeholders possess power and urgency,
5. Dormant ones have just power,
6. Discretionary stakeholders have only legitimacy,
7. Demanding – only urgency,
8. Non-stakeholders – possess none of the attributes.

Different authors propose different list of stakeholders participating in the policy process in the field of healthcare. However it is agreed that stakeholders can be divided in 2 main groups. Actors involved directly into provision of healthcare which include providers of healthcare and

⁸⁶ Grimble and Wellard 1996; Engel 1997; Röling and Wagemakers 1998

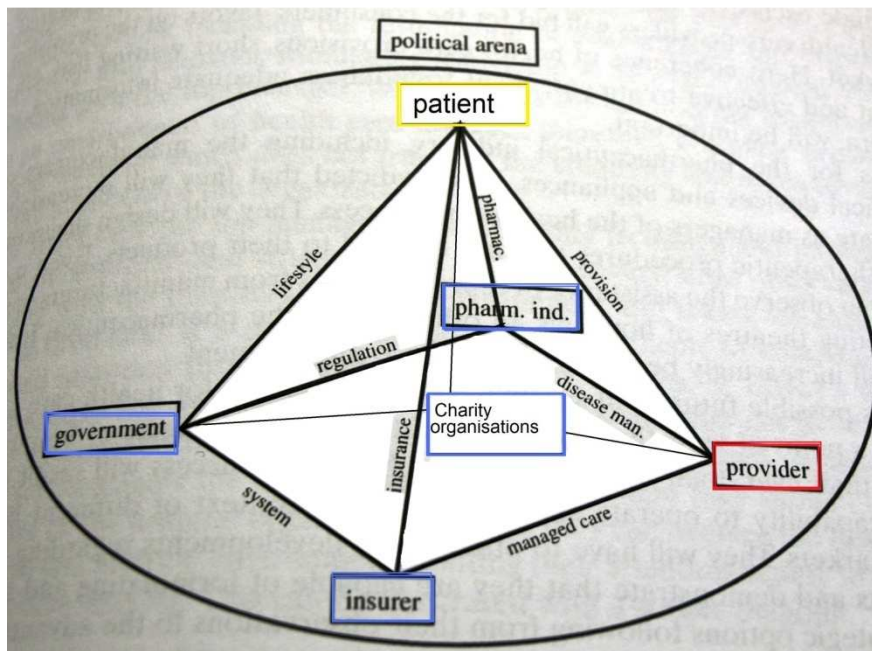
⁸⁷ Grimble et al. 1995, pp. 3–4

⁸⁸ Freeman, R. E. (1984). *Strategic Management: A stakeholder approach*. Boston, Pitman.

⁸⁹ Mitchell, R. K., B. R. Agle, et al. (1997). "Toward a Theory of Stakeholder Identification and Saliency: Defining the Principle of Who and What Really Counts." *The Academy of Management Review* 22(4): 853-886.

patients; and those not involved, which include governmental bodies, charity organisations, insurers and pharmaceuticals. The division can be represented in the following way:

Figure 4. Mapping of main stakeholders in the healthcare, (Gooijer 2007)



The stakeholders in blue frame are the ones united by the group Side organisations. On the basis of this figure the following list can be made:

1. Actors involved directly into provision of healthcare

Providers of healthcare:

- Polyclinics/ primary care institutions;
- Secondary health institutions;
- Doctors and medical staff, professional associations.

Patients:

- Children, parents and parent organisations.

2. Actors not involved directly in service provision⁹⁰ (can be subdivided according to possession of legislative power):

- Insurance companies
- Pharmaceutical companies\ providers of equipment;
- International/national non-profit organisations (incl. charity);
- Governmental bodies.

This general list is going to be modified in accordance with the real-life situation in the exact country.

⁹⁰ Do not provide or receive healthcare services

4.1. Russian Federation

4.1.1. Stakeholder analysis

To begin with the main groups of stakeholders that are connected with the process of policy formulation and implementation in the field of child cancer treatment will be defined.

1. Actors involved directly into provision of healthcare:
 - a. Providers,
 - b. Patients.
2. Side organisations:
 - a. With legislative power,
 - b. Without direct legislative power.

Providers of healthcare in Russian situation will be divided into the 2 levels: the primary level, where cancer is detected, and the secondary level, where the cancer is treated. On the secondary level we should distinguish the Federal and regional hospitals due the different funding system and position in the system⁹¹. Thus we have 3 stakeholders: **primary healthcare institutions for children** (polyclinics), **Federal secondary healthcare institutions for children** (research hospitals, university hospitals) **and general secondary healthcare institutions** (general hospitals that have departments for cancer treatment).

Patients in our case are represented by the **children with cancer and their parents**.

Side organisations can be first divided into 2 main groups: the ones possessing legislative power and the ones without it.

Legislative power in healthcare belongs to governmental organisations. They can be divided into 3 levels: Federal, regional and local. Federal authorities are represented by the **Ministry of healthcare of Russian Federation** and **President of Russian Federation**. Regional authorities are represented by the **Governors of the regions** and **regional departments of healthcare**. Local authorities are represented by the members of **local Administration** responsible for healthcare provision. Due to the fact that national policy on child cancer treatment is the topic of the present research, only Federal authorities will be taken as stakeholders.

Organisations without direct legislative power can be also divided into 2 groups: profit and non-profit organisations. Profit organisations include **private insurers**, **pharmaceuticals** and **private clinics**. Non-profit organisations are the mostly **charity organisations**.

Thus the following list of possible stakeholders involved in the process of healthcare provision for the children with cancer can be formed.

- Providers of healthcare
 - Polyclinics,
 - Research hospitals,
 - General hospitals,
 - Community of Medical doctors in the sphere of oncology.

⁹¹ Federal hospitals are believed to possess more power than the regional ones.

- Receptionists
 - Children with cancer + their parents.
- Side organisations
 - Ministry of Health,
 - President of Russian Federation,
 - Pharmaceuticals,
 - Private insurers,
 - Private clinics,
 - Charity non-profit organisations.

For us the main stakeholders, whose belief systems will be analysed, are going to be only definitive, dominant, dependent and dangerous ones. By power the ability to change situation with healthcare provision is assumed, legitimacy – whether participation in cancer treatment provision is legitimised. Urgency defines whether stakeholder has a need for changes in the system.

Table 6. Stakeholders in System of child healthcare in Russia

Stakeholder	Power	Legitimacy	Urgency	Type of stakeholder
• Providers of healthcare				
○ Polyclinics,	-	-	+/-	Demanding
○ Research hospitals	-	+	+	Dependent
○ General hospitals	-	+	+/-	Dependant/ discretionary
○ Community of Medical doctors in the sphere of oncology	-/+	+	+	Definitive/ Dependent
• Receptionists				
○ Children with cancer + their parents	-/+	+	+	Definitive/ dependant
• Side organisations				
○ Ministry of Health	+	+	-	Dominant
○ President of Russian Federation	+	+	-	Dominant
○ Private clinics	-	-	-	Non-stakeholder
○ Pharmaceuticals	+	-	-	Dormant

○ Private insurers	-	-	-	Non-stakeholder
○ Charity non-profit organisations	+/-	+	+	Definitive/dependant

After stakeholder mapping, we have the final list of the stakeholders, whose belief systems will be analysed:

- Federal authorities (President, Parliament, Ministry of health);
- Medical community (Research Hospitals, community of medical doctors);
- Charity non-profit organisations, children with cancer and their parents⁹².

4.1.2. Policy core beliefs

In this part of the work the core policy beliefs of the key groups of stakeholders identified above will be discussed. The key points that are going to be discussed are the following: definition of the problem, identification of social groups whose welfare is most critical, basic choices concerning policy instruments and desirability of participation by various segments of society.

4.1.2.1. Definition of the problem

In this chapter the frame, through which the situation with child cancer treatment is seen by the different actors in the system of policy formation, will be discussed.

First the definition of the situation given by the **officials** will be identified. In 2006 several Priority National Programs were started by the president of Russian Federation V. Putin and the Government of Russian Federation. One of the national programs was aimed to increase the efficiency and effectiveness of the national system of healthcare and to ensure the development of the new methods of prevention and prophylactics. The Program is targeted also on improvement of quality of healthcare for children. Special parts of the Program designed to fight against AIDS, tuberculosis, infectious diseases. However the child oncology is left aside⁹³. This is also noted by Michail Davidov, the director of N. N. Blokhin Cancer Research Centre of Russian of Academy of Medical Science, during the conference on problems of child oncology in Russia held in Moscow on 15 February 2007. He states that nowadays child oncology is not seen by the authorities as the prior field for actions, though in Russian Federation according to the Federal Centre of Statistics, oncology is the second most common reason of mortality among children after accidents⁹⁴.

The list of priority issues reflected in the Priority National Program shows the priorities in the Russian System of healthcare. The list of possible priorities in the child healthcare is defined by the causes of mortality: external causes, infectious diseases, tumours, blood circulation diseases, endocrine system failures, digestive system failures, urogenital system diseases. If we see the text of the Priority National Program, out of these causes only infectious diseases and external causes of death are mentioned. Thus, we can state that public health issues

⁹² The believes or non-profit organisations are similar to the ones of patients due to the fact that patients and their parents are usually members of such organisations.

⁹³ National Program Healthcare (2006). Retrieved May 15, 2009 from Priority National Projects of Russia Official web site. Web site: <http://national.invur.ru/index.php?id=116>

⁹⁴ Surinov A.E., O.I. Antonova, et al. (2007). Health care in Russia. Moscow, Federal Agency of the Governmental Statistics (RosStat): 355.

are being priorities and attention is mainly paid to the socially important, transmittable diseases. This can be reflection of the cultural frame held by the federal authorities towards the healthcare provision that can be inherited from the healthcare system of the Soviet era.

However the problem is not denied by the representatives of the Federal research universities and institutes. **Medical workers** are searching for any opportunity to manifest the difficult situation with child cancer treatment in Russia. The problem of child oncology is defined in scientific and public articles as the one that should be solved by the government due to the fact that «present system is ineffective»⁹⁵. As it is stated by Michail Davidov, in the current situation the Centre has to take care not only about the research being done and the treatment of young patients, but also providing place for parents to live in, provide food not only for children, but also for those, who are taking care of them. In other words the curing and service functions of the Centre are mixed. Financial funds for all functions are taken from the limited budget provided from the Federal Budget.

Positions of parents and NGOs are close to the position of the representatives of the hospitals. The system is not effective because not all children are receiving the necessary treatment. However the position of parents is more fatalist like. They are assuming that there is nothing that can be done to change the system, thus if you want to survive you need to depend on the other citizens, that may help you in difficult situation. That is why right now on the web-site V-Kontakte (Russian analogue of Hyves) there are so many groups and mailings, asking for help with treatment of cancer⁹⁶.

Now let us summarize the visions of the problem by different stakeholders.

- *Authorities* are denying the importance of the problem. *Nothing more than promises is done in the field by them.* The priority in the sphere of child healthcare can be called public health, incl. infectious diseases and prevention instead of treatment. This is proved by the additional funds issued for these purposes annually in the budget of Russian Federation⁹⁷. Such approach can be explained through path dependency between the healthcare approach in USSR and present Russian vision of role of healthcare system. Among the peculiarities of the Soviet system of healthcare we can name the special attention to preventive medicine and prophylactics of the infectious diseases⁹⁸. The path dependency is also traced through the definition of main problems in Healthcare system in the USSR and in Russian Federation. Rowland and Telyukov in their work point out that Soviet healthcare was plagued by «chronic underfunding, antiquated and deteriorating facilities, inadequate supplies and outmoded equipment, poor morale and few incentives for health care workers, and consumer dissatisfaction⁹⁹», the same is said about the present situation¹⁰⁰. However, government is continuously trying to use their power to prevent issue of ineffective healthcare

⁹⁵ Minkevich, G. (2007). Interview on failures in child healthcare. G. Lyashenko. Moscow, www.gzt.ru: 3.

⁹⁶ This is not typical only for child cancer, but for cancer of all age groups

⁹⁷ Budget of Russian Federation for Healthcare field (2005). Retrieved June 16, 2009 from Budgetary System of Russian Federation official web site. Web site: <http://www.budgetrf.ru/dbfree/VedBudget2003/second.php?action=show&id=1236&forwardto=&maxid=2955>

⁹⁸ Rowland, D. and A. V. Telyukov (1991). "Soviet health care from two perspectives." *Health Aff* **10**(3): 71-86., Schultz, D. S. and M. P. Rafferty (1990). "Soviet health care and perestroika." *Am J Public Health* **80**(2): 193-197.

⁹⁹ Rowland, D. and A. V. Telyukov (1991). "Soviet health care from two perspectives." *Health Aff* **10**(3): 71-86.

¹⁰⁰ Burger, E. J., Jr., M. G. Field, et al. (1998). "From assurance to insurance in Russian health care: the problematic transition." *Am J Public Health* **88**(5): 755-758.

system from appearance on the national policy arena. The vision of problem held by authorities can be characterised as **hierarchic\egalitarian** one. The Government knows better, all citizens are equal for the government.

- Definition of the problem by the *medical community* can be summarized as: *The system of Healthcare in the sphere of child oncology is right now not effective. Government cannot provide necessary finances to provide treatment to all children in need. The changes in system are desirable to increase efficiency, improve communication and task division.* Here we can also find traits of path dependency. Since the USSR era there is common belief that government is responsible to provide all necessary healthcare treatment for free. The new insurance system is not fully understood and accepted by the citizens. By the words of Simon Kordonsky, prof. of Public administration department of the Higher School of Economics, ex-referent of President Putin, this may happen because citizens themselves do not transfer the money to the insurers; this is done without direct citizen participation. Thus, people get an illusion of «free healthcare»¹⁰¹. As the result of this misconception both patients and medical community blame the government and the system. We can observe the demoralisation of the medical community by the government through underpayment. Because of that, medical specialists do not believe themselves to be able to change anything and hope for authorities to solve all problems. This vision can be described as mixture of **Fatalist and Hierarchical** cultures.
- NGOs and parents do believe that the problem exists, however they do not believe that intervention of the authorities can change it. Thus their vision of the problem can be defined as: We need treatment and money for the children. Government should provide it, but it does not, thus we need to help ourselves. We need to raise money for our children. Here the misconception of the problem can be seen. NGOs and parents believe that provision of more funds can solve the problem of ineffective treatment provision in the field of child oncology. However this is a narrow vision of the situation, these stakeholders do not take the problem of medical personal training, research and bureaucratic procedures into consideration. They are holding the same vision as medical community, that government should provide free treatment to all patients. Because the beliefs of patients are similar to ones of the medical community prevailing of **Fatalist and Hierarchical** cultures can be observed.

4.1.2.2. Identification of social groups whose welfare is most critical

In this part of the work social groups whose welfare is most crucial both in system of child healthcare in general and in child oncology in particular will be discussed.

First we will try to identify the priority group in child healthcare according to the point of view of Federal Authorities. Texts of Priority National programs «Health» and «Children of Russia» will be analysed. In the program «Children of Russia» there is a project «Healthy generation» in which problems of child healthcare in Russia are discussed and solutions are proposed. It is important to note, that aims of the projects are, as stated:

1. Prophylactics and reduction of morbidity among children;
2. Reduction of mortality among newborns and mothers;

¹⁰¹ Kordonsky, S. (2007). System of Education and Healthcare in Russian Federation. E. Syurina. Moscow, Not Published.

3. **Preservation of gene-fund of Russian Federation;**
4. Propaganda of healthy lifestyle as prophylactics of illnesses.

The main factors according to which child healthcare status is analysed are:

1. Infant mortality during the first year of life;
2. Mortality of children 0-4 years old;
3. Number of handicapped children at age 0 to 14.

After analysing the aims and events stated in the National project «Healthy generation», it is possible to state that the prioritised group in the sphere of child healthcare is infants 0 – 4 years old and their mothers. However if we want to find out the disease to which the most attention is paid we can name diseases of digestive system and diseases of reproductive organs. These are the ones that according to the concept of the project require additional attention. This however does not fully correspond with the ranks of mortality reasons among children and young adolescents.

For other stakeholders it is hard to define the common priority group, it can be said that for doctors their patients are the most important. The same can be said about the parents. In the NGO sector is very broad, however on the web-site of the Union of Charitable organisations of Russia, the main attention is paid to children with cancer, handicapped and homeless children¹⁰².

After defining the general priority groups in child healthcare, priorities in the field of child oncology will be researched upon. It is common knowledge that the main social group in any intervention in the policy on child cancer treatment would be children that were diagnosed with oncologic diseases. According to the text of the Russian Federal program «Oncology» in the part «Child oncology»¹⁰³ the main aims of the interventions in the sphere of child cancer treatment in Russia are the following: Provision of the federal and regional funding to the system of specialised medical institutions and provision of all the necessary sub institutions with the modern equipment and technological supplies to decrease the mortality rate, decrease the number of people becoming handicapped and to increase the quality of life of the *children and adolescents, sick with oncology diseases*.

Despite the fact, that children and adolescents are considered to be the main social group, whose interests are to be protected in first instance, the group of medical workers, dealing with such children, is also considered as an important one. In the description of the Federal program «Oncology» one of the tasks of the program is to improve the system of education and postgraduate education of the medical personnel, which is working with children and adolescents diagnosed with oncology diseases. This vision is common for all stakeholders.

Representatives of the medical and research community are pointing out the necessity of lowering the level of inequality in the access to the Medicare. The inequality happens due to the size of the country and little number of the institutions professionally dealing with cancer treatment among children.

It is important to note that according to the data collected from the web site of Union of Charitable organisations of Russia, during their history they collected money for 224 children. If all the children are divided into age groups the most help was provided to children 11-15 years old. According to the Federal Bureau of statistics of Russian Federation, the number of cancer cases among children below 14 is twice as big as number of cancer cases among children of 15

¹⁰² Information on Charity projects (2008). Retrieved July 02, 2009 from Union of Charitable Organisations of Russia official web site. Web site: <http://www.sbornet.com/>

¹⁰³ Program ended in 2006 and never was restarted

to 19 years old¹⁰⁴. However no information could be found about division of cases inside these age groups. Thus such division could be either implicit priority in the field of child cancer, or reflection of the actual situation in the field.

Table 7. Division of children benefited from charity since 2005 (<http://www.sbornet.com/>)

Age group	0-5	6-10	11-15	16 and higher
Number of children	65	50	95	14

To sum up it is possible to state that *children and adolescents diagnosed with oncology disease are considered to be the social group whose welfare is most crucial in the field of child oncology*¹⁰⁵. However analysis of the national policy in the field of child healthcare showed that *child oncology is off the list of priorities made by the Federal government*.

4.1.2.3. Basic choices concerning policy instruments

Any government tends to represent all policy issues as structured problems and thus facilitate the task of solving it¹⁰⁶. However, such actions may bring in the mistake of 3rd type: solving the wrong problem. In the case of child oncology Government does not accept the fact that child oncology in Russia is a problem. Thus we can talk about execution of the 2nd and third faces of power connected with non-decision making in the policy field and shaping of the priority list. That why recently a lot is said about child mortality in general and the need for development of more effective system of prophylactic. Government is trying to solve an issue of high number of child deaths by trying to prevent the illnesses without changing the system of treatment provision. Also we can find no specifications on which illnesses actually need to be prevented. In general the whole text of the program on Development of Child healthcare is poorly written with specification of goals, methods to achieve them and steps that are going to be taken to achieve each goal. Some critics point out that the program was written just to justify the budgetary expenditures, not to achieve the results¹⁰⁷.

In the scientific and medical community problems of the Russian system of child oncology healthcare are usually told to be connected to the lack of funds for provision of the modern treatments and medications. As was said by Vladimir Polyakov, the main child oncologist of Russian Federation: "not a single state in the world, even the richest one, does not provide 100% financing of cancer treatment of its citizens, however the money that we receive per one sick child is not enough even for half of the treatment. More intervention of the government is needed"¹⁰⁸. Some representatives of medical specialists note, that they are

¹⁰⁴ In 2006 among children 0-14 were registered 2 470 cancer cases, for group 15-19 only 1 661 cases in the same year.

¹⁰⁵ While World Cancer research centre and American Institute for Cancer research state the necessity of cancer prevention, which brings in the group of healthy children as important social group

¹⁰⁶ Hoppe, R. (1993). Political Judgement and the Policy Cycle: The case of Ethnicity Policy Arguments in the Netherlands. The argumentative turn in Policy Analysis and planning

J. F. Frank Fischer. Durham and London, Duke University press: 77-100.

¹⁰⁷ Roshal, L. (2007). The present state of affairs in child healthcare in Russia. F. P. Chamber. Moscow, Moskva: 30.

¹⁰⁸ Mentkevich, L. D. C. (1997). "Pediatric Hematology/Oncology in Russia." Pediatric Hematology and Oncology 14(2): 103 - 107.

constantly handing in the reports on the problems in the child oncology field, however neither Federal, nor regional governments of the areas, where high-tech centres are situated, are doing anything to improve the financial situation. They note that this situation occurs due to the fact that in the country nobody is responsible for the child oncology on the Federal level. While such diseases as HIV, tuberculosis and some other are being controlled by the special commissions on the Federal level, nothing like that is being done in the sphere of child oncology. This can serve the proof of path dependency in child healthcare from the USSR times, when emphasis was put on the prevention and prophylactics of the transmittable diseases rather than addressing diseases of relatively small group of population.

Michail Davidov, states that the system of the insurance right now is not adequate and too bureaucratic, so he is speaking about turning more towards the USA model of insurance. However, the benefits of such change are more than doubtful. Other analysts see the solution in the increase of the role of government in the Healthcare system, often there are references to the modified Soviet model of the healthcare provision as the most optimal solution for the country with the resource-based economy. They opt for this model because in their opinion state must control the provision of healthcare and secure the access to treatment for all citizens through equal funds redistribution.

So as we can see there is general consent on the fact that some changes are needed in the system of child oncology healthcare, so that more children would have access to the qualified medical help. Within the medical community there is no total consent on the measures that has to be taken in the field. But there is consent that changes of the system executed by the Federal government would improve the situation. Thus we are facing the moderately structured problem with goal consent. **This vision is closer to the Hierarchical culture.**

The NGOs and parents' organisations are not making any official statements about the changes needed in the sphere of child oncology. Both of them mostly manifest the problems of concrete children, not of the system in general. Thus, it is possible to say, that for parents and charity NGOs do not believe in their ability to change the existing system, and thus are trying to change situation locally and prefer charity solutions. **Thus their vision can be described as Fatalist one.**

Now, let us summarise the beliefs of the stakeholders about the instruments that can be used to change current situation with provision of child oncologic help.

- *Authorities* are denying the existence of the problem in the sphere. *The focus is to continue with present policy.*
- *The medical community* states that: *In the sphere of healthcare in Russia the preferred policy instruments are connected with the direct interference of the government and use of regulatory tools.*
- *NGOs and parents* believe that *nobody can help them to change situation, thus it is better to try to survive on their own.*

4.1.2.4. Desirability of participation by various segments of society

Here it is necessary to distinguish the participation in the decision-making process about the possible changes in the system of child oncology and the participation in solving the recent problems of the lack of finances.

In the decision-making process participation of the representatives of the medical field is very much desirable by the representatives of the medical field themselves. However the past experience states, that the projects of changes are being designed on solely governmental level with minimal involvement of the side observers. It is important to add that most managers in the public administration field have the background of engineers or public administrators, which shows the lack of knowledge about the peculiarities of the administration in the sphere of healthcare.

Different situation can be observed in during attempts to find solution for current financial problems. Due to the lack of funds available for the sphere of healthcare, the NGO help and private donations are one of the main sources of the financial and psychological help for the children and their parents. Right now the government provides 109 thousand roubles per child per year which is about 2,5 thousand Euros¹⁰⁹. This amount of money right now is enough just for 2 full courses of chemical therapy with basic drugs, however in some cases, 4 to 8 courses a year is needed¹¹⁰. Thus a lot of charity organisations are helping the children with cancer and their families. One of the most recent examples is the action of Russian Cell phone operator Megafon «Billion in coins» during which the customers of this mobile operator had an opportunity to donate small sums of money to the charity fund just by sending short text messages to the certain number. During the period of 2 years from autumn 2006 till spring 2008 more than 60 million roubles were collected, which makes around 1,4 million Euros. In this respect it is important to note, that private organisations that were donating money for charity had some benefits in taxes only till January 1st, 2002. After abolition of these privileges the amount of charity was constantly decreasing until 2006, which was declared the year of charity in Russian Federation. From 2006 on the charity activity of private organisations was constant and even slightly increasing¹¹¹. Thus we can observe the use of power by Government in addressing problematic issues.

When talking about the influence of the scientists and medical workers on the policy process it is important to mention the Public Chamber of Russian Federation, which was formed in accordance with the Federal Law «On the Public Chamber of Russian Federation» dated 4 April 2005 from number 32. It was designed to enforce the interaction of citizens with government bodies and local self-government in order to accommodate the needs and interests of citizens. The Chamber consists of representatives of different fields: social scientists, medical workers, representatives of Mass Media, actors etc. This is done for better representation of different sectors of life. Experts are giving their opinion about situation in different fields of life thus consulting the Federal authorities on the best solutions in different situations. Right now child cancer is off the agenda; however some steps are done in the field of child healthcare provision in general.

Now let us summarise the beliefs about participation of different segments of society. There is a common consent ***that the decision-making process in the field of public health is closed for participation of the outsiders***¹¹², however in the emergency situation private agents might be invited. Right now there is a tendency of increased influence of the professional experts

¹⁰⁹ Information 10. 2008, course of currency of the following month.

¹¹⁰ The average price of 1 year of cancer treatment according to American Cancer Society is 70 000 Euros, direct costs only.

¹¹¹ Information on Charity projects (2008). Retrieved July 02, 2009 from Union of Charitable Organisations of Russia official web site. Web site: <http://www.sbornet.com/>

¹¹² As we are talking about the National policy, only Federal level is taken into consideration.

through the Federal Public Chamber¹¹³. These beliefs about the level of openness of the system correspond both to the hierarchical and egalitarian cultures. For hierarchists it is common to stick to complex bureaucracies, while egalitarians tend to permit participation in the process for restricted group of like-minded people¹¹⁴.

*Parents and NGOs are proved to possess the fatalist beliefs, as they tend to organise themselves without hope for intervention of the Government. As it is noted by Prof. Hoppe, expression «God is high, and the King is far» best describes the attitude of isolates¹¹⁵. Both parents and NGOs in field of child oncology in Russia lack faith in the governmental actions, thus they prefer to unite together in small group to try to solve their problems alone. Thus we cannot say, that they are possessing solely fatalist beliefs, but the fact that they can unite to solve problems can be indicator of **Networking beliefs** as well.*

4.1.3. Secondary beliefs

In this section the secondary beliefs about the performance of the stakeholders or their vision of policy actions in the field are being analysed.

4.1.3.1. Decisions concerning administrative rules, budgetary allocations, statutory interpretation and revision

Recently there were several legislative acts on the Federal level that have impact on development of the child oncology in Russia. However, neither of them was actually targeting the changes in the child oncology. One of the most important ones was the order of Federal Custom Service issued on 29th of May 2007 that prohibited the export of any human biological probes abroad, for child oncology it meant disability to export the blood samples of children sick with cancer and disability to send bone marrow samples to the international sample banks. After considerable pressure from the medical community, mass media and NGOs the order was cancelled on 21 July 2007, however the difficulties remained. Now to send the biological samples abroad much more documents are needed to prove that these materials are being sent in order to provide treatment for oncology patients.

Federal projects are also worth mentioning. As it was mentioned earlier in the work, two major national projects started in 2006: Health and Children of Russia. However, in neither of them child oncology is mentioned. It resulted in the decrease of salary of medical workers involved in the process of treatment provision and decreasing subsidise for the hospitals, because their some of their federal and regional benefits were cancelled and redistributed to other medical doctors.

Third legislative act was targeted in changes in the legislature on the Non-Governmental organisations. On the 5th of August 2005 the changes were made in the Taxation code of the Russian Federation. The results of this intervention had double meaning for all NGOs in the country. On the one hand the tax on profit of the NGOs was eliminated, but on the other hand the process of procurement of the grants both from national and international organisation became more complicated and unclear.

¹¹³ Description of Federal Public Chamber of Russian Federation (2008), retrieved June 10, 2009 from Federal Chamber of Russian Federation official web site. Web site: <http://www.oprf.ru/> and <http://www.oprf.ru/structure/comissions2008/112>

¹¹⁴ Hoppe, R. (2006). Applied cultural theory: tool for Policy Analysis. *Handbook of Public Policy Analysis: Theory, Politics and Methods*. Frank Fischer, G. Miller and M. S. Sidney. London, CDC Press: 289-308.

¹¹⁵ Hoppe, R. (2002). "Cultures of Public Policy Problems." *Journal of Comparative Policy Analysis* 4: 305-326.

Let us start the analysis of the secondary beliefs about the child oncology with the beliefs of the authorities on the rules, budget allocation and regulations in the sphere of child oncology in Russia. It is hard to find any references to the sphere among the official statements or national programs. Moreover, child oncology was not included into the Federal project «Healthcare», thus the medical doctors and nurses were refused to have the addition to their salary. In 2007 the salary of the nurse in the Federal Oncologic Hospital was just 200 Euros per month. However, in the press there were materials about the construction of the Child Oncology centre in Moscow, which was planned to be one of the biggest in Europe. This news appeared in 2005, by the end of 2008 nothing was done. To sum up the position of *authorities* is: *we are doing everything necessary, money for the field is provided. The rules and regulations are effective, because the contrary is not proven. This approach can be characterised as the one closer to **Hierarchical culture**.*

Now let us analyse the beliefs of the medical community. Previously a lot was said about the lack of funds in the sector. However this is not the only problem that is seen by the medical community in the governmental regulation of the sphere. On many meeting of the medical specialists it is pointed out that in Russia nowadays there is no sufficient statistics on the illnesses. There is no centralised data bank on the sick children, operations made, kind of cancer diagnosed etc. Thus all statistics that is available is gathered from the regional centres, not all of which are actually updating this statistics. This also leads to absence of unified procedures of treatment of cancer and practically isolation of the centres dealing with cancer treatment. Also mechanism of regional quota division, which was introduced in 2008, is still new to most of the regions and it takes time for them to adapt to it. To sum up we can say, that position of the *medical community* can be summarised as following: *further enforcement of cooperation of different hospitals and authorities is needed. The legislation is not effective due to the fact that it does not concentrate on the urgent problems in the field. The regulation can be strengthen by creation of the common data bank on the child oncology from one side, and participation of the medical community in the decision-making process in the sphere. The supposition of importance of joint efforts of medical community and authorities tell us that there are some aspects of **Networking culture** in secondary beliefs of medical community, but the fact that they see government responsible for all changes prove the presence of **Hierarchical** beliefs as well.*

The position of *parents and charity NGOs* is relatively close to the position of the medical community and can be summarised as following: *Maybe legislation in the sphere of child oncology is the best possible, but it is not effective because it is not reaching its major goal, that is to provide treatment to all children sick with cancer. However, we can do nothing to influence it – this is typical reasoning of stakeholders with **Fatalist** beliefs.*

4.2. The Netherlands

4.2.1. Stakeholder analysis

The analysis of the policy beliefs on the child cancer treatment in the Netherlands will start with the stakeholder mapping. First, main subgroups of the stakeholder are identified:

- Providers of healthcare;
- Receptionists;
- Side organisations.

In the Netherlands there are 5 Paediatric Oncology Departments in hospitals: two in Amsterdam, one in Rotterdam, Groningen, Nijmegen; and 2 Child Centres of Neurogenic Stem Cell Transplantation in Utrecht and Leiden. In this network all the medical institutions are working in close collaboration with one another. General paediatricians and workers of the general hospitals are participating only on the diagnosis stage. Usually all diagnostic operations are being made within 24 hours. Thus we are defining only Paediatric oncology hospitals and 2 Child Centres of Neurogenic Stem Cell Transplantation as stakeholders representing the providers of the healthcare.

In the present work we are talking about both children from 0 to 15, residents of the Netherlands and their parents as patients.

Other organisations involved in Child healthcare provision in the Netherlands are divided into the Governmental, private and Non-Governmental organisations. Governmental organisations are having considerably less influence on the process of healthcare provision, due to the private insurance in the country.

Private companies are represented by the pharmaceutical industries and insurance companies. However here we cannot talk about their considerable influence due to their dual cooperation with healthcare providers. By the Dutch legislature no drug can start being used before it is approved for the treatment of children. Hospitals also have power over the industrials. The insurance companies are providing the general insurance plans, which are common for all citizens of the Netherlands.

Non-Governmental organisations, on the contrary have considerable power. Here it is worth mentioning 2 main organisations: Dutch Child Oncology Group (DCOG)¹¹⁶ and Association "Parents, Children and Cancer"¹¹⁷. DCOG is an organisation responsible for the national statistic on cancer cases; it also creates the national protocols on treatment of different types of cancer. Oncology group can be seen as the representative of the Medical community in the present research.

The aims of VOKK are:

- The support and guidance of parents, siblings and grandparents of children with cancer and children with cancer during and after illness and treatment;
- Improving the situation of children and adults with cancer cure children cancer;

¹¹⁶ Stichting Kinderenoncologie Nederland (SKION)

¹¹⁷ Vereniging 'Ouders, Kinderen en Kanker' (VOKK)

- The promotion of the interests of parents, children and ex-patient events;
- Promoting quality of care and scientific research.

This organisation is the biggest in the country and has a control power over the providers of Healthcare and Dutch Child Oncology group.

There is a considerable number of national and international charity organisations in the country. However their influence on the policy formulation is extremely low and their task is more provision help to the hospitals and patients.

Table 7. Stakeholders in System of child healthcare in the Netherlands

Stakeholder	Power	Legitimacy	Urgency	Type of stakeholder
• Providers of healthcare				
○ Paediatricians in general hospitals	-	+	+/-	Discretionary/dependant
○ Paediatric oncology centres and Centres for Neurogenic Stem Cell Transplantation	+	+	+	Definitive
○ Dutch Child Oncology Group (SKIOM/ DCOG)	+	+	+	Definitive
• Patients and patient organisations				
○ Children with cancer + their parents	-/+	+	+	Definitive/dependant
○ Association «Parents, Children and Cancer»	+	+	+	Definitive
• Other organisations				
○ Charity NGOs	-	+	+	Dependant
○ Health Insurance companies	-	+	-	Discretionary
○ Ministry of Health	-/+	+	-	Dormant/discretionary

So after the stakeholders analysis is done, the main groups of stakeholders, whose vision will be analysed, are being formed.

- Healthcare providers (incl. Paediatric Oncology Centres, Centres for Neurogenic Stem Cell transplantation and Dutch Child Oncology Group);
- Children and parents (Incl. Association "Parents, Children and Cancer);
- National Authorities (incl. Ministry of Health).

4.2.2. Policy core beliefs

In this part of the work the main beliefs of the key stakeholder about the situation in child oncology in the Netherlands will be discussed. The key points that are going to be focused on are the following: definition of the problem, identification of social groups whose welfare is most critical, basic choices concerning policy instruments and desirability of participation by various segments of society.

4.2.2.1. Definition of the problem

The information used in this part was gathered during an interview with Prof. Dr. Pieters from the Oncologic department of Sophia Children's Hospital in Rotterdam. Prof. Dr. Pieters is also Chairman of the Supervisory board of the Dutch Childhood Oncology Group (DCOG).

The system of child oncology care in the Netherlands is believed to be effective, due to the fact that survival rate of children with cancer is higher than the one of the adults. However child cancer is relatively rare disease and is responsible only for 1% of all cancers. This is also the reason of the absence of queues both for diagnosis and treatment procedures. In most cases the treatment starts in 24 hours after the cancer is diagnosed.

There are several problems pointed out by the **Medical community**. The treatment is organised in accordance with the national treatment protocols that are adopted by the DCOG. The protocols are prepared by the medical specialists in the exact type of tumour and then verified on the meeting of the oncology specialists. In the process of protocol preparation international experiences, latest publications on the topic and consultation with doctors worldwide are used. Treatment protocols are obligatory for all oncology specialists in the Netherlands. **The problem is that if the protocol changes it takes time for the medical personnel to learn the new procedures that are to be applied.** The research showed that treatment is more effective at the second half of the application period. However, this difficulty is inevitable and can hardly be avoided.

The other problem in child oncology is connected with **the need for cost reduction and the increase of efficiency**. Right now the annual budget for treatment of one child with cancer is 175 000 Euros¹¹⁸. This is both direct and indirect costs of treatment. Annually there are 500 new cases in the Netherlands. This results in 87,5 million Euros only for the new cases, however some children are being treated for several years. It is also worth mentioning that the finances of the hospitals are very closed systems: the money that are reimburses from the insurance companies are going to the general budget of the hospital, so nobody knows for sure how much money is received and what is it spent on.

Representatives of **Medical community** admit that improvements can be made in the system. Special attention should be paid to the research in the sphere of child cancer. Research is one of the main activities of the Dutch Child Oncology Group¹¹⁹. Their position is that child oncologists from different countries should unite their effort in the research of child cancer. We can see that Medical community agrees on the goals of improvement policy, however there is no clear consent on the means, thus they are dealing with a moderately structured problem, with consent on goals. This vision of the policy problems is typical for **Egalitarian or Networking**

¹¹⁸ According to American Cancer Society, the average direct costs for cancer treatment are around \$5 000 per month, that makes \$100 000/ 70 100 Euros per year. However these costs do not include indirect costs such as building, electricity, salaries etc.

¹¹⁹ Main activities of SKION, Retrieved July 02, 2009 from Dutch Child Oncology Group Official web site. Web site :www.skion.nl

cultures¹²⁰. Representatives of Medical community are also searching for the usable knowledge through the scientific network, and medical community sees problems of child oncology as opportunities for improvement¹²¹, which proves the fact that they are also holding beliefs common for **Networking culture**.

Now let us move to the next stakeholder group, **patients and patient organisations**, represented by the Association «Parents, Children and Cancer». As it is reflected on the web-site of the organisation, the system of care and treatment for children with cancer had considerably improved since the organisation was established in 1987: new treatments were invented, new protocols for surgeries adopted. However the organisation is still underlining the urge for "cooperation" in the sphere: parents and children hand in hand, but also parents and doctors hand in hand¹²². The Association "Parents, Children and Cancer" performs an ongoing dialogue with children oncologists, nurses and other professional experts.

Patient organisations admit the seriousness of the problem with child oncology. «During the year two children out of 1 000 get cancer. More children die of cancer than of any other disease¹²³». The **parents' organisation** is promoting the voluntary work and financial aid to the children with cancer and their families. However the parents' organisation is not promoting any changes in the present system, but participation of more people in the voluntary help and assistance. Parents see the problem of child cancer also see the problem as moderately structured with consent on goals. Thus we cannot say that this organisation holds the fatalist views as their Russian colleagues, but the beliefs of the **Networking culture**.

Now let us move to the position of **National Authorities**. Information about it is limited. The Dutch authorities have little influence on the way the treatment in any sphere is provided. The national authorities are excluded from financial relations between insurance companies and hospitals, they have no legislative power on what kind of treatment and how should be provided. Thus National authorities in the Netherlands have mostly control function and influence the process of child cancer treatment by providing funds for the fundamental research for the University hospitals.

Governmental bodies are constantly developing the healthcare legislation. They are ready to give certain autonomy for the medical professionals and they agree with the existence of the NGOs that are facilitating some activities and support the patients' rights. Having accepted the fact, that they do lack professional knowledge to regulate in the field of healthcare, government agreed to let Medical community to govern itself. However to make citizens more secure it decided to give them more participatory rights. We can see strong belief in application of usable knowledge, which is typical for **Networking culture**.

Summary of the beliefs and opinions of stakeholders in the Netherlands show us that in general the point of view of the *medical community* is that *the system of treatment provision we have right now is one of the best ones. However some changes are necessary to make it even better, improved. This is typical for Network culture. However the way the problem is structured is closer to the Hierarchists culture.*

¹²⁰ Hoppe, R. (2006). Applied cultural theory: tool for Policy Analysis. Handbook of Public Policy Analysis: Theory, Politics and Methods. Frank Fischer, G. Miller and M. S. Sidney. London, CDC Press: 289-308.

¹²¹ Ibid.

¹²² Mission of VOKK (2009). Retrieved June 07, 2009 from VOKK official web site. Web site: <http://www.vokk.nl>

¹²³ Elk jaar krijgen twee van de duizend kinderen tot 18 jaar een vorm van kanker. Aan kanker sterven meer kinderen dan aan enige andere ziekte. http://www.vokk.nl/website/ned/u_kunt_helpen/index.html

The vision of the Association «Parents, Children and Cancer» can be identified as: *the system is constantly improving and is effective; however more dialogue among the stakeholders is needed both in the process of treatment provision and in the control over it.* This characterises their beliefs as Networking ones.

The position of the authorities is *to give the hospitals and research centres as much autonomy as possible due to the belief that medical specialists know better how to deal with the situation and how to provide better treatment.* They belong both to Networking cultures.

4.2.2.2. Identification of social groups whose welfare is most critical

In the Netherlands, unlike in Russia, no single direction of the national child healthcare policy could be detected. Children with all illnesses are equally important. It is common knowledge that the aim of any policy connected with treatment of any disease is to cure all possible patients. Thus the main focus is on those, who can benefit from the treatment. In the case of child cancer treatment children diagnosed with cancer are the ones, whose welfare is the most important for all the stakeholders.

Dutch system of healthcare is defined by the high value of equality in access to the Medicare. The Netherlands as the most countries in OECD share 3 main objectives that are to be reached in any developed country. One of them is to provide adequacy and equity of access to healthcare for all citizens, based on solidarity between poor and rich, sick and healthy and young and old¹²⁴. **Thus for the Dutch system of healthcare it is important that all children sick with cancer receive adequate and timely treatment.** Even if it turns out that for some reason a child, who is resident of the Netherlands is not insured, the treatment will still be provided and expenses would be taken care of by the hospital¹²⁵. This is made to be sure that the access to the Healthcare does not depend on the social status or income.

However, the most of the NGOs inc. "Parents, Children and Cancer» (VOKK) are concerned not only about the children with cancer, but also their parents and relatives. At their web site VOKK states that the whole family in the period of illness of the child lives in great uncertainty and is under heavy pressure. Consistent financial implications, problems at work and changing social contacts often result in extra tension. One of the aims of the organisation is to support both children and their parents (and other relatives) during and after treatment¹²⁶.

To sum up we can say that all the stakeholders: *Medical community, parents, NGOs and authorities, agree that it is children who constitute the social group which health is of the most importance. However, NGOs and parents also state, that parents and relatives should supported. In the country there is no single bias of the policy on child healthcare. This is explained by the minimal inclusion of the policy-makers in the healthcare provision. As it was noted in the precious part, self-governance is the characteristics of the **network culture**. On the other hand the whole Dutch system of healthcare is built on the basis of the egalitarian principles of equal access to services. Thus we can say that a mixture of Network and egalitarian cultures is common.*

¹²⁴ OECD (1994). The Reform of Healthcare. A review of 17 OECD Countries. Health Policy Studies O. f. E. C. a. D. (OECD). Paris. 5.

¹²⁵ Pieters, P. R. (2009). Interview on child cancer treatment in the Netherlands. Rotterdam.

¹²⁶ Doelstellingen van de Vereniging 'Ouders, Kinderen en Kanker' (VOKK) (2008), Retrieved June 21, 2009 from VOKK official web site. Web site: http://www.vokk.nl/website/ned/wie_zijn_wij/index.html

4.2.2.3. *Basic choices concerning policy instruments*

In this part of the analysis we will leave out the authorities' point of view due to the fact that they do prefer to give autonomy to the hospitals, thus they do not participate in decision-making process on the changes in the way treatment and care is provided for the children with cancer.

Let us start with the position of the medical community. They agree on the fact that system right now is quite effective, but unlike the medical community of the Russian Federation, they consider further centralisation of healthcare provision the most rational step for improvement of situation. Right now the idea of uniting all the Paediatric oncology departments in hospitals in one Centre is being discussed. According to representatives of medical community this will bring the system of treatment in accordance with the principles set by OECD for its members:

1. Adequacy and equity of access to healthcare for all citizens, to some extent, based on solidarity between poor and rich, sick and healthy and young and old,
2. Macro-economic efficiency, expressed in terms of an acceptable level of spending, as related to national resources,
3. Micro-economic efficiency aiming at the achieving good health outcomes and patient satisfaction at acceptable costs¹²⁷.

The project will considerably decrease the spending on the personnel education and training. Right now the learning curve of the personnel in all 7 institutions is too long, it as well results in 7 times more risks for the patients treated in the centres. It will also facilitate the fundamental research being done in the field due to the fact that all research material will be collected in one place.

When talking about centralization, we need to take into consideration the size of both countries. In the Netherlands time spent to get from any place in the Netherlands to the Child oncology hospital cannot exceed 3,5 hours, while in Russia it can be considerably longer. Instead of task division the Dutch medical community point out the benefits of the unification.

*For the **Dutch medical community** the self-governance of the field by the multi-sphere professionals is the optimal way of regulation in the child oncology treatment provision. The principle that can be seen here is «as little mediators as possible between the patient and treatment provider». This supports the previous tendency of Dutch authorities to hold **networking beliefs** in the field of healthcare.*

For the parents and children there are not preferred instruments, however they would like to have some control over the actions of the medical professionals. This opportunity is provided to them by the authorities through legislation in field of patient rights.

*The **national authorities** are ready to give some room for freedom towards the medical community, because representatives of the medical community have more information about the problem of child cancer. However despite the fact that government is ready to decrease the regulation in the medical field, they are still ensuring that the right of the patients are taken care of. Thus the point of the governmental bodies is: through combination of knowledge of all stakeholders that possess relevant information. This is typical reasoning of actors holding **Networking beliefs**.*

¹²⁷ OECD (1994). The Reform of Healthcare. A review of 17 OECD Countries. Health Policy Studies O. f. E. C. a. D. (OECD). Paris. 5.

4.2.2.5. *Desirability of participation by various segments of society*

In this part as well as in the part connected with the participation of the different stakeholders in the Russian system of child oncology help, we need to distinguish between the participation in the decision-making process about the possible changes in the system of child oncology and the participation in solving the recent problems in the system.

One of the specific features of the Dutch system of healthcare is the consensus nature of the decision making in the field. This is embedded in a long history of the shared responsibilities and discussions among the stakeholders. As the result in most cases such functions as advice, administration, interest representation and control were divided among different institutions. For example, the Council of Public Health and Social Services is specialising in the major health policy topics at the request of the Ministry of Health or Parliament. In the Netherlands the system of Consultative bodies exists. Each body plays one of the following roles:

- Preparatory policy-making;
- Policy development;
- Policy implementation;
- Policy assessment.

This division of responsibility means that the policy-making process in the field of child cancer treatment is executed within the medical community with participation of the governmental agencies and NGOs. The Dutch Childhood Oncology Group (DCOG) plays an important role in the decision-making process. The meetings are held by this organisation during which the national treatment protocols are discussed. However despite the fact that such meetings are held in a democratic way (all present specialists can provide their opinion on the topic) decisions are made by the small group of medical doctors, that specialising in the given illness. Thus in every case there are participants of the meetings that are believed to possess more information about the topic.

All meetings are open for participation for all medical specialists and public. Thus we can say that this situation can be described by the high desirability of participation of the interested stakeholders. But there is a natural information gap, which prevents the high variety of stakeholders from participation. This situation corresponds with the description of the openness of the process in the **Network culture**.

Now let us move towards the desirability of participation of the stakeholders in the administrative organisational issues in the sphere. Aside from Medical community (representatives of the hospitals and research centres), the Dutch Childhood Oncology Group (DCOG) and governmental agencies, the national parent association has a considerable power in the administrative issues. Though it does not influence the decision-making process, it is monitoring the quality of the treatment provision. This organisation can influence the decision-making process by attracting Mass-Media attention to the certain problems in the field.

Despite the fact that a lot of NGOs and individual volunteers are present in the field, their role is more provision of additional help to the patients and their families. Centres are organised to facilitate the life of the families that faced the child oncology illnesses. Such centres provide information about the illness, the treatments available, physiological help and specialties activities for the children, who are staying in the hospitals for a long time.

To sum up, *in the Netherlands we see the open decision-making process which is more common for the Networking process of decision-making. Different stakeholders are given the chance to present their opinion about the organisation of the care. However the decision-making*

process about the different types of treatment used is rather closed ones and has natural limitation due to the specification of knowledge. This view is supported by all the stakeholders.

4.2.3. Secondary beliefs

In this part of the work the secondary beliefs or believes about methods of implementation of policy core beliefs of stakeholders in the Netherlands will be analysed. The empirical information used in this part was received during interviewing and from official legislation, public projects and scientific articles.

4.2.3.1. Decisions concerning administrative rules, budgetary allocations, statutory interpretation and revision

The Dutch legislation in the field of healthcare consists of 5 main topics: health promotion, professions, health insurance, provision of care and patients. Several parts of the legislation correspond to the child cancer treatment. First, it is health promotions as a way to prevent cancer from appearing in children. In this field government is seen as a main regulator, which can influence situation. It can not only promote healthy lifestyle through special projects and programs, but also influence the situation indirectly, for instance, by increasing tax on tobacco. In the field of professional regulation the role of the governmental interference in constantly is decreasing in the Netherlands. Both medical professionals and the government representatives agree that promotion of self-governance is the best way to regulate such areas as protocols, standards and professional ethics¹²⁸. The field of governmental regulation in the health insurance is still the topic of heated political debate. However it is agreed that the rights of the insured should be supported. In the field of provision of healthcare the substantial deregulation is seen. Market forces and laws may totally replace the government interference. Government agrees on this tendency, however only if the rights of the patients are protected and taken care of.

The situation with administrative rules applied to the system of Dutch healthcare in general and the child cancer treatment in particular. It can be summarized as following – *governmental regulation should be used in promotion of healthcare and protection of rights of patients as the most vulnerable group in the healthcare provision relations.*

In general in the system of healthcare the system of budgeting is built by combination of **private and public funding**. The money is being transferred to the hospitals or General practitioners after the patients' referral. Thus we can state the Dutch healthcare system in general and child cancer treatment in particular is applying the result-based budgeting.

To sum up, *Dutch legislation in the sphere of healthcare in general and child cancer treatment in particular is not a stable system, but is a characterised by constant changes and improvements. In some parts of the legislation considerable deregulation is being observed while in the others, that are aimed at protection of rights of vulnerable stakeholders, the regulation is being enforced. The budgeting is being executed through result-based schemes. No considerable system conflicts are observed in the Netherlands. All stakeholders agree on the shared participation in the healthcare provision process. **This proves again that stakeholders in the Netherlands tend to hold more Networking beliefs.***

¹²⁸ Vos, P. (2002). Legislation and Consultative Bodies - Relation between Political and Participative Democracy. Health and Healthcare in the Netherlands. A Critical Self-assessment of Dutch Experts in Medical and Health Sciences. E. Rooij (van), Kodner L.D, Rijsemus T and S. G. Maarssen, Elsevier Gezondheidszorg: 301-309.

Chapter 5. Explanation of the current situation in child oncology in the Russian Federation

To compare the differences in the views on child oncology in Russia and the Netherlands let us first decide which cultural ideas prevail in every group of stakeholders in each country. For this purpose let us construct a scheme with all stakeholders represented and all groups of questions discussed. After all views on different subjects are characterised the calculation will be made to figure out the prevailing ones.

Table 8. The system of policy core beliefs and secondary beliefs about child oncology in the Russian Federation

	Authorities	Medical community	NGOs	Parents and children
Definition of the problem	Hierarchy	Hierarchy	Networking\ Fatalist	Fatalist
Social group of most importance	Egalitarian	Egalitarian	Fatalist	Fatalist
Policy instruments	Hierarchy\ Egalitarian	Hierarchy	Fatalist	
Participation of stakeholders	Hierarchy	Hierarchy	Fatalist/ Networking	
Administrative rules	Hierarchy	Hierarchy/ egalitarianism	Fatalist/Networking	

Table 9. The system of policy core beliefs and secondary beliefs about child oncology in the Netherlands.

	Authorities	Medical community	NGOs, parents and children
Definition of the problem	Networking + Isolates	Hierarchy +Networking	Networking
Social group of most importance	Egalitarian	Egalitarian +Networking	Egalitarian + Networking
Policy instruments	Networking	Networking	Networking
Participation of stakeholders	Networking	Networking	Networking

Administrative rules	Networking	Networking	Networking
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It is reasonable to start the analysis of the presented tables with comparison of attitude towards the problem of child cancer treatment in two countries. In the Netherlands problems in child oncology are believed to be connected with the necessity of cost reduction and increase of efficiency and effectiveness of treatment. Analysis of Table 9 shows us relative consent of all stakeholders about the policy in child oncology field. No specific policy "camps" can be identified. That means that no significant controversies exist in the field of child cancer treatment provision in the Netherlands. One of the latest projects being discussed in the Netherlands is the establishment of the unified Centre for child oncology instead of 5 oncology departments around the country. This became the source of some controversies because none of the hospitals is interested in closure of their child oncology departments, so now there is an ongoing discussion about the place where the centre is going to be situated.

If we analyse Table 8, we can detect three main camps in the field of child oncology policy formulation in Russia. First camp consists of representatives of Medical community that which talk about problems of child oncology, but present it through failure of national government to provide necessary treatment to all children. They see the government as the one, who should solve the present difficult situation, because they believe government to be responsible for all healthcare services provision. This misconception appears because government has ability to distribute and redistribute financial funds. The Federal authorities that make decisions concerning the national policy on child healthcare form the second group of stakeholders. They are believed to have the most policy-making power, however they do not admit the existence of the problem in child oncology in Russia. Last group of actors includes NGOs and patients who manifest the problems of children with cancer in Russia, but believe themselves not to possess enough power to solve the problem in the nation scale, thus their local actions can be best described as struggle for survival. The relations of the stakeholders in field of child oncology are characterised with low level of interaction. Some communication exists between representatives of Medical community, NGOs and patients. On the other hand almost no evidence can be found about the dialogue of the authorities and other stakeholders. All communication between Medical community or patients and authorities can be described as monologue of those in difficult situation. Thus it can be summarised that no consent exists in Russia concerning attitude towards child oncology in Russia, which together with low level of interaction makes any policy-making difficult.

The fact that both supporters of current policy and their formal opponents hold hierarchical views proves the existence of strong federal government dominance in the field of child healthcare. Here it is necessary to give some theoretical explanations. According to the theory reflected in the work of Lukes Power: the Radical view¹²⁹ there are three distinguished dimensions of the power. First dimension sees power as ability to make decisions in the policy sphere. Decision-making is seen as conflict of interests of different actors¹³⁰. Second view sees power in policy field as ability to suppress political decisions, or non-decision-making. Here

¹²⁹ Lukes, S. (2005). *Power: A Radical View*. Basingstoke, Palgrave Macmillan.

¹³⁰ Dahl, R. A. (1961). *Who governs? Democracy and Power in an American City*. New Haven, CT, Yale University Press.

political scientists speak about the control of the authorities over the agenda-setting process. The last third vision of power is exercised through shaping the opinions and views of people. These three visions are seen as three faces of power. While decision-making power can result in the conflict of interests among different groups, non-decision making and control over political agenda limits opportunities for the conflict of interests. Thus, if there are problems in some sphere of life of society, which is denied by the authorities, this situation can be seen as attempt to execute the power over agenda setting by the authorities¹³¹.

Based on the theory developed by S. Lukes we can say that Federal government in Russia possess not only power of decision-making, but also non-decision-making. In other words Federal government has authority to prevent the issue of child oncology from entering policy-making field. Centralisation is strengthened by the resource dependency in the situation of scarcity of resources in the field in general, as well. In the Netherlands, on the contrary, the system is decentralised. The absence of the hierarchical views in beliefs of different stakeholders also brings us to conclusion that government is not seen as the main provider of the healthcare services, but more as one of the observers with mainly control. The role of authorities in the Dutch system of child healthcare is to ensure equal access of all citizens to the best qualified healthcare help. This is one of the major differences between Dutch and Russian systems.

Due to the fact that government in the Netherlands is not considered to be the main responsible for the care provision, other stakeholders participate more in the decision-making process. There is a common consent on the fact that the one, who is specialised in the field and possesses more knowledge should be responsible for care provision. Networking approach gives more freedom for the medical community for self-regulation. Empowerment of the patients, so that they could have some control over healthcare service providers, is also one of the main priorities of Dutch legislation in the field. Several years ago Parent organisation achieved the acceptance of the protocol according to which children can be diagnosed with cancer only in the specialised centres by attracting public attention to the topic. At the present time 99% of the children are diagnosed in the oncology centres.

In Russia there are two areas for actions in the field of child oncology. First one is the area of official policy formulation; here the number of participating stakeholders is limited to the representatives of the Federal and sometimes regional or local authorities. Other stakeholders have right to participate only as advisers, for example the Public Chamber of the Russian Federation. The other area of action is charity; here all stakeholders that can provide any help are welcome to participate. Charity is seen by representatives of NGO and parents as the only way of surviving in difficult situation, as they do not have faith in the authorities anymore. Representatives of the medical community and NGOs state that despite their constant complaints to the federal authorities on poor state of child oncology in Russia, no reply is given to them. For them joining efforts is considered to be the best way out.

Unlike Russian government Dutch one, as it was mentioned above, is executing mainly controlling power. It is making sure, that main principle of equality in access to healthcare for all Dutch citizens is used. It can be noted that both countries according to their legislation support

¹³¹ Amit, R. (2008). "Power: A Pragmatist, Deliberative (and Radical) View*." *Journal of Political Philosophy* 16(3): 272-292.

egalitarian vision of child healthcare provision. However in reality, in Russia the tradeoffs among children with different illnesses are being done. Some diseases are seen as priority ones, while others are being considered to be not equally important. In chapter 4, part 4.2.2.2. the list of the implicit priorities of Russian authorities in the field of child healthcare was discussed. To sum up, we can state that group of children 0-4 years old and their health is a nation-wide priority for policy-makers. If talking about group of priority illnesses, prevention and prophylactics of infectious diseases, diseases of digestive system and diseases of reproductive organs are the one requiring special attention. This set of priorities however does not fully correspond with structure of child mortality in the country. Some comments should be made also about prioritising the age group of 0-4. It is true that infant mortality in Russia is very high, this results in 20,4 deaths per 100 000 children below 1 year old. After 1 year the possibility of death in children drops drastically and is quite stable till the age of 14. The table dealing with frequencies of deaths in different age groups in Russia can be found in Appendix 7.

If we analyse the priority diseases, we can see, that most attention is given to the infectious diseases, which are dangerous for the society due to their transmittable character. Combining this issue with statements on importance of preventive medicine and prophylactics, we can see that government pays attention to mostly socially important diseases. It is possible that diseases of urogenital system are considered important because of the concerns about the future generations and demographic situation in the country¹³².

In the country with dominance of the networking culture the following algorithm of construction of public issue is applicable. After professional research in the field, the issue can be taken up by the mass circulation publications. Such publications if they are frequent and dramatic enough raise public interest, which in turn encourages even more publications. After some time public panic and demand towards the government to do something about the topic forces government to admit the issue as a social/public problems and take some steps to solve it¹³³.

However in Russia this algorithm seems not to work due to several reasons. First, there is hardly any research in the field of organisation and provision of child cancer treatment. All information that is relatively easy accessible (through internet or libraries) is either about methods of treatment or seriously outdated¹³⁴. Thus information on the topic can be found mostly on personal internet blogs or news threads of specialised newspapers, such is MedLinks. This scarcity of accessible information and the fact that it can be found only through special search can be called the second reason for non-appearance of child oncology as policy issue. It is important to note that representatives of federal and regional TV stations pay no attention to the problem, while TV is considered to be the main source of information for most citizens despite fast development of the Internet resources¹³⁵. Third reason can be influence of the government which is trying to attract attention to other issues of child healthcare, such as infectious diseases and necessity of preventive medicine. Forth reason is the high number of social problems in the

¹³² Constant decrease of population can be observed since 1990s.

¹³³ Nelson, B. J. (1984). *Making an issue of child abuse*. Chicago, University of Chicago Press: 169.

¹³⁴ Mentkevich, L. D. C. (1997). "Pediatric Hematology/Oncology in Russia." *Pediatric Hematology and Oncology* **14**(2): 103 - 107.

¹³⁵ Sergeev, M., Influence of Internet may soon become comparable to the influence of the TV (2006). Retrieved August 05, 2009 from Politcom resource website. Web site: <http://www.politcom.ru/2467.html>

country, Compared to closures of main manufacturers in some cities, growth of price level or high crime rate child oncology is not considered by the citizens to be the major issue that should be dealt with¹³⁶. Due to these four major reasons child oncology could not become a public/social problem in Russia.

In the Netherlands because of drastically different economical and political situation in the country, it is easier for issues to enter the policy field. The presence of egalitarian culture in the Netherlands leads to appearance of social problems as the ones that discriminate some social group. In case of child oncology it can be for example group of uninsured children with cancer. In Russia fatalist views held by the patients and their parents together with governmental dominance makes it difficult to change situation in child oncology.

¹³⁶ Kordonsky, S. (2007). System of Education and Healthcare in Russian Federation. E. Syurina. Moscow, Not Published.

Chapter 6. Conclusions and Recommendations

This work discussed the comparative situation in child oncology in between the Russian Federation and the Netherlands. As a result, it was found that the situation for child cancer in Russia is not as stable as in the Netherlands. In Russia, cancer appears to be the second most common reason of child mortality, while in the Netherlands cancer is the major reason for child mortality¹³⁷ among children 0-9 years old and second most common reason of death among children 0-15 years old¹³⁸. However, it was found out that the percentage of children dying from cancer in Russia is considerably higher than that in the Netherlands. The government were therefore expected to act on the problem, however little attention is still paid to the field of child cancer in Russia. The aim of the research was to find out the reasons for such behaviour. The hypothesis was that such lack of attention to the child oncology can be explained through the cultural beliefs of the stakeholders, resulting from the inheritance of the beliefs from the Soviet system of healthcare.

The research found that different cultural beliefs prevail in both countries. In the Netherlands there is a relative consent on holding the Networking beliefs, which are characterised with a high level of interaction among stakeholders, an open system for all who possess usable information, and decentralisation. In the Russian Federation there is no consent, neither in belief systems, nor in definition of the problem. Thus 3 major camps of stakeholders can be detected: Authorities, Medical community, Parents+NGOs. Authorities and the Medical community tend to hold more hierarchical views; however they interpret the situation differently. The medical community defines the system changes as the main options for the improvement of child oncology, while the authorities on the Federal level deny the existence of a problem in general. Parents and NGOs are holding fatalist/isolated points of view. They do not believe in the possibility of positive changes and thus opt for self-organisation and self-support as the best strategy in the fight for survival. Though views held by parents and NGOs can be characterised as mainly isolated/ fatalists ones, the fact that some representatives of this stakeholder group tend to unite in order to solve their problems, shows the presence of the Networking beliefs as well.

After an analysis of the beliefs of the Russian authorities, the list of national priorities in child healthcare was mentioned. However, child cancer was not present there. In the field of child healthcare, attention is mainly focused on prevention and prophylactics of infectious diseases on the national level. On the one hand, prioritising of the preventive medicine is common for most developing healthcare systems. On the other hand, presence of diseases of digestive and reproductive systems among national priorities cannot be explained by going through the developing stage. Taking into consideration the dominance of the hierarchical views held by stakeholders, we can state that due to peculiarities of organisation of child healthcare in Russia, the field of child oncology can hardly be influenced without admittance of the importance of the problem by the federal authorities. The combination of hierarchical and fatalist views, common for the Russian system, makes it impossible for the stakeholders to influence the behaviour of federal authorities, who are believed to be responsible for the healthcare provision. Authorities also possess more power due to their role in the resource redistribution process. In the Netherlands, due to the fact that all stakeholders have relative consent on the Networking

¹³⁷ The prenatal reasons are excluded

¹³⁸ Numbers provided for 2007.

beliefs about child healthcare and child oncology, the system is more flexible. Relative power of stakeholders does not fully depend on the financial resources. All stakeholders with useful knowledge can influence the policy making process.

Based on the analysis of the beliefs systems of the stakeholders in Russia, several possible scenarios for action can be recommended. However, it must be noted that an initiative for actions should come from either parents or NGOs. These groups have similar cultural beliefs about the issue of child oncology and thus possess potential for joining efforts in order to influence policy decisions. This potential can be explained through a high level of urgency for actions from these stakeholders. The current situation shows that independent actions of stakeholders do not have much influence on the general system. Scientific works of the medical specialists are either not published or not taken into consideration by the authorities. Parents and NGOs are struggling to help in some particular cases, but their actions hardly influence the general situation on a national level.

In a situation of non-ability of separate stakeholders to influence policy-making, theory of public policy analysis as well as policy practice indicates coalition strategy as an optimal strategy. Such a strategy will help them to influence the actions of the stakeholders with more power, but less urgency. In the case of child oncology in Russia, parents and NGOs together with representatives of the medical community are stakeholders with high urgency and low power. Federal authorities are representatives of more powerful stakeholders. The best way to make authorities act in the field would be to increase their urgency for changes. This can be done through the increase of public pressure. As it is mentioned by B.I. Page there is usually a relatively strong connection between public opinion and general directions of Governmental policy¹³⁹. However, as it was previously noted, in the Russian situation the algorithm of raising public awareness of the situation is failing. That is why actions targeted to increase public interest in the issue should be made. The aim of any joint actions of the coalition should be to attract attention of the Mass Media: main newspapers and TV stations, to the issue of child oncology in Russia.

Action should be taken by both the scientific field and the field accessible to the general public. To draw attention to the problems of child oncology these problems should be described and compared to the situation in other countries. Next, attention should be drawn to the results of such research, to do so national or international research projects can be organised. As the result of such projects, an international conference could be held. Big events tend to draw the attention of the representatives of Mass Media as well as providing more information for federal authorities.

Advocacy Coalition Framework developed by Paul A. Sabatier, tells that advocacy coalitions of united stakeholders with similar policy core beliefs and secondary beliefs, in the case that where they are also supported by resources, can have an influence on the decisions of sovereigns¹⁴⁰. Sabatier argues that policy coalitions resist changing their policy core beliefs or important parts of secondary beliefs; however they can be convinced to do so by solid empirical

¹³⁹ Page, B. I. and R. Y. Shapiro (1983). "Effects of Public Opinion on Policy." The American Political Science Review **77**(1): 175-190.

¹⁴⁰ Sabatier, P. A. (1987). "Knowledge, Policy-Oriented Learning, and Policy Change: An Advocacy Coalition Framework." Science Communication **8**(4): 649-692.

evidence. If we look at the Russian situation, it is doubtful that bare scientific proof of system inefficiency can make authorities admit there is a problem. However, if this evidence would be supported by the international as well as domestic research and presented by the national medical specialists association, the effect could be multiplied. On the other hand Advocacy Coalition Framework points out that though policy-oriented learning is an important aspect of policy change, it mainly influences the secondary beliefs of stakeholders¹⁴¹. To influence changes in the policy of core beliefs, more factors are needed.

On the other hand the joint efforts of NGOs, parents and child oncologists can result in the establishment of national or international charity events. A good opportunity would be to use the influence of prominent individuals from different fields: art, cinema, literature and politics. However the attractiveness of covering such an event by the Mass Media will also be dependent on the PR strategy adopted.

A third possible direction for actions is connected with enlargement and empowerment of the coalition. This can be done through attracting new members: individuals as well as organisations; and creating strong a network with a high number of communicational ties. One wise move would be attracting representatives of political parties. This can help move the issue to the national political arena.

In the present chapter recommendations for some possible directions for actions were named. However, extra research is needed on the policy on healthcare in Russia in general, due to the lack of information on policy efficiency. More information about resource distribution and redistribution is needed to assess the rationality of priority setting in the country. It may appear that relatively low mortality from the infectious diseases or diseases of digestive and reproductive systems among children results from the governmental actions. And in the absence of such measures the mortality would have been higher than the one from cancer. It may appear as well, that little attention is paid to child healthcare in general compared to the adult healthcare.

To sum up, the possible solution for representatives of parents of sick children, NGOs and medical community in the field of child oncology in Russia is to join the efforts and form policy coalition. Actions should be done both in persuading government that changes in child oncology are vital, and in joining resources to influence situation themselves (through charity actions). It is not guaranteed that Federal government is going to change its priorities, because it might have different line of reasoning in priority setting process. The result of the attraction of international community is not clear; the negative effect from the government is possible. However, the need for actions in the field is obvious and strategy can be shaped according to first actions results.

¹⁴¹ Sabatier, P. A. (1998) "The advocacy coalition framework: revisions and relevance for Europe." *Journal of European Public Policy* **Volume**, 98-130 DOI: 10.1080/13501768880000051

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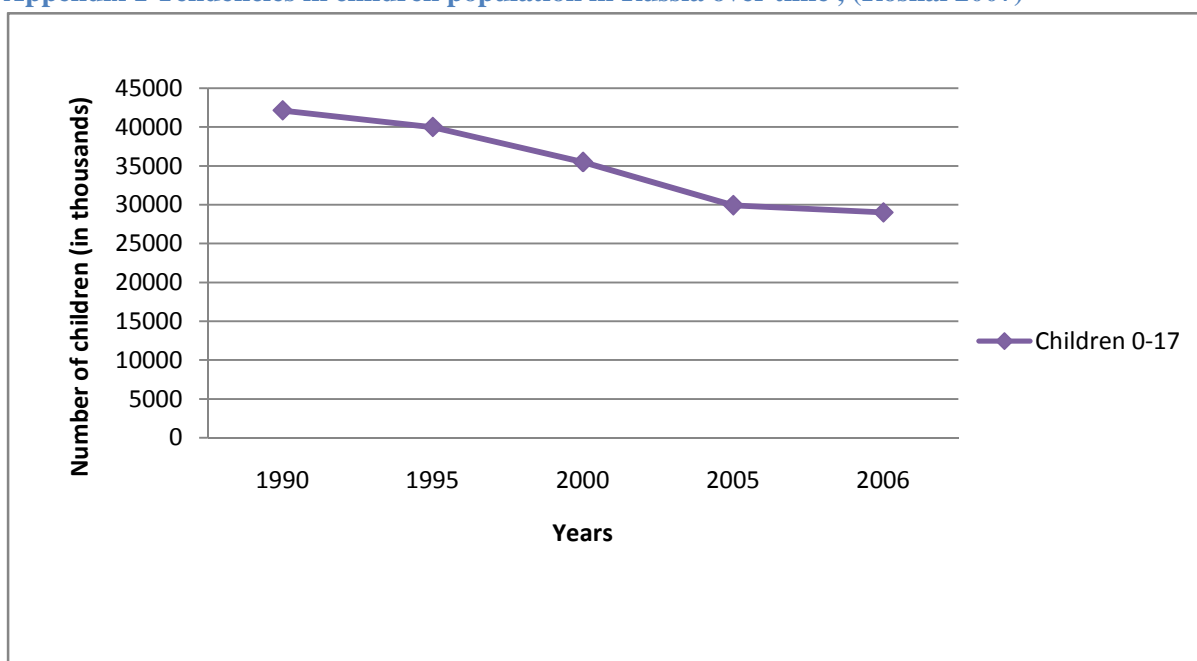
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Appendices

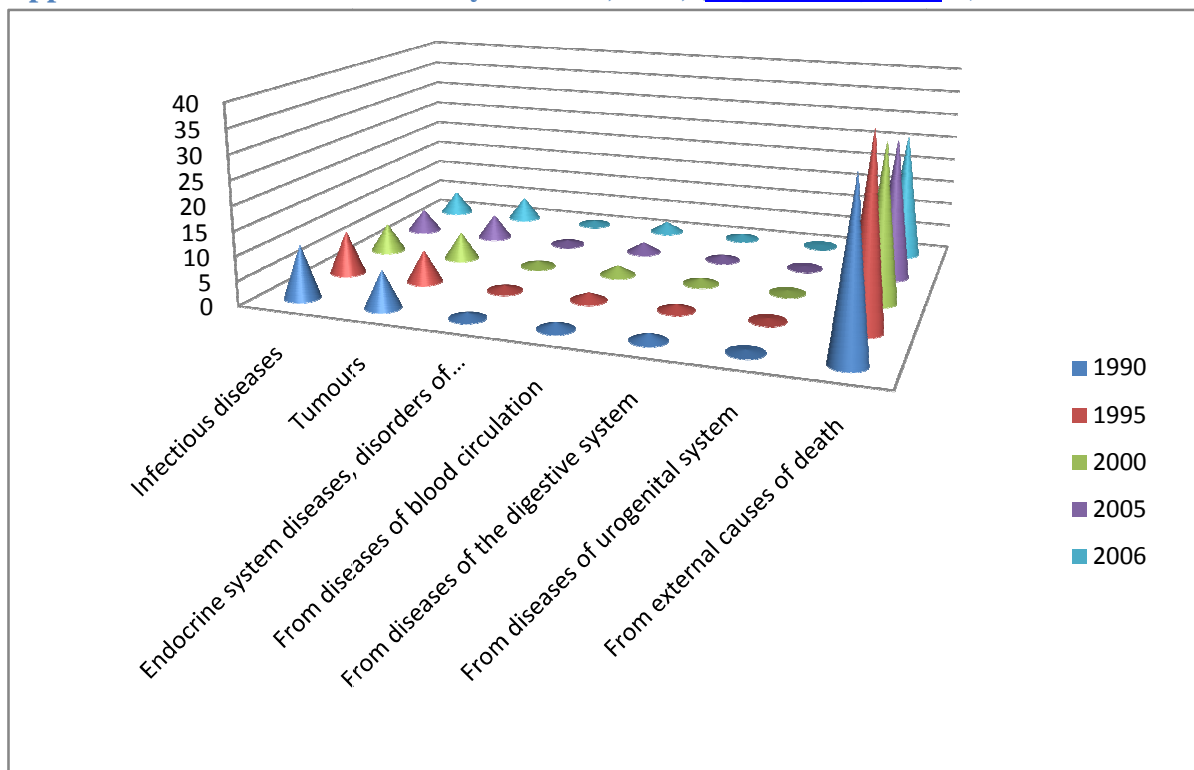
Appendix 1 Tendencies in children population in Russia over time , (Roshal 2007)



Appendix 2 Division of mortality causes among children 0-14 in Russia (per 100 000 children of the age), (www.gks.ru)

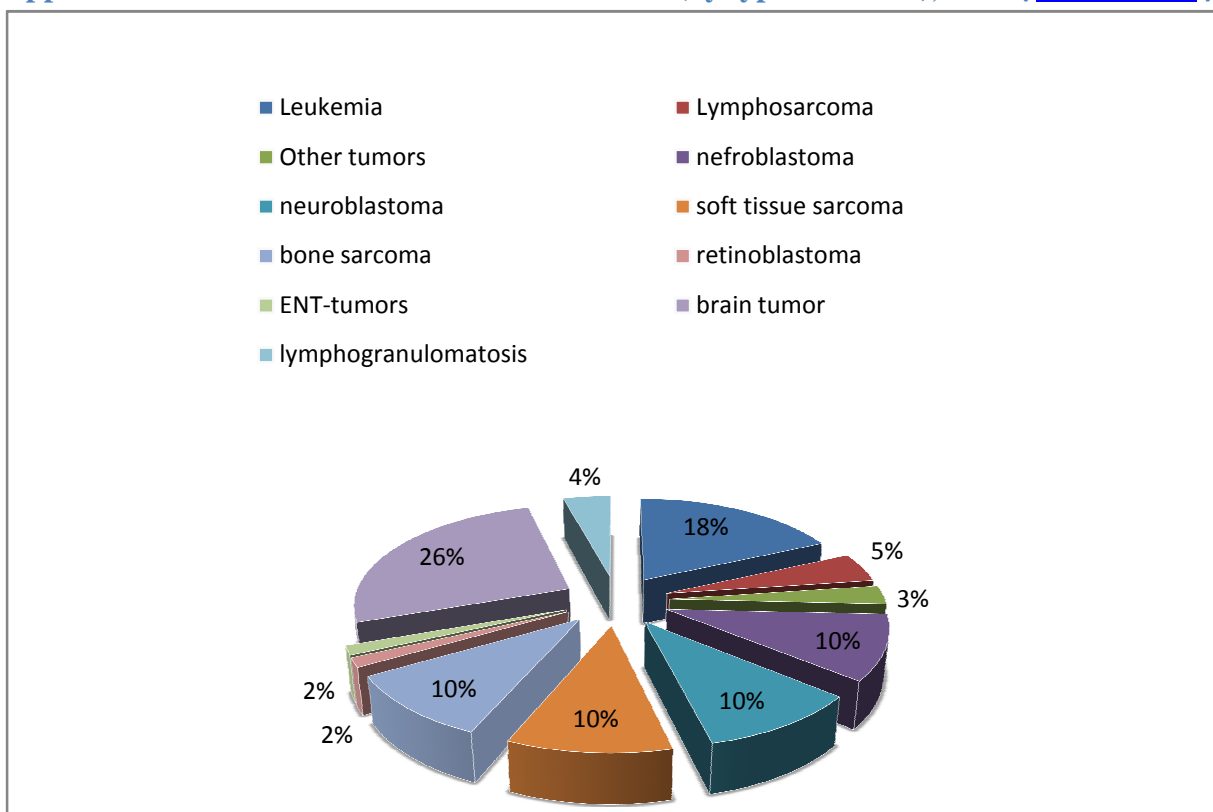
	1990	1995	2000	2005	2006
Total mortalities among children	163,1	142,8	127,8	121,6	114,8
including:					
Infectious diseases	10,7	8,7	5,7	4,5	4,6
Tumours	7,5	6,4	5,5	4,9	4,7
Endocrine system diseases, disorders of nutrition and metabolic disorders	1,1	1	1	0,8	0,8
From diseases of blood circulation	1,3	1,5	1,9	2	2,1
From diseases of the digestive system	1,4	1,2	1,1	1	0,9
From diseases of urogenital system	0,5	0,5	0,4	0,3	0,2
From external causes of death	34,2	38,1	32,2	28,8	26
of which:					
from all kinds of transport accidents	8,6	7,1	6,3	5,9	5,8
from accidental alcohol poisoning	-	0,1	0,1	0,1	0,1
of suicides	0,9	1,4	1,9	1,3	1,3
of homicides	1,1	1,8	2,2	1,7	1,5

Appendix 3 Causes of child mortality in Russia, 2006, (<http://www.gks.ru/>¹⁴²)



¹⁴² Statistics on Children (2006). Retrieved May 07 2009 from The Federal Bureau of Statistics of Russian Federation official web site: <http://www.gks.ru/>

Appendix 4 Child cancer cases division in Russia (by type of cancer), 2005 (www.gks.ru)

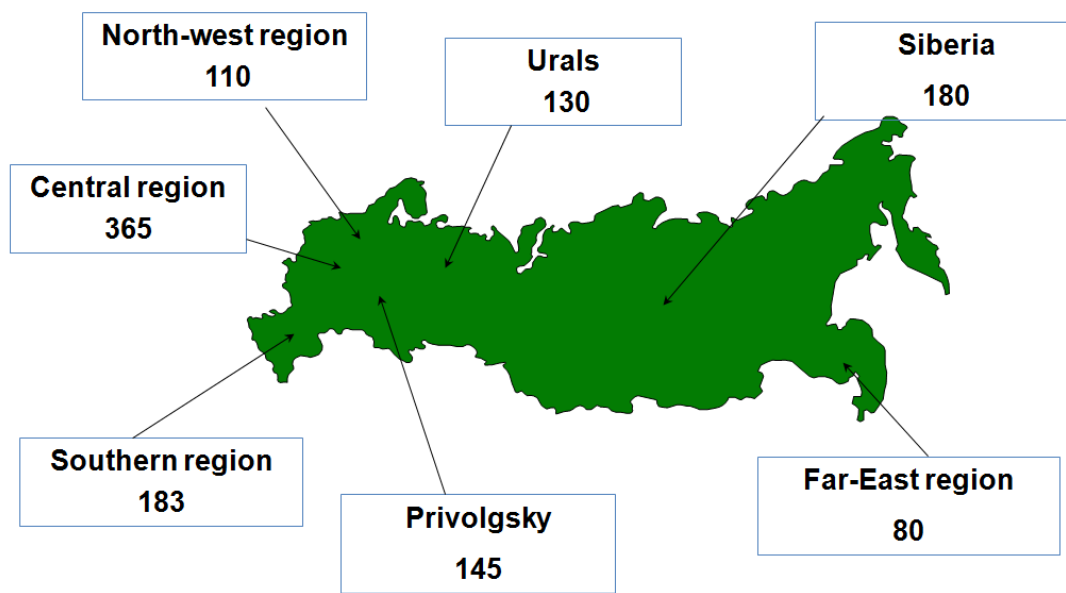


Appendix 5 Expenditures on Healthcare, by country in % of GDP, (Retrieved May 28, 2009 from www.gks.ru)

	Year	% of GDP spent on Healthcare		Year	% of GDP spent on Healthcare
Russia	2006	3,6	Armenia	2006	1,5
Europe			India	2002	1,3
Austria	2003	5,1	Kazakhstan	2006	2,3
Belarus	2006	4,5	Kirgizstan	2006	2,7
Belgium	2003	6,3	China	2003	2,0
Bulgaria	2003	4,1	Republic of Korea	2003	2,8
Hungary	2003	6,1	Tajikistan	2006	1,1
Germany	2003	8,6	Turkey	2003	5,4
Denmark	2003	7,5	Japan	2003	6,4
Italy	2003	6,3	Africa		
Latvia	2003	3,3	Alger	2003	3,3
The Netherlands	2003	6,1	Egypt	2003	2,5

Norway	2003	8,6	Republic of South Africa	2003	3,2
Poland	2003	4,5	America		
Moldova	2006	4,8	Argentina	2003	4,3
Great Britain	2003	6,9	Brazil	2002	3,6
			Canada	2003	6,9
Ukraine	2006	3,7	Mexico	2003	2,9
Estonia	2003	4,1	USA	2003	6,8
Asia					
Azerbaijan	2006	0,9	Australia	2003	6,4

Appendix 6. Amount and position of child oncology beds in different regions in Russian Federation, (Durnov 2003)



Navigation icons: back, forward, search, and refresh.

Appendix 7. The frequency of child mortality by age groups in Russia, cases per 100 000 children (retrieved July 15, 2009 from www.gks.ru)

