

# Project report

## **The heart link**

eHealth contribution to life quality for  
people with cardiovascular diseases in  
North-West Russia

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Summary: This project is supported by the Barents health program / Norwegian Ministry of health and care services. The project focused on prevention of lifestyle and social related health problems and promotion of healthy lifestyle in northern territories. Carrying out preventive training of the population on risk factors of cardiovascular diseases and ways of their correction, could considerably improve the epidemiological situation connected with such illnesses. Project's objective is to create information service for the patients and medical workers of the Arkhangelsk area on prophylaxis and treatment of cardiovascular diseases. The most significant achievement of the project is the development and introduction of the Register of patients with AH into the pilot health institutions. During the project implementation 1000 electronic records of the AH patients were entered into the register database. Register data allow analyzing the situation with AH in Arkhangelsk city and in some rural districts.

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## Preface

*"We had long had a strong desire to change this situation with CVD,  
but now **we know what we will do**"*

Elena Agafonova, July 2008

For many years cardiovascular diseases (CVD) have been the leading reason of death of the population in many economically developed countries, including Russia, making 55-56 % from the general death rate. However during the last 20-30 years in the countries of Western Europe, the USA and Canada there is a constant tendency in decrease of death rate from CVD, in Russia from the middle the eighties this parameter is steadily growing.

In the Arkhangelsk area illness in the system of blood circulation takes the second place in the structure of population morbidity (57,3 %), they are a principal cause of primary physical inability. More than 22 % of the population of the area suffers from these diseases. Moreover this parameter has increased 2,2 times within the last ten years. Growth of death rate from illnesses of the system of blood circulation occurs basically due to losses at able-bodied age. Now increase of morbidity and mortality rate from CVD is one of the major factors of formation of unfavorable demographic situation in the region. Thus, the intense epidemiological situation on the designated problem emphasizes its urgency.

The concept of risk factors has become the scientific concept of prophylaxis of cardiovascular illnesses. The major risk factors are the arterial hypertension (AH), the raised level of cholesterol, smoking, alcohol abuse and overweight.

Since 2003 in the Russian Federation the system of monitoring of the epidemiological situation connected with AH, among the population of 19-64 years has been developed. The Arkhangelsk area takes part in this research, is included 1800 persons. By the results of the first stage of the monitoring which came to an end in 2004, prevalence of AH has made 49 %. 23 % from them did not know about presence of disease, and only 16 % was effectively treated for AH and reached the necessary target levels of the arterial pressure, allowing to lower risk of development of complications (a heart attack of a myocardium, stroke). Many patients with AH had additional risk factors of CVD: obesity - 21 %, the raised level of cholesterol - 30 %, smoking - 26 % of patients. It is proved, that effect from the long moderate decrease in risk factors, including decrease in arterial pressure upon 10 % and decrease in cholesterol in blood of 10 %, leads to decrease in death rate from CVD up to 45 % (*Emberson et al. Eur. Heart J. 2004; 25 : 484-491*). Sociological pool shows that 20% of the population of Russia is seeking information on health of the Internet.

In 2009, the Arkhangelsk region starts implementation of two new major programs of the Russian national projects "Health" aimed at reducing deaths from cardiovascular disease.

Thus, carrying out preventive training of the population on risk factors of CVD and ways of their correction, could considerably improve the epidemiological situation connected with such illnesses.

This project is based on results of the pre-project supported by the Barents Secretariat in 2007. The project Heart link is supported by the Barents health program / Norwegian Ministry of Health and Care services.

## Abbreviations

AH – Arterial hypertension

ARCMP – Arkhangelsk regional Centre for Medical prophylaxis

CHD – Congenital heart disease(s)

CVD – cardiovascular disease(s)

GUCH – growing up with congenital heart failure

MD – medical doctor

NSMU – Northern State Medical University in Arkhangelsk

NST - Norwegian centre for integrated care and telemedicine

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# 1 Project's geographical area

The project's geographical area is Arkhangelsk region, North-West Russia

# 2 Project's target groups

Project's target groups are:

1. People with cardiovascular diseases, especially:
  - a. patients with the most common disease in the world, arterial hypertension (AH);
  - b. children with congenital heart diseases (CHD) which require urgent diagnosis and treatment.
2. Health workers, especially in rural districts / at Primary Healthcare.

# 3 Project's objective

Project's objective is to create information service for the patients and medical workers of the Arkhangelsk area on prophylaxis and treatment of cardiovascular diseases (CVD).  
Project focused on prevention of lifestyle and social related health problems and promotion of healthy lifestyle.

## 3.1 Sub - goals of the project

The sub-goals of the project are:

1. The analysis in the Arkhangelsk area of prevalence of the risk factors causing development of CVD, including congenital.
2. The organization of available information / consultative service for the population of the Arkhangelsk area concerning prophylaxis and treatment of CVD.
3. Creation of an information system for medical workers about modern methods of preventive maintenance and treatment of CVD.
4. Formation of a system of continuous monitoring patients with CVD: CHD and AH.

## 3.2 The projects expected results

- To create a register of patients with CHD and AH for their continuous monitoring.
- To train medical workers in the area of an individual approach to patients with CHD and AH, and methods of diagnostics, treatment and prophylaxis of CVD.
- Training of medical personnel in remote districts working with computers and information technology for the transmission of medical information at a distance
- Improving the delivery of cardiac care to the population
- Development of health care in remote areas.

## 4 Implementation of the project

According to the plan gradual implementation of the project “E-Health” started in June 2008.

### 4.1 Health institutions

Arkhangelsk Regional Health Administration selected medical institutions on the base of which to implement the project. Institutions were selected based on their interest in participating in the project and the availability of staff who could work in the project.

Two hospitals at regional level (a), two hospitals at city level (b) and three hospitals at district level (c) participated in the project in 2008-2009:

- a). Arkhangelsk Regional hospital,  
Arkhangelsk Regional Hospital for children,
- b). Arkhangelsk City hospital №7,  
Severodvinsk city hospital of acute care №2,
- c). Kotlas Central City hospital,  
Velsk central district hospital,

Initially, Kamenka hospital wasn't a part of the project. It was included in the project in the frames of the regional program of the rural health development.

In addition, **the project actively participants** were: Institute for Family medicine, Northern State Medical University (NSMU), especially its head, Professor Vladimir Popov, in development and analysis of questionnaires and register clusters, and Arkhangelsk Clinical Children's Hospital, especially Department for cardiology, in development and work with the register for children with CHD.

### 4.2 Specialists

The project selected the specialists to carry out consultations with the health professionals and cardiac patients:

Leonid Zubov, MD, associate professor of NSMU, senior cardiologist of Arkhangelsk region;

Sergei Martushov, head of the department of hospital therapy at NSMU, professor;

Andrei Agafonov, MD, vascular surgeon;

Konstantin Krivonkin, MD, consultant-cardiologist, associate professor of NSMU;

Vyacheslav Nikulichev, senior narcologist in Arkhangelsk region;

Victoriya Merkulova, specialist on consumption, head of methodological unit of the Center for medical prophylaxis (ARCMP);

Tatiana Tarutina, cardiologist at ARCMP;

Irina Kudryavtseva, internist at ARCMP  
and others.

### 4.3 Seminar for the project leading actors

In July 2008 in Tromsø, Norway, a seminar for the project leading actors was held.

The Russian delegation comprised Elena Agafonova, chief doctor of the Center for medical prophylaxis, Russian project coordinator;  
Leonid Zubov, senior children cardiologist of the region;  
Irina Ivanova, head of the unit of the Center for medical prophylaxis;  
Natalia Bykova, head of the office for medical prophylaxis in Kotlas hospital;  
Yulia Maximova, leader of Arkhangelsk GUCH-patients.



Figure 1: Project actors from Arkhangelsk in Tromsø

The following issues were in the agenda:

1. The use of the internet in health issues;
2. Principles of web-site development, technologies used for effective web-site development and support;
3. Principles of technical tasks formation for the developers of web-sites and registers;
4. Legislative basis:
  - a. medical care and consultations through the internet
  - b. principles of register formation
  - c. patients' personal data protection
5. Issues of safe data storage and exchange in the internet.

During the seminar the participants discussed the plan of the project implementation, made some corrections to the plan, discussed conditions of the contract between «Norwegian centre for integrated care and telemedicine, University hospital North Norway» (NST) and «Arkhangelsk regional center for medical prophylaxis» (ARCMP). Seminar participant were introduced to the activity of Norwegian LHL.

The seminar resulted in the project group establishment; it consists of specialists of ARCMP, leading cardiologists of Arkhangelsk region, Director of the family medicine institute of NSMU, analysts and programmers of the firm «SOFT - M», the leader of the GUCH-group.

The project group's task was to develop the technical assignment and supervise its realization in the following directions:

- a). web-site [www.zdorovie29.ru](http://www.zdorovie29.ru)
- b). Software programs on keeping the register and forms' procession

Project group had regular meetings: 2-3 times a week during all the steps of the program development and introduction.

The knowledge obtained during the study visit to Tromsø let create effective tools for the successful project implementation.

#### 4.4 Web-site «Zdorovie29.ru»

Web-site was set up to inform and consult the population of Arkhangelsk region on the issues of prophylaxis, diagnostics and treatment of the CVD and serves the following tasks:

- 1) To provide the presence of ARCMP in the internet and to give information about the project «Heart link».
- 2) To create an additional channel for the clients' feedback through the internet.
- 3) To provide the clients with information support.

The site has several pages:

«[New accent «Heart link...](#)» about the latest news of the project, here one can find all the list of news;

«[News from the Center](#)» - three latest news, here one can find all the list of news;

«[Tell me, doctor](#)» shows the last three answers to the questions asked in children and adult section. Here one can find the list of all questions and to ask a new one;

«[Medical journal](#)» shows the latest volume of the journal “Your formula of health” and article from this journal;

«[Persons](#)» introduces the staff of the center for medical prophylaxis and the project team;

«[WHO calendar](#)» this module depicts the current month of the year and World days connected with health. One can look through the list of all World health days and their description;

«[Tests](#)» shows three of the most popular tests, gives the chance to try them and to get the result.

Creeping line on the bottom of the site shows «[Center's news](#)».

Thus, the web-site is interesting not only to people with health problems, health professionals but also to those who just think about their health. The web-site is regularly renewed. To increase the number of visits to site <http://zdorovie29.ru>, it was placed in different Internet catalogues and added to searching systems, such as [www.yandex.ru](http://www.yandex.ru), [www.rambler.ru](http://www.rambler.ru).

At the same time the first consultations of clients with the doctors-specialists began, from December 2008, when the site started to function properly, the consultations became regular. The visitors ask questions concerning different medical aspects. **Visitors often find useful information in detailed and qualified answers of the specialists already placed on the site.**

##### 4.4.1 Examples of the questions:

- Tell me how to low diastolic blood pressure? – 161 requests.
- How can I identify that I have high blood pressure? – 106 requests.
- What to do to prevent stroke and infarction? – 107 requests.
- Does headache always accompany high blood pressure – 88 requests.

Questions concerning cardiovascular disease are very popular among the visitors; it proves that this is an acute problem in our region.

## 4.5 Software

### Software products on keeping register and forms procession

The aim of the project «Heart link» was to develop and introduce in pilot health institutions three programs:

Register of patients with congenital heart disease,  
Register of patients with arterial hypertension,  
Questionnaire «System of monitoring of population's life quality and state of health».

For effective solution of this task the project examined existing registers both in Russia: Diabetes register; Asthma register and others; and functioning medical information systems on-going in Arkhangelsk cancer hospital and Arkhangelsk ophthalmological hospital.

## 4.6 Register of patients with arterial hypertension

Register of patients with arterial hypertension (AH) is an automatic information system that allows collecting, storing and analyzing the medical data of AH patients and medical aid provided to these patients in the health institutions.

### 4.6.1 *Aims of AH register*

To form continuing monitoring of the AH patients

To improve the quality of medical aid to AH patients basing on the monitoring of preventive, diagnostic and therapeutic activities

To improve primary medical documents of the AH patient and to provide full and proper registration of the clinical data.

### 4.6.2 *Tasks*

- Established register fulfils definite tasks:
- Collection of the necessary information about the patients and formation of the unified data base.
- To provide continuing monitoring of the AH patients.
- To use the register data base to analyze the situation concerning AH and risk factors for CVD in the region.
- To control the quality of medical aid to AH patients.
- To identify the needs in examination, drug supply to AH patients, needs of the patients in particular groups and the names of the drugs.
- To use the register data to assume the measures on improvement the quality of medical aid to AH patients and correction of cardiovascular risk factors.

- To evaluate the register data in dynamics in each individual case to improve the quality of medical care to a particular patient.
- To use the register data base in the work of schools for patients with AH and analyze the efficiency of their work.
- To form the general report on the base of the register data.

#### 4.6.3 *Information base*

To make up the register map the following documents from the Health ministry in Russia was used:

- 1). Recommendations on prophylaxis, diagnostics and treatment of hypertension, adopted by the law of Russian Health ministry, 24.01.2003;
- 2). Russian recommendations «Prophylaxis, diagnostics and treatment of hypertension» developed by the expert committee of the Russian science society of cardiologists (2008);
- 3). Guidelines on out-patient cardiology and laboratory methods of diagnostics, recommended by Russian health ministry to Primary health care physicians.

#### 4.6.4 *Principles*

For mapping the register and development the computer program to work with the register we used some particular principles:

- To make work with the register comfortable;
- To shorten the time the doctor spends to enter the register data and their search in the medical documentations, to make the process ergonomic;
- Clear and plain statements of register fields on requested data, excluding double interpretation;
- Easiness of entering data into the register using the method of multiple choices;
- Minimum of manual typing of data;
- Entrance of maximum useful information about the patients into sections;
- Possibility of fast making of different reports;
- The base of the register contains different reference materials, e.g. about medicaments;
- It is comfortable to use the register data to analyze the activities on prophylaxis, diagnostics and treatment of hypertension;
- It is comfortable to search the patients' information.

All the entered patients' data are kept in the register data base therefore the loss of the information is excluded.

Register base saves the data about each patient's visit, it lets follow up the patients' situation in dynamics.

It is possible to use the register data of a single health institution to improve their quality of the public health care and to make the necessary reports.

The source of the clinical data for the AH register are standard patients' records. Besides the first patient's visit, the register records all subsequent visits.

#### 4.6.5 Develop map

Develop map of the AH register comprises nine clusters:

- Identification
- Address
- Disability
- Information about illness
- Examination results
- Complications and associate clinical cases
- Treatment
- Withdraw from the register
- Doctor

Developed computer program for the AH register was successfully introduced in the pilot health institutions in Arkhangelsk city and districts, and 1001 patient records were put in the register.

Health institution	Arkhangelsk hospital №7	Kotlas hospital	Severodvinsk city hospital №2	Velsk hospital	Kamenka hospital	Total
Number of entered records	143	236	200	210	212	1001

Table 1: Number of patient records in the AH register per 25.03.09.

The register gives a perfect possibility to work with the database and create the reports. **The register program contains a constructor of reports.** Constructor of reports is able to choose the necessary parameters from all possible ones and organizes them into a table with numerical values and into multidimensional analytical diagrams.

Moreover the register program contains static reports, in advance chosen and fixed combinations of the definite parameters. Besides absolute numerical values of measures the reports have their percentage values as well. Two types of reports in the register program give great possibilities in getting the necessary data and results while working with AH register database.

We have made 120 static reports to use for operative analysis.

#### 4.6.6 Examples of the reports:

- The number of males and females among AH patients, age distribution of AH patients including working and nonworking age,
- Distribution of patients in regards of social status,
- Distribution of patients according to privileged categories,
- Structure of reasons of visits to a doctor,
- Reasons and structure of disability,
- Number of patients with CVD in anamnesis,
- Number of smoking patients,
- Number of patients with diabetes and without tolerance to glucose,
- Number of patients with overweight and obesity,
- Number of patients with high blood cholesterol,
- Number of patients who reached target level of blood pressure,
- Number of strokes and myocardial infarctions,
- Structure of antihypertensive therapy of AH patients

We received above mentioned indicators both in general and in different health institutions.

These reports and the register data base can be used by pilot health institutions and ARCMP to reach the stated goals and aim. Moreover, register's data and reports can be used in the further work of the center for medical prophylaxis to analyze the situation with hypertension in Arkhangelsk and to develop effective prophylactic programs and projects. In the future, AH Register can be introduced in other health institutions of the region.

Percent of males and females with AH in working and nonworking age in pilot health institutions (status per 25.03.09.):

Age	Gender	
	Female	Male
Working	22,3	50
Nonworking	77,7	50

Table 2: Percent of males and females with AH in 5 pilot districts

Structure of the causes of visits to doctor caused AH in districts participated in the Heart link:

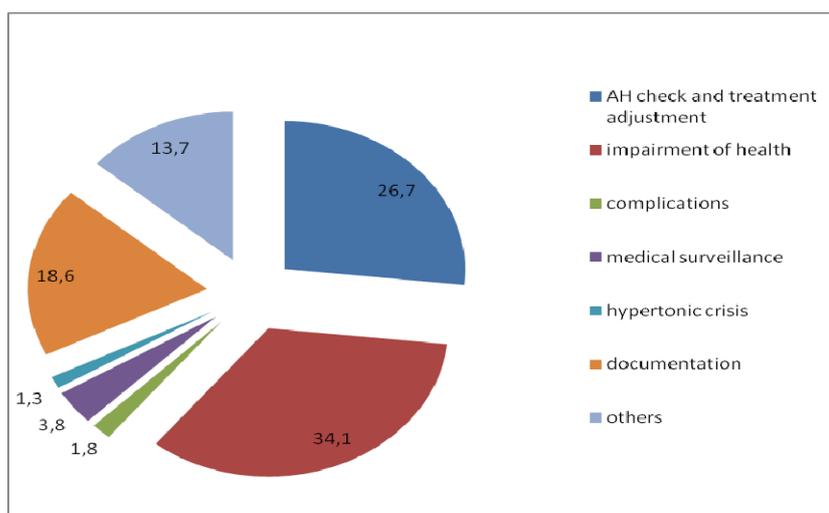


Figure 2: Structure of the causes of visits to doctors in districts (%)

#### 4.6.7 *The following activities*

Specialists of the project group have realized the following activities:

- Development of Register records of the patient with AH
- Development of the computer program of entrance and procession of the AH patients data (software product «Register of patients with AH»)
- Introduction of the soft-ware product «Register of patients with AH» in pilot health institutions and in the ARCMP
- Data of the AH patients have been entered into the register data base in the pilot health institutions
- Computer program «Register of patients with AH» was adapted, i.e. its technical characteristics were worked through and optimized.

Unified data base of the patients with AH was formed in the ARCMP.

Received the first reports about the AH patients both static and made by the report designer.

Doctors got a good experience of working with the register.

#### 4.7 **Register of children with congenital heart disease**

Information about 520 patients with congenital heart disease (CHD), followed up by the Regional children's hospital, was entered into the register. The register gave the possibility to put in order and standardize the information about the children with CHD.

Basing on this information it is easy to:

Select the patients for operative treatment. Annually, in different cardio surgical centers, 150-160 children with CHD are operated;

Control the planning of regular and timely observation of the patients with CHD from different districts of Arkhangelsk region;

Encourage interaction between the doctors of the regional children hospital and cardiologists from the central district hospitals.

**A working place of a cardiologist in the regional children's hospital has become electronic.** Electronic patient's history gives full information about the dynamics of a disease development, helps to control the treatment and plan rehabilitation.

**The scheme of transition of CHD patients from pediatric to adult medical service** was discussed. A selection of articles for the doctors on the issue of medical support of CHD patients throughout their life was made (**6 literature reviews on this topic**). The scheme needs further technical improvement. It allows providing continuity in observation and treatment of CHD patients, gives full information about the dynamics of a disease development from the child to adult age, to plan individual rehabilitation which comprises the activities favorable for the improvement of the patients' quality of life:

- Rational physical load, sport activity;
- Psychological support of the patients;
- Arrangement of medical and social expertise;
- Reproductive possibilities of patients;
- Patients' trips and traveling;
- Diet recommendations;
- Control the CHD patients' quality of life.

## 4.8 System of monitoring of population's life quality and state of health



Figure 3: Prof. Vladimir Popov

While development of the questionnaire risk factors for the CVD were taken into consideration. Professor Popov, Leader for Institute for Family medicine at NSMU took an active part in designing the questionnaire and analyzing the material collected during this work.

The scheme of the program is similar to the previous one. There is a “data base” and a module of reports but there is no module of exchange. The tables include only a “questionnaire register”, in the interface of data entry there is only a “card of questionnaire entry”. They contain more than 500 fields of entry! To enter such a volume of information manually takes much time. In the future we are planning to organize the on-line entry of questionnaire through the web-site of the center for medical prophylaxis.

After being entered, the data is analyzed according to the same scheme and the same instruments as in AH register.

## 4.9 Interaction of the partners in the Heart link project

On October 13-14, 2008 in Arkhangelsk regional center for medical prophylaxis there was a Norwegian-Russian seminar «**Interaction of the partners of the Heart link project**».

36 participants of the seminar included people from the pilot institutions, specialists-consultants, representatives from the firm Soft Master, and patients with CVD. Elena Agafonova, Russian project coordinator, told about the perspective development of the project, and about the activities held in the frames of the project implementation.

One of the important topics was the discussion about the registers of the patients with hypertension and congenital heart disease. Leonid Zubov – MD, senior cardiologist of Arkhangelsk region, Vladimir Popov – Professor, Director of the Family Medicine Institute of NSMU and Tatiana Tarutina – cardiologist at ARCMP prepared the maps of these registers; firm Soft-Master created its software.

It was also decided to carry out from November 1, 2008 the study “Life and health of the population of Arkhangelsk region”.

On the second day of the seminar people responsible for the project implementation in pilot institutions had training on the work with the software «Register of patients with AH».

## 5 Improving and transfer of competence and knowledge

During the whole project the aim has been provided and works to improve the competence of its participants and sharing knowledge between the Russian and Norwegian sides.

### 5.1 Use of the computers and ABC of computer literacy

For the successful project implementation 3 three day courses «**General principles of the use of the computers and ABC of computer literacy**» for the PHC personnel were held. Pilot health institutions organized into three groups were the participants of these courses:

Month	Health institutions	Number of participants
October	Arkhangelsk regional hospital for children Arkhangelsk city hospital №7	17
November	Velsk central district hospital, Kotlas city central hospital	19
December	Severodvinsk city hospital of acute aid №2, Severodvinsk city children's hospital, Kamenka hospital №2 of Mezen district	20

Table 3: Number of participants of data-courses



Figure 4: Data-course

The courses were arranged to those willing to get or improve their knowledge and skills in the work with computers and modern software. These courses are necessary for the further work with the software. Health professionals acquired the knowledge and skills to be able to work with MS Word, MS Excel, Internet and e-mail.

The participants learnt about the resources on medicine found by themselves with the search systems [www.rambler.ru](http://www.rambler.ru); [www.yandex.ru](http://www.yandex.ru), [www.google.ru](http://www.google.ru)

For successful and qualitative support of the register and procession of questionnaires and site management, the majority of pilot health institutions were provided with the PC. The project financed the computers for Arkhangelsk city clinical hospital №7, Kotlas Central City hospital, Severodvinsk city hospital of acute care №2 and Velsk central district hospital.

Arkhangelsk regional children's hospital, Kamenka hospital №2 of Mezen' district and Arkhangelsk regional center for medical prophylaxis bought the computers with their own money.

## 5.2 Videoconference “Actual challenges of the children cardiology”

On January 14, 2009, to develop the project and to attract other potential participants the senior children cardiologist of the Arkhangelsk region Leonid Zubov carried out a video conference “Actual challenges of the children cardiology” with the doctors of the city hospital for children in Mirny.



Figure 5: Dr. Leonid Zubov

Twelve pediatricians of the children’s polyclinic participated in the conference. Based on the examples of some clinical patients they managed to develop tactics of management of the patients with the most complicated heart diseases and algorithm of referral of the patients from the districts for cardiologic treatment.

**28 children with cardiac illness** from the remote district got telemedicine consultations.

## 5.3 Inter-district conference in Kotlas

On January 29, 2009 the project organized an interdistrict conference in Kotlas «**Prophylaxis in the help to patients with cardiovascular diseases**». 113 health professionals from Kotlas and neighboring areas, including the students of Kotlas medical college participated in the conference.



Figure 6: Participants in Kotlas



Figure 7: Professional discussion

Lectures of leading cardiologists of the region: Sergei Martushov, head of the NSMU department of hospital therapy, Professor, and Leonid Zubov, senior cardiologist of Arkhangelsk region, MD,

informed about drug treatment of patients with CVD, early diagnostics of these diseases and interaction between pediatric and adult service in treatment of such kind of patients.

Natalia Bykova, head of Kotlas office for medical prophylaxis, and Vera Sitnikova, head of Kotlas cardiology department, shared their experience on how to work with cardiac patients.

In the interview, conference participants underlined practical significance of the conference.

While being in Kotlas, Sergei Martushov and Leonid Zubov gave **consultations to over 20 cardiac patients**. During the consultations, health personnel of Kotlas hospital were shown to modern methods of diagnostics, treatment and prophylaxis of CVD. *“Our patients are happy: the specialists from Arkhangelsk consulted them”*.

#### 5.4 Actual issues of hypertension prophylaxis and treatment

A videoconference “Actual issues of hypertension prophylaxis and treatment” between Arkhangelsk and Kotlas was held on February 25, 2009.

This conference was carried out thanks to the fruitful joint work of ARCMP, medical prophylactics office in Kotlas city hospital, Arkhangelsk regional center for telemedicine and lectures from NSMU. The conference participants were the instructors of patients’ AH schools and the patients of the departments of internal medicine and cardiology at the Arkhangelsk regional hospital.

Professor of NSMU Sergey Martyushov delivered a very interesting and informative lecture. In accessible for the patients manner professor Martyushov told about the risk factors of AH, its complications such as myocardial infarct and stroke, about self-help at hypertensive crisis, drug and non-drug methods of AH treatment.



Figure 8: Professor Sergey Martyushov

After the lecture the audience asked some more questions on hypertension and its treatment. Such a dialogue between the patients and the doctors became possible due to the modern technologies of the telemedicine.

Conference participants received informational materials about AH prophylaxis and treatment. At the end of the conference the participants were questioned:

- a) Evaluate the conference, please.
- b) Have you got useful information about strengthening and preservation of your health?
- c) Do you like the form of the conference?

59 people took part in questioning, among them 16 health professionals and 43 patients.

37% answered that they liked the conference very much, 63% of participants liked the conference in general.

57% acquired useful information, 40% got some useful information, for 3% all the information was known before.

92% liked the form of the conference, 6% liked it partly, 2% found difficulty in replying.

Nevertheless the majority of the participants liked the conference and stated that they had gained new information about their health. Another important point here is that all the participants were satisfied with the form of the conference.

## 5.5 Organization of the information service for patients and health professionals

On March 25 2009, at the international conference "Organization of the information service for the patients and health professional of the Arkhangelsk region with the focus on prophylaxis and treatment of cardio-vascular diseases", the results of "The heart link" were summed up and its perspectives were defined.

98 health professionals from many districts in Arkhangelsk region took part in the conference.



Figure 9: Conference participants

Within the frames of the project a scaled social study about the life quality of AH patients was carried out. 600 patients were questioned. Here are some of the results:

- Relatives of every second patient have hypertension; every third has a sudden death or stroke in the family history.
- 39% of respondents regularly take medicine to norm arterial pressure, 43% sometimes take pain killers.
- During the last year, 37% spent less than one thousand rubles' on health services, 24% didn't buy recommended drugs, 26% of them because of high price. 51% of respondents refused medical assistants several times.
- In the food of the patients flour products prevail; they lack fiber, fruit and vegetables. Every day 33% of respondents eat meat, 31% - potato, 28% - porridge, 25% dairy products. There was detected insufficient amount of fruit and vegetables in respondents' nutrition, only 10% of respondents eat fresh vegetables and fruit every day.

- 18% are smokers, 57,5% never smoked, 42% were affected by tobacco smoke in childhood or live together with a smoker.

During the project implementation, the specialists of the Arkhangelsk regional children's hospital headed by Leonid Zubov developed and introduced the Register of children with CHD in their hospital.

The development of the Register of patients with AH and introduction into the pilot health institutions has become the most significant achievement of the project. During the project implementation 1000 electronic records of the AH patients were entered into the register database. Register data allow analyzing the situation with hypertension in Arkhangelsk city and in the districts.

The "Heart Link" project created a website about health issues [www.zdorovie29.ru](http://www.zdorovie29.ru). It contains the information about different health topics both for children and grown-ups. Special attention is paid to CVD. Every day there are doctors on duty in the website, they are cardiologists, psychotherapists, Physician narcologist, experts in nutrition, pediatricians and internists.

**Many thousand people** visited the site for the less than half a year it operated. 40% were from the Arkhangelsk region, 22% were from Moscow, 5% were from St. Petersburg. The web-page «Tell me, doctor!» caused a great interest among patients and health workers. The number of visits is **more than 3 000**. For the patients it is possible to stay at home and get a quick answer to their question about health. The doctors can quickly help patients by giving them a comprehensive answer. It is also a new and unique experience in gaining a new method of communication and consulting through the internet.

The second part of the conference started with the performance of a pupils' team from Arkhangelsk secondary school nr. 43, the winner of the Second regional contest 2008 «Make your own decision!».

The conference continued with the presentations from the pilot health institutions. Sergey Burlyai, an internist from Kamenka hospital № 2 told about his experience of the work with AH patients' register in the remote area. Natalia Bykova, the head of the office for medical prophylaxis in Kotlas city hospital, shared her impressions of being involved in the project and expressed her strong wish to continue the project "Heart link".

Yulia Maximova, the leader of Arkhangelsk GUCH patients, told about perspectives and plans to establish a NGO of GUCH patients in the region. It can be done in the frames of the Norwegian-Russian GUCH project. Arkhangelsk city, Kotlas and Velsk districts are going to be pilot areas. In the final part of the conference the Norwegian partners gave their presentations.

Sociologist Halgeir Holthe spoke about information systems and their importance in the modern health care sector. Rita Roaldsen from LHL Region Nord spoke about the plans of the GUCH project for 2009 and its correlation with the "Heart link" project. The project leader Svetlana M. Bye summarized the conference results and told about the plans on the project continuation, particularly about the further introduction of electronic solutions to increase the patients' and medical professionals' awareness in order to improve the treatment and prophylaxis of CVD.

## 6 The project`s results

This project has helped the population in the Arkhangelsk region to draw more attention to risk factors for CVD. Particular risk factors those are present in everyday life, and which can be partly combated by changing habits.

Health workers in the pilot districts received information, sometimes quite unexpected, about the prevalence of these risk factors. This information becomes a tool to change their approach to treatment of such patients. Medical staff in remote areas gets an opportunity to update professional knowledge, regardless of distance to regional health institutions.

The meeting in Tromsø, Norway, in July 2008 gave the working group the possibility to get a lot of information in the sphere of IT, legislative literacy. This knowledge was very useful for the project`s success.

The most significant achievement of the project is the development and introduction of the Register of patients with AH into the pilot health institutions. During the project implementation 1000 electronic records of the AH patients were entered into the register database. Register data allow analyzing the situation with AH in Arkhangelsk city and in some rural districts.

“The heart link” has shown that many patients do not pay due attention to the anti-risk factors and the importance of ongoing treatment of the disease. 1001 patients with AH from 5 pilot districts participated in the pilot project. 525 people responded the questionnaire «*Quality of life and Population state of health*». Most of them, 65 %, assess their quality of life as mediocre. Only 17% respondents felt their quality of life was good and excellent. However, in their view, their participation in the pilot project had challenged their view on the disease and attitude towards treatment and the work of medical staff. It gives hope for more attention to health and especially to own risk factors.

During the project implementation the specialists of the Arkhangelsk regional children`s hospital headed by Leonid Zubov, developed and introduced the Register of children with congenital heart disease in their hospital. Information about 520 patients with CHD was entered into the CHD register. The register made it possible to put in order and standardize the information about the children with CHD. A work place of a cardiologist in the Regional clinical hospital for children has become electronic.

The “Heart Link” created a website about health issues [www.zdorovie29.ru](http://www.zdorovie29.ru). It contains the information about different health topics for both children and grown-ups. Every day there are doctors on duty in the website, they are cardiologists, psychotherapists, Physician narcologist, expert in nutrition, pediatricians and internists. The questions patients asked were not so easy. **More than 3 000 people** visited the site for less than half a year of its work. There are people from many regions in Russia, incl. regions in Far East, and people from 13 countries abroad. This website is an additional channel for communication between patients and health workers.

### 6.1 Knowledge by health care workers

The most important result, however, is how the introduction of electronic media had an impact on knowledge and self-reliance by health care workers, particularly in remote areas.

Elena Agafonova, the Russian project coordinator, said after the first project meeting in Tromsø in 2008: “We had long had a strong desire to change this situation with CVD, but now **we know what we will do**”.

The conference in Kotlas caused great interest, we were happy that the amount of participants was beyond our expectations. Conference participants were impressed with the information they got. Thanks to project leading specialists in children and adult cardiology came to the remote area and consulted over 20 patients (initially we planned only 6 patients).

After the videoconference “Actual issues of hypertension prophylaxis and treatment” between Arkhangelsk and Kotlas in February 2009, 16 health professionals and 43 patients had answered the questions about the conference and their satisfaction: 37% liked the conference very much, 63% of participants liked the conference in general. 57% acquired useful information, 40% got some useful information. 92% liked the form of the conference. Natalia Bykova: *“All stressed the fact that the most interesting for them was - a living communication in real time /on-line.”*

During the conference in Arkhangelsk on March 2009, representatives of remote districts said in their reports that their attitude towards patients and approach to treatment and prevention of illness had changed, and that they feel part of a whole - general system for the prevention of CVD. That they are independent of location and distance from the regional center makes an important cause.

Natalia Bykova, Kotlas: *“The website gives attention and important support to people/patients living in remote areas. Patients like to visit this website and read the latest news about CVD.”*

Sergey Burlyaj, Kamenka, Mezen distrikt: *“Work with AH register taught us to think concretely and helped to save time. We feel full support from ARCMP to receive and impart information and computer work. The patients become more responsible towards their own health. All of them received information leaflets.”*

Tatjana Ershova, Velsk: *“The analysis of blood pressure in healthy people is very important to work with risk factors. That helps us to treat a patient in any other way.”*

Yulia Maksimova, GUCH patient: *“Most patients think either that they are healthy and can do all they wish, or they are too ill and need more treatment than they get. We try to change these views. Therefore each patient needs reliable information about how to live.”*

## **6.2 Differences and the reasons between anticipated and actual results**

With the software products: «Register of patients with CHD» and «Register of patients with AH» the information about the patients is registered and collected in one place. Health workers report that the program is handy and easy to work with. Despite big amount of entered information it is rather fast to fill in the records. With the first results we can make optimistic prediction about the introduction of these programs into the working practice of the medical institutions in the region.

Questionnaire «Quality of life and Population state of health» was distributed among 600 patients with hypertension. 525 people responded to the questionnaire. It was beyond the expected result, nevertheless it was impossible to process the results with the help of a scanner because the quality of the questionnaire filling out wasn't good enough. So it took much longer to get the results ready.

We expected more patients to address the specialists for internet consultations. Regretfully, the internet is not available to all the people living in Arkhangelsk and Arkhangelsk region, and computer literacy is rather low among the grown up population (young generation of the northerners has good computer skills), therefore the actual result has been less than expected.

### **6.3 Additional / non-planned activities during the project:**

- Videoconference with the doctors of Mirny city hospital “Actual problems of children cardiology».
- 28 telemedicine consultations of the children with cardiac pathology living in remote places were held.

### **6.4 Problems encountered in execution of the project**

During the project we identified aspects that became a challenge:

- Insufficient activity of the specialists of the medical institutions;
- Understaffing of doctors on the regional polyclinics;
- High price of the advertisement didn't allow arranging a large-scale promotion of the web-site;
- Insufficient computer literacy of the target group of the patients;
- No internet in the remote districts of the region.

## **7 Plan for the project continuation**

In 2009, the Arkhangelsk region starts implementation of two new major programs of the Russian national projects “Health” aimed at reducing deaths from cardiovascular disease. This would be a great help for the implementation innovations and the results of our project in the daily activities of the health service in Arkhangelsk region.

This project will continue. New districts will be included in the project work. This means that many thousand people may become more aware of their risk factors, methods of treatment and healthy lifestyle.

The plan of the project continuation comprises:

- further introduction into medical institutions both the AH Register and CHD Register;
- further work of the web-site and development of the new web-page “Quit smoking” (in 2010);
- development of the web-forum of the patients with CVD;
- development of the computer program for the offices of medical prophylaxis in order to improve prophylactic work in health institutions;
- to open Telephone of trust, i.e. distant school of health for the population of the region;
- to carry out regular video conferences for patients and medical professionals from the remote areas about treatment and prophylaxis of CVD;
- to include a larger number of people in the project and in the registers;
- to compare results at different institutions and districts.

## 8 Appendix

### 8.1 Program for the project start meeting at NST in Tromsø, July 2008

Prosjekt- / møtedeltakere fra Russland:

ELENA AGAFONOVA, direktør, Regionalt Senter for forebyggende helsearbeid i Arkhangelsk

IRINA IVANOVA, avdelingsleder, Regionalt Senter for forebyggende helsearbeid i Arkhangelsk

LEONID ZUBOV, kardiolog, Fylkets Barnesykehus i Arkhangelsk

SERGEY ZUBOV, turnuslege, Northern State Medical University i Arkhangelsk

YULIA MAXIMOVA, bibliotekar, Fylkets vitenskapsbibliotek i Arkhangelsk, medlem av GUCH prosjektet

NATALIA BYKOVA, avdelingsleder, avd. for forebyggende helsearbeid i Kotlas distrikt, Arkhangelsk fylke

03.07.08.			
0900	Omvisning på NST		Svetlana M. Bye
0945	Velkommen		Halgeir Holthe, Dr. polit., sosiolog +47 95729563 <a href="mailto:Halgeir.holthe@telemed.no">Halgeir.holthe@telemed.no</a>
1000	Hvordan IKT best kan brukes til å støtte mennesker i å gjøre livstilsendringer. Røykfri på Internett An Internet-based intervention for smoking cessation		Silje Camilla Wandberg, Spesialpsykolog +47 95744158 <a href="mailto:Silje.Camilla.Wangberg@telemed.no">Silje.Camilla.Wangberg@telemed.no</a>
Møte: webteknologier, nettbasert kompetanseutvikling			
1245	Kompetanseoverføring på nett Nettbasert kompetanse - en mulighet for mange?		Kirsten Eriksen, Leder Nettbasert kompetanseutvikling +47 91349562 <a href="mailto:Kirsten.eriksen@telemed.no">Kirsten.eriksen@telemed.no</a>

1400	Web / webteknologi /  Publisering på web: hvilke modeller finnes, og hvilke ressurser som kreves.		Vegard Johansen, Spesialkonsulent Nettbasert kompetanseutvikling +47 41417731 <a href="mailto:Vegard.jonahsen@telemed.no">Vegard.jonahsen@telemed.no</a>
1530	Prosjektmøte og kontrakforhandling		
04.07.08.			
0830	Besøk Landsforeningen for Hjerte- og Lungesyke (LHL) Nord-Norge		Rita Roaldsen
Møte: juridiske aspekter, sikkerhet og personvern			
1030	Russiske deltakere snakker om utfordringer		
1300	Sikkerhet, personvern		Eva Skipenes, sikkerhetsrådgiver, Cand.scient i matematikk +47 91177515 <a href="mailto:Eva.skipenes@telemed.no">Eva.skipenes@telemed.no</a>
1400	Juridiske aspekter		Ellen Kari Christiansen, jurist +47 416 84705 <a href="mailto:Ellen.christiansen@telemed.no">Ellen.christiansen@telemed.no</a>
1500	Prosjektmøte – veien videre		
07.07.08.			
0900	Oppsummeringsmøte – prosjekt Hjertelinken – veien videre, planer, praktisk arbeid		Svetlana M. Bye, spesialkonsulent, prosjektleder +47 90518326 <a href="mailto:Svetlana.manankova.bye@telemed.no">Svetlana.manankova.bye@telemed.no</a>
	Møte med journalister fra PINGVINEN – intern avis på UNN		

## 8.2 Project sheet, Norwegian:

# Hjertelinken: Hjerte-karsykdommer i Nordvest-Russland

### Bakgrunn:

Hjerte-karsykdommer er en av de største sykdomsgruppene i verden. I Arkhangelsk fylke i Nordvest-Russland er dette den største dødsårsaken, og 22 % av befolkningen, dvs. nesten 300.000 mennesker har denne typen lidelser.



Dette er et felt innen helsearbeid som fordrer høy kompetanse hos helsearbeidere og tilstrekkelig kunnskap om egen sykdom hos pasientene

Derfor kreves det hyppig oppdatering på helsestatusen til pasientene og oppdatering og samhandling mellom helsepersonell og pasienter. Elektroniske løsninger vil gjøre slik samhandling enklere.

### Formål:

e-helsebidrag skal gi bedre livskvalitet for mennesker med hjerte-karsykdommer i Nordvest-Russland.

### Metode:

Prosjektet innebærer nettverksbygging mellom parter i Nord-Norge og i Arkhangelsk fylke. Vi vil tilpasse og prøve ut e-helsesystemer som kan bidra til å styrke samhandling mellom helseinstitusjoner og mellom helsefaglig personell og pasienter, bl.a. elektronisk informasjonsportal og elektronisk pasientregistrering.

Det vil bli lagt vekt på å ta i bruk e-helse-tjenester i forebygging av hjertekarlidelser i Nordvest-Russland. Det vil også bli brukt elektroniske systemer for monitorering, som kan bedre den medisinske oppfølgingen av den enkelte pasient.

### Prosjektbeskrivelse:

Målet er å etablere en informasjonsservice for pasienter og helsearbeidere i Arkhangelsk fylke for forebyggende arbeid og behandling av hjertekarsykdommer.

Prosjektet fokuserer på promotering av sunn livsstil og forebygging av helseproblemer som er relatert til livsstil og sosiale forhold. Prosjektet vil bidra til utvikling og integrering av primærhelsetjenester og sosiale tjenester.

Prosjektet skal gjennomføres i Arkhangelsk fylke i Nordvest-Russland. Målgruppen er pasienter i utkantstrøk med medfødt hjertefeil og helsepersonell i primærhelsetjenesten.

### Prosjektperiode:

01.06.08 – 30.04.09

### Finansiering:

Helse- og omsorgsdepartementet gjennom Barents helseprogram

### Prosjektpartnere:

Regionalt Senter for forebyggende helsearbeid i Arkhangelsk, Russland

Helseadministrasjonen i Arkhangelsk fylke

2 regionale og 2 lokale sykehus i Arkhangelsk fylke

Landsforeningen for hjerte- og lungesyke (LHL), avd. Nord-Norge

Nasjonalt senter for telemedisin /WHO Collaborating Centre

### Kontaktperson:



Prosjektleder Svetlana M. Bye, spesialkonsulent, telefon 905 18 326 og e-post [Svetlana.manankova.bye@telemed.no](mailto:Svetlana.manankova.bye@telemed.no)

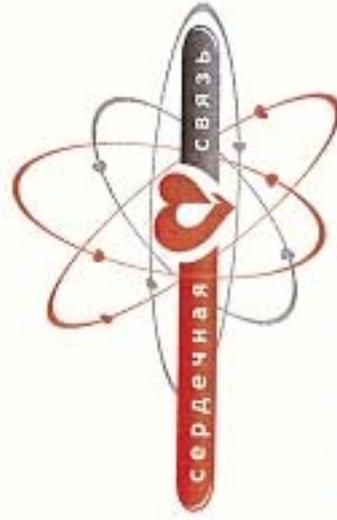
Prosjektmedarbeider dr. polit., Halgeir Holthe, telefon 957 29 763  
[halgeirh@holthe.no](mailto:halgeirh@holthe.no)

Nasjonalt senter for telemedisin, Universitetssykehuset Nord-Norge Pb 35, 9038 Tromsø, Norge

### **8.3 Conference program and poster**



АРХАНГЕЛЬСКИЙ ОБЛАСТНОЙ ЦЕНТР  
МЕДИЦИНСКОЙ ПРОФИЛАКТИКИ



## Программа конференции

«Организация информационной службы для пациентов и медицинских работников Архангельской области по профилактике и лечению сердечно-сосудистых заболеваний в рамках проекта «Сердечная связь». Первые итоги и перспективы».



NST | Norwegian Centre for Telemedicine  
UNIVERSITY HOSPITAL OF NORTH-NORWAY  
West Collaborating Centre for Telemedicine

г. Архангельск, Набережная Северной Двины, 88,  
конференц-зал гостиницы «Пур-Наволох Отель»

**25 марта 2009 г.**

09.30 – 10.00 Регистрация участников.



**10.00 – 10.10** Открытие конференции. Приветственное слово.

Русинова Т.В., консультант отдела лечебно-профилактической помощи взрослому населению департамента здравоохранения Архангельской области, ответственная за проект «Сердечная связь» со стороны департамента здравоохранения Архангельской области.



**10.10 – 10.30** «Первые итоги системного исследования качества жизни и состояния здоровья у пациентов с артериальной гипертензией в Архангельской области».

Агафонова Е.Ю., главный врач ГУЗ «Архангельский областной центр медицинской профилактики», координатор проекта «Сердечная связь» в Архангельске.



**10.30 – 11.20** «Актуальные проблемы сердечно-сосудистых патологий у детей. Ведение регистра для детей с врожденными пороками сердца, передача их во взрослую сеть здравоохранения».

Зубов Л.А., доцент кафедры педиатрии факультета повышения квалификации ГОУ ВПО «Северный государственный медицинский университет», главный внештатный детский кардиолог департамента здравоохранения Архангельской области.



**11.20 – 11.45** «Важность ведения регистра для больных с артериальной гипертензией. Сайт как дополнительный канал общения пациентов и медицинских работников».

Тарутина Т.М., заведующая отделом ГУЗ «Архангельский областной центр медицинской профилактики», врач – кардиолог.



**12.35 – 12.50** «Опыт работы с регистрами артериальной гипертензии в удаленном районе Архангельской области»  
Бурляк С.Н., врач-терапевт Каменской районной больницы № 2 МУЗ «Мезенская центральная районная больница».



**12.50 – 13.10** «Информационные системы на службе у медицинских работников и пациентов. Опыт работы».

Быкова Н.Т., заведующая кабинетом медицинской профилактики МУЗ «Котласская центральная городская больница».



**13.10 – 13.25** «Проект «Сердечная связь» с точки зрения рядового пользователя-пациента»

Максимова Ю. А., представитель пациентов.



**13.25 – 13.50** «Информационные системы – неотъемлемая часть современного здравоохранения»

Халгейр Холте, д.п.н., сотрудник норвежского центра телемедицины.



**13.50 – 14.20** «Российско-норвежский проект GUSN: корреляция с проектом «Сердечная связь», планы на 2009 г.»

Рита Росалдсен, сотрудник норвежской организации пациентов с сердечно-легочными заболеваниями (LHL).

**4.20 – 14.50** Дискуссия.



**14.50 – 15.20** «Итоги и перспективы развития российского – норвежского проекта «Сердечная связь».

Мананикова С.Е., руководитель проекта «The Health link – Сердечная связь», специалист-консультант норвежского центра телемедицины.

Вручение сертификатов участникам проекта.

11.45 – 12.20  
Кофе-пауза.



**12.20 – 12.35** Выступление агитбригады МОУ СОШ № 43 г. Архангельска (победитель II областного конкурса агитбригад «Решение за тобой!»)

**15.20 – 16.00** Ланч.



**[www.zdorovie29.ru](http://www.zdorovie29.ru)**

**зайди на new сайт**



**сердечная забота о твоём здоровье!**