Perspectives of establishment of a new coordinating center for health related data integration and analysis in Kyrgyzstan on the basis of the Swedish model: a Study Protocol

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**Abbreviations.**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AMI</td>
<td>Acute Myocardial Infarction</td>
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<td>CIOMS</td>
<td>Council for International Organizations of Medical Sciences</td>
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<td>DSS</td>
<td>Demographic Surveillance System</td>
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<td>EpC</td>
<td>Centre for Epidemiology</td>
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<td>FGP</td>
<td>Family Group Practices</td>
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<td>FMC</td>
<td>Family Medicine Centers</td>
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<td>FOP</td>
<td>Feldsher-Obstetrical Points</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
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<tr>
<td>INDEPTH</td>
<td>International Network of field sites with continuous Demographic Evaluation of Populations and Their Health in developing countries</td>
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<tr>
<td>HIS</td>
<td>Health Information System</td>
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<td>HRS</td>
<td>Household Registration System</td>
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<td>MHIF</td>
<td>Mandatory Health Insurance Fund</td>
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<td>NBHW</td>
<td>National Board of Health and Welfare</td>
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<td>NEDSS</td>
<td>National Electronic Disease Surveillance System</td>
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<td>NSC</td>
<td>National Statistical Committee</td>
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<td>PHI</td>
<td>Public Health Infrastructure</td>
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<td>PHII</td>
<td>Public Health Information Infrastructure</td>
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<td>PIN</td>
<td>Personal Identification Number</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Abstract.

Development of an effective Health Information System (HIS) remains as one of the priorities in the development of the health care system in Kyrgyzstan. In an analysis and evaluation of population’s health status one needs to take into consideration socioeconomic variables of individuals. That could allow Government to target vulnerable groups within the population and plan interventions towards them more effectively. Following-up individuals over time, would make it possible to identify negative and positive trends regarding the health and socioeconomic situation of the society and react to these trends timely. This may be realized to a larger extent through an implementation of a new HIS in Kyrgyzstan on the basis of Swedish model of HIS.

Therefore, the objective of this thesis is to develop a study protocol for future research on possibilities to establish a coordinating centre for health related data integration and analysis in Kyrgyzstan on the basis of the Swedish model. On the basis of this study protocol a research proposal will be submitted to the Ministry of Health and National Medical Ethical Committee in Kyrgyzstan for approval before the future study can be conducted.

The expected outcome of the study is an establishment of a coordinating center that would first monitor the population in a pilot region of Kyrgyzstan, then further widen its activity to the whole country.

Key words: health information system, personal identification number, health care system, implementation, monitoring, plan, costs.
1. Introduction.

One of the vitally important elements in the strategy of any health care system is the availability of information. That is population’s health status related information and information regarding environment where the population lives and between which there are strong interconnection and interdependence. Such information would help to identify which layers within the population are most or least affected by disease, most or least exposed to risk factors and would allow the most efficient allocation of scarce resources and targeting vulnerable groups of population for study and interventions. It has been said that accurate information is the lifeblood of decision-making, and in the present day the demand for reliable data is greater than ever (Basch, 1999). Thus, in the data analysis, it is very important to take into consideration the socioeconomic status of individuals and to link it with their health status when, e.g. planning health interventions.

The problem on HIS in Kyrgyzstan is in the following:
1. It is not possible to interlink health indicators of individuals with their socioeconomic.
2. It is not possible to follow-up individuals prospectively and retrospectively as well, i.e. it is not possible to make a longitudinal approach in the data analysis.

Why? Firstly, there is not a coordinating center in Kyrgyzstan on centralized data management, where all data may be interlinked with each other for the analysis as it is successfully done in Sweden, namely in the Centre of Epidemiology (EpC) under the National Board of Health and Welfare (NBHW). Secondly, it is not possible to do that technically because of the absence of a Personal Identification Number (PIN) system which is widely used in Sweden.

A big advantage of using a PIN system for conducting research is pointed out by many authors. Thus, according to Weitoft (2003), a unique national registration number, personal identification number (PIN), is assigned to each inhabitant, and is used in Sweden’s population-based registers. This individual identifier makes it possible to link information between different data sources, and take advantage of this in the data analyses, i.e. to adopt a longitudinal approach, to cover a broad range of background characteristics, to have a low dropout rate, and to obtain full population coverage of an entire country.

Therefore, HIS is important in order to:
1. Describe and analyze the previous and current situation regarding a population’s health status, and targeting and prioritizing vulnerable groups within the population of study.

2. Plan and monitor interventions and evaluate their outcomes.

3. Anticipate potential trends in the changes of a population’s health status.

The production of health information is an important function of a health care system. It has been said that health information is what holds a health system together (Thieren, 2005). According to Cibulskis and Hiawalyer (2002) such information can help an organization to increase its effectiveness and responsiveness in several ways. First, it can help managers to align health system resources with client needs (a planning or prospective role) and determine whether their plans are progressing satisfactorily or whether there is a need for corrective action (a monitoring or retrospective role). Second, information can be used to increase accountability within an organization and allow the public, their elected representatives, or donors to determine whether they are obtaining value for money. Third, information can be used to market health programs, secure appropriate levels of funding or engage public support. Fourth, information amassed over time can help an organization to learn what works and what does not work and thereby provide valuable knowledge, which can lead to greater efficiency in the production process.

HIS is developing rapidly worldwide and undergoing a transformation, demanding more attention to itself within the health care system, becoming gradually more strongly interconnected with the information systems of other spheres of the country, such as social and economic and attracting more attention from the governments. For instance, in the wake of terrorist attacks with anthrax in 2001, the Bush administration made 1.1 billion dollars available for improvements of states’ Public Health Infrastructure (PHI). As a key step that time was the adoption and implementation of National Electronic Disease Surveillance System (NEDSS). This was the single largest investment in basic Public Health infrastructure since the Second World War (Lumpkin and Richards, 2002). HISs are tending to be called often even as a whole Public Health Information Infrastructure (PHII). Thus, according to Lumpkin and Richards (2002), the PHII comprises an intricate web of data recourses, information systems, epidemiological analysis, and investigation, standards, laws, and values that public health agencies at the local, state, and federal levels use to prevent illness and promote health. The PHII exists to collect and analyze data, form and confirm hypotheses, and manage interventions.
The data collected by the HIS should be timely, precise and safe. Otherwise, disregard of such requirements for HIS could have dangerous consequences for the society and even lead to the human deaths. Thus, in 1998 an outbreak of invasive Group A streptococcus occurred in a small metropolitan area in central Illinois. Three months passed during which ten people died before the first case was reported to the Public Health authority (Lumpkin and Richards, 2002).

As it has been already indicated earlier, on the next stage, all collected data should be described and analyzed epidemiologically in order to make a reasonable conclusion and present it to Public Health authorities and policy-makers. Epidemiology, as an analytical tool of Public Health strategy, is the science of the distribution and determinants of health related states and events in populations with the ultimate aim of controlling and preventing health problems. Epidemiological studies combine descriptive and analytical approaches. Descriptive studies usually relate to time, place and person while analytical studies seek for risk factors and the aetiology behind a certain disease (Persson and Wall, 2003). One can say that the Swedish model of HIS with its EpC, deals with these epidemiological approaches successfully using a unique PIN system which allows it to interlink all health related data and different socioeconomic variables, making a longitudinal approach in the data analysis and dealing with demographic data as well. This methodology of functioning permits EpC to formulate and present more complete conclusions on collected health related data.

The problem of creating an analogous centre in Kyrgyzstan on the basis of the Swedish model which would deal with collection and analysis of data, interlinking between each other different types of health related data in order to make a complete approach to the situation on population’s health, and evaluating perspectives of its implementation from an economic point of view, is the object which I would like to focus on in my thesis. After a study and economic analysis of perspectives to implement new HIS in Kyrgyzstan on the basis of Swedish model, it would be reasonable to offer a plan on perspectives of this implementation to the policy-makers and health care authorities.

2. Background.

2.1 General information about Kyrgyzstan.
Kyrgyzstan is situated in Central Asia. It borders, as it is shown in figure 1., to Kazakhstan in the north, to China in the East, to Tajikistan in the South and to Uzbekistan in the West. The population of Kyrgyzstan is 5,146,281 (estimated in July, 2005). The capital city is Bishkek. The area of Kyrgyzstan covers 198,500 sq. km. The relief of Kyrgyzstan is entirely mountainous. Only 7.3% of the whole area is arable, whereas approximately other 92.7% covered by mountains. Natural resources include: abundant hydropower; significant deposits of gold and rare earth metals; locally exploitable coal, oil, and natural gas; other deposits of nepheline, mercury, bismuth, lead, and zinc. Life expectancy at birth among males is 64.16 years; among females is 72.38 years and for the total population is 68.16 years (estimated in 2005). Ethnic groups in Kyrgyzstan are the next: Kyrgyz 64.9%, Uzbek 13.8%, Russian 12.5%, Dungan 1.1%, Ukrainian 1%, Uygur 1%, other 5.7% (1999 census). Among religions Muslim consists 75%, Russian orthodox - 20%, other - 5%. Languages: Kyrgyz (official), Russian (official). Literacy rate: 98.7%. Gross Domestic Product (GDP) per capita: 1800 U.S. dollars (estimated in 2005). Industrial activity: small machinery, textiles, food processing, cement, shoes, sawn logs, refrigerators, furniture, electric motors, gold, rare earth metals (CIA World Factbook, 2006).
climate varies regionally. The south-western Fergana Valley is subtropical and extremely hot in summer, with temperatures reaching 40°C (104°F.) The northern foothills are temperate and the Tian Shan varies from dry continental to polar climate, depending on elevation (Wikipedia, 2006).

2.2 General information about Sweden.

Sweden is a Nordic country in Scandinavia, in Northern Europe. It is bordered by Norway in the west, Finland in the northeast, the Skagerrak Strait and the Kattegat Strait in the southwest, and the Baltic Sea and the Gulf of Bothnia in the east (Wikipedia, 2006). The population of Sweden is 9 001 774 (estimated in July, 2005). The capital city is Stockholm. The area of Sweden covers 449 964 sq km. Peculiarities of relief mostly determined by the forests. Arable land is 6.54% of the total area. Natural resources include: iron ore, copper, lead, zinc, gold, silver, tungsten, uranium, arsenic, feldspar, timber and hydropower. Life expectancy at birth among males: 78.19 years; among females: 82.74 years; total population: 80.4 years (estimated in 2005). Ethnic groups in Sweden are: Swedes and Finnish and Sami minorities; foreign-born or first-generation immigrants: Finns, Yugoslavs, Danes, Norwegians, Greeks and Turks. Among religions Lutheran constitutes 87%, others are Roman Catholic, Orthodox, Baptist, Muslim, Jewish, Buddhist. Languages: Swedish, small Sami- and Finnish-speaking minorities. Literacy rate: 99%. GDP per capita: 29 600 U.S. dollars (estimated in 2005). Agricultural products: barley, wheat, sugar beets; meat, milk. Industrial activity: iron and steel, precision equipment (bearings, radio and telephone parts, armaments), wood pulp and paper products, processed foods, motor vehicles. Climate: temperate in south with cold, cloudy winters and cool, partly cloudy summers; sub arctic in the north (CIA World Factbook, 2006). The map of Sweden is shown in figure 2.
Fig. 2. The map of Sweden and its geographic situation.

3. Objectives.

3.1 General objective:

To develop a study protocol for future research on possibilities to establish a coordinating centre for health related data integration and analysis in Kyrgyzstan on the basis of the Swedish model.

3.2 Specific objectives:

3.2.1 To do a study protocol, i.e. to make a plan for a study, which will provide knowledge on how to implement a coordinating center in Kyrgyzstan and on costs for the implementation of such a center. On the basis of this study protocol a research proposal will be submitted to the Ministry of Health and National Medical Ethical Committee for approval before the future study can be conducted.

The study protocol will include:

3.2.2 To, as a background, describe the essential characteristics of the health care systems and health information systems in Kyrgyzstan and Sweden. This background will facilitate the understanding, of how to establish a center for health related data integration in Kyrgyzstan.

3.2.3 Ethical clearance.

3.2.4 To analyze what should be done in Kyrgyzstan in order to protect a privacy of individuals dealing with large datasets with sensitive information.

3.2.5 To analyze which types of health related data that could be interlinked by a Personal Identification Number system, such as e. g. the Swedish system.
3.2.6 To analyze the advantages of interlinking health related data using a Personal Identification Number system for data analysis.

   a. Longitudinal approach in the study (possibilities to follow up individuals retrospectively and prospectively as well)

   b. Socioeconomic variables (possibilities to take into account socioeconomic variables of individuals during the health related data analysis)

3.2.7 To make a plan on how the selection of a pilot region and implementation of interlinked data monitoring should be done in Kyrgyzstan.

3.2.8 To make a plan for the human and other resources that must be employed to develop a coordinating center in Kyrgyzstan.

3.2.9 To make a plan on how the costs can be measured and calculated.

3.3 To make a time plan for the establishment of a coordinating center in Kyrgyzstan.

3.3.1 To summarize the expected results.

4. Study protocol for future research on possibilities to establish a coordinating centre for health related data integration and analysis in Kyrgyzstan on the basis of the Swedish model.

4.1 The essential characteristics of the health care systems and health information systems in Kyrgyzstan and Sweden.

   The health care system in Kyrgyzstan.

   Organizational structure of the health care system.
Health services in Kyrgyzstan are organized and administered at three levels: national, oblast, and rayon. Kyrgyzstan is divided into seven oblasts. In each oblast there are several rayons (districts). Beneath the rayon are the village administrations. Seventeen cities are administered separately by city administrations. The main actors involved in management of health services are the Ministry of Health, the Ministry of Finance, and oblast health administrations.

The Ministry supervises the activities of all health related institutions including the training and research institutions, coordinates their activities, and approves normative and methodological documents concerning health. The Ministry of Finance has direct responsibility for financing health care.

The local health administration is responsible for implementing the constitutional rights of citizens for the health care and administering the health services. They develop health programs, prepare local budgets, and ensure the implementation of programs and provision of health services.

After the independence the private sector has been represented more in comparison with the Soviet period, but even nowadays it is as a very small share within the whole health care sector.

Planning, regulation and management.

In Soviet times, planning, regulation and management were under the central control of the Soviet state. Following independence, the Ministry of Health of Kyrgyzstan has got a leading role in health planning, regulation and management, but is gradually decentralizing its functions as it has been mentioned above. The overall management of the health system still largely follows a hierarchical top-down model. Laws, decrees or other regulations are adopted by the Jogorku Kenesh (parliament of Kyrgyzstan), and the Ministry of Health subsequently issues orders that are compulsory for all government-owned health facilities. The administrations of health facilities, in turn, issue internal orders, with timetables and responsibilities. They are obliged to monitor their implementation and to report the results back to the Ministry of Health.

The Ministry of Health directly administers the republican health facilities, such as the scientific research institutes and national centers. It also manages the Kyrgyz State Medical Academy. The main regulatory functions of the Ministry of Health include: the development of
methodical guidelines that are compulsory for all health care providers; the licensing and attestation of health providers; and quality assurance procedures. The Ministry coordinates the activities of donors and distributes humanitarian aid. It also procures centrally drugs and medical equipment for health facilities in the public sector. The Ministry of Health is also responsible for financial planning and budgetary management. It develops a health budget based on national health policies and health revenue estimates. In particular, it plans the scope and types of health services needed for the country’s population and the financial resources required to provide these services.

At subnational level, health planning and regulation are the responsibilities of local state administrations.

Health care financing and expenditure.

Currently, the Kyrgyz health sector is financed from the following main sources of funds:
1. General budget revenues (republican and local) make up 44.0% of health care financing;
2. Contributions to the Mandatory Health Insurance Fund (MHIF) – 4.0%;
3. The Public Investment Programme – 0.9%;
4. Out-of-pocket payments – 51.1%.

According to the 2004 Public Expenditure Review of the World Bank, private out-of-pocket payments constitute the main source of health financing, contributing to more than half of total health financing. General budget revenues (of the republican and local governments) constitute 44.0%. The Public Investment Programme, which is financed by loans from the World Bank and the Asian Development Bank, constitutes 0.9% of health financing, while social insurance contributions contribute 4.0% to total health financing.

Government health spending decreased from 4.0% of GDP in 1995 to 1.8% in 2003. The decline occurred both because overall public spending declined and because the share of the state budget allocated to health fell from 13.6% in 1995 to 9.0% in 2003 (Rechel and McKee, 2005).

Primary health care.
Primary care, defined as the first point of contact with the health care system, is provided by feldsher (the medical assistant)-obstetrical points (FOPs), family group practices (FGPs), family medicine centers (FMCs), ambulance and emergency care services.

Feldsher-obstetrical points and family group practices are the first points of contact with the health care system for patients in rural areas. Feldsher-obstetrical points were established in the Soviet period to serve small villages and remote localities with populations between 500 and 2000. They are staffed by at least one health worker, called a feldsher, i.e. a medical assistant. Services rendered by feldsher-obstetrical points are limited to very basic curative, antenatal and postnatal care, immunization and health promotion.

Family group practices have been formed in recent years instead of preexisting health facilities (feldsher-obstetrical points, rural doctor ambulatories, polyclinics and rural district hospitals). Family group practices are staffed by at least one physician, in addition to nurses and midwives, and serve villages with a population of more than 2000 inhabitants. The number of staff depends on the size of the village.

Family medicine centers are the largest outpatient health facilities and are situated in the main settlement in the rayon. They combine primary care and secondary outpatient care services, ranging from general medical care to specialized care and diagnostics (including X-ray and ultrasound). Family medicine centers provide care for children, minor surgery, rehabilitation, family planning, obstetric care, perinatal care, first aid, pharmaceutical prescriptions, certification, home visits, and preventive and health promotion services. Health personnel in family medicine centers usually comprise 10–20 specialists. One family medicine centre has been established in each rayon, replacing polyclinics.

Secondary health care.

All hospitals on rayon, city and oblast levels belong to the secondary level of the health care.

Tertiary health care.
Tertiary care is provided by the republican health facilities at national level (national hospitals, centers and scientific research institutes) and specialized dispensaries and hospitals at subnational levels. These facilities are narrowly specialized and cover cardiology, tuberculosis, oncology and radiology, obstetrics and pediatrics, treatment of infectious diseases and treatment of mental illnesses (Rechel and McKee, 2005).

The health care system in Sweden.

Organizational structure of the health care system.

The Swedish health care system is organized on three levels: national, regional and local. The regional level, through the county councils, together with central government, form the basis of the health care system. Overall responsibility of the health care sector rests at the national level, with the Ministry of Health and Social Affairs.

National level.

The responsibility of the Ministry of Health and Social Affairs lay in the controlling role of execution of legislative norms in health care, supervision of the activities of the health care facilities on the lower levels and allocation of financial resources within the health care. The National Board of Health and Welfare has a supervisory function over the county councils, acting as the government’s central advisory and supervisory agency for health and social services. The board supervises implementation of public policy matters and legislation in health care and social welfare services. It’s most important duty is to follow and evaluate the services provided to see if they correspond to the goals laid down by the central government. The board also keeps official statistics on health and health care. It is assisted by the EpC, whose objective is to describe, analyze and report on the distribution and development of health and diseases. In carrying out these functions, EpC uses a nation-wide PIN system which allows it interlinking different registers in the data analysis.

All health care personnel are under the supervision of the National Board of Health and Welfare. The board is also the licensing authority for physicians, dentists and other health service
staff. Moreover, the board is responsible for the issues related to mutual recognition of diplomas concerning health professions within European Community.

Regional level.

Provision of health services on the regional level is done by the county councils, which are independent, regional government bodies.

The county councils are in charge of the health care delivery system from primary care to hospital care, including public health and preventive care. The county councils have an overall authority over the hospital structure and responsibility for all health care services delivered. The county councils also regulate the policy on private health care services. County councils control the establishment of new private practices and the number of patients private practitioners can see during a year. If the private provider does not have any agreement or if the private provider does not use the regulated fee schedule, the provider does not get reimbursed and a patient will have to pay the full charge to the provider.

Local level.

Health care is also provided on the level of municipalities in the Swedish health care system. Municipalities' duties are related to issues on child care, school health services, environmental hygiene and care of the elderly, disabled and long-term psychiatric patients.

Health care financing and expenditure.

According to Hjortsberg and Ghatnekar (2001), total expenditure on health in Sweden as a percentage of GDP in Sweden amounted to 9.2 in 2002.

As an addition to this the social insurance system, managed by the National Social Insurance Board, provides financial security in case of sickness and disability. This sickness insurance is mandatory and covers part of individual income losses due to illness and health care services. The largest part of the sickness insurance is financed by employers’ contributions and the rest by specific transfer payments from central government. Both private and public
employers pay a contribution per employee to the health insurance system: 8.5% (in 2000) of the employee’s salary.

The sources of revenue for health care in Sweden are: taxation, the national social insurance system and private expenditure (i.e. out-of-pocket payments and private insurance).

Primary health care.

The aim of the primary care level is to improve the general health of the population and to treat diseases and injuries which do not require hospitalization. The primary care services deliver both basic curative care and preventive services through local primary health care centers.

Patients can choose between different health centre and hospital outpatient departments within the county council. The health centers are administered by the county councils, which are obliged to organize primary health care so that everyone living in the county has access to it.

Secondary and tertiary health care.

For conditions requiring hospital treatment, medical services are provided at county and regional hospitals.

Sweden’s hospitals are divided into regional hospitals, central county hospitals and district county hospitals. In the district county hospitals, there are at least four specialties; internal medicine; surgery; radiology; and anesthesiology.

At county hospitals, medical competence and equipment enables treatment of patients suffering from almost all diseases, including psychiatric problems. Somatic care is provided through inpatient and outpatient care.

Patients with complicated and/or unusual diseases and injuries need highly specialized care and are attended at regional hospitals. The regional medical care system is responsible for patients whose medical problems require the collaboration of a large number of specialists and sophisticated diagnostic or treatment facilities. Regional hospitals provide an extensive range of medical specialties and have a broader spectrum of specialists than at county level, including neurosurgery, thoracic surgery, plastic surgery and highly-specialized laboratories (Hjortsberg and Ghatnekar, 2001).
The Health Information System in Kyrgyzstan.

The HIS in Kyrgyzstan is presented in the form of activities of two separate organizations: National Statistical Committee (NSC) and Ministry of Health.

NSC is a central statistical organization in Kyrgyzstan. It is responsible for statistics of: population, demography, industry, agriculture, prices, trade, national accounts, state finances, labor and social spheres in society. All ministries are accountable to NSC which is an independent structure that is accountable to the President of the Kyrgyz Republic. In its organizational structure, the NSC has a central bureau in the capital city Bishkek, main center for statistical calculations, oblast and rayon representative committees, institute of statistical research and training center. On the first stage all collected data are gathered by rayon representative committees. Then, on the second stage these data are passed to the oblast committees and then to the main center for statistical calculations. The functions of NSC are:

- Creation of a statistical database based on reports, census, surveys and monitoring of the living conditions in the Kyrgyz Republic.
- Control of the quality and reliability of statistical data.
- Conducting of registrations for enterprises, organizations and institutions on the territory of Kyrgyz Republic.
- Provision of storage and protection of statistical information, observance of the state and commercial secrets.
- Realization of the united technical policy in the technology of gathering, elaboration and conducting of statistical information.
- Preparation of monthly, quarterly and annual reports on the socioeconomic development of the Kyrgyz Republic and its particular regions.
- Study of social processes and living conditions in the Kyrgyz Republic.
- Conducting of census, sociodemographic investigations and interrogations.
- Realization of systematic observation on the changes of prices and tariffs for the analysis of inflation processes.
- Gathering statistics on the external economic relations of the Kyrgyz Republic using statistical data of the custom.
- Provision of reports on export and import in the Kyrgyz Republic.
- Elaboration and presentation of an annual program of the Committee’s activity to the Government of the Kyrgyz Republic for approval (National Statistical Committee, 2006).

As it has been said earlier, the Ministry of Health in Kyrgyzstan has a supervisory and policy-making role, under the terms of the people’s health protection act. The Ministry supervises the activities of all health related institutions including the training and research institutions, coordinates their activities, and approves normative and methodological documents concerning health.

According to regulations, the Ministry of Health verifies the reliability of health related data jointly with NSC at the same time reporting these data to NSC (Ministry of Health, 1999). Thus, one can make the following observations:

1. One can notice duplication of each other’s function between NSC and Ministry of Health in their health related data analysis.
2. None of them, i.e. neither NSC nor Ministry of Health can not deal with personal information of individuals in the data analysis because of technical impossibility, i.e. lack of a PIN system.
3. It is not possible to follow-up individuals prospectively and retrospectively as well, i.e. it is not possible to have a longitudinal approach in the data analysis.
4. It is difficult to identify and target vulnerable groups of the population for study and interventions.

Therefore, one can conclude that the development of a PIN system in Kyrgyzstan would be desirable in order to link different data according to corresponding registers and to use them within the interlinked data analysis.

The Health Information System in Sweden.

In its activity EpC notes that knowledge of the causes of diseases or the effects of interventions improves the possibility of doing good as an important aspect of humanity. Thus, according to EpC, knowledge of disease trends or risk groups, or of social inequalities in health, improves politicians’ and other decision-makers’ possibilities of action to create a society based on justice and solidarity. But on the other hand, it is a huge responsibility to protect personal
privacy dealing with large data bases with sensitive information on individuals. Therefore, it has been concluded that monitoring public health and social conditions is a question of humanity, solidarity, justice, democracy, efficiency, trust and responsibility (Rosen, 2003). A well-developed information system is a necessity in a democratic society. There is a long tradition in Sweden of collecting information on health and social conditions of the population which provides an excellent base for monitoring disease and social problems. One should note that through a unique person identification number being given to every citizen, there is a main ground for such a success in monitoring public health and social conditions in Sweden, which makes it possible to link exposure and outcome data from several decades (Centre for Epidemiology, 2005).

In a structural organization of HIS, several organizations contribute to the Swedish system of monitoring public health and social conditions. Nationally, the Swedish EpC at the NBHW has the main responsibility, while other governmental bodies such as the National Institute of Public Health and Statistics Sweden also make important contributions.

The EpC was founded by NBHW in January 1992 to strengthen the use of epidemiology and registers and thereby the potential for monitoring health and social conditions in Sweden. Being as a department of NBHW, the EpC has had its own advisory board with representatives from the NBHW, the Federation of County Councils, the National Institute of Public Health, the Association of Local Authorities, the Swedish Council on Technology Assessment in Health Care and the research community.

The EpC is organized in six units:
1. Management and administration.
2. Terminology and classification systems.
3. Centre for patient classification system.
6. Analysis (research and development).

The overall objective of the EpC is to describe, analyze and report on the distribution and development of health, diseases, social problems, the use of health and social services and their determinants in different population groups in Sweden.
The main responsibilities of the EpC are to:

- Collect and maintain epidemiological registers of high quality
- Develop and adapt classification systems and co-ordinate national terminology work within the areas of health and social services
- Produce National public health and social reports
- Initiate and conduct research and development
- Co-ordinate statistics within the areas of health and social services

Monitoring public health and social conditions is based on three basic principles:

- Defining and structuring information.
- Collecting information.
- Data analysis.

The necessary tools are terminology and classification, administration of registers and epidemiological and social analysis (Rosen, 2003).

General information about PIN in Sweden.

The personal identity number is the Swedish national identification number, introduced in 1947. At the beginning it was issued by the Tax Agency as a part of the Population Register.

The personal identity number consists of 10 digits and a hyphen. The first six correspond to the person's birthday, in YYMMDD form. They are followed by a hyphen. The seventh through ninth are a serial number. For the ninth number an odd number is assigned to men, and an even number to women. One can identify that difference using the following examples: 760812-5736 and 811218-9845.

The tenth digit is a checksum which was introduced in 1967 when the system was computerized. Originally, when the personal identity number was introduced, it had nine digits and the seventh and eighth denoted the county in which the subject was born. It was replaced with the current system in 1990. People over the age of 100 replace the hyphen with a plus sign. In some counties, such as Stockholm, they have started using 12 digit numbers to allow YYYYMMDD. This format is also used on official Swedish ID-cards.
People who have no Swedish personal identity number can receive a co-ordination number instead. It is issued by the Tax Agency at the request of a public agency. It is used for contact between a person and an agency which would otherwise require the use of a personal identity number (Wikipedia, 2006).

4.2 Comparative analysis of the Swedish model of health information system and Demographic Surveillance System used in developing countries

Telling about the perspectives of establishment of a new coordinating center for PIN based health related data integration and analysis in Kyrgyzstan, one needs to discuss about DSS (Demographic Surveillance System) as well, for instance the INDEPTH (International Network of field sites with continuous Demographic Evaluation of Populations and Their Health in developing countries) as an alternative to a HIS whose integrative and analytical activity will be based on the functioning of a PIN.

So far INDEPTH’s activity is spread to such developing countries as Mali, Senegal, Guinea Bissau, Gambia, Ghana, Burkina Faso, Bangladesh, Vietnam, Indonesia and Thailand.

In its activity INDEPTH is guided by the following key objectives:

- To initiate and facilitate cross-site, longitudinal health and social studies and impact assessments in severely resource constrained populations.
- To disseminate study findings with all external stakeholders to maximize impact on policy and practice.
- To foster and support capacity building and cross-site collaborations among INDEPTH member sites.
- To facilitate the process for donors to fund multi-site health and social research projects in the developing world and especially Africa and Asia.

INDEPTH’s mission is to harness the collective potential of the world's community-based longitudinal demographic surveillance initiatives in resource constrained countries to provide a better, empirical understanding of health and social issues, and to apply this understanding to alleviate the most severe health and social challenges (INDEPTH, 2006).

Thus, the principles of the INDEPTH’s functioning is in longitudinal population-based surveillance which involves following the members of a geographically defined population over
time, collecting data on the core components of demographic change – birth, death and in- and out-migration defined by age, sex and geographic area.

Basic strengths of DSS are in:
- possibilities to get data on socioeconomic background of the residents, being interviewed according to certain questionnaires, besides demographic data mentioned above
- possibilities to gather data on birth, morbidity and mortality cases that have not been registered and reported by health care facilities
- longitudinal approach
- cost saving, because DSS software is freely possible to be downloaded and installed via the Internet, making it possible to initiate HRS (Household Registration System)-based surveillance at any time

Saying about weaknesses of DSS, one needs to point out the following:
- Inaccurate reporting by respondents during interviews
- Incorrect entries of the data into data-collection books
- Data-entry errors on the computer
- Insufficient tools so far to catch and correct these errors

Analysing comparatively two HISs, i.e. DSS and PIN based HIS, one should note the following disadvantages of DSS:

1. Subjectivity of information being gathered according to specific questionnaires during the interviews. In other words, self-estimation and self-description of health and socioeconomic status, and demographic data by the residents themselves may be inaccurate intentionally and unintentionally as well. PIN based HIS is guided more by objective approach in its activity.

2. Dealing only with sampled part from the whole population in case of DSS. It means that the difficulties and restrictions to generalize the findings may emerge during the data analysis. In opposite to that, PIN based HIS has all potentials to deal with data of the whole population under the study.

Besides these advantages before the DSS, one should mention again that PIN based HIS can provide collection and analysis of all these data, i.e. data regarding health, socioeconomic
status of the population and demographic processes as successfully as DSS does it having a longitudinal approach in the data analysis.

Understanding of these basic differences in the principles of the functioning of two HISs that I have found making a comparative analysis, has been my personal motivation to focus on the PIN based HIS within my Master’s thesis.

4.3 Ethical clearance.

Any research that deals with medical or/and social aspects of individuals should be given approval from an appropriate authority concern. According to the World Medical Association declaration of Helsinki (1964) and international guidelines for biomedical research involving human subjects proposed by WHO and the Council for International Organizations of Medical Sciences (CIOMS) (1991), any research activity should always adhere to the principles of respect for persons, beneficence, non-maleficence and justice (Persson and Wall, 2003). Since the study will be focused on dealing with data on health and socioeconomic status of a pilot region’s individuals, the research proposal will be submitted to the Ministry of Health and National Medical Ethical Committee in Kyrgyzstan for approval before the future study can be conducted.

4.4 To analyze what should be done in Kyrgyzstan in order to protect the privacy of individuals dealing with large datasets with sensitive information.

Storage and protection of the privacy for the individuals included in different data registers are the basic and crucial requirements for the activity of a coordinating center in Kyrgyzstan. The rules on how to use, store and protect information contained within these data bases should be strictly stipulated by laws.

The problem on privacy of individuals within datasets should be discussed by the Parliament of Kyrgyzstan as by legislative branch of the power and appropriate laws should be adopted.

That is why after approval by the National Medical Ethical Committee, the research proposal will be presented for the scrutiny to the Parliament of Kyrgyzstan.
During the work of the Parliament such questions should be discussed and solved as, e.g. the following:

1. Who is allowed to use information from the nation-wide data bases?
2. Who should give permission to use information from the nation-wide registers?
3. Which aims the information from the registers can be used and interlinked by a PIN system for?
4. Which registers will be allowed to be interlinked by a PIN system and which registers will be forbidden?
5. Which sanctions should be taken in case of rules of privacy being violated?

It is obvious that there will be a lot of other questions that will appear during discussions of the deputies in the Parliament. All these questions will facilitate the creation of the legislative ground for the activity of a coordinating center in Kyrgyzstan.

Swedish legislative basis for the EpC’s activity will be scrutinized and used as a basic guidance in the process of elaboration of the legislative basis for a coordinating center’s activity in Kyrgyzstan.

Moreover, discussing about ethical considerations, one need to note one more technical aspect of a coordinating center’s activity. All data gathered by health care facilities and other corresponding institutions using a PIN, will be directed to a coordinating center regularly only through the use of separate disks just for safe transportation and for entering into the software for registration and analysis at a coordinating center afterwards. It means that the probability of use of Internet for data sending purposes will be excluded absolutely because of potential risks of data misuse.

4.5 To analyze which types of health related data that could be interlinked by a Personal Identification Number system, such as e.g. the Swedish system.

As it has been mentioned already, health related data in Sweden, which are aggregated according to certain registers, have been collected for decades and include a unique PIN for all registered persons. These registers are nation-wide and cover the whole Swedish population. Therefore, the EpC has the national responsibility for the following health related registers:
The data in all these registers, excepting for two of them, are possible to be interlinked in data analysis with other variables, i.e. with data on socioeconomic status of individuals.

Thus, within a future research there is a big necessity to compare all currently existing health related data sources and data sources on individuals’ socioeconomic status in Kyrgyzstan with analogues Swedish data sources. However, it should be mentioned within this study protocol that there is an obvious and cardinal difference between Kyrgyz and Swedish models of HIS – it is the PIN system which is absent in Kyrgyzstan. The PIN system is the most important and crucial prerequisite for creation of a new HIS in Kyrgyzstan on the basis of Swedish model. Basing on differences between HISs, being found after a comparative analysis, new registers will be created in Kyrgyzstan according to analogues Swedish datasets.

4.6 To analyze the advantages of interlinking health related data using a Personal Identification Number system for data analysis.
Besides being responsible only for the National Public Health Reports, the EpC in its activity focuses on Social Reports as well. It means that in the process of prioritization and targeting of vulnerable layers within a society in Sweden, EpC interlinks data from the health related registers with the data on different socioeconomic variables of individuals, such as data from the registers on income, taxes, education, marital status, occupation, information on whether individual is employed or unemployed etc. A vivid example for such an interlinked data analysis could be the following example. Thus, several studies of the health and social outcomes of single parents and their children have been conducted by EpC researchers. The results of these studies have been shown that children of single parents showed lower educational attainment than children in two-parent families. Socioeconomic disadvantages, especially scarce material resources, largely explain some of these differences (Rosen, 2003). Another research that was conducted by Weitoft (2003), has shown that the lone mothers in Sweden have a risk to die because of external causes almost to 60% more than two-parent families.

Which other examples of conclusions from previous studies based on a PIN system might be presented? Thus, it has been shown that cancer patients in Sweden run greater risk of committing suicide than the general population does. The severity of the cancer increases the suicide risk (Björkenstam et al., 2005). Other studies have demonstrated issues on occupations at high risk of cancer and premature mortality. Occupations at high risk of cancer and premature mortality have been followed and analyzed using record linkages of population censuses and the Cancer Register or the Cause-of-death Register. By linking two population censuses, 1960 and 1970, with the Cancer Register, risks of long-term occupational exposure could be studied. People with the same occupation in both years were defined as long-term exposed. Based on analysis of this data set, some research results were confirmed, while other hypotheses were rejected. Excess risks found earlier, such as that for lip cancer among farmers and fishermen, and excess lung cancer risks among miners and chimney sweeps were confirmed. On the other hand, as a result of research being conducted by EpC, there has not been found any association between bladder cancer and dental technicians or between brain tumors and engine-drivers (Rosen, 2003).

One should mention that the strategy of targeting vulnerable groups within the population has been focused by Swedish government through adoption of a document called “Invest in Health – Prioritize Health”. Thus, in 1994, the government presented a document entitled “Invest in Health – Prioritize Health”, where new methods of health promotion and disease prevention
were highlighted in order to reach the groups at greatest risk. In 2000, a report from a National
Committee on Public Health presented national goals in public health, which emphasized the
need for decreasing gaps in terms of health among different social groups (Hjortsberg and
Ghatnekar, 2001). This is also an example, where the use of PIN in order to find the groups of
population at greatest risk would be as a crucial tool for achievement of that goal. The EpC
supplies information to the Parliament and the Government, other public authorities, county
councils, municipalities, researchers, media and the general public. This information is
summarizing by EpC as reports. These reports of EpC, i.e. National Public Health Reports and
Social Reports serve as a basis for national social and health policy considerations. This
advantage means that the government can allocate resources effectively taking into consideration
current demands and responding to different challenges within a society.

There is a big advantage in the research activity on national level and international level
as well. Thus, the EpC conducts research in collaboration with national and international
researchers as well as clinicians, planners, and other professionals in the health and social
sciences. The research program has included studies on different subjects, such as cancer
survival, equity in health care, social inequality in health, incidence, social consequences of
illness, forecasting public health issues in society, socio-economic problems etc.

In EpC’s activity, the personal identification number makes it possible to follow a patient
between different hospitals and over time (Centre for Epidemiology, 2005).

According to Black (2003), there are several reasons why it may be necessary for
individuals to be identified in data bases:

- Linkage within a database. It might be necessary to interlink several episodes or events
  happening to an individual patient. For example, to find out if someone is readmitted to hospital.
- Linkage between databases. It might be necessary to link between databases if the outcome of
  interest is not available in the database that contains the information on an exposure (such as an
  environmental hazard or a medical treatment).
- Ensure that comparisons are meaningful. That means an importance to take into account
  potential confounding factors, which commonly include identifiers such as age, sex and
  socioeconomic status.
● Ensure completeness of recruitment. To check that a database has included data on all eligible patients under the study, it is necessary for comparison and analysis against another source of data. It is also necessary to avoid duplicate entries.
● Investigation of social factors. Any study that needs to take a patient’s social circumstances into account must include data on factors such as age, sex and place of residence.
● Assessing the applicability of research findings. The results of a study may not apply equally to all ages, sexes, ethnic groups and socioeconomic groups. That is why it is important to include these different variables in the dataset during investigation of the effect such factors.

These advantages of interlinking health related data using a Personal Identification Number system for data analysis has shown that using a longitudinal approach in the study (possibilities to follow up individuals retrospectively and prospectively as well) and socioeconomic variables (possibilities to take into account socioeconomic variables of individuals during the health related data analysis) are key instruments to target vulnerable groups within the population and to plan interventions effectively. Understanding of these Swedish HIS’s advantages has been my main personal motivation to initiate this plan for future research.

4.7 To make a plan on how the selection of a pilot region and implementation of interlinked data monitoring should be done in Kyrgyzstan.

Selection of a pilot region in Kyrgyzstan should be done with an assumption that all already available resources (human resources, computer technologies and another infrastructure) should be concentrated as maximum as possible in a chosen pilot region at the time of a start for the project to establish a coordinating center. The capital city, Bishkek, could correspond to this selection criteria being performed better in terms of available infrastructure in comparison with other potential candidates for being a pilot region, i.e. in comparison with seven oblast centers in Kyrgyzstan. This advantage of a capital city should be taken into account during selection process of a pilot region. Kyrgyzstan is divided to seven administrative units called oblasts. They are Chui, Naryn, Talas, Issyk-Kol, Osh, Jalal-Abad and Batken oblasts. Each oblast is divided to
smaller administrative units called rayons. There is an oblast center, i.e. biggest city in each oblast.

After selection of a pilot region all residents of this chosen region will be registered within a population register and they will be given a personal identification number. Then, other registers containing data on socioeconomic conditions of the individuals of a pilot region will be established. After this procedure, all health care facilities in Kyrgyzstan will be informed about the individuals of a pilot region in terms of their general passport data, i.e. name, date of birth and place of residence. It would be reasonable to ask: why should all health care facilities in Kyrgyzstan be informed about the pilot region’s residents? It is in order to take into account migration processes connected to the residents of a pilot region, i.e. if the resident of a pilot region will take a medical assistance somewhere outside of a pilot region, i.e. in other hospitals of Kyrgyzstan, then it will be valuable to gather information on where, why, when and what medical assistance has the resident of a pilot region got etc. Then these health care facilities outside of a pilot region will send gathered information monthly to a coordinating center situated in the pilot region.

Because the activity of a coordinating center will be similar with the activity of a Swedish model in organizational and technical aspects, creation of missing data sets in Kyrgyzstan is required, which should be done after detailed comparison of two HISs within a future study. A final plan for an establishment of a coordinating center will depend on a selected pilot region, i.e. its extent of willingness for such an intervention in terms of necessary human resources and infrastructure. Creation of a PIN system in a pilot region is the crucial requirement for a further activity towards the establishment of a new HIS in Kyrgyzstan. Organizational and technical aspects of a PIN system’s creation will follow the principles of a Swedish PIN system as well, which will be studied in details within a future study.

The final decision on a selection of a pilot region will be adopted after consultations with the officials of the Ministry of Health and the Government in Kyrgyzstan.

4.8 To make a plan for the human and other resources that must be employed to develop a coordinating center in Kyrgyzstan.
Availability of a background among recruited employees in statistics, informatics, medicine and health economics according to coordinating center’s activity will be required. Other criteria concerning the personnel’s background that will be valuable for the activity of a coordinating center are the following:

- evaluation of the academic titles of the personnel
- evaluation of the skills in foreign languages
- analysis on whether the potential candidate has an experience of being involved previously in the studies about health information systems and personal identification number systems
- analysis on whether the candidate participated previously in international conferences dedicated to the problems of health information systems and personal identification number systems
- analysis on whether the candidate has got an education abroad previously related to the problems of health information systems and personal identification number systems

As these systems, i.e. Swedish models of HIS and PIN systems are absolutely new for Kyrgyzstan, training courses to introduce these systems for the personnel of a coordinating center will be required. Solution of a problem on acquisition and installation, quantity of software, hardware and other necessary equipments and also number of staff for coordinating center’s activity will be based on detailed knowledge about the Swedish HIS’s activity within a future study.

4.9 To make a plan on how the costs can be measured and calculated.

The total cost for an establishment of a coordinating center will consist of the following:

- **Staffing.**
  That means the total annual cost of the wages for the whole personnel involved in the activity of a coordinating center. The total annual cost of the wages will be determined according to the number of staff employed for.

- **Administration.**
The administration cost will include such expenses as for:
- phone bills
- postal charges
- stationery charges
- software/hardware acquisition
- office furniture
- monthly payments for:
  - water supply service
  - current
  - heating
  - INTERNET connection etc.

- Training courses.
  This cost will include expenditures for the conducting of the preparatory training courses for the personnel of a coordinating center. Thus, this cost will consist of the expenditures for:
  - wages for the staff involved in the teaching process (lectures, seminars)
  - teaching materials, i.e. handouts, articles, books etc.
  - rent payments for the rooms in order to conduct lectures and seminars

- Transport.
  This cost will include expenses for the fuel and technical maintenance.

  The total cost that should be calculated through summing up all the expenses which have been mentioned above, will be measured then in monetary units. Final evaluation of the effects of a coordinating center’s activity by representatives from the Ministry of Health, Government and Parliament of Kyrgyzstan should be based on an analysis of a center’s report at the end of the first year of its activity.

  Based on the comments, offers and final decisions which could have been taken during discussions from the representatives of the institutions mentioned above, further plan for future activity of a coordinating center will be adopted.

4.10 To make a time plan for the establishment of a coordinating center in Kyrgyzstan.
Time plan for the establishment of a coordinating center in Kyrgyzstan is given within the following table:

<table>
<thead>
<tr>
<th>Expected duration of the establishment of a coordinating center in Kyrgyzstan (in months)</th>
<th>Planned activity.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 6 months</td>
<td>All residents of a pilot region will be registered and will be given a personal identification number.</td>
</tr>
<tr>
<td>7 – 12 months</td>
<td>Creation of new registers containing data on socioeconomic variables of the residents of a pilot region.</td>
</tr>
<tr>
<td>13 – 24 months</td>
<td>Staff recruitment and conducting of training courses.</td>
</tr>
<tr>
<td>25 – 30 months</td>
<td>Establishment of a coordinating center itself, i.e. establishment of a, e.g. building, computerization, provision by a current, water supply, heating system etc.</td>
</tr>
<tr>
<td>31 – 42 months</td>
<td>Time for the functioning of a newly established coordinating center with the final report on its activity at the end of this time interval.</td>
</tr>
</tbody>
</table>

4.11 To summarize the expected results.

The expected short time benefits of the functioning of a coordinating center will be the possibilities of targeting vulnerable social groups within a society and facilitating an effective resource allocation. Thus, it will help, e.g. to answer such questions as:

- What are the most vulnerable layers within a society?
- What leading disorders are these vulnerable groups suffering from?
- What are the possible explanations for these disorders?
- Is there any connection between disorders and occupation, marital status, income level, place of residence?
- What should be done in order to improve this situation etc.?

In long time perspective, it would be useful to elaborate and adopt the strategies for interventions in order to improve population’s health status.
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