

**Palliative Care Needs Assessment  
Republic of Kazakhstan**

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## EXECUTIVE SUMMARY

This needs assessment calculates that approximately 94,200-97,900 patients annually require palliative care in Kazakhstan, with a minimum of 15,500 patients on service at any given time. In addition, as there are usually two or more family members directly involved in the care of each patient, care would be given to a minimum of approximately 282,600 persons annually. To provide home-based and inpatient palliative care to this extent would require substantial reallocation of healthcare professional resources for both the urban and rural areas; approximately **6675** staff and **825** palliative care beds would be required for this need to be fully met.

There has been much progress in the development of palliative care in Kazakhstan in recent years, involving many highly committed individuals and organizations. However, in a survey conducted by Thomas Lynch in 2011, hospice representatives identified a number of problems that still exist in the country: a shortage of hospice and palliative care services; lack of education and training opportunities; legislative and policy barriers to the development of the discipline; lack of awareness and understanding about palliative care amongst healthcare professionals and wider Kazakhstan society; barriers to the accessibility and availability of opioids; lack of intersectoral collaboration/coordination (for example, between the Ministry of Health and the Ministry of Social Care); the absence of a National Palliative Care Association; and the lack of an advocacy framework for the integration of palliative care into the Kazakhstan healthcare system.

There are currently five organizations providing inpatient palliative care in five areas of Kazakhstan – Almaty, Pavlodar, Karaganda, Ust-Kamenogorsk, and Kostanai; there is also one organization providing home-based palliative care in Semei. Most palliative care for children still occurs at home in Kazakhstan, although ‘some pediatric palliative care’ provision is available at Almaty Center for Palliative Care. The organizations

currently working in palliative care appear to provide an excellent service often under very difficult and demanding conditions, and patients (adults and children) and their caregivers appear 'very satisfied' with the treatment and care that they receive there.

However, hospice representatives suggest that there is 'far from universal palliative care coverage' in Kazakhstan; development is occurring spasmodically rather than according to any specific strategy, and this often results in large areas with little coverage. The number of hospices in Kazakhstan is described as 'too low and insufficient for the number of people requiring palliative care' and many trained palliative care staff 'do not want to work in rural areas'. There are a number of excellent palliative care education and training initiatives in Kazakhstan, although hospice representatives identified a number of difficulties in this area; for example, a 'lack of experienced trainers and educators' in the discipline. A major challenge for the future is the contrast between the enormous need for palliative care services in Kazakhstan in relation to the limited number of trained professionals to deliver such care.

Hospice representatives stated that 'limited forms of opioids' were available at their organization, that they 'rarely ran out of medication', and most had guidelines on how to gain access to opioids for pain relief and how to use those opioids effectively. However, 'some difficulties' were encountered: concerns that 'medicines will be used illegally'; the 'quality of medication available'; the low level of opioid consumption related to INCB quotas; a lack of choice of opioids; a lack of knowledge/awareness about opioid use amongst physicians; and a fear of opioid addiction/dependence amongst the patient and family members. Excessively strict legislation and bureaucracy in relation to licensing, transportation, prescribing practices, storage procedures, etc. was also reported.

A normative base for palliative care is beginning to be developed in Kazakhstan and progress is being made on legislation - there are some Orders, Articles and documents

that stipulate 'what palliative care is' (based on the WHO definition) and which patients are entitled to it and palliative care is currently included in a number of legal documents. However, the sequence of documents relating to palliative care in Kazakhstan appears to be rather unclear and although palliative care provision is included in the legal framework, it is not adequately addressed and 'often underdeveloped'. The lack of uniform documents regulating palliative care provision at a national level and the absence of guidelines for the assessment and evaluation of the quality of such services results in a lack of coordination and integration of the discipline across health care settings and services; this, in turn, results in limited palliative care service capacity. The area of health policy in Kazakhstan is closely linked to the concept of palliative care and the availability and accessibility of opioids as a fundamental human right; however, most respondents acknowledge that the 'human rights approach' is 'very new to Kazakhstan' and that it 'may take some time' before it is fully embraced.

There are a number of socio-cultural aspects relating to the provision of palliative care in Kazakhstan; for example, lack of awareness about the discipline amongst healthcare professionals and wider Kazakhstan society. Yet despite such limitations in awareness, much progress has been made by a relatively small number of doctors and nurses who are specialized in the discipline, in combination with other highly committed and enthusiastic individuals. These palliative care 'champions' have served to accelerate the pace of palliative care development in Kazakhstan and increase a base of support for the discipline. For example, some excellent awareness-raising initiatives are occurring in the country thanks to organizations such as SFK. In September 2012, palliative care featured on the agenda of the 7<sup>th</sup> CIS Oncology and Radiotherapy Congress in Astana for the first time (at both the Plenary and Scientific Session level) generating a number of television interviews promoting the concept of palliative care (including a full-length interview with Thomas Lynch on *World Hospice and Palliative Care Day*, 13<sup>th</sup> October 2012).

## MAIN RECOMMENDATIONS

### Implementation

- Most people in Kazakhstan die at home, and would prefer to do so: although there is a need to develop inpatient services in the future they should be smaller in size, positioned strategically throughout the country (particularly in rural areas of Kazakhstan) and (most importantly) possess the capacity to deliver effective **home-based** palliative care services;
- Focus on developing palliative care teams in existing healthcare institutions - for example, fund pilot palliative care doctor and nurse teams in oncology hospitals;
- Improve inter-sectoral collaboration/coordination between health and social service agencies in relation to the provision of palliative care.

### Education and training

- Develop and support the institutionalization of sustainable undergraduate and post-graduate palliative care education and training programs for physicians, nurses, psychologists, social workers, chaplains, volunteers etc;
- Palliative care in Kazakhstan can often be delivered at home; appropriate training should be provided to 'lay' carers (family, neighbors and community members);
- Increase the number of trained palliative care educators in Kazakhstan.

### Opioid availability

- Update the National (Republic) Drug Formulary to ensure that all WHO Essential Medicines are stocked (including oral morphine) and a rational prescription policy exists;

- Provide education and training ‘for physicians and nurses at the under-graduate and post-graduate level to increase knowledge and awareness about opioids’ (including issues surrounding pain management and in relation to the concepts of ‘addiction and dependence’);
- Reduce the excessive bureaucracy associated with the storage and prescription of opioids (paperwork, legal restrictions, etc.)/remove the restrictions in Kazakhstan National Drug Control Policy to both the amount of drug prescribed and the duration of treatment.

### **Policy**

- Increase understanding amongst key stakeholders, politicians and policymakers of the changes needed in public health policy in order to develop a legislative framework for palliative care implementation within the Kazakhstan health care system;
- Develop a strategic five-year Action Plan for implementing palliative care services including an ‘economic evaluation of palliative care’ to develop ‘effective finance control mechanisms’ (there is a need for programs to be both ‘cost-effective’ for the State and effective for the patient);
- Actively promote the concept of palliative care and the availability and accessibility of opioids in Kazakhstan as a basic and fundamental human right.

### **Awareness-raising and collaboration**

- Establish a *National Association of Palliative Care* that can help other organizations in Kazakhstan wishing to open a hospice/develop palliative care services;

- Increase advocacy activities around *World Hospice and Palliative Care Day* that will help raise awareness about the importance of palliative care at national and regional levels;
- Enhance collaboration between various sectors, government and state organizations civil society groups and religious/spiritual organizations (including those which are not yet directly involved in palliative care activities).

## **INTRODUCTION**

### **Aim of the Needs Assessment**

The aim of this palliative care needs assessment is to identify the need for palliative care in Kazakhstan and highlight the challenges and opportunities that are associated with future development of the discipline. The needs assessment includes comprehensive data on the healthcare system in Kazakhstan, the country, the population needing palliative care, the workforce required to deliver palliative care, and preliminary recommendations for the further implementation of palliative care services.

### **Target audience**

The primary audience for this palliative care needs assessment is the Kazakhstan Ministry of Health, which is responsible for health care planning in the country. Also targeted are the other leading health care institutions in Kazakhstan, policy makers, government officials and all other Ministries, legislators, public health officials, healthcare professionals involved in palliative care practice and development, non-governmental organizations (NGOs) and civil society organizations in the country.

### **Definition of Palliative Care**

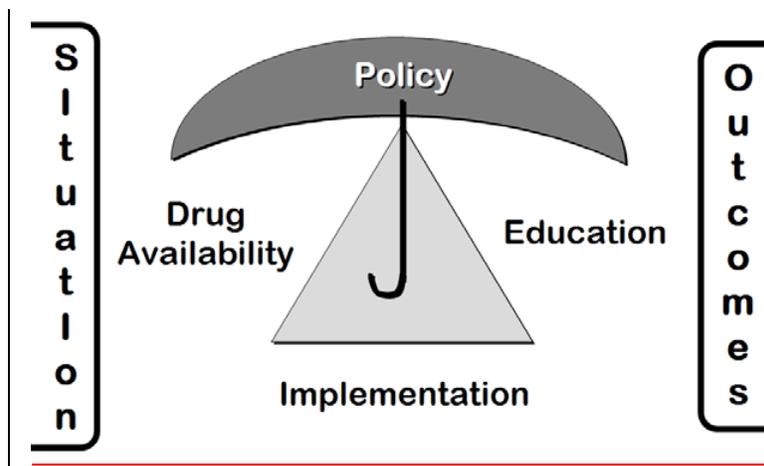
This palliative care needs assessment is based on the World Health Organization's (WHO) definitions of *palliative care* (**Appendix A**) and *pediatric palliative care* (**Appendix B**). 'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care for children represents a special, albeit closely related field to

adult palliative care. Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.'<sup>1</sup>

### WHO Public Health Model

Believing that palliative care should be accessible to all patients, the author adopted a public health perspective to assess the situation in Kazakhstan. The modified World Health Organization (WHO) Public Health Model was used to provide a framework for the study and for this report. A public health approach aims to protect and improve the health and quality of life of a community by translating new knowledge and skills into evidence-based, cost-effective interventions that will be available to everyone in the population who needs them. As palliative care is an integral part of care for all patients, and the most beneficial approach to care for patients with advanced disease, it is important that all countries integrate palliative care into their healthcare systems at all levels.

### WHO Public Health Model for Palliative Care<sup>2</sup>



<sup>1</sup> World Health Organization. WHO Definition of Palliative Care. <http://www.who.int/cancer/palliative/definition/en/>

<sup>2</sup> Stjernsward, J., The public health strategy for palliative care. *Journal of Pain and Symptom Management*, 2007

## Methods

This palliative care needs assessment for Kazakhstan has been prepared by Open Society Foundation (OSF) International Palliative Care Consultant Dr. Thomas Lynch with assistance from Soros Foundation Kazakhstan (SFK), the Republican Center for Development of Health Care (RCDH) and the Kazakhstan School of Public Health (KSPH). The majority of work in compiling this report was conducted during four visits to Kazakhstan by Dr. Lynch between 2010 and 2012. Both quantitative and qualitative research methodologies were utilized to gather data for this needs assessment; for example, some interviews were conducted with key stakeholders in the development of palliative care in Kazakhstan and a number of specific questionnaires and surveys were completed by them.

In addition, representatives from hospices in Kazakhstan completed a Strategy Planning Worksheet that asked them to describe a specific problem relating to palliative care; the underlying reasons for the problem; objectives that would address the problem; the action steps required to achieve that objective; those individuals and organizations that possessed the authority/responsibility to undertake the necessary action; the timeline for completion of the action steps; and the technical and financial assistance required to achieve each objective. Results from the Strategy Planning Worksheet are described within the relevant chapters of this palliative care needs assessment.

### Interviews Conducted/Questionnaires and surveys completed

Date	Name	Organization
November 23 <sup>rd</sup> 2010	Ainur Shakenova and Aida Aidarculova	Open Society Foundation Kazakhstan
November 23 <sup>rd</sup> 2010	Maksut Kulzhanov and Saltanat Yegeubayeva	Kazakhstan School of Public Health
April 26 <sup>th</sup> 2011	Ainur Shakenova and Aida Aidarculova	Open Society Foundation Kazakhstan

April 26 <sup>th</sup> 2011	Saltanat Yegeubayeva	Kazakhstan School of Public Health
April 27 <sup>th</sup> 2011	Aman Zhangireyev and Dr. Kulzanov	National Tuberculosis Center, Almaty
April 28 <sup>th</sup> 2011	Maksut Kamaliev	State Medical University, Almaty
April 29 <sup>th</sup> 2011	Adzanobe Doze and Dr. Izmukhomvetove	Republican Medical College
April 29 <sup>th</sup> 2011	Nagima Plokhikh and Olzhas Zhandosov	Alsager Foundation, Almaty
November 11 <sup>th</sup> 2011	Aizhan Oshakbayeva	Open Society Foundation Kazakhstan
November 12 <sup>th</sup> 2011	Saltanat Yegeubayeva	Kazakhstan School of Public Health
November 14 <sup>th</sup> 2011	Seysembaevna Gulmayra Kenjebayeva	Karaganda Nursing Hospital
November 14 <sup>th</sup> 2011	Galina Kosovo	Karaganda Nursing Hospital
November 14 <sup>th</sup> 2011	Lidiya Fedorova	Kostanai Regional Oncology Center
November 14 <sup>th</sup> 2011	Marina Scherbatyuk	Kostanai Regional Oncology Center
November 14 <sup>th</sup> 2011	Anarhan Nurkerimova	Almaty Center for Palliative Care
November 14 <sup>th</sup> 2011	Erbolat Bairov	Ust-Kamenogorsk Hospice
November 15 <sup>th</sup> 2011	Bakytgul Nabiyeva	Ust-Kamenogorsk Hospice
November 15 <sup>th</sup> 2011	Assem Kassenova	'Solaris' Hospice, Pavlodar
November 15 <sup>th</sup> 2011	Alain Ozdoyev	'Solaris' Hospice, Pavlodar
November 15 <sup>th</sup> 2011	B M Zhumadullaev	Institute of Oncology and Radiology
November 15 <sup>th</sup> 2011	Aman Zhangireyev	National TB Center, Almaty
November 15 <sup>th</sup> 2011	Askarovna Smailova	National TB Center,

	Gulnara	Almaty
November 15 <sup>th</sup> 2011	G. M. Akhmetov	National HIV/AIDS Center, Almaty
September 10 <sup>th</sup> 2012	Zhanna Kalmatayeva	Kazakhstan School of Public Health
September 11 <sup>th</sup> 2012	Bakhyt Tumenova	Non-governmental organization 'Aman Saulyk'
September 11 <sup>th</sup> 2012	Raikul Kopzhasaroka	Almaty Center for Palliative Care

A series of Working Group Meetings were conducted in Almaty and Astana to discuss the development of palliative care standards in Kazakhstan; in November 2010 (**Appendix C**), April 2011 (**Appendix D**) November 2011 (**Appendix E**) and September 2012 (**Appendix F**). Representatives from all hospice and palliative care providers and other key stakeholders were present at these meetings.

#### KAZAKHSTAN – THE COUNTRY



Kazakhstan is a landlocked country in Central Asia that is bordered by China, Kyrgyzstan, Russia, Turkmenistan, and Uzbekistan. The capital is Astana, with a population of approximately 650,000 (2009); the former capital Almaty has a population of 1.383 million (2009). Kazakhstan is comprised of 2,724,900 sq km of land (9th largest country in the world according to land mass); in comparative terms, Kazakhstan is slightly less than four times the size of Texas, USA. The land boundaries of Kazakhstan total 12,185 km, bordering: China 1,533 km; Kyrgyzstan 1,224 km; Russia 6,846 km; Turkmenistan

379 km; and Uzbekistan 2,203 km. Russia leases approximately 6,000 sq km of territory enclosing the Baykonur Cosmodrome; in January 2004, Kazakhstan and Russia extended the lease to 2050. Kyrgyzstan has yet to ratify the 2001 boundary delimitation with Kazakhstan; field demarcation of the boundaries with Turkmenistan commenced in 2005, and with Uzbekistan in 2004; ongoing demarcation with Russia began in 2007; demarcation with China was completed in 2002; creation of a seabed boundary with Turkmenistan in the Caspian Sea remains under discussion; Azerbaijan, Kazakhstan, and Russia ratified Caspian seabed delimitation treaties based on equidistance, while Iran continues to insist on a one-fifth slice of the lake.

The climate in Kazakhstan consists of cold winters and hot summers, arid and semiarid; the terrain is a vast flat steppe extending from the Volga in the West to the Altai Mountains in the East and from the plains of Western Siberia in the North to oases and deserts of Central Asia in the South. Natural resources include major deposits of petroleum, natural gas, coal, iron ore, manganese, chrome ore, nickel, cobalt, copper, molybdenum, lead, zinc, bauxite, gold, and uranium. Natural hazards include earthquakes in the South and mudslides around Almaty. Despite being party to a number of international agreements (Air Pollution, Environmental Modification, Hazardous Wastes, etc.), environmental issues include radioactive or toxic chemical sites associated with former defense industries and test ranges scattered throughout the country that pose health risks for humans; industrial pollution is also severe in some cities (for example, harmful layers of chemical pesticides picked up by the wind and blown into noxious dust storms) and there is soil pollution from overuse of agricultural chemicals. Agricultural products include: grain (mostly spring wheat), cotton, and livestock. Industry produces oil, coal, iron ore, manganese, chromite, lead, zinc, copper, titanium, bauxite, gold, silver, phosphates, sulfur, uranium, iron and steel; tractors and other agricultural machinery, electric motors, and construction materials. There is significant illicit cultivation of cannabis for markets in the Commonwealth of Independent States, as well as limited cultivation of opium poppy and ephedra (for the

drug ephedrine); limited government eradication of illicit crops; transit point for Southwest Asian narcotics bound for Russia and the rest of Europe; significant consumer of opiates.

## **Background**

Ethnic Kazakhs, a mix of Turkic and Mongol nomadic tribes who migrated into the region in the 13th century, were rarely united as a single nation. The area was conquered by Russia in the 18th century, and Kazakhstan became a Soviet Republic in 1936. During the 1950s and 1960s agricultural "Virgin Lands" program, Soviet citizens were encouraged to help cultivate Kazakhstan's northern pastures. This influx of immigrants (mostly Russians, but also some other deported nationalities) skewed the ethnic mixture and enabled non-ethnic Kazakhs to outnumber natives. Independence in 1991 drove many of these newcomers to emigrate. Kazakhstan's economy is larger than those of all the other Central Asian states largely due to the country's vast natural resources. Current issues include: developing a cohesive national identity; expanding the development of the country's vast energy resources and exporting them to world markets; diversifying the economy outside the oil, gas, and mining sectors; enhancing Kazakhstan's economic competitiveness; developing a multiparty parliament and advancing political and social reform; and strengthening relations with neighboring states and other foreign powers. Kazakhstan has 14 provinces (oblystar, singular - oblysy) and three cities (qalalar, singular - qala); Almaty Oblysy, Almaty Qalasy, Aqmola Oblysy (Astana), Aqtobe Oblysy, Astana Qalasy, Atyrau Oblysy, Batys Qazaqstan Oblysy [West Kazakhstan] (Oral), Bayqongyr Qalasy [Baykonur], Mangghystau Oblysy (Aqtau), Ongtustik Qazaqstan Oblysy [South Kazakhstan] (Shymkent), Pavlodar Oblysy, Qaraghandy Oblysy, Qostanay Oblysy, Qyzylorda Oblysy, Shyghys Qazaqstan Oblysy [East Kazakhstan] (Oskemen), Soltustik Qazaqstan Oblysy (Petropavlovsk), Zhambyl Oblysy (Taraz).

The Kazakhstan State owns nearly all radio and TV transmission facilities and operates national TV and radio networks; nearly all nationwide TV networks are wholly or partly owned by the government; some former state-owned media outlets have been privatized; households with satellite dishes have access to foreign media; a small number of commercial radio stations operating along with state-run radio stations; recent legislation requires all media outlets to register with the government and all television providers to broadcast in digital format by 2015.

### **Economy: an overview**

Kazakhstan, geographically the largest of the former Soviet republics, excluding Russia, possesses enormous fossil fuel reserves and plentiful supplies of other minerals and metals, such as uranium, copper, and zinc. It also has a large agricultural sector featuring livestock and grain. In 2002 Kazakhstan became the first country in the former Soviet Union to receive an investment-grade credit rating. Kazakhstan's economy has largely recovered from the global financial crisis of 2008, and GDP increased 7% year-on-year in 2011. Extractive industries have been and will continue to be the engine of this growth. Landlocked, with restricted access to the high seas, Kazakhstan relies on its neighbors to export its products, especially oil and grain. Although its Caspian Sea ports, pipelines, and rail lines carrying oil have been upgraded, civil aviation and roadways have been neglected. Telecoms are improving, but require considerable investment, as does the information technology base. Supply and distribution of electricity can be erratic because of regional dependencies. At the end of 2007, global financial markets froze up and the loss of capital inflows to Kazakhstani banks caused a credit crunch. The subsequent and sharp fall of oil and commodity prices in 2008 aggravated the economic situation, and Kazakhstan plunged into recession. While the global financial crisis took a significant toll on Kazakhstan's economy, it has rebounded well. In response to the crisis, Kazakhstan's government devalued the tenge (Kazakhstan's currency) to stabilize market pressures and injected around \$10 billion in economic stimulus. Rising

commodity prices have helped revive Kazakhstan's economy, which registered roughly 7% growth in 2010-11. Despite solid macroeconomic indicators, the government realizes that its economy suffers from an overreliance on oil and extractive industries, the so-called "Dutch disease." In response, Kazakhstan has embarked on an ambitious diversification program, aimed at developing targeted sectors like transport, pharmaceuticals, telecommunications, petrochemicals and food processing. In 2010 Kazakhstan joined the Belarus-Kazakhstan-Russia Customs Union in an effort to boost foreign investment and improve trade relationships. The government expects to join the World Trade Organization in 2012, which should also help to develop the manufacturing and service sector base.

In 2011, industrial production growth rate in Kazakhstan was estimated at 3.5% (96<sup>th</sup> in comparison to other countries of the world); it was estimated that Kazakhstan had GDP (purchasing power parity) of \$216.4 billion (USD) (53<sup>rd</sup> in comparison to other countries of the world); GDP (official exchange rate) was estimated at \$180.1 billion; GDP real growth rate was estimated at 7.5% (16<sup>th</sup> in comparison to other countries of the world). In 2010, Kazakhstan had a labor force of approximately 8.733 million (55<sup>th</sup> in comparison to other countries of the world) comprising of: agriculture 25.9%; industry 11.9%; and services 62.2%. In 2011, Kazakhstan had an unemployment rate of approximately 5.4% (52<sup>nd</sup> in comparison to other countries of the world); the inflation rate in Kazakhstan was 7.4% (162<sup>nd</sup> in comparison to other countries of the world). In Kazakhstan, the population below the poverty line is 8.2% (2009).

## **Population**

Languages are: Kazakh (Qazaq, state language) 64.4%, Russian (official, used in everyday business, designated the "language of interethnic communication") 95% (2001). Ethnic groups in Kazakhstan include: Kazakh (Qazaq) 63.1%, Russian 23.7%, Uzbek 2.8%, Ukrainian 2.1%, Uighur 1.4%, Tatar 1.3%, German 1.1%, other 4.5% (2009 census).

Religious groups include: Muslim 47%, Russian Orthodox 44%, Protestant 2%, other 7% (2001). In July 2012, the population of Kazakhstan was estimated at 17,522,010 - the 60th largest populated country in the world; the net migration rate was 0.43 migrant(s)/1,000 population (64<sup>th</sup> in comparison to other countries of the world).

In 2011, the age structure in Kazakhstan was estimated at: 0-14 years: 21.6% (male 1,709,929/female 1,637,132); 15-64 years: 71% (male 5,373,755/female 5,654,461); 65 years and over: 7.4% (male 392,689/female 754,407). Median age was estimated at a total of 30.2 years; male: 28.7 years; female: 31.9 years. In 2012, population growth rate was estimated at 1.235% (94<sup>th</sup> in comparison to other countries of the world); birth rate was estimated at 20.44 births/1,000 population (87<sup>th</sup> in comparison to other countries of the world); and death rate was estimated at 8.52 deaths/1,000 population (83<sup>rd</sup> in comparison to other countries of the world).

In 2012, the sex ratio in Kazakhstan was: at birth: 0.94 male(s)/female; under 15 years: 1.01 male(s)/female; 15-64 years: 0.94 male(s)/female; 65 years and over: 0.52 male(s)/female; total population: 0.92 male(s)/female. In 2012, the infant mortality rate was: total: 23.06 deaths/1,000 live births; male: 25.83 deaths/1,000 live births; female: 20.46 deaths/1,000 live births (85<sup>th</sup> in comparison to other countries of the world). In 2012, life expectancy was: total population: 69.63 years; male: 64.34 years; female: 74.59 years (148<sup>th</sup> in comparison to other countries of the world).

## **Cancer**

Cancer is an important public health problem in Kazakhstan, and is the third leading cause of premature death in the country. Every year more than thirty thousand Kazakhstani people are diagnosed with cancer. The most common types of cancer are lung, skin, breast and stomach. Lung cancer is the most common cancer in men, and breast cancer is the most common cancer in women. In addition to lifestyle factors

such as tobacco use and alcohol intake, it is believed that many of the health problems of the population (including cancer) have arisen from deteriorating environmental conditions; for example, through industrial and agrochemical pollution, and toxic chemical sites associated with former defense industries.<sup>3</sup>

In Kazakhstan, the rate of cancer incidence per 100,000 population decreased gradually since 2005 (but increased slightly in 2009): 192.6 (2005); 186.5 (2006); 184.7 (2007); 179.7 (2008); 181.9 (2009);<sup>4</sup> cancer prevalence in Kazakhstan (2009) was 0.87%. The standardized death rate (SDR) for malignant neoplasms (all ages per 100,000 population) was 156.57.<sup>5</sup> It can be assumed that the decrease in mortality rates related to cancer may be at least partially attributed to a gradual recovery in the Kazakhstan healthcare system following the collapse of the Former Soviet Union at the end of the twentieth century. The early part of the twenty-first century witnessed stability in the healthcare system and the implementation of improved programs in the area of cancer treatment (supply of chemotherapy medication, modernization of x-ray machines), screening (100 new mammography machines were purchased for different regions and oblasts) and early diagnosis.<sup>6</sup> Early detection programs in the areas of breast and cervical cancer have been taking place in Kazakhstan since 2008. According to these programs, every woman aged 35–60 years has a mammography and Pap smear test every five years.<sup>7</sup>

Decreases in mortality rates are also attributed to the education of specialists (particularly the training of cytologists in relation to cervical cancer); for example, in 2009, a ‘scientific-educational-practical cluster group’ was created by the *Kazakhstan*

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<sup>3</sup>Baizhumanova, A., Sakamoto, J., 2010. Cancer in Kazakhstan: Present situation. *Ann. Cancer Res. Therap.* Vol. 18(2): 65-68.

<sup>4</sup><http://www.mz.gov.kz/index.php?wakka=Eng/Media/PressRelizy/10112010eng1>

<sup>5</sup>[http://data.euro.who.int/hfad/b/tables/tableA.php?id=tbla\\_997682001334325769&ind=1510](http://data.euro.who.int/hfad/b/tables/tableA.php?id=tbla_997682001334325769&ind=1510)

<sup>6</sup><http://www.mz.gov.kz/index.php?wakka=Eng/Media/PressRelizy/10112010eng1>

<sup>7</sup>Baizhumanova, A., Sakamoto, J., 2010. Cancer in Kazakhstan: Present situation. *Ann. Cancer Res. Therap.* Vol. 18(2): 65-68.

*Institute of Oncology and Radiation* to consolidate the efforts of eight medical university oncology departments, seven oncology dispensaries, and the oncological scientific community. Conferences, sectional meetings and master-classes dedicated to questions of early diagnosis, screening, and treatment of breast, cervical, colorectal, and prostate cancer were held; international cancer specialists also collaborated with the group. Kazakhstan is the Commonwealth of Independent States (CIS) partner of the *European School of Oncology* (2009-2014).

In 2009, 29,071 patients were registered as cancer patients in Kazakhstan; in terms of morbidity, lung cancer accounts for 12.3% of all cases; breast cancer (11.3%); skin cancer (10.6%); stomach cancer (9.2%); and cervical cancer (4.65%).<sup>8</sup> In 2009, trachea, bronchus and lung cancer incidence per 100,000 was 22.44; SDR, trachea/bronchus/lung cancer, all ages per 100,000 population was 28.63; SDR, trachea/bronchus/lung cancer, 0-64 per 100,000 population was 15.96; cervical cancer incidence per 100,000 population was 16.38; SDR, cancer of the cervix, all ages, per 100,000 population was 9.35; SDR, cancer of the cervix, 0-64, per 100,000 population was 7.4; female breast cancer incidence per 100,000 population was 39.61; SDR, malignant neoplasm female breast, all ages per 100,000 population was 19.7; SDR, malignant neoplasm female breast, 0-64 per 100,000 population was 14.18.<sup>9</sup> A retrospective study undertaken by the Kazakh Scientific and Research Institute of Oncology and Radiology involving 28,707 patients with breast cancer over a ten-year period (1999-2008) concluded that the highest incidence of the disease was amongst women aged between 50-59 years.<sup>10</sup>

## **HIV/AIDS**

The Kazakhstan Ministry of Health coordinates the multi-sectoral response to the HIV/AIDS epidemic, provides the legal and policy framework and strengthens

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<sup>8</sup><http://www.mz.gov.kz/index.php?wakka=Eng/Media/PressRelizy/10112010eng1>

<sup>9</sup>[http://data.euro.who.int/hfad/b/tables/tableA.php?id=tbla\\_997682001334325769&ind=1510](http://data.euro.who.int/hfad/b/tables/tableA.php?id=tbla_997682001334325769&ind=1510)

<sup>10</sup>Igisinov, N., Bilyalova, Z., Igisinov, S., Seytkazina, G. 2010. *Breast Cancer in Kazakhstan: Epidemiological aspects*. Kazakh Scientific and Research Institute of Oncology and Radiology

partnerships among all stakeholders (including providing increased support to NGOs in the country). In 2006, the *National Programme against HIV/AIDS* in the Republic of Kazakhstan was adopted, with the aim of stabilizing HIV prevalence amongst high-risk groups. The *National AIDS Coordination Committee* coordinates the multi-sectoral response to the epidemic, provides the legal and policy framework, and strengthens partnerships among all stakeholders. The *National Centre for AIDS Prevention and Control* provides overall management and coordination of the health sector response to HIV/AIDS, including prevention, care and treatment services. The HIV/AIDS infrastructure consists of 21 centres for AIDS prevention and control, operating in all major *oblasts* and cities. Hospitals, TB Centres and oncology dispensaries provide treatment for opportunistic diseases and also provide **some elements of palliative care** (*but do not provide palliative care services*) for terminally-ill patients. In 2008, the Ministry of Health issued two important Orders expanding HIV/AIDS prevention measures in the country:

- Ministry of Health Order No. 45 of 5<sup>th</sup> February 2008 *On the Monitoring and Evaluation of Activities to Counteract AIDS Epidemics* introduced a comprehensive set of indicators to monitor the HIV/AIDS situation in the country;
- Ministry of Health Order No. 699 of 29<sup>th</sup> December 2008 regulated measures aimed at prevention of mother-child transmission and approved clinical standards based on WHO Guidelines.<sup>11</sup>

The Code of Health of the Republic of Kazakhstan (endorsed September 2009) does not contain any restrictions on entry, stay or residence for people living with HIV (PLHIV) in Kazakhstan, although some orders containing restrictions on entry are not yet abolished

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<sup>11</sup>Katsaga, A., Kulzhanov, M., Karanikolos, M., Rechel, B. *Kazakhstan: Health System Review*. Health Systems in Transition. 2012.

and a number of issues in the Code of Health in relation to HIV need clarification.<sup>12</sup> The Kazakhstan government included HIV as part of a Governmental Programme of Public Health Development (2011- 2015).

The Ministry of Health plays a leading role in community mobilization activities. International non-governmental organizations such as Population Services International are active in social marketing programmes.<sup>13</sup> In addition to the existing National Health Council, the Coordinating Committee for work with donors and international organizations was established in December 2009, and is chaired by the Minister of Health.<sup>14</sup> National government organizations such as the Astana and Almaty City Healthy Lifestyle Centres undertake information, education and communication activities on HIV/AIDS issues among the general population and youth and also coordinate health education activities in the mass-media and education sectors.<sup>15</sup> HIV interventions are incorporated into reproductive health, tuberculosis, mother and child health programmes. HIV education in schools is optional but needs be strengthened.

However, there are some problems related to HIV/AIDS in Kazakhstan: lack of understanding about the disease amongst government officials; government staff turnover is rather high; experienced governmental staff are often allocated to other projects (thereby weakening the technical capacity of national institutions); a lack of coordination and multi-sectoral interaction between relevant government departments; and the fear that HIV activities will not be properly and fully reflected in the Health Programme, and may even be lost amongst other health priorities – for example government commitment to fund harm reduction activities is low, so they are funded from the Global Fund to Fight AIDS, Tuberculosis and Malaria Project (GFATM).

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<sup>12</sup><http://www.unaids.org/en/Regionscountries/Countries/Kazakhstan/>

<sup>13</sup>[http://www.who.int/hiv/HIVCP\\_KAZ.pdf](http://www.who.int/hiv/HIVCP_KAZ.pdf)

<sup>14</sup><http://www.unaids.org/en/Regionscountries/Countries/Kazakhstan/>

<sup>15</sup>[http://www.who.int/hiv/HIVCP\\_KAZ.pdf](http://www.who.int/hiv/HIVCP_KAZ.pdf)

International assistance for the prevention and treatment of HIV/AIDS in Kazakhstan is paramount; of particular note is the support provided by GFATM who provided a USD 35,335,883 million grant (2009-2014). UNAIDS provides support to the government on policy issues. The *United Nations Theme Group for Kazakhstan on HIV/AIDS, Drugs and Vulnerable Groups* supports various government ministries in developing strategic HIV/AIDS prevention programmes. The National Centre for AIDS Prevention and Control provides overall management and coordination of the health sector response to HIV/AIDS, including prevention, care and treatment services. The *Knowledge Hub for the Care and Treatment of HIV/AIDS in Eurasia* (supported by the German Gesellschaft für Technische Zusammenarbeit (GTZ) and the WHO Regional Office for Europe in conjunction with the *American International Health Alliance*) supports capacity-building efforts in Kazakhstan. The United States Agency for International Development Regional Mission for Central Asia allocated US\$ 13 million through the Capacity Project (Central Asian Program on AIDS Control and Intervention Targeting Youth and High Risk Groups), under which technical assistance is provided to five Central Asian countries over a five-year period; approximately 35% of the funding has been allocated to Kazakhstan. Kazakhstan allocated approximately USD 55 million to the National AIDS Programme. Additional resources are available through the World Bank Central Asian countries.<sup>16</sup> WHO, UNAIDS and the Office for Central Asia of the United States Centers for Disease Control and Prevention provide support for surveillance activities.<sup>17</sup>

In 2009, the HIV/AIDS prevalence rate among adults aged 15 to 49 years was estimated at 0.1% (134<sup>th</sup> in comparison to other countries of the world); there were approximately 13,000 people living with HIV/AIDS in Kazakhstan (89<sup>th</sup> in comparison to other countries of the world), with approximately 500 deaths from HIV/AIDS (89<sup>th</sup> in comparison to other countries of the world).<sup>18</sup> It is estimated that approximately 1,900 people became

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<sup>16</sup><http://www.unaids.org/en/Regionscountries/Countries/Kazakhstan/>

<sup>17</sup>[http://www.who.int/hiv/HIVCP\\_KAZ.pdf](http://www.who.int/hiv/HIVCP_KAZ.pdf)

<sup>18</sup> Central Intelligence Agency (CIA) World Factbook  
[<https://www.cia.gov/library/publications/the-world-factbook/geos/kz.html>]

newly infected during 2009.<sup>19</sup> Incidence of HIV per 100,000 population (2009) was 13.07; incidence of AIDS per 100,000 population (2009) was 1.09.<sup>20</sup>

By the end of 2010, Kazakhstan reported a cumulative total of 15,754 HIV cases, and 1,242 AIDS cases. In total, 1,507,630 people over the age of 15 were tested for HIV and received their results during 2010; 1,988 new HIV cases, 256 new AIDS cases and 165 HIV/AIDS deaths were reported during this year. The rate of newly diagnosed HIV infections in 2010 was 12.4 per 100,000 population. The new HIV cases in 2010 for which the mode of transmission was known (96%) include: 43% who were infected heterosexually; 55% infected through injecting drug use; 1% infected through sex between men; and 1% infected through mother-to-child transmission. Kazakhstan has reported a cumulative total of 155 mother-to-child transmission cases, including 21 in 2010. Most people living with HIV/AIDS are men, although the proportion of women infected is reported to be increasing; in 2009, it was estimated that approximately 7,700 women were living with HIV in Kazakhstan. All women have equal access to services along with men, but decision making about safe sex in the majority of cases is still a prerogative of men.

Of newly reported cases in 2010, 63% were male.<sup>21</sup> In Kazakhstan, HIV/AIDS disproportionately affects young men, with those on the margins of the economy especially vulnerable; the most severely affected age group is 20–29 years.<sup>22</sup> The 2009 United Nations General Assembly Special Session (UNGASS report) suggested that young people require more education - only 19% correctly identified ways of HIV transmission and many had misconceptions about it.

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<sup>19</sup>[http://www.unaids.org/globalreport/documents/20101123\\_GlobalReport\\_full\\_en.pdf](http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf)

<sup>20</sup>[http://data.euro.who.int/hfadb/tables/tableA.php?id=tbla\\_997682001334325769&ind=1510](http://data.euro.who.int/hfadb/tables/tableA.php?id=tbla_997682001334325769&ind=1510)

<sup>21</sup>[http://www.unaids.org/globalreport/documents/20101123\\_GlobalReport\\_full\\_en.pdf](http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf)

<sup>22</sup>[http://www.who.int/hiv/HIVCP\\_KAZ.pdf](http://www.who.int/hiv/HIVCP_KAZ.pdf)

All oblasts (regions) have reported HIV cases, but the most severely affected regions of the country are Karaganda, Pavlodar, Southern Kazakhstan and Kostanai oblasts and Almaty City. Critical issues include the complexity of working with vulnerable populations and concurrent epidemics of both injecting drug use and sexually transmitted infections (coverage by prevention is reported to be approximately 50%);<sup>23</sup> although HIV/AIDS is also spreading to other vulnerable groups including youth, migrants and truck drivers. Kazakhstan is at the centre of intensive drug-trafficking routes, and the number of drug users continues to increase annually. Injecting drug users belong to the poorest group, which limits their access to services including information, health care services, clean needles and treatment. The existing legal framework does not facilitate HIV/AIDS prevention or treatment among groups with high-risk behaviour and discourages their contact with government institutions. Lack of social and legal tolerance for activities directed towards vulnerable populations, insufficient money, and unfavorable socio-economic conditions including increasing poverty, unemployment, and declining social services have created the potential for a rapid increase in HIV infection; three-quarters of people diagnosed with HIV are unemployed.<sup>24</sup> Almost a third of PLHIV are in prison and there is concern about their access to HIV prevention and treatment.<sup>25</sup> Another determinant negatively affecting the epidemic is the high migration of the population, including from areas of military conflict, as many Chechens and refugees from Tajikistan and Afghanistan currently live in Kazakhstan.<sup>26</sup>

WHO/Europe is rendering technical assistance in the development of a strategy for the integration of essential services to improve the quality of care for people living with HIV/AIDS. The biennial collaborative agreement for 2010–2011 between WHO/Europe and Kazakhstan identifies not only the priorities for action but also the results to be

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<sup>23</sup><http://www.unaids.org/en/Regionscountries/Countries/Kazakhstan/>

<sup>24</sup>[http://www.who.int/hiv/HIVCP\\_KAZ.pdf](http://www.who.int/hiv/HIVCP_KAZ.pdf)

<sup>25</sup><http://www.unaids.org/en/Regionscountries/Countries/Kazakhstan/>

<sup>26</sup>[http://www.who.int/hiv/HIVCP\\_KAZ.pdf](http://www.who.int/hiv/HIVCP_KAZ.pdf)

delivered. Priorities within the agreement include: strengthening surveillance and control of communicable diseases; management of HIV/AIDS; and strengthened capacity to address the main obstacles to delivery of expanded prevention, treatment and care interventions for HIV/AIDS. Strengthened capacity includes a HIV/AIDS evaluation report and recommendations on the priorities to be addressed. The national protocols and guidelines for the treatment and care of this patient group will continue to be updated.<sup>27</sup>

Under the overall goal of improving the prevention and control of HIV/AIDS, technical support related to delivering antiretroviral therapy will include support in implementing funding from the Global Fund, HIV/AIDS prevention and increased coverage of high-risk groups, voluntary counselling and testing, adapting and implementing the WHO treatment and care protocols at the local and national levels, ensuring quality standards for procuring antiretroviral drugs, building technical capacity through regional and national networks for training in HIV/AIDS treatment, addressing the links between HIV and TB, building the capacity of nongovernmental organizations and integrating HIV/AIDS prevention and control efforts with primary health care; however, there is a need to involve civil society in HIV/AIDS outreach work.

Over 80 HIV/AIDS non-governmental organizations (NGOs) are active in Kazakhstan – mainly funded from international grants (for example, GFATM).<sup>28</sup> Although the number of NGOs is increasing, they still experience problems in implementing their tasks. To a large extent, these problems stem from the lack of comprehensive and targeted State support and an unclear delineation of the role of NGOs in HIV/AIDS prevention.<sup>29</sup> The Law on HIV/AIDS Prevention stipulates that the government is responsible for providing treatment free of charge to people living with HIV/AIDS and for their social protection. It

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<sup>27</sup><http://www.euro.who.int/en/where-we-work/member-states/kazakhstan/areas-of-work>

<sup>28</sup>[http://www.unaids.org/globalreport/documents/20101123\\_GlobalReport\\_full\\_en.pdf](http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf)

<sup>29</sup>Katsaga, A., Kulzhanov, M., Karanikolos, M., Rechel, B. *Kazakhstan: Health System Review*. Health Systems in Transition. 2012.

also calls on the government to provide information on HIV/AIDS, to carry out prevention activities and to guarantee the human rights of people with HIV/AIDS. Mandatory HIV testing only applies to blood donation and organ donations, but testing is available on a voluntary basis for the rest of the population. Although the Law on HIV/AIDS Prevention makes provision for treatment free of user charges for people living with HIV/AIDS, in practice, state and local budgets do not usually allow such costly medicines to be procured. As a result, most people do not have access to antiretroviral therapy due to its high cost.<sup>30</sup>

In Kazakhstan, 10,057 people were enrolled in HIV care by the end of 2010. The number of people receiving antiretroviral therapy (ART) increased from seven in 2002 to a total of 1336 by December, 2010. Of the 1336 receiving ART, 734 (65%) were male (212 had an unknown gender), 182 (14%) were prisoners and 673 (50%) were infected through injecting drug use. As of 2010, 513 facilities in the country provided ART. In 2010, 1% of people receiving HIV care were co-infected with Hepatitis B and 8% co-infected with Hepatitis C.<sup>31</sup> According to Global Fund statistics, there are approximately 1,600 people currently receiving ART in Kazakhstan.<sup>32</sup>

As part of a joint United Nations plan on HIV/AIDS for 2010 to help Kazakhstan achieve universal access to prevention, treatment, care and support, WHO/Europe is facilitating a widening spectrum of registered second-line anti-retroviral (ARV) drugs in line with WHO recommendations. Along with the United Nations Children's Fund and the Joint United Nations Programme on HIV/AIDS, WHO/Europe is assisting the government in the procurement and supply management of ARV drugs and providing technical assistance in the revision of national HIV/AIDS treatment and care guidelines in line with WHO recommendations. This assistance will continue throughout the design, approval,

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<sup>30</sup>[http://www.who.int/hiv/HIVCP\\_KAZ.pdf](http://www.who.int/hiv/HIVCP_KAZ.pdf)

<sup>31</sup>[http://www.unaids.org/globalreport/documents/20101123\\_GlobalReport\\_full\\_en.pdf](http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf)

<sup>32</sup><http://portfolio.theglobalfund.org/en/Country/Index/KAZ>

submission, publication and distribution of the final report to the United Nations General Assembly Special Session.

## **TUBERCULOSIS**

Kazakhstan is among the top priority countries in Europe targeted for improved tuberculosis (TB) control and prevention. In November 1998, the Ministry of Health (MOH) issued an official regulation making DOTS (the internationally recommended strategy for TB control) the standard national protocol for TB treatment and DOTS coverage has been maintained at 100 percent since 1999. In 2008, USAID committed additional financial resources to assist in DOTS expansion to five additional regions. However, although incidence is declining and the overall management of TB in the country is improving, intensified measures are needed to stem Kazakhstan's increasing prevalence of multidrug-resistant (MDR) TB.

The National TB program is coordinated by the National TB Center at the national level. TB dispensaries guide TB control under supervision of the Ministry of Healthcare at the oblast level. A TB laboratory network has been established in the country including the National Reference Laboratory. However, the Center faces many challenges in terms of financial and human resource allocation within the TB program. Despite these difficulties, Kazakhstan is considered a relatively successful country compared to other Central Asian Republic countries. The Government of Kazakhstan recognizes the importance of TB control and is working to establish an effective system to fight TB. Much progress has been made toward integrating TB diagnosis and treatment into primary care.<sup>33</sup>

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<sup>33</sup>[http://www.usaid.gov/our\\_work/global\\_health/id/tuberculosis/countries/asia/kazakhstan\\_profile.html](http://www.usaid.gov/our_work/global_health/id/tuberculosis/countries/asia/kazakhstan_profile.html)

TB is an acute problem in the penitentiary system and among former prisoners. Most case detection occurs within the primary health care (PHC) system, and all TB and PHC providers are responsible for identification and referral of TB suspects. In Kazakhstan, the notification rate of new TB cases (2008) was 125.5 per 100,000 population in the civil sector and 767.7 per 100,000 population in the prison sector; TB mortality rate (2008) was 16.9 per 100,000 population in the civil sector and 115.9 per 100,000 population in the prison sector due to lack of adequate treatment of drug resistant tuberculosis (DR-TB). In 2008, 7,808 MDR-TB patients were registered in the civil sector and only 30% of them were put on treatment with second line drugs (SLDs). In relation to the prison sector there was no MDR-TB treatment available at that time; treatment follow-up of released prisoners is a further challenge to the control of TB in Kazakhstan.

In 2009, the incidence of tuberculosis per 100,000 population (2009) was 128.78; standardized death rate (SDR) from tuberculosis (all ages) per 100,000 population (2009) was 14.04.<sup>34</sup> The total number of reported cases of tuberculosis in 2010 was 15,563; rates of tuberculosis by age group were: 0-14 years – 726; 15-17 years – 887; 18-34 years – 7909; 35-54 years – 4472; 55-64 years – 1014; 65 years and over – 555.<sup>35</sup>

The biennial collaborative agreement for 2010–2011 between WHO/Europe and Kazakhstan identifies management of tuberculosis as a priority objective. Strengthened capacity includes recommendations for improving the performance of the National TB programme and capacity building in critical performance areas.

Partnerships are an important element in combating TB in Kazakhstan. USAID is one of the main donors in Kazakhstan and has provided support mainly through the Project HOPE, the lead member of a consortium that included John Snow, Inc, Johns Hopkins University's Center for Communication Programs, and the New Jersey Medical School's

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<sup>34</sup>[http://data.euro.who.int/hfadb/tables/tableA.php?id=tbla\\_997682001334325769&ind=1510](http://data.euro.who.int/hfadb/tables/tableA.php?id=tbla_997682001334325769&ind=1510)

<sup>35</sup><http://www.eng.stat.kz/digital/Health%20care/DocLib1/tuberkulez.xls>

Global Tuberculosis Institute. USAID has also supported a two-year MDR-TB case management and social support project implemented by the Tuberculosis Control Assistance Program, and managed by the KNCV Tuberculosis Foundation. The KfW (German Development Bank) has supported TB control through investments in facility renovations and procurement of equipment for laboratories. USAID has also provided support to the U.S. CDC for national TB surveillance and information systems, the Capacity Project, and the ZdravPlus Project.<sup>36</sup>

In November 2009, WHO organized a mission to Kazakhstan with EXPAND-TB, a project to accelerate access to diagnostics for patients at risk of multidrug-resistant TB; the project was run jointly by WHO, the Global Drug Facility (GDF) and the Foundation for Innovative New Diagnostics (FIND), within the framework of the Global Laboratory Initiative (GLI). The aim of the project was to strengthen TB laboratory services to anticipate the impact of novel technologies for rapid detection, identification, and drug susceptibility testing of *Mycobacterium tuberculosis*, and to ensure that the associated laboratory infrastructure, and financial and human resources are mobilized to facilitate their absorption in Kazakhstan.

The project included representatives from WHO headquarters and FIND, who had meetings with the Ministry of Health and National TB Control Programme officials. A round table event was held with relevant stakeholders (including the Ministry of Justice's department of penitentiary facilities, the Global Fund, East-West, the United States Agency for International Development, the Ministry of Health and the National TB Control Programme focal point), who also worked with the national TB reference laboratory staff to fill in a mission software application assessing the laboratory capacity of the country. The draft of a memorandum of understanding to be concluded with FIND/WHO and the Government of Kazakhstan was shared with the Ministry of Health;

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<sup>36</sup>[http://www.usaid.gov/our\\_work/global\\_health/id/tuberculosis/countries/asia/kazakhstan\\_profile.html](http://www.usaid.gov/our_work/global_health/id/tuberculosis/countries/asia/kazakhstan_profile.html)

this enabled innovative equipment and consumables to be purchased, and the capacity of laboratory staff to be strengthened.<sup>37</sup>

The HIV status of 97% of TB patients is known with approximately 1% being HIV-positive.<sup>38</sup> In Kazakhstan, approximately 46% of HIV-positive people are diagnosed with TB. They are much more likely to develop TB, which is an opportunistic disease, because of a depressed immune system; those living with HIV/AIDS are five times more likely to contract TB. In Kazakhstan, more than a third (36%) of people living with HIV die of TB.<sup>39</sup>

### **Kazakhstan Red Crescent Society (Credo)**

The *Kazakhstan Red Crescent Society (Credo)*, through funding from AstraZeneca via the British Red Cross, is working in the area of TB/HIV. Since 1998, Credo has been a member of the *European network of the Red Cross and Red Crescent societies to fight HIV/AIDS (ERNA)* and the organization has been implementing its TB/HIV integrated programme in the towns of Almaty, Temirtau and Karaganda since 2005. As part of Credo's plan to tackle tuberculosis (TB) in Kazakhstan, TB and HIV co-infection has been singled out as vital to making progress in reducing TB incidence and mortality. Credo works very closely with the Ministry of Health to ensure that services are coordinated. The project aims to strengthen the country's health system by working as an auxiliary to the government TB and HIV programmes.

The Tuberculosis (TB) prevention programme provides direct observation of treatment, social, psychological support and counselling to people with TB and multi-drug resistant TB (MDR-TB) and targets those with co-infection who are considered most likely to default on their treatment. Proper use of TB drugs and completion of treatment are essential not only for patients to be cured, but also to prevent the development of

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<sup>37</sup><http://www.euro.who.int/en/where-we-work/member-states/kazakhstan/areas-of-work>

<sup>38</sup><http://www.tbcare1.org/countries/car/kaz/>

<sup>39</sup> <http://www.ifrc.org/docs/appeals/annual06/Logframes/Europe/CA/KAZAK-Prof.pdf>

multidrug-resistant tuberculosis (MDR-TB), and extensively drug-resistant tuberculosis (XDR-TB), forms of the disease which are much more difficult and expensive to treat, and with lower rates of cure.

Credo's multi-disciplinary team of a psychologist, social worker and a lawyer support each client; approximately 18 volunteers within the project have been recruited from the client group as volunteer peer supporters. The programme provides clients and their families with psychosocial, medical advice and peer support, as well as monthly food parcels, in order to maintain adherence to lengthy treatments; the programme facilitates access to medical consultations for reviews of treatment regimens or advice on side-effects of treatment. Legal assistance is also provided and deemed as essential because those who are HIV positive are often discriminated against, and it is sometimes hard to find employment, or even register for citizenship. Educational activities on the diagnosis and treatment of TB as well as the promotion of safer sexual and drug use behaviour – to reduce further transmission of both TB and HIV - are also included, mainly targeting injecting drug users or sex workers. Clients are usually referred by the AIDS Centres and may also come on their own. Nearly three quarters of clients (74%) are former prisoners of which 52% are injecting drug users and homeless.<sup>40</sup>

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<sup>40</sup><http://www.ifrc.org/docs/appeals/annual06/Logframes/Europe/CA/KAZAK-Prof.pdf>

## THE HEALTHCARE SYSTEM

Kazakhstan is subdivided into 16 administrative divisions (*oblasts* and cities). *Oblast* governors are key players in decisions relating to the health care system, as are finance departments at *oblast* level. Following independence, Kazakhstan initially encountered a severe economic recession and a crisis in the healthcare system.<sup>41</sup> Reduction in healthcare expenditure resulted in a shortage of physicians and the closure of many primary health care centers (especially in rural areas); consequently, access to the healthcare facilities for the Kazakhstan population was often difficult.<sup>42</sup> Since becoming independent from the Former Soviet Union, the situation has become more stable, and Kazakhstan has undertaken major efforts to reform its healthcare system and implement new programs of reform. Two comprehensive programs have been developed since independence: the *National Programme for Health Care Reform and Development* (2005-2010) and the *State Health Care Development Programme* (2011-2015) *Salamatty Kazakhstan*. Changes in health service provision included a reduction of the hospital sector and an increased emphasis on primary health care.<sup>43</sup> There has also been progress on promoting evidence-based medicine and developing and introducing new clinical practice guidelines, as well as facility-level quality improvements. However, key aspects of health system performance are still in need of improvement. A key challenge is regional inequities in health financing, health care utilization and health outcomes, although some improvements have been achieved in recent years.<sup>44</sup> In 2009, total health expenditure as % of GDP was 4.3% (155th in comparison to other countries of the world);<sup>45</sup> total health expenditure, PPP\$ per capita was 553.84; public sector

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<sup>41</sup>Katsaga, A., Kulzhanov, M., Karanikolos, M., Rechel, B. *Kazakhstan: Health System Review*. Health Systems in Transition. 2012.

<sup>42</sup>Baizhumanova, A., Sakamoto, J., 2010. Cancer in Kazakhstan: Present situation. *Ann. Cancer Res. Therap.* Vol. 18(2): 65-68.

<sup>43</sup>Katsaga, A., Kulzhanov, M., Karanikolos, M., Rechel, B. *Kazakhstan: Health System Review*. Health Systems in Transition. 2012.

<sup>44</sup><http://esa.un.org/unpd/wpp>

<sup>45</sup>Central Intelligence Agency (CIA) World Factbook

[<https://www.cia.gov/library/publications/the-world-factbook/geos/kz.html>]

health expenditure as % of total health expenditure was 59.22; and public sector expenditure on health as % of total government expenditure was 11.28.<sup>46</sup>

The Ministry of Health is the governmental department in charge of the healthcare system in Kazakhstan. The Ministry is a central executive authority, which directs and (in conformation with the Law of the Republic of Kazakhstan, the acts of the President and the Government of the Republic of Kazakhstan, other legal acts and Decrees) provides inter-sectoral coordination in the field of citizens' health protection and medical and pharmaceutical education. The principal aims of the Ministry are: to create State policy in relation to the protection of the health of the Kazakhstan population; medical science, medical and pharmaceutical education; provide treatment with safe, effective and quality medicines; and organize and develop international collaborations. The Ministry has the following agencies: the Committee of national sanitary-and-epidemiological control; the Committee of Pharmacy; and the Committee of medical services quality control.<sup>47</sup>

The Ministry of Health reorganized the structure of its departments and committees during 2008–2009. The main activities of the Ministry of Health focus on: reforms and development of the health delivery system (primary health care, sanitary epidemiological services, and health promotion); improvement of the health management system; maternal and child health; and training and re-training of health personnel (reform of medical and pharmaceutical education).

Kazakhstan faces high maternal, infant and under-five mortality rates, and the Ministry of Health has declared its decrease to be its number one priority. In addition, there is high morbidity from diseases of the cardiovascular system and mental health, unhealthy lifestyles, high morbidity from communicable diseases (such as tuberculosis, HIV/AIDS

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<sup>46</sup>[http://data.euro.who.int/hfadb/tables/tableA.php?id=tbla\\_997682001334325769&ind=1510](http://data.euro.who.int/hfadb/tables/tableA.php?id=tbla_997682001334325769&ind=1510)

<sup>47</sup><http://www.mz.gov.kz/index.php?wakka=/Eng>

and sexually transmitted diseases), and infections (such as hepatitis and HIV/AIDS through unsafe blood transfusion). Other characteristics are poor access to essential services, especially in rural places and through the old managerial capacity of health service delivery institutions. Diseases such as Crimean-Congo haemorrhagic fever, anthrax, brucellosis, and plague are still endemic in the country. Too much emphasis has been placed on high technology projects and activities, with heavy investments in new equipment and infrastructure over the last few years; relatively little attention is paid to the strengthening of basic public health measures; for example, sexually transmitted infections have increased sharply since independence.

In 2009, the number of hospitals per 100,000 population in Kazakhstan was 6.41; the number of hospital beds per 100,000 was 761.36; hospital bed density in Kazakhstan was 7.6 beds/1,000 population (11<sup>th</sup> in comparison to other countries of the world). In 2010, in Kazakhstan there were 998 hospitals; 119,026 hospital beds; 20,502 pediatric hospital beds; 143,822 medical personnel (including 63,855 physicians). The number of physicians of all specialties per thousand population was 63.8; the number of medical personnel per thousand population was 143.8.<sup>48</sup>

**Selected health data for Kazakhstan (2009)<sup>49</sup>**

<b>Data</b>	<b>Indicator</b>
SDR all causes, all ages, per 100,000	1239.58
Acute (short-stay) hospitals per 100,000	5.8
Primary health care units per 100,000	49.31
Acute care hospital beds per 100,000	559.36
Nursing and elderly home beds per 100,000	133.12
Private in-patient hospital beds as % of all beds	5.75

<sup>48</sup><http://www.eng.stat.kz/digital/Health%20care/19992007/Dynamics%20of%20public%20health.xls>

<sup>49</sup>[http://data.euro.who.int/hfadbf/tables/tableA.php?id=tbla\\_997682001334325769&ind=1510](http://data.euro.who.int/hfadbf/tables/tableA.php?id=tbla_997682001334325769&ind=1510)

Physicians, medical group of specialties (PP), per 100,000	85.81
% of physicians working in hospitals	43.6
General practitioners (PP) per 100,000	26.1
Nurses (PP) per 100,000	711.22
% of nurses working in hospitals	58
Physicians graduated per 100,000	18.56
Nurses graduated per 100,000	18.88
Average length of stay, all hospitals	12.1
Average length of stay, acute care hospitals only	9.7
Bed occupancy rate in %, acute care hospitals only	88.5

In Kazakhstan, physicians are trained for six years following a one-year internship based on six major specialties (residency). After the internship, physicians can specialize in more than 80 disciplines with a training period of between two and four years duration. Further education is conducted at the Postgraduate Medical Institute or at one of the medical research institutes. Physicians must do a short retraining course every five years and clinical lecturers every three years. However, this requirement has faltered due to budget cuts and the difficulties of taking leave from employment. There are considerable regional variations, with the highest concentration of health care workers in the major cities and shortages in rural areas. Despite some reform initiatives, the quality of training and retraining remains poor and salaries for health care workers are far below the national average.<sup>50</sup>

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<sup>50</sup>Baizhumanova, A., Sakamoto, J., 2010. Cancer in Kazakhstan: Present situation. *Ann. Cancer Res. Therap.* Vol. 18(2): 65-68.

## **GOVERNMENTAL ORGANIZATIONS WORKING IN THE AREA OF PALLIATIVE CARE (BUT NOT PROVIDING PALLIATIVE CARE SERVICES)**

There are a number of governmental organizations *working in the area of palliative care* in Kazakhstan and providing **some elements of palliative care** (*but not providing palliative care services*). For example, a nursing hospital in Ekibastuz is providing **some elements of palliative care**, as is a pediatric HIV/AIDS Hospital in South Kazakhstan where there are 30 rooms on two-storeys comprising of two people per room (one child plus one parent). In 2010, 200 pediatric HIV/AIDS patients received care at the hospital (18 deaths - South Kazakhstan only). Psychologists work at the hospital and in the community to 'reintegrate children with HIV/AIDS back into schools, social life, etc.' A TB hospital is providing **some elements of palliative care** in the Kazgurt region of South Kazakhstan (one doctor, six nurses).

### **Kazakh Scientific and Research Institute of Oncology and Radiology (Department of Paid Services)**

*Kazakh Scientific and Research Institute of Oncology and Radiology* is the equivalent of the *National Cancer Institute* in the United States. The Institute is responsible for all cancer control programs in Kazakhstan, providing a multidisciplinary approach to cancer treatment, education and training. The Institute is also responsible for developing cancer policy in Kazakhstan. Two nationwide screening programs for breast and cervical cancer were launched in 2008 with the support of the Ministry of Health; the Institute is currently working on developing screening programs for colorectal, prostate and gastric cancer.<sup>51</sup>

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<sup>51</sup><http://www.uicc.org/membership/kazakh-research-institute-oncologyradiology>

The Institute provides **some elements of palliative care** in the form of inpatient and daycare services. The Institute is 'self-financing' as there are 20 'fee-paying beds' for patients; 'approximately five or six beds' are allocated for 'incurable cancer patients' (Stage III or IV), 'four or five beds' are allocated for patients 'receiving X-ray treatment' and 'ten beds' are allocated for 'surgery patients'. In addition, the Institute cares for 'approximately 25 HIV/AIDS patients' each month. In the Institute, there is no separate department for patients receiving **some elements of palliative care** – all groups of patients receive care in the same department 'due to cost'.

There are 'approximately 16 employees' at the Institute: one Head of Department, four physicians (chemotherapist, radiation therapist, surgeon, cardiologist), five nurses, and six 'nurse aids'. Staff at the Institute have not received any specific training in aspects of palliative care, but have received training in aspects of pain management; the training was two weeks in duration, and focused on general aspects of pain treatment, and more specific aspects such as 'techniques for safe dilution of drugs for use in chemotherapy'. Staff at the Institute would like to receive more training in these and other related-areas (for example, the use of opioids in oncology).

Each year, 'approximately 300 patients' receive opioids at the Institute (approximately 30 patients per month). Medications currently available at the Institute include 'antibiotics (for infusion therapy) analgesics, and haemostatics'; the Institute 'ran out of morphine' in the six-month period May–October 2011. The Institute 'has guidelines on pain relief' but does not have guidelines on 'how to use opioids for pain relief' or 'how to gain access to opioids for pain relief'. The Procurement Department is responsible for submitting orders for supplies of opioids; a physician is responsible for prescribing opioids; the Head of Department is responsible for maintaining drug stock levels and records of opioid use (along with physicians); either a physician or the duty nurse assume responsibility for dispensing opioids, whilst responsibility for administering opioids belongs to the Head of Department, in conjunction with 'a commission which

consists of five representatives from the Department of Administration'. The Institute encounters 'some difficulties' in managing opioids due to excessive and restrictive bureaucracy; for example, 'limits to the amount of opioids that can be prescribed at any one time'. A barrier to providing patients with adequate pain relief in Kazakhstan is the 'lack of transdermal opioids'.

### **National HIV/AIDS Center**

The National HIV/AIDS Center provides **some elements of palliative care** in the form of 'daycare and psychosocial assistance'. The Center is funded by a combination of 'State budget and paid services'. There are six daycare beds at the Center that provide care for 'approximately 30 patients per month'. There are eight employees at the Center: one physician, one daycare nurse, three social workers and three volunteers. Staff at the Center have received training in 'some aspects' of palliative care ('two days duration'), but have received 'no training' in pain management; staff would like to receive additional training in a number of areas; for example, 'palliative care for patients with double infections (TB and HIV/AIDS)' as this group of patients face a 'difficult mental/cultural attitude towards them in Kazakhstan society'. Medication currently available at the Center includes 'antiretroviral (for preventive treatment) and antibiotics (for symptomatic treatment)'. The Center 'has run out of some antiretroviral medicines' in the six-month period May-October 2011 and does not have guidelines on pain relief or how to gain access and use opioids for pain relief. Morphine is not used at the Center.

### **National Tuberculosis Center**

The National Tuberculosis Center provides **some elements of palliative care** at their inpatient unit which comprises of 'approximately 425 beds'. Staff at the Center have received training in 'some aspects' of palliative care (for example, a two-day training

course on 'protocol development'), but have received 'no training' in pain management. Staff at the Center would like to receive more training, particularly in the area of 'palliative care for chronic Tuberculosis patients'. 'No medication' is currently available at the National Tuberculosis Center, and the Center does not have guidelines on pain relief or how to gain access and use opioids for pain relief. A barrier to providing patients with adequate pain relief in Kazakhstan is the 'lack of oral opioids'.

In an interview with Aman Zhangireyev from the National Tuberculosis Center, some of the inherent difficulties encountered in this area were highlighted. In 1985, the 'first case of HIV/AIDS in Kazakhstan was thought to be TB'. A 'Decree from the President' in 1998 halted the TB screening programme and 'caused an epidemic' of the disease. Reduction in the incidence of TB since that era has been due 'to better diagnostics' as opposed to 'economic reasons'; for examples, TB mortality/morbidity rates 'remain high in West Kazakhstan, despite income from oil revenues'. The period 2003-2005 is described as 'a problematic era as TB centres were unable to collaborate with HIV/AIDS Centers'. During this time, 'physicians had difficulty in locating the exact physical symptoms of TB in Ministry of Health (MoH) cases', partly due to 'inaccurate statistics'. For example, in 2005, the MoH reported the 'number of drug users in Kazakhstan at 286' (other sources estimated the actual number to be nearer to 250,000); statistics were also produced that suggested 'multi-strain TB could be cured "more easily" than ordinary TB'. Current Government statistics are also described as 'inappropriate' (as they are 'too favourable'). In Kazakhstan, it costs 'approximately 50USD per day' to treat a TB patient. A physician used to get extra money for TB patients but this system of remuneration was subject to abuse so physicians now refer patients to hospital for treatment. TB patients in Kazakhstan are described as 'much younger' than cancer patients. Many young people/teenagers develop TB and Kazakhstan has one of the highest rates of incidence of the stable form of TB in CEE/CIS; there are 'many financial costs and social implications' of this rate of incidence.

The most common type of TB among HIV/AIDS patients is 'lung/meningitis' and only '4/100 patients experience "no change" in their lung capacity' following TB treatment. However, other forms of TB do exist - for example, spinal TB and TB meningitis patients that are described as 'hard to treat'. Aman suggests that TB among HIV/AIDS patients 'may come in waves'. TB/HIV patients 'do not want injectable medication (just oral) but there is a problem regarding accessibility/availability'. In addition, TB/HIV patients need antibiotics but also require ARVs (the combination of which may cause liver damage). Blood tests for TB/HIV patients are described as 'unpredictable due to changes over short periods of time', and 'resistance to antibiotics amongst TB/HIVAIDS patients is rapid' so drug regimens must be changed regularly (even weekends, national holidays, etc.).

Multi-resistant TB may develop from initial TB on a secondary basis. Aman is the head of a group of clinical researchers who are developing a new anti-TB medicine that has been tested on 66 HIV/TB patients in the second phase of TB. In terms of effectiveness, patients have had a 'good reaction' to the treatment. During a four-to-five month period, patients stopped developing TB bacteria 'in 100 per cent of cases' and both their clinical state and psycho-social state 'substantially improved'.

Currently, every TB hospital has one room solely for TB/HIV patients; there are therefore 'approximately fifteen beds nationwide' available for TB/HIV patients, but the treatment for this group of patients is described as 'sub standard'. Palliative care for TB/HIV patients is described as 'different to other groups of patients' as treatment may be withdrawn due to an increased number of side-effects (for example, kidney infections, etc.) Also, although 'approximately 50% of TB/HIV patients may need palliative care', it is often deemed 'unethical to treat them in a normal hospital' ('ill patients next to dying patients') – they cannot go to a traditional hospice either due to contagion (it is currently illegal to allow TB/HIV patients who may be considered contagious into a hospice). The current situation is that groups of patients with TB/HIV

and no possibility of a cure are 'sources of infection' and as they cannot access a hospice or hospital, they inevitably 'must die at home'. Aman also highlights the fact that in many cases people with TB/HIV are shunned by their family and relatives who refuse to let them remain at home due to the stigmatized and taboo status of the disease; they are almost always unemployed and therefore 'a very socially vulnerable group'.

Aman therefore suggests that a new TB/HIV hospice is needed in Kazakhstan. Thanks to support from the local health department, Aman has been provided with facilities on the site of the existing TB hospital where TB/HIV patients will be able to stay for 'as long as is needed' at nil cost. The proposed hospice is described as a 'free-standing building' which it is hoped will be a 'special place' where patients will be allowed to die in 'normal conditions'. The new hospice will contain 'between forty and sixty beds' and may be able to receive some budget from the Kazakhstan government in the first year as a 'pilot project' - this support could continue if it can be demonstrated that caring for patients in the hospice is 'cost-effective and also justifiable on both moral and ethical grounds'. The hospice will offer paediatric palliative care but the inherent problem of children/young people 'sharing a social space with adults' is acknowledged. The main aim of the new hospice is to provide an isolated space due to the risk of contagion, as a patient with an open form of TB may infect a large number of people very quickly. Therefore the concept of a TB/HIV hospice is not only 'morally correct' but also 'socially and financially viable'. However, Aman accepts that doctors and nurses will need specialist training and education in order to provide the care that is required but knows of 'almost no other' countries with experience of caring for TB/HIV patients. Within this context, Aman suggests that 'technical support will be needed' in order to prepare members of the interdisciplinary team (for example, social workers, psychologists, etc.) for when the hospice opens. Aman also suggests that 'moral and social support' will be required for health care professionals.

## THE NEED FOR PALLIATIVE CARE IN KAZAKHSTAN

Representatives from hospices in Kazakhstan were asked a series of questions about the status of palliative care in the country; their responses are shown in the table below:

**Table 1: Questionnaire responses from Kazakhstan hospice representatives**

Question	Hospice representative responses
<b>'What do you consider the primary purpose of palliative care to be?'</b>	<ul style="list-style-type: none"> <li>• 'Both pain relief and end of life care'</li> <li>• 'End of life care only'</li> <li>• 'Care which addresses suffering'</li> </ul>
<b>'What other care and/or support do you think people with a chronic illness need?'</b>	<ul style="list-style-type: none"> <li>• 'Psychological support'</li> <li>• 'Moral and emotional support'</li> <li>• 'Financial support'</li> <li>• 'Access to medical care'</li> <li>• 'Social support'</li> </ul>
<b>'What services do you think the Kazakhstan government should provide to people with chronic illnesses such as cancer and HIV/AIDS?'</b>	<ul style="list-style-type: none"> <li>• 'Treatment and care'</li> <li>• 'All services that are provided to people with other diseases'</li> <li>• 'Exchange of experience with patients from other countries'</li> <li>• 'Psycho-emotional support'</li> <li>• 'Financial support (allowances, benefits)'</li> <li>• 'Free opioids, free treatment at the hospital level, quality medical services'</li> <li>• 'Information for relatives'</li> </ul>
<b>'How do you think people in the community should provide support to people with HIV/AIDS and people with cancer?'</b>	<ul style="list-style-type: none"> <li>• 'Moral and financial'</li> <li>• 'Non-discrimination and understanding'</li> <li>• 'To provide care, to treat pain'</li> <li>• 'To be kind'</li> <li>• 'Without stigma'</li> </ul>
<b>'What information do you think should be included in national palliative care guidelines?'</b>	<ul style="list-style-type: none"> <li>• 'Alleviating pain and symptoms'</li> <li>• 'Emotional and psychological support'</li> <li>• 'Legal issues'</li> <li>• 'Training and education'</li> </ul>
<b>'How would you evaluate the overall progress in hospice and palliative care in Kazakhstan?'</b>	<ul style="list-style-type: none"> <li>• 'Beginner level'</li> <li>• 'Level at start of development'</li> <li>• 'No progress yet'</li> <li>• 'Average/moderate'</li> </ul>

<p><b>'What are some of the most significant changes that have taken place in the hospice and palliative care sector in Kazakhstan and what has contributed to those changes?'</b></p>	<ul style="list-style-type: none"> <li>• 'Definition of palliative care'</li> <li>• 'Very important that this issue is being discussed and that guidelines are being developed'</li> <li>• 'Improvement in financing'</li> <li>• 'Hospice for children'</li> </ul>
<p><b>'What would you like to see happen next to improve hospice and palliative care in Kazakhstan?'</b></p>	<ul style="list-style-type: none"> <li>• 'Development of palliative care standards'</li> <li>• 'Informing the population'</li> <li>• 'Define normative basis of palliative care'</li> <li>• 'Changes in legislation are needed'</li> <li>• 'Hospice for TB patients'</li> <li>• 'Good financing/develop sponsorship'</li> <li>• 'New hospices in regions (rural) and towns'</li> <li>• 'Recognition at the governmental level'</li> </ul>
<p><b>'How has the provision of palliative care developed in hospitals; nursing homes; residential homes; other community settings?'</b></p>	<ul style="list-style-type: none"> <li>• 'Palliative care is provided in nursing homes'</li> <li>• 'Development has just started'</li> <li>• 'In all these organizations staff are taught how to care about patients and about ethics in palliative care'</li> </ul>
<p><b>'Has palliative care in Kazakhstan been expanded from a focus on cancer patients to address the needs of 'non-cancer' patients?'</b></p>	<ul style="list-style-type: none"> <li>• 'Yes, to HIV/AIDS and TB patients'</li> <li>• 'Should also be Asthma, psychosis, heart disease, etc.'</li> <li>• 'Just a little'</li> </ul>
<p><b>'What are the most significant issues facing hospice and palliative care in Kazakhstan in the next three years?'</b></p>	<ul style="list-style-type: none"> <li>• 'Informing the public'</li> <li>• 'Creation of a palliative care system'</li> <li>• 'Financing'</li> <li>• 'Training and education'</li> <li>• 'Changing the mentality of the Kazakhstan population'</li> <li>• 'Absence of legislation'</li> <li>• 'Founding of new hospices'</li> </ul>
<p><b>'What role do you envisage your association or organisation will play in addressing these issues?'</b></p>	<ul style="list-style-type: none"> <li>• 'Contributing to organizing palliative care for HIV/AIDS patients'</li> <li>• 'Providing organizational and methodological assistance in founding a TB hospice'</li> <li>• 'Generate human resources'</li> <li>• 'Education and counselling'</li> </ul>
<p><b>'Given the current economic crisis, what do you anticipate to be the challenges ahead and their</b></p>	<ul style="list-style-type: none"> <li>• 'Adopting particular legislation for palliative care'</li> <li>• 'Appearance of a leader who will work on</li> </ul>

<p><b>implications for palliative care in Kazakhstan?’</b></p>	<p>palliative care development’</p> <ul style="list-style-type: none"> <li>• ‘Attracting sponsors and foundations’</li> <li>• ‘Support from the government (financial)’</li> <li>• ‘Founding a center for further development of palliative care in Kazakhstan’</li> <li>• ‘Attract national companies for solution of internal issues’</li> <li>• ‘Teaching general practitioners about palliative care and pain relief skills’</li> <li>• ‘Understanding that it is necessary!’</li> </ul>
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Hospice representatives completed Strategy Planning Worksheets that identified a number of barriers to the development of palliative care in Kazakhstan. The first barrier identified was the shortage of hospice and palliative care services in the country. The number of hospices in Kazakhstan was described as ‘too low, and insufficient for the number of people requiring palliative care’ in the country; an uneven spread of palliative care services also results in a lack of comprehensive coverage across rural areas. A number of underlying reasons for this problem were suggested: a lack of public awareness and underestimation of the problems associated with providing palliative care; inadequate financing mechanisms; a low level of understanding amongst governmental departments which meant that there was ‘no concrete State program’; a lack of palliative care ‘champions’ in Kazakhstan; no legislative base; low levels of awareness amongst other healthcare professionals; and a ‘lack of volunteers/social workers/ fundraisers’. A survey conducted in 2009 by the ‘Healthy Ageing’ project in collaboration with international agencies suggested that palliative care is only at an early stage of development and in high demand. Lack of palliative care facilities was identified by respondents as one of the major problems.<sup>52</sup>

The hospice representatives stated a number of objectives that, in their opinion, would serve to address some of these problems. For example, increased media involvement

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<sup>52</sup>Aman Saulyk (2010b) *Socio-medical problems of elderly and disabled people: today and tomorrow*. Astana, Aman Saulyk. <http://www.amansauilyk.kz/library/socium/9/>

and communication strategies to raise awareness about hospices in Kazakhstan; additional legislation relating to the cost-effectiveness of palliative care; development of a normative base and palliative care standards; and increased education about palliative care amongst healthcare professionals.

Hospice representatives suggested that a number of action steps were required in order to achieve these objectives, including the need to 'change the attitude' of the Kazakhstan government; the participation of international donors; the identification of new palliative care 'champions'; and the development of 'new methodologies and study programs'. A number of individuals and groups that possessed the authority and/or responsibility to take the necessary action were identified: governmental departments (for example, Ministry of Health, Ministry of Social Affairs, Ministry of Justice, Ministry of Finance, etc.); local authorities; public health organizations; heads of hospitals, etc. When asked to consider a realistic timescale for completion of the action steps, hospice representatives suggested 'three to five years'. In order to achieve these objectives, financial resources for 'study programs and social marketing' are required, an 'economic evaluation is needed', and an 'improvement in the material and technical base' will be necessary.

A barrier to the development of palliative care in Kazakhstan that was identified by hospice representatives was the lack of a National Palliative Care Association in the country. A number of underlying reasons for this problem were suggested: a low level of palliative care development; the lack of palliative care 'champions'; and because there are 'few palliative care specialists' in the country which often results in a 'loss of continuity' within the discipline. The hospice representatives stated a number of objectives that, in their opinion, would serve to address some of these problems. For example, 'gather specialists and other interested parties together for dialogue', and 'experience exchange' with other countries where a National Association has been successfully established.

Hospice representatives suggested that a number of action steps were required in order to achieve these objectives, including 'the acknowledgement of palliative care in Kazakhstan', the 'creation of palliative care networks' and 'seminars for palliative care specialists'. A number of individuals and groups that possessed the authority and/or responsibility to take the necessary action were identified: governmental departments (for example, Ministry of Health, Ministry of Justice, etc.); local authorities (for example, Akims, Chiefs of District); 'international partners'; all hospices in Kazakhstan; palliative care specialists and international 'experts'. When asked to consider a realistic timescale for completion of the action steps, hospice representatives suggested 'approximately one to two years'. In order to achieve these objectives, State funding will be required to 'provide financial support for seminars, etc.' The concept of forming a National Association was an idea that was roundly supported. The hospice representative from Ust-Kamenogorsk stated that this had been considered following the Round Table discussions in 2003 but there had been 'insufficient coordination' following the meeting to take things forward.

Another barrier relating to the development of palliative care in Kazakhstan is demographic and relates to the elderly population; out of 'every 1000 oncology patients, 700 will be 'incurable', and 'most of these are elderly'; palliative care does 'not just relate to oncology and HIV/AIDS patients', but the elderly also, and Kazakhstan is an 'aging population'. Comments from hospice representatives reflected the lack of clarity in this particular area; palliative care is 'not nursing home care and nursing home care is not palliative care' although there are certainly elements in both. A survey conducted in 2009 by the 'Healthy Ageing' project in collaboration with international agencies suggested that the inadequate access of older people to specialized and tertiary care is one of the high causes of morbidity rates amongst this group.<sup>53</sup>

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<sup>53</sup>Aman Saulyk (2010b) *Socio-medical problems of elderly and disabled people: today and tomorrow*. Astana, Aman Saulyk. <http://www.amansaulyk.kz/library/socium/9/>

Other barriers to providing patients with palliative care in Kazakhstan identified by hospice representatives include a 'lack of understanding' about palliative care amongst society, an 'absence of continuity and collaboration' with primary health care services and oncological hospitals, and 'no coordinating center for palliative care'. In addition, healthcare organisations and social care organisations 'do not work in collaboration with each other' so it is often very difficult to develop an interdisciplinary approach (for example, the Ministry of Health 'does not collaborate particularly well' with the Ministry of Social Care).

In Kazakhstan, palliative care includes both 'health care' and 'social care'. Healthcare is divided into inpatient care and 'at home' services but social care also implies 'at home' services. Yet both forms of 'at home' services are different from each other and are provided by different types of healthcare professionals. Also, social care is not only limited to 'at home' services – it also encompasses other different types of services such as 'out-of-hours' or 'crisis' situations. Taking into account the Kazakhstan socio-cultural context, where the concept of family is very important, it is necessary to understand that people wish to spend their last days at home, and not in healthcare institutions. Inpatient services need to be developed but **in conjunction** with 'at home' services.

## **CURRENT HOSPICE/PALLIATIVE CARE SERVICES**

There are currently five inpatient hospice/palliative care services operating in five areas of Kazakhstan - Almaty, Pavlodar, Karaganda, Ust-Kamenogorsk, and Kostanai; home-based palliative care is provided in Semei. Hospices in Kazakhstan are described as 'very different from similar institutions in developed countries' as they are 'funded almost

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entirely by the State'. Hospice facilities are funded by the Government to 80%, while the remaining funds are provided by international organizations.<sup>54</sup>

### **Almaty Center for Palliative Care**

*Almaty Center for Palliative Care* is a State Municipal Management Organization that is funded by a contract from the Kazakhstan government (and partially from a local budget). The Center was opened in 1999 and currently has 100 inpatient beds, of which 70 are 'budget beds' (provided free of charge to the patient) and 30 are fee-paying; approximately 90% of beds are for cancer patients, 10% of beds are for 'other chronic terminally ill patients'. Patients are referred from outpatient clinics but there are 'some difficulties' with specialists from other disciplines who 'inappropriately refer patients to the Center'; the criteria for receiving care at the Center is 'three to six months to live' but sometimes specialists 'refer patients earlier than this'.

The Center serves a population of 'approximately 1.4 million people' and provides palliative care to 'approximately 1000 patients each year'. The total number of patients at the Center in 2008 was 1,952; 2,026 (2009); and 2,079 (2010). The average number of days of bed occupancy per patient was 17.3 (2008); 17.0 (2009); and 16.0 (2010). The main disease group receiving care at the Center is cardiovascular patients: 73% (2008); 59% (2009); and 53% (2010). The second biggest disease group is cancer patients: 22% (2008); 32% (2009); and 39% (2010). Respiratory disease patients accounted for 2% (2008), 4% (2009), and 4% (2010); digestive disease patients accounted for 2% (2008), 5% (2009), and 4% (2010); whilst HIV/AIDS patients accounted for only 0.1% (2008), 0.1% (2009) and 0.1 % (2010). HIV/AIDS patients in general are 'not covered by palliative care programs as such', but rather 'within the general healthcare system'; although Almaty Hospice has a separate wing solely for HIV/AIDS patients. The Center often

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<sup>54</sup>Katsaga, A., Kulzhanov, M., Karanikolos, M., Rechel, B. *Kazakhstan: Health System Review*. Health Systems in Transition. 2012.

'cannot reach' HIV patients due to 'different funding streams'. Also, in HIV/AIDS clinics, staff receive 'additional money' (60% addition to basic salary) for the 'environmental hazards' associated with working with HIV/AIDS patients – as staff at the Center do not receive any additional payment, they are therefore 'reluctant to work with this group of patients'.

There are approximately 175 people employed at the Center, including ten physicians, and 63 'nurse aids'; the ratio of doctor to patient is approximately 1:20 and nurse to patient is approximately 1:5. However, Anarhan Nurkerimova from Almaty Center for Palliative Care highlights the fact that many nurses have a 'fear of caring for people at the end of life' and this often deters them from becoming involved in palliative care. There is also one lawyer, one social worker, two chaplains and a number of volunteers from religious organizations (such as the Orthodox Church) who provide 'a lot of psychological and spiritual support' for patients and their families (they also provide some practical assistance, for example, feeding and bathing patients, etc.). All volunteers are interviewed by the Chief Nurse prior to commencing work at the Center; volunteers are sent to the Center 'by the church' so 'no background checks' are made. Anarhan suggests that volunteers 'solve many problems' at Almaty hospice. Psycho-emotional problems among healthcare professionals working in palliative care are an area not currently covered by Kazakhstan legislation, and psychologists in Kazakhstan who may provide assistance in this area are usually only found in universities; there are 'very few' psychologists working in medical facilities. However, support for hospice staff is reported as 'not a problem' as hospices have 'some publicly funded budgets' for psycho-emotional initiatives in this area.

The staff at Almaty Hospice have undertaken palliative care education and training initiatives in a number of countries, including Russia, Romania and Poland; topics included models of service delivery, pain management (including the assessment of pain and new methods for treating it), hospice philosophy, spiritual aspects of palliative care,

providing psychological support for patients and relatives, and adopting a multidisciplinary approach. The duration of education and training ranged from 'one day to two weeks'. Staff 'would like to receive more education and training' in the areas of spirituality and palliative care, pain management and 'guidance on treating diseases other than cancer'. Staff at the Center 'at the basic level of entry' receive training on how to inform the patient and family about the diagnosis/prognosis, but 'some staff fear breaking bad news' and additional education and training in the area of communication skills 'would be advantageous'. This situation is compounded by the fact that 'sometimes many deaths at once' occur at the Center (causing 'considerable emotional difficulties' amongst staff members) and also because hospital staff 'rarely inform' the patient/relatives of the diagnosis/prognosis prior to referral – they 'prefer to send them to the Center' to receive that information. The evaluation criteria relating to the quality of palliative care at the Center is being 'continuously improved'. For example, daily activities at the Center include maps of pain assessment (including scales assessing the severity of cancer pain), use of the WHO-recommended Pain Treatment Scale, lists of bedsores risk assessment, and regularly updated lists of patient care (for nurses). Anarhan suggests that the hospice may at some stage act as a methodological centre for the whole of Kazakhstan, emulating 'the First Centre Hospice in Moscow'.

Medication is currently available at the Center 'according to Formulary and by the needs of State demand' (this includes 'medicines for symptomatic treatment and injectable opioids'), although 'only injectable morphine' is available in the country. The Center has guidelines on how to gain access to opioids for pain relief and how to use those opioids effectively (Decree N173) and 'has not run out of any essential medications' in the six month period May – October 2011. The Director (Head of Pharmacy) and Vice-Director (Physician) are responsible for submitting orders of opioids at the Center; a physician (following the Director's decree), or the Head of Pharmacy is responsible for prescribing opioids. A physician, the Head of Pharmacy and the Chief Nurse are responsible for maintaining opioid stock levels, opioid use records, and dispensing opioids at the

Center; the Director, and Vice-Director of Nursing Services are responsible for administering opioids. The Center 'encounters some difficulties' in the management of opioids; there are concerns that 'medicines will be used illegally' or that 'medicines may be stolen by people from outside'. There are also problems with excessive bureaucracy (for example, regulations relating to the date of expiry of opioids must be strictly followed) and lack of choice and availability of opioids. 'Approximately 50%' of all patients (500) are provided with opioids at the Center each year. Barriers to providing patients with adequate pain relief in Kazakhstan include a lack of oral and transdermal forms of opioids and the 'absence of an interdisciplinary approach' in relation to opioids at the Ministerial level (for example, between the Ministry of Health, Ministry of Home Affairs, National Safety Committee, etc.).

Anarhan highlighted some of the socio-cultural difficulties in developing palliative care in Kazakhstan; for example, Almaty hospice recently hosted a charity walk where families and friends of patients walked for sponsorship for the hospice. An official from the Kazakhstan government visited Anarhan and accused her of corruption, and ordered for the charitable money to be removed from the hospice and handed over to the government. All other sources of charitable donation were also removed from the hospice - including collection boxes.

### **Red Crescent Society ('Credo'), Karaganda**

Public fund 'Credo' has been working for approximately twelve years on many projects but predominantly with socially vulnerable communities of people, aiming for equality amongst all marginalized groups. The objective of Credo is to improve the quality of life of people by 'solving problems' through activities such as improving legal knowledge amongst HIV/AIDS patients and their families, or providing social support. For example, 'special social services' are included in the Credo decree; a combination of services provided for both patient and families in difficult life situations - Credo work with

children in orphanages who have had 'parental problems' and also people with 'socially significant diseases'. However, Credo encounter a number of difficulties when working with these groups: for example, a lack of discipline and low self-esteem among clients.

There are three points of access to Credo: their social services office in Abai Town, a charity house and a consultative centre in Temitrau city. Credo enrol clients, assess their needs and develop individual plans of care based on team approaches and organisational principles. The scope of the care plan includes 'all WHO elements including a list of both challenges and opportunities'. Many clients of Credo are independent people but 'unaware of Kazakhstan laws and human rights legislation' i.e. the right to receive care. In terms of access to and availability of palliative care, Credo developed an integrated program of palliative care for HIV/AIDS infected people. A report was funded by Open Society Foundation Kazakhstan and although there was 'not a great deal of interest in the report', some individual interests were expressed. The report concluded by calling for university lecturers and medical doctors to develop a methodological base, standards, and evaluation process for training medical and social workers in palliative care. Credo suggest that there is a 'very low level' of knowledge about palliative care amongst both society and organisations and that the main issue is the provision of information to communities, as many people do not know about their rights to palliative care. There is also a need to discuss who is entitled to home-based palliative care with equal access for all. In Karaganda, palliative care for HIV/Aids patients is provided in small groups only and it is described as 'very difficult' to provide such care to larger groups. Credo have written to the Ministry of Health to seek advice on how to implement initiatives to provide care for larger groups of people.

Credo focus particularly on the area of HIV/AIDS, working in close collaboration with the regional HIV/Aids centre that 'provides all the necessary medication and equipment'. The mission of Credo is to attempt to change public opinion in relation to HIV/AIDS, and protect the rights of, and provide support to, HIV/AIDS patients. Previous projects

undertaken by Credo include: HIV/AIDS in the penal setting - Credo work in prisons and also work with families of prisoners; working with people living with HIV/AIDS to improve adherence to treatment; various harm reduction projects (syringe exchange amongst injecting drug users, publicity and education campaigns relating to sexually-transmitted diseases, psychological help for people working in harm reduction projects); and seminars for medical workers and PLWHA on legal issues surrounding HIV/AIDS. However, Credo have little funding so development of many initiatives is described as 'rather slow'.

The main people employed within Credo are consultants who aim to provide social support and create levels of knowledge amongst beneficiaries; Credo also employ psychologists and social workers. Palliative care in social work is based mainly on 'an understanding of the concept as opposed to a legal document', with social services 'only provided for children and the elderly'. According to the experience of Credo, palliative care must be a combined effort between all members of the interdisciplinary team including NGOs.

Credo representatives stress that continuity of care is needed from 'hospital to home' and that there is a need to work in collaboration with state hospitals. A pilot home-based palliative care project has been introduced in Temitrau city for people living with HIV/AIDS; the team includes family and friends of the patient. The reason why this particular group was chosen for the pilot project is that this region was one of the first in Kazakhstan where HIV/AIDS was diagnosed. Credo suggest that although there is 'no formulated palliative care strategy or standards of palliative care', the Kazakhstan government is 'slowly beginning to understand' what is required to deliver effective home-based palliative care. However, whilst Credo believe that the process of implementing home-based palliative care could relieve the pressure on hospices for inpatient care, they acknowledge that this could prove to be 'a very slow process'; as home-based palliative care has not been provided previously in Kazakhstan it is going to

be a 'very large job'. Credo view the main problem as collaboration between governments and NGOs as it is 'very unusual' for the state to relinquish all responsibility to NGOs.

Inpatient palliative care is provided at the Nursing Hospital, Department of Hospice Red Crescent Society, Karaganda, which opened in 2006. The hospice is State funded through a government budget. There a total of fifty inpatient beds at the nursing hospital; thirty beds are in the Nursing Department and twenty beds are in the hospice. A population of 'approximately five hundred thousand' is served by the hospice; each month, 'approximately fifty to one hundred HIV/Aids patients' and 'one to five cancer patients' receive palliative care at the hospice. Credo provide various forms of support to patients, including both spiritual and psycho-social care.

There are 'approximately forty people' employed at the nursing hospital, including seven physicians, eight nurses and twenty two 'nurses aids'. Credo staff visited Poland to see how effective home-based palliative care could be established and learnt the 'most effective way to recruit volunteers' from their experience in the country; in Poland they have 'quality enrolment systems' and their own volunteer website, there are competitions for volunteers to enter and they are only allowed to become volunteers following a trial period. There is also a law/decreed related to hospice volunteers in Poland, where volunteers are considered as bringing 'many benefits' to hospice and palliative care. In Kazakhstan, volunteers are often students and it can be difficult to enrol mature people as volunteers. Credo have requested the Kazakhstan government to fund volunteer work. A good example of voluntary work is provided by the Almaty hospice which has a well established system of volunteerism, and where the State Medical University provides students on a regular basis. A particular sensitive area of volunteerism is working with HIV/AIDS patients and the stigma that may be attached to this form of voluntary work. Credo suggests that in palliative care it is very important to enrol volunteers 'on a humanistic basis' in order to provide support to patients.

Staff at the hospital have been trained in 'many aspects' of palliative care, including pain management; this training was three days in duration and focused on the assessment of pain (in particular stages of pain management). Most Credo volunteers and social workers possess some qualifications (for example diploma in social work) and staff at the hospital 'do not feel that they need' any further education and training. However, Credo suggest that the provision of home-based palliative care must be via a multi-disciplinary team and that all members of this team should have 'appropriate palliative care education and training qualifications'. Palliative care training is provided for doctors at Karaganda Medical University within different courses (for example, six hours of palliative care education is provided within oncology and paediatric courses), although there is no separate course for palliative care itself. For social workers working within the multidisciplinary team, palliative care training and education is described as 'almost non-existent' in Kazakhstan. Credo have 'some internal resources' to provide a limited amount of education and training, but government support is needed to provide specialist courses in palliative care.

The hospital provide opioids to 'between fifty and seventy patients per year' ('six to seven patients per month'). Medications currently available at the hospital include analgesics (for symptomatic treatment) and 'all necessary opioids' (including morphine and Promadol). The hospital 'has not run out of any medication' in the six month period May to October 2011. The hospital has guidelines on how to gain access to opioids for pain relief (and how to use opioids). The Vice Director of the hospital is responsible for submitting orders for supplies of opioids and also for administering and prescribing opioids; physicians at the hospital are also responsible for prescribing opioids. The Vice Director, physicians, and Chief Nurse are responsible for maintaining opioid stock levels and records of opioids use. The Chief Nurse assumes the main responsibility for dispensing opioids. The hospital 'does not encounter any difficulties' in managing opioids, but acknowledges that there are barriers to providing patients with adequate

pain relief in Kazakhstan; for example, excessive bureaucracy/administration; lack of certification of 'essential medicines'; and the high cost of opioids in the country.

### **Kostanai Palliative Care Department**

Kostanai Palliative Care Department, Karaganda Oblast Cancer Dispensary is a State Municipal Management Organisation funded by both State and local budgets. The Palliative Care Department was opened in 1999 and serves a population of 'approximately two hundred and fifteen thousand'; both inpatient and day care are provided within the department. There are fifteen inpatient beds (serving 'approximately four hundred and fifty patients' per year) and five daycare beds (serving 'approximately one hundred and twenty patients' receiving chemotherapy each month). Each month, the Palliative Care Department provides care for 'approximately forty cancer patients' (nil patients with HIV/Aids).

There are 'approximately eighteen people' employed in the Palliative Care Department; one physician (Head of Department), seven nurses, nine 'nurses aids', and one chaplain (who is available upon request of the patient/family members). Staff have been trained in 'many aspects of palliative care', including pain management (one day duration focusing on types of pain, treatment regimens, and communication about pain with the patient and family members). However, staff in the Palliative Care Department 'require more education and training' in this area (for example, in 'administering the correct dosage of opioids').

The Palliative Care Department provides opioids to 'between 350 and 400 patients per year' ('approximately 30 patients per month'). Medications currently available in the department include Tramadol, analgesics, NSAIDs, etc. and they 'have not run out of any medication' in the six month period May-October 2011. However, the quality of medication available in the department is described as 'very bad' (it is imported from

India). The Palliative Care Department has guidelines on how to gain access to opioids for pain relief (and how to use opioids). The Director of the pharmacy and Director (Head of Department) are both responsible for submitting orders for supplies of opioids; the Director (Head of Department) and physician are responsible for prescribing opioids. The Director of the pharmacy and the Chief Nurse are responsible for maintaining opioid stock levels, whilst the Chief Nurse, physician, and Head of Department are responsible for maintaining records of opioid use. The physician and nurses are responsible for dispensing opioids in the Department, and the Director (Head of Department) and physician assume the major responsibility for administering opioids. The Palliative Care Department encounters 'no difficulties' in managing opioids, but acknowledges that barriers to providing patients with adequate pain relief in Kazakhstan do exist; for example, the 'insufficient quality' of opioids in the country.

### **Solaris Hospice, Pavlodar**

In the city of Pavlodar, there is a relatively high level of cancer incidence; the presence of metallurgical and chemical manufacturers in the city may contribute to this. In addition, the South of Pavlodar region is a part of the Semipalatinsk nuclear polygon. *Solaris Hospice, Center for Palliative Care*, Pavlodar opened in 1999. In its first 18 months of operation, the hospice was staffed entirely by volunteers and operated a home-based service only, providing palliative care for 'approximately 70 patients'. The hospice worked with international charity organizations, donor agencies, state and business organizations, and the mass media to generate funding that enabled it to undertake essential building repairs. The hospice received a state license, and resources for medication, transportation, and salaries. At the end of 2002, the inpatient department for 15 patients was established.<sup>55</sup>

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<sup>55</sup>[http://www.hospicecare.com/newsletter2004/july04/index\\_Page348.htm](http://www.hospicecare.com/newsletter2004/july04/index_Page348.htm)

The hospice is currently State funded through a government budget. There are a total of 15 inpatient beds at the hospice; home-based palliative care ('approximately four to five visits per week by physicians and nurses'), day care ('one to two patients attending per week') and 'psychological support' are also provided at the hospice. A population of 'approximately 330,000' is served by the hospice. Each month, the hospice provides palliative care to 'approximately 15 HIV/Aids patients' and 'approximately 30 cancer patients'.

There are 'approximately 19 people' employed at the hospice, including two physicians (one 'therapeutic physician' and one psychiatrist), five nurses, one Chief Nurse, five 'nurses aids', two volunteers and four administrators. Staff at the hospice have been trained in 'many aspects' of palliative care; for example, the 'structure and processes' of palliative care (including 'physical, psychological and social care of the dying person'). Staff have also received training in aspects of pain management; for example, two-week courses in Russia and Poland that focused on treatment regimens in the inpatient and daycare setting. Staff at the hospice feel that they require further education and training in the area of 'developing clinical and diagnostic treatment guidelines'. Hospice staff have 'developed palliative care projects' and 'participated in prospective cross-sectional and socially significant programs' with other hospices in Kazakhstan. The hospice has also participated in 'developing palliative legislation' and in 'promoting professional teaching and international exchange'. A number of publications (booklets, brochures, etc.) have also been developed to 'explain the principles of palliative care' to patients and family members.

The hospice provides opioids to 'approximately 200 patients per year' ('approximately 7 to 10 patients each month'). Medications currently available at the hospice include analgesics, anti-nausea medication, antibiotics, etc. and they did 'not run out of any

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medications' in the six month period May-October 2011. The hospice has guidelines on how to gain access to opioids for pain relief (and how to use opioids). The Hospice Director is responsible for submitting orders for supplies of opioids, and the physicians are responsible for prescribing opioids. The Chief Nurse at the hospice is responsible both for maintaining opioid stock levels and records of opioid use. The Chief Nurse also assumes responsibility for dispensing opioids (in conjunction with the physicians), whilst the Hospice Director and the physicians are responsible for administering opioids. The hospice encounters 'some difficulties' in managing opioids; for example, restrictions relating to the storage and prescription of opioids ('limits to the amount that can be prescribed', etc.).

### **Hospice/Charity Service Social Fund, Semei**

Hospice/Charity Service Social Fund opened in 2000 in Semipalatinsk (Semei), an industrial city in North-East Kazakhstan. The service is funded partially by the Kazakhstan government and partially by charitable donation; for example, from the Irish charity *The Greater Chernobyl Cause* who have unveiled plans to build a new hospice in the grounds of the city's general hospital.<sup>56</sup> The current service offers home-based palliative care only, covering a population of 'approximately 300,000'. The service employs 'three to four people' (one part time physician and two to three nurses) who provide 'social, legal and psychological assistance' for patients and their families. Pain relief is provided by the service, along with teaching relatives how to care for the patient at home. 'Social assistance' is provided in the form of cooking, cleaning, assistance with welfare payments and pensions, etc. According to the Ministry of Health there are 'at least 1,500 patients' that require palliative care in Semei. The home-based team work in close collaboration with Family Physician Centers and the ambulance service to provide

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<sup>56</sup><http://www.greaterchernobylcause.ie/>

palliative care to 'approximately 160 to 180 patients per year' (with stage IV cancer diagnosis). The German government has also provided some financial support to the service.

### **Ust-Kamenogorsk Hospice**

Ust-Kamenogorsk Hospice is a 'limited liability partnership' hospice that is funded through the Kazakhstan State budget. The hospice opened in 2000 and serves a population of 'approximately 310,000'. The hospice provides inpatient palliative care; it has a total of 60 beds (20 located in the hospice and 40 located in the nursing hospital). It is 'unknown' how many people with cancer or HIV/Aids receive palliative care at the hospice each month. Special attention is paid to the dietary requirements of patients receiving care at the hospice; practical forms of support are also provided to the patient and family (for example, assisting with legal issues, completion of documentation, addressing household problems, etc.)

There are 'approximately 28 people' employed at the hospice; 11 physicians (including a psychiatrist, oncologist and a 'physician therapist'), 12 nurses, one social worker, two chaplains and two volunteers. Staff have received training in 'many aspects' of palliative care, including 'three days of pain management training every year'. However, staff at the hospice 'would welcome' more training in this particular area.

Medications currently available at the hospice include analgesics and antibiotics, although the hospice 'ran out of analgesics' during the six month period May-October 2011. The hospice has no guidelines on how to gain access to opioids for pain relief (or how to use opioids) and 'nobody is responsible' for submitting orders for supplies of opioids as the hospice 'does not have a license for them'.

### **Pediatric palliative care**

Pediatric palliative care provision is available at Almaty Center for Palliative Care, but this has only recently been established and most palliative care for children still occurs at home. In 2012, the public foundation for 'support of people living with cancer' *Alsager Foundation* opened the first hospice for children with a terminal illness and their families at Almaty Center for Palliative Care: *I Am with You: Hospice for Children*. Approximately 160 terminally-ill children and their families will receive palliative care from this fully-functional hospice which includes a pharmacy; a psychologist, doctors, and nurses are employed at the hospice. The hospice has eight rooms and a mobile team for home-based care. The hospice will operate with a multidisciplinary team including volunteers. There will also be room for parents to sleep at the hospice.

The paediatric hospice is to be funded 25 per cent by the State and 75 per cent through a special charity programme which is funded by a mobile communications company in Kazakhstan called Bee-Line and a company which manufactures pain treatment machines. In addition to the support provided by the Alsager Foundation, governmental bodies, commercial organizations, churches, international companies and their representative offices as well as ordinary Kazakhstani people combined their efforts to enable the hospice to open.<sup>57</sup>

In an interview with Nagima Plokhikh and Olzhas Zhandosov from the Alsager Foundation, the hospice was described in further detail. Nagima is a Doctor in oncology and programme co-ordinator at the Alsager Foundation; Olzhas is also a Doctor of oncology and they both highlighted the need for a children's hospice in Kazakhstan because it is a 'different type of care' that is required. The Alsager Foundation has been initiating this project since 2008 and has encouraged the Kazakhstan government to develop a specific law in relation to pediatric palliative care. Nagima stresses it is the

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<sup>57</sup><http://minicassiavoice.com/breaking/burley-missionary-helps-open-hospice-in-kazakhstan-2/>

‘right of every person to receive palliative care’ and especially so in the case of children as this is a particularly vulnerable group in society. Nagima stressed the need to develop a normative base and change legislation relating to pediatric palliative care. The Kazakhstan government has supported the hospice by providing medicines through their local government health care initiative; Nagima stresses that it is important to demonstrate to the Kazakhstan government how effective paediatric palliative care can be in order to secure funding to develop other paediatric hospices around the country.

The Alsager Foundation is linked with the National Oncology Centre in Turkey and has undertaken a number of initiatives to raise public awareness about the new paediatric hospice including a charity concert, a bike marathon, and advertisements in the mass media. A ‘master-class’ in palliative care was delivered at the Kazakh Scientific and Research Institute of Oncology and Radiology and the City Hospital, Almaty (June 13<sup>th</sup>-June 17<sup>th</sup> 2011), organized by the Alsager Foundation. The master-class was dedicated to the opening of the first pediatric hospice in Kazakhstan and to train hospice staff in relevant areas. The master-class was delivered by Professor Mikheil Shavdia, Department of Oncology, Tbilisi State Medical University. The master-class had been preceded by six-months of regular consultation between Professor Shavdia and approximately 30 hospice staff in order to prepare for the opening of the hospice.<sup>58</sup> However, Nagima feels that staff would benefit from some additional training and education in this area. Nagima suggests that the Cancer Prevention Centre in Georgia would be ideal for training staff as Kazakhstan has the ‘same mentality’ as Georgia.

Since the pediatric hospice opened in April 2012, there have been ‘seventeen children treated there’ (to September 2012). However, it is unclear whether the children at the hospice have been receiving ‘palliative care’ as such; it appears that the hospice is not yet accredited to provide this form of care as such but rather is used for children

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<sup>58</sup>[http://www.tsmu.edu/eng/index.php?option=com\\_content&view=article&id=718:master-class-in-palliative-care-held-in-alma-ata-by-georgian-professor&catid=1:latest-news&Itemid=107](http://www.tsmu.edu/eng/index.php?option=com_content&view=article&id=718:master-class-in-palliative-care-held-in-alma-ata-by-georgian-professor&catid=1:latest-news&Itemid=107)

undergoing treatment such as chemotherapy and respite care for their parents. The maximum length of stay in the pediatric hospice is 25 days (although the total number of stays is unlimited).

## **Mortality**

The UN reports an estimated medium variant crude death rate for Kazakhstan (2010-2015) at 9.6/1000 inhabitants.<sup>59</sup> For the current population estimate of 17,522,010<sup>60</sup> this would yield total mortality at approximately 168,000 deaths. The *Agency of Statistics of the Republic of Kazakhstan*<sup>61</sup> estimates that the total number of deaths in Kazakhstan in 2011 was approximately 146,000. A median figure of approximately 157,000 annual deaths in Kazakhstan can therefore be taken.

Two different existing methods can be utilized to estimate the need for palliative care in Kazakhstan. The population-based approach recommended by Gomez and Stjernsward (2005),<sup>62</sup> calculates 60% of total mortality as in need for palliative care. If a median figure of total mortality of approximately 157,000 deaths annually is taken, it results in an estimated total of approximately 94,200 patients requiring palliative care in Kazakhstan each year.

Higginson's (2003)<sup>63</sup> method is based on 100% of cancer mortality and 66% of mortality from other chronic illnesses; the 'chronically ill non-cancer population' is estimated by including mortality from circulatory, respiratory, digestive, and other related deaths.

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<sup>59</sup> United Nations Statistics Division; data accessed 5th March, 2012 at:

<http://data.un.org/Data.aspx?d=PopDiv&f=variableID%3A65>

<sup>60</sup> <https://www.cia.gov/library/publications/the-world-factbook/geos/kaz.html>

<sup>61</sup> [http://www.eng.stat.kz/news/Pages/n1\\_15\\_02\\_2012.aspx](http://www.eng.stat.kz/news/Pages/n1_15_02_2012.aspx)

<sup>62</sup> Gomez X.G., Stjernsward J. WHO Public Program for Palliative Care, cap V, 2005.

<sup>63</sup> Higginson I. The Palliative Care for Londoners: needs, experiences and future strategy, NCHSPC, 2003.

<http://data.un.org/Data.aspx?q=cause+of+death+moldova&d=POP&f=tableCode%3a105%3bcountryCode%3a498>

According to statistics from the *Agency of Statistics of the Republic of Kazakhstan*,<sup>64</sup> the estimated number of deaths from cancer in 2011 was approximately 17,900; the number of deaths from other causes (for example, injury, poisoning, accident, external causes, etc.) was approximately 17,800. From these figures it can therefore be assumed that the total number of deaths in Kazakhstan within the 'chronically ill non-cancer population' was approximately 121,300. Using this method, a total of approximately 97,900 patients requiring palliative care is projected (17,900 cancer and 80,000 chronic non-cancer).

Given that additional patients will need palliative care prior to their year of death, if we propose that a minimum of 94,200 patients per year will need palliative care, and we assume an average of two months of service, we project a minimum daily census of approximately 15,500 patients on service at any given time for the full need to be met. In addition, as there are usually two or more family members directly involved in the care of each patient, care would be given to a minimum of approximately 282,600 persons annually.

### **Health Workforce Needs**

Hospice representatives suggest that there are 'approximately 150 thousand nurses' in Kazakhstan which is '70 per cent' of the total medical personnel in the country. However, the distribution of nurses is spread unevenly with the major cities of Almaty and Astana suffering from a lack of personnel whereas in other parts of the country there are 'a lot of nurses'. The same dilemma is true for doctors and in Kazakhstan there are on average one doctor for every 2.2 nurses. There is therefore 'a need for the Ministry of Health to introduce more nurses in to the primary health care system'.

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<sup>64</sup> [http://www.eng.stat.kz/news/Pages/n1\\_15\\_02\\_2012.aspx](http://www.eng.stat.kz/news/Pages/n1_15_02_2012.aspx)

The current population of Kazakhstan is approximately 17.52 million people. Using a population approach we can also project the need for palliative home care services and hospice and palliative care inpatient beds/units. To provide home-based and inpatient palliative care to a minimum population of approximately 15,500 patients per day would require substantial reallocation of healthcare professional resources for both the urban and rural areas.

Two methods are used to use to calculate the staffing needs for home-based care and inpatient care. One is based on the projected average daily census and the second is an epidemiological 'population based approach'.

Using the minimum average daily census (15,500 patients per day), for home-based care we will use a ratio of one full time equivalent (FTE) nurse for every five patients on daily service and for physicians we will use one FTE for every 25 patients on service. In addition other staff are needed for the clinical services including social workers, home care aids, therapists, and drivers. It is estimated that one FTE of other clinical is needed for every 10 patients on service.

Using these data we can project that approximately 3,100 nurses will be required, 620 physicians, and 1,550 other clinical support staff.

Using the population based approach the following ratios are used:

For home-based care:

3 physicians per 100,000 population

12 nurses per 100,000 population

6 other clinical staff per 100,000 population

For inpatient care:

- 1.5 MD's for every 10 inpatients
- 15.5 nurses for every 10 inpatients
- 4 other clinical staff for every 10 inpatients

Using these ratios we would project a need for a population of 17,522,000 the following staffing:

For home-based care:

- 525 physicians
- 2,102 nurses
- 1,051 other clinical staff

For inpatient care (for 825 beds – see below)

- 124 physicians
- 1278 nurses
- 330 other clinical staff

Comparison of Projected Need by Method	
Total Staffing using the population based method	Total Staff using the ADC method
649 physicians	620 physicians
3,380 nurses	3,100 nurses
1381 other clinical staff	1,550 other clinical staff
<b>5410 total clinical staff</b>	<b>5270 total clinical staff</b>

It can be seen that the total staffing requirement from each method produces a relatively similar figure: taking the median, approximately **5340** clinical staff will be required for the palliative care need to be fully met.

This projection does not include administrative staff. If we use an estimate of 25% additional administrative staff we would add approximately 1,335 more people - or a total of approximately **6675** staff. Palliative care teams generally work well with caseloads of up to 50 patients. Additional teams can be formed under one administrative authority for a given geographic area, as scale up continues. To care for a minimum daily census of approximately 15,500 patients would eventually require approximately **310** such teams to serve the country.

### **Bed Need**

To estimate the need for inpatient hospice or palliative care beds, the average daily census (minimum 15,500 patients) can be used and a percentage applied to the number of patients needing inpatient care on a given day. In the United States the percentage is 3% of hospice days, however this does not account for other non-hospice palliative care patients so an estimate of 5% will be used. If we apply this percentage to the average minimum daily census of 15,500 patients we have a need for approximately 775 beds. Another method used in Spain to estimate bed need is five beds per 100,000 population; using this method results in a projection of approximately 876 beds. Given the fact that the vast majority of patients die at personal residences in Kazakhstan and the desire to continue that trend, care should be taken not to over-emphasize inpatient palliative care. For planning purposes, need for occupancy turn over and growth in the population it would be safe to estimate bed need of approximately **825** beds for the country at present. However, Anarhan Nurkerimova from *Almaty Center for Palliative Care* suggests that there is 'no need for 100 beds per region – perhaps 10 beds per region will suffice', provided there are properly trained nurses and volunteers for '**at-home' services**'.

## EDUCATION AND TRAINING

A barrier to the development of palliative care in Kazakhstan that was identified by hospice representatives was the lack of palliative care education and training opportunities in the country. A number of underlying reasons for this problem were suggested: a lack of knowledge about palliative care in Kazakhstan; a lack of experienced trainers and educators in the discipline; and low levels of awareness about palliative care amongst healthcare professionals and within Kazakhstan society. The hospice representatives stated a number of objectives that, in their opinion, would serve to address some of these problems. For example, experience exchange with countries and regions where palliative care 'is more developed'; increase the number of trained palliative care educators in Kazakhstan; develop 'appropriate study programs'; and invite international palliative care 'experts' to deliver presentations in Kazakhstan. For example, a 'master-class' in palliative care was delivered at the Kazakh Scientific and Research Institute of Oncology and Radiology and the City Hospital, Almaty (June 13<sup>th</sup>-June 17<sup>th</sup> 2011) by Professor Mikheil Shavdia, Department of Oncology, Tbilisi State Medical University. Approximately 300 medical specialists (including many oncologists) from all areas of Kazakhstan attended the master-class which included a specific lecture on 'The Main Principles of Chronic Pain Management'.

Hospice representatives suggested that a number of action steps were required in order to achieve these objectives, including the need to 'increase human resources', prepare 'new study materials and programs', and 'find physicians interested in palliative care'. A number of individuals and groups that possessed the authority and/or responsibility to take the necessary action were identified: governmental departments (for example, Ministry of Health, Ministry of Education, etc.); Kazakhstan School of Public Health; education institutions (State Medical University, Almaty State Institute for Lifelong Education, etc.); and 'other key stakeholders and educated people'. When asked to consider a realistic timescale for completion of the action steps, hospice representatives

suggested 'approximately three years'. In order to achieve these objectives, additional funding for 'study programs and trips and resource centers' would be required.

### **Republican Medical College**

The Republican Medical College was established in 1937 as a school of obstetricians for female Kazakhs from children's homes in different regions of the country. In August 1954, the school was reformed into a Republican Medical College in accordance with the Resolution of the Kazakh Soviet Socialist Republic. In April 1996, it emerged as a Republican Medical College for 'training and retraining medium-level medical workers'. Education is provided in seven departments: medicine; nursing; obstetrics; laboratory diagnostics; sanitary and epidemiology; pharmacy; and stomatology. The college offers more than forty specialties including palliative care training in a clinical specialty (health care and nursing care). The college also offers diplomas in general practice, etc. There are 270 lecturers at the Republican Medical College and 1,700 students. Practical lessons are provided for students in a laboratory setting and the college collaborates closely with 25 hospitals in the country. The Republican Medical College has developed into one of the largest educational centers for intermediate-level medical personnel training in Kazakhstan, enrolling 2000 post-graduate students per year on average since 1996, mainly from Almaty. Over 32,000 graduates from the Republican Medical College currently work in Kazakhstan.

There are fifty-eight medical colleges in Kazakhstan with approximately half being state-run and half being financed privately; if palliative care curricula are to be implemented in them, they 'need to be developed on a Republican level based on a decision that is made by the Ministry of Health'. There is a need for staff at the Republican Medical College to be trained and educated with additional knowledge about palliative care prior to the development of curricular at the college.

The programme of study developed by the Republican Medical College has been 'rolled out across Kazakhstan' for all nurses. However, a specific course on palliative care for nurses at the undergraduate level is 'very much needed' in Kazakhstan and this should be available not only to hospice nurses but 'all nurses' throughout the primary health care system - especially for those who provide home-based palliative care. Palliative care is included in the first specialisation that nurses choose (oncology, etc.) at the time of their internship. This initial specialisation lasts for six months after which nurses may change discipline and undertake 'advanced courses in higher education'. Practical work is undertaken at Almaty Hospice which serves as a basis for the training of college students who also attend lectures delivered by hospice representatives; for example, 'Lessons of Charity' by Urmurzina Gulshara Gazizovna. Classes in clinics are provided by experienced and qualified teachers of medical institutions and scientific centers. A further aim of the Republican Medical College is to establish an *Association of Nurses in Palliative Care* and perhaps produce a journal which could be published by this association.

Republican Medical College is currently working on the development of a palliative care training and education course in two specific parts:

- 1 Post-diploma students (this is considered a flexible process e.g. for nurses). Some courses are undertaken within the State Order on the programme which involves 108 hours of teaching (with two weeks teaching in palliative care as a specialty).
- 2 Under-graduate diploma students; this course does not include palliative care as a specific subject but palliative care is included in other disciplines such as surgery, geriatrics, etc. In 2010, new standards of education were implemented by the Kazakhstan government and this State programme of education 'poses a challenge' on how to implement palliative care into the existing curriculum.

**Almaty City Medical College**

Almaty City Medical College has a variety of teaching methods including work place setting, formal lectures, self study, and practical experience involving case studies and presentations. The national standards in nursing that were established by the Ministry of Health originally specified 360 hours in total for the nursing programme but this has since been reduced to 180 hours in total; this has affected nurse training and the 'ability to provide effective care'. Nursing standards incorporate aspects of sport and mathematics, etc. which is considered by most nurses as 'both inappropriate and ineffective'. A conference was held by Almaty hospice in collaboration with the college relating to nurse training; the college 'would like to act as a base' for the education of nurses in palliative care and also for nurses working in primary health care.

The role and responsibility of nurses in Kazakhstan has substantially changed in recent years and nurses are now able to provide pain management for the patient in their last days of life. This is due in part to the palliative care education provided at Almaty City Medical College which involves organisation in palliative care, assessment of patient symptoms, diet and nutrition, health education, and the differences between basic care and palliative care.

At the Postgraduate Training Center for Nurses, foundations of theory and practice in palliative care are taught and this is considered 'very important' for nurses. The knowledge base in palliative care is developed amongst students at the college who are taught about such issues as quality of life in patients, and how to provide both social and psychological assistance. Nurses are also taught the importance of working closely with the family of the patient and the need to involve the family in palliative care. Nurses at the college have suggested that they find the palliative care programme 'very interesting' and stress the need to develop 'clinical thinking' and to become familiar with all aspects and principles of palliative care.

The first palliative care training course established at the college was for nurses and not doctors. Following the Salzburg Seminar on palliative care and pain management, the Director of the college introduced a post-graduate diploma for nurses, *Palliative Care Nursing*, involving 108 hours of palliative care education that consists of 18 hours of contact with patients, 54 hours of practical experience in a hospital or hospice environment, and 36 hours of self-study. This elective module is now described as one of the 'main courses' at the college. Palliative care is being considered as a separate programme at the college but all post-graduate courses currently contain an element of palliative care in their curricula. Practical work is undertaken at Almaty Center for Palliative Care which serves as a basis for the training of college students.

However, there is a need to establish a specific study programme in palliative care for nurses. The course needs to be 'mainly theoretical' but also incorporate thirty six hours of practice to conform to national standards which should be 'based on provision of care and not treatment'. Currently, the college provides eight to ten hours of undergraduate study in palliative care in different disciplines (for example, pediatrics, surgery, etc.). The college tried to introduce a specific palliative care study programme for nurses involving 48 hours of study, but this was considered unrealistic as palliative care nurses need 'more practice than theory'.

The main problem with establishing nursing in palliative care as a separate specialty is that the introduction of additional standards requires detailed demonstration to the Ministry of Health that absence of knowledge about palliative care in Kazakhstan is 'a big problem'. Providing additional education standards for nurses in palliative care is not possible without changing educational standards, which in turn require approval from the Ministry of Health - the topics can be changed but not the number of hours of study required. However, this problem with national standards in nursing care may be overcome if a letter was sent to the Ministry of Health to explain the situation - a similar

problem existed with dentistry in Kazakhstan where a letter to the Ministry of Health enabled the required changes to be made.

Nurses who work with patients at the end of life need to be aware of the psychological aspects of palliative care; for example, psycho-emotional stress and the reasons for this developing. Nurses also need to be aware of the process of palliative care in relation to the diagnosis/prognosis of the patient and also be aware of their disease and symptoms. A further important point in nurse training is being able to differentiate between patients in terms of their personality, fears, mood, and social and cultural differences (language barriers, employment, religion and spiritual factors, etc.). There is now 'a need to establish standards and to evaluate the nursing programme of palliative care at Almaty City College'.

### **State Medical University**

The Kazakhstan State Medical Institute was opened in the city of Alma-Ata in February, 1931 with a single medical faculty comprising of 135 students; in 1933 the Institute was renamed the Alma-Ata State Medical Institute. In August 1996, it was renamed the Kazakhstan State Medical University by Governmental order, and in June 2001, the Kazakhstan National Medical University. There are currently ten thousand students enrolled at the University, comprising of thirty six different nationalities. Nine specialties are offered at the University including both public health and nursing. The University offers post-graduate education in a number of specialties. Post Soviet Union, the University built a residential clinic and adopted a different model and approach whereby they entered into an agreement with hospitals to provide practical experience for students. Currently all hospitals in Almaty work in collaboration with the University and hospitals in a number of external cities also. The Kazakhstan National Medical University also has thirty-three agreements with international hospitals and Universities abroad. The University has 870 doctors on their database – these are 'all the main doctors' in

Kazakhstan. The college is interested in developing a pilot project to find other interested health care professionals in different countries.

Although there is no specialist course on palliative care offered within the state programme (palliative care is only implemented within different disciplines), the University works in close collaboration with Professor Kulzhanov and KSPH (for example, a curriculum on palliative care training for nurses is currently being developed) and also collaborates with Almaty Center for Palliative Care which serves as a basis for the training of medical students. The nursing hospital is also used as a base for practical training, but both the hospice and the nursing hospital work on 'old standards' of treatment which were based on the state schedule of 'one nurse per forty patients'. A social work training course needs to be introduced so that social workers are enabled to work with all problems associated with palliative care, but a problem relates to the function of social workers and their responsibility within the hospice setting. Although the responsibility of a social worker is equivalent to a medical worker within the hospice, this is 'inappropriate' as social workers do not receive any specific training in palliative care at the University and are therefore unclear about their role and responsibility in the hospice.

The State Medical University has a 'strategic, global way of thinking' that is interested in the whole of Kazakhstan society but particularly in two groups of services. All education in Kazakhstan is framed by the state standard of education; there is no such discipline as palliative care in the State standard but this could be developed once the Rector has given his approval to palliative care curriculum being developed. There are seventy departments at the University which mainly work in therapeutic areas but also deal with chronically ill patients; therefore there is an interest in the development of palliative care curricula. The additional courses on palliative care could be provided by distance learning; currently there is no end of life care research except 'in the area of gerontology'. In sum, the integration of a palliative care curriculum into all aspects of

nurse education and the University becoming involved in the development of such curricula are 'rather new concepts' – but such development is a 'possibility in the future'.

### **Kazakhstan School of Public Health**

Awareness of palliative care in Kazakhstan is 'very low' even amongst doctors, so Kazakhstan School of Public Health (KSPH) are to introduce one- to two-week courses to raise awareness of hospice and palliative care in the country. KSPH are also considering developing a specific study programme for hospital managers, social workers, etc. entitled *Foundations of palliative care; palliative care challenges and future expected development in Kazakhstan*. This will be a short term course as opposed to an MA or PhD; 144 hours of palliative care teaching will be provided within this course. A study programme for 144 hours of palliative care is required for nurses but this has not yet been developed at KSPH. Currently, a programme for nurses *Foundations of palliative care; palliative care nursing* is being developed comprising of seventy two hours of study.

KSPH is trying to encourage both Masters and PhD students to choose palliative care themes and conduct their own research. In 2011, an elective module *Foundations of Palliative Care* was offered to eighteen Masters Students at KSPH; twelve out of eighteen students opted for this module which comprised of 15 hours of lectures and 27 hours of workshop activity relating to palliative care. Masters students who select palliative care as an elective module within their study undertake seventy five hours of academic work in order to gain one credit (thirty hours of self study). Palliative care education is also given from an organisational perspective as well as a theoretical and ethical perspective. The palliative care component of the Masters course was previously provided through formal lectures, but now is provided on a more practical basis through workshops, etc. dealing with cancer pain, pediatrics, HIV/AIDS, etc. Students are also

expected to undertake individual projects, and a number of them have undertaken these projects at Almaty Center for Palliative Care (how to break down stigmatization, taboo status, etc.). The Center is also developing a nursing curriculum in palliative care and a clinical base for nurse education in conjunction with KSPH and the Republican Medical College. KSPH is also interested in engaging its staff in research in the field of palliative care because it is a new and underdeveloped area both for KSPH and the Kazakhstan healthcare system. Therefore, KSPH will 'benefit greatly' from participating in this process.

## OPIOID AVAILABILITY

During interviews with patients and their caregivers at Almaty Center for Palliative Care, respondents were asked to describe their pain at its most intense (1=low 10=high); responses ranged from ‘8/10 very strong and continuous’ to ‘10/10 during chemotherapy treatment, where ‘cramps and stomach contractions’ were experienced which lasted for ‘approximately one week’ in duration. When experiencing maximum pain, the medication was given to relieve it did so – but only gradually (not immediately – on some occasions ‘only after thirty minutes’); most respondents ‘did not know’ what type of medication they had been prescribed.

Seven hospice representatives were asked a series of questions about the accessibility and availability of opioids in Kazakhstan. Their responses are shown in the table below:

**Table 2: Hospice representative responses to opioid questionnaire**

Question	Hospice representative responses
<b>‘Do you think that the practice of managing pain for people with cancer and HIV/AIDS is adequate in Kazakhstan?’</b>	<ul style="list-style-type: none"> <li>• ‘Yes, because physicians prescribe according to medical conditions’ (Two hospice representatives)</li> <li>• ‘No’ (Five hospice representatives)</li> </ul>
<b>‘If not, why do you think that it is inadequate and what can be done to improve the situation?’</b>	<ul style="list-style-type: none"> <li>• ‘Because of ‘physician problems’</li> <li>• ‘Limited access to opioids’</li> <li>• ‘Lack of knowledge/information’</li> <li>• ‘Excessive control of opioids’</li> <li>• ‘Need to revise normative and legislative documents’</li> <li>• ‘Need to change laws and programs’</li> <li>• ‘Too little information is provided’</li> </ul>
<b>‘Do you think current opioid control measures are adequate in hospitals/healthcare facilities in Kazakhstan?’</b>	<ul style="list-style-type: none"> <li>• ‘Yes’ (Four hospice representatives) - because they are ‘controlled by proper decrees and many organizations’, ‘regulated by normative documents’ and ‘controlled not only by the Department of Health but also by prosecutors’</li> </ul>

	<ul style="list-style-type: none"> <li>• ‘No’ (Three hospice representatives) – ‘the scope of services needs to be extended to achieve full-scale provision’</li> </ul>
<p><b>‘Do you think doctors/nurses/health workers in Kazakhstan understand how to help people who are in pain?’</b></p>	<ul style="list-style-type: none"> <li>• ‘Yes’ (Six hospice representatives) – because ‘they understand that adequate pain treatment and care is needed’; ‘they know how to use opioid analgesics’; they provide ‘not only medication but also sympathy and understanding towards the patient’; and they are ‘educated to treat patients’.</li> <li>• ‘No’ (One hospice representative) – ‘due to lack of knowledge’</li> </ul>
<p><b>‘Do you think doctors/nurses/health workers in Kazakhstan understand how to help people with symptoms other than pain?’</b></p>	<ul style="list-style-type: none"> <li>• ‘Yes’ (Five hospice representatives) – because they ‘understand and can help patients with such symptoms’, and ‘because they are professional’</li> <li>• ‘No’ (Two hospice representatives) – due to ‘poor diagnostics/lack of medicines’ and ‘lack of knowledge (in some regions)’</li> </ul>
<p><b>‘Do hospitals/healthcare facilities have guidelines on pain relief and how to use opioids for pain relief?’</b></p>	<ul style="list-style-type: none"> <li>• ‘Yes’ (One hospice representative)</li> <li>• ‘No’ (Three hospice representatives) - there are ‘no guidelines but common rules on pain relief’</li> <li>• ‘Don’t know’ (Three hospice representatives)</li> </ul>
<p><b>‘Is there a standard process for prescribing and acquiring opioids in Kazakhstan?’</b></p>	<ul style="list-style-type: none"> <li>• ‘Yes’ (Six hospice representatives)</li> <li>• ‘No’ (One hospice representative)</li> </ul>
<p><b>‘With regard to opioids such as morphine, who is responsible for prescribing and dispensing in hospitals/healthcare facilities?’</b></p>	<ul style="list-style-type: none"> <li>• ‘The top manager of the medical organization’</li> <li>• ‘Physician/Vice Director of the hospital’</li> <li>• ‘Physician, but opioids prescribed by concilium’.</li> </ul>
<p><b>‘Do you know whether any difficulties are encountered in managing opioids in hospitals/healthcare facilities?’</b></p>	<ul style="list-style-type: none"> <li>• ‘Limits to the amount that can be prescribed’</li> <li>• ‘Restricted availability’</li> <li>• ‘Insufficient order of opioids’</li> </ul>
<p><b>‘What do you think might be barriers to providing patients with adequate pain relief in hospitals/healthcare facilities in Kazakhstan?’</b></p>	<ul style="list-style-type: none"> <li>• ‘Legal and normative restrictions’</li> <li>• ‘Inadequate access to opioids’</li> <li>• ‘Restrictive regulations such as maximum number of doses per patient’</li> <li>• ‘Lack of awareness amongst the patient and their relatives’</li> <li>• ‘Too many controlling organizations’</li> </ul>

<p><b>‘Have there been any initiatives in Kazakhstan to promote attitudinal change in relation to “opiophobia”?’</b></p>	<ul style="list-style-type: none"> <li>• ‘No’ (Seven hospice representatives)</li> </ul>
<p><b>‘Have there been any initiatives undertaken in Kazakhstan that consider access to essential medication for pain and symptom management as a legal and human right?’</b></p>	<ul style="list-style-type: none"> <li>• ‘No’ (Seven hospice representatives)</li> </ul>
<p><b>‘What initiatives are currently taking place in Kazakhstan to improve the accessibility and availability of opioids?’</b></p>	<ul style="list-style-type: none"> <li>• ‘None’ (Seven hospice representatives)</li> </ul>
<p><b>‘What initiatives are needed in Kazakhstan to improve the accessibility and availability of opioids?’</b></p>	<ul style="list-style-type: none"> <li>• ‘Inform medical workers and the wider population about this problem’</li> <li>• ‘“Champions” should be persistent in promoting these ideas to government ministers’</li> <li>• ‘A wider choice of different forms of opioids is needed (oral tablets, etc.)’</li> <li>• ‘Availability of quality palliative care programs’</li> <li>• ‘Education and training programs for medical workers in order to provide outreach in the best possible way’</li> <li>• ‘Change the National Formulary List’</li> <li>• ‘Prescribe based on medical reasons’</li> <li>• ‘Provide information through the media about prescriptions of opioids for patients’</li> </ul>

The accessibility and availability of opioids in Kazakhstan is described by hospice representatives as a ‘very sensitive sphere’ within the Kazakhstan healthcare system. The accessibility of opioids is described as a ‘big challenge’; the Committee on Drug Control at the Ministry of Internal Affairs is described as ‘very, very sensitive’ about this issue. All organisations in Almaty ‘follow WHO Guidelines on Pain Management’ but opioids are ‘only used in extreme conditions’ (for a list of opioids used in Kazakhstan please refer to **Appendix G**). For example, in the Almaty Center for Palliative Care, the use of opioids is rare and ‘mostly resisted’, except for at the end of life. Patients who

attend the Center for pain relief are provided with other medication which relieves their pain 'very successfully'.

A significant barrier to the development of palliative care in Kazakhstan identified by hospice representatives was the lack of accessibility and availability of opioids in the country. In 2011, out of 31 medicines on the Essential List of Medicines, 'only four' were available in Kazakhstan. A number of associated problems were highlighted including the low level of opioid consumption related to INCB quotas – 'limited quantity due to inaccurate estimation'. A 'pharmacy committee' goes to each medical specialty in Kazakhstan to ascertain the average usage for last year (based on patient documents). Under Article 8, the Government of the Republic of Kazakhstan makes an estimated request to the International Narcotics Control Board (INCB) for opioid analgesics for the following calendar year. In Kazakhstan, this estimated amount (which is supposed to reflect the country's demand for opioid analgesics) is not based on a thorough assessment of the population's needs.

Article 91 *Patients' Rights* of the Code of the Republic of Kazakhstan on People's Health and Healthcare System reads that the patients have a right "for alleviation of their sufferings to the extent permitted by the current level of medical technologies." Yet there is a lack of choice of opioids in Kazakhstan – for example, oral morphine is not available, and morphine via injection is available in hospital only. In 2010, The National Drugs Formulary (which serves as a recommendation for purchase of medicines for healthcare facilities in Kazakhstan), contained only **5** out of **12** registered analgesics. Hospice representatives reported a lack of knowledge/awareness about opioid use amongst physicians; and a fear of opioid addiction/dependence amongst the patient and family members. There is also a cultural belief in some sections of Kazakhstan society that 'pain is necessary, pain is essential for diagnosis' and that the patient is 'not supposed to ask about pain relief'.

A major barrier to the accessibility and availability of opioids in Kazakhstan identified by hospice representatives was excessively strict legislation and bureaucracy in relation to licensing, transportation, prescribing practices, storage procedures, etc. Citizens of Kazakhstan may purchase opioid analgesics only at pharmacies and healthcare organizations licensed to perform such types of activity. Opioids can be used for medical purposes by medical institutions, but they need to possess a special license. In addition, dosage must be 'written in letters and words and not numbers', and the patient must present an official letter confirming that they should receive the opioids – a 'signature' document containing a yellow line. In relation to storage, there are further difficulties; for example, Promadol must be stored at an 'appropriate temperature' but this is not always possible as it must also 'be stored in a safe'. The amount of opioids that can be prescribed is also described as 'problematic' – opioids for terminally-ill patients can be prescribed 'for one month', but for all other groups of patients they can be prescribed 'for one week only'. The restrictions for daily dose of morphine apply in Kazakhstan; the number of days for which morphine can be prescribed and sold at a time is also limited. Doctors can prescribe opioids using a special blank prescription that must be countersigned by the chief physician; these prescriptions are valid for the following seven days only. Other barriers include physician fear of prosecution for 'unintended technical violations' relating to opioids (physicians 'do not know their rights') and prejudices and stigma relating to opioid use; and cost – on average, opioids cost 'approximately 1000 Tenge for a three-day supply (\$6).

The main document currently regulating the Kazakhstani health sector is the **Code of the Republic of Kazakhstan on the People's Health and Healthcare System**. Within the code, there are a number of articles that guarantee medicines to the citizens of the Republic of Kazakhstan. However, there is only one law directly pertaining to the use of opioid analgesics - The Law of the Republic of Kazakhstan No 279-I of 10 July 1998 *On Narcotic Drugs, Psychotropic Agents and Precursors, and the Measures Preventing Illegal Turnover and Abuse Thereof*. However 'outdated/lack of appropriate legislation' was

mentioned as another barrier to the accessibility and availability of opioids in Kazakhstan. For example, the use of transdermal opioids is regulated and polyclinics stock them, but it is seldom used as there is 'no regulation on dosage, so it cannot be prescribed'. A 'lack of collaboration' between governmental departments in relation to opioids was described. For example, an application to be able to prescribe transdermal opioids was submitted to the Ministry of Justice in 2009 but there was 'no reply for over two years'. In summer 2011, the Ministry of Justice agreed to pass the legislation (Decree 173) but this was immediately blocked by the Ministry of Health who insisted that the Ministry of Justice 'could not pass such a decree'.

The hospice representatives stated a number of objectives that, in their opinion, would serve to address some of these problems: the provision of information about opioids to the patient and family members; improve the accessibility and availability of opioids 'for legitimate medical purposes'; education and training of physicians 'to increase knowledge and awareness about opioids'; change physician attitudes so there is a 'correct estimation of opioid need', and advocacy initiatives to 'remove excessive restrictions on opioids'. The Ministry of Health is partly responsible for the construction of new pharmaceutical factories, which may cover the national demand for opioids in the framework of the government programme '30 manufacturing leaders of Kazakhstan'; a programme coordinated and funded by the Fund for Sustainable Development 'Samruk-Kazyna'.<sup>65</sup>

Hospice representatives suggested that a number of action steps were required in order to achieve these objectives, including 'statistical indicators to demonstrate the need for opioids to the legal entities, 'developing normative documents relating to the prescription of opioids', media coverage to improve the public perception of opioids, 'efficient pharmaceutical management' and 'education and training about opioids for

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<sup>65</sup><http://www.euro.who.int/en/where-we-work/member-states/kazakhstan/areas-of-work>

physicians and nurses at the under-graduate and post-graduate level'. A number of individuals and groups that possessed the authority and/or responsibility to take the necessary action were identified; for example, the Ministry of Health, Kazakhstan Parliament, and international palliative care 'experts'. When asked to consider a realistic timescale for completion of the action steps, hospice representatives suggested 'approximately one to three years'. In order to achieve these objectives, additional State funding would be required for media campaigns and education/training initiatives, the training of specialists in pharmaceutical management and the creation of technical/working groups to develop normative legislation. A film produced by SFK about the availability and accessibility of opioids in Kazakhstan entitled 'Golden Fish' was screened for the first time at the 7<sup>th</sup> *CIS Oncology and Radiotherapy Congress* in Astana in September 2012.

The biennial collaborative agreement for 2010–2011 between WHO/Europe and Kazakhstan identifies not only the priorities for action but also the results to be delivered. An aim of the collaboration is to 'improve capacity to develop and implement national policies on access, quality and use of essential medical products and technologies'. In order to achieve this aim, 'a training package will be developed to strengthen the regulatory capacity of the National Drug Agency in the area of medicine regulation' and the 'National Drug Formulary developed according to WHO recommendations and used as a basis for procurement of essential medicines'.<sup>66</sup>

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<sup>66</sup><http://www.euro.who.int/en/where-we-work/member-states/kazakhstan/areas-of-work>

## **POLICY**

In relation to policy, hospice representatives suggested that a number of legislative barriers were affecting the development of palliative care in Kazakhstan: these included the socio-economic stage of development in Kazakhstan compared to other countries; cultural traditions, beliefs and values; the lack of an advocacy framework for integration of palliative care into the Kazakhstan healthcare system; and 'bureaucratic mechanisms'. It was suggested that legislation relating to palliative care is 'imperfect' as it is created by people 'with a mentality that does not understand the problem', and that 'although some regulations and laws are in place, there are no practical mechanisms to implement them'.

A barrier to the development of palliative care in Kazakhstan that was identified by hospice representatives was a lack of intersectoral collaboration/coordination in the country. A number of underlying reasons for this problem were suggested: the gap between the Ministry of Health and Ministry of Social Development - 'no interrelationship between the two' and 'no official mechanism for collaboration between the organizations'; a lack of effective channels of communication and information between government departments; and 'financial difficulties' for doctors working in palliative care - 'large amounts of money' were allocated to other medical specialties/disciplines and only a 'very small amount' to palliative care (that was 'sometimes diverted' to other specialties). In addition, the 'order of palliative care development' was described as 'very poor, separated and fragmented'. A further policy problem related to the lack of palliative care standards in Kazakhstan. A number of underlying reasons for this problem were suggested: a low level of palliative care development; the lack of palliative care 'champions'; because there is 'little experience in this area' in the country; and the mass media is 'relatively unaware of the problem'.

The hospice representatives stated a number of objectives that, in their opinion, would serve to address some of these problems: for example, the creation of working groups comprising of 'specialist, experts and "champions" of palliative care, psychologists, social workers, religious and spiritual leaders, healthcare professionals, and legal/human rights advocates'; 'increased human resources' (including volunteers); conduct a 'needs assessment' of palliative care that can 'promote the discipline within the Kazakhstan healthcare system'; promote a 'change in mentality' amongst government officials; and develop a palliative care 'mission statement' with detailed and specific instructions relating to the provision of palliative care in Kazakhstan.

Hospice representatives suggested that a number of action steps were required in order to achieve these objectives, including: the need to increase financing; 'explain the objectives at the Ministerial and Parliamentary level'; utilise 'international expertise and experience'; develop an effective media/social network campaign to improve communication and information channels between organizations; provide 'an analysis of the palliative care situation' in Kazakhstan in order to 'create a strategic plan of development'; exchange of experience with other countries that have successfully developed advocacy frameworks; improve the legislative base of palliative care; provide education and training to 'inform doctors what palliative care means'; promote 'greater interrelation with religious/spiritual organizations' as there is a 'problem with the definition of dying in Kazakhstan' (including with other medical specialties/disciplines).

A number of individuals and groups that possessed the authority and/or responsibility to take the necessary action were identified: governmental departments and Ministers - for example, Ministry of Health, Ministry of Social Protection, Ministry of Finance, etc. (junior Ministers should be included); local authorities such as the 'Akim (Mayor of district) and regional Departments of Health; Kazakhstan Parliament; religious organizations and 'spiritual groups'(with an 'interest in palliative care'); 'international partners'; all hospices in Kazakhstan; and the mass media. When asked to consider a

realistic timescale for completion of the action steps, hospice representatives suggested ‘approximately three to five years’ due to bureaucratic limitations and an inability to lobby effectively’.

In order to achieve these objectives, and ‘develop the material and technical base’ of palliative care in Kazakhstan, funding for ‘technical analysis and strategic planning’ from ‘both State and local government budgets’ will be required, as will ‘private financing’ comprising of ‘an independent fund to support palliative care’; it will therefore be necessary to ‘provide statistical indicators of need’ - for example, a National Registry of how many patients require palliative care, that is ‘disease-specific’ (number of cancer, HIV/AIDS, TB patients, etc.). It will also be necessary to demonstrate the cost-effectiveness of palliative care and develop ‘effective finance control mechanisms’.

### **Legal and regulatory framework for palliative care services in Kazakhstan**

There is a ‘legal hierarchy’ in Kazakhstan: There are **Laws** (that provide an ‘umbrella’ or a ‘framework but with little detail, just the basic principles); to detail the Laws there are state **Standards**; and below this specific **Rules**. KSPH participated in research on palliative care in Kazakhstan as part of a ‘process of stimulation’ within the Government Order relating to palliative care. A normative base for palliative care is beginning to be developed and progress is being made on legislation - there are some Orders, Articles and documents that stipulate ‘what palliative care is’ (based on the WHO definition) and which patients are entitled to it. The sociological survey undertaken by Soros Foundation Kazakhstan reported that when the ***Code of the Republic of Kazakhstan on the People’s Health and Healthcare System (September 18, 2009)*** was created, Orders of Palliative Care became embraced by the Government and the discipline was incorporated into the Health Code. The Code is the main document currently regulating the Kazakhstan healthcare sector and includes a number of references to palliative care.

Another key Legislative Act relating to the delivery of healthcare in Kazakhstan is the *Decree of Governmental program of Public Health Development in the Republic of Kazakhstan “Salamatty Kazakhstan” for 2011-2015*. This State program is approved for the purpose of implementation of the Decree of the President of the Republic of Kazakhstan of February 1<sup>st</sup> 2010 No. 922: *About the strategic development plan of the Republic of Kazakhstan till 2020*. Its main objective is improvement of the health of citizens of Kazakhstan for ensuring sustainable social and demographic development of the country.

Among health protection by-laws, the following should be noted:

- *Decree No. 184 On Standardization in Health Protection*, issued by the Government of the Republic of Kazakhstan on 16<sup>th</sup> February 2004;
- *Decree No. 1729 On Approving Rules of Organizing and Conducting Purchases of Medicines, Preventive (Immunobiological, Diagnostic, Disinfecting) Preparations, Products of Medical Purposes and Medical Equipment, Pharmaceutical Services for Rendering the Guaranteed Volume of Free Medical Services*, issued by the Government of the Republic of Kazakhstan on 30<sup>th</sup> October 2009;
- *Order No. 481 On Approving Rules of Conducting Medical Examination with the Aim of Establishing a Citizen as a Sufferer from a Contagious Form of Tuberculosis*, issued by the Minister of Health of the Republic of Kazakhstan on 30<sup>th</sup> September 2009;
- *Resolution No. 2136 On Approving the List of Guaranteed Volume of Free Medical Services*, issued by the Government of the Republic of Kazakhstan on December 15<sup>th</sup>, 2009;
- *Resolution No. 2299 On Approving Rules and Conditions for Rendering Fee-paying Services in Medical Organizations*, issued by the Government of Kazakhstan on 30<sup>th</sup> December 2009;

- *Decree No. 183 On Strategic Plan of the Ministry of Health of the Republic of Kazakhstan for 2011-2015*, issued by the Government of the Republic of Kazakhstan on 25<sup>th</sup> February 2011, as amended 23<sup>rd</sup> May 2011;
- *Resolution No. 336 On Approving of the Program of Development of the Oncological Help in the Republic of Kazakhstan for 2012-2016*, issued by the Government of the Republic of Kazakhstan on 29<sup>th</sup> March 2012;

Palliative care is currently included in the following legal documents in Kazakhstan:

- Kazakhstan Code from 18.09.2009 **Code of the Republic of Kazakhstan on the People's Health and Healthcare System (September 18, 2009)** (art. 32; 34; 53) **(Appendix H)**
- Government Decision from 26.11.2009, № 1938 **On Approval of List of the Population Categories Subject to Palliative and Nursing Care (Appendix J)**
- Decree of the Ministry of Health of the RK from 02.11.2009 № 632 **On Approval of rules for palliative care and nursing care (Appendix K)**
- Decree of the Ministry of Health of the Republic of Kazakhstan (proposed 12.05.2009/passed 07.04.2010) № 238 **On approval of standard staff and state standards for health care organizations (Appendix L)**
- **State program for development of public health of RK "Salamatty Kazakhstan" on 2011-2015 years** - section 2.3.1. *Improving palliative care for patients (Appendix M);*
- Decree No. 1343: **On Approval of the Rules of Executing Palliative and Nursing Care**, issued by the Government of the Republic of Kazakhstan on 15<sup>th</sup> November 2011.

There is a problem with financing treatment as it is adjusted to the Health Protocols and Clinical Guidelines of Care. The Order of the Kazakhstan Government states that palliative care must be provided consistently in line with clinical standards, but there are

no clinical standards at the moment so there is currently a legal vacuum. At the early stage of development of Almaty Center for Palliative Care, the Terms of Reference (TOR) stipulated that patients can receive treatment there for 'as long as necessary'. The average treatment stay is 20-25 days but this is a great problem as the Government defines the limit of inpatient treatment. The cost of one bed day in 2010 was 5000 Tenge (approximately \$34), but regardless of duration of treatment in the hospice, the Government will only pay a maximum of 50,000 Tenge (10 days). Additional bed days cannot be classified as inpatient or even hospice care but rather **long-term social care** – there is a clear need to distinguish between these terms. The tension between inadequate funding and the unclear delineation of health/social care was a point of much concern for a number of hospice representatives. In Kazakhstan, there is a division between the Ministry of Social Care and the Ministry of Health Care which is mainly represented by medical services. Palliative care is seen as 'given' to medical workers but *perceived* as part of social care. This is a fundamental difficulty in Kazakhstan that is described as 'very difficult to break down' – how social work can be included in the budget of the state hospital.

In 2007, a palliative care project commenced between Credo and Soros Foundation Kazakhstan. The research involved social questionnaires for religious organisations and hospitals and a palliative care needs report was written. The recommendations were to be introduced at the governmental level. A working group on the development of palliative care in Karaganda was established and a report produced by Credo. A working group on the methodological justification of palliative care organization in Kazakhstan held its first meeting on May 15<sup>th</sup> 2009, where the Credo report was presented to working group members and a normative legal base and regulatory framework for palliative care developed. At the second meeting of the working group on July 31<sup>st</sup> 2009, the concept of palliative care in Kazakhstan was introduced and additional medical education programs were suggested. A tutor from a medical college attended the second Credo working group meeting where proposals for additional points to

Decree of the Ministry of Health № 657 *On Approving the Rules of Palliative Care and Nursing Care* from 28.12.2006 were formulated by all members of the working group. Working group members A. Sagyndykova, M. Kulzhanov, A. Nurkerimova, and I. Mingazova continued work on this decree after the meeting. The group also worked on models of home-based palliative care provided by inter- and multi-disciplinary teams in conjunction with NGOs and Credo. Credo drafted documents relating to problem solving in palliative care but stressed the need to focus on other standards and national decrees in developing palliative care standards in Kazakhstan. Recommendations from the report were accepted at the governmental/republican level and the six hospices in Kazakhstan began to work on the development of palliative care standards. Credo suggested that the development of palliative care in Kazakhstan could be approached in two different ways:

- *Reform existing health care by-laws:* Although this strategy possessed a number of advantages (for example, no development of additional programs or state funding would be required), Credo suggested that it possessed more disadvantages. For example, palliative care would be dependent on local budget funding streams and the level of palliative care awareness among local health authorities. There would be a lack of a unified standard of palliative care within this approach and an uneven development of palliative care services among regions;
- *Develop a national concept of palliative care:* Although this strategy possessed some disadvantages (for example, lack of adequate inter-agency coordination) Credo suggested that it possessed more advantages as palliative care could be implemented at different levels and fully integrated into national public health policy; this would provide financial stability and ensure access and equal distribution of palliative care services for people with different types of disease. Although this approach would involve a system of state control, it could also

enable NGOs to produce capacity building amongst their workforces and create high-quality network services and training systems.

Both these approaches were fully considered, and following a third working group meeting on October 22<sup>nd</sup> 2009, a number of points relating to palliative care were introduced into the *National Programme of Health Care Reform (2010-2015)*, the *Decree On Approving the Rules of Palliative Care and Nursing Care* was revised, and partnerships with interested organizations were further developed. A number of other organizations are actively involved in the development of palliative care policy in Kazakhstan. For example, NGO *Association of Social Workers, Disabled and Volunteers* (a public association that develops professional social assistance for people) is involved in the development of legal and normative documents and laws, including 'three specifically related to palliative care'.

Credo stressed the need to develop and implement clinical guidelines relating to palliative care, establish training and education initiatives for both doctors and nurses, introduce a coherent strategy to develop palliative care awareness amongst social workers, and implement palliative care protocols regarding treatment. Credo carefully reviewed palliative care standards in both Poland and the United States and suggested the need to adjust these standards to the socio-cultural context of Kazakhstan. Credo acknowledged that review of the standards was only undertaken within the context of home-based palliative care and stressed the need to develop a structured plan to accomplish all these aims within the standards. Credo stress that in order to develop effective palliative care standards there is a definitive need for interdisciplinary working and for discussion with other health care professionals; for example, every interdisciplinary member should be fully aware of regulations relating to infection control and this should be stipulated in the palliative care standards. However, some key stakeholders have expressed concern at the level of socio-cultural awareness that would be demonstrated within the development of palliative care standards in Kazakhstan and the danger of 'simply imposing a US/UK model' of palliative care.

However, the sequence of documents relating to palliative care that need to be developed appears to be rather unclear and although palliative care provision is included in the legal framework, it is not adequately addressed and 'often underdeveloped'. There are some protocols in the delivery of palliative care but there is a need to examine whether they are up-to-date; if palliative care legislation is to progress further, 'much organizational and structural work needs to be done'. In addition, hospice representatives suggest that the government ministries involved in the development of palliative care 'do not believe that it is important'. They also suggest that it is 'always the same' in Kazakhstan, where decrees are formulated but not always implemented - just because a decree has been established, support from the government is not guaranteed. It was stated that the Ministry of Health 'agree with the need' for both home-based care and inpatient hospices. There is a need to compile a list of 'people who need palliative care' within the development of standards but also a need to amend social care standards as there is 'no mechanism' to provide palliative care within the context of social care. However, if social work standards related to palliative care are developed there is a risk that they may only be relevant to social work; therefore 'an interdisciplinary approach is essential'.

Other policy difficulties include the fact that there is a Kazakhstan law that stipulates 'where medical treatment can be provided'; hospices are included on this list and this means that 'many additional reports are required'. A further problem in relation to the government is a succession of changes in personnel in relevant government departments, for example, in the MOH or Ministry of Social Affairs/Protection (MOSAP). Capacity-building in Kazakhstan is reported as 'very important due to lack of palliative care experience'; changes in MOH or MOSAP personnel 'hinder capacity-building and advocacy'.

The work undertaken in relation to the development of palliative care standards has continued in Kazakhstan, and in October 2012, as the result of a joint initiative between SFK, RCDH, KSPH and IPCI, standards will be submitted to the Ministry of Health (MOH) as an essential tool and guide for the continued development and provision of palliative care in Kazakhstan, and as an integral part of the legislative and regulatory health care framework; it is anticipated that the standards will facilitate programme improvement and development and influence the planning and delivery of palliative care services by determining the cost of palliative care and therefore the volume of services that are provided by the state.

The standards are underpinned by the World Health Organization's definition of palliative care, and recognize that scaling up palliative care requires a public health approach with four pillars: policy, education, drug availability and implementation. The standards can be seen as a set of criteria to be accomplished by any potential hospice/palliative care service, and are designed to allow the development and improvement of palliative care across different service levels and within the organisational capacity of various service providers. It is therefore expected that these standards will influence the planning and delivery of palliative care services at all levels of health care service delivery. In addition, the increasing need to establish specific indicators of quality and effectiveness for palliative care has been a driving force behind these comprehensive standards which can also be used by health authorities and financiers in order to evaluate the existing and emerging palliative care services in Kazakhstan and provide a framework for the development of performance indicators that can facilitate programme improvement.

The team that contributed to the development and publishing of these standards did not attempt to define them as a level to aspire to, but simply as a core of basic requirements to ensure the quality of palliative care services provided for patients in advanced and terminal stages of their disease. It is meant to be a quality improvement

tool and does not duplicate or replace the clinical standards currently maintained by service providers. Indeed, it is intended to complement such standards.

The primary audience for these palliative care standards is the Kazakhstan Ministry of Health, which is responsible for health care planning in the country. Also targeted are the other leading health care institutions in Kazakhstan, policy makers, government officials and all other Ministries, legislators, public health officials, healthcare professionals involved in palliative care practice and development, non-governmental organizations (NGOs) and civil society organizations.

To ensure widespread implementation, it is important that palliative care is integrated into all levels of the Kazakhstan healthcare system and delivery models, including specialist, regional and district facilities. Thus these standards have been developed with the aim of targeting all those in service provision for people living with life-limiting illnesses and they are applicable to all settings of care delivery, i.e. home-based care, inpatient services, outpatient programmes, day-care programmes, hospital settings, etc.

The process of developing standards was highly participatory and was undertaken through consultations with stakeholders at different levels. These stakeholders contributed to the development of various aspects of the standards mainly through committees or consultant work. Working group meetings were held on a regular basis over a three-year period (2009-2012) in both Almaty and Astana to discuss progress of the standards and sub-groups were requested to develop specific chapters and engage government officials involved in relevant areas: for example, development of normative legal documents on ethical issues; an interdisciplinary approach to service development; study program development in the form of palliative care education and training initiatives; and the development of clinical protocols for palliative care. The Working Group comprised of coordinators from SFK, KSPH and RCDH; other international and national palliative care and related field experts; key governmental health policy

decision-makers (e.g. representatives from Ministry of Health, Ministry of Social Affairs and Protection); service providers dealing with HIV/AIDS, tuberculosis and cancer patients (e.g. hospices, oncological institutions, nursing homes, etc.); key personnel working within those organizations (e.g. managers, directors, doctors, nurses, and other members of multidisciplinary teams - social workers, clerical staff, psychologists, therapists, pharmacists etc.); religious and spiritual leaders; legal/human rights advocates; and all relevant NGOs.

The palliative care legal and regulatory framework in Kazakhstan was thoroughly reviewed; palliative care standards, guidelines, policies, laws and regulations that exist in other countries were also reviewed by International Palliative Care Consultant Thomas Lynch with recommendations made to the Working Group on what elements of these should be included in the Kazakhstan version, taking into account specific social, cultural and economic contexts. The expertise and the information supplied by the foreign partners, along with the Kazakhstan specialists' contributions, resulted in adapting the international experience to the Kazakhstan social and economic conditions as well as to the specific regulations of the national healthcare system. The draft document was reviewed at a working group meeting in Astana in September 2012 between all the key stakeholders and a representative from the Ministry of Health; the draft standards were agreed in principle by all participants after which they were finalized ready for dissemination and implementation. Clinical guidelines that were developed at the third working group meeting in November 2011 are not included with this version of the standards (they are to be incorporated at a later stage). The development of these palliative care standards is part of a wider process of increasing understanding amongst key stakeholders, politicians and policymakers of the changes needed in public health policy in order to develop a legislative framework for palliative care implementation within the Kazakhstan health care system.

## **HUMAN RIGHTS, ETHICAL ISSUES, AND PALLIATIVE CARE IN KAZAKHSTAN**

The area of health policy in Kazakhstan is closely linked to the concept of palliative care and the availability and accessibility of opioids as a fundamental human right. In an interview on September 11<sup>th</sup> 2012, Bakhyt Tumenova described the work of the International Health and Human Rights Non-Governmental Organization 'Aman Saulyk'.

Bakhyt suggests that the 'human rights approach' is 'very new to Kazakhstan'. The organization is celebrating its fifth anniversary of being 'the only NGO in Kazakhstan where medical doctors defend the human right to health.' There are 'other patient defendant organizations' operating in Kazakhstan, but they are 'disease-specific (epilepsy, diabetes, etc.)' and 'often work in close collaboration with pharmaceutical companies'. Aman Saulyk 'are different' because the organization is 'autonomous, stable financially, and receive no money from pharmaceutical companies'. The organization 'is funded entirely' by 'international project organizations' related to 'mental health, drug provision and HIV/AIDS'. As well as receiving funding from international organizations, Aman Saulyk receive some funding from the 'business and private sector' in Kazakhstan, and this means that the organization is 'well equipped' and 'in a good position in relation to other NGOs'. The organization works on a variety of projects such as 'Access to Women's Health Services in Rural Areas' and 'Women in Prison'; however, palliative care is also described as 'a very important part' of the work of the organization. Bakhyt suggests that people are 'beginning to understand the right to palliative care from a bottom-up perspective' and that 'civil society needs to advocate' for the people of Kazakhstan in this area. The organization provides 'assistance to opinion and policy leaders' and has 'widened palliative care from a human rights angle'.

The human rights 'hotline' at Aman Saulyk has received '17,000 enquiries in the last five years'. In relation to the hotline, 'approximately 70%' of enquiries are from people who

are 'over 50 years of age'; '34% of calls' are from people 'with a specific disease'. The film from SFK 'Golden Fish', which was screened at the 7<sup>th</sup> CIS Oncology and Radiotherapy Congress in Astana in September 2012, featured people that had contacted the Aman Saulyk hotline initially; SFK are preparing to make another film in this area and have already 'requested more palliative care patients' from the organization to feature in it. The organization would like the hotline to be open 24/7 – currently it is 'not manned at evenings or weekends' but this is when 'many problems occur' as healthcare staff are also often unavailable at these times. A monthly newsletter has recently been published about the organization (in Russian only) and the organization has two websites: the 'Medical Right to Health' and 'Aman Saulyk'. They also offer online consultation and whilst acknowledging that this not 'as personal' as speaking to an individual, it 'has advantages' as it 'encourages discriminated patients' (for example, those with STDs, or HIV/AIDS) to contact the organization as it is anonymous. Bakhyt suggests that 'most elderly people' use the hotline as they often have 'limited access to the internet' whilst 'young people' tend to use the internet more. The concept of the website is described as 'quite new' although there have already been 'more than 8,000 hits' (and multiple hits from the same person only count as one so there have been many more in total).

Under the remit of the Aman Saulyk project, individuals trained in human rights at an OSF seminar in Salzburg, have 'trained 120 NGOs' in Kazakhstan about the 'right to health' – 'a further 60 law and medical students' have also received similar training. Following official presentation of the manual, 'more training of doctors' will take place in addition to 'other advocates' and 'public council NGOs'. In all training, there is a specific section on 'palliative care from a human rights perspective' that is 'conducted by lawyers'. In addition, a booklet has been prepared on palliative care and human rights' (although this is not available in English) which 'approaches palliative care from a human rights angle'. A number of human rights/healthcare training initiatives have been provided by the organization in the South-East region of Kazakhstan because this area

has the 'highest rate of oncological disease' in the country, and is the 'poorest region in Kazakhstan'. Although 'only 25 places were available', Bakhyt suggests that '52 people applied' to undergo this training. Bakhyt also stresses the need for 'increased education/training initiatives', suggesting that 'it makes sense' to 'invest in doctors, lawyers and advocates to generate a new way of thinking'.

In regards to human rights in Kazakhstan, there are no 'advanced directives' as such, but documents do exist that enable patients to express their wishes regarding end-of-life care, although they 'may not be honoured' if physicians do not agree with them; for example, withholding food and water (patient would be drip-fed and referred to a psychiatrist). The concept of 'do not recover' (DNR) is 'not well-understood' nor 'deemed necessary' – not seen as a problem as it is a 'doctor's duty' to resuscitate a patient (even if it is not in their best interests). Indeed, the issue of 'autonomy' is 'not particularly well understood overall'.

Bakhyt knows of 'no cases' relating to advanced directives to withdraw treatment. However, she highlights the 'very high suicide rate' in Kazakhstan, 'particularly amongst young girls'; this is described as 'a very sensitive subject' that 'no-one wants to discuss' but may be linked to issues of 'vulnerability, poverty and unemployment' or a 'combination of those factors'. Bakhyt suggests that issues such as withdrawal of treatment should be 'decided by the patient/family in conjunction with healthcare professionals' but that this is 'a personal decision, not a legal one'.

There are a number of other ethical aspects relating to the provision of palliative care in Kazakhstan. For example, relatives usually prefer the patient to die at home and often feel 'a sense of shame' if their loved one dies in a hospice or hospital environment as they believe it to be the 'duty of the family'. This often 'causes much stress' (particularly for people of working age) with responsibility 'often resting on the shoulders' of a small number of people (usually women) who are described as 'inadequately prepared' for

the provision of such care. In certain situations, often due to 'severe financial difficulties' where family members are unable to leave their employment, adult children may 'abandon their elderly parents' – patients will only be taken into the hospice in these circumstances if they are 'within 6 hours of death'.

In many hospitals there are several departments that segregate cancer or HIV/Aids patients from other patients who 'do not want to mix with them'. In Kazakhstan law, people who are aware that they have the HIV/AIDS virus do not need to tell their partner; however if the partner is infected with the HIV/AIDS virus the person may be subject to prosecution. Participants of the working group provided some specific examples of moral and ethical dilemmas that they had encountered: a recent ethical case in Kazakhstan involved a mother with HIV/AIDS who transmitted the virus through childbirth but refused ART for the child on religious grounds. The mother refused this treatment because she believed that they 'were both going to die anyway'. Cancer patients may also refuse treatment on this basis.

Communication skills between healthcare professionals and patients at the end of life may also be of ethical concern. For example, in Kazakhstan, there is 'one nurse for twenty patients' so nurses are overworked and 'communication is very limited with the patient and their family'. A further ethical problem relates to communication between doctor and patient; for example, the case of a newly married woman with breast cancer where the doctor told her husband that she had Stage IV breast cancer 'in a very rude way'. The problems relating to communication are compounded by the fact that in Kazakhstan, there is an underlying problem with patient aggression towards health care professionals; outside of Kazakhstan health care professionals tend to be 'very well respected' whereas in Kazakhstan community, health care professionals are 'not respected' due to their low salary.

The organization Aman Saulyk was due to officially present a practical manual relating to human rights in health care on 17<sup>th</sup> September 2012. **Human Rights in Patient Care: a Practitioner Guide** is a result of the joint project of the Law and Health Initiative (LAHI) of the Open Society Public Health Program, and the Open Society Foundations' (OSF) Human Rights and Governance Grants Program (HRGGP), and Soros Foundation Kazakhstan (SFK).

### **Human Rights in Patient Care: a Practitioner Guide**

The important norms of international and regional law concerning standards of human rights in the rendering of medical care are included in the Practitioner Guide. Rights and duties of patients and medical workers are revealed through the national constitutional provisions, laws and byelaws. The guide also targets lawyers, health care managers, and patient advocates. Designed as a practical “how to” manual, it aims to provide an understanding of how to use legal tools to protect basic rights in the delivery of health services. The guide systematically reviews the diverse statutes, regulations, and orders applicable to patients and health care providers and categorizes them by right or responsibility. The guide specifically addresses the concept of “human rights in patient care,” which brings together the rights of patients and health care providers. The concept of human rights in patient care refers to the application of general human rights principles to all stakeholders in the delivery of health care. These general human rights principles can be found in international and regional treaties, such as the *International Covenant on Civil and Political Rights*; the *International Covenant on Economic, Social and Cultural Rights*; the *European Convention on the Protection of Human Rights and Fundamental Freedoms*; and the *European Social Charter*. These rights are universal and can be applied in the context of health care delivery just as they can be in any other context. However, In Kazakhstan, the field of human rights in patient care is still new and evolving. Many of the statutory provisions cited in the guide have not been authoritatively interpreted by courts, and those that have still remain open to additional

application and interpretation. There remain huge gaps in understanding how, in practice, to apply human rights in patient care.

The Constitution of the Republic of Kazakhstan (1995), states that the Republic of Kazakhstan respects the principles and rules of International Law (Article 8). According to the Constitutional Council, these rules mean that the Republic of Kazakhstan endeavors to consider the principles and rules of International Law in the process of domestic law development. When the Constitution of the Republic of Kazakhstan was written, the basic international documents concerning the rights and freedom of the person and the citizen - the *General Declaration of Human Rights* accepted by Resolution 217A (III) General Assembly of the United Nations, 10 December 1948 - were used. However, the current law of the Republic of Kazakhstan should comply with the constitutional provision of the Republic of Kazakhstan and only international treaties ratified by the Republic of Kazakhstan shall prevail over the laws.

Among important international conventions and treaties which Kazakhstan has ratified or has joined, it is necessary to note:

- *Convention on the Rights of the Child* - adopted November 20, 1989 - ratified June 8<sup>th</sup>, 1994;
- *International Covenant on Economic, Social and Cultural Rights* - adopted December 16<sup>th</sup>, 1966 - ratified November 21<sup>st</sup>, 2005 - Entry into force April 24<sup>th</sup>, 2006;
- *International Covenant on Civil and Political Rights* - adopted December 16<sup>th</sup>, 1966 - ratified November 28<sup>th</sup>, 2005 - entry into force April 24<sup>th</sup>, 2006;
- *WHO Framework Convention on Tobacco Control* - adopted May 21<sup>st</sup>, 2003 - ratified November 25<sup>th</sup>, 2006;
- *Convention on Psychotropic Substances* - adopted February 21<sup>st</sup>, 1971 - accessed June 29<sup>th</sup>, 1998;

- *UN Convention Against Illicit Traffic in Narcotic Drugs and Psychotropic Substances* - adopted December 20<sup>th</sup>, 1988 - accessed June 29<sup>th</sup>, 1998;
- *Convention on the Rights of Persons with Disabilities* - adopted December 13<sup>th</sup>, 2006 - signed December 11<sup>th</sup>, 2008;
- *A Model Law On the Protection of Human Rights and Dignity in Biomedical Research in CIS* - adopted November 18<sup>th</sup>, 2005;
- *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* - adopted December 10<sup>th</sup>, 1984 - accessed June 29<sup>th</sup>, 1998;
- *Single Convention on Narcotic Drugs* - adopted March 30<sup>th</sup>, 1961 - accessed July 1<sup>st</sup>, 1998.

### **Legal Health Protection in the Republic of Kazakhstan**

The Basic Law of the Republic of Kazakhstan – the *Constitution of the Republic of Kazakhstan* (1995: Article 29) states that:

- Citizens of the Republic of Kazakhstan have the right to health protection;
- Citizens of the country have the right to free and legally-guaranteed medical assistance;
- A fee-paying health service in public and private healthcare establishments and from private medical practitioners is received in line with procedures specified by law.

Citizens' basic right to health protection is also covered in **Article 88** of the **Code of the Republic of Kazakhstan On the Health of the People and the Healthcare System** of 18<sup>th</sup> September 2009. The Code regulates social relations in health care with a view to implementing the citizens' constitutional right to health protection and is aimed at streamlining health legislation, harmonizing it with international standards and regulations, and improving the status of national medicine, medical care quality and

level of medical services provided to citizens, as well as providing high-quality pharmaceutical drugs, medical products, and medical equipment:

Under **Article 88** of the Code, citizens of the Republic of Kazakhstan shall be entitled to:

- Free guaranteed extensive medical assistance in accordance with the list approved by the Government of the Republic of Kazakhstan;
- Provision with medical products and medical devices within the limits of the free guaranteed medical assistance, including provision of certain categories of citizens having specified diseases (conditions) with free or beneficial (having special discounts) pharmaceutical products and specialized medicinal products at the ambulatory level according to the list approved by the authorized body;
- Free choice of medical organization and qualitative and timely medical assistance;
- Additional medical services over and above guaranteed free medical assistance at patients' own expense, using the funds of organizations, the voluntary insurance system and other unprohibited sources;
- Medical assistance abroad funded through the budget when clinically indicated in an Order defined by the Government of the Republic of Kazakhstan;
- Compensation for damage caused to health due to incorrect prescription or use of medicinal products, medical devices and medical equipment by medical professionals;
- Ascertainment of temporary disability including issuance of a sheet of temporary disability form or temporary disability certificate;
- Free obtaining of reliable information on preventive measures, diagnostics, treatment of diseases and medical rehabilitation, clinical researches, factors influencing health, including environmental conditions, conditions of work, household and leisure, healthy nutrition and food safety, including sanitary-epidemiological expertise from governmental bodies, organizations and the attending medical doctor within the limit of their competence;

- Obtaining free information on safety, efficiency and quality of distributed medicinal products, medical devices and medical equipment from governmental bodies, independent expert organizations and entities in the field of circulation of medicines, medical devices and medical equipment;
- Appeal against actions or omissions of medical and pharmaceutical personnel to a public health organization, a higher authority (Authors' note: An example of higher authorities are the district and then regional levels) and/or in a judicial procedure;
- Application for involvement of independent experts in case of disagreement with the conclusions of the State medical examination.

Other relevant Articles in the Code include:

- Sub-items 1 and 4 of **Article 112** of the Health Code (accessibility and quality of voluntary anonymous and/or confidential medical examination on a non-paying basis for HIV-positive and AIDS patients; prevention of any forms of discrimination because of the nature of the disease). Sub-item 5 of Article 112 of the Health Code provides for State guarantees on the prevention, diagnosis and treatment of HIV infection and AIDS;
- The *Code of Ethics of Medical and Pharmaceutical Workers of the Republic of Kazakhstan* was incorporated into the Health Code and stipulated in **Article 184**. The Code determines the moral responsibility of healthcare and pharmaceutical professionals in their activities before the citizens and society as a whole; Sub-item 2 of Item 2 of Article 184 provides that medical and pharmaceutical workers 'should help improve the health of citizens of the Republic of Kazakhstan';
- Since the Health Code was adopted, 11 Laws of the Republic of Kazakhstan (**Article 186**) that regulated public relations in the sphere of health care, rendering of medical care, provision of medicines, carrying out preventive activity, etc. have been repealed.

## Patient rights in Kazakhstan

### *Right to access*

Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness or time of access to services (European Charter of Patients' Rights).

Relevant legislation includes:

- Article 29 of the **Constitution of the Republic of Kazakhstan** states that citizens of the Republic of Kazakhstan have the right to health protection;
- Item 2 of Article 14 of the **Constitution of the Republic of Kazakhstan** states that no one shall be subjected to any discrimination on grounds of origin, social or property status, sex, race, nationality, language, religion, creed, place of residence or any other circumstances;
- Item 3 of Article 39 of the **Constitution of the Republic of Kazakhstan** establishes the prohibition on restriction of the rights and freedoms provided by a number of articles of the Constitution, including Article 14;
- Sub-items 2) and 3) of Article 87 of the **Health Code** (providing a guaranteed volume of free medical services and equal access to medical care). A guaranteed volume of free medical care is provided free of charge at medical organizations regardless of their ownership, in accordance with the profile of their activities as per their license and subject to the conclusion of a contract for the provision of guaranteed free medical assistance with the territorial Department of the Committee for Payment of Medical Services of the Ministry of Health or with the oblast health authorities (Rules ensuring the provision of citizens with a guaranteed volume of free medical services of November 19, 2009);

- Sub-item 2 of Item 1 of Article 91 of the **Health Code** (rendering medical services in order of priority defined exclusively by medical criteria without the influence of any discriminatory factors);
- Sub-items 1 and 4 of Article 112 of the **Health Code** (accessibility and quality of voluntary anonymous and/or confidential medical examination on a non-paying basis for HIV-positive and AIDS patients; prevention of any forms of discrimination because of the nature of the disease);
- **Resolution No. 2136** *On the Approval of the List of Guaranteed Volume of Free Medical Services* issued by the Government of the Republic of Kazakhstan on December 15, 2009;
- **Resolution No. 1263** *On the Approval of the Rules of Health Care and Attaching of Citizens to Organizations of Primary Health Care* issued by the Government of the Republic of Kazakhstan on December 15, 2009;
- Article 45 of the **Health Code** specifies rules that determine the order of primary health care (hereinafter PHC) and the order of assigning of citizens to PHC organizations. Article 45 explains that PHC is before-doctor or qualified medical assistance without round-the-clock medical monitoring, including a complex of available medical services provided to a human being, family and public. According to Article 45 of the Health Code of the Republic of Kazakhstan, PHC shall be provided by primary health physicians, pediatricians, general practitioners, paramedics, obstetricians and nurses. Article 45 also states that the organizations providing PHC carry out their activities on a geographic area basis to enable availability of medical assistance to members of the population according to their residence and/or by assignment that takes into consideration the right of free choice of medical organization;
- Sub-item 2 of Item 3 of Article 184 of the **Health Code** (rendering medical services to anyone who needs them).

*Right to information*

The provision of information to patients appears to be patchy and sporadic at times. During interviews with patients and caregivers at Almaty Center for Palliative Care, one interviewee stated that they were 'told nothing' about their illness and that 'no information' was provided to them – although their caregiver had been kept 'fully informed' about the diagnosis/prognosis but 'refused to tell him anything'. At the time of interview, they had still been 'told nothing' about the illness - although at this stage they stated that they were 'not interested anymore'. In contrast, another interviewee stated that they had received 'adequate information' about their treatment and what they 'should expect in the future'.

In Kazakhstan, although there does appear to be an element of shared decision-making involving the patient, family members, and clinicians, there are many difficulties surrounding prognosis and diagnosis which are 'still big issues'. Many patients do not know of their diagnosis and think nothing is seriously wrong; for example, patients receiving chemotherapy 'often believe they will get better' - even well educated people may not be aware of their diagnosis/prognosis. Patients who are unaware of their diagnosis and have been told that they are suffering from 'something else' other than cancer are often very shocked when they have to attend the hospice. However, even though the patient may not be aware of their condition family members often are. Although according to Kazakhstan constitution there is 'a right to know', it is often family members who take responsibility for this and make decisions on the patient's behalf. A further ethical issue in this area relates to the high incidence of HIV/AIDS in young people; the ethical dilemma is whether to tell the young person about their diagnosis in case this increases the risk of suicide.

Every individual has the right to access to all kinds of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available. According to the laws of the Republic of

Kazakhstan, medical organizations and specialists should provide a patient with all information concerning the methods of treatment or forthcoming surgery, including information on possible risks, discomfort, side effects and alternatives. Medical organizations and specialists should provide the information in a language known to the patient and in a form that is understandable by the person not being a specialist in this field (European Charter of Patients' Rights). Bakhyt suggests that the provision of information 'gives people the expertise they need' to make informed decisions. However, she acknowledges that the provision of information to patients in this area is 'very low'. There is a 'legal obligation' on physicians to inform patients about their prognosis/diagnosis, but this done in 'a very general way'. Patients have to sign a consent form 'prior to treatment' and have a right to 'basic information' about the treatment they receive, but this is written in 'general healthcare documents' and is 'not specifically related to palliative care.

Relevant legislation includes:

- Item 2 of Article 20 of the **Constitution of the Republic of Kazakhstan** provides for the right of free access to and distribution of information under conditions established by the national laws;
- Item 3 of Article 18 of the **Constitution of Republic of Kazakhstan** obliges state authorities, public associations, officials and mass media to provide to each citizen the possibility to familiarize himself/herself with documents, decisions and information sources about infringement of his/her rights and interests;
- Sub-item 9 of Item 1 of Article 88 of the **Health Code** (accessing information on the safety, efficiency and quality of medicines, products for medical purposes and medical equipment for patients to purchase);
- Sub-item 6 of Item 1 of Article 91 of the **Health Code** (obtaining an independent opinion on the state of health and conducting counseling);

- Item 2 of Article 91 of the **Health Code** (obtaining information about rights and duties, services offered, fee-paying services and the rules of their provision);
- Item 4 of Article 91 of the **Health Code**: While receiving medical services, patients have the right to comprehensive information about the state of their health, including information on possible risks and the advantages of available and alternative methods of treatment, information about possible consequences of the refusal of treatment, information on diagnosis, prognosis and a program of treatment. The information must be in a form accessible to patients. This right includes the explanation of reasons for discharging patients to their homes or transferring to another medical organization;
- Sub-item 2 of Article 114 of the **Health Code** (informing the population, through the media, about the epidemiological situation on the HIV virus and measures of prevention);
- Item 5 of Article 115 of the **Health Code** (healthcare establishments that detect the HIV virus during medical examination must notify patients about the results obtained in writing and inform them about precaution measures to protect their health and the health of people around them and warn about their administrative and criminal responsibility in the event of avoiding treatment and infecting other people);
- Sub-item 1 of Item 1 of Article 157 of the **Health Code** (the prevention of non-contagious diseases by informing the population through the media and training programs on the prevention of disease);
- Item 9 of Article 91 of the **Health Code** (the right to comprehensive information about prescribed medicines);
- Sub-item 3) of Item 6 of the **Rules of Rendering of the Stationary Help**, approved by the resolution of the Government of the Republic of Kazakhstan on December 5, 2011 (upon planned hospitalization of the patient in a hospital the medical organization informs the patient of the hospitalization date);

- Item 16 of the **Rules of Rendering of the Stationary Help**, approved by the resolution of the Government of the Republic of Kazakhstan on December 5, 2011 (upon admission in a hospital the patient should be informed about regulations of the medical organization, first and last name of medical workers who will render medical services and their professional status).

### *Right to Consent*

Every individual has the right of access to all information that might enable him or her to actively participate in decision-making regarding his or her health; this information is a prerequisite for any procedure and treatment, including the participation in scientific research (European Charter of Patients' Rights). In medical practice, according to the International Covenant on Civil and Political Rights (ICCPR), informed consent means the patient's voluntary acceptance of treatment procedures after the doctor's providing the patient with adequate information. Researches in the biomedical field attach special importance to receiving patient informed consent. Voluntary informed consent means health care providers' non-use of force, lies, threats, etc., during the patient's decision-making.

Relevant legislation includes:

- Item 1 of Article 16 of the **Constitution of the Republic of Kazakhstan** provides for the right to personal liberty;
- Article 17 of the **Constitution of the Republic of Kazakhstan** stipulates that human dignity is inviolable. No one shall be subjected to torture or to cruel or degrading treatment or punishment;
- Article 29 of the **Constitution of the Republic of Kazakhstan** provides for the right to health protection;

- Sub-item 3 of Article 91 of the **Health Code** (medical assistance should be provided after obtaining informed oral or written voluntary agreement from a patient);
- Item 1 of Article 139 of the **Health Code** (surgical intervention, transfusion of blood, its components and the use of invasive diagnostic methods are conducted with a patient's written consent);
- Item 16 of the **Rules of Rendering of the Stationary Help**, approved by the resolution of the Government of the Republic of Kazakhstan on December 5, 2011 (medical care is provided after receiving a written voluntary consent of the patient or his lawful representative);
- Sub-item 3 of Item 2 of Article 184 of the Health Code (in their work medical and pharmaceutical workers should take decisions only in the interests of patients).

### *Right to Free Choice*

Each individual has the right to freely choose from among different treatment procedures and providers on the basis of adequate information (European Charter of Patients' Rights). According to the laws of the Republic of Kazakhstan, a patient shall have the right to decide which diagnostic examinations and types of treatment he/she will undergo and which health care professional and hospital he/she will consult and visit. Health authorities must ensure this right for patients by providing them with the information on different medical centers and doctors, which offer certain types of treatment, as well as about the results of their activities. Any obstacles interfering with the realization of this right should be eliminated. A patient who distrusts his/her physician shall have the right to choose another physician.

Relevant legislation includes:

- Article 29 of the **Constitution of the Republic of Kazakhstan** states that citizens of the Republic of Kazakhstan have the right to health protection;
- Sub-item 3 of Item 1 of Article 88 of the **Health Code** (free choice of medical organization, quality and timely medical services);
- Sub-item 3 of Item 1 of Article 91 of the **Health Code** (free choice and replacement of a doctor or a medical organization);
- Sub-item 2 of Item 3 of Article 184 of the **Health Code** obligates medical and pharmaceutical workers, in their interactions with patients, to offer medical services to everyone who needs them. This is a general requirement set in the ethics of medical and pharmaceutical workers' behavior.

#### *Right to Privacy and Confidentiality*

Each individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic and therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general (European Charter of Patients' Rights). Republic of Kazakhstan legislation, with the relevant provisions on privacy and confidentiality, aims at observing international standards in the healthcare sphere.

Relevant legislation includes:

- Item 1 of Article 18 of the **Constitution of the Republic of Kazakhstan** provides for the right to privacy, personal and family confidential information, protection of honor and dignity;
- Sub-item 7 of Item 1 of Article 87 of the **Health Code** (the State gives guarantees to citizens of the Republic of Kazakhstan that information classified as medical secrecy will be preserved);

- Item 3 of Article 95 of the **Health Code**, entitled “Medical Secrecy,” defines: “With the consent of a patient or his/her lawful representative, it is allowed to disclose information classified as medical secrecy to other individuals and/or legal entities in the interest of the examination and treatment of the patient and for scientific research and the use of this information for educational or other purposes”;
- Item 4 of Article 95 of the **Health Code** (general provisions on medical secrecy): Without the consent of a citizen or his/her lawful representative, the disclosure of information classified as medical secrecy is allowed in the following cases: with the aim of examining and treating a citizen who cannot express his will because of the state of his health; under the threat of the spread of a disease that is dangerous to other people; at the request of investigation bodies, a prosecutor, a lawyer (in certain instances) and/or a court in connection with an investigation or trial; while offering medical assistance to a minor or an incapacitated person, informing their lawful representatives; if there are grounds to suggest that a citizen’s health was damaged as a result of unlawful actions;
- Sub-item 1 of Article 112 of the **Health Code** (anonymity and/or confidentiality of medical examination of HIV positive and AIDS patients);
- Item 1 of Article 115 of the **Health Code** (anonymity of HIV tests);
- Item 1 of Article 131 of the **Health Code** (anonymity of provision of medical and social rehabilitation at a patient’s request);
- Item 2 of Article 142 of the **Health Code** (information on anatomic specifics should not be made public);
- Article 144 of the **Criminal Code** of the RK “Disclosing medical secrets”;
- Under Sub-item 4 of Item 2 of Article 184 **Code of Ethics of Medical and Pharmaceutical Workers of the Republic of Kazakhstan** the disclosure of confidential information about a patient is, on the one hand, a violation of ethics and, on the other, it violates a patient’s right to privacy and confidentiality.

### *Right to the Observance of Quality Standards*

Each individual has the right of access to high quality health services on the basis of specification and observance of precise standards (European Charter of Patients' Rights). Access to health services, their quality and timeliness are determined by one of the fundamental principles of the state policy of the Republic of Kazakhstan in the area of health protection. The quality of medical assistance is the level of correspondence of medical services to standards adopted by an authorized body and based on the modern level of the development of medical science and technology. Provisions of the following Acts secure guarantees of the quality, content and volume of medical services rendered on a free and/or fee-paying basis in line with the single healthcare standards, the establishment of control over the quality of medical services offered and, in some cases, checks on the quality of these services.

Relevant legislation includes:

- Article 29 of the **Constitution of the Republic of Kazakhstan** ensures the right to health protection;
- Sub-item 1 of Item 2 of Article 33 of the **Health Code** (healthcare entities should offer quality medical services in line with licenses);
- Sub-item 4 of Article 87 of the **Health Code** (the state guarantees quality medical services for citizens of the Republic of Kazakhstan);
- Sub-item 3 of Item 1 of Article 88 of the **Health Code** (the right to quality and timely medical assistance);
- Article 114 of the **Criminal Code** of the Republic of Kazakhstan: *Inadequate performance of professional duties by medical and pharmaceutical workers*;

- **Resolution No. 2296:** *On Approval of the Rules for Executing State Control in the Healthcare Sector*, issued by the Government of the Republic of Kazakhstan on 30<sup>th</sup> December 2009;
- **Resolution No. 1577:** *On Approval of the Rules of Organizing and Executing External and Internal Expert Opinion on the Quality of Medical Services*, issued by the Government of the Republic of Kazakhstan on 22<sup>nd</sup> December 2011;
- Sub-item 5 of Item 2 of Article 184 of the **Health Code** requires medical and pharmaceutical workers to perform their official duties honestly and qualitatively.

### *Right to Safety*

Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractices and errors, and the right of access to health services and treatment that meet high safety standards (European Charter of Patients' Rights). In the context of the constitutional right to health protection, the implementation of the right to safety means that healthcare procedures should include the diagnostic, treatment and preventive procedures, medications, items and equipment used in medicine that have passed standardization and quality control. The right to safety should be understood in the way that allows only professional health establishments to provide health services.

Relevant legislation includes:

- Article 13 of the **Health Code** states that medical and pharmaceutical activities need to be licensed;
- Item 1 of Article 15 of the **Constitution of Republic of Kazakhstan** states that everyone has the right to life;

- Article 29 of the **Constitution of Republic of Kazakhstan** states that citizens of the Republic of Kazakhstan have the right to health protection;
- Article 84 of the **Health Code** (prohibition, suspension or seizure of medicines, products for medical purposes and medical equipment that do not meet the safety standards for health of a human being);
- Sub-item 5 of Article 87 of the **Health Code** (accessibility, quality, efficiency and safety of medicines as a guarantee of ensuring rights in the healthcare sphere);
- **Resolution No. 1729:** *On Approval of the Rules of Organizing and Conducting Purchases of Medicines, Preventive (Immunobiological, Diagnostic, Disinfecting) Preparations, Products for Medical Purposes and Medical Equipment, Pharmaceutical Services for Rendering the Guaranteed Volume of Free Medical Services*, issued by the Government of the Republic of Kazakhstan on 30<sup>th</sup> October 2009;
- **Resolution No. 2135:** *On Approval of the Rules for the Provision of Medicines to Citizens*, issued by the Government of the Republic of Kazakhstan on 15<sup>th</sup> December 2009;
- **Resolution No. 2296:** *On Approval of the Rules for Executing State Control in the Healthcare Sector*, issued by the Government of the Republic of Kazakhstan on 30<sup>th</sup> December 2009;
- **Resolution No. 856:** *On Approval of the Rules of Ensuring Timely Preventive, Preliminary and Mandatory Medical Examinations of Individuals Subject to These Examinations*, issued by the Government of the Republic of Kazakhstan on 8<sup>th</sup> September 2006;
- Article 184 of the **Health Code** does not have direct references to ethical standards in the context of “the right to safety.” But Sub-item 1 of Item 2 of Article 184 obliges medical and pharmaceutical workers to observe the present Code and the Code of Honor in their practice. Because a number of articles of the Health Code listed in the above section entitled “The National Legislation” directly stipulate the observance of the right to safety, Sub-item 1 of Item 2 of

Article 184 can be regarded as a significant condition of the code of medical ethics.

### *Right to Avoid Unnecessary Suffering and Pain*

Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness (European Charter of Patients' Rights). Medical organizations and facilities should assume the obligation to take all reasonable measures in this regard, such as palliative treatment and facilitating of patients' access to such treatment. The observance of this right is especially important for terminally ill patients who suffer from chronic pain. All of the actions of medical workers must focus on facilitating their relief from suffering.

Relevant legislation includes:

- Article 29 of the **Constitution of the Republic of Kazakhstan** ensures the right to health protection;
- Sub-item 6 of Item 2 of Article 34 of the **Health Code** (the guaranteed volume of free medical services includes palliative assistance and nursing for groups of the population, specified by the Government of the Republic of Kazakhstan);
- Article 53 of the **Health Code** (palliative assistance and nursing) states that palliative care is provided under the guidance of a doctor to patients who are in terminal (final) stage of the disease in the specialized divisions of hospitals, independent health care organizations (hospices) or at home. Nursing care is provided in cases that do not require medical supervision, in the specialized divisions of hospitals, independent medical organizations (nursing homes) or at home;
- Sub-item 5 of Item 1 of Article 91 of the **Health Code** (easing sufferings to the extent allowed by existing medical technologies);

- Article 141 of the **Health Code** (euthanasia is banned);
- **Decree No. 1938**: *On Approval of List of Categories of the Population, Entitled to Palliative and Nursing Care*, issued by the Government of the Republic of Kazakhstan on 26<sup>th</sup> November 2009;
- **Decree No. 1343**: *On Approval of the Rules of Executing Palliative and Nursing Care*, issued by the Government of the Republic of Kazakhstan on 15 November 2011;
- Sub-item 3 of Item 2 of Article 184 of the **Health Code** (taking a decision exclusively in the interests of a patient).

### *Right to Personalized Treatment*

Each individual has the right to diagnostic or therapeutic programs tailored as much as possible to his or her personal needs (European Charter of Patients' Rights). A patient should be ensured an individual approach to treatment, based on his personal needs. Economic factors should not prevail over the right to high-quality medical care. Every patient should be ensured an individual approach in terms of treatment methods, the seriousness of disease, the age, the individual specifics of organisms, adjustment to medicines, etc.

Relevant legislation includes:

- Article 29 of the **Constitution of the Republic of Kazakhstan** ensures the right to health protection.
- Article 52 of the **Health Code** states that recovery treatment and medical rehabilitation are offered to citizens suffering from...consequences of...chronic diseases;
- Item 4 of Article 89 of the **Health Code** states that...HIV carriers and AIDS patients have the right to receive free medical...support in educational and

medical establishments in line with the Republic of Kazakhstan's legislation in the healthcare sphere;

- Sub-item 1 of Item 1 of Article 91 of the **Health Code** (decent handling in the process of diagnostics, treatment and care and respectful treatment of cultural and personal values);
- Sub-item of 3 of Item 2 of Article 184 of the **Health Code** (taking a decision exclusively in the interests of a patient).

## **PERSPECTIVE OF PATIENT AND FAMILY CAREGIVER**

In order to gain the broadest perspective possible about the palliative care needs of patients and their caregivers in Kazakhstan, I attempted to interview people with a variety of illnesses and in as many regions of Kazakhstan as possible. Unfortunately, I was only able to interview patients (adults and children) with either a cancer diagnosis or a HIV/AIDS diagnosis (and their caregivers where applicable), and all of these interviews were conducted at Almaty Center for Palliative Care (although many of the patients and caregivers had come from different regions, often up to 1000-1800km away). As the development of palliative care in Kazakhstan is a 'work in progress', I would like to extend the range of interviews to include other life-limiting illnesses and within other regions of the country. In addition, I conducted a number of informal discussions with patients and family members during my four visits to Kazakhstan (2010-2012).

The adult patients were a combination of males and females aged between 60 and 74 years of age (cancer or HIV/AIDS), and were from a variety of locations (but mainly Almaty). Their current length of time in the hospice ranged from one day to 21 days; the length of their illness ranged from to 'a few weeks' to 'six months'. All of the caregivers that I interviewed were married to the patient and all couples had children and grandchildren who either lived at home or independently of their parents/grandparents. The patients and caregivers had received varying levels of education ranging from secondary school to University degree level. Caregivers were the primary or main carer of the patient; none of them received any remuneration for their caring role or had any form of paid employment either. None of the caregivers had received any formal education or training in this area, although some had received 'informal advice' from healthcare personnel or relatives on the 'best way' of caring for their loved one (nutrition, post-operative exercise, etc.). Patients and their caregivers were of either Muslim or Christian denomination. In general, the preferred place of care at the present

time for most patients and caregivers was the hospice because they were 'unable to do normal things' and there was 'no professional help at home'; although the majority stressed that 'under normal circumstances', they would prefer to be cared for 'at home'.

The pediatric patients were a combination of males and females (between 11 and 14 years of age) but all their caregivers were women (aged between 37 and 45 years of age). None of the caregivers had received any formal education or training in this area, although some stated that they would benefit from some psychological training in 'how to communicate with a sick child'. Both patient and caregiver had often travelled a long distance to receive treatment at the Center – up to 1800 km in one instance (36 hours travelling); in some cases NGOs or charitable organizations had funded the cost of their travel to the hospice. All children that were interviewed were of secondary school age but none were currently attending school – they received tuition at the hospice and tuition at home when recovering from treatment. The children that were interviewed had been at the hospice for a period of between three and 25 days (the maximum number of days allowed); some children and their parents had stayed at the hospice previously. The children interviewed had been receiving treatment for their illness (all cancer) for between one and two years; some children had been referred from the Oncological Institute. The children and their parents were of either Muslim or Christian denomination. All children lived with their parents (who were married) in their family home, often with other siblings.

Firstly, patients and carers were asked a number of subjective questions about life satisfaction; their current health status; whether they (or the person they cared for) had ever been discriminated against because of their illness; and how they were feeling emotionally at the present time. Following this initial set of questions, patients and carers were asked in what ways they made themselves feel happier; and both their greatest fears and needs at the present time. It should be noted that in some circumstances either the cancer patient or their caregiver (or both) may have been

unaware of their diagnosis/prognosis, and this may have biased their responses to the set of subjective questions that they were asked.

## Discussion

From the limited number of interviews with patients and their caregivers (adults and children) that were undertaken, both groups appear very satisfied with the treatment and care they were receiving at the hospice. One interviewee stated that care received from staff at the hospice was 'very good' and that from the first day they entered the hospice they felt 'warm and cared for' and that the staff made them feel 'very optimistic' about their situation. Another stated that since entering the hospice, they had 'felt much better', were 'eating three meals a day' and experiencing 'no pain'. When asked about their current health status, most patients suggested that it was 'neither poor nor good'. The majority of caregivers also gave an ambivalent response, suggesting that their own health was also 'neither poor nor good'.

No patients [or caregivers] reported that they had ever felt either stigmatized or discriminated against because of their [or their loved one's] illness; indeed, most reported the opposite – that Kazakhstan mentality is 'not to discriminate' against people in a 'harmful situation' but rather to 'provide much social support' often from a variety of sources. When asked if they had felt stigmatized or discriminated against since their illness began, one interviewee reacted rather angrily and said that this was 'a stupid question' – all they had ever received since their illness began had been 'much love and support from family and friends'; however, it should be noted that in a number of instances, family and friends were the only people that were aware of the patient's illness (as it was considered it to be 'no-one else's business'). Spending time in the hospice had changed some interviewee's attitudes towards it; one interviewee stated that before they had entered hospice, they always thought that it was a 'place to die' but now they describe it as 'just like any other hospital'.

In terms of their emotional status, most patients and caregivers stated that they were 'neither happy nor unhappy' although one interviewee stated that it was 'too early to say'. The main way of alleviating negative emotional states for both patients and caregivers was through talking with family, friends and neighbours, reading books and religious and spiritual activity. One interviewee stated that they felt 'very good emotionally' and that this was 'thanks to God' and their strong religious beliefs; they felt at their happiest 'when praying' and got much comfort and support from the Christian prayer room at the hospice (which is 'regularly attended by a priest') and also from volunteers who spend much time providing patients at the hospice with 'psychological support'; one interviewee suggested that the volunteers at the hospice were 'easy to talk to' and that this form of communication was 'different' to talking to healthcare professionals (about health/illness issues and treatment regimens, etc.). Distress was an emotion often expressed by respondents; for example, one caregiver of a pediatric patient felt 'very upset' about the 'potential cause' of their child's illness, believing that it was due to 'environmental toxicity' associated with a local nuclear plant. One interviewee stated that although they did not currently have physical pain, they were experiencing a 'bad feeling' covering the 'whole of the body' which they described as 'spiritual pain'. In contrast, another interviewee suggested that they 'felt good', because they had a loving partner and children/grandchildren who are 'all settled' and this gave them 'much satisfaction'.

The most commonly expressed fear amongst patients and caregivers related to fear of dying, fear of the future; fear for the well-being of loved ones was also expressed. However, some interviewees expressed 'no fear' and were 'not afraid' of what the future held for them. One interviewee stated that they put their trust in the doctors at the hospice and 'in God', suggesting that 'doctors are the friends of God'. When asked if they had any fears, worries or concerns, one interviewee simply replied 'not at my age'.

The most commonly expressed need related to employment and financial issues; the lack of money from the patient being unemployed (or retired) combined with the inability of the caregiver to work (due to their role of caring for the patient) and the increase in costs associated with medication, transport, etc. One interviewee highlighted the fact that there was 'no worker in the family' and that the Kazakhstan government was subsidizing the family – they received a total of \$300 per month which was described as 'simply not enough'. Another interviewee stated that they would like 'massage/physiotherapy' but that they 'cannot afford' such treatment as it is 'too expensive'. In addition, the need for increased social, personal and psychological support was expressed, as was the need for more specific information and advice – particularly about the illness and what to expect in the future.

From this limited sample size, and acknowledging the limitations of undertaking such research, it can be cautiously concluded that in spite of the difficulties that may be faced by patients and caregivers in Kazakhstan, their overall life satisfaction, health and emotional status is 'average'. Discrimination relating to their illness is not at all reported by either patients or their carers; however, it should be noted that the majority of interviewees were cancer patients and/or their caregivers, and that the responses from other categories of patients could be significantly different. A number of different fears were expressed by patients and caregivers. Talking with family, friends and peer groups are all very important sources of support, as is praying - the spiritual assistance provided to patients and their caregivers was often described as being 'of great significance' to them.

## **SOCIO-CULTURAL ISSUES**

A barrier to the development of palliative care in Kazakhstan identified by hospice representatives was the lack of awareness about the discipline amongst healthcare professionals and wider Kazakhstan society. A number of associated problems were highlighted including a lack of coverage about hospice and palliative care in the Kazakhstan media who 'do not inform the population about this problem', and 'authorized bodies that do not listen'. The hospice representatives stated a number of objectives that, in their opinion, would serve to address some of these problems. For example, the creation of working groups to 'educate medical workers and the population', additional financing to 'attract and motivate the media towards promoting palliative care', and increased palliative care education and training initiatives 'for medical workers'.

Palliative care in Kazakhstan is described by hospice representatives as a 'very sensitive sphere' within the healthcare system. This particular comment is also relevant in the context of social and cultural beliefs about death and dying, stigmatized and taboo status of 'hospice' etc. A major challenge to the development of palliative care in Kazakhstan has traditionally been 'societal attitude' towards the discipline – 'only 3% know what it means' therefore it is 'not considered as important'. The general public has not been well informed about palliative care; people think it is 'all about death and pain' so it has a taboo and stigmatized status and is therefore 'not open to discussion'. A sociological survey was undertaken by the Soros Foundation to determine public awareness of palliative care amongst four groups: general population; religious organizations; NGOs; and health care professionals. There was an expectation that those cities with a hospice would have a higher level of public awareness than those without a hospice but in fact there was no recorded difference. The survey also reported a poor understanding of palliative care amongst policy-makers, and found that resources are targeted towards 'curing patients' as opposed to 'people who are going to

die anyway'. Even among healthcare professionals awareness of palliative care was extremely low. For example, in 2000, the hospice at Ust-Kamenogorsk was established without realizing that a hospice existed in Almaty.

Hospice representatives suggested that a number of action steps were required in order to achieve these objectives, including the need to 'organize conferences and seminars', highlight 'palliative care progress and development in other countries', and 'involving physicians from other disciplines in palliative care conferences'. A number of individuals and groups that possessed the authority and/or responsibility to take the necessary action were identified; for example, palliative care specialists and the Ministry of Health as 'local Health Management Departments do not hear'. When asked to consider a realistic timescale for completion of the action steps, hospice representatives suggested 'approximately one to three years'. In order to achieve these objectives, additional State funding 'for educational program development' would be required. However, some awareness-raising is occurring in Kazakhstan – five years ago, hospices were heavily stigmatized and many people did not understand their role. But now, people perceive hospices 'in a more positive manner' compared to previous generations because they know that they have better qualified staff, good equipment, etc. This is also due to specific initiatives developed by SFK in relation to *World Hospice and Palliative Care Day* which attracts NGOs, journalists, youth organizations, hospices/hospital units and Medical Universities and Colleges to work as a partnership on public awareness issues about palliative care. Small grants are provided to organizations to enable them to participate, and a variety of different events are supported; for example, in 2012 a video about palliative care from Public Foundation *Aurora* entitled *Relive my pain* was supported by SFK. Also in 2012, a social media campaign to raise awareness about hospice and palliative care services was launched in the city Kyzylorda; *World Hospice and Palliative Care Day* was celebrated by two NGOs (Youth Centre for reconstruction and development and "Rasar" Creative Group) and a number of other organizations.

Activities included a 'creative competition' and press coverage.<sup>67</sup> In September 2012, palliative care featured on the agenda of the 7<sup>th</sup> *CIS Oncology and Radiotherapy Congress* in Astana for the first time at both the Plenary and Scientific Session level; Thomas Lynch delivered a presentation at the Plenary Session entitled 'The Development of Palliative Care Standards in the Republic of Kazakhstan'. The inclusion of palliative care on the agenda for the first time generated much media interest, including a number of regional television interviews promoting the concept of palliative care. In addition, a full-length interview with Thomas Lynch is to be screened on Kazakhstan State Television to celebrate *World Hospice and Palliative Care Day* on 13<sup>th</sup> October 2012. The interview, which lasts for approximately one hour, is to be screened in its entirety to an anticipated audience of many millions of people, and is also to be posted on You Tube in order for it to be accessible to an even wider audience. It is hoped that this extensive coverage will significantly raise awareness about the development of palliative care in Kazakhstan.

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<sup>67</sup>[http://www.worldday.org/events/?2636964\\_entryid45=91855](http://www.worldday.org/events/?2636964_entryid45=91855)

## CONCLUSION

This needs assessment calculates that approximately 94,200-97,900 patients annually require palliative care in Kazakhstan, with a minimum of 15,500 patients on service at any given time. In addition, as there are usually two or more family members directly involved in the care of each patient, care would be given to a minimum of approximately 282,600 persons annually. To provide home-based and inpatient palliative care to this extent would require substantial reallocation of healthcare professional resources for both the urban and rural areas; approximately **6675** staff and **825** palliative care beds would be required for this need to be fully met.

There has been much progress in the development of palliative care in Kazakhstan in recent years, involving many highly committed individuals and organizations. However, in a survey conducted by Thomas Lynch in 2011, hospice representatives identified a number of problems that still exist in the country: a shortage of hospice and palliative care services; lack of education and training opportunities; legislative and policy barriers to the development of the discipline; lack of awareness and understanding about palliative care amongst healthcare professionals and wider Kazakhstan society; barriers to the accessibility and availability of opioids; lack of intersectoral collaboration/coordination (for example, between the Ministry of Health and the Ministry of Social Care); lack of palliative care standards; the absence of a National Palliative Care Association; and the lack of an advocacy framework for the integration of palliative care into the Kazakhstan healthcare system.

There are currently five organizations providing inpatient palliative care in five areas of Kazakhstan – Almaty, Pavlodar, Karaganda, Ust-Kamenogorsk, and Kostanai; there is also one organization providing home-based palliative care in Semei. Most palliative care for children still occurs at home in Kazakhstan, although ‘some pediatric palliative care’ provision is available at Almaty Center for Palliative Care. The organizations

currently working in palliative care appear to provide an excellent service often under very difficult and demanding conditions, and patients (adults and children) and their caregivers appear 'very satisfied' with the treatment and care that they receive there. Hospices in Kazakhstan are described as 'very different from similar institutions in developed countries' as they are 'funded almost entirely by the State' with the remaining funds provided by international organizations. There are also a number of governmental and non-governmental organizations *working in the area of palliative care* in Kazakhstan (but not providing palliative care services); for example, hospitals, TB Centres and oncology dispensaries. These organizations often provide '**some elements** of palliative care' but should not be classed as 'palliative care providers'.

Due to the vast size of the country, there is far from universal palliative care coverage in Kazakhstan; development is occurring spasmodically rather than according to any specific strategy, and this often results in large areas with little coverage. The number of hospices in Kazakhstan is described as 'too low and insufficient for the number of people requiring palliative care'. A number of underlying reasons for this problem were suggested including 'inadequate financing mechanisms' and the fact that 'no concrete State program' relating to palliative care exists. In addition, many trained palliative care staff 'do not want to work in rural areas'. For example, although nurses account for 'a large proportion' of the total number of medical personnel in Kazakhstan, their distribution is spread unevenly (the same dilemma is true for doctors). Another barrier relating to the development of palliative care in Kazakhstan identified by hospice representatives is demographic and relates to the 'aging population'. In Kazakhstan, palliative care includes both 'health care' and 'social care'. Healthcare is divided into inpatient care and 'at home' services but social care also implies 'at home' services. Yet both forms of 'at home' services are different from each other and are provided by different types of healthcare professionals; palliative care is 'not nursing home care and nursing home care is not palliative care' although there are 'certainly elements in both'.

There are a number of excellent palliative care education and training initiatives in Kazakhstan; for example, at Almaty City Medical College Postgraduate Training Center for Nurses, where a post-graduate diploma in palliative care for nurses is taught. Palliative care is being considered as a separate programme at the college but all post-graduate courses currently contain an element of palliative care in their curricular. International palliative care experts have visited the country to deliver courses; a number of Kazakhstan palliative care experts have also attended international courses abroad. For example, with support from SFK and IPCI, healthcare professionals have undertaken palliative care education and training in Romania, Poland and Russia. Hospice representatives suggest that their staff have been trained in 'many aspects' of palliative care; for example, the 'structure and processes' of palliative care, aspects of pain management, etc. A number of innovative palliative care education and training initiatives are being developed at KSPH.

However, hospice representatives identified a number of difficulties relating to palliative care education and training opportunities in the country; for example, a 'lack of experienced trainers and educators' in the discipline. In general, hospice representatives suggest that their staff would benefit from additional training and education in a number of specific areas; for example, 'developing clinical and diagnostic treatment guidelines'. Although palliative care is included in the first specialisation that nurses choose at the Republican Medical College (oncology, etc.), a specific course on palliative care for nurses at the undergraduate level is 'very much needed' and this should be available not only for hospice nurses but 'for all those who provide home-based palliative care'. There is no specialist course on palliative care offered at the State Medical University (palliative care is only implemented within different disciplines), although the University does 'collaborate closely with Almaty Center for Palliative Care' which serves as a basis for the training of medical students. A major challenge for the future is the contrast between the enormous need for palliative care services in Kazakhstan in relation to the limited number of trained professionals to deliver such

care; shortages of skilled palliative care staff due to lack of education and training may affect the delivery of palliative care in Kazakhstan.

Hospice representatives stated that 'limited forms of opioids' were available at their organization, and that they 'rarely ran out of medication'. Most hospices had guidelines on how to gain access to opioids for pain relief and how to use those opioids effectively. However, 'some difficulties' were encountered; for example, concerns that 'medicines will be used illegally/may be stolen by people from outside' and the 'quality of medication available'. A number of problems relating to the accessibility and availability of opioids were highlighted including the low level of opioid consumption related to INCB quotas. There is a lack of choice of opioids in Kazakhstan – for example, oral morphine is not available, and morphine via injection is available in hospital only. Hospice representatives reported a lack of knowledge/awareness about opioid use amongst physicians; and a fear of opioid addiction/dependence amongst the patient and family members. The general population also think that pain and suffering are 'normal things'; a cultural belief in some sections of Kazakhstan society that 'pain is necessary' and that the patient is 'not supposed to ask about pain relief'.

Excessively strict legislation and bureaucracy in relation to licensing, transportation, prescribing practices, storage procedures, etc. was also reported. For example, a special license is needed, dosage must be 'written in letters and words and not numbers', and the patient must present an official 'signature' document. In relation to storage, there are further difficulties; for example, Promadol must be stored at an 'appropriate temperature' but this is not always possible as it must also 'be stored in a safe'. The amount of opioids that can be prescribed is also described as 'problematic' – opioids for terminally-ill patients can be prescribed 'for one month', but for all other groups of patients they can be prescribed 'for one week only'. Doctors can only prescribe opioids using a special blank prescription that must be countersigned by the chief physician; these prescriptions are valid for the following seven days only. Other barriers include

physician fear of prosecution for 'unintended technical violations' relating to opioids (physicians 'do not know their rights') and cost – on average, opioids cost 'approximately 1000 Tenge for a three-day supply (\$6). 'Outdated/lack of appropriate legislation' was mentioned as another barrier to the accessibility and availability of opioids in Kazakhstan, as was a 'lack of collaboration' between governmental departments; the 'absence of an interdisciplinary approach' in relation to opioids at the Ministerial level (for example, between the Ministry of Health, Ministry of Home Affairs, National Safety Committee, etc.).

A normative base for palliative care is beginning to be developed in Kazakhstan and progress is being made on legislation - there are some Orders, Articles and documents that stipulate 'what palliative care is' (based on the WHO definition) and which patients are entitled to it and palliative care is currently included in a number of legal documents. Work undertaken in relation to the development of palliative care standards continues in Kazakhstan, and in October 2012, as the result of a joint initiative between SFK, RCDH, KSPH and IPCI, standards will be submitted to the Ministry of Health (MOH) as an essential tool and guide for the continued development and provision of palliative care in the country, and as an integral part of the legislative and regulatory health care framework; it is anticipated that the standards will facilitate programme improvement and development and influence the planning and delivery of palliative care services by determining the cost of palliative care and therefore the volume of services that are provided by the state.

However, the sequence of documents relating to palliative care in Kazakhstan that need to be developed appears to be rather unclear and although palliative care provision is included in the legal framework, it is not adequately addressed and 'often underdeveloped'. Hospice representatives highlighted a number of legislative and policy problems including the socio-economic stage of development in Kazakhstan compared to other countries, cultural traditions, beliefs and values, and 'bureaucratic

mechanisms'. It was suggested that legislation relating to palliative care is 'imperfect' as it is created by people 'with a mentality that does not understand the problem', and that 'although some regulations and laws are in place, there are no practical mechanisms to implement them'. The lack of an advocacy framework for integration of palliative care into the Kazakhstan healthcare system was also mentioned as a potential barrier as was the 'order of palliative care development' which was described as 'very poor, separated and fragmented'. The tension between inadequate funding and the unclear delineation of health/social care was also a point of concern for a number of hospice representatives, as was the succession of changes in personnel in relevant government departments which 'hinder capacity-building and advocacy'. The lack of uniform documents regulating palliative care provision at a national level and the absence of guidelines for the assessment and evaluation of the quality of such services results in a lack of coordination and integration of the discipline across health care settings and services; this, in turn, results in limited palliative care service capacity. The area of health policy in Kazakhstan is closely linked to the concept of palliative care and the availability and accessibility of opioids as a fundamental human right; however, most respondents acknowledge that the 'human rights approach' is 'very new to Kazakhstan' and that it 'may take some time' before it is fully embraced.

A barrier to the development of palliative care in Kazakhstan identified by hospice representatives was the lack of awareness about the discipline amongst healthcare professionals and wider Kazakhstan society. A number of associated problems were highlighted including a lack of coverage about hospice and palliative care in the Kazakhstan media who 'do not inform the population about this problem', and 'authorized bodies that do not listen'. Palliative care in Kazakhstan is described by hospice representatives as a 'very sensitive sphere' within the healthcare system. This particular comment is also relevant in the context of social and cultural beliefs about death and dying, stigmatized and taboo status of 'hospice' etc. A major challenge to the development of palliative care in Kazakhstan has traditionally been 'societal attitude'

towards the discipline – ‘only 3% know what it means’ therefore it is ‘not considered as important’. The general public has not been well informed about palliative care; people think it is ‘all about death and pain’ so it is therefore ‘not open to discussion’. However, some excellent awareness-raising initiatives are occurring in Kazakhstan. Five years ago, hospices were heavily stigmatized and many people did not understand their role, but now people perceive hospices ‘in a more positive manner’ compared to previous generations because they know that they have better qualified staff, good equipment, etc. This is also due to a variety of specific initiatives developed by organizations such as SFK.

There are a number of ethical aspects relating to the provision of palliative care in Kazakhstan. For example, relatives usually prefer the patient to die at home and often feel ‘a sense of shame’ if their loved one dies in a hospice or hospital environment as they believe it to be the ‘duty of the family’. This often ‘causes much stress’ (particularly for people of working age) with responsibility ‘often resting on the shoulders’ of a small number of people (usually women) who are described as ‘inadequately prepared’ for the provision of such care. There are also severe financial challenges for terminally-ill patients and their families in Kazakhstan due to the loss of income in combination with an associated increase in costs (transport, medication, etc.). Communication skills between healthcare professionals and patients at the end of life may also be of ethical concern. Although there appears to be an element of shared decision-making involving the patient, family members, and clinicians, there are many difficulties surrounding prognosis and diagnosis which are ‘still big issues’. There are no ‘advanced directives’ as such, but documents do exist that enable patients to express their wishes regarding end-of-life care - although they ‘may not be honoured’ if physicians do not agree with them.

Despite limited knowledge about palliative care in Kazakhstan amongst both healthcare professionals and society in general, much progress has been made by a relatively small

number of doctors and nurses who are specialized in the discipline, in combination with other highly committed and enthusiastic individuals. These palliative care ‘champions’ have served to accelerate the pace of palliative care development in Kazakhstan and increase a base of support for the discipline. For example, in September 2012, palliative care featured on the agenda of the 7<sup>th</sup> CIS Oncology and Radiotherapy Congress in Astana for the first time (at both the Plenary and Scientific Session level) generating a number of television interviews promoting the concept of palliative care (including a full-length interview with Thomas Lynch on *World Hospice and Palliative Care Day*, 13<sup>th</sup> October 2012).

## GENERAL RECOMMENDATIONS

### Implementation

- Increase the number of palliative care providers and workforce (particularly in rural areas of Kazakhstan);
- Develop new models that enable palliative care to be provided on a 'wider and cheaper basis';
- Most people in Kazakhstan die at home, and would prefer to do so: there is a need to develop inpatient services in the future but **in conjunction** with home-based palliative care services;
- Ensure continuous palliative care at all levels of medical assistance from primary care to tertiary care;
- With Ministry of Health support, focus on developing palliative care teams in oncology hospitals: for example, fund a pilot palliative care doctor and nurse team in the National Cancer Hospital that may be adopted for use at the national level (full support of the cancer hospital leadership will be required);
- The role of civil society and NGOs needs to be much more strongly articulated in Kazakhstan;
- Stress the relevance of palliative care beyond cancer patients to incorporate other groups with life-limiting illnesses (for example, HIV/AIDS, TB, etc.);
- Improve the capacity to implement quality palliative care in a variety of sectors (for example, nursing homes, the prison system, etc.);
- Promote the concept of inter-disciplinary collaboration in palliative care between healthcare professionals from different specialties;
- Develop a consultative process between nurses, primary health care practitioners and oncologists to establish a partnership in palliative care;
- Provide psychological and emotional support for all healthcare professionals working in palliative care (especially nurses);

- Promote the involvement of religious and spiritual workers in palliative care;
- Improve inter-sectoral collaboration/coordination between health and social service agencies in relation to the provision of palliative care;
- Implement external monitoring/quality assurance procedures at all hospices in Kazakhstan to further improve the quality of existing palliative care programs;
- There is a need for the Ministry of Health to introduce more nurses into the primary health care system.

### **Education and training**

- Develop and support the institutionalization of sustainable undergraduate and post-graduate palliative care education and training programs for physicians, nurses, psychologists, social workers, chaplains, volunteers etc;
- Encourage the development of a specific course on palliative care for all nurses (palliative care and primary health care) at the undergraduate level at both the Republican Medical College and Almaty City Medical College;
- Encourage the State Medical University to integrate palliative care curriculum into nursing education (with the University leading on this development);
- Provide site visits for staff from educational institutions to other countries (with a 'common history' and comparable income levels to Kazakhstan) that have successfully implemented specific under- and post-graduate palliative care curricula;
- Arrange a meeting between all the key stakeholders and the Ministry of Health to establish formal links in the development of palliative care education and training curricula;
- Develop a list of recommendations on improving practical palliative care skills at the undergraduate level;
- Increase the number of trained palliative care educators in Kazakhstan;

- Organize training workshops for primary health care doctors on ‘what palliative care means’;
- Promote palliative care training and education initiatives for physicians in cancer, HIV/AIDS, and TB hospitals (then GPs/Family Practice);
- Provide technical support and specialist training/education for all members of the multidisciplinary team working in the new pediatric hospice and proposed HIV/TB hospice in Almaty;
- Additional training of hospice staff in a number of specific areas may be advantageous: for example, in ‘developing clinical and diagnostic treatment guidelines’;
- Palliative care in Kazakhstan can often be delivered at home; appropriate training should be provided to ‘lay’ carers (family, neighbors and community members);
- Financial resources for ‘study programs and new methodologies’ are required: there is a need for ‘a direct financial flow to the training of healthcare staff’ in palliative care;
- A need is highlighted for translation of palliative care materials into Russian as ‘most state officials do not speak English’.

### **Opioid availability**

- Ensure the accessibility and availability of all opioids needed to control pain and other symptoms;
- Work with the Kazakhstan government to compile a joint strategy for pain management (extend the choice of medication, liberalize legislation, raise awareness, etc.);
- Promote ‘an interdisciplinary approach’ in relation to opioids at the Ministerial level (for example, between the Ministry of Health, Ministry of Home Affairs, National Safety Committee, etc.);

- Update the National (Republic) Drug Formulary to ensure that all WHO Essential Medicines are stocked (including oral morphine) and a rational prescription policy exists;
- Develop a strategy on accessibility and availability of opioids in Kazakhstan based on successful strategies in other comparable countries;
- ‘State funding is required’ for the ‘training of specialists in pharmaceutical management’;
- Establish a legal and regulatory framework to fully meet the demand for opioid analgesics for palliative care patients;
- Create technical/working groups to develop normative legislation relating to prescribing practices, etc;
- Provide education and training ‘for physicians and nurses at the under-graduate and post-graduate level to increase knowledge and awareness about opioids’ (including issues surrounding pain management in all residential specialties);
- Change physician attitudes so that realistic future determinations of opioid requirements are made to the INCB and the Kazakhstan government ensure that annual estimates reflect **actual need**;
- Provide education and training to ‘change the mentality’ amongst family doctors in relation to the concepts of ‘addiction and dependence’;
- Examine Kazakhstan opioid control policy and develop advocacy initiatives to ‘remove excessive restrictions on opioids’ that may affect pain management;
- Reduce the excessive bureaucracy associated with the storage and prescription of opioids (paperwork, legal restrictions, etc.);
- Remove the restrictions in Kazakhstan National Drug Control Policy that restrict both the amount of drug prescribed and the duration of treatment;
- Take steps, in coordination with licensees, to ensure that there are no shortages of supply of opioid medications caused by inadequate procurement, manufacture and distribution systems;

- Further simplification and liberalization of opioid dispensing regulations is needed;
- Increased funding from the Kazakhstan government is required to reduce the cost of opioids to patients and their families;
- Media initiatives are required to overcome stereotypes and preconceptions and ‘improve the public perception of opioids’;
- In relation to ‘opiophobia’, promote a media campaign involving politicians and the Church to reassure the Kazakhstan population that pain can be adequately addressed (and is not a ‘normal’ or ‘necessary’ part of suffering).

## **Policy**

- Review the palliative care legal and regulatory framework in Kazakhstan;
- Integrate palliative care into the Kazakhstan healthcare system and Governmental Budget (federal, municipal and regional) at all levels;
- Promote recognition of palliative care as a medical specialty in its own right to facilitate the development of palliative care services;
- Increase understanding amongst key stakeholders, politicians and policymakers of the changes needed in public health policy in order to develop a legislative framework for palliative care implementation within the Kazakhstan health care system;
- Advocate for sustained national funding for both home-based and inpatient palliative care services in Kazakhstan;
- Additional State funding is required for ‘technical analysis and strategic planning’ to ‘develop the material base’ of palliative care in Kazakhstan;
- ‘Private financing’ comprising of ‘an independent fund to support palliative care’ will also be required;
- Encourage international donors to include palliative care in their funding agendas;

- To achieve additional funding, it will be necessary to ‘provide statistical indicators of need’ - for example, a National Registry of how many patients require palliative care, that is ‘disease-specific’ (number of cancer, HIV/AIDS, TB patients, etc.);
- Elaborate a strategic and financial development plan for implementing palliative care services (including the necessary financial resources and infrastructure);
- An ‘economic evaluation of palliative care is needed’ to develop ‘effective finance control mechanisms’: there is a need for programs to be both ‘cost-effective’ for the State and effective for the patient;
- Develop clinical guidelines which will compel the Kazakhstan Government to pay for **actual bed days**;
- Devise an Action Plan to further develop a ‘strategy for inter-sectoral working’ to improve collaboration/coordination between the Ministry of Health and Ministry of Social Development in Kazakhstan;
- There is a need for a clear definition of ‘health’ and ‘palliative care’ within healthcare service policy;
- ‘Explain the objectives of palliative care at the Ministerial and Parliamentary level’;
- More evidence-based research in palliative care is needed – a ‘letter should be drafted to the Ministry of Health giving recommendations on what is required’;
- There is a need to ‘change the attitude’ of the Kazakhstan government towards palliative care;
- Implement further palliative care needs assessments in Kazakhstan to calculate the demand for palliative care services and improve the quality of those services;
- Develop a normative base and palliative care standards;
- Invest in technical and logistical assistance (TA) for the development of palliative care in Kazakhstan;
- Implement WHO recommendations concerning the need for development and introduction of a National Palliative Care Policy;

- Develop and implement a National Cancer Control Program that prioritizes cancer pain relief and palliative care in terms of health resources;
- Develop a palliative care ‘mission statement’ with detailed and specific instructions relating to the provision of palliative care in Kazakhstan.

### **Awareness-raising and collaboration**

- Highlight palliative care in the Kazakhstan mass media: for example, publish articles in newspapers and magazines, and encourage prominent experts to make presentations about the importance of promoting palliative care in the country;
- Develop the ‘promotion of palliative care as a human right via the media’;
- Organize palliative care working groups (psychologists, social workers, religious and spiritual leaders, healthcare professionals, palliative care specialists and legal/human rights advocates);
- New palliative care ‘champions’ need to be identified;
- Develop an effective media/social network campaign to improve communication and information channels between organizations;
- Increase advocacy activities around World Hospice and Palliative Care Day that will help raise awareness about the importance of palliative care at national and regional levels;
- Expand the pool of people who may be empathic towards the development of palliative care in Kazakhstan (for example, social workers, Kazakhstan Members of Parliament);
- Gain the attention of policymakers working in the healthcare system and responsible for providing palliative care to the population: advocate at the MOH and MOSAP, making officials more aware of palliative care;
- Establish a *National Association of Palliative Care* that can help other organizations in Kazakhstan wishing to open a hospice;

- Within Kazakhstan society, the 'mentality' surrounding hospice and palliative care needs to be changed;
- Support the design and implementation of community activities in order to reduce the stigma associated with terms such as 'cancer', 'hospice', etc;
- Enhance collaboration between various sectors, government and state organizations and civil society groups (including those which are not yet directly involved in palliative care activities);
- Promote 'greater interrelation with religious/spiritual organizations' as there is a 'problem with the definition of dying in Kazakhstan' (including with other medical specialties/disciplines);
- Twinning arrangements should be established between Kazakhstan and US/UK hospices in order to raise awareness, exchange experiences and generate income;
- Develop an awareness-raising campaign involving national/local celebrities (as in Hungary).

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## Appendix A: WHO Definition of Palliative Care

'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications'.

## **Appendix B: WHO Definition of Palliative Care for Children**

Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family;
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease;
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress;
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited;
- It can be provided in tertiary care facilities, in community health centers and even in children's homes.

### Appendix C: Working Group Meeting 1 – list of participants

	<b>Name</b>	<b>Organization</b>
1	Raushan Kabykenova	Ministry of Health
2	Aima Sagyndykova	Ministry of Health
3	Saule Sarsembayeva	Almaty Department of Social Security
4	Madina Aldamzharova	Almaty Department of Social Security
5	Anarhan Nurkerimova	Almaty Center for Palliative Care
6	Assem Kassenova	'Solaris Hospice, Pavlodar
7	Lidiya Fedorova	Kostanay Regional Oncology Center,
8	Erbolat Bairov	Ust-Kamenogorsk Hospice
9	Bakytgul Nabiyeva	Ust-Kamenogorsk Hospice
10	Nadezhda Kozachenko	"Credo" Public union
11	Gulshara Urumzina	«Active aging» Public Union
12	Gulnur Hakimzhanova	NGO «Association of Social Workers»
13	Nuriya Kalimuratova	State Health College
14	Damir Dauletbayev	Almaty Health College
15	Gulnar Erdesova	Almaty Health College
16	Irina Meschaninova	Almaty City Oncology Center
17	Aida Aidarculova	"Legal Reform" FSK
18	Ainur Shakenova	"Legal Reform" FSK
19	Maksut Kulzhanov	Kazakhstan School of Public Health
20	Saltanat Yegeubayeva	Kazakhstan School of Public Health
21	Aigul Dosmailova	Kazakhstan School of Public Health
22	Dina Terloyeva	Kazakhstan School of Public Health
23	Gulmaira Kenzhebayeva	Karaganda Nursing Care Hospital
24	Zhetkergen Arzykulov	Oncology and Radiology Research Institute
25	Assel Tumanova	Oncology and Radiology Research Institute

**Appendix D: Working Group Meeting 2 – list of participants**

	<b>Name</b>	<b>Organization</b>
1	Nadezhda Kozachenko	“Credo” Public union
2	Irina Mingazova	“Credo” Public union
3	Ainur Shakenova	“Legal Reform” FSK
4	Saltanat Yegeubayeva	Kazakhstan School of Public Health
5	Galina Kausova	Kazakhstan School of Public Health
6	Anarhan Nurkerimova	Almaty Center for Palliative Care
7	Aigul Dosmailova	Kazakhstan School of Public Health
8	Kalisa Dosbayeva	Kazakhstan School of Public Health, Translator
9	Ainur Shakenova	“Legal Reform” FSK
10	Saltanat Yegeubayeva	Kazakhstan School of Public Health
11	Galina Kausova	Kazakhstan School of Public Health
12	Gulnar Erdesova	Almaty Health College
13	Maya Ababkova	Almaty Health College
14	Nuriya Kalimuratova	State Health College
15	Manshuk Nurmanova	State Health College
16	Anarhan Nurkerimova	Almaty Center for Palliative Care
17	Aigul Dosmailova	Kazakhstan School of Public Health
18	Kalisa Dosbayeva	Kazakhstan School of Public Health, Translator

### Appendix E: Working Group Meeting 3 – list of participants

Number	Name	Organization
1	Saltanat Yegeubayeva	Kazakhstan School of Public Health
2	Aizhan Oshakbayeva	Open Society Foundation Kazakhstan
3	Saltanat Yegeubayeva	Kazakhstan School of Public Health
4	Seysymbaevna Kenjebayeva	Karaganda Nursing Hospital
5	Galina Kosovo	Karaganda Nursing Hospital
6	Lidiya Fedorova	Kostanai Regional Oncology Center
7	Marina Scherbatyuk	Kostanai Regional Oncology Center
8	Erbolat Bairov	Ust-Kamenogorsk Hospice
9	Bakytgul Nabiyeva	Ust-Kamenogorsk Hospice
10	Assem Kassenova	'Solaris' Hospice, Pavlodar
11	Alain Ozdoyev	'Solaris' Hospice, Pavlodar
12	B M Zhumadullaev	Institute of Oncology and Radiology
13	Aman Zhangireyev	National TB Center, Almaty
14	Askarovna Smailova Gulnara	National TB Center, Almaty
15	G. M. Akhmetov	National HIV/AIDS Center, Almaty
16	Oksana Shatkovskaya	Almaty City Oncology Clinic
17	V. Kopzhasarova Love	Almaty City Oncology Clinic
18	Albrusovna Guljan Tulepova	Almaty City TB clinic
19	Anarhan Nurkerimova	Almaty Center for Palliative Care
20	Maryanovna Kotova Galina	Almaty Center for Palliative Care
21	Rafailovna Marina Rakhimov	Almaty Center for Palliative Care
22	Muratbekovna Raigul Kopzhasarova	Almaty Center for Palliative Care
23	Tursynovna Clara Sybanova	Almaty Center for Palliative Care
24	Nusipovna Nurziya Aliyev	Almaty Center for Palliative Care
25	Ospanovna Ryskaysha Ospanov	Almaty Center for Palliative Care
26	Kuandykovna Aigul Izhanova	Almaty Center for Palliative Care
27	A. A. Zhankin	Almaty Center for Palliative Care

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**Appendix G: Opioids and other medication available in Kazakhstan**

<b>Medication</b>	<b>Route</b>	<b>Amount</b>	<b>Frequency</b>
Morphine	Injection	1 mg	Twice per day
Dihydrocodeine	Oral	30mg	Four to six hours
Dihydrocodeine (acute pain)	Oral	40 – 80 mg	Three times per day
Trimeperidine	Oral	25 – 50 mg	Maximum dosage 50 mg per day
Trimeperidine	Injection	10-30 mg	Maximum dosage 40 mg per day
Pentazocine	Oral	25-100 mg	Three to four hours
Pentazocine	Injection	30-60 mg	Three to four hours
Buprenorphine	Sublingual	200mg	Six to eight hours
Buprenorphine	Injection	300 mg	Six to eight hours
Tilidine	Oral	50-100 mg	Four times per day
Tilidine	Rectal	50-100 mg	Four times per day
Tilidine	Injection	50-100 mg	One to two times per day
Tramadol	Rectal	100 mg	Maximum dosage 400 mg per day
Tramadol	Injection	50-100 mg	Maximum dosage 400 mg per day
Butorphanol	Injection	1-2 mg	Dependent upon circumstances
Nalbufine	Varies	Varies	Dependent upon circumstances

## **Appendix H: Code of the Republic of Kazakhstan on the People's Health and Healthcare System (September 18, 2009)**

The *Code on People's Health and the Health Care System* specifies the provision of palliative care as follows:

### Article 32: Healthcare Entities

2. The following health organizations are working in the healthcare system:
  - b) Organizations providing palliative and nursing care.

### Article 34: Guaranteed Free Medical Care

2. The guaranteed free medical care includes:
  - b) Palliative care and nursing care for the population categories approved by the Government of the Republic of Kazakhstan.

### Article 53: Palliative Care and Nursing Care

1. Palliative care is provided under the guidance of the doctor to incurable patients in the terminal (final) stage at the specialized hospital units, independent medical facilities (hospices) or on an in-home outpatient basis.
2. Nursing care is provided in those cases where medical supervision is not required, at the specialized hospital units, independent medical facilities (nursing homes) or on an in-home outpatient basis.
3. The palliative care and nursing care procedures are set by the relevant authorities.

## **Appendix J: List of the Population Categories Subject to Palliative and Nursing Care**

The list of population categories referred to palliative care and nursing care includes:

1. Patients with:

- 1) Stage IV cancer;
- 2) AIDS in its terminal stage; and
- 3) Chronic progressive diseases in a terminal stage (decompensation of heart, lung, liver, renal failure, severe consequences of stroke).
- 4) People who are unable to care for themselves because of an illness and (or) disability whose duration is limited.

## **Appendix K: On Approval of rules for palliative care and nursing care**

Rules for delivering palliative and nursing care were stipulated in Decree no. 632 from the Minister of Health of the Republic of Kazakhstan in 2009:

- Palliative care is delivered under the supervision of a doctor to patients with incurable illnesses in the terminal stage in specialized departments of healthcare facilities or specialized healthcare organizations (hospices) or as home visiting services.
- Nursing is provided in cases which do not require doctor's supervision in specialized departments of healthcare organizations, specialized healthcare organizations (nursing hospitals) or as home-visiting services.
- Patients are hospitalized to palliative and nursing care organizations in the following cases: the patient has oncologic, renal, hepatic, heart, pulmonary or neurologic disorder in the terminal stage, or AIDS in the terminal stage, or patients disabled due to illness, whose life expectancy is limited, which is confirmed by the medical assessment made by doctors of a healthcare organization; patient needs supporting, pain relieving therapy for further treatment in out-patient settings; the patient has a social-psychological disorder: depression, reactive state, family conflict, or poor living conditions inappropriate for providing care.
- Palliative and nursing care is provided in in-patient settings or in the form of hospital-substituting care (at-home services, daytime inpatient services).
- In-patient care ensures high quality management of incurable patients under 24-hour medical supervision.
- Palliative and nursing care in the form of hospital-substituting services is provided as first-aid, high quality, specialized or highly specialized care with medical supervision from four to eight hours a day.

## **Appendix L: On approval of state standards for health care organizations**

Decree no. 238 by the Minister of Health of the Republic of Kazakhstan stipulates the following qualifying standards for hospice staff:

### **Chapter 3: Qualifying standards for hospice staff**

- Standard underlying organization of a hospice is 30 beds per 400 thousand population. The optimal number of beds is from 15 to 45.
- The number of health specialists is based upon the following calculation: one physician per 15 beds; one oncologist per 30 beds; one psychotherapist for the whole organization.
- Home-visiting department is organized to provide at-home services. It consists of a home-visiting team (home-visiting teams). The number of teams is determined by the amount of work. The number of health specialists of the home-visiting department is based upon the following calculation: one physician; one oncologist.
- The position of a head of in-patient department shall be established when the number of beds is at least 30.
- If there is a position of a head of the home-visiting department, it shall substitute one position of a doctor in a home-visiting team.
- There shall be a position of an assistant medical director in every hospice.
- The number of nurses (in-patient) is based upon the following calculation: one 24-hour post per five beds and one additional post per two to three beds for comatose patients.
- Each department has one full-time treatment nurse (the nurse who carries out treatment manipulations, such as intravenous injections or infusions). Each home-visiting team has two treatment nurses.
- Each department has one full-time dressing room nurse.

- The position of a head nurse of a department is established in concordance with the position of a head of a department.
- There is one position of an admission department nurse per hospice.
- There shall be a part-time position of a diet-nurse in every hospice (0.5 of a basic rate).
- There shall be a position of a medical statistician in every hospice.
- There shall be a position of a nursing director in every hospice.
- There shall be a position of a matron in every department.
- There shall be one 24-hour post of a junior nurse per five beds.
- The positions of junior nurses in treatment and dressing rooms shall be established in concordance with the positions of dressing and treatment nurses.
- There shall be one position of a supply-room junior nurse per shift.
- There shall be one position of a hospital cleaner per department.
- There shall be one position of a bath junior nurse per department.
- There shall be one 24-hour post of a junior nurse, who accompany patients or carry corpses, per hospice.
- There shall be one position of a pharmacist per 50 beds.
- There shall be one position of a social worker per hospice.

## **Appendix M: Salamatty Health Care Development Programme (2011-2015)**

The *State Health Care Development Programme (2011-2015) Salamatty Kazakhstan*, envisages several measures to strengthen palliative care services:

### 2.3.1. Improving palliative care for patients

- Improve the palliative care system by creating a network of palliative care organizations, including the reorientation of some hospitals and sanatoriums;
- Expand the network of home-based palliative care and day care services;
- Develop standards and protocols for the treatment of palliative and nursing care patients in accordance with international requirements;
- Develop and introducing palliative care training programs for doctors and nursing staff (standard training program for students of medical universities and colleges, post-graduate training program);
- Staff palliative care organizations with suitably qualified personnel;
- Improve the health care of older people through adopting a comprehensive approach in addressing their medical, biological, social and psychological needs (geriatric palliative care);
- Establish performance targets that reflect the quality of care provided by palliative care organizations.