

R.A. Winkelmann · F.D. Tretyakov · N.V. Startsev
I.B. Kolyado · B.I. Gusev · B. Grosche · H.H. Storm
P. Hall

Cause-of-death registers in radiation-contaminated areas of the Russian Federation and Kazakhstan

Received: 29 May 2001 / Accepted: 1 October 2001 / Published online: 9 March 2002
© Springer-Verlag 2002

Abstract Since the early 1990s, information on radiation-exposed populations other than those exposed from the Chernobyl accident in 1986 has become increasingly available for international scientific research. It is essential to understand how the cohorts of exposed populations have been defined and what mechanisms can be used to study their health outcomes. Different international scientific research collaborations currently investigate four population groups chronically exposed to ionizing radiation during the late 1940s and early 1950s in the Russian Federation and in Kazakhstan. In this frame-

work, collaborations have been established to develop cause-of-death registers in each of these four areas for future mortality follow-up purposes with the aim of studying the health effects of ionizing radiation. The emphasis of this effort is on assessing the information sources available, the mechanisms of data collection and coding, and the data quality and completeness of the information collected. One of the major challenges is the harmonization of all these aspects between the four different centers to the extent possible, taking into account that much of the actual data has been collected over many decades.

R.A. Winkelmann (✉)
Department of Cancer Prevention, Danish Cancer Society,
Copenhagen, Denmark
e-mail: winkelmannr@who.int
Tel.: +41-22-7913428, Fax: +41-22-7914843

H.H. Storm
Department of Cancer Prevention, Danish Cancer Society,
Copenhagen, Denmark

F.D. Tretyakov
Southern Urals Biophysics Institute, Ozyorsk,
Chelyabinsk Region, Russian Federation

N.V. Startsev
Urals Research Centre for Radiation Medicine,
Chelyabinsk, Russian Federation

I.B. Kolyado
Institute of Regional Medico-Ecological Problems,
Barnaul, Altai Region, Russian Federation

B.I. Gusev
Kazakh Scientific Research Institute for Radiation Medicine and
Ecology, Semey (Semipalatinsk), Kazakhstan

B. Grosche
Institute for Radiation Hygiene,
Federal Office for Radiation Protection, Oberschleissheim,
Germany

P. Hall
Department of Medical Epidemiology, Karolinska Institute,
Stockholm, Sweden

New address:

R.A. Winkelmann, World Health Organization (EÜB/CCO),
20 Avenue Appia, 1211 Geneva 27, Switzerland

Introduction

The accident at the Chernobyl nuclear power plant in Ukraine on 26 April 1986, the largest-ever radiation accident involving a nuclear reactor, has resulted in radioactive fallout throughout Europe and caused widespread public health concern in many countries. Given the prevailing political context at the time, scientific investigations on the health effects started to be conducted independently in western European countries and in the Soviet Union. In the latter, much of the efforts were concentrated on creating registers of people exposed from the Chernobyl accident and the medical follow-up of these populations.

With the dissolution of the Soviet Union into the New Independent States (NIS), collaborative investigations between western and NIS scientists became feasible. Initially, a number of international collaborations were developed to assess the health effects of the Chernobyl accident. From the radiation protection perspective, research into the Chernobyl accident was expected to provide clues about health effects of protracted exposure to low doses of ionizing radiation. Cancer risk estimates related to ionizing radiation have so far been derived from the Japanese A-bomb survivors and patients treated with radiotherapy, both groups of which received high doses of radiation during a very short period of time.

During the 1990s, information about radiation hot-spots in the NIS other than Chernobyl became increasingly available. Whereas many of the latter resulted in limited population exposure (i.e. cemetery of nuclear submarines in the Murmansk area, accident at the Tomsk nuclear power plant etc.), three particular areas in the Russian Federation and Kazakhstan experienced significant population exposures. Two of these areas are located in the Chelyabinsk region of the Russian Federation, in the south-west part of the Ural mountains. The source of radiation exposure for these two sites is the same: the Mayak Production Association for the production of plutonium for nuclear weapons and reprocessing of fission products. The Mayak facility was built in the late 1940s and started operation in 1949. During 1949–1951, the radioactive water from the Mayak site was directly released into the Techa River, which resulted in radiation exposure of over 50,000 inhabitants of villages along the river banks during the period 1950 through 1960. Also the inhabitants of the closed administrative territorial unit of Ozyorsk (approximately 50,000 inhabitants in 1959), the city in which most of the adult inhabitants worked at the nearby Mayak facility, were exposed almost continuously during the first decade of operation of the plant due to gas-aerosol emission releases. The third area is the Semipalatinsk region in the desert in the north of Kazakhstan, where several hundreds of atmospheric nuclear bomb tests during 1948–1965 resulted in radiation exposure in the nearby resident populations in this region in Kazakhstan and across the border in the Altai region of the Russian Federation. On-going international research into the health effects of these radiation-exposed populations is expected to provide important clues to health risks of protracted radiation exposure.

One of the first tasks for international research groups into the health effects of radiation-exposed populations in the New Independent States was to assess what kind of infrastructure was available in these countries to conduct epidemiological investigations and to evaluate the quality and completeness of these tools. Such assessments have first been conducted in the framework of Chernobyl-related projects, and concentrated mainly on disease registers, in particular cancer registries, for prospective follow-up of the Chernobyl-exposed populations [1]. For the follow-up of the populations of Kazakhstan and the Urals, primarily exposed during the 1950s, the only available health outcome measure systematically collected over time is mortality, with records in the New Independent States dating back to 1935. The present report describes efforts underway to develop cause-of-death registers in areas of chronically radiation-exposed populations of the Russian Federation and Kazakhstan.

Rationale for developing cause-of-death registers in these areas

The goal of the present project is to develop an epidemiological infrastructure for the scientific investigation

of health effects in radiation-contaminated areas of the Russian Federation and Kazakhstan to ultimately gain further insight into the health effects of chronic exposure to ionizing radiation on human beings.

The specific objectives are threefold. The first aim is to better understand the process of death certification, the availability of death information over time, the quality of general population mortality statistics and their potentials and drawbacks for the use in epidemiological investigations. Second, scientific institutions involved in assessing the health effects in chronically radiation-exposed populations have accumulated a wealth of information on mortality on paper carriers in their archives. It is important to safeguard this information and make it available for research purposes. Third, so far the four research institutions have collected information on death entirely independently from each other, using different processes and methods. The present project aims to map these existing differences and ensure as much as possible harmonization of the principles and methods used in order to increase comparability of the cause-of-death register information between the four centers as far as possible.

Death registration and mortality statistics in the NIS

Similar to the process of compulsory reporting of vital events in other countries, information on births, deaths and marriages is registered in all New Independent States since 1935. In each of these countries a network of district or city vital registration departments are responsible for data collection at the lowest administrative level. In some sparsely populated areas, such vital registration departments also operate for sub-district administrative units.

Death certificates are registered as part of the vital registration system and annual mortality statistics are compiled by the regional statistical administration. Two death registration documents are used in this process: the medical death certificate and the legal death registration act.

Medical death certificates are completed by medical doctors, and sometimes by medical assistants (i.e. feldshers) particularly in rural areas. In the event of a death, the medical doctor (or feldsher) will complete the medical death certificate and give it to the relatives of the deceased. The relatives are then expected to register the death within 3 days at the district vital registration office (i.e. ZAGS in Russian), mainly at the place of residence of the deceased, although some deaths are registered at the place of death. Registration of the death is a requirement for the relatives to obtain the authorization for burial of the body and relevant certificates for social benefits (i.e. transfer of pension benefits, property, etc.).

During the registration process the relatives provide the medical death certificate to the district vital registration department, which establishes two legal death regis-

tration acts, one of which is kept indefinitely at the district level, and the second of which is submitted to the regional statistical department at regular intervals together with the medical death certificate, where the information is coded, computerized and compiled for statistical purposes.

The statistical reporting process in the New Independent States starts at the regional level with the coding of the death certificates. During the Soviet era and well into the 1990s, the underlying cause of death was coded according to a "Short classification for deaths, based on the international classification of diseases, injuries and causes of death (ICD)", which consists of some 200 groups of causes of deaths developed by the Soviet administration on the basis of the A-list of the ICD, revisions of which are published by the World Health Organization (WHO) at regular intervals. Cause-of-death coding is mostly performed by non-medically qualified staff. Annually, mortality statistics are calculated at the regional level and aggregated at the national level. Number of deaths by group of causes of deaths are compiled by sex and age group for each region, and only total numbers of deaths are available for districts. In most of the New Independent States the statistical reporting process was computerized during the 1980s, before which it was performed entirely manually. As a consequence, historical mortality statistics are available only in tabular form.

From the epidemiological perspective, the medical death certificate is the primary document of interest. The medical death certificate currently in use in the NIS follows the internationally recommended layout (see WHO [2]). The international comparability of medical death certificates from earlier periods, especially the ones of interest for the creation of the cause-of-death registers in the present framework (i.e. 1949 onwards), is however, somewhat more difficult to establish considering that several changes have occurred in the layout of the form over time and that the medical death certificates are only kept for 6 years in the archives of the regional statistical departments and are destroyed thereafter. Thus it is practically impossible to use medical death certificates for retrospective epidemiological purposes in the New Independent States.

The only historical information on death available in the NIS is the legal death registration act, which is kept indefinitely in the relevant archives of the vital registration departments: one copy at the district level and one copy at the regional level.

From the epidemiological perspective the legal death registration act, however, represents a major problem: the way in which the information on cause of death is recorded. During the registration process the registrar transcribes the information on the causes of death from the medical death certificate to the legal death registration act. Whereas in the former the causes are arranged according to the sequence of events leading to the immediate cause of death, including the mention of contributory causes of death, thus facilitating the selection of the underlying cause of death used for statistical purposes, dur-

ing the transcription process the information on sequence is lost, as all causes are listed in one single line on the legal death registration act.

The cause-of-death register in Ozyorsk, Russian Federation

The city of Ozyorsk is situated approximately 70 km north-west of the city of Chelyabinsk, and 10–15 km from the Mayak nuclear complex. The city of Ozyorsk is a Closed Administrative Territorial Unit, which is a closed city of special military security status, not normally mentioned on geographical maps and accessible only with special permission.

Ozyorsk as a city was built alongside the creation of the Mayak nuclear complex. The Mayak site was constructed during 1946–1948, and the first plutonium concentrate was obtained at the radiochemical plant in February 1949, followed by metal plutonium two months later. With these ingredients the first USSR atomic bomb was developed and tested at the Semipalatinsk test site (STS) during the same year. During the following decade the nuclear complex was further developed: five more production reactors became operational during 1950–1952, a new radiochemical plant started operation in 1959, and in 1960 the plutonium production plant was extended and modernized.

According to census data, the population in Ozyorsk has increased from approximately 50,000 inhabitants in 1959 to 81,000 inhabitants in 1989, with an age structure in recent years being close to that of highly developed countries (Fig. 1). The socio-demographic characteristics of the inhabitants of this city are very different from the general Russian population. Inhabitants of Ozyorsk in general are highly qualified professional specialists, among the best in the country, with advanced educational backgrounds. Also, residents in this city were provided with much better supplies and enjoyed better health care compared to the rest of the country.

The population of Ozyorsk experienced radiation exposure mainly as a result of gas-aerosol emissions from the Mayak site. The largest amounts of radiation were released during the first decade of operations of the plant, due to a leaking gas-cleaning system and so-called technical releases of radioiodines. Two accidents caused further environmental radiation releases: a thermal explosion in the high-level waste repository in 1957, known as the Kyshtym accident, and radioactive silts from the Karachi lake nuclear waste dump site in 1967, but did not affect the city of Ozyorsk.

Information on deaths occurring in the resident population of Ozyorsk during 1948–1997 has been reconstructed. The primary information was abstracted from medical death certificates, being held by the city's only vital registration department. In addition, further information was obtained from autopsy reports and forensic-medical examination reports. The city of Ozyorsk represents a very special situation, where during the 1950s–

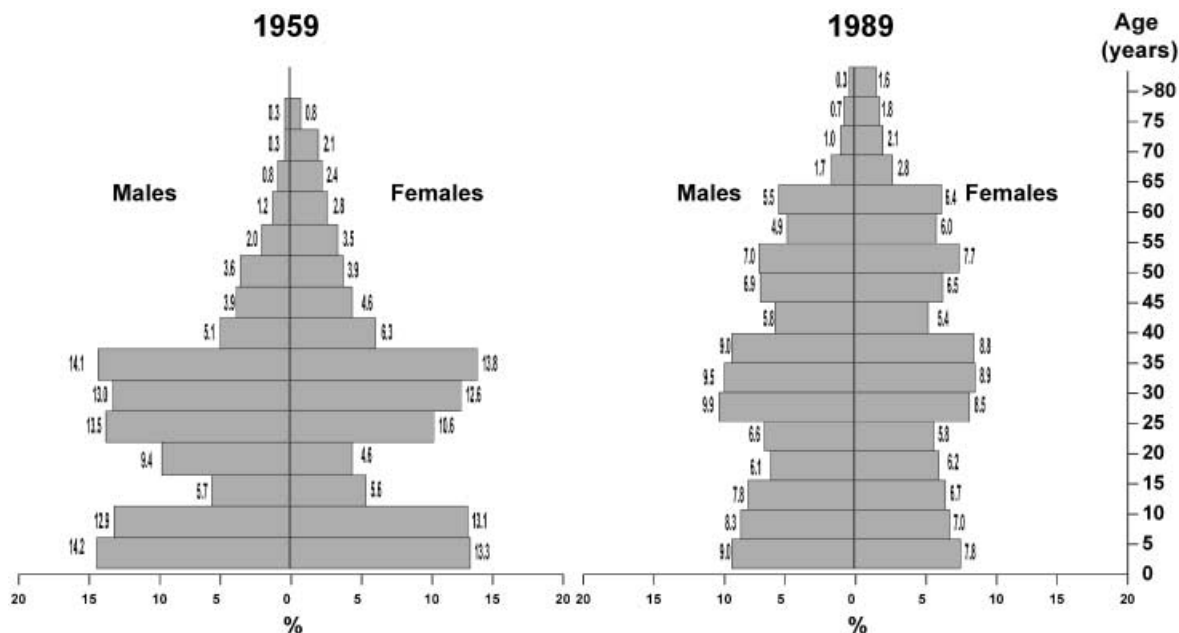


Fig. 1 Age structure of the population of Ozyorsk at the 1959 and 1989 censuses

1970s the proportion of autopsies was exceptionally high (78–80%), thereafter gradually decreasing to 44% during the 1990s and since the late 1990s being close to the proportion of deaths autopsied in the general Russian population (in 1997, 35.7% of all deaths in Ozyorsk underwent autopsy, compared to a national average of 33%).

In the framework of the present project, information on a total number of approximately 20,000 deaths occurring during 1948–1997 was collected. The underlying cause of death has been coded according to the 8th revision (ICD-8) of the ICD [2, 3] until and including 1980 and to the 9th revision (ICD-9) thereafter [4, 5]. Corresponding population data by sex and age groups, however, is available only for census years (1959, 1970, 1979, 1989).

The cause-of-death register in the Chelyabinsk region, Russian Federation

The Mayak nuclear facility was also at the origin of the radiation contamination of the Techa river, resulting in exposure of the inhabitants of settlements located along the river banks, known as the Techa river population. With the beginning of the operations of the first production reactor at the radiochemical plant in 1949 until 28 October 1951, radioactive waters from the Mayak facility were directly released into the Techa river.

The Techa river flows through the Chelyabinsk and Kurgan regions in the south-east part of the Urals mountain range. As of early 1950, 41 villages were located on the river banks, representing a total population of 23,500 inhabitants. Most of these villages belong to two districts in the Chelyabinsk region (Krasnoarmeysky and Kunas-

haksy districts), and two districts in the Kurgan region (Kataysky and Dalmatovsky districts), the geographical location of which is shown in Fig. 2. Following the assessment of the radiological situation in the area, 26 villages were re-settled within their respective administrative regions to villages located further away from the river banks (21 in the Chelyabinsk region and 5 in the Kurgan region).

In the framework of the present project, information on some 38,000 causes of death were abstracted for 2 districts (Krasnoarmeysky and Kunashaksky) in the Chelyabinsk region covering a 43-year period (1950–1992). The legal death registration acts in vital registration archives of the regional statistical administration served as information sources. Causes of death were coded according to ICD-9 using a computer-assisted approach based on dictionaries of ICD coding terms.

The cause-of-death register of individuals living in radiation-exposed settlements in the Semipalatinsk region, Kazakhstan

Between 1949 and 1989 nuclear weapons tests were conducted at the Semipalatinsk test site. The Semipalatinsk region (Semey region in Kazakh) is a sparsely populated area located in the north of Kazakhstan, close to the borders of the Russian Federation and China. During the 40 years of operation of the test site, a total number of 458 nuclear weapons tests were conducted. Whereas from 1962 onwards the nuclear tests were underground tests, of the 118 tests conducted during 1949 and 1961, about 30 were near or at ground level resulting in local fallout. Some of the earlier tests caused considerable population exposure in villages located close to the test site. But even more distant villages in Kazakhstan and areas in the adjacent Altai region of the Russian Federation were affected.

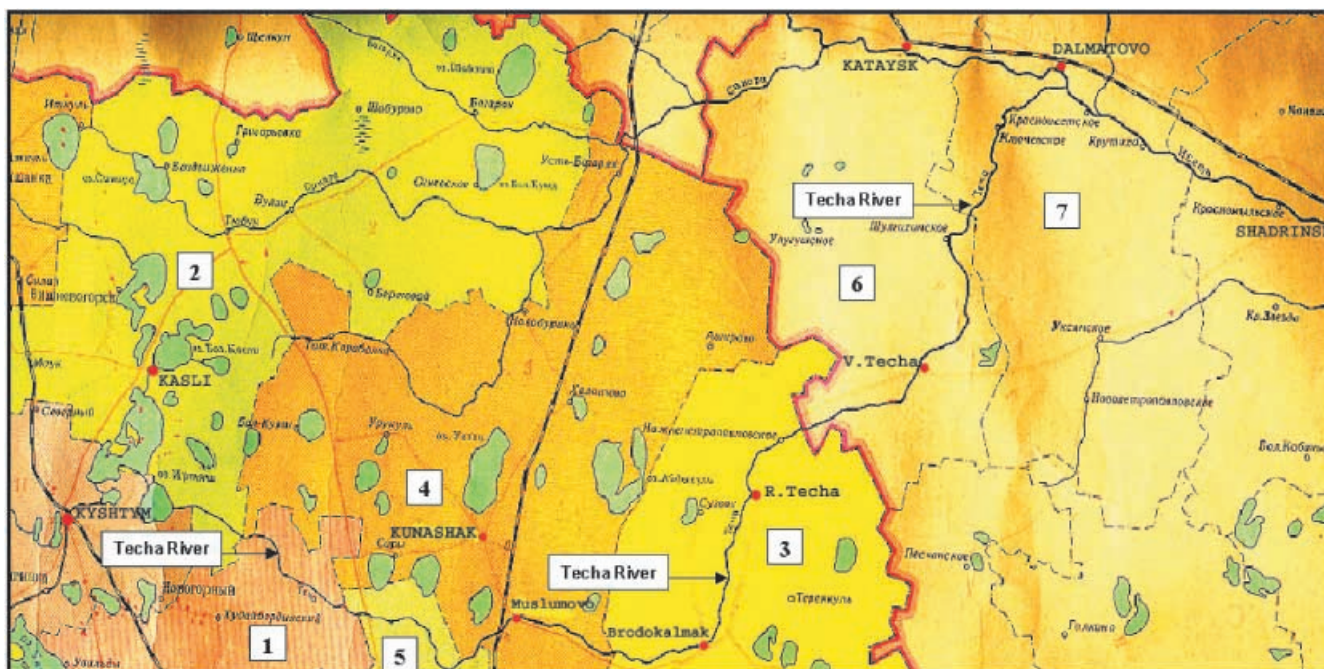


Fig. 2 Map of the Techa river basin. Districts (1) Argayashsky, (2) Kaslinsky, (3) Krasnoarmeysky, (4) Kunashaksky, (5) Sosnovsky, (6) Kataysky, (7) Dalmatovsky

Table 1 Composition of the cause-of-death register in the Semipalatinsk region of Kazakhstan. Numbers of deaths during the observation period (1949–1975) and population figures in 1949 according to exposure group and settlement

Exposed settlements			Comparison settlements		
	Population in 1949 (approx.)	Deaths during 1949–1975		Population in 1949 (approx.)	Deaths during 1949–1975
Abaisky and Abralinsky settlements	10,000	3,292	Zharminsky settlement	38,000	7,944
Beskaragaisky settlement	16,000	6,799	Charsky settlement	14,000	4,678
Zhana-Semeisky settlement	12,000	3,547	Kokpektinsky settlement	23,000	6,104
			Borodulikhinsky settlement	15,000	5,639

As from 1957 onwards, a register was established at the Dispensary No. 4, now the Kazakh Research Institute for Radiation Medicine and Ecology, including information on the population living in radiation-exposed settlements close to the Semipalatinsk test site, their health status and causes of death for deceased individuals [6, 7]. The assessment of the population radiation doses from the nuclear weapons tests started in 1960. Following these assessments, the individuals in the register were grouped according to geographical radiation contamination levels at their place of residence, with settlements of more than 0.07 Sv representing the exposed populations and those below this value being considered as the comparison population.

Information on cause of death has been abstracted from the household tax records in the settlements and the legal death registration acts at the vital registration offi-

ces for all settlements under observation. For the period 1949–1975, the information for a total number of approximately 38,000 deaths has been abstracted for this population. The distribution of the total number of deaths between the exposed and the comparison settlements is shown in Table 1. All causes of deaths were coded according to ICD-9.

The cause-of-death register in the Altai region, Russian Federation

The nuclear weapons testing at the Semipalatinsk test site in Kazakhstan was also responsible for the radiation exposure of some of the adjacent territories in the Altai region of the Russian Federation. For these populations, the first atmospheric explosion on 29 August 1949

caused most of the radiation exposure. Districts along the explosion trace of the 1949 test were selected as the exposed populations (i.e. Rubtsovsk, Zmeinagorsk, Krasnoshekovsk, Kurinsk, Loktevsk, Pospelinkhinsk, Tretyakovsk and Uglovsk). The Krasnogorsk district was chosen as a non-exposed control population [8].

Information on deaths and their causes occurring in each of the nine districts were abstracted from the legal death registration acts, stored at the vital registration archives of the Altai regional statistical administration. The observation period for this particular cause-of-death register was defined as 1993–1998. This period also allowed information on the causes of deaths from a sample of medical death certificates to be obtained (i.e. for each 20th death identified from the legal death registration acts). This particular design will allow the relationship between the quality of the two different information sources and the reliability of the ICD coding to be assessed.

At the end of December 2000, a total number of approximately 30,000 causes of death had been abstracted for the period 1993–1998 for the 9 districts. All causes of deaths were coded to ICD-9 by a physician.

Discussion

The development of cause-of-death registers for chronically radiation-exposed populations in the Russian Federation and Kazakhstan presents a major challenge: the comparability of the information collected between the four cause-of-death registers and with national background mortality statistics. A number of factors influence the degree of comparability:

- The information sources used by the four centers for the development of the cause of cause-of-death registers differ. There exist a number of information sources concerning the cause of death, which are more or less accessible for historical reconstruction: legal death registration acts, medical death certificates, autopsy reports and reports of medical expert committees. The quality of the cause of death reported from these sources varies, with the clinical reports being more precise, but such reports are not available for all deaths. The information available for the development of the cause-of-death registers in a given region depends on when and how the data were collected. In Ozyorsk and Semipalatinsk, the data collection started many decades ago and continued prospectively over time. Similarly, in the Altai region retrospective data collection was initiated during the mid-1990s and continued prospectively. The prospective approach allowed multiple information sources on death to be used by these three centers. In contrast, data in the Chelyabinsk region were collected retrospectively, based on the legal death registration act, which is the only data source consistently available over time. On the one hand, the use of multiple data sources increases the reliability of the information on the cause of

death. On the other hand, it limits the comparability of the death information, not only between the four centers, but more importantly, for comparisons with general population mortality rates. However, no such limitations apply for center-internal comparisons, such as the comparisons of subgroups within the same cause-of-death register.

- Similar variations between the cause-of-death registers exist in terms of the coding. In all four centers, the coding was performed according to ICD. In Ozyorsk the deaths were coded over time, using the ICD-8 until the end of 1980 and the ICD-9 since then. This implies the use of several coders over time and the difficulty to ensure consistency in applying the coding rules. In the other three centers, although information on deaths may have been collected over time, the information was coded according to ICD-9 only during recent years. In all four centers the coding was performed by physicians, based on a complete set of volumes of the Russian version of the ICD. However, whereas in the Semipalatinsk and Altai regions this was done manually, in the Chelyabinsk region coding was performed using a computer-assisted approach. Again, the coding practices in the cause-of-death registers considered here differ from the coding practices of the national mortality statistics. The latter were coded at the regional statistical departments by non-medically qualified personnel following the Soviet modification of the ICD short list. Furthermore, the proper application of ICD coding rules required the causes of death arranged following the subdivision of the international medical death certificate into two groups of causes of death, with the direct, intervening and underlying causes of death listed in order in part 1 and other significant conditions mentioned in part 2. Based on this structure the physician certifying the death decides on the order and the coder follows the appropriate ICD coding rules. No such divisions are mentioned on the legal death registration acts, nor on the autopsy or medical expert committee reports. In these latter cases the coder selects the underlying cause of death from the conditions listed in the information source(s).
- The cause-of-death registers differ in terms of population coverage. In all centers except Semipalatinsk, information on deaths was abstracted for entire districts. In Semipalatinsk, however, such information was abstracted only for populations living in radiation-exposed settlements. Whereas general population mortality statistics are available for comparison purposes on the district level, no such data exist for settlements.
- Finally, the time period for which the cause-of-death register was developed differs between the four centers. The aim was to collect population-based cause-of-death information since first exposure, which could be achieved in three centers, as the information had already been abstracted from the vital registration offices over time and was available in archives at the re-

spective research institutes. In the Altai region, however, the actual data abstraction process was only initiated in the late 1990s, with population-based cause of data for the nine districts currently being available for the period 1993–1998. In addition, cause-of-death data for exposed subjects is available since the 1950s.

Conclusions

During the first phase of the development of cause-of-death registers in areas of chronically radiation-exposed populations in the Russian Federation and Kazakhstan, efforts have been devoted to systematically collect and computerize information on deaths that had previously been collected more or less routinely for many decades and for various purposes. Whereas the data collected can now be routinely employed for the follow-up of the radiation-exposed population whenever the aim of the investigation is to assess the health effects in different subgroups within each of these four exposed regions, the comparability of the death information between registers as well as with general population mortality statistics need further investigation.

The issue of cross-death-registry comparison requires careful consideration, and special investigations into comparability are warranted. This is particularly important, as the cause-of-death registers will be the basis for the mortality follow-up of the chronically radiation-exposed populations, and the comparison of the health effects experienced by the radiation-exposed populations in these four areas is of particular interest for radiation protection and public health purposes.

Acknowledgement This work was supported by the European Commission under contract IC15-CT98–0204 for the Russian Federation and under contract IC15-CT98–0218 for Kazakhstan.

References

1. Storm HH, Winkelmann RA, Okeanov AE, Prisyazhniuk AE, Ivanov VK, Gulak L, Yakimovitch G (1996) Development of infrastructure for epidemiological studies in Belarus, the Russian Federation and Ukraine. In: Karaoglou A, Desmet G, Kelly GN, Menzel HG (eds) The radiological consequences of the Chernobyl accident. Proceedings of the first international conference, Minsk, Belarus, 18–22 March 1996. European Commission, DG XII, EUR 16544 EN, pp 879–893
2. WHO (1967) Manual of the international statistical classification of diseases, injuries, and causes of death, Vol 1. World Health Organization, Geneva
3. WHO (1969) Manual of the international statistical classification of diseases, injuries, and causes of death, Vol 2. World Health Organization, Geneva
4. WHO (1977) Manual of the international statistical classification of diseases, injuries, and causes of death, Vol 1. World Health Organization, Geneva
5. WHO (1978) Manual of the international statistical classification of diseases, injuries, and causes of death, Vol 2. World Health Organization, Geneva
6. Gusev BI, Abylkassimova ZN, Apsalikov KN (1997) The Semipalatinsk nuclear test site: a first assessment of the radiological situation and the test-related radiation doses in the surrounding territories. *Radiat Environ Biophys* 36:201–204
7. Gusev BI, Rosenson RI, Abylkassimova ZN (1998) The Semipalatinsk nuclear test site: a first analysis of solid cancer incidence (selected sites) due to test-related radiation. *Radiat Environ Biophys* 37:209–214
8. Shoikhet YN, Kiselev VI, Zaitsev EV, Kolyado IB, Konovalov BY, Bauer S, Grosche B, Burkart W (1999) A register for exposure and population health in the Altai region affected by fallout from the Semipalatinsk nuclear test site. *Radiat Environ Biophys* 38:207–210