Cancer in Estonia: Rates and Validity

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Abstract

Estonia is a small country in the north-eastern Europe, with its history dating back more than 5 000 years. This thesis gives an overview of the history, development and current cancer registration process in the Estonian Cancer Registry. Cancer registration in Estonia dates back to 1953, when it mostly adhered to cancer registration principles of the Soviet Union which the country was part of. Since 1970s the cancer registration principles diverged from the Soviet ones. The current procedure of cancer registration in Estonia (which restored its independence in 1991) operates on principles that are quite similar to those used in the Western countries. Over the recent years, the Estonian Cancer Registry has established itself as a high standard cancer registry with a rather extensive use of data.

Up to now, no special studies concerning the quality of cancer registration have been carried out in Estonia. The three studies performed in the framework of this thesis looked at different quality characteristics of Estonian Cancer Registry data, such as validity and completeness of cancer registrations items, as well as completeness of coverage. The data quality in the Estonian Cancer Registry was found to be good in general.

The Estonian Cancer Registry data were used to analyse trends and variations in cancer incidence and mortality for all cancers as well as by most frequent sites. The analysis showed that total cancer incidence and mortality in Estonia increased during 1985-1997. From specific cancer sites, incidence and mortality of all urologic cancers increased. At the same time, decline in lung cancer incidence in men and stomach cancer incidence in both sexes were observed.

Cancer incidence and mortality in Estonia was compared with that for the Nordic and the Baltic countries. The comparison revealed that Estonia is positioned rather high for the incidence of all smoking related cancers as well as stomach, kidney and prostate cancers.

Cancer incidence between ethnic Estonians and Russians was compared to illustrate the use of the ECR data. This study showed that ethnic differences exist. For example, there is a higher incidence of cancers of stomach and pancreas in Russians compared to Estonians in Estonia for both sexes, and lung cancer for men.

Recommendations for improvements in cancer registration system in Estonia as well as for further studies on the quality of cancer registrations and for the Estonian health care system were given.

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Declaration that this thesis is my own work
(Re Sections 6.3.3 and 6.3.6 Degree Regulations)

I formally declare that the work contained in this thesis is the result of my own work. While the accuracy and completeness of case ascertainment studies (Sections 4.1 and 4.2) were designed in collaboration with colleagues from the Estonian Cancer Registry, the rest of the work contained in this thesis is my own.

Katrin Lang
October 2004

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Abbreviations

CI	confidence interval
CIS	Commonwealth of Independent States
CNS	central nervous system
DCN	death certificate notified
DCO	death certificate only
ECR	Estonian Cancer Registry
ENCR	European Network of Cancer Registries
ETS	environmental tobacco smoke
EU	European Union
GDP	gross domestic product
HDI	human development index
IARC	International Agency for Research on Cancer
ICD	International Classification of Diseases
ICDO	Classification of Diseases for Oncology
M/I	mortality/incidence ratio
MV	morphological verification
NIS	New Independent States
PSA	prostate specific antigen
SE	standard error
SIR	standardised incidence rate
SMR	standardised mortality rate
SRR	standardised rate ratio
WHO	World Health Organisation

Chapter 1. Introduction

In this chapter, an overview of Estonia's geography, demography and history is presented. It also presents a summary of the recent political, economic, as well as demographic changes.

Figure 1.1 Position of Estonia and its neighbouring countries on the map of Europe.

1.1 Estonia

1.1.1 Geography and language

Estonia, officially called the Republic of Estonia, is the smallest of the three Baltic Republics (the other two being Latvia and Lithuania) on the east coast of the Baltic Sea (Figure 1.1). Its capital city is Tallinn, located in the north of the country.

Estonia covers an area of 45 227 square kilometres. It is located mainly between 57°30' and 59°49' N, and 21°46' and 28°13' E. Coastal length is 3 794 km, and land border is 633 km long. Estonia has many islands, large and small (over 1 500 in total).

Estonia is a generally low and flat country with elevations that rarely exceed 100 metres above sea level. The average altitude of the land surface is about 50 metres. Suur-Munamägi (Hill) in the south-eastern corner, reaches 318 metres above sea level, being the highest point not only in Estonia, but in all of three Baltic countries.

The climate is relatively mild due to the closeness of the North Atlantic and the Baltic Sea. In February the mean air temperature ranges from –4˚C (in the west), to –7.5˚C (in the east), and in July respectively 16.5–17.5˚C. The annual average temperature is +5.3˚C. Annual precipitation ranges from 500 mm (on the coast) to 700 mm (in the uplands).

Administratively, Estonia is divided into 15 counties (*maakond*) and these, in turn, are divided into 241 smaller local governmental units (39 towns and 202 municipalities). The president is elected for the period of five years and the state's governing body is Parliament (*Riigikogu*), which has 101 members who are elected for the period of 4 years.

Estonian is the native language and the official language of the Republic of Estonia. Slightly more than one million people speak Estonian, which belongs to the Balto-Finnish group of the Finno-Ugric languages. Thus Finnish is closely related to Estonian (the similarity is comparable to that between Italian and Spanish), while Hungarian is a more distant relative (approximately as close as Polish to Italian). The Latin alphabet is used in written Estonian. The oldest examples of written Estonian are names, words, and phrases found in early 13th century chronicles. The second language, which the majority of Estonians speak, is Russian, although this is now much less common among those of school age. In addition to that, many people speak English, German or Finnish as their third language.

1.1.2 Demography

Estonia has a population of 1 356 045 people (on January 1st 2003). The urban population constitutes 69.1% of the total population. The last full census took place in 2000.

The percentage of literacy in the adult population was 99.8% in 2000. The educational level of the population is reflected by the percentages of persons having tertiary education – 23.6% (15–17 years of education), upper secondary education – 49.7% (11–12 years of education) and below upper secondary education – 26.7% (8–9 years of education) (Statistical Office of Estonia 2004).

The marriage rate per 1 000 population for 2002 was 4.31 and divorce rate was 3.0. In absolute numbers there were 696 divorces per 1 000 marriages registered in 2002
The total fertility rate was 1.37 in 2002 (*Statistical yearbook of Estonia 2003*).

Average life expectancy at birth. In 2001 the average life expectancy at birth in Estonia was 70.5 (64.7 for males and 76.2 for females) (*Statistical yearbook of Estonia 2003*), which is very similar to life expectancy in the neighbouring countries of Latvia (70.1) and Lithuania (71.7) (World Health Organisation Health for All Database 2003).

Figure 1.2 shows life expectancy in Estonia compared to other European countries for the year 2000. The average life expectancy at birth in Estonia was 65.4 for males and 76.3 for females. It is clear from that figure that life expectancy at birth for Estonia is considerably lower than the Nordic average, European average, and the respective value for many European countries. At the same time, it is higher by a few years than the average life expectancy at birth as an average for the Commonwealth of Independent States (CIS, 12 countries of the former USSR, not including the Baltic countries).

When looking at sex-differences in average life expectancy at birth, it is seen that for women in Estonia it is much higher than for men, the difference being 10.9 years. This is much bigger than the respective difference for the European average which is 8.2 years or the Nordic average at 5.5 years.

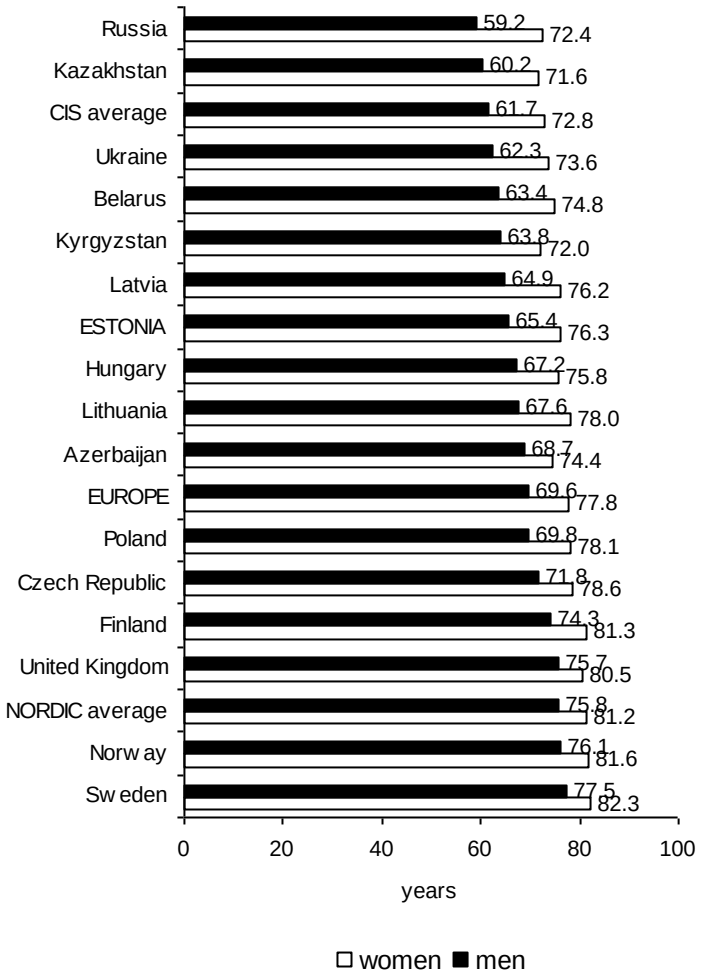

Figure 1.2. Average life expectancy at birth for males and females in different countries in the European region in 2000.
Source: WHO Health for All Database (2003c).

Infant mortality. Figure 1.3 shows the infant mortality rate in Estonia in comparison with other European countries for the year 2000. The same countries and regional averages where chosen as for presenting the comparison of life expectancy figures.

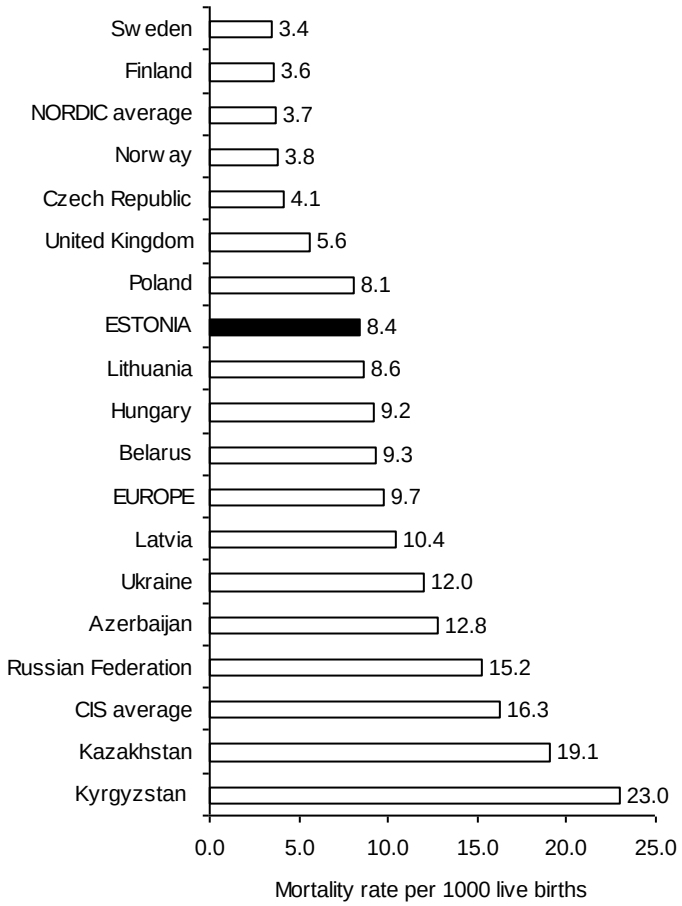

Figure 1.3. Infant mortality rates per 1000 live births for different countries in the European region in 2000.
Source: WHO Health for All Database (2003b)

It is seen that infant mortality rates vary a lot between the countries compared. Comparing infant mortality rate between the Baltic countries it is seen that the rates for Estonia and Lithuania are very similar. Infant mortality in Latvia is somewhat higher when compared to the other two Baltic countries.

Comparing infant mortality rate for Estonia with the regional averages, it is seen that it is slightly lower than the European average at 9.7 per 1 000 births. It is as small as half the rate for the CIS countries. At the same time, it is more than double of the average rate of the Nordic countries.

1.1.3. Cancer as a cause of death

As the main focus of the current thesis is on cancer, it is of interest to look at the importance of cancer as a cause of death, as compared to other main causes of death, in Estonia and other countries. Tables 1.1 and 1.2 present this kind of information for men and women, respectively.

Country	**Cancer (C00-C97)**		**Circulatory diseases (I00-I99)**		**External causes of death (V00-Y99)**		**All causes**	
	%	**SDR**	**%**	**SDR**	**%**	**SDR**	**%**	**SDR**
Kyrgyzstan	9.2	(142.7)	50.6	(788.3)	9.2	(142.7)	100.0	(1558.8)
Azerbaijan	12.2	(144.2)	59.7	(706.7)	3.6	(42.7)	100.0	(1183.1)
CIS average	12.7	(239.3)	52.2	(987.0)	15.4	(292.1)	100.0	(1891.6)
Kazakhstan	13.2	(264.5)	51.7	(1032.7)	14.6	(292.2)	100.0	(1999.3)
Russian Federation	13.3	(283.5)	50.0	(1068.3)	18.3	(390.6)	100.0	(2137.6)
Ukraine	13.3	(246.7)	53.4	(986.2)	14.5	(268.5)	100.0	(1847.8)
Belarus	14.7	(279.5)	50.1	(953.5)	15.2	(289.4)	100.0	(1904.0)
ESTONIA	**18.0**	**(295.3)**	**47.4**	**(776.9)**	**17.9**	**(292.6)**	100.0	**(1637.7)**
Latvia	18.3	(300.2)	49.7	(815.7)	15.5	(254.0)	100.0	(1640.5)
EUROPE	19.4	(246.0)	46.5	(589.4)	11.6	(147.2)	100.0	(1267.0)
Lithuania	19.8	(292.3)	46.7	(689.3)	18.6	(274.5)	100.0	(1475.0)
Finland	21.9	(199.3)	40.5	(368.4)	12.1	(109.6)	100.0	(908.7)
Poland	24.8	(302.4)	44.7	(545.0)	8.3	(101.3)	100.0	(1218.7)
Sweden	25.1	(185.3)	43.1	(318.5)	7.9	(58.6)	100.0	(739.4)
Norway	26.3	(214.6)	38.1	(310.4)	6.9	(56.1)	100.0	(814.6)
Hungary	26.9	(374.4)	45.7	(635.2)	8.8	(123.0)	100.0	(1391.5)
Czech Republic	27.6	(315.9)	49.6	(567.6)	7.9	(90.4)	100.0	(1143.6)
United Kingdom	28.0	(233.2)	39.1	(325.8)	4.8	(40.1)	100.0	(834.0)

Table 1.1. Selected and all causes of death, age-standardised death rates (SDR) per 100 000, and row percentages for males in different countries in the European region in 2001.
Source: WHO Health for All Database (2005)

Country	Cancer (C00-C97)		Circulatory diseases (I00-I99)		External causes of death (V00-Y99)		All causes	
	%	SDR	%	SDR	%	SDR	%	SDR
Kyrgyzstan	9.6	(91.0)	58.9	(560.6)	3.9	(36.7)	100.0	(952.4)
Azerbaijan	10.3	(85.7)	63.7	(529.3)	1.6	(13.5)	100.0	(831.1)
CIS average	12.2	(121.2)	62.8	(624.7)	6.7	(66.9)	100.0	(994.2)
Kazakhstan	12.6	(121.1)	66.3	(639.2)	5.8	(55.6)	100.0	(964.1)
Russian Federation	12.7	(118.3)	57.3	(532.6)	6.6	(61.6)	100.0	(928.9)
Ukraine	12.9	(139.9)	60.8	(659.1)	6.3	(68.4)	100.0	(1083.7)
Belarus	13.3	(137.3)	61.5	(632.8)	8.6	(88.8)	100.0	(1029.5)
ESTONIA	**17.2**	**(141.1)**	**58.0**	**(475.0)**	**7.7**	**(62.9)**	100.0	**(818.4)**
Latvia	18.5	(143.5)	55.6	(431.9)	8.3	(64.6)	100.0	(776.5)
EUROPE	18.8	(133.2)	53.4	(378.7)	5.5	(39.0)	100.0	(709.5)
Lithuania	19.9	(140.6)	59.2	(417.3)	8.3	(58.5)	100.0	(705.1)
Finland	23.2	(158.0)	50.9	(346.0)	4.2	(28.2)	100.0	(680.0)
Poland	23.7	(121.3)	40.6	(207.3)	6.8	(34.9)	100.0	(510.8)
Sweden	24.7	(191.7)	52.8	(409.3)	5.7	(44.3)	100.0	(775.4)
Norway	25.8	(178.3)	55.1	(381.7)	4.9	(33.8)	100.0	(692.2)
Hungary	28.6	(140.5)	39.5	(193.9)	4.8	(23.7)	100.0	(490.6)
Czech Republic	28.9	(162.9)	35.8	(201.7)	2.9	(16.3)	100.0	(563.1)
United Kingdom	29.0	(148.5)	35.5	(181.6)	5.0	(25.4)	100.0	(511.6)

Table 1.2. Selected and all causes of death, age-standardised death rates (SDR) per 100 000, and row percentages for females in different countries in the European region in 2001.
Source: WHO Health for All Database (2005)

The proportion of the all cause age-standardised death rate accounted for by cancer in Estonia is unremarkable in a European context, comprising almost 20% for men and women. For all countries shown, including Estonia, the largest simple contributor is circulatory disease. As shown, however, there is very substantial variation across countries in the relative importance of external causes of death.

1.1.4 Economy and human development

The Estonian economy, though small by global standards, is organised on free market principles. The currency is the Estonian kroon (EEK: 1 kroon=100 cents). The Estonian *kroon* is bound to the German mark: 8 EEK= 1 DEM.
The gross domestic product (GDP) for 2001 was 5 524 (USD billions) (World Health Organisation Health for All Database 2003).

Comparison of GDP for Estonia, some neighbouring countries, and regional averages is presented in Figure 1.4.

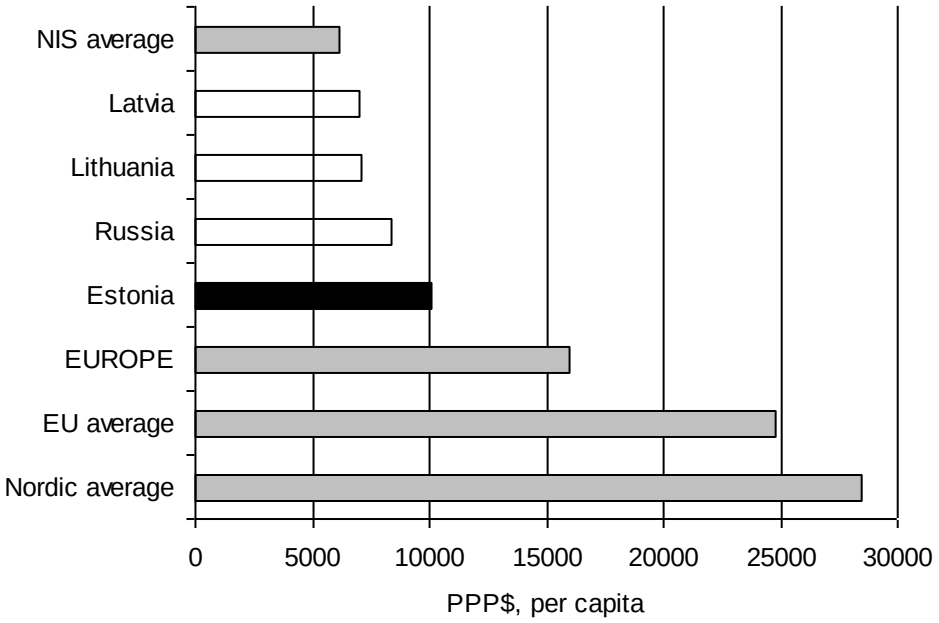

Figure 1.4. Comparison of real gross domestic product (GDP) in 2000, PPP$ per capita*.
Source: WHO Health for All Database (2003a)
*GDP expressed in purchasing power parity (PPP) is adjusted to the relative domestic purchasing power of the national currency as compared to the US dollar, rather than using the official exchange rate.

It can be seen from Figure 1.4 that the GDP for per capita Estonia is somewhat higher than the average for the CIS countries. It is much smaller than that of the European average and lags far behind the European Union (EU) and the Nordic average.

The main areas of production include producing foodstuffs and textiles, but also fuel, machinery and timber industry. Overall 25% of employed persons work in

manufacturing, while 7% are involved working in agriculture, hunting, forestry and fishing.

Estonia's main trading partners are Finland, Sweden, and the Russian Federation. The main export items are machinery and equipment, textiles, timber, mineral products, chemical products, foodstuffs, electric power (to Russia and Latvia). A growing export industry is electronics. Major import items are machinery and equipment, fuel (oil, petrol, gas, coal), automobiles, chemicals, and foodstuffs. In 2002 the unemployment rate was 10.3% (*Statistical yearbook of Estonia 2003*).

The human development index (HDI) has been compiled by the United Nations Development Programme since 1990. Its components are the following: per capita GDP calculated according to purchasing power parity, life expectancy at birth and adult literacy, and the enrolment ratio data of those in society receiving education. The human development ranking for Estonia in 1999 was 54, while in 2001 it had risen ten ranks up to 44 (Estonian Human Development Report 2001). This rise in the ranking meant that Estonia transferred from countries with average human development to countries with high human development. The HDI estimates in the Baltic and Nordic countries for 2001 are presented in Table 1.3.

Table 1.3. Human Development Index estimates in the Baltic and Nordic countries for 2001. Source: Estonian Human Development Report (2001).

Country	**HDI**	**World ranking**
Norway	0.939	1
Sweden	0.936	4
Iceland	0.932	7
Finland	0.925	10
Denmark	0.921	15
Estonia	**0.812**	**44**
Lithuania	0.803	47
Latvia	0.791	50

In this Baltic-Nordic comparison it can be seen that Estonia ranks first among the Baltic countries, but if compared with the other Nordic countries, it does considerably less well.

The European Commission's *Avis* (formal declaration) on candidate countries was released on July 16, 1997, and it was recommended by the Commission that six candidate countries to European Union, including Estonia (the others being Cyprus, the Czech Republic, Hungary, Poland and Slovenia) be included in the first wave of

European Union (EU) enlargement. Since then, Estonia has been participating in the accession process: screening of the *acquis* (accession agreement), presenting its negotiating positions to the EU Member States and conducting essential negotiations. On September the 14th, 2003, Estonian citizens participated in a referendum joining the EU, and 66.8% of voters voted in favour of joining the EU. Estonia became a member of the EU 1st of May, 2004.

1.2 History

1.2.1 From antiquity to 1940

The name *Eesti* is apparently derived from the word *Aisti*, the name given by the ancient Germans to the peoples living northeast of Vistula (Arjakas *et al.* 1998). The first to mention Aisti was Tacitus, the Roman historian of the 1st century (*Aestii*). The earliest signs of habitation date back to the 8th millennium BC. Estonians, who belong to the Balto-Finnic group of the Finno-Ugric nations, settled Estonia as aborigines possibly having arrived there as far back as the 3rd millennium BC.

Early independence. In the nineteenth century Estonia was a part of Imperial Russia and had been one of its most developed regions. Lying on the connecting route between Russia and Europe, modern technologies, equipment, as well as specialists had arrived there (Laur 1995). Because of the existence of the vast Russian market, a broad production in industry and agriculture could be developed.

For the first time during the more than 5 000-year-long history of Estonians, the independence of Estonia was declared on 24th of February 1918 (Arjakas *et al.* 1998). After Estonia gained independence, its role as a mediator in the relations between Russia and Europe decreased, and the Russian market and sources of raw material also diminished.

The ethnic composition of Estonia's population prior to World War II was relatively homogenous (Arjakas *et al.* 1998). According to the 1934 census, Estonians constituted 88.2 per cent of the total population. The average life expectancy in 1922 was 51 years, and in 1932–34 it was 53.1 years for men and 59.6 years for women (Noor 1993).

Economy. The economic indicators that were considered good in terms of the Russian Empire, were modest by European standards, and the goods produced in Estonia could not easily compete with the goods produced in Europe. In addition, the

economy in Estonia had been affected by wars and revolutions. But the decline in the economy associated with the First World War and military conflict with Russia (1918–20) was followed by an extensive economic expansion in the early 1920s. The number of industrial enterprises grew considerably, from 2900 in 1920 to 3700 in 1924. It should be added, though, that the newly established enterprises were smaller than the previous ones. The most important branches of industry were the homemade fuel industry (based on oil-shale and peat), the timber industry, and the construction of machinery and engines.

Agriculture became the most important branch of economy in 1924, when a large-scale restructuring of this sector took place. From the mid-1920s, Estonian agricultural products such as butter and bacon were exported to Germany and England.

In the 1920s, Estonia was able to create an independent economic structure and began its integration into the European economic space. Like many countries, Estonia was affected by the 1929 world economic crisis, as it could no longer sell its foodstuffs and agricultural products to Europe. In 1934, the development of Estonian economy resumed. Industry developed most remarkably and by 1938, for the first time industrial production in total was greater than agricultural production. Estonia was changing from an agricultural to an industrialised country. In the 1930s the main foreign trade partners for Estonia were Germany and England, with lesser partners including Finland, Sweden, and Latvia (Noor 1993).

Education. Compulsory 4–year basic education was introduced in 1920 and 6–year education in 1930. The first university to teach in Estonian was the University of Tartu (established in 1632) that was reopened in 1919, even before the end of the War of Liberation (1918–1920). This university quickly established itself as a national higher educational institution, where national sciences were given high priority. It became a national centre of scientific importance.

1.2.2 Soviet occupation and annexation

On June 17, 1940, the Soviet Union occupied the Republic of Estonia. The Soviet annexation of the country and World War II had a significant impact on the size of population: deportations (1940–41), war casualties, and mass emigration by refugees, reduced the Estonian population by 25%. Further mass deportations followed, but the severest impact on the population structure was caused by Moscow's empire-building

policy of forced assimilation. The net immigration from Russia, Ukraine, and Belorussia totalled 240 000 in 1945–50. This policy was continued throughout almost all of the Soviet period. As a consequence, the proportion of Estonians in the population dropped to 61.6 per cent at the 1989 census.

As a part of the Soviet Union, Estonia was forced to carry out further industrialisation. The main branches of industry that were developed, were oil shale industry, machine industry, and light industry (Laur 1995). In fact the Estonian Soviet Socialist Republic was turned into an economic support for Leningrad (St. Petersburg): the oil-shale industry had to produce gas for Leningrad and fuel for the Baltic navy. The modest pre-war oil-shale exploitation at Kohtla-Järve (north-east of Estonia) was rapidly expanded so that by 1948 the gas production from it was able to meet all the needs of Leningrad. Phosphate and uranium mines, chemical plants, and paper mills were also developed and expanded in this area.

Secret armament and military equipment factories were established in several cities of Estonia, where the workers were brought from other parts of the Soviet Union. These areas and military bases were closed to local citizens.

The first large-scale restructuring carried out in agriculture during the Soviet period was the nationalisation of land. Two thirds of this land was given to people who did not have any land before. However, the newly established farms were not economically viable and in 1948 the forced creation of collective farms (kolkhozes) started.

Estonia was set as an example republic among the Soviet Republics. In the1960s agricultural production became specialized so that one farm would be devoted to growing crops, while another would specialize in dairy farming, and in 1970s all small and average kolkhozes were united to form big collective farms.

The expansion of the economy and the wasteful use of natural resources during the Soviet period caused marked deterioration of the ecological situation. Moreover, the Soviet Army and its military bases caused considerable pollution of the environment.

Behind the iron curtain. Being separated from the rest of the world by the ‘iron curtain’, it was very difficult to obtain information about the West in Soviet Estonia. The main source of information was western radio-broadcasts. The most well known of these was the Voice of America, which was an official source of information in the United States and where not more than 15% of the broadcasting time could be allocated to news related to Estonia.

An important ‘window’ to the West for Estonians was the neighbouring country Finland. Its TV broadcasts could be watched in northern Estonia and a ferry connection opened in 1965 which brought a large number of tourists for the time to Soviet Estonia. Thus Estonia became a western oasis, the so-called Soviet-West.

Russification. In the 1970s the main idea of the Soviet national politics was that of all nations living in the Soviet Union melting in one ‘Soviet nation’ – *homo sovieticus* – which in fact meant another wave of russification. Most migrants to Estonia had no earlier contacts with Estonia, and the lifestyle often seemed strange and hostile to them (Katus 1990). The migrant population made for a very heterogeneous society with great internal differences which complicated social development. Also, the migration incentive policy was based upon people's aspiration for material wealth (Katus 1990), and was responded to primarily by people who lived in less developed parts of the Soviet Union. Compared to most parts of the Soviet Union, Estonia was a particularly attractive place to move to, with greater availability of consumer items.

The migrants were mainly concentrated in cities and also in military bases. As a result of this enourmous in-migration, the demographic behaviour in the population was very different. In fact two behavior types were established: one typical of Estonians and the other of non-Estonians. As Katus (1990) states, this differentiation was mostly caused by the time differences in proceeding through the demographic transition and the corresponding general cultural background. The second generation of the migrants managed to preserve the behavioural model typical of their home region.

The migrants did not assimilate well into the society. One reason for this was the ‘two track’ schooling system in which pre-school to university teaching was carried out in two languages.

Active propaganda was initiated in the late 1970s regarding the usefulness of the Russian language. The usefulness of knowing two languages was stressed: ‘knowing two languages makes double the person’. This policy worked in one direction only. Namely, the Estonians were forced to learn Russian (starting from pre-school day-care centres), but the Russians did not have any obligations to learn Estonian.

Cultural life. The cultural life in Soviet Estonia also showed signs of the governing regime. The main aim of the policy was to promote culture that was ‘socialist by nature and national by expression’. A great number of the intelligentia who were afraid of the Soviet regime had fled to the west during the last years of the Second World War.

Destruction of the cultural heritage of the 'bourgeois society' was a part of the Soviet cultural policy. A considerable number of the periodicals and fiction books from the independence period were destroyed in the libraries. The copies that were preserved were kept in special facilities where access could only be obtained with the permission of the authorities.

In the second half of 1950s, a partial self re-establishment of the national culture began, where the new generation of educated people started to play an increasing role. The tradition of Song Festivals, originally dating back to 1869, was restarted in 1947. Despite the red flags and slogans that were hanging on the festival grounds, this brought together large crowds of people from all over the country, many of whom came in order to express their Estonian national identity.

Data form 1959 and 1989 censuses point to a marked increase in the educational level of Estonian people (Heinlo 1998). In this period, the proportion of people having higher, vocational, or secondary education grew considerably. In the 25–34 year age group, the proportion of persons with higher or vocational education tripled over the period of 30 years, and the share of persons with secondary education quadrupled.

In 1979 a letter was composed by fighters for freedom from Estonia, Latvia and Lithuania, and sent to the governments of the Soviet Union, German Democratic Republic, and other countries, and to the Secretary General of United Nations. It was called the Baltic Appeal and it requested independence for the three Baltic Republics. As a result, a resolution was passed by the European Parliament where it requested that independence should be regained in the Baltic Republics.

Religion. The main religion is Lutheran. Whilst confession of faith was free in principle, in everyday life churches and religious people faced many difficulties during the Soviet period. The churches were nationalised and the congregations had to pay high rents. The Faculty of Theology at the University of Tartu was closed down and clergymen were educated at the Institute of Religious Science in Tallinn where their training was carried out in the form of long-distance learning. The influence of the church in the society was diminished by atheist propaganda and the establishment of worldly (lay) traditions.

Medical care. Medical care in the Soviet period was free of charge and accessible for everybody. Medical care was provided at three different levels. The outpatient care was carried out at polyclinics (outpatients' clinics), each serving a medical district of

about 1000–1500 people. Regional hospitals served as second level medical care institutions. Specialised care institutions were located in Tallinn and in Tartu, and covered a wide range of specialised departments. Some clinics were attached to the medical faculty of the University of Tartu, and some to research institutes in Tallinn. Child health care was entirely separated from adult medical care, and was also carried out at three levels.

Public health. Public health activities in Soviet period were carried out by sanitary-epidemiological stations (Saava A 2005 – personal communication). These were organised at central and regional (one station in each rayon) level. The main areas of expertise were industrial, communal and general hygiene. Most of the activities were aimed at sanitary surveillance. In addition, the sanitary-epidemiological stations were engaged with surveillance and registration of infectious diseases and provided prophylactic vaccinations for a number of infectious diseases. While the surveillance was rather efficient, the main limitation of the soviet public health system was the lack of investigation of health hazards.

Some form of health promotion was carried out through sanitary-educational departments that were located at sanitary-epidemiological stations. This included distributing health promotion leaflets and giving lectures on health related topics in schools, medical establishments and work places. During Soviet period, cancer screening was not organised.

1.2.2.1 Demographic changes

During the Soviet occupation, the demographic changes in Estonia were remarkable. In Table 1.2 population figures and percentages of urban population for selected years are presented. It is see that population growth during this period was very rapid. According to the Estonian demographer Katus (1998), during 1970–1990 the population of Estonia grew very rapidly. The cumulative growth for that period was 17% (Katus 1998) and the growth of the urban population, at a rate of 30%, was even more marked (Table 1.2). This was due to the double effect of a very large in-migration component: that is increase in population from migrants per se and increase due to the children that the migrants had in Estonia.

Table 1.4. Population size and proportion of urban population in Estonia for some selected years of Soviet occupation.
Adapted from the data of Statistical Office of Estonia.

Year	Total population	Urban population, %
1959	1 196 791	56.4
1970	1 356 079	65.0
1979	1 464 476	69.4
1989	1 565 662	71.5

Data about life expectancy for the Soviet period are rather scarce. They have been estimated for these years only, when the census took place (Katus 1998). The respective estimates are shown in Figure 1.5. It is seen that up to the 1960s there was a period of increasing life expectancy, especially for women. This was followed by a period of stagnation for women and moderate decline for men up to the end of 1970–s. A moderate increase in life expectancy, which was more pronounced in men, was seen in the 1980–s.

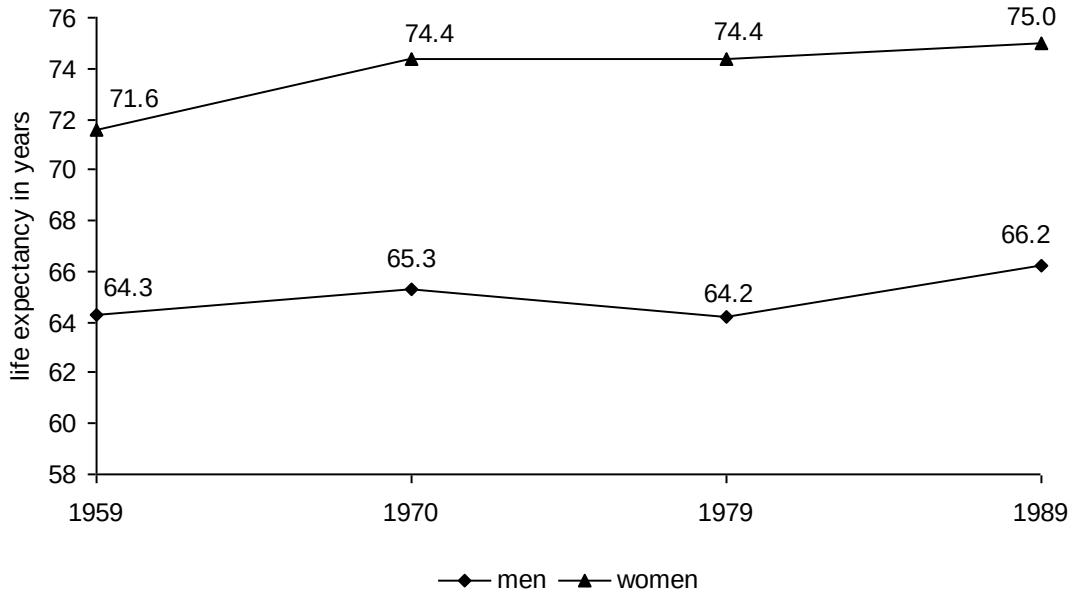

Figure 1.5. The average life expectancy for men and women in Estonia in 1959–1989.
Source: Katus 1998.

1.3 Transition and independence: the 1990s up to present time

1.3.1 Political change

The first signs of a complex social crisis in the former Soviet bloc were apparent as early as the mid 1970s as the Soviet system began to collapse under its own internal pressures (After the fall. The human impact of ten years of transition 1999). The Berlin Wall came down in 1989. Following this event major changes took place in the former Soviet bloc over the next decade. What had been eight countries all together, became 27 countries, bringing about not only huge transformation in societies and infrastructure, but also a vast human impact.

Estonia took advantage of the ongoing changes to regain its independence. In 1989, Estonian was again recognised as the official language. The illegality of the incorporation of Estonia by Soviet Union in 1940 became apparent with the publication of the full text of the Ribbentrop-Molotov Pact, in Pravda in Moscow in 1989. After this it became impossible for the Soviet government to maintain its claim that Estonia had 'voluntarily' joined the Soviet Union in 1940. The popular pressure for independence in Estonia and other Baltic countries on the 50th anniversary of the pact on August 23rd 1989 was marked by a rare and very effective symbol of Baltic cooperation: a human chain of two million people that stretched from Vilnius to Tallinn.

In reaction to the pressure for independence, in 1991 Moscow increased its military activity in the Baltics. Thirteen civilians were killed in Vilnius defending the television tower and four in Riga defending the radio station. Similar violence did not occur in Estonia, partly because of a smoother relationship between the Estonian government and the local Soviet commanders. A referendum held in Estonia on March 3rd 1991 gave substantial support for the independence movement, with 64% voting in favour and 17% voting against.

On August 20, 1991, the second day of the coup in Moscow, the parliament of Estonia declared the independent Republic of Estonia to be restored (*restitutio in integrum*). On August 24, the Russian government under Boris Yeltsin made clear its support for the new Estonian government, and within days diplomatic recognition was granted by over 40 countries.

1.3.2 Economic change

Large-scale economic reforms took place after Estonia regained its independence in 1991. Prices controls were abolished and state subsidies for non-profitable enterprises were ended, privatisation continued and the abolition of state monopolies began. On June 20th, 1992, the Estonian currency reform went into effect as part of the economic stabilisation programme. The Estonian currency was pegged to the German mark and the currency board system was put into practice in Estonia. Shortly after regaining independence there was a short period of massive price inflation of over 100%. Subsequently this declined substantially. The role of foreign and also domestic private capital increased, and banking, the service sector and tourism developed rapidly.

During the first years of independence economic production declined, mostly because the raw materials from Russia were cut off. However, the total industrial production in 1995 exceeded the level of the previous year by 2%, in 1996 by 3% and in 1997 by 15%. Production increased first of all due to the growth in manufacturing. The main factor enhancing this development was the growth in the external demand as a result of which enterprises increased their production and labour capacity. Compared to the beginning of the 1990s, in 1997 a considerable increase occurred in the production of textiles, wood, rubber, plastic, building materials, metal products and furniture. Small and large private companies were established, some were 100% Estonian and others were joint ventures. The proportion of persons of working age employed in manufacturing fell from 28% in 1989 to 23% in 1998. Agricultural production declined substantially at the beginning of the 1990s, briefly stabilised in 1994–1996, and has continued to decline to date. The proportion of persons employed in agriculture fell from 21% in 1989 to 13% in 1998.

Currently the economy in Estonia is doing rather well. Estimated economic growth between 2003 and 2002 was 4.3%. Change of GDP at 2000 constant prices was 4.6 between 2003 and 2002 (Statistical Office of Estonia database 2004), and the change of consumer price index was 1.3 for the same period.

1.3.3 Demographic change

The profound political, economic, and social changes brought about by Estonia's return to independence have greatly affected demographic developments (Arjakas *et al.* 1998).

The following is a brief overview of demographic changes. Since 1989, the Estonian population has decreased considerably, mostly because of migration of Russians to Russia and negative natural increase. Figure 1.6 shows the numbers of persons who left Estonia in 1989–98.

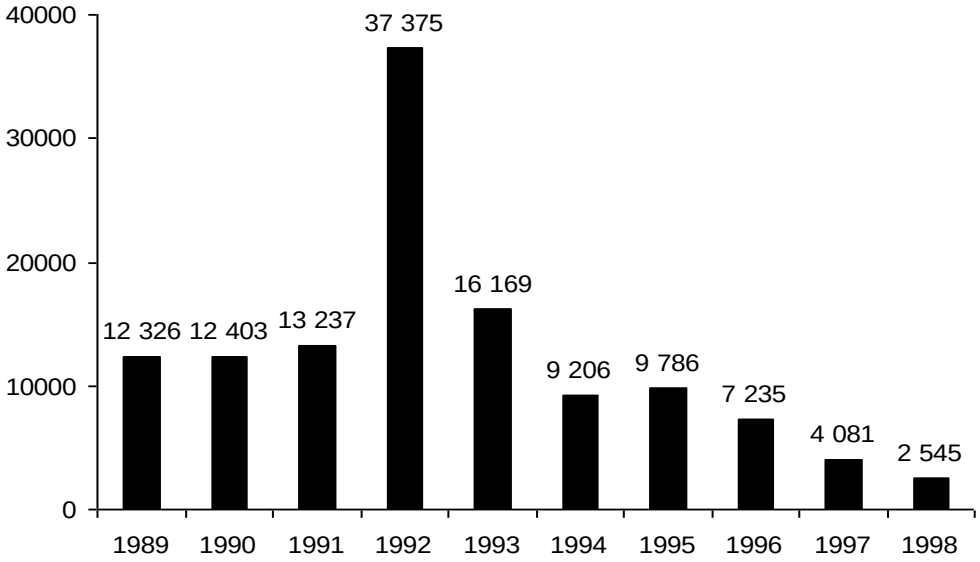

Figure 1.6. Numbers of persons who left Estonia in 1989–1998.
Source: *Statistical Yearbook of Estonia* (1999)

As can be seen from this figure, some 12–13 thousand people left Estonia each year in 1989–1991, and the biggest number of persons (37 375) left Estonia in 1992. Most of the people who left the country at that time were members of the Soviet military and their families. After 1992 this figure started to decrease, and only about 2.5 thousand people left Estonia in 1998. Still, the results of the 2000 Population and Housing Census (Statistical Office of Estonia 2004) showed that the quality of the migration data is low, and should therefore be interpreted with caution. Over the more recent years, the numbers of persons leaving Estonia have not been published.

Table 1.5 shows ethnic composition of the population in 1989 and 1994–2000 per 100 000 inhabitants. It can be see that the ethnic composition has changed only a little, with the proportion of Estonians increasing from 61.5 to 67.9% and the proportion of Russians decreasing from 30.3 to 25.6 of the total Estonian population. As the population censuses only took place in 1989 and 2000, the population figures for 1994–99 are the estimates.

Table 1.5. Ethnic composition of the population in 1989, and 1994–2000, per 10 000 inhabitants. Source: *Statistical yearbook of Estonia* (1999) and *Statistical yearbook of Estonia* (2003)

Nationality	**Year**							
	1989*	**1994**	**1995**	**1996**	**1997**	**1998**	**1999**	**2000***
Estonians	**6 153**	**6 386**	**6 422**	**6 459**	**6 498**	**6 511**	**6 520**	**6 790**
Russians	3 033	2 897	2 872	2 848	2 822	2 814	2 809	2 563
Ukrainians	308	269	265	261	255	254	254	212
Belorussians	177	157	155	153	150	148	148	126
Finns	106	100	97	94	93	92	90	86
Jews	29	20	19	18	17	17	16	16
Tatars	26	24	23	23	23	22	22	19
Germans	22	12	12	10	9	9	9	14
Latvians	20	19	19	19	19	19	18	17
Poles	19	17	17	17	16	16	16	16
Lithuanians	16	16	16	15	15	15	15	15
other	90	83	83	83	82	83	83	69
unknown	–	–	–	–	–	–	–	58

* 1989 and 2000 census data, 1994–1999 data are estimated

Figure 1.7 shows recent changes in birth and death rates. There was a considerable decrease in birth rate in the 1990s. It almost halved between 1989 and 1994. Compared to such big changes, the following decrease in 1995–98 was very small, and some very slight increase can be seen over the most recent years. Looking at the death rate, we can see that it increased quite considerably from 1989 to 1994. Over the recent years the death rate has stagnated at about 13.5–14 deaths per 1000 persons.

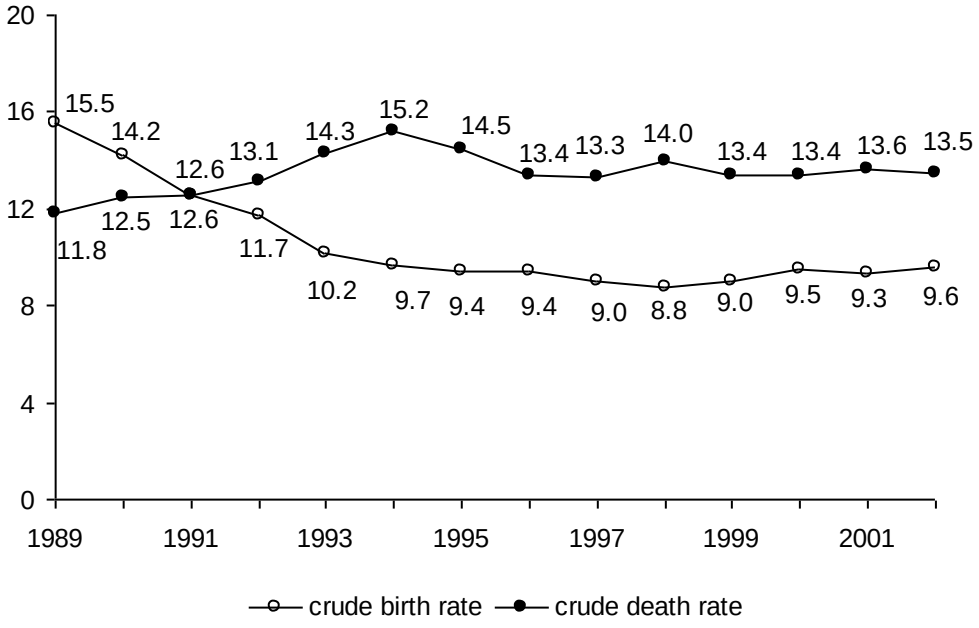

Figure 1.7. Crude birth and death rate per 1000 persons in Estonia 1989–2002.
Source: (Statistical Office of Estonia 2004)

Life expectancy at birth for males and females in Estonia in 1989–2001 is shown in Figure 1.8.

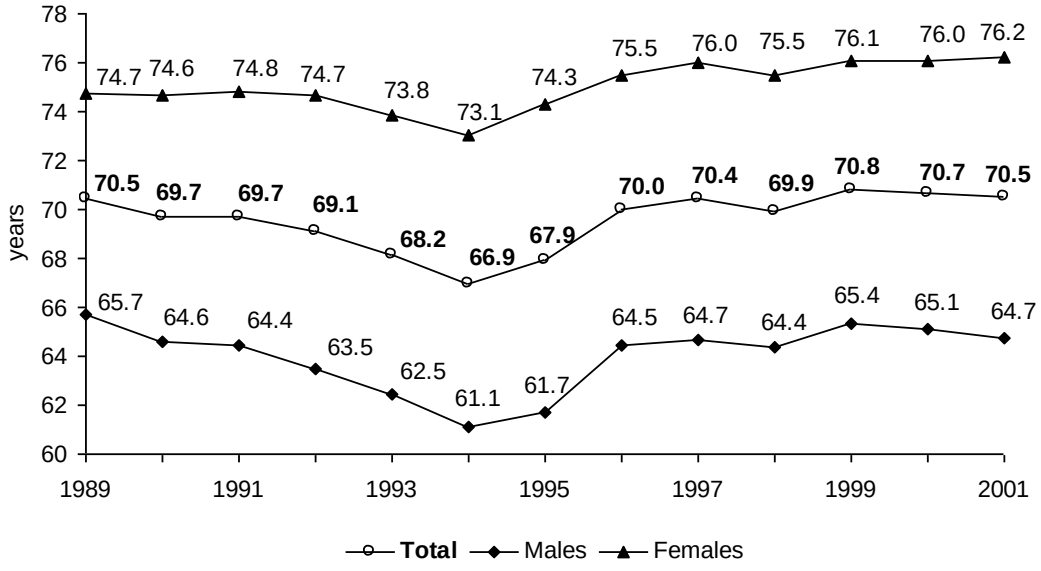

Figure 1.8. Life expectancy at birth for men and women, and total in Estonia 1989–2001.
Source: *Statistical yearbook of Estonia* (2003)

For men, life expectancy declined from 1989, reaching its lowest value in 1994, but has subsequently increased. For women, the decline in life expectancy can be seen since 1992 only, and also reaching the lowest value in 1994, and starting to increase after that. Since about 1997, the average life expectancy rates have been rather stable, with a slight increase which is more marked in women.

Infant mortality rates for boys and girls over the recent years are presented in Figure 1.9. As can be seen from Figure 1.9, infant mortality increased transiently around the time of the collapse of the Soviet Union. However, the increase in 1992 is in part an artefact due to adoption of the standard World Health Organisation (WHO) definition of live birth. Since 1992 all infants with extremely low birth weight (500-999g) who die within the first week of birth are considered as live-borns. Such cases accounted for around 12% of all infant deaths in 1992-1996 (*Population. General Demographical Data 1998*). Since 1995 it started to decrease, with the difference between 1995 and 1996 being considerably large. It should be noticed that because of the small numbers of absolute figures, some of the variation in rates may be due to random fluctuation.

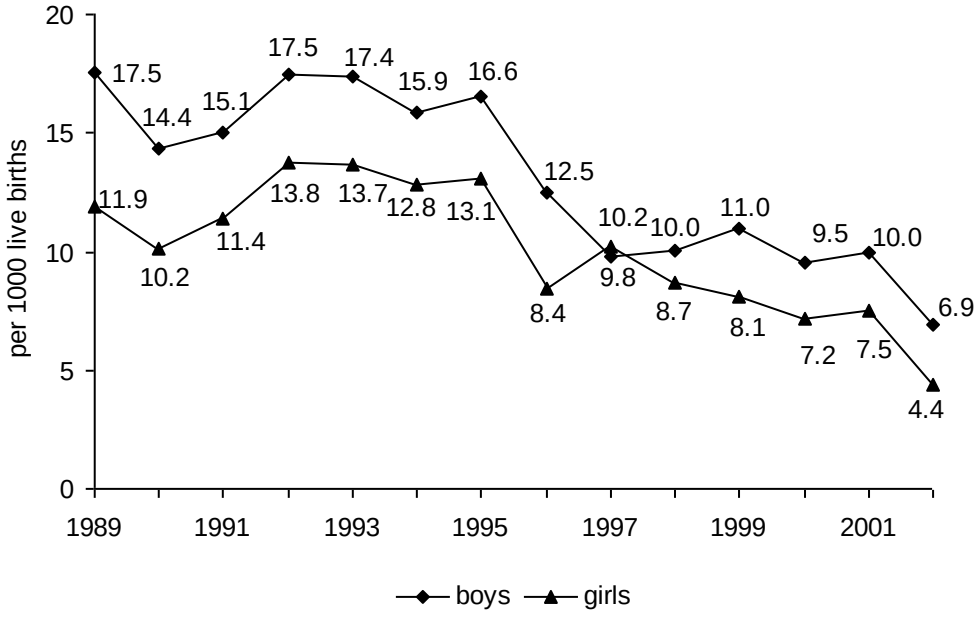

Figure 1.9. Infant mortality for boys and girls in Estonia in 1989–2002.
Source: Statistical Office of Estonia database (Statistical Office of Estonia 2004).

The number of marriages contracted in Estonia continued decreasing in the nineties. While the crude marriage rate per 1000 persons was 8.1 in 1989, the corresponding number for 2001 was only 3.4 (Statistical Office of Estonia 2004).

1.4 Summary

The transition period that Estonia entered in early 1990s, brought about not only huge transformation in the society, but also a vast human impact. As was seen from the data presented in this section, this was reflected in the changes of main demographic indicators: the decrease of the birth rate, increase in the mortality rate, and consequently the decrease of life expectancy.

This vast human impact could have also had some negative influence on cancer incidence and especially mortality rates in Estonia and should be considered when interpreting the respective rates in Chapters 5 and 8. Latvia and Lithuania, which are the other two Baltic countries, underwent similar changes in the society after breaking up from the former Soviet Union. This should be accounted for when interpreting cancer incidence and mortality rates for the Baltic countries in Chapter 6.

Objectives of PhD

To describe and evaluate the process of cancer registration in Estonia and to use the registry data to assess incidence and mortality trends in Estonia, cancer incidence between Estonian and Russian ethnicities in Estonia, and incidence and mortality rates in Estonia in comparison with neighbouring countries.

The specific aims are to:

- Provide an authoritative overview of the history, development and uses of cancer registration in Estonia up to the present;

- Systematically assess for the first time the validity and quality of data collected by the Estonian Cancer Registry today;

- Suggest ways in which the quality and relevance of the data collected by the Estonian Cancer Registry may be improved;

- Assess the burden of cancer mortality and incidence in Estonia over time, and in comparison with other countries;

- Assess the ethnic differences of cancer incidence between Estonian and Russian ethnicities in Estonia

Chapter 2. Cancer registration

In this chapter an overview of cancer registration in Estonia is presented. It covers the early days of cancer registration, as well as establishing of the Estonian Cancer Registry, its historic development and current status. A summary of the uses of the ECR data is also provided.

2.1 Uses of cancer registry data

Cancer registration is an essential element of any cancer control strategy (Parkin *et al.* 1985, Brewster 1995) as it helps to quantify the cancer burden in a society. A cancer registry can be defined as an organisation for the collection, storage, analysis and interpretation of data on persons with cancer (Parkin *et al.* 1985). However, only when use is made of the collected cancer data, is the collection of information justified.

The main objective of a cancer registry is to collect and classify information on all cancer cases in order to produce statistics on the occurrence of cancer in a defined population and thus provide a framework for assessing and controlling the impact of cancer on the community (Jensen *et al.* 1991). The minimum objective is to estimate incidence rates in the population at risk (Parkin *et al.* 1994a). Information on cancer incidence trends over time and in different age groups forms the scientific basis for the planning and organisation of cancer prevention, diagnosis and treatment in the community (Hakulinen *et al.* 1986). It is thus very important to collect data over a long period of time, as data become useful for more and more purposes as they accumulate over time.

Analyses of cancer incidence (and mortality) trends over time may give rise to hypotheses concerning the etiology of cancer. These indicators are also useful for testing hypotheses raised in clinical and experimental oncology. Some population-based registries also collect information on mortality of registered cases, and are thus able to calculate survival and to estimate prevalence.

Cancer registry information and cancer statistics can be used in a multitude of areas. The emphasis of how to use its data differs from registry to registry according to interests of the cancer registry workers, and researchers, as well as local circumstances. Uses range from the core function of estimating incidence rates to using cancer registry data in epidemiologic research, health-care planning, and studies of treatment efficacy. These areas of use benefit both the individual and the society.

2.2 Cancer registration in the Soviet Union and the New Independent States

The structure of cancer registration in Estonia was influenced by the Soviet tradition. It is therefore important to start by reviewing this tradition.

In 1932, compulsory registration of all new cancers was introduced in the Ukraine (Napalkov *et al.* 1983). Special forms for reporting tumour patients were introduced in four Soviet cities with oncological institutes in 1946. In 1951 all cities in the Soviet Union began using a special reporting form. In 1953, compulsory cancer registration was extended to the whole of the Soviet Union. According to Rahu (1992), death certificates and autopsy reports as information sources were included as from 1961 onwards.

Although some descriptive data about cancer occurrence in the Soviet Union were available at international level, virtually no information existed concerning the process of cancer registration. During the Soviet era the access to and use of cancer incidence statistics was severely restricted and controlled in the Soviet Republics (Rahu 1992). Cancer incidence data or studies based on it could not be published or otherwise disseminated. This is one of the main reasons that data about cancer in the Soviet Union was so limited. Descriptive epidemiological data about cancer incidence in the Soviet Union has been published as a supplement to *Cancer Incidence in Five Continents vol. III* (Napalkov *et al.* 1983) for the years 1969–1971.

A recent study by Winkelmann (1998) sheds some light on the quality and completeness of cancer incidence statistics from the New Independent States (NIS), and the registration practices these registries have used in the past. In 1995, she conducted a survey of cancer registration practices in Belarus, the Russian Federation and Ukraine. It is notable, however, that Winkelmann explicitly excluded consideration of the

Estonian Cancer Registry, as her view was that it was completely atypical of the cancer registration systems in the Soviet Union and the NIS.

Based on her study, Winkelmann concluded that the design and functioning of the cancer surveillance system was the same throughout the Soviet Union.

Furthermore, seven years after the dissolution of the Soviet Union, the organisation of cancer registration principles remained almost the same in the NIS states that she studied. Therefore, what she found out about the principles of cancer registration in the New Independent States, can be seen as simply a continuation of the cancer registration system in the Soviet Union. However, as discussed in the next section, Estonia, although having some of the Soviet features, diverged from this uniform approach quite early on, and today is very different.

The rationale for cancer registration in the NIS, as it was in the Soviet Union, is health care planning. Data from cancer registries are not very widely used for epidemiological research or for patient care. Cancer registration principles developed in the Soviet Union almost independently from the principles of cancer registration in the West (Winkelmann 1998).

As described by Winkelman (1998), “in all NIS a nation-wide network of regional population-based cancer registries forms the basis for cancer registration. Cancer registration in these countries is part of a specialised cancer care infrastructure, where regional oncological dispensaries are responsible for diagnosis, treatment and registration of all newly diagnosed cancer cases occurring in the resident population. Cancer cases are also notified from regional cancer registries to the district oncologist for registration in the district cancer registry and follow-up of the patient at his/her place of residence. The completeness of the regional cancer registries is systematically monitored by two complementary processes: verification of all cancer deaths in the region, followed by trace-back wherever necessary, and regular mutual comparisons of the district cancer registry data with the data of the regional cancer registry.“

In the Soviet Union, information about cancer patients was kept in the form of manual follow-up cards and only a very limited amount of computerisation of data was carried out. During the Soviet period the official cancer reports were intended to describe the "cancer control" situation of the previous calendar year and were completed about 6 weeks after the end of the year (Rahu 1992). These reports were very limited and mainly consisted of cancer incidence data in a tabulated form. These yearly reports were final and no amendments were made to the annual incidence statistics, and thus

did not truly reflect the numbers of new cases of cancer in each calendar period. In the registries surveyed by Winkelmann (Belarus, the Russian Federation and Ukraine), for example, because of the peculiarities of the reporting system, cancer cases diagnosed before December of the previous year, and registered after January of the subsequent year are not included in any annual statistical report on cancer incidence.

The specific features of Soviet cancer registries have been summarised in an article by Rahu (1992). According to him, first, for decades, cancer registration in the Soviet Union was carried out without learning form the experience of other countries and international institutions. Secondly, little interest was taken in the data quality and possibilities of using by data collectors and administrators. Thirdly, the managers of medical care got gradually used to limited information on cancer. The inadequacies of the official cancer registration system led some epidemiologists to create their own independent databases, in order to try and establish an adequate and internationally comparable basis for measuring cancer incidence.

Throughout most of the Soviet period, cancer surveillance in Estonia was largely based on Soviet principles. But unlike most of the other NIS, it has now established the principles of cancer registration quite similar to those used in the Western countries. The following is an overview of the historic development and current procedure of cancer registration in Estonia, which as it will become apparent are very different to those in most other NIS.

2.3 Cancer registration in Estonia

2.3.1 Development of the Estonian Cancer Registry

In this section the history of cancer registration in Estonia is described. Key stages in this process are summarised in Figure 2.2. The history has previously never been fully recorded and in order to do this, I undertook a systematic survey as described below.

2.3.1.1 Survey methodology

I visited the Estonian Cancer Registry (ECR) and made contact through its director to see all the four currently employed staff members, and one previously employed staff member. The staff members were then interviewed regarding the history of cancer

registration and setting up cancer registry. In addition, I obtained information from Mati Rahu, who has been working closely with the cancer registry since the late 1960s and whose input to the development of cancer registration system in Estonia is very valuable. He currently acts as a scientific adviser for the ECR. On the basis of this information I wrote a draft version of the history of the registry, also composing a flow chart with the most important dates of the history of the registry. These materials were then shown to the staff and systematically discussed with them. In the light of this feedback amendments were then made. The history of cancer registration, constructed using this approach, is presented in the following sections.

2.3.1.2 Setting up the cancer registry in Estonia

As previously discussed in Section 2.2, notification of cancer was compulsory in the former Soviet Union from 1953 (Napalkov *et al.* 1983). From the very beginning, cancer registration covered all the population of Estonia, as all medical institutions diagnosing cancer were requested to complete notifications for all new cancer cases. Such institutions included all general hospitals and outpatient's clinics, as well as specialised oncology hospitals (oncological dispensaries).

A translated facsimile of the very first type of cancer notification form as used in Estonia is presented in Figure 2.1. This was used from the early 1950s. At that time, notification of cancer was not seen as a discrete entity. It is striking that cancer notification was part of general disease notifications, mostly used to report on infectious diseases, including sexually transmitted and certain skin diseases, but also psychiatric disorders. These notifications were sent to sanitary and epidemiological stations, which provided environmental sanitation as well as epidemiological control of communicable diseases. Thus cancer notification was handled through a system which had mainly been established for dealing with communicable diseases, and people handling cancer notifications were not specialists in this field. The use of this general system was stopped at the end of 1977. In 1978 special forms by which only cancer was notified were introduced and a separate and specialised system for collation of cancer notifications was established as described below.

Recto

Ministry of Health of the USSR

Medical Documentation Form
No. 281

Approved Ministry of Health USSR 16.07.1954

Name of the institution

**NOTIFICATION OF A PATIENT WITH
FIRST TIME DURING LIFE DIAGNOSED WITH
active tuberculosis, sexually transmitted disease, skin mycoses,
trachoma, cancer or other malignant neoplasm, psychiatric disorder**

1. Surname, name, patronymic _____
2. Sex ____ 3. Age _____ 4. Date of first visit to a doctor _____
5. Address of the patient: town/village _____ rayon _____
   street _____ house no _____ apt. no _____
6. Residence: urban/rural (record which one) _____
7. Diagnosis*) _____
8. Diagnostic confirmation by laboratory tests, X-ray, biopsy, endoscopy, for patients with tuberculosis indicate whether they are BK+ _____

_____

Signature of the physician

Verso

***) NOTIFICATION IS COMPLETED FOR THE FOLLOWING TYPES OF DISEASE**

1. Active tuberculosis of respiratory organs (BK+/BK- indicated)
2. Tuberculosis meningitis
3. Active tuberculosis of bones and joints (localisation indicated)
4. Active tuberculosis of the skin
5. Other forms of tuberculosis
6. Syphilis I, II – primary; II– secondary; III– active
7. Congenital syphilis, presenting early, active
8. All other forms of syphilis
9. Gonorrhoea, acute and chronic
10. Skin mycosis caused by Trichophyton
11. Skin mycosis caused by Microsporum
12. Tinea

indicate localisation:
a) scalp b) nails
c) other skin

13. Trachoma, I, II, and III stage
14. Cancer
15. Sarcoma
16. Other malignant neoplasms

indicating localisation and clinical group

17. Psychiatric disorders

INSTRUCTIONS

1. Notification is completed for each patient being diagnosed with the specific disease for the first time in his/her life, regardless of whether the person lives in an urban or rural area
2. Notification is completed in any treatment or prophylactic institution, regardless of whether it is a general or specialised institution
3. Only one diagnosis should be recorded, there is no need to record two (as for example tuberculosis of the lung and tuberculosis of the joints). Only the disease that is dominating should be recorded
4. In case of two different infections occurring simultaneously, both should be recorded

Figure 2.1. Disease notification form used for cancer 1953 to 1978.

A special system for collating cancer registrations was first established in 1968. As indicated in Figure 2.2, from 1968 the notifications for cancer were sent to the Tallinn Oncological Dispensary, which served as regional care institution for cancer patients. All the notifications were entered in a registry book, organised by regions (one book for each region), and in each book the cancer patients were listed according to alphabetic order of the first letter of their surname. One book could hold information on cancer patients (name, cancer site) over several years. This book served as a quick reference, when information was required about a cancer patient in particular about whether this person had been previously registered as having cancer.

In 1968 information on all prevalent cancers was recorded on cards that were made for this purpose. These cards actually served as follow-up cards. Follow-up visits for cancer patients were anticipated to occur in first 6 months, 1 year and 3 years thereafter (Kukk L 1998 – personal communication). These developments in 1968 were rapidly followed by computerisation.

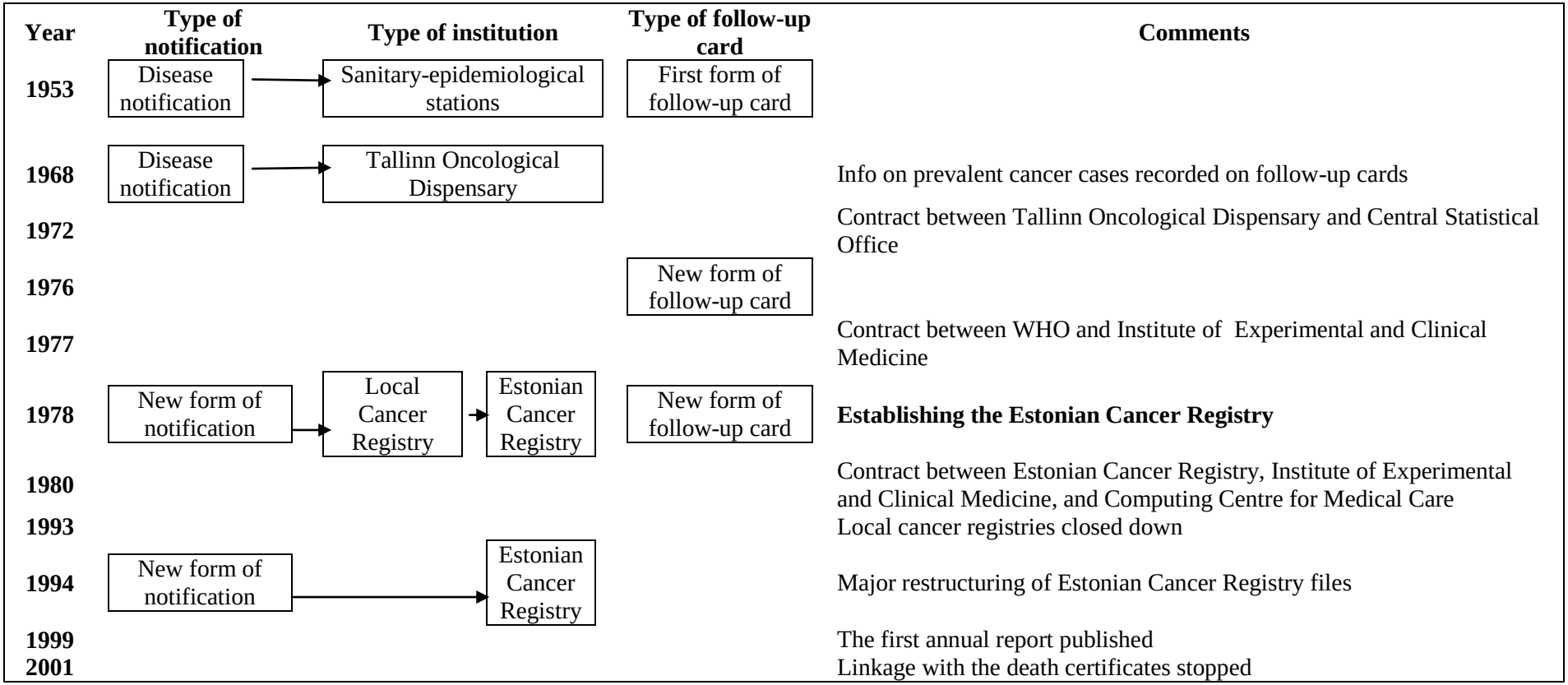

Figure 2.2. History of the cancer registration process in Estonia.

2.3.1.3 Computerisation of cancer registration in Estonia

The year 1972 deserves special mention as it was in that year that a first attempt to computerise the Estonian cancer registration system was made. This aimed at assisting preparation of annual cancer incidence reports. To serve this purpose, a contract was signed between the Tallinn Oncological Dispensary and the Estonian Central Statistical Office that the latter one would enter the cancer data on the computer and then produce the summary reports.

The process of entering data on the computer was very laborious and time-consuming and could lead to multiple errors. Namely, information from follow-up cards was transferred on the so-called intermediate cards, and after that the information was transformed to a perforated computer tape and taken to the Estonian Central Statistical Office. The big problem was that all names had to be transcribed into Cyrillic alphabet (the Estonian language uses Latin alphabet). Follow-up information regarding treatment and other details could be added, but to perform this, linkage was carried out by name (including surname, first name, and patronymic). Repeated (multiple) transcribing could produce errors and make linkage impossible. If one letter in the spelling of the name of the patient did not correspond, linkage failed. Also, once the data were entered on to the computer, only 3–4 data entry fields could be corrected for each patient. If there were more than four fields that needed correction, then all the information regarding the case had to be re-entered.

Changes that improved the process of cancer registration and decreased the number of linking errors were introduced in 1976. In that year a new form of follow-up card was worked out and introduced to allow cancer information to be entered to a paper 'teletape' straight from these cards. Nevertheless, the system was still far from efficient. The tape had to be then taken to the Radio Broadcasting Centre, which had the most advanced data processing system in the Soviet Union at the time (Rahu M 2000 – personal communication). The biggest advantage of using this more advanced system was that each character (field) could be corrected in the computer files.

In 1977 another important step was taken towards the creation of a modern cancer registry. A contract was signed between WHO and Institute of Experimental and Clinical Medicine, according to which the latter one got some extra funding in order to promote cancer registration in the Soviet Union as a pilot project. As a result of this, the

International Classification of Diseases (ICD) was for the first time used for coding of cancers, as previously only the Soviet classification was used. This contract was for approximately two years.

2.3.1.4 Establishing the Estonian Cancer Registry

In 1978 the Estonian Cancer Registry was founded. A key motivation for establishing the ECR was the fact that medical doctors and scientists wanted to get more detailed and more accurate information on cancer than what was sent to Moscow in the form of annual reports (Rahu M 2000 – personal communication).

When it was established, the ECR consisted of two subdivisions, one belonging to the Estonian Cancer Centre (previously named Tallinn Oncological Dispensary) and responsible for collecting the data, while the other – Department of Biostatistics and Epidemiology at the Institute of Experimental and Clinical Medicine – was responsible for statistical and epidemiological interpretation of the information.

The new notification form was introduced in 1978 which was designed solely for cancers. This can be regarded as a key development as this represented a definitive break from a past tradition in which cancer was notified along with other diseases (Figure 2.1). The notification form (translated into English) is presented in Figure 2.3. This notification form is much more sophisticated than the previous one with regard to personal as well as clinical information. Regarding items of personal information, the 1978 notification form collects information for a large number of variables such as place of birth, nationality, profession, numbers of births and pregnancies, duration of living in Estonia as well as living in the current area. As for clinical data, the new form enables the collection of very detailed information, including date of referral, circumstances of diagnosing, as well as in-depth information on diagnosis.

Ministry of Health of the USSR
No. U-281-6 (E)

NOTIFICATION
of a patient with first time during life diagnosed with cancer or other malignant neoplasm

_____
Name of the medical institution

The notification is forwarded to: _____

_____
Surname, name, patronymic

3. Sex: male, female 2. Date of birth _____
(year, month, day)

3. Place of birth _____
(republic, oblast, city)

4. Nationality _____ 5. Marital status

married	1	widow/er	3
not married	2	divorced	4
		not known	

6. Profession _____

7. Number of births _____ ; not known 8. Number of pregnancies _____ ; not known

9. Permanent address _____
(city, town, village)

_____
(street, house and apartment number)

10. Duration of living in the ESSR _____ ; not known
11. Duration of living in the current city, town, or village _____ ; not known
12. Circumstances of disease detection: self-referral –1; diagnosed by gynaecologist on routine check-up – 2; diagnosed on other routine check-up – 3; notified after death with being diagnosed during life – 4; after death, without autopsy – 5; after death, with autopsy – 6
13. Date of referral _____ 14. Date of diagnosis _____
15. Diagnosis _____
(clinical diagnosis, involvement of other organs, histology and behaviour)

_____
16. Stage _____ T _____ N _____ M _____ N +
M –
17. Clinical group _____
18. Diagnostic confirmation:
only clinical – 1, laboratory tests – 2, X-ray – 3, isotope method – 4, endoscopy – 5, surgery without histopath. examination – 6, specific biochemical/imm. tests – 7, cytology – 8, histopath examination of the metastasis – 9, histopath. examination of the primary – 10; _____ – 11

19. Medical institution where the patient is referred to _____
Signature of the physician who completed the notification _____
(surname) (signature)

Figure 2.3 Cancer notification form used from 1978–1993.

A new follow-up card in DIN A-4 format was also introduced in 1978. After a follow-up card was filled in for each patient, the procedure of cancer registration was still the same as before: cancer information of patients was entered to the teletape from the follow-up cards and the tape was then taken to the Radio Broadcasting Centre, where it was entered to the computer.

Also in, 1978 a new format of the registry book was introduced: a bigger one (often containing information for 2–3 rayons), but the contents were the same as before: name and localisation of cancer of patients.

When the ECR was established, there were 17 local cancer registries located within clinics and hospitals in the country, combining catchment areas for cancer patients. For the purposes of follow-up and updating information at the ECR this system, although processed manually, served its purpose quite efficiently. Namely each follow-up card, containing information about treatment, status of the patient, date and cause of death, etc., abstracted from notifications, in- and outpatient records, and death certificates, was made in duplicate, one copy being kept at a local registry and another in the ECR. Quarterly the registrars of the local cancer registries would visit the ECR to check the follow-up cards for completeness of information detail and to update them.

As the ECR is located at the Estonian Cancer Centre, where about half of the Estonian cancer patients are treated, the follow-up cards of those patients often contained more information and thus the registrars were in its turn able to update regional follow-up cards. So we can see that this procedure was beneficial in both ways, adding to the accuracy of the information the registration cards contained. At this time period, at monthly intervals all death certificates kept in the Estonian Statistical Office (now the Statistical Office for Estonia) were checked manually by an abstractor of the ECR. From each certificate where cancer was mentioned, the relevant information was rewritten onto a blank certificate form. In the ECR, the follow-up cards were updated on the basis of these copies and the lists of dead persons were typed. The lists were sent to local cancer registries to be matched against other lists, made by registries' abstractors using regional civil office documentation.

In 1980, the first computers were installed at ECR. A contract was signed between ECR, Institute of Experimental and Clinical Medicine and Computing Centre for Medical Care. According to this contract, the latter provided ECR with computers and staff to perform data entry and produce annual reports. The clerical staff of ECR could

also enter some information, mostly concerning follow-up of the patients, on those computers. However, this computerised information was still taken to the Radio Broadcasting Centre where the main database was maintained.

Some of the new principles of cancer registration that were introduced during the early years of ECR should be mentioned. The first one was that the annual reports could be produced based on one source document only, namely the follow up card. To be able to use only follow-up cards, those were also completed for cancer cases that had been registered based on the information from the death certificates. Previously only notifications existed for those cases. Before introducing these new principles, the reports were based on two separate sources: follow-up cards and notifications. Secondly, the ECR started providing local registries with annual reports. Thus the main task of local registries was notifying cancer, and they no longer had to deal with reporting annual figures. Thirdly, results of the annual reports could be updated and corrected the following year, as additional information became available.

When the ECR was established in 1978, coding was performed in ICD-8 for cancer sites. For morphology, ICD-0-1 locally was used. From 1983, both site and morphology coding of cancer cases was carried out in International Classification of Diseases for Oncology (ICD-O), first version, until 1997. From 1998, coding is performed in ICD-O-2. In 1999, in connection with compiling data for the EUROCIM 4.0 database, the coding of all cancer cases in the ECR database was converted to ICD-O-2. For the statistical reports, ICD-O-2 is converted to ICD-10, using the IARC-Check-Convert program (T.Aareleid – 2005 – personal communication).

International recognition of the standard achieved by the ECR came in 1989 when it became a member of the International Association of Cancer Registries.

From December 1991 the Department of Epidemiology and Biostatistics was no more treated as a part of the ECR.

In 1993 the regional cancer registries were closed down, mostly because of economic considerations. From then on, cancer registration forms were sent directly to the ECR. Due to this reorganisation the type of follow-up of cancer patients changed from active to passive.

In 1994, a new form of notification was introduced that is also used currently. This is presented in Figure 2.4 (translated into English). Compared to the previous notification form (Figure 2.3), it no longer has fields for some details of personal

STATE STATISTICS

NOTIFICATION TO THE CANCER REGISTRY

ID no. | 1 ☐ Male 2 ☐ Female | Medical record no.

Surname Previous surnames **First name**

Date of birth (day / month / year)

Marital status 1 ☐ Married 2 ☐ Cohabitation 3 ☐ Single 4 ☐ Divorced 5 ☐ Widowed

Ethnicity code

Place of birth code
Municipality
County
Country

Place of residence Postal code
Municipality
County code
Str. address/Village

Previously diagnosed malignancies
Sites
Name of hospital where diagnosis was made or treatment was given Dates

DIAGNOSIS (primary site, as specific as possible) code
Date of diagnosis (day / month / year)

Basis of diagnosis
1 ☐ Clinical examination
2 ☐ X-ray, ultrasound, endoscopy etc.
3 ☐ Surgery without HPE (**H**isto**P**athological **E**xamination)
4 ☐ Specific biochem./imm. test
5 ☐ Cytology or hematology
6 ☐ HPE of metastasis
7 ☐ HPE of primary
8 ☐ Autopsy with HPE
9 ☐ Autopsy without HPE
0 ☐ Unknown

Histology and behavior code

EXTENT OF DISEASE
Stage: T N M
1 ☐ In situ
2 ☐ Localized
3 ☐ Regional, nodes **only**
4 ☐ Regional, direct extension
5 ☐ Distant
6 ☐ Non-localized, NOS
7 ☐ Unstaged

THERAPY

1 ☐ Surgery
1 ☐ Curative
2 ☐ Palliative
3 ☐ Unknown
Hospital Date
Description of surgery

2 ☐ Radiation therapy
1 ☐ Curative
2 ☐ Palliative
3 ☐ Unknown
Hospital Date
Radiation dose and method

3 ☐ Chemotherapy
Hospital Date
Specify treatment

4 ☐ Hormonal therapy
Hospital Date
Specify treatment

5 ☐ Other cancer therapy
Hospital Date
Specify treatment

6 ☐ Reason for non-curative therapy
1 ☐ Advanced age or other diseases
2 ☐ Too advanced
3 ☐ Refused treatment
4 ☐ Treatment elsewhere (where)
5 ☐ Other reason (specify)

7 ☐ No data

Date of death (day / month / year) code

Underlying cause of death

Reporting physician
Name Date
Hospital Telephone

Figure 2.4. Current cancer notification form to the Estonian Cancer Registry.

information such as profession, duration of living in Estonia and in the patient's current area of residence, and numbers of births and pregnancies. As this kind of information is rather important when using cancer registration information in epidemiologic research, loosing this on the notifications can be seen as a negative development. On the other hand a lot of detail regarding diagnosis has been added to the new form, with information about treatment being included for the first time. This is definitely a very positive development. Also, major restructuring of the ECR files was undertaken in 1994.

The working procedure of the ECR today is described in the following section.

2.3.1.5 Estonian Cancer Registry today

Today the ECR is the responsibility of Ministry of Social Affairs of Estonia and this ministry is the funding body for the ECR. It issues all legislation documents regarding data collection, registration, and use for scientific research. Currently, the data collection process at the ECR is regulated by the decree of the Ministry of Social Affairs (No 21/2, February 2001). Under this decree cancer registration is compulsory.

The ECR has an obligation to submit annual reports to the ministry. The types of neoplasms that must be reported are listed in Table 2.1.

Table 2.1. Malignancies that are reported to the Estonian Cancer Registry.

Neoplasms	**ICD–10 code**
All neoplasms, including:	C00.0–C97
Neoplasms of lymphoid, haematopoietic and related tissue	C81.0–C96.9
Carcinoma in situ	D00.0–D09.9
Benign neoplasms or neoplasms of uncertain behaviour, localising in the brain and central nervous system	D32.0–D33.9; D35.2–35.4; D42.0–D43.9; D44.3–D44.5

The ECR covers the whole of Estonia. The way the ECR works is that all hospitals and laboratories are requested to report all cases of cancer that come to their attention. They are provided with cancer notification forms in batches and with instructions about how to complete them. The strategy for getting all new cancer cases that are diagnosed registered in the ECR is that all clinicians and pathologists, who diagnose a new cancer

case must send a notification to the ECR. By doing this, the ECR often receives multiple notifications of cancer cases. However these are later combined into one electronic registration for each diagnosed cancer.

At the moment, all the follow-up information, concerning details of treatment as well as patient status, is entered into the computer at the ECR. Follow-up cards are no longer in use.

Mortality data were obtained from the death certificate files of the Estonian State Statistical Office (record linkage) until the year 2000. On the rare occasion when cancer was first notified from a mention on the death certificate the certifying physician or hospital was contacted to obtain additional information. There were very few 'death certificate only' cases every year in the ECR. In 2000, for example, the proportion of such cases was 1% (Aareleid *et al.* 2003). Since the year 2001 the linkage with death certification data is prohibited by law. Access to mortality data at individual level is only permitted to institutions purely dealing with research and the ECR is not classified as such.

The process of handling notifications at the ECR is as follows. The cancer notifications arrive at the registry in batches or separately, most of them sent by mail or taken to the registry directly. The paper notifications are filed in alphabetical order.

The notifications are entered into the computer in a file called the notifications file. A separate record is created for each registered primary tumour. Range and consistency checks (Parkin *et al.* 1994a) are used for a number of data fields. The clinical information on cases on the computer is updated as new information on the cases arrives at the registry. This information is reviewed and coded after a period of two years, assuming that by then the information on cancer cases is complete. At this stage the cancer case also get a registration number. If a new malignancy is registered on the same patient, then the registration number (that is unique to the individual) is the same, but the new malignancy is given a new sequence number.

Online coding is carried out, and the primary site and histology are classified according to the International Classification of Diseases for Oncology (Percy *et al.* 1990), where coding of the primary site corresponds to ICD-10.

2.3.1.6 Accuracy and completeness of the Estonian Cancer Registry data

The ECR data have only been evaluated as part of routine quality assessment and when they are submitted for international comparisons (as will be described in Chapter 6 Section 6.2).

Surprisingly, none of the *ad hoc* studies or quality audits on the accuracy and/or completeness of the Estonian Cancer Registry data had been carried out to date. As for completeness of cover, for example, a rough estimate of for the ECR (95–98%) (Adami *et al.* 1994) has not been accompanied by *ad hoc* studies.

2.3.2 Uses of data from the Estonian Cancer Registry

The value and quality of cancer registration data is both reflected by and enhanced to the degree that it is used and published in clinical and epidemiological research. The following is a summary of uses of data from the ECR.

2.3.2.1 International comparisons and routine publications

Summary data on cancer incidence and quality indices in Estonia for the most recent years, 1993–97, are internationally available from *Cancer Incidence in Five Continents volume VIII* (Parkin *et al.* 2002) and *International Incidence of Childhood Cancer, volume II* (Parkin *et al.* 1998), which presents data from Estonia for 1980–1989. The Estonian cancer incidence data were first internationally published in *Cancer Incidence in Five Continents volume VI* (Parkin *et al.* 1992) and cover the years 1983–87. The reason why Estonian data could not be published before was that population data were classified during the Soviet period (Rahu 1992).

Data about cancer incidence and prevalence in Estonia are provided in the form of annual reports. These reports are relatively comprehensive, containing the numbers of incident and prevalent cancer cases for the given year, crude and standardised incidence rates for all ages, as well as age- and area-specific cancer incidence rates. The most recent annual report was published for the year 2000 (*Statistical yearbook of Estonia 2003*).

Routine publications also include annual reports that are prepared for the Ministry of Social Affairs. The ECR cancer data are included in the "Malignant neoplasms" chapter of the medical statistics yearbooks (*Estonian Health Statistics 2001–2002*).

2.3.2.2 Participation in European-wide projects

Estonian Cancer Registry data have been included in studies of cancer survival among European countries as a part of EUROCARE and EUROCARE II and EUROCARE III projects (Berrino *et al.* 1998, Capocaccia *et al.* 2003).

The European Childhood Leukaemia-Lymphoma Incidence study (ECLIS) was set up to investigate trends in incidence rates of childhood leukaemia and lymphoma in Europe (Parkin *et al.* 1993) in relation to the exposure to radiation which resulted from the accident at the Chernobyl nuclear plant in April 1986. In its first report, the incidence of leukaemia in children aged 0–4 is presented from 20 European countries, including Estonia (Parkin *et al.* 1996). The risk of leukaemia in the period 8–32 months post accident relative to that before the accident, was compared with estimated average dose of radiation received by the population in 30 geographic areas. For that time period, the observed changes in rates did not relate to exposure level in each area.

2.3.2.3 Descriptive studies

A number of descriptive studies have been carried out to analyse cancer incidence and mortality, and survival trends. These include comparisons with cancer data from other countries. The following is an overview of these studies in chronological order. All these studies are summarised in Table 2.2.

Survival of 4 090 female breast cancer patients in Estonia in 1968–1981 was studied on the basis of the ECR (Aareleid 1985). Using the life table method, the overall estimated 5–year relative survival rate was 55.9%. Survival was related to stage of disease and patient's age at diagnosis.

Incidence and some epidemiologic features of female breast cancer in the German Democratic Republic (GDR) and Estonia were compared on the basis of data from the cancer registries of the two countries by Aareleid *et al.* (1985).

Table 2.2. Descriptive studies based on the ECR data.

Authors and year of publication	**Study year/period**	**Cancer characteristics and/or sites studied**
Aareleid (1985)	1968–81	Survival of female breast cancer patients in Estonia
Aareleid *et al.* (1985)	1968–80	Comparison of female breast cancer in the German Democratic Republic and Estonia
Aareleid *et al.* (1990)	1968–81	Comparison of age-specific survival patterns and differences between the survival rates of female breast cancer patients in the GDR and Estonia
Aareleid and Rahu (1991)	1978–87	cancer survival in Estonia
Leinsalu and Rahu (1993)	1965–89	time trends in cancer mortality in Estonia
Aareleid *et al.* (1993)	1987	cervical cancer incidence and mortality trends in Estonia and Finland
Aareleid *et al.* (1994)	1968–87	time trends of lung cancer in Estonia
Thomson *et al.* (1996)	1968–92	overview of cancer occurrence in Estonia
Timberg *et al.* (1997)	1968–92	bladder cancer incidence, mortality, prevalence and survival
Liigant *et al.* (2000)	1986–96	description of primary central nervous system tumours in Estonia
Liigant *et al.* (2001)	1986–96	survival of primary central nervous system tumours in Estonia
Aareleid and Brenner (2002)	1969–98	trends in cancer patient survival, by application of period analysis

From 1968 to 1980, 68 626 new breast cancer cases were reported in the GDR and 3 768 in Estonia. Age-standardized incidence rates were consistently higher in the GDR. Overall, 95.2% of breast cancers in the GDR and 80.6% in Estonia were histologically verified.

Another study by Aareleid *et al.* (1990) described the age-specific survival patterns and analysed the differences between the survival rates of female breast cancer patients in the GDR in 1976–1977 and Estonia in 1968–1981. The estimated 5–year relative survival rate was 64.1% in the GDR and 55.9% in Estonia. It concluded that the main source of the differences in overall breast cancer survival rates between the GDR and Estonia were the discrepancies in stage distribution, particularly in older age groups.

Data on cancer survival in Estonia from 1978 to 1987 have been published (Aareleid and Rahu 1991). The highest relative survival rates were documented for cancers of the lip, corpus uteri, and skin (melanoma, women). The lowest relative

survival rates were found for acute myeloid leukaemia (women), and cancers of the liver, pancreas, and oesophagus (men). For most cancer sites, the survival rates for women exceeded those of men. Comparison of Finnish and Estonian survival rates showed that Estonian rates were lower.

Leinsalu and Rahu (1993) studied time trends in cancer mortality in Estonia 1965–1989 to assess overall progress in controlling cancer. The time trends in mortality from all cancers combined showed that in Estonia, over the previous 25 years no progress against cancer had been made.

A study about cervical cancer incidence and mortality trends, based on data from the ECR as well as from the Finnish Cancer Registry has been carried out (Aareleid *et al.* 1993). This showed marked differences in the incidence and mortality of cervical cancer in Finland and Estonia, with the Estonian figures being much higher. Data were presented for 1987, and showed that age-standardised cervical cancer incidence was 14.0 per 100 000 women in Estonia and 3.8 in Finland (mortality rates were 6.0 and 1.6 respectively). The authors state that, although the difference in these rates can be partially attributed to socio-economic factors, the main reason is the difference in health policies of the two countries: an effective cervical cancer mass screening programme has been implemented in Finland but not in Estonia. Pap–smear screening is recognized as an effective means of reducing cervical cancer morbidity and mortality through detection of preclinical lesions (Stuver and Adami 2002). Peto *et al.* (2004) have recently reported that the introduction of national screening in the United Kingdom in 1988 has played an important role in reversing the rising trend of cervical cancer incidence.

Time trends and public health impact of lung cancer in Estonia in 1968–87 have been studied (Aareleid *et al.* 1994). The results revealed a steady upward trend in the incidence and mortality rates of lung cancer during the 20–year period, with the relative increase was more pronounced in women than in men. The authors conclude that the high and still rising occurrence of lung cancer at that time was closely related to the high prevalence of smoking.

A comprehensive overview of cancer occurrence in Estonia for 1968–1992 (Thomson *et al.* 1996) has been published. This publication presents data on cancer incidence, mortality, prevalence, and survival, and provides the rates with some explanatory text, also showing regional differences in cancer incidence and mortality rates in Estonia and places them in the context of rates for other countries.

A descriptive epidemiological study of bladder cancer in Estonia was carried out by Timberg *et al*. (1997), presenting incidence, mortality, prevalence and survival for 1968–1992.

An epidemiologic description of primary central nervous system (CNS) tumours in 1986–1996 has been published (Liigant *et al.* 2000). According to the results of the study, no significant difference was observed between the sexes for all primary CNS tumors. The age-specific incidence increased from the age of 30, reached a maximum in the age range of 50–69 years and declined in the elderly which may reflect under-diagnosis. The age-adjusted incidence rate for CNS tumors was 8.5/100 000 population.

Another study by Liigant *et al*. (2001) looked at survival of primary central nervous system tumours in Estonia between 1986 and 1996. Median survival time for all tumours was 33.2 months and 1– and 5–year survival rates were 59.3 and 46.0%, respectively.

Using data from the ECR, Aareleid and Brenner (2002) assessed trends in cancer patient survival, by application of period analysis, a new method of survival analysis. Their study included 83 138 patients diagnosed with 1 of the 11 most frequent malignancies in Estonia from 1969–1998. Patients were followed up to the end of 1998. Prognosis for many common forms of cancer, such as stomach, colorectal, breast and ovarian cancer, remained considerably worse than the survival rates achieved in more affluent European countries many years earlier. By contrast, a very steep increase in survival rates was observed for common urologic cancers, including prostate, kidney and bladder cancer, which went along with a rise in incidence rates of these cancers over time. For prostate cancer, similar survival rates as in other European countries have now been achieved. The authors concluded that despite recent improvement, major efforts in delivering modern cancer care to the population of Estonia will be required to close the gap that continues to exist between prognosis of cancer patients in this country and other European countries.

2.3.2.4 Etiological investigations

Etiological investigations have been conducted using the ECR data. These are described below and the briefly listed for key information in Table 2.3.

An investigation about cancer incidence in Estonian migrants to Sweden has been undertaken (Nilsson *et al.* 1993). This study compared cancer incidence in Estonians

who took refugee in Sweden in 1944–1945 with that in the total Swedish population and that among Estonians in Estonia in 1974–1985 using data from Estonian and Swedish national population-based cancer registries. The main finding of the study was that the migrant population showed an intermediate incidence relative to Estonians in Estonia and the entire Swedish population. An exception to this was the colon cancer risk in Estonian migrants to Sweden, which was higher than the risk for Estonians in Estonia and the Swedish population.

On the basis of the ECR data a number of studies related to the Chernobyl nuclear accident have been initiated. Among these, a cohort study of Chernobyl clean-up workers was initiated by assembling a cohort of 4 833 clean-up workers who had participated in the clean-up activities in the Chernobyl area sometime between 1986 and 1991 (Tekkel *et al.* 1997). Exposure and disease information was collected to provide new knowledge about cancer risks due to protracted exposures to ionizing radiation. Incidence and mortality in the clean-up workers was assessed relative to national rates. The study concluded that exposure to ionizing radiation while at Chernobyl did not cause a detectable increase in the incidence of cancer among clean-up workers from Estonia (Rahu *et al.* 1997).

A retrospective study of furniture workers, cancer incidence in 3 723 men and 3 063 women between 1968 and 1995 was compared to the incidence in general population of Estonia, using the ECR data (Innos *et al.* 2000) to test the hypothesis that wood dust exposure is associated with increased risk of sinonasal cancer. This study found an excess of colon and rectal cancer in furniture workers, but there was no detectable increase in sinonasal or total cancer.

To evaluate whether the presumed knowledge of physicians about healthier lifestyle decreases their risk of cancer and mortality, a retrospective cohort study of male and female physicians was conducted in Estonia (Innos *et al.* 2002). The cancer incidence and cause-specific mortality of 3 673 physicians in Estonia was compared with the rates of the general population. Information on cancer cases and deaths in the cohort between 1983 and 1998 was obtained from the Estonian Cancer Registry and the mortality database of Estonia. The standardized incidence ratio for all cancers was 1.32 (95% CI 1.15–1.48 in women and 0.92 95% CI 0.73–1.13 in men. No health risks were observed in the cohort that could be linked to the occupational exposures of physicians.

Suicide risk among Estonian cancer patients has bee investigated (Innos *et al.* 2003). This risk was examined in a cohort of 65 419 persons diagnosed with cancer in 1983–

1998. Standardised mortality ratios were calculated using the suicide rates of the population of Estonia as a reference. An increased suicide risk was found for men diagnosed with cancer, but not for women.

Table 2.3. Etiologic studies based on the ECR data.

Authors and year of publication	**Study period**	**Cancer characteristics studied**
Nilsson *et al*. (1993)	1974–85	cancer incidence in Estonian migrants to Sweden compared to that of Estonians in Estonia
Rahu *et al*. (1997)	1986–91	a cohort study of cancer risk in Chernobyl cleanup workers
Innos *et al*. (2000)	1968–95	a retrospective study of cancer incidence in furniture workers
Innos *et al*. (2002)	1983–98	a retrospective cohort study of physicians cancer incidence and cause-specific mortality
Innos *et al*. (2003)	1983–98	suicide risk among Estonian cancer patients

2.4 Cancer screening in Estonia

Cancer screening in Estonia has been started rather recently. The first screening activities were carried out as a pilot project in Tallinn in 1996-2000 (A. Aasma – 2005 – personal communication). This was aimed at early detection of breast and cervical cancers in women aged 40-59. Only three districts in the capital city of Tallinn were involved. Women were invited to participate (contact addresses were obtained from district population registries) and were offered mammography and Pap-smears. Two efforts of breast cancer screening were undertaken in the city of Tartu. These involved breast cancer screenings for women aged 45-69 and were advertised in the media.

Similar efforts have been made to start cervical cancer screening in Estonia. So far these have involved Pap-smears for 10 000 women per year in 2003 and 2004.

No other screening activities have been carried out in Estonia.

2.5 Summary

Cancer registration in Estonia dates back to 1953 when it was established as part of compulsory cancer registration in the Soviet Union. This chapter reviews the historic development and current procedure of cancer registration in Estonia against the background of the general developments in the country. Throughout the Soviet period, cancer surveillance in Estonia mostly adhered to the Soviet principles, although from the late 1970s it started to diverge. Soon after the dissolution of the Soviet Union, there was a definitive break with the Soviet cancer registration principles. The ECR nowadays operates on principles that are quite similar to those used in the Western countries.

It is of interest to look at the types of uses of the ECR data. As the current chapter showed, the ECR data have been used in international comparisons, routine statistical publications, as well as epidemiologic studies. The participation of the ECR in international projects is remarkable when compared to other NIS cancer registries. However, these data could be used even more widely, as there is underutilization of data. This is particularly in terms of government, public health, non-governmental organisations, and media. In addition, the ECR data have been used only very little for the purpose of clinical investigations.

Given that the ECR data has been used relatively extensively it is important to note that to date there have been no systematic attempts to evaluate the accuracy and completeness of the ECR data. It is to this issue that I now turn my attention to in the next two chapters.

Chapter 3. Data quality studies

This chapter defines the main quality characteristics of cancer registration data. It also describes ways in which their values may be affected as well as provides a systematic review of methods to asses these characteristics. Furthermore, it presents a literature review of published studies that have investigated the quality of cancer registration data.

3.1 Quality issues and definition

3.1.1 Overview

The value of cancer registration data is largely dependent on their quality (Blanchard *et al.* 1997; Schouten *et al.* 1997). As cancer registry databases are extensively used in clinical and epidemiological research, it becomes increasingly necessary to assess the quality of the data (Brewster 1995; Gulliford *et al.* 1993; Harvey *et al.* 2001; Lapham and Waugh 1992).

Quality of registration data depends on several aspects. First of all, as the main aim of any cancer registry is to collect epidemiologic data on cancer incidence, a cancer registry should be able to define the area that it covers, also known as catchment area. Also, a registry must have available accurate estimates of the population at risk, in order to apply the incidence figures to the population (Schouten *et al.* 1997). The range of neoplasms reportable to a specific registry should be clearly defined. Once these prerequisites for cancer registration are met, data quality issues arising from the cancer registration process itself can be addressed.

According to Stiller (1997), the perfect cancer registry would contain a single complete and accurate record for every case of cancer occurring among residents of the region covered by that registry. In practice this can rarely be achieved as there may be problems with diagnosis and cancer case ascertainment as well as shortcomings in the reporting or registering of every specific case. Therefore the question arises by what

margin do registries fall short of the ideal. Every cancer registry should be able to quantify the level of completeness at which it operates (Nwene and Smith 1982). Several methods of quality assessment have been developed, each looking at a different data quality characteristic. The main quality characteristics are defined in Section 3.1.2.

In addition to making improvements in data collection and processing, data quality is also enhanced by making use of cancer data in research or international comparisons.It is often only when data are used that problems and errors are revealed and validated before entering them to a study. For example, for submitting data for *Cancer Incidence in Five Continents* (a regular publication of the IARC), data are requested in the form of case listings, which are checked using a group of standard computer programmes. These checks are rather extensive, including verification of coding, identifying possible duplicate registrations, querying the participating registries unlikely or impossible combinations of codes etc. (Parkin *et al.* 2002). Similarly, quality of data can be reviewed after obtaining the results of an epidemiologic study. For example, if a study involves comparison of incidence rates between different areas or countries, differences in those rates may indicate, among other factors, to problems in case ascertainment. Therefore, assessing the extent that data from a given registry are used can provide an indirect measure of data quality.

Besides enchancing data quality by using cancer registry data in research, some registries have a legal or contractual obligation to monitor the validity of their data (Stiller 1997). In Norway, for example, it has been obligatory since 1983 for the national cancer registry to assess the quality of its own data. In the United Kingdom, standards are specified for certain quality characteristics of cancer registration and the model core contract for cancer registries includes a requirement for continuing evaluation.

3.1.2 Definitions and terms

In the cancer registration literature, the terminology regarding data quality is confused and is not completely consistent with the use of it in the broader epidemiology literature. In this section the main terms used in relation to studies of cancer data quality are defined ans discussed.

Case completeness of registration can be defined as the extent to which all the incident cancers occurring in a target population are included in the registry database (Parkin *et al.* 1994). The synonyms for case completeness are completeness of cover and completeness of case ascertainment.

Validity is the proportion of cases in the registry with a given characteristic (e.g. cancer site or age) which truly have the attribute or the extent to which the information recorded on the different variables is true, or accurate (Parkin *et al.*1994). It is usually measured as the level of agreement with "gold standard" material (Teperi 1994). Validity depends first of all upon the accuracy of the cancer data source documents (Parkin *et al.*1994).

Completeness of data items refers to the proportion of cases at the cancer register with missing information for indicator variables (Parkin *et al.*1994).

Other quality characteristics of cancer registration include timeliness of data, coding constancy, and publication constancy (Hilsenbeck *et al.* 1985; Skeet 1991). These latter aspects of quality are used considerably less often than the main quality characteristics that were defined above. They will not be dealt with in this thesis. The reason for excluding these quality characteristics from this thesis is that it focuses mainly on validity aspects of quality rather than process measures.

Methods of checking data quality are directed to assessing each of the quality characteristics. According to whether these methods use data routinely collected by the cancer registries or involve the collection of additional data from source documents, quality control methods are classified as *routine* or *ad hoc*. *Ad hoc* studies collect

information about the quality of registration data from source documents such as hospital records etc. or make other special efforts to validate the quality of data.

The following sections give an overview of the methods to assess the main quality characteristics of cancer registration data.

3.2 Completeness of cancer registration

One of the aims of a population-based registry is to include every reportable cancer within its catchment population. Achieving this aim would mean 100% case completeness. As defined above, case completeness is the extent to which all the incident cancers occurring in a target population are included in the registry database.

In reality, though, for different reasons it is not easy to obtain 100% completeness. Missing registrations lead to under-registration. Incomplete ascertainment of cases is generally an important and widespread problem. This can result for the reason that not all cancers eligible for registration are reported to the registry, especially if it is not obligatory to report them. There are differences between countries with respect to obligations to report on cancer cases. In some countries like Norway (Harvei *et al.* 1996) and Denmark (Danish National Board of Health 1998) it is obligatory for the hospitals and pathology departments to report on cancer cases that come to their attention. This is also the case in Estonia today. In other countries like England and Wales, voluntary notification is practiced.

Moreover, incomplete ascertainment may depend on medical coverage and diagnosis rate, i.e. it may happen that a cancer is never diagnosed as the case never comes into contact with the medical care system (Parkin *et al.* 1994a). This is not under-registration as a registry can only include diagnosed cancers. Still this fact should be accounted for, especially when comparing cancer data from less developed countries, where medical coverage may be lower.

Over-registration can also occur. It may result from duplicate registrations. Duplicates are searched for during the process of data entry as part of edit checks. Upon entering a new registration to the registry database, if there is a possibility that this registration already exists in the database, based on the comparison of surname spelling, this case is checked for other items of patient's identification and diagnostic information. It is always necessary to check the diagnostic information as a person

already registered with cancer may develop a consecutive cancer. If this is the case, it is registered, provided that the cancer is eligible for registration. On the other hand, the consecutive notification of the primary tumour already registered may contain information on metastases recorded as a primary tumour, and thus is not eligible for registration. All these cases should be resolved by means of edit checks performed at data entry.

Other mechanisms can lead to over-registration of incident cancer cases. For example, a false-positive diagnosis of cancer will lead to over-registration of incident cancer cases. This situation is beyond the control of the cancer registry *per se* and relates to the quality of medical practice in a given country.

Over-registration can also occur if cases from outside the catchment population are registered. This happens if, for example, the catchment population is not clearly defined or there is only limited residency information for persons diagnosed with cancer.

Reporting of cancer cases depends on the motivation and knowledge of medical and clerical staff responsible for reporting. For example, some registries in England and Wales use 'active notification' where clerks from the registry visit hospitals and outpatients' departments and actively search for new cases of cancer that have been diagnosed. This is also the case in the Netherlands Cancer Registry, where lists of newly diagnosed cancer cases are received on a regular basis from the pathology and haematology departments, the medical records departments, and some radiotherapy institutes. Following this notification, trained registration personnel from the cancer registry abstracts the relevant information for the cancer registry from the medical records at the hospital concerned (Schouten *et al.* 1997). In other registries, like the ECR, reporting is "passive" whereby reporting sources like hospitals and pathology laboratories complete cancer notifications for every new cancer case that comes to their attention and send the notifications to the registry. There have been no studies to find out which reporting system, active or passive, results in completeness of case ascertainment, although from an *a priori* perspective one would think an active system would be more complete.

The number of sources that a cancer registry receives its data from varies. It can be restricted to patient case notes from hospitals diagnosing cancer, regarded as one source. In other cases, in addition to hospital data, it can include data sources such as pathology and autopsy reports, radiotherapy notes, and death certificates. Completeness of

registration is likely to be maximised by using multiple sources of case ascertainment. The rationale is that "few cases will escape the net" (Parkin *et al.*1994).

3.2.1 Routine methods

In the two following sections the routine methods of assessing case ascertainment such as the death certificate and the mortality/incidence ratio are discussed.

3.2.1.1 Death certificate method

Where possible, many cancer registries, including the ECR[*], routinely obtain information on deaths where he death certificate mentions cancer.

Cancer registries generally obtain death certificates in the form of an electronic data file from the vital statistics offices and match them against their files. For a proportion there will be no record of a previous registration in the cancer registry. Some registries do not make additional enquiries about these cancer cases and include them in the totals of registered cases of cancer. Other registries contact the certifying doctor and/or hospital and make an enquiry whether the individual had been seen, and/or investigated at another medical institution at an earlier date. If this information is received by the registry, it then decides whether the underlying evidence for cancer is sufficiently strong for the case to become registered. If there is adequate additional information regarding the case, it is registered as a case first notified via death certificate (DCN). If no or inadequate additional information is received, the registry regards the case as a death certificate only case (DCO). Some registers do not distinguish between the DCO and DCN cases and regard all of them as DCO cases.

This is one of the most often used methods for estimating the case completeness and is practiced by cancer registries as a routine quality check. It takes account of the proportion of cases which first come to a registry's attention in the form of a death certificate (Parkin *et al.* 1994a). Death certificates enable those cancers that were not registered during a person's lifetime to be registered, given that cancer is mentioned on the death certificate. In order to do that, access to mortality data should be granted for the cancer registry. In some countries cancer registries do not have access to death

[*] At the moment the ECR no longer receives information on death certificates that mention cancer from the Statistics Office of Estonia. This was stopped in the year 2000 for reasons of data protection.

certification data for reasons of data confidentiality and linkage of the files can not be performed.

The proportions of DCN's and DCO's for a specific registry from all cancers registered for a given year can be calculated and are used as data quality indicators. For example in the publications of IARC such as *Cancer Incidence in Five Continents*, the DCO's are used. Registries with high level of completeness generally will have low proportions of DCN's and DCO's.

3.2.1.2 Mortality incidence ratio

In addition to calculating the death certificate only cases, in the situation where mortality data are available for the registry, it is possible to calculate mortality/incidence (M/I) ratio. The ratio is a comparison of the number of deaths attributed to a specific cancer and the number of incident cases in the same time-period (Parkin *et al.* 1994). The M/I ratio should equal (1─ survival probability) in a steady state of constant incidence and survival. For cancers where survival is very low, the M/I ratio is close to 1, and for cancers with more favourable survival it is less than 1. The M/I ratio exceeding 1 can be a sign of under-registration, but other causes such as rapid decline in cancer incidence or decrease in survival rates should be considered also. On the other hand, the M/I ratios are affected when mortality statistics are of poor quality, where there is incomplete certification or inaccurate statement on cause of death (Parkin *et al.* 1994). In this situation the M/I would be less than 1, even when there is very incomplete registration of cancer.

Also, the interpretation on M/I ratios is difficult when the DCO cases have been incorporated in the incidence data. This means that cancer mortality data have been used to increase the completeness of cancer incidence registration. The M/I ratios estimate possible under registration of cancer incidence by the proportion of cancer cases contributing to cancer mortality and not incidence, and this should, at least in theory, be reduced by including the DCO cases in the cancer incidence data.

As there are several factors which can influence the magnitude of the M/I ratio, operating in different directions, it is often difficult to judge on the level of registration completeness based on the M/I ratios. Some more discusssion on this subject will be presented in Section 6.2. To conclude the M/I ratios should be interpreted with caution as measures of completeness of cancer registration.

3.2.2 Independent case ascertainment

3.2.2.1 Principles

Independent case ascertainment involves comparing the total number of cases registered by the cancer registry to the data from another source, that is judged to be relatively complete, and has the same target population. It provides the best but also the most costly method for determining completeness. These independent data sets may comprise databases of cancer patients recruited into special studies (e.g. clinical trials), or administrative databases (hospital registries, medical insurance databases). However, if separate registration is set up, for example as a part of a clinical study, it has certain limitations, such as being carried out on a local basis or being restricted to only a few sites of cancer (Silcocks 1989). The validity of results is restricted accordingly.

A subtype of independent case ascertainment is a study where only one of the sources of a cancer registry, usually hospital, is used for a case-finding exercise (Parkin *et al.* 1994). This is known as re-screening or active retrieval of cancer cases.

If administrative or any other databases are used for comparison, these may include in addition to patients with incident cancer diagnosis those patients with an earlier cancer diagnosis, the so called prevalent cases, who should not contribute to the new incident cases for the period being assessed. Several studies have found that the data in hospital registries are often crude or possibly incomplete, since they have been developed for administrative or clinical management purposes (Kjaergaard *et al.* 2001; Parkin *et al.* 1994). It should be noted that clinic or hospital databases often exist as independent entities that run in parallel to the data collection process used to report to the national or regional cancer registry.

Pathology data (histopathology and post mortem reports) also represent potentially excellent source of case ascertainment (Brewster 1995), as they often are an easy and reliable way to obtain data for registration purposes. Using pathology data for case ascertainment would mean reviewing other medical documentation of these patients as pathology data alone, although they contain reliable data as to tumour type, may lead to loss of detail about other cancer characteristics such as subsite or incidence date of cancer diagnosis (Lapham and Waugh 1992).

Whichever databases are used, methodological issues such as the definitions and accuracy of diagnosis, place of residency of the patients within the catchment area for

the registry, and so on, should be considered. The lists of patients that are used for such comparison should be reliable and complete.

The estimated completeness of case ascertainment by the cancer registry is usually calculated by dividing the existing number of registrations by the sum of the newly identified cases (using independent data sets) and the cases already registered.

3.2.2.2 Review of studies of completeness using independent case ascertainment

The following sections review the studies which have looked at case completeness, using independent case ascertainment. All these studies are summarised in Table 3.1. The studies are organised by the country and chronological order. Some of these studies have also looked at validity of cancer registration and are summarized for these results in Section 3.3.1.3.

United Kingdom. There have been five *ad hoc* studies in the literature looking at the completeness of case ascertainment in the United Kingdom.

In a study of completeness of cancer registration in the north-western region of England, Nwene and Smith (1982) used five independent sources covering 11 cancer sites to perform data linkage with the registry. These lists were either related to particular hospitals where recording and follow-up was meticulously maintained and some region-wide lists of patients with particular tumours which had been made the subject of special clinical and histological studies. The chosen sites were of moderate to low fatality as the registration of such cases generally tends to be less complete. The mean level of completeness was 94%, ranging from 81.6 to 98.5% for different sites.

Benefits and limitations of pathology databases to cancer registries were studied by Brewster *et al.* (1996). They obtained computerised pathology records of malignant neoplasms diagnosed in 1992 for a defined area of Scotland for which pathology data were not routinely used for cancer registration. Completeness of registration by the Scottish Cancer Registry was approximately 94%. They concluded that pathology databases represent a useful additional source of cases, but the fact that a number of apparently missed cases were found to be ineligible for registration suggested that unverified computerised pathology data should be checked before using for cancer registration.

A study was carried out by Brewster and *et al.* (1997b), where they assembled a collection of databases containing possible cancer registrations from 14 separate sources (hospital discharge data, death records, histopathology and cytology data, autopsy data, radiotherapy register, site-specific tumour registries) and linked these to cancer registration records. The eligibility of cases for registration was determined by reference to medical records. The overall estimate of completeness was 96.5%, and varied considerably according to cancer site.

The completeness and validity of notification of cancers by the National Health Service Central Register for England and Wales was investigated in a study carried out by Dickinson and *et al.* (2001). They compared 720 cancer registrations ascertained from National Health Service Central Register with those ascertained for the same cohort from six other sources (five regional cancer registries and death registrations) and a pathology review of the National Health Service Central Register cancer registrations. The study covered the age range of 0–39 years. Completeness was estimated to be up to 90% (95% CI 85–94). Undernotification was more marked for cases that had not died. The authors concluded that without additional ascertainment from multiple sources and diagnostic review, it would be incautious to use National Health Service Central Register cancer registrations as the sole basis of an epidemiological study.

The rate of case ascertainment for brain tumours was studied by Pobereskin (2001) in the United Kingdom. He compared the data from a clinical database set up for tumour incidence study with a cancer registry. Only 52% of the brain tumour cases present in the clinical database appeared in the cancer registry with under registration of more benign tumours in younger patients.

Sweden. There have been five *ad hoc* studies looking at the completeness of case ascertainment in Sweden.

Undernotification of diagnosed cancer cases to the Stockholm Cancer Registry was studied by Mattson and *et al.* (1985) by linking the data of two independent sources of information: the cause-of-death register and the in-patient care register. The idea was to investigate undernotification of non-fatal as well as fatal cancers. The study showed that registration deficit for fatal cancers was 6%, which was significantly higher than the deficit for non-fatal cancers (3%). The combined deficit was 4%. The researchers were able to show that the registration deficit was increased when the diagnosis was only on

clinical grounds, and related to patients' age, as non-notification was most common among patients younger than 15 or older than 69 years.

Completeness of registration of breast cancer from one hospital into the Swedish National Cancer Registry and validity of recorded information has been studied twice by Garne *et al*. (1995). In the first study that covered study period 1961–1970 they revealed a 3.5% undernotification of breast cancer, which varied with age, being the highest for ages <35 and >85 years. Interestingly, they were also able to detect an overregistration of 9.2%. This was most of all related to carcinoma *in situ* registered as an invasive tumour, but also duplicate registrations, single tumours registered twice, diagnosis of cancer being made outside the period of study, and tumours occurring in patients resident outside the area covered by the cancer registry.

Flam and Rutqvist (1992) carried out a study where they evaluated the completeness of registration of hydatiform mole and gestational trophoblastic neoplasia in the Swedish Cancer Registry over 15 years. They identified non-notified cases through a computerised register covering nearly all hospital admissions in the region, and local hospital patient register. They concluded that of all patients treated for trophoblastic malignancy, as many as 66% were not recorded in the cancer register, the probable main reason for under-registration being the frequent absence of histopathological confirmation.

A second study of the Swedish Cancer Registry was carried out by Garne and *et al.* (1995) to estimate validity and completeness of female breast tumour data of female residents of Malmö for 1971–1991 in the Swedish Cancer Registry. To identify cases not registered in the Swedish Cancer Registry, the authors examined patient registers at various hospital departments including mammography records. They found that 1% of cases detected in hospital registers were not registered at the cancer registry.

The completeness of registration of acute leukemias in a Swedish population was studied by Aström *et al*. (2001). They compared the Swedish Cancer Registry and Cause of Death Registry, and in addition, when available, used listings of pathology bone marrow reports and inpatient discharge diagnoses. As a result the authors found 15.4% of acute leukemias in the study population as not registered in the Cancer Registry, which gives the completeness estimate of 84.6%.

In the Nordic countries, in addition to Sweden, there has been one study reported in each: Finand, Norway, and Denmark.

Finland. The completeness of the Finnish Cancer Registry for 1985–88 was studied by Teppo *et al.* (1994), performing record linkage with the hospital discharge registry, checking the medical records and actively retrieving the cancer cases missing from the cancer registry. Initially they detected 6 034 patients who had been hospitalised with a diagnosis of cancer and were missing from the cancer registry, but the checking of the medical records revealed that in about two thirds of the cases, the cancer code at the hospital discharge registry proved to be erroneous. Also, during this checking process, several hundreds of 'missing cases' from the cancer registry were notified spontaneously to the cancer registry as late entries. Finally the number of missing cases decreased to 965, which was 1.4% of all tumours to be included in cancer statistics. Benign neoplasms of the central nervous system, chronic lymphatic leukaemia, and multiple myeloma were most under registered with a roughly 10% of under registration on the average.

Norway. Completeness of registration of ovarian cancer in the Cancer Registry of Norway for 1987–96 has been studied (Tingulstad *et al.* 2002) by evaluating the registry data against hospital discharge data. Completeness of registration of ovarian cancer was very high, reaching 99.6%. The same study also looked at validity of data, the results for which are presented in Section 3.3.1.3.

Denmark. Kjaergaard *et al.* (2001) studied the completeness of registration of surgically treated malignant gynaecological cancer cases for the years 1977–1988 in the Danish Hospital Registry by comparison with the Danish Cancer Registry. They found that the completeness of registration in the Danish Hospital Registry was 87% overall, and concluded that in epidemiological cancer research the Danish Cancer Registry is the better alternative when information on malignant tumours is needed.

The Netherlands. There are two *ad hoc* studies in the literature assessing the completeness of case ascertainment in the Netherlands.

A study was carried out (Berkel 1990) to evaluate the role of the general practitioner as a source of information for a cancer registry. A special general practitioner cancer file was set up, which was afterwards linked with the cancer registry data base to estimate missed cases. A total of 1637 tumours were identified from the general practitioners, of which 252 (15.4%) were not included in the cancer registry. Thus the completeness was 84.6%. The authors also noted that missed cases were mostly older patients with digestive tract tumours.

Schouten and *et al.* (1997) compared the data of Netherlands Cancer Registry for childhood leukaemia with data from a registry specially set up for studying childhood leukaemia – the Dutch Childhood leukaemia Study Group. They revealed high completeness of case ascertainment in both registries: 95.5% in Netherlands Cancer Registry and 96.9% in the Dutch Childhood leukaemia Study Group data.

The United States of America. An effort to quantify completeness of case reporting in the Surveillance, Epidemiology and End Results Program of the National Cancer Institute in the United States of America was made by Zippin (1995). Files in the medical record, pathology, and radiation oncology departments of the selected hospitals were reviewed for reportable cases. These cases were then matched against the Surveillance, Epidemiology and End Results Program case listings to identify unreported cases. Completeness of reporting was 97.7% and it varied by hospital cancer caseload and hospital department.

Uganda. Completeness of registration in an African cancer registry in Kampala, Uganda, was assessed (Parkin *et al.* 2001), using a file of cancer patients enrolled into the HIV Cancer study (a study about the influence of HIV infection on cancer risk). For adults aged 15 or more, the completeness of registration was 89.6% (95% CI 87.0–92.7). It varied with age (with better ascertainment for younger cases) and cancer site, and cases with histology report were more likely to be registered than those without.

Table 3.1. Overview of studies which have looked at case completeness, using independent case ascertainment.

Authors	Cancer registry / region covered / programme	Study period	No of sources	Independent sources used	Cancer sites/type	Complete-ness (%)	Comments
United Kingdom							
Nwene and Smith (1982)	North-western region of England	1974–77	5	Hospital lists and some region-wide lists of patients with particular tumours of special clinical and histological studies	11 sites of moderate to low fatality	94 (95% CI 81.6– 98.5)	Completeness varied appreciably with cancer site and source of data.
Brewster *et al.* (1996)	Scottish Cancer Registry	1992	1	Pathology database	all reportable cancers	95.3	Ascertainment of cases for most sites seemed to be high.
Brewster *et al.* (1997)	Scottish Cancer Registry	1982	14	Hospital discharge data, death records, histopathology, cytology and autopsy data, radiotherapy register, site-specific tumour registries	invasive neoplasms excluding non-melanoma skin tumours	96.5 (95% CI 25–100)	Completeness varied considerably according to cancer site
Dickinson *et al.* (2001)	National Health Service Central Register for England and Wales	1971–89	6	Five regional cancer registries and death registrations	All reportable cancers	90 (95% CI 85–94)	Undernotification was more marked for cases that had not died.
Pobereskin (2001)	United Kingdom	1992–96	1	A database set up for brain tumour incidence study	brain tumours	52	Under registration of more benign brain tumours in younger patients.
Sweden							
Mattson *et al.* (1985)	Stockholm Cancer Registry	1978	2	The cause-of-death register and the in-patient care register	all reportable cancers	94 for fatal cancers, 97 for non-fatal cancers, combined deficit 96%	Completeness increased when the diagnosis was only on clinical grounds, and was related to patients' age (most common among patients <15 or > 69 years.

continued

Table 3.1. Overview of studies which have looked at case completeness, using independent case ascertainment. (continued)

Authors	Cancer registry / region covered / programme	Study period	No of sources	Independent sources used	Cancer sites/type	Completeness (%)	Comments
Sweden (continued)							
Garne *et al.* (1990)	Swedish Cancer Registry	1961–70	2	Clinical records and local registries at the departments of surgery, oncology, and pathology	breast cancer	96.5%	Underregistration was the highest in the age groups <35 and >85 years. Overregistrations (9.2%) were also detected.
Flam and Rutqvist (1992)	Swedish Cancer Registry	1971–86	1	Register of hospital admissions	trophoblastic malignancies	66	Main reason for under-registration was the frequent absence of histopathological confirmation.
Garne *et al.* (1995)	Swedish Cancer Registry	1971–91	1	Patient registers at various hospital departments	breast cancer	98.9 for invasive and 63.3 for cancer in situ of the breast	Completeness was good. All aspects of registration improved during the study period.
Astrom *et al.* (2001)	The Swedish Cancer Registry	1987–92	3	Swedish Cancer Registry and Cause of Death Registry data were compared	leukaemia	84.6	When available, the authors used in addition to patients records, listings of pathology bone marrow reports and inpatient discharge diagnoses.
Finland							
Teppo *et al.* (1994)	Finnish Cancer Registry	1985–88	1	Hospital discharge registry	all reportable cancers	98.6	For solid tumours, the coverage was generally rather good.
Norway							
Tingulstad *et al.* (2002)	Cancer Registry of Norway	1987–96	1	Hospital discharge registry	ovarian and fallopian tube cancers	99.6	The organ specific completeness of histologically verified ovarian cancer was 95.3%.

continued

Table 3.1. Overview of studies which have looked at case completeness, using independent case ascertainment.(continued)

Authors	Cancer registry / region covered / programme	Study period	No of sources	Independent sources used	Cancer sites/type	Complete-ness (%)	Comments
Denmark							
Kjaergaard *et al.* (2001)	Danish Cancer Registry	1977–88	1	The data from the Danish Cancer Registry were used to study the completeness of the Danish Hospital Registry	surgically treated malignant gynaecological cancer cases	87	The Danish Cancer Registry is the better alternative as compared to administrative databases when information on malignant tumours is needed.
The Netherlands							
Berkel (1990)	The Comprehensive Cancer Centre Middle-Netherlands	1987–88	1	A special general practitioner cancer file was set up	all reportable cancers	84.6	Missed cases were mostly older patients with digestive tract tumours.
Schouten *et al.* (1997)	Netherlands Cancer Registry	1989–92	1	The central reference base for the diagnosis and treatment of childhood leukaemia	leukaemia	95.5	The completeness of the other source also estimated (96.9)
United States of America							
Zippin *et al.* (1995)	Surveillance, Epidemiology and End Results Program	1987	3	Files in the medical record, pathology, and radiation oncology departments of selected reporting hospitals	all reportable cancers	97.7	Variation of case completeness was noted by hospital cancer caseload and hospital department.
Uganda							
Parkin *et al.* (2001a)	Kampala Cancer Registry, Uganda	1994–96	1	A file of cancer patients enrolled into the HIV Cancer study	cancers of any type	89.6 (95% CI 87.0–92.7)	Completeness varied with age (with better ascertainment for younger cases) and site.

3.2.3 Capture-recapture

3.2.3.1 Principles

The capture-recapture methods originate from studies of animal ecology, where they have been used for counting free-living animal populations by capturing and tagging independent samples of animals and estimating the size of animal population by numbers of animals captured and recaptured in overlapping samples. These methods have been developed to estimate the number of missing cancer cases from a given cancer registry, by making use of the numbers of cases present in independent sources. Administrative, clinical, or other databases containign information on cancer patients are regarded as sources. In epidemiological monitoring, cases notified via various incomplete sources are regarded as overlapping samples and by counting these samples the estimate for the total number of cases is given.

Capture-recapture methods have been widely used for estimating the completeness of cancer registration (Brenner et *al.* 1994; Brenner *et al.* 1996; Hook 1996; Robles *et al.* 1988), and other diseases, including diabetes (Berger *et al.* 1998; Blanchard *et al.* 1997; Garancini *et al.* 1995; Littorin *et al.* 1996; Morris *et al.* 1997; Schober *et al.* 1995; Wadsworth *et al.* 1995), inflammatory bowel disease (Tragnone *et al.* 1996), coeliac disease (Corrao *et al.* 1996), stroke (Taub *et al.* 1996), fetal syndrome (Sorensen *et al.* 1996), epilepsy and epileptic seizures (Murphy *et al.* 1995), cerebral palsy (Topp *et al.* 1997), tuberous sclerosis (O'Callaghan *et al.* 1998), and meningococcal disease (Ackman *et al.* 1996).

In recent years, capture-recapture methods have been increasingly used for investigating completeness of case ascertainment (Brenner 1995; Brenner 1996; Brenner *et al.* 1994; Parkin *et al.* 1994).

To use this technique, cases have to be identified uniquely, either by names or some other unique identifiers (Parkin *et al.* 1994a). According to Parkin "The cases are then classified as present or absent in each of the data sources. If there are n sources available, there are 2n possible ways of classifying cases according to which combination of sources they are found and are not found in. For example, with two sources – e.g. hospital records and death certificates – there are four possible combinations: both hospital report and death certificate, hospital report only, death certificate only, and neither source. The last of these represents 'missing cases', undetected by neither source."

Sources of data can be distinguished as ‘original’, e.g. particular list of cases from some institution, or ‘analytic’, which is a list that may be constructed by the investigator from one or more original sources (Hook and Regal 1995). Analytic sources can be pooled to derive larger group that may be considered as an additional source for analysis. The use of additional sources, such as drug user files or health insurance company files can contribute to maximising the estimate of case completeness of the disease registry (Papoz *et al.* 1996).

The limitation of the capture-recapture method is that the data sources have to be independent (Parkin *et al.* 1994a). If the data sources are positively dependent, meaning that a case notified in the first source is more likely to be notified in the second source, then the missing cases will be an underestimate of the true value. If the two sources are negatively dependent, with a case notified in the first source less likely to be notified in the second source, the number of missing cases will be overestimated. To avoid such errors, it is sometimes recommended that sources of case-finding with a high degree of dependence be combined prior to the application of capture-recapture analysis.

As compared to independent case asertainment, the current method has the following differences. First of all, a shortcoming of the capture-recapture study is that one can only find out an estimate of the number of missing cancer cases from the cancer registry, and not be able to view these cases or, what would be even more important, incorporate these in the registry files if they are eligible for registration. On the other hand, capture-recapture study is more comprehensive at coverage, i.e. looking at the completeness of case ascertainment of a cancer registry as a whole. Independent case ascertainment only includes one or a rather small number of databases and is therefore confined at estimating case completeness of registration from one specific hospital or regarding one or a few cancer sites.

3.2.3.2 Review of studies of completeness using capture-recapture method

In the following section, some examples of studies which have looked at case completeness in cancer registries, using capture-recapture method, are described. These are ordered by countries they were performed in and are all summarised in Table 3.2.

Canada. The completeness of registration at the Ontario Cancer Registry was investigated by Robles *et al*. (1988). They used a simple capture-recapture method with two data sources and a modelling approach, using three data sources: hospital discharge

data, pathology reports, and death certificate data. They concluded that completeness was remarkably similar for all sites together, 95.2% using three sources (ranging from 94.9–96.1% for different models) and 95.9% using two sources. The estimates of completeness varied by site, ranging from about 91% to 100%.

The Netherlands. To find out whether capture-recapture method was a useful tool for estimation of cancer registry completeness, Schouten *et al.* (1994) carried out the following study. Using the data from the pathology registration system and hospital discharge system, they assessed the completeness of registration of three regional cancer registries in the Netherlands. They used simple analysis as well as modelling approach. As a result, they estimated the completeness to be 98.3%. They noted that the estimate of completeness was dependent on patient's age and cancer site. The authors were able to point at some drawbacks of this method such as its inability to estimate the number of cases that are not routinely notified to the registry by one or both notification sources and the lack of statistical power to detect incompleteness at an early stage.

Germany. Brenner *et al.* (1995) conducted a study aimed to assess the performance of the two source capture-recapture method in estimating the completeness of cancer registration. They conducted a study in the population-based cancer registry of Saarland, Germany, for which there are three main sources of notifications: reports by clinicians and pathologists, and death certificates. For groups of cases notified by one of the three sources, known completeness of registration by the other two sources was compared with the corresponding two source capture-recapture estimates. The authors concluded that deviations of estimated completeness from known completeness were generally small or moderate.

New Zealand. The completeness of childhood cancer registration, using capture-recapture method, has been assessed by Dockerty and *et al.* (1997). They used three different data sources, such as the New Zealand Cancer Registry, the patient management system , and a separate children's cancer registry. Capture-recapture methods were used to estimate the total number of incident cases that would have been expected if ascertainment had been complete. The authors used simple calculations to estimate the number of cases based on two notification sources, and fitted log-linear models using data from all three sources. During the study period, 409 incident cases of childhood cancer were confirmed. The capture-recapture estimate for the total number of cases for the study period and population was 410. The New Zealand Cancer

Registry ascertained 97% of the confirmed cases, the patient management system ascertained 98% of the cases and children's cancer registry 86% of the cases.

Korea. A study was carried out by Kim and *et al.* (1999), who evaluated the completeness of cancer case ascertainment in the Seoul Male Cohort Study during three years, using capture-recapture method. Cancer cases were ascertained from three different sources: medical records, death certificate data, and two cancer registries. Using a log-linear model, the estimated completeness of overall case ascertainment was 89.9%.

Table 3.2. Studies which have looked at case completeness in cancer registries, using capture-recapture method

Authors and year of publication	Cancer registry/study	Study period	Method used	No of sources	Independent sources	Completeness (%)
Canada						
Robles *et al.* (1988)	Ontario Cancer Registry, Canada	1982	Simple analysis (two data sources) and a modelling approach, using three data sources	3	Hospital discharge data, pathology reports, and death certificate data.	95.2 for three-sources and 95.9 for two-sources comparison
The Netherlands						
Schouten *et al.* (1994)	Three regional cancer registries in the Netherlands	1990	Simple analysis and a modelling approach	2	The pathology registration system and hospital discharge system.	98.3
Germany						
Brenner *et al.* (1995)	Saarland Cancer Registry, Germany	1970, 1975, 1980, 1985 and 1990	A three-sources modelling approach	3	Notification by clinicians, pathologists, and death certificates.	95.5–96.9
New Zealand						
Dockerty *et al.* (1997)	New Zealand Cancer Registry	1990–93	Simple calculations and log-linear models	3	Cancer registry, patient management system, and children's cancer registry.	For each of the three sources: 86, 97 and 98 respectively
Korea						
Kim *et al.* (1999)	Seoul Male Cohort Study, Korea	1993–95	Log-linear model	3	Medical records, death certificate data, and two cancer registries.	89.9

3.2.4 Other *ad hoc* methods

3.2.4.1 Comparison with other populations

Comparison of cancer incidence in two populations can be used to find out differing completeness of registration between the populations compared. The historic data method, for example, compares the number of cases observed in the registry with the number 'expected' derived from some notionally similar population (Parkin *et al*. 1994a) such as earlier data from the same registry. By carrying out comparison of cancer incidence in two populations, absolute numbers of cases as well as their distribution by age can be examined as an indicator of completeness of case-finding.

The assumptions used by this method can be rather unrealistic. Namely, it assumes that differences in completeness of registration become evident when populations with high degree of similarity are compred. It would mean comparing populations with high similarity of lifestyle and environmental exposures, as well as age structure and other relevant demographic factors. However, this is probably difficult to achieve with any confidence. In addition, another problem is a question how completeness was estimated in the reference population as in reality 100% completeness can never be achieved.

Because of the severe methodological issues described here, comparison with other populations should be only used to detect step changes over time and/or serious problems in case completeness.

3.3 Validity of registration

3.3.1 Principles

As stated above, validity denotes the proportion of cases recorded at the registry with a given characteristic (sex, age, diagnosis etc.) which truly have this attribute (Parkin *et al.* 1994a). The validity of recorded data depends upon the quality of the data source documents, and the level of skill in abstracting, coding, data entry, and recoding this information for the registry data base (Parkin et al. 1994a; Schouten 1996).

The quality of the data source documents is in fact the most essential component to guarantee valid records at the cancer registry. As the data source documents such as hospital case notes, pathology reports, or radiotherapy notes are regarded as a complete source of cancer information, the so-called "gold standard", it is difficult to judge their quality. Validity of registration is likely to be maximised by using multiple sources of

data. The rationale is that the quality of the data will be enhanced by bringing together in a single file every item relating to the patient, derived from different sources.

Abstracting cancer registration data from the source documents is a task that requires training and care.

Data abstracted by clinicians have been compared with data abstracted by registration personnel (Schouten *et al.* 1993). This study showed that registration personnel are able to abstract data with a high degree of accuracy. A recent study (Reisch *et al.* 2003) stressed the importance of training of medical record abstractors. The quality of the trained abstractors was monitored by asking them to abstract a number of medical records, a procedure which was replicated and reviewed by a second abstractor. High agreement was found between initial and replicated abstractions.

Several methods estimate validity like the internal consistency method, the diagnostic criteria method, and the reabstraction method (Kuntoro *et al.* 1994). An overview of these methods is presented in the following sections.

3.3.1.1 Internal consistency checks

The internal consistency method is performed by means of validity tests to check the registry database for legitimate codes. There are different levels for edit checks (Parkin *et al.*1994), with the most basic edit check designed to reject records with topographic or morphological codes outside the permitted range. Other checks are designed to exclude illogical dates (for example cancer incidence date before the date of birth of the patient etc.) or impossible combinations (for example cancer of prostate in a woman). Most of these checks are developed by international institutions working on cancer registration such as International Agency for Research on Cancer or International Association of Cancer Registries. Using standard edit checks across different registries guarantees higher levels of accuracy and better comparability of cancer data from different registries.

3.3.1.2 Diagnostic criteria

This method estimates the validity of diagnosis only. The diagnostic criteria method determines the proportion of registry cases that meet stringent diagnostic criteria (Parkin *et al.* 1994). Cancer cases registered vary in terms of the specificity and quality

of the diagnostic information. There are several indicators that measure validity of registration of the specific cancer diagnosis: histology, autopsy, clinical, DCO and others. The diagnostic criteria method estimates the proportions of cancer cases which are based on each of these diagnostic methods.

Two of these indicators – the proportion of cases with histological verification of diagnosis, and DCO cases – have been particularly widely used. The rationale for using the DCO cases in connection with maximising case completeness was described in Section 3.3.1.1. As for case completeness, the proportion of DCO's is used as a negative indicator of registration validity with higher rates of DCO's meaning lower validity. The rationale here is that reporting of cause of death on death certificate is not always accurate, especially if the autopsy was not performed and reporting the cause of death depends on disease history and/or results of clinical investigations. Another concern about using death certificates is that the cause of death on these is frequently coded to a less specific category. This was shown in a study performed by Percy *et al.* (1981). They compared death certificates with an underlying cause of death to the hospital diagnosis for 48 826 cases of primary cancers. The accuracy of the death certificate code was assessed by comparing the primary cancer site reported on the hospital diagnosis with the cancer site coded as the underlying cause of death on the death certificate. They found that about 80% of cases had good agreement between the primary site diagnosed in the hospital and that recorded on the death certificate. For a number of sites the agreement percentage was much lower. Similar findings were reported by Cameron and McGoogan (1981), who compared clinical diagnoses with autopsy findings. In this study the major cause of death was confirmed only in 61%, although agreement was higher when taken at a level of broader cause of death categories.

The proportion of cases with histological verification (HV%) of diagnosis implies that a portion of the suspected neoplasm has been examined by microscopic examination by a histopathologist (Parkin *et al.*1994). It shows the thoroughness of investigation and therefore HV% is regarded as a positive indicator of data validity. Some authors include in the HV% diagnoses made on the cytological examination of smears or aspirates, this latter wide definition being named "morphologically verified cases" (MV%) as for example used in *Cancer Incidence in Five Continents vol. VIII* (Parkin *et al.* 2002).

The proportion of MV% varies considerably by cancer site, depending upon accessibility to biopsy. It also depends on the clinical practice and availablility of resources such as alternative diagnostic techniques. The emergence of new imaging techniques such as ultrasound, computerized tomography and nuclear magnetic resonance may cause a fall in MV%'s for some of the cancer sites as they provide as convincing evidence for the presence of a cancer as does morphological examination. The overall MV% for a cancer registry should be examined in the context of the types of cancers occurring in the area and the availability of other accurate diagnostic methods.

3.3.1.3 Reabstraction

The reabstraction method consists of reabstracting a random sample of records from medical case notes and then comparing them with the original cancer registry records. The reabstraction process is thought to be more thorough than the original cancer registration process as more effort is made in the completion of each cancer notification to achieve maximum validity. Therefore the reabstracted records are assumed to be correct.

The validity is measured as the agreement proportion between the reabstracted and the registry records by key variables in the cancer registration data and those comparisons can be made by cancer site. Disagreements are investigated.

3.3.2 Review of studies of validity of registration based on reabstraction

The following is an overview of studies that have looked at validity using reabstraction method, the results of these studies are all summarised in Table 3.3. In all, there were seven studies that came from the United Kingdom, two from the Nordic countries (Sweden and Norway), and one from the Netherlands.

United Kingdom. Lapham and Waugh (1992) carried out an audit of coding of the site and morphology of cancers registered at the Tayside Regional Cancer Registry. Thus this study looked at the validity of diagnosis only. They compared the data of 200 consecutive patients (about 10% of the annual total) registered at the Tayside Regional Cancer Registry with the pathology reports (including histopathology surgical reports and post mortem reports) of these patients and in case those were missing, data were

obtained from hospital notes. Cancer site and morphology were coded by the researcher and later the discrepancies between the reabstracted diagnosis and the diagnosis registered at the cancer registry were investigated and graded according to severity. Eleven serious differences were detected, composing mainly of two categories, firstly secondary tumours classed as primaries, and secondly wrong sites. The conclusion based on this study was that the quality of cancer registration data was good, but could be improved.

Gulliford *et al.* (1993) investigated the validity of Thames Cancer Registry data with data obtained from hospital case notes and radiotherapy records for all men resident in the South East and South West Thames Regions, who were aged less than 75 years at diagnosis and who had bladder cancer first diagnosed in 1982. Data were abstracted by one medically qualified investigator using standard data collection forms. Comparisons were made for ten items of data, most of which comprised diagnosis-related items and only two items such as date of birth and date of death related to patient information. For five continuous variables and for tumour morphology, the levels of agreement were high, ranging from 84 to 93%. Data concerning tumour stage did not clearly distinguish superficial from invasive tumours.

Brewster *et al.* (1994) carried out an extensive study to assess the overall accuracy of Scottish cancer registration data. It should be noted that Brewster uses the term "accuracy" instead of "validity". They selected a random sample of 2 200 cancer registrations, which comprised 6.9% of all cancer registrations in that area in 1990 and estimated accuracy by reabstracted records method. The authors visited the institutions where diagnosis had been first established, and one person reabstracted selected items of data from medical records. Comparing the abstracted data with the registry files, it was revealed that discrepancies ranging from 3.5% for identifying items of data to 28.3% for morphology codes, existed, with the overall 2.8% of cases having serious discrepancies. This finding lead to the conclusion that Scottish cancer registration data show a high level of accuracy. Results of this study have been published according to tumour site such as lung (Brewster et al.1995b), colorectal (Brewster et al.1995a), and non-melanoma skin cancer (Brewster et al.1995c), all three sites regarded to show high level of registration accuracy.

Another study looking at the validity of cancer diagnosis and comparing the registry data with the histopathology records was undertaken by Lancaster and *et al.* (1994). These researchers looked at the validity of cervical cancer registered by the North

Western Regional cancer Registry during 1989–1990. After inspecting the histopathology reports and comparing the diagnosis codes with those recorded at the cancer registry they were able to conclude that 97% of the cases had been recorded correctly at the registry, with 3% incorrectly coded either for site or behavioural code.

The validity for cancer registration of 5 744 sets of hospital case notes was studied by Middleton *et al.* (2000). These case notes had been electronically captured by the Northern Ireland Cancer Registry in 1993–1995 using patient administration system as a source. Examining the medical records showed that 7.4% of the cases coded on discharge as cancer had no malignancy recorded in case notes while 4.1% had in situ or benign tumours. Accuracy of demographic data was very high. Major changes in the site of the tumour were found in 26.9% of the cases, where case notes recorded a completely different organ or system from that reported by patient administration system. The date of the diagnosis was the least accurate item collected, with only 25.6% of patients having the correct date of diagnosis assigned to them by the patient administration system. However, the actual date of diagnosis differed only slightly for a large number of cases.

A study by Dickinson *et al.* (2001), which was summarised for results of completeness of case ascertainment above, also looked at the validity of cancer registrations, carrying out a pathology review of the registered cases. Cancer diagnosis differed substantially from this pathology review for 7% of cases (95% CI 5–9%). Over one third of these discrepancies were attributable to failures in data capture or coding by the cancer registration system and almost a half to changes in diagnosis. Agreement on date of diagnosis was generally high, with dates for fewer than 1% of the cancers discrepant by over one year.

Brewster *et al.* (2002) studied the accuracy of a sample 3 500 cancer registrations to the Scottish Cancer Registry. Reabstracted information was compared with the information stored at the cancer registry. Accuracy was high for demographic, diagnostic, and fact of treatment details, but less reliable for grade of differentiation, staging variables, and dates of treatment. Data accuracy was concluded to be high overall.

The Nordic countries

Sweden. The study carried out by Garne *et al.* (1995) that was summarised above for results of case completeness, also looked at validity of cancer diagnosis, namely of breast cancer registration, comparing the cancer registry entries with clinical records. After reviewing the cases from clinical records, the authors confirmed 93.3% of registered invasive breast cancer cases and 78.0% of bilateral cancers. They were able to see improvement of validity with time, as they were looking at cancer registrations during the period of 20 years.

Norway. The study carried out by Tingulstad *et al.* (2002) was aimed at assessing completeness as well as validity of registration of the ovarian cancer. Regarding validity, it only looked at the validity of diagnosis, which was estimated at 92%. Coding errors were found in 2% of the cases, and in 6% of the cases it was not possible to reproduce the original diagnosis of ovarian cancer at re-evaluation.

The Netherlands. As part of their study, Schouten and *et al.* (1997) estimated the validity of childhood leukaemia registration in The Netherlands. The data files of two cancer registries – Dutch Childhood Leukemia Group and the Netherlands Cancer Registry – were linked. Unlinked records or records with disagreements (birth date, sex, type of leukaemia and incidence date) were checked with original source. Disagreement proportions were relatively small, rating from 0.5–2.5% and the validity of these registries was considered to be high. One of the registries – The Netherlands Cancer Registry – had also recorded incorrectly nine cases (the total for leukemias recorded for this period was 445) that were not eligible, and part of the disagreement was ought to be caused by difference in coding rules.

Table 3.3. Studies which have looked at validity of cancer registration, using reabstraction method.

Authors and year of publication	Cancer registry	Study period/ year	Results	Comments
United Kingdom				
Lapham and Waugh (1992)	Tayside Regional Cancer Registry, UK	1988	11 serious differences detected in 200 notifications	The quality of cancer registration data was good, but could be improved.
Gulliford *et al*. (1993)	Thames Cancer Registry, UK	1982	For most data items, the levels of agreement were high, ranging from 84 to 93%.	Discrepancies occurred with staging.
Brewster and Muir (1994)	Scottish Cancer Registry	1990	Discrepancies ranging from 3.5% for identifying items of data to 28.3% for morphology codes, existed, with the overall 2.8% of cases having serious discrepancies.	A high level of validity.
Lancaster *et al.* (1994)	North Western Regional Cancer Registry	1989–90	97% of the cases had been recorded correctly	The incorrectly coded cancers were either site or behavioural code.
Middleton *et al.* (2000)	The Northern Ireland Cancer Registry	1993–95	7.4% of the cases coded on discharge as cancer had no malignancy recorded in case notes while 4.1% had in situ or benign tumours.	Accuracy of demographic data was very high. The date of the diagnosis was the least accurate item collected.
Dickinson *et al.* (2001)	The National Health Service Central Register for England and Wales	1971–89	Cancer diagnosis differed substantially for 7% (95% CI 5–9%) of cases.	Agreement on date of diagnosis was generally high, with dates for fewer than 1% of the cancers discrepant by over one year.

continued

Table 3.3. Studies which have looked at validity of cancer registration, using reabstraction method.(continued)

Authors and year of publication	Cancer registry	Study period/ year	Results	Comments
United Kingdom (continued)				
Brewster et al. (2002)	The Scottish Cancer Registry	1997	Accuracy was high for demographic, diagnostic, and fact of treatment details, but less reliable for grade of differentiation, staging variables, and dates of treatment.	Data quality is high overall.
Sweden				
Garne *et al.* (1995)	The Swedish Cancer Registry	1971–91	Validity was 93.3% for cancer diagnosis	This study looked at the validity of diagnosis only. The authors were able to see improvement of precision with time.
Norway				
Tingulstad et al. (2002)	The Cancer Registry of Norway	1987–96	The validity of diagnosis was 92%.	Coding errors were found in 2% of the cases, and in 6% of the cases it was not possible to reproduce the original diagnosis of ovarian cancer at reevaluation.
The Netherlands				
Schouten *et al.* (1997)	Dutch Childhood Leukemia Group and the Netherlands Cancer Registry	1989–92	Disagreement proportions, rated from 0.5–2.5%	The validity of these registries was considered to be high.

3.4 Completeness of data items

Validity is influenced not only by erroneous data but also by missing data. The proportion of cases with missing information for indicator variables is also an indicator of quality and validity (Parkin *et al.* 1994). According to Parkin, certain items are deemed essential, as for example gender, while others, such as marital status or occupation, are not so important to have complete data on. It is not always possible to complete each item for every patient as this information may be missing from the source documents, or even worse, the source documents may be designed so that they do not routinely record this item. The range of data items recorded on medical case notes may vary from one hospital to another. It is important to be able to distinguish between these two situations when the proportion of missing values is calculated for each item.

When missing code rates are calculated, several factors such as the importance of the item, the ease or difficulty of obtaining data regarding the item, and the specific interests of each registry must be taken into account (Parkin *et al.* 1994). Monitoring of missing information is often conducted through the tabulation of missing code percentages by site and item.

In their study Mettlin and *et al.* (1997) compared completeness of data items in two large data sets, designed for distinctly different purposes that rely on different methodologies. The first one was the National Cancer Data Base, which uses hospital-based cancer reporting system. The second one was the Surveillance, Epidemiology, and End Results Program, which is a population-based registry project of the National Cancer Institute. They selected specific cancer sites, such as female breast cancer, colorectal cancer, lung cancer, and prostate cancer, and obtained data for cancers diagnosed during one year from the Surveillance, Epidemiology, and End Results Program and National Cancer Data Base. The authors admit that the numbers of patients studied were very large and statistical significance of observed differences had to be distinguished from clinical or public health significance. They observed similar levels of data completeness for both databases. The authors state that epidemiologic cancer data can be recorded accurately only by a population-based system, such as the Surveillance, Epidemiology, and End Results Program.

3.5 The need for data quality studies in Estonia

As stated in Section 2.3.1.6, no *ad hoc* studies to evaluate data quality at the ECR have been carried out up to now.

The Estonian Cancer Registry as it operates today carries out some routine procedures of checking its data quality. As part of cancer registration procedure, edit checks are performed for most of the data items. In the course of routine data quality checks, the percentage of DCO's and MV% are calculated. These are presented in the annual statistical reports as well as in international comparisons. Examples of the DCO's and MV%'s for the ECR in comparison with the neighbouring countries will be presented in Chapter 6.

The ECR also performs linkage of its information with data files of some of the bigger hospitals that have electornic databases. This constitues another routine quality check procedure aimed at increasing case completeness.

The data from ECR have been used in international studies and therefore the some of its data have been checked to meet the quality criteria of those studies. In recent years, the ECR data have been increasingly used for research purposes, and to some extent, this has enhanced the quality of its data. On the other hand, it is important to quantify the quality characteristics.

Therefore there is a great need for quality studies of the ECR data to guarantee high quality of the registration data because if data are not complete and valid, they affect the results and conclusions of the studies they are used in.

The next chapter presents three quality studies of the ECR data undertaken for this thesis: a study estimating the completeness of registration using independent case ascertainment, a study assessing the validity of the ECR data using reabstraction method, and a study looking at the completeness of data items at the ECR.

Chapter 4. Validating the Estonian Cancer Registry

The importance of assessing data quality of a cancer registry and literature review of methods looking at different aspects of quality were provided in Chapter 3. In this chapter three *ad hoc* studies looking at the quality of the Estonian Cancer Registry data are presented. The following quality characteristics that were defined in Chapter 3 Section 3.1.2 were estimated by these studies: case completeness, validity of cancer registrations, and completeness of data items. These data quality studies were conducted and overseen by K. Lang (KL) in 1999–2000.

The first two studies use a cross-sectional design and cover cancer registration for the year 1998. This year was chosen for the study of case completeness and validity of registrations as this was the most recent year for which cancer registration was complete at the time this component of the research was started. The study of completeness of data items is a retrospective study and covers the years 1995–2000 in order to show how this quality characteristic has changed over time. It was undertaken after the other two studies.

In the analyses there was no age–restriction on the cancers studied. Thus included childhood cancers as well as adult malignancies are included. However, because the number of adult cancers far outnumber those in childhood, the conclusions are going to apply first and foremost to adult cancers. Whether data quality is different with respect to childhood cancers *per se* had not been directly addressed in this thesis.

Ethics approval for conducting these studies was granted by the Ethics Committee of the University of Tartu (protocol no. 84/22).

The aim of these studies was to estimate the quality of data collected by the ECR and suggest ways in which the quality of the data may be improved.

4.1 Case completeness

This study was designed and conducted by KL, with the assistance of T. Aareleid, the director of the ECR, and M. Mägi, a medical cancer registrar at the ECR. This study was recently published (Lang *et al.* 2003), and a copy of the article is attached to this thesis in Appendix 1.

4.1.1 Aims and setting

This study had two aims. The first was to assess the completeness of registration at the ECR from two major hospitals in Estonia. The second aim was to look at the quality and usability of data bases used for linkage with the ECR data files for quality studies.

Tartu is the second largest city in Estonia with a population of 101 246 (Statistical Office of Estonia 2004) situated in the south-central part of Estonia. It is the home to the only medical school in Estonia, the Medical Faculty of the University of Tartu. The Tartu University Clinics contain 17 specialised clinics and provide tertiary care mainly for the population of Southern Estonia, which accounts for about one third of the Estonian population. Maarjamõisa Hospital and Lung Clinic, that participated in this study, both operate as part of the Tartu University Clinics.

4.1.2 Material and methods

This study estimated the registration completeness at the ECR, using the method of active retrieval. This is a subtype of independent case ascertainment method that was described in detail Chapter 3 Section 3.2.2. In brief, it involves comparing the total number of cases registered by the cancer registry to those ascertained from another source, which is judged to be relatively complete, and has the same target population.

The ECR cancer data for 1998 were compared with hospital discharge data from Maarjamõisa Hospital, and the medical insurance data file from the Lung Clinic by electronic linkage of their data with ECR data and active retrieval of missed records deemed eligible for registration was carried out.

These two hospitals were selected for the study because they contribute considerable numbers of cancers to the ECR, and have an electronic data base. Only a small number

of hospitals in Estonia have this. The Lung Clinic was also chosen for linkage for the reason that the number of cancer notifications from this clinic fell by over a half compared with 1997 (57 in 1998 *versus* 134 in 1997), which suggested a decline in the completeness of notification.

The data base from the Maarjamõisa Hospital collected discharge information mainly for administrative purposes. The data base from the Lung Clinic contained medical insurance data that are used as reimbursement claims for hospital stays. These are handled by the National Sickness Fund, which implements the medical insurance system introduced in Estonia since 1992 (Nielsen 2001).

The discharge data base of the Maarjamõisa Hospital contained data on patients with a discharge diagnosis of malignant, benign or *in situ* neoplasm, or neoplasms of uncertain or unknown behaviour (ICD–10 C00–C97, D00–D48). The insurance data base of the Lung Clinic contained information about patients diagnosed with malignant tumours (ICD–10 C00–C97).

Both of the hospital data bases were linked with the ECR data base by computerised probability matching, using first name, surname, date of birth and ICD code as matching variables. Clerical checking was carried out to resolve cases in which the automated matching could not definitely indicate a successful match.

Patient identification data and codes of diagnoses for cases missing from the ECR data base were sent to the hospitals. The medical records departments of the hospitals were asked for permission to review the case notes. The researchers then visited the hospitals and reviewed the case notes. If the diagnosis of cancer for a specific case was confirmed by them as a result of reviewing the case notes, they filled in a notification form and the case was registered at the ECR.

Case completeness was calculated (Parkin *et al.* 1994) by dividing the number of existing cases reported by the respective hospital(s) to the ECR by the sum of existing in the ECR and actively retrieved cancer cases from the same hospital(s).

4.1.3 Results

The Maarjamõisa Hospital **discharge data base** for 1998 contained 699 records of individuals whose diagnosis appeared to be eligible for cancer registration at the ECR, i.e. these persons had been diagnosed during 1998 with a cancer registrable to the ECR.

Of these, 640 (96.6%) were classified in the discharge summary as having a malignant tumour, 43 (6.2%) as having a benign neoplasm or neoplasm of uncertain or unknown behaviour of the meninges, brain or other parts of the central nervous system (CNS) (D32–33, D43), and 15 patients had a neoplasm of uncertain or unknown behaviour of intracranial endocrine glands (D35.2–35.3; D44.3–44.5). One patient had carcinoma *in situ.*

Of these 699 registrable cancer patients, 621 (88.8%) were already registered at the ECR at the time of review, seven months later, and 78 were unregistered. Out of 621 registered patients, 345 (55.6%) had been registered from the Maarjamõisa Hospital and 276 (44.4%) had been registered from a different medical institution.

After review of the case notes, 48 (6.9%) of the 78 unregistered patients were found to be eligible for cancer registration (Table 4.1). For 18 of these patients, the notification had actually been completed by the doctor but had been left in the medical record, rather than sent to the ECR. For all 48 unregistered cancer patients a notification was filled in and the case was registered at ECR.

Of the remaining 30, initially considered to be eligible for cancer registration, a diagnostic coding error was detected for 20 patients, and case notes could not be retrieved for 10 patients (Table 4.1). Typical coding errors included: another disease coded as a tumour, benign tumour not registrable to the ECR coded as a malignant or *in situ* carcinoma, wrong site code (e.g. skull instead of brain), metastasis coded as a primary tumour (e.g. breast cancer metastasis in orbital bone coded as malignant neoplasm of the eye). Neoplasms of the CNS, prostate and digestive organs were most frequently unreported (Table 4.2).

The completeness of case ascertainment by the ECR based on cases present in the Maarjamõisa Hospital data base was 92.8% (95% CI 90.6–94.7).

The Lung Clinic **insurance data base** contained information on 200 patients diagnosed in 1998. Of these, 146 (73%) had been registered at the ECR by 31.01.01. From these 146, the notification had been received from the Lung Clinic for 57 (39.0%) and from another medical institution for 89 (61.0%) patients.

Among the 54 who were not registered, 30 patients were found to be eligible for cancer registration. Out of the 30 eligible patients, 18 had lung cancer, which is a high number of lung tumours being not registered by the Lung Clinic. The 24 patients initially

Table 4.1. Distribution of cancer cases missing from the ECR as a result of data linkage and search for these cases at Maarjamõisa Hospital and Lung Clinic.

Type/site of the neoplasm	Eligible cancer case not recorded in ECR	Medical record not found	Coding error	Uncertain diagnosis	Total
The Maarjamõisa Hospital					
Malignant neoplasm (C00–C97)	37	6	15	–	58
In situ neoplasm (D00–D09)	–	–	1	–	1
Benign neoplasm of meninges, brain, and other parts of CNS (D32–D33)	8	2	–	–	10
Benign neoplasm of other and unspecified endocrine glands (D35.2–D35.4)	1	2	1	–	4
Neoplasm of uncertain or unknown behaviour of meninges, brain, and other parts of CNS (D42–D43)	2	–	3	–	5
Total	**48**	**10**	**20**	**–**	**78**
The Lung Clinic					
Malignant neoplasm (C00–C97)	**30**	**12**	**8**	**4**	**54**

Tabel 4.2. Cancer cases by primary site registered for the first time following active retrieval from Maarjamõisa Hospital and Lung Clinic.

Primary site	**ICD–10**	**Maarjamõisa Hospital**	**Lung Clinic**
Pharynx, other lip, and oral cavity	C14	1	–
Digestive organs	C15–C26	6	–
Lung	C34	1	18
Mediastinum	C38	1	–
Mesothelioma	C45	–	2
Prostate	C61	7	–
Bladder	C67	3	–
Brain, malignant	C71	6	–
Thyroid gland	C73	–	8
Primary site not specified	C80	2	1
Lymphoma	C81–C85	4	1
Myeloma	C90	2	–
Lymphoid leukaemia	C91	4	–
Central nervous system, benign	D32–D33	8	–
Hypophysis (pituitary), benign	D35.2	1	–
Central nervous system, uncertain behaviour	D42–D43	2	–
Total		**48**	**30**

considered to be eligible for cancer registration fell into the following categories: diagnostic coding errors were found in 8, a cancer diagnosis could not be firmly established in 4, and the medical records of 12 patients (22.2% of all patients whose records suggested eligibility for cancer registration) could not be located (Table 4.1).

The completeness of case ascertainment by the ECR based on cases present in the Lung Clinic data base was 83.0% (95%CI 76.6–82.2).

For Maarjamõisa Hospital and Lung Clinic, among 132 patients whose records suggested eligibility for cancer registration at either of these hospitals, 78 unregistered tumour patients (67 malignant tumours and 11 cases of tumours of benign, uncertain or unknown behaviour of CNS and intracranial endocrine glands) were detected by means of active retrieval (Table 4.2).

The overall completeness of case ascertainment by the ECR based on the linkage of data bases from these two hospitals was 90.8% (95% CI 88.6–92.6). Among malignant neoplasms, cancers of the lung, thyroid and prostate were the most frequently missed. Diagnostic coding errors were detected in 28 cases. These were mainly misclassification of another disease as a malignant tumour, or of a lung metastasis as a primary site; in all

these cases the true primary site had already been notified to the ECR. For four patients, a cancer diagnosis could not be firmly established from the information in the medical records, and the medical records of 22 patients (16.7% of all patients whose records suggested eligibility for cancer registration) could not be retrieved.

Only 344 (55.4%) of the cancer cases that had been registered from Maarjamõisa Hospital and 57 (39.0%) from Lung Clinic data base were marked in the ECR files as notified by these specific hospitals. The rest of the notifications had been reported to the ECR from other medical centres where the patients had also been seen for diagnosis and/or treatment.

4.1.4 Discussion

This project led to 1.1% increase in the total number of malignant tumours registered for 1998, from 5 824 to 5 891. Among malignant neoplasms, cancers of the lung, thyroid gland and prostate were most frequently undernotified. For these sites, the number of cancer cases for 1998 for Estonia as a whole increased 2.6%, 11.8% and 2.2%, respectively as a result of this exercise.

In addition, 11 cases of neoplasms of benign, uncertain or unknown behaviour of CNS and intracranial endocrine glands were registered as a result of this study. This raised the total number of these neoplasms from 94 to 105, a rather considerable increase of 10.5%.

The overall completeness of case ascertainment of (90.8%, 95% CI 90.6–94.7) by the ECR was not remarkably high. Yet it does not represent the case completeness of ECR as a whole as it is based on the case completeness estimates from two hospitals only. Also, it includes the non-malignant neoplasms of the CNS that only started to be notified in 1998 and presented with a rather serious undernotification problem. It should be noted that the Lung Clinic was included in this study precisely because there were concerns that there may have been substantial underregistration in 1998. Furthermore, two of the cancer sites that were missed most often, lung and thyroid, were missed from the Lung Clinic. As for prostate cancer that appeared third in the list of cancer sites missed most often, this was missed from the Maarjamõisa Hospital, and it is not clear why this specific site remained unregistered in a relatively high number of occasions.

The fact that a number of case reports (at least some of which contained information on patients eligible for cancer registration) were not obtainable makes it likely that the real case completeness is lower than that detected by this study. All these issues influencing case completeness of cancer registration are discussed below and some predictions about the extent of the variation of its value are presented.

The case completeness of cancer registries varies between countries, as the registration system used and the nature of medical practice differs. However, it is nevertheless interesting to see how completeness of case ascertainment in the ECR compares with other cancer registries. When comparing the results of this study with the results from similar studies, that were also presented in Chapter 3 Section 3.2.2.2, the following observations can be made. The overall completeness of case ascertainment in the current study was a bit lower than detected in most studies that have included all reportable cancers (i.e. malignant neoplasms) and used only one data source (Brewster *et al.* 1996; Brewster *et al.* 1997; Mattson *et al.* 1985; Teppo *et al.* 1994; Zippin *et al.* 1995), a design resembling the current study most. In these studies completeness of case ascertainment ranged between 95.3 and 98.6%.

It should be noted that unlike from other studies which have included only malignant neoplasms, our study included all neoplasms reportable to the ECR, i.e. the non-malignant CNS neoplasms in addition to the malignant ones. As described below, for 1998 there was a particular problem with registering the non-malignant CNS neoplasms to the ECR that affected total case completeness.

The results of a study carried out by Parkin *et al.* (2001) that looked at the Uganda Cancer Registry and used a file of cancer patients enrolled into the HIV cancer study as an independent source, case completeness was 89.6% (95% CI 87.0–92.7), which is very similar to the result of the current study. Yet another study (Dickinson *et al.* 2001) that looked at the case completeness of the National Health Service Central Register for England and Wales used more than one source: five regional cancer registries and death registrations as independent data sources for cancer registrations, found that completeness of cancer ascertainment at 90% (95% CI 85–94) was also similar to the one detected in the current study.

In our study completeness of cancer ascertainment varied between the two hospitals studied, being as high as 92.8% (95% CI 90.6–94.7) for cases reported from the

Maarjamõisa Hospital and considerably lower (83.0%, 95% CI 76.6–82.2) for cases reported from the Lung Clinic.

Because case completeness was lower in **the Lung Clinic**, I will start by discussing the problems with cancer registration in the Lung Clinic. Two factors affected completeness of cancer notification in this clinic. Firstly, it was chosen for linkage because the number of cancer notifications from this clinic fell by over a half compared with 1997, which suggested a decline in the completeness of notification. In fact in the year 1998 a major reorganisation of the Lung Clinic took place, which seems to have contributed to the fall in cancer notifications as well as to the availability of medical records. Regarding cancer registration by the Lung Clinic during the more recent years, the number of notifications has increased: there were 95 notifications in 1999 and 107 in 2000.

Secondly, a rather high proportion (22.2%) of medical records of patients initially thought to be eligible for cancer registration could not be obtained for review from the Lung Clinic. The reasons were probably either the records had been misplaced in the archive or they were being used for a research project. The fact that a number of medical records were not available for review is likely to have an impact on the results of the study as several cancer patients eligible for registration could have been lost. In a scenario where 50% of all the missing case notes in the Lung Clinic contained information on cancers eligible for registration at the ECR and were registered in the course of active retrieval, completeness of case ascertainment from this clinic would have been as low as 80.2% This finding suggests that in fact the cancer registration completeness in the Lung Clinic may be lower than estimated by this study. It also shows that estimates made on such small numbers of cases are prone to random fluctuation of the results.

A related issue to this one regarding the medical case notes in the Lung Clinic is the finding that a cancer diagnosis could not be firmly established in four cases suggesting eligibility for cancer registration. It refers to the problem of low quality medical information recording in the Lung Clinic, which can affect the completeness of cancer registration from this source.

As for **the Maarjamõisa Hospital**, although the completeness of case ascertainment was higher than at the Lung Clinic, the following observations regarding cancer notification can be made.

First of all, a reasonable number of notifications from the Maarjamõisa Hospital (18) had not been forwarded to the ECR but left in the medical record. It means that the doctors had filled in notification forms, but at the medical records department of the hospital these notifications for some reason were not forwarded to the ECR. It is very likely that it happened as a result of carelessness of the staff at the medical records department. If these cancers had been notified in the first instance, the completeness from the Maarjamõisa Hospital would have been as high as 95.5%. Such failures are perhaps relatively easily remedied. Steps should be taken to improve the standard of work of clerical staff at the medical records departments of the hospitals to guarantee the processing of the notifications from the hospital to the ECR.

The 11 cases of non-malignant neoplasms of the CNS (8 neoplasms of benign behaviour (D32–D33) and 2 neoplasms of uncertain or unknown behaviour (D42–D43) of meninges, brain and other parts of the CNS and 1 neoplasms of benign behaviour of intracranial endocrine glands (D35.2–D35.4) that were registered from the Maarjamõisa Hospital as a result of active retrieval, deserve special attention. The registration of neoplasms of benign and uncertain or unknown behaviour of brain and (other parts of the) central nervous system and of intracranial endocrine glands (D32–D33, D35.2–D35.4, D42–D43, D44.3–D44.5) to the ECR was a new initiative that had only been proposed by neurologists and neurosurgeons to start from 1998. Thus our study year was the first year these neoplasms were to be registered and this perhaps explains this fairly large underregistration. Cancer registries are shown to have rather low completeness of cover in the first years after the start (Berkel 1990), and this apparently applies to a new type of neoplasm starting to be registered. The completeness of case ascertainment for non-malignant CNS neoplasms from the Maarjamõisa Hospital in 1998 was 89.5%. If these cases had been notified initially, the completeness of case ascertainment from the Maarjamõisa Hospital would have been 94.5%. Furthermore, excluding these neoplasms from this project would have increased the total case completeness from the two studied hospitals to 92.0%.

It can be concluded that much of the underregistration from the Maarjamõisa Hospital can be attributable to two specific problems which can be remedied.

For over a half (55.6%) of the cancer cases figuring in the Maarjamõisa Hospital data base and close to two thirds (61.0%) of cases present in the Lung Clinic data base, and eligible for cancer registration, the cancer notifications were in fact received from other

hospitals where these patients had also been seen. The fact is each cancer patient may be seen in several medical institutions. Thus the system operates so that each doctor notifies the cancer case when it first comes to his/her attention, regardless of whether it has been notified to the ECR already. The ECR receives several notifications for each case of cancer. This practice has been recommended (Parkin *et al.* 1994) as a means of enhancing case completeness.

Actively retrieving the 78 cases of neoplasms was quite laborious. Another very time-consuming activity was checking the 28 sets of notes where the diagnosis of a reportable to the ECR neoplasm appeared in the hospital data base, but which were 'false positives', i.e. not neoplasms. The medical case notes of these patients had to be reviewed most attentively and time spent on each such case was considerably longer than spent on each case actively retrieved. It shows that the accuracy of diagnostic detail in the hospital data bases is not very high. The explanation for this may be that these systems are designed and used for administrative purposes or reimbursement of claims for treatment rather than for disease monitoring. Although the data bases that were used in this study are fairly complete, the accuracy regarding clinical information is not very high as discussed above and that makes it rather difficult to use them in independent case ascertainment. On the other hand, it is not easy to find data bases for this kind of exercise as in routine cancer registration process all possible data bases are utilised to maximise completeness of cover.

4.1.5 Conclusions

Based on the findings of the current study, the completeness of cancer reporting varied between the two hospitals studied, as well as by cancer site. For reasons given in the discussion, the results are not generalizable to the ECR as a whole. It does suggest however that a more comprehensive validation of case completeness should be undertaken, involving at least all the main medical centres reporting on cancer to the ECR.

It also shows that because the target population of the ECR is fairly small, errors in the reporting systems such as yearly fluctuations or upheavals in just one or two medical centres can affect the overall completeness considerably.

Active retrieval as described in this study is still a very important exercise in increasing the completeness of case ascertainment by the ECR. Yet the method is labour intensive. One of the reasons is that the quality of hospital data bases regarding diagnostic information is not very good for this kind of exercise. Therefore, other ways of enhancing case completeness, such as raising doctors' awareness about the importance of cancer notification in the first place, should be undertaken.

4.2 Validity of cancer registrations

This study was designed by KL, in collaboration with T. Aareleid, the director of the ECR, and M. Rahu, a scientific consultant to the ECR. Data for this study were collected and analysed by KL with the assistance in data collection of a medically trained research assistant.

4.2.1 Aims

The main aim of the study was to assess the completeness and validity of information recorded on cancer notification forms.

The specific aims were to:

1) estimate what proportion of medical case notes (from which cancer notifications are derived) that can be retrieved from statistical departments/archives

2) estimate by hospital which is the quality of case notes as a source for completing cancer notifications, i.e. for which variables that are important in cancer registration, the sections are in fact present in the case notes pro formas

3) detect any differences in personal and clinical items of information and estimate the agreement percentage between the ECR data on each cancer case and that obtained by reabstraction from the case notes, treating the latter ones as the 'gold standard'

4.2.2 Methodology

Validity of cancer registrations was assessed by carrying out a reabstraction study. This methodology was described in Chapter 3 Section 3.3.2.3. In the current study, we compared the information as entered from cancer notifications and recorded at the ECR data files, to the details reabstracted from clinical notes undertaken in the course of this study. The reabstracted cancer notification was considered as a 'gold standard'.

A random sample of 1206 cases (20.5% of the total number of cancers registered) of cancers registered at the ECR in 1998 was requested from the ECR, stratified by the size of the hospital. This included all new cancer cases diagnosed in 1998 and having only one hospital notification, selected at random. We excluded those cases that had

multiple notifications (hospital or pathology), because for these cases the ECR data base contains information combined from all sources and it would be very difficult to determine what information was derived from which source. For the purpose of this study it would not be possible for cases based on multiple notifications in the ECR to use the reabstracted notification from any single source as the "gold standard".

For all cases in the sample, personal data were extracted from ECR computer files. The variables for each case included first name and surname, date of birth, name of the doctor notifying the cancer, medical record serial number and name of the hospital at which cancer was diagnosed. The patient list was sorted by hospital. The lists of patients were taken to the hospitals. Information about the availability of personal and clinical information in the case notes, relevant for cancer registration, was evaluated. Information requested on the cancer notification form was recorded on a blank notification form for each patient in the study sample. This formed the 'gold standard' notification, against which the ECR data base was compared for the validity of detail for selected variables.

We did not attempt to record items of clinical information such as stage or treatment of cancer on the reabstraction notifications because we did not have the expertise in clinical oncology, needed for this. We also did not record information on treatment details because of its complexity. Moreover, information on treatment is often updated in ECR data files after the original cancer notification form is received, and thus would have not been comparable with what we would have abstracted. It should be noted that clinical stage and treatment of cancer are not considered to be among the items of basic information that should be collected by registries (Parkin *et al.* 1994).

The reabstracted notifications were entered on the computer using the same data input system as used by the ECR. These data as well the original dataset from the ECR, containing information on the study subjects were then transformed to STATA statistical package, where data linkage and analysis was performed.

Sample size. Before undertaking this study we determined what would be an appropriate sample size for reabstraction in order to get estimates of agreement that were relatively precise. The sample size required for this exercise was calculated using the following formula:

$$N = \frac{\Pi(1-\Pi)}{\ell^2}$$

where N is sample size, Π is the agreement proportion between the hospital case notes and reabstracted cancer notifications and ℓ is the required standard error, which is calculated as follows: if we require ± 1% 95% confidence interval (CI) then:

$$\ell = \frac{0.01}{1.96}$$

The values for the required sample size can be obtained from Figure 4.1 and are also presented in Table 4.3.

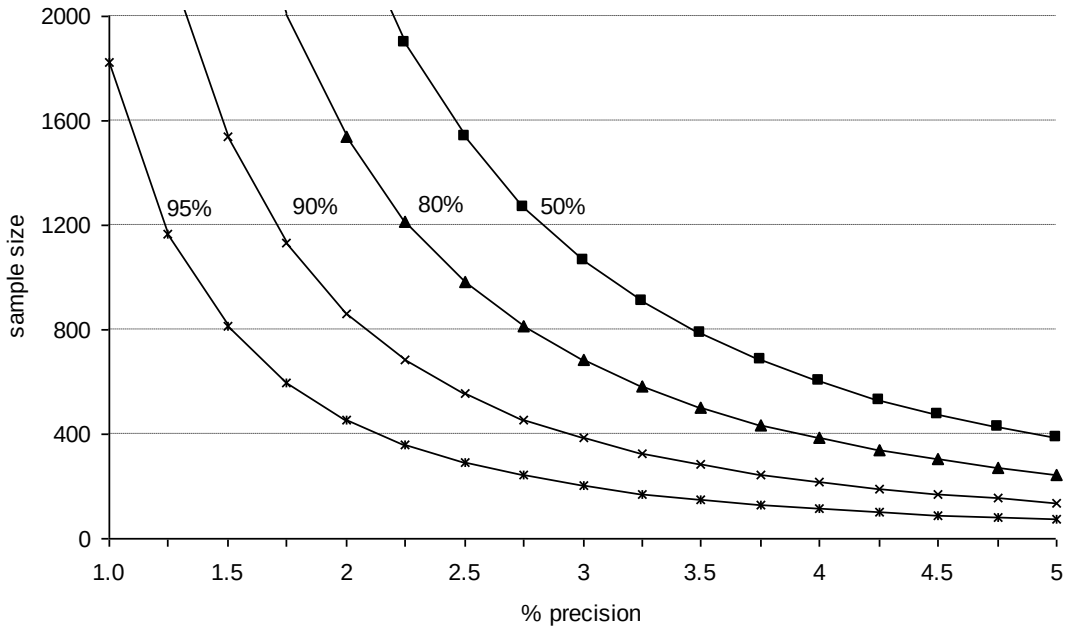

Figure 4.1. Sample size against % precision for different values of the agreement proportion.

Table 4.3. Estimates for required sample size.

Π	**± % precision of 95% CI-s**																
(%)	**1.0**	**1.25**	**1.5**	**1.75**	**2**	**2.25**	**2.5**	**2.75**	**3**	**3.25**	**3.5**	**3.75**	**4**	**4.25**	**4.5**	**4.75**	**5**
50	9604	6147	4268	3136	2401	1897	1537	1270	1067	909	784	683	600	532	474	426	384
80	6147	3934	2732	2007	1537	1214	983	813	683	582	502	437	384	340	304	272	246
90	3457	2213	1537	1129	864	683	553	457	384	327	282	246	216	191	171	153	138
95	1825	1168	811	596	**456**	360	292	241	203	173	149	130	114	101	90	81	73

The percentages in the first column of the Table 4.3 indicate the agreement percentage between the original cancer notification and the reabstracted one. The sample size calculation is based on the precision with which this agreement is detected, and the values for this, from 1–5 %, are given at the top of this table. It should be noted that the sample sizes shown in the table go up to nearly 10 000, but only sample sizes up to 2 000 are included in the figure as for pragmatic reasons we did not consider a sample size bigger than that.

The sample size needed from each stratum was 460. As can be seen from the figure and table, the sample size selected would be sufficient to detect 95% agreement with 2% precision. To this 460 cases we added 10% for unobtainable case histories, and got a minimal sample size of 500 cases in both strata.

Sampling strategy. As can be seen from Table 4.4 the number of registrations notified by each centre to the ECR varies dramatically. The majority (98%) of registration notifications came from 27 main centres. In contrast there were 34 centres that reported very few cases (<10 in 1998). Given the very small proportion of all registrations that come form these minor centres (2%) and the disproportionate effort required to visit each one, registrations from them were excluded from the reabstraction study. The other reporting centres were divided into two strata according to the number of cancers that they report each year: hospitals reporting 100 or more cases and hospitals reporting 10–99 cases.

Table 4.4. Numbers of cancer cases reported by hospitals and included in the study.

Hospital	**No of cases reported per year**	**Target sample size**	**No of cases actually retrieved**	**% of target cases retrieved**
Hospitals reporting 100 and more cases per year				
Estonian Oncology Centre*	2313	278	268	96.4
Tartu Radiology and Oncology*	831	100	98	98.0
Maarjamõisa Hospital*	344	41	36	87.8
Tallinn Central Hospital*	221	40	34	85.0
Narva Central Hospital	126	40	32	80.0
Pärnu Hospital	121	40	39	97.5
Viljandi Hospital	106	40	24	60.0
Kohtla-Järve Hospital	100	40	37	92.5
Total/average%	**4162**	**619**	**568**	**87.2**
Hospitals reporting 10–99 cases per year				
Magdaleena Hospital	92	92	82	89.1
Võrumaa Hospital	63	63	47	74.6
Tartu Lung Clinic	57	57	41	71.9
Eesti Meremeeste Hospital*	40	40	36	90.0
Tartu City Outpatients Clinic	33	33	12	36.4
Pärnu Outpatients Clinic	32	32	30	93.8
Mustamäe Hospital*	30	30	27	90.0
Kuressaare Hospital	29	29	0	0
Valgamaa Hospital	27	27	12	44.4
Pelgulinna Hospital	26	26	21	80.8
Rakvere Hospital	25	25	20	80.0
Läänemaa Hospital	19	19	19	100.0
Põlva Hospital	19	19	14	73.7
Puru Hospital	18	18	18	100.0
Elva Hospital	17	17	16	94.1
Keila Central Hospital	17	17	17	100.0
Põltsamaa Hospital	16	16	9	56.3
Jõgeva Hospital	15	15	14	93.9
Tartu Womens Clinic	12	12	12	100.0
Total/average%	**587**	**587**	**447**	**81.6****
Total number reported by hospitals reporting up to 10 cases per year	**108**			
Grand total/average%	**4857**	**1206**	**1015**	**83.3****

* hospitals that had computerised data bases of medical records

** excluding Kuressaare Hospital where no access to medical records was granted

The sampling strategy used for retrieving cases from these two strata is described as follows. Hospitals reporting 100 and more cases per year reported 4162 cases altogether for the year of 1998. We picked 12% cases from each hospital at random. For those hospitals in this group, where 12% was less than 40 cases, we still attempted to reabstract 40 cases. This lead to the total of 619 cases. Hospitals reporting 10–99 cases per year reported 587 cases for the year of 1998, and we picked all of these for reabstraction.

4.2.3 Results

4.2.3.1 Availability of medical records and overview of archiving systems

The average availability of medical records was 87.2%(95%CI 60.0–98.0) in the first (larger) hospital group and 81.6%(95%CI 36.4–100) in the second (smaller) hospital group (Table 4.4). The availability of medical records was considerably higher in the first group (p=0.007) than in the second group. One hospital in the second group had to be excluded from calculations about medical records availability as no access was permitted to patient records due to reasons of patient information security.

Based on the calculated required sample size we attempted to obtain 500 cases in both groups of hospitals. However in reality we retrieved 568 (113.6%) in the first group and 447 (89.4%) in the second group. Thus the first group was a little larger than planned while the second group was smaller.

Regarding the archiving systems, the following observations can be made. Only six out of 26 hospitals had computerised data bases of medical records, and these included the year 1998 which our study covered. In general, the availability of case notes in these hospitals was higher.

The medical records were archived by year of admission of the patient and ordered by sequence number of the case notes in the majority of hospitals. In one hospital only, were the medical notes archived by the year of admission and then ordered by the alphabet (by the surname of the patient). This hospital did not have any record book of the case notes that were archived. This made the search complicated as, for example, when the patient died during the specific admission that the cancer was reported to the ECR, there was no mention anywhere about this fact. As the medical records of the patients who had died in this hospital were archived separately, the other location of medical records had to be sought additionally for each person for whom the case notes were missing from the first location.

In another hospital, the gynaecological records for some reason were archived separately. Yet in another hospital, the archiving system was set up in the following manner: each time that the patient was transferred from one department of this hospital to the other, his/her case notes were given a new registration number. The case notes were archived according to the department from which the patient was discharged and then ordered by the sequence number of the case notes. In this hospital the availability of case notes was below the average for this study.

The availability of case notes Tartu City Outpatients Clinic deserves special mention. Namely, it was rather low (36.4%). When visiting this medical centre and presenting the list of patients whose case notes were needed for reabstraction, it became apparent that a majority of these patients were not present in the patient registry. This finding indicated that the notification source to the ECR was in fact different from that stated in the computerised files of the ECR. We checked the paper notifications at the ECR for the original data source recorded on them, and it was revealed that for most cases the data source was the Tartu Radiology and Oncology Clinic (the outpatients department), which had been mistakenly recorded and coded as Tartu City Outpatients Clinic on data entry at the ECR.

4.2.3.1.1 Discussion

Availability of medical records in this reabstraction study varies considerably. It is higher as an average in hospitals reporting 100 and more cases per year as compared to hospitals reporting up to 99 cases per year.

Availability tends to be higher for those hospitals which have computerized discharge data bases. At the same time, only six out of 26 hospitals in this study had computerized databases. Thus increasing the number of electronic databases would enhance the availability of medical records as all the case notes would be numbered and labelled for placing them in archive.

The low availability of medical records at one of the centres, Tartu City Outpatients Clinic, is an artefact as explained in the previous section. It points out that the source of notification recorded at the ECR files may at some instances be erroneous and would need more attention when entering this information to the ECR.

In other studies (Brewster *et al.* 2002; Gulliford *et al.* 1993) the availability of medical records has been found to be higher than we found, typically being around 90%.

4.2.3.2 Items of personal and clinical information included in case notes

According to the second aim of this study, we attempted to estimate, by hospital, the quality of case notes as a source for completing cancer notifications, i.e. which data

items, important for cancer registration, are in fact present in the case notes pro formas so that this information for each patient can be recorded.

Case notes in all hospitals that we visited contained sections for items of personal information such as first name, surname, gender, date of birth, identification code, and residential address. For other items of personal information such as previous surname (referring to the fact that the person has changed his/her surname), marital status, nationality, and place of birth, the case notes in the majority of the hospitals visited did not contain these data items.

For example, the availability of respective sections on the case notes pro formas to record marital status and nationality was available in three and four hospitals, respectively. In two cases for both data items, this information was reabstracted from the case notes in the situation where sections for these were not available. It means that this information was recorded in the text of the notes such as completed upon admission of the patient to the clinic.

For data items such as place of birth only one of these hospital had a section available in the case notes and for patient's previous surname none of the hospitals contained specific sections in the pro formas.

Regarding items of clinical information, diagnosis written as text was available from all case notes.

As for the date of diagnosis, it was not available as such from the case notes. Instead, it had to be constructed, using the to the European Network of Cancer Registries (ENCR) guidelines (European Network of Cancer Registries website).

4.2.3.2.1 Discussion

As expected, the case notes pro formas in all hospitals that we visited contained sections for items of personal information such as first name, surname, gender, date of birth, identification code and residential address. This information is essential in both identifying patients in the hospital information systems and cancer registry records. In cancer registration, these are deemed items of basic information (Parkin *et al.* 1994). In analyses of cancer registration data date of birth and residential address are also used for calculations of age-specific and regional cancer rates.

For other items of personal data, such as for example marital status and nationality, it is seen that these sections are only seldom present in the case notes. On the other hand, in the ECR files the completeness for this kind of data is rather high. Therefore, the case notes can not be the only source of information. Most probably the doctor or nurse completing the cancer registration form asks the patient about marital status and nationality and records this information on cancer notification. This finding points out one of the weaknesses of active retrieval method: it does not account for the pro formas of the source documents used for reabstraction not to contain sections for some variables.

4.2.3.3 Personal and clinical information as recorded on reabstraction compared to ECR

Personal information

In the following section, the differences in those items of information are summarised and estimated as the agreement percentage, considering the reabstracted cancer notification as a 'gold standard'.

In the results, when analysing the discrepancies between the reabstracted and the original information, the percentages are calculated from the total number of cases studied (1015) for those data items that were present in both datasets. For those data items, for which some data were missing, percentages of disagreement were calculated from the total of specific items present in both datasets.

Surnames. For surnames, completeness was 100% in both datasets. Comparing the reabstracted registration details with those recorded at the cancer registry, there were 25 (2.6%, 95% CI 1.6–3.6) differences in surname spelling (Table 4.5). Out of these, 20

(2.0%) were differences in the spelling of one letter, and 5 (0.5%) included difference in two letters.

Forenames. For this data item, completeness was 100% in both datasets. Comparing the reabstracted and original cancer records for the differences in forename spelling, 26 (2.6%, 95% CI 1.7–3.7) differences were detected (Table 4.5). Out of these, 18 (1.8% 95% CI 1.1–2.8) were differences in the spelling of one letter, and 8 (0.8% 95% CI 0.3–1.5) were larger differences. From the latter ones, we detected in 4 cases a middle name that had not been recorded and in one case there was a middle name recorded in the ECR file which we were not able to detect on reabstraction. In general, in Estonia people very rarely have a middle name.

In addition, there was one person in the study, for whom at the ECR the surname had been recorded as forename and vice versa, apparently because the surname is not a typical Estonian name and rather refers to some nationality other than Estonian.

Table 4.5.Comparison of names, the ECR files compared against reabstracted notifications as a standard.

Type of discrepancy	**Surnames**	**Forenames**
	Number of cases (%)	
None – full agreement	**990 (97.4)**	**989 (97.4)**
Difference in one letter		
Wrong vowel	5	2
Missing vowel	2	6
Extra vowel	4	4
Wrong consonant	1	1
Missing consonant	4	3
Extra consonant	3	3
Consonant instead of vowel	1	2
Total	**20 (2.0)**	**18 (1.8)**
Difference in two letters or other difference		
Extra consonant and wrong vowel	1	
Wrong vowel and extra vowel	1	
Missing consonant and wrong vowel	1	
Missing vowel and wrong vowel	1	
Consonant instead of vowel and vowel instead of consonant	1	
Completely different name		2
Missing middle name		4
Extra middle name		1
Missing vowel, wrong consonant and extra consonant		1
Total	**5 (0.5)**	**8 (0.8)**
Grand total for differences in name spelling	**25 (2.5)**	**26 (2.6)**
Total studied	**1015 (100)**	**1015 (100)**

Gender and date of birth there was a 100% completeness and no differences in these data items.

National identification code had been recorded for 996 (98.2%) persons in ECR dataset and 984 (97.0%) persons in the reabstraction dataset. For 976 (96.3%) persons it was recorded in both datasets. Out of these, there was disagreement in 7 (0.7 %, 95% CI 0.3–1.5) of the cases

Nationality had been recorded for 902 (88.9%) persons in ECR dataset and 347 (34.2%) persons in the reabstraction dataset. For 333 (32.8%) persons it was recorded in both datasets. Out of these 333, there was disagreement in 11 (3.3 %, 95% CI 1.7–5.8) of the cases with different nationality recorded on reabstraction (Table 4.6).

Table 4.6. Discrepancies in recording nationality, the ECR files compared against reabstracted notifications as a standard.

Type of discrepancy	**Number (%)**
None – full agreement	**322 (96.7)**
Recording "other" nationality as Estonian	1
Recording Russian nationality as Estonian	4
Recording "other" nationality as Russian	6
Total discrepancies in nationality recording	**11 (3.3)**
Total studied	**333 (100)**

Residency code is allocated to the cancer cases at the ECR and is based on the residential area recorded as a part of the patient's address written as text on the notification. This code was present for 1012 (99.8%) cases from the ECR and 998 (98.4%) reabstracted cases, which were also present in the ECR dataset. In 69 (6.9%, 95% CI 5.4–8.7) of these cases there were differences in residency code.

Marital status. Data for marital status were present for 762 (75.1%) of cases from the ECR and only for 88 (8.7%) reabstracted cases, which were also present in the ECR dataset. Out of these, 7 (7.9%, 95% CI 3.3–15.7) had different code for marital status.

Place of birth. Data for place of birth were present for 763 cases from the ECR and only 64 (6.3%) reabstracted cases. Out of these 64 patients, which were also present in the ECR dataset, 11 (17.2% 95% CI 8.9–28.7) had different code for the place of birth recorded.

For none of the items of clinical information, the results for which were presented above, differences in completeness or validity between the two groups of hospitals existed ($p>0.05$).

Clinical information

Date of diagnosis. In the original ECR file, the actual date for diagnosis was present for 997 (98.2%) and missing for 18 (1.8%) patients for both date and month. In the reabstracted dataset, the actual date of diagnosis was also present for 997 (98.2%) and missing for 18 (1.8%) cases. The date of diagnosis was present in two datasets for 994 (97.3%) cases. Two patients had the date of diagnosis missing from both the ECR and the reabstraction. There was no difference in date of diagnosis for 416 (41.9%) cases and some difference in 578 (58.1%, 95% CI 55.0–61.2). The difference was bigger than 6 weeks for only 51 (5.0%, 95% CI 3.8–6.7) cases. For 12 (1.2% 95% CI 0.6–2.1) cases the year of diagnosis was different from the study year: for 4 (0.4% 95% CI 0.1–1.0) cases it was 1997 and for 8 (0.8% 95% CI 0.3–1.6) cases it was 1999.

Diagnosis. For all study cases, information about diagnosis was available. In the following sections the results for discrepancies in diagnosis are presented separately for cancer site and morphology, and divided by tumour type, such as malignant tumours (976) and tumours of benign, uncertain, or unknown origin (39), as well as for all neoplasms together (1015). The first columns of Tables 4.7 and 4.8 describe the types of discrepancies of reabstracted notifications against the original ECR dataset.

Discrepancies in cancer site are presented in Table 4.7. In total, these were detected

Table 4.7. Discrepancies of site for all neoplasms, malignant tumours and other neoplasms*, the ECR files compared against reabstracted notifications as a 'gold standard'.

Discrepancy type (the ECR data relative to reabstracted data)	**Malignant tumours**		**Other neo-plasms***		**All neoplasms**	
	No. of cases	**%**	**No. of cases**	**%**	**No. of cases**	**%**
Specific subsite (ECR) recoded to subsite unspecified (reabs.)	105	10.4	2	0.2	107	10.6
Discrepancy in site (3 digit level)	53	5.2	2	0.2	55	5.4
Subsite unspecified (ECR) recoded to a specific subsite (reabs.)	15	1.5	4	0.4	19	1.9
Specific subsite (ECR) recorded to a different (specific) subsite (reabs.)	16	1.6			16	1.6
Other (overlapping subsites) (ECR) recoded to subsite unspecified (reabs.)	12	1.2			12	1.2
Other (overlapping subsites) (ECR) recoded to a specific subsite (reabs.)	3	0.3			3	0.3
Specific subsite (ECR) recoded to other (overlapping subsites) (reabs.)	1	0.1			1	0.1
Subsite unspecified (ECR) recoded to other (overlapping subsites) (reabs.)	1	0.1			1	0.1
Total/% all study cases	**206**	**20.3**	**8**	**0.8**	**214**	**21.1**

* Tumours of benign, uncertain or unknown behaviour

in 214 (21.1%, 95%CI 18.6–21.7) neoplasms, out of which 206 (20.3%, 95%CI 17.8–22.9) related to malignant tumours and 8 (0.8% 95%CI 0.3–1.5) to tumours of benign, uncertain or unknown behaviour.

As for some of the more frequent discrepancies, in 107 (10.5%, 95% CI 8.7–12.6) of cancer cases, the specific subsite was recoded to subsite unspecified during reabstraction and in 55 (5.4% 95% CI 4.1–7.0) cases discrepancy in cancer site at 3–digit level (ICD–coding).

Discrepancies in morphology (Table 4.8) were detected in 334 (32.9. 95%CI 30.0–35.9) neoplasms, 313 (30.8%, 95%CI 28.0–33.8) related to malignant tumours and 21 (2.1%, 95%CI 1.3–3.2) to tumours of benign, uncertain or unknown behaviour.

As for specific discrepancies regarding morphology, it is seen from the table, that most frequently (10.7%) a more specified morphology code (higher number) in the ECR was coded to a less specified morphology code (lower number) in the reabstraction data. At the same time, the opposite situation where a less specified morphology code was coded to a more specified morphology code occurred in 3.5% of study population. In 8.3% of cases morphology code was not allocated during reabstraction for cases that had a specific morphology code in the ECR dataset. The rest of the discrepancies in morphology occurred considerably less often.

There were 72 (7.2, 95%CI 5.6–8.9) neoplasms in total which had discrepancies in both site and morphology, 64 (6.6%, 95%CI 4.9–8.0) where malignant tumours and 6 (0.6%, 95%CI 0.2–1.3) tumours of benign, uncertain or unknown behaviour.

In all, there were no differences in the validity of either neoplasm site or morphology as regard to the hospital size between the two groups compared ($p>0.05$).

Table 4.8.Discrepancies of morphology, for all neoplasms, malignant tumours and other neoplasms*, the ECR files compared against reabstracted notifications as a 'gold standard'.

Type of discrepancy		Malignant tumours		Other neoplasms*		All neoplasms	
Originally registered morphology	**Reabstracted morphology**	**No. of cases**	**%**	**No. of cases**	**%**	**No. of cases**	**%**
Carcinoma, NOS 8020/3	Carcinoma, NOS 8010/3	1	0.1			1	0.1
Higher number	Lower number	109	10.7			109	10.7
More specific code	Carcinoma, NOS	16	1.6			16	1.6
More specific code	Malignant tumour cells	12	1.2			12	1.2
Specific code	Morph. code not allocated	81	8.0	3	0.3	84	8.3
Lower number	Higher number	35	3.5			35	3.5
Carcinoma, NOS	More specific code	7	0.7			7	0.7
Carcinoma, NOS	Malignant tumour cells	3	0.3			3	0.3
Carcinoma, NOS	Morph. code not allocated	22	2.2			22	2.2
Malignant tumour cells	More specific code	2	0.2			2	0.2
Malignant tumour cells	Carcinoma, NOS	1	0.1			1	0.1
Malignant tumour cells	Morph. code not allocated	10	1.0			10	1.0
Morph. code not allocated	More specific code	9	0.9			9	0.9
Morph. code not allocated	Carcinoma, NOS	2	0.2			2	0.2
Morph. code not allocated	Malignant tumour cells	3	0.3			3	0.3
Carcinoma in situ, lower number	Carcinoma in situ, higher number			1	0.1	1	0.1
Carcinoma in situ, NOS	Carcinoma in situ, specific code			3	0.3	3	0.3
Carcinoma in situ, specific code	Carcinoma in situ, NOS			1	0.1	1	0.1
Malignant tumour (carcinoma, NOS)	Carcinoma in situ (specific code)			1	0.1	1	0.1
Malignant tumour (morph. code not allocated)	Tumour of uncertain behaviour (morph. code not allocated)			4	0.4	4	0.4
Malignant tumour	Benign tumour			2	0.2	2	0.2
Carcinoma in situ	Tumour of uncertain behaviour (morph. code not allocated)			1	0.1	1	0.1
Carcinoma in situ	Malignant tumour			2	0.2	2	0.2
Tumour of uncertain behaviour	Malignant tumour			2	0.2	2	0.2
Benign tumour (morph. code not allocated)	Tumour of uncertain behaviour (morph. code not allocated)			1	0.1	1	0.1
Total/% all study cases		**313**	**30.9**	**21**	**2.1**	**334**	**32.9**

* Tumours of benign, uncertain or unknown behaviour

4.2.3.3.1 Discussion

Personal information. The completeness and validity of items of personal information was in general high. For the basic items of personal information such as first name, surname, gender, and date of birth, completeness was 100% and validity was also close to 100%, with minimal differences in name spelling. For identification code, completeness as well as validity were both very high. This is a very positive finding as it can be used as a key variable in electronic linkages with other data bases, both in quality assessment as well as epidemiologic studies.

To compare to other studies, the findings have been very similar for the basic items (also called identifying data) (Brewster *et al.* 2002; Brewster *et al*. 1994; Gulliford *et al*. 1993; Lancaster *et al.* 1994).

For other items such as nationality, residency code, marital status, date of diagnosis, and place of birth, some data were missing. Completeness for these items of data in the case notes examined varied a lot, from 6.3% for place of birth to 98.4% for residency code. As was shown in Section 4.2.3.2, for these items of data the respective sections are often missing in the case notes pro formas, and that is why this information can not be recorded. The exception is residential address, which is routinely recorded in the case notes and from which the residency code was derived when entering the data for our study. This was nearly 100% complete.

The following observations can be made about differences in the data items listed in the previous section. Validity in these items varies. From the point of view of cancer registration, nationality is perhaps the most important data item, enabling comparisons between ethnic groups. Validity for this one was very high, with only 3.3% disagreement. Also, in epidemiologic studies, precise location of residency of cancer patients is a basis for regional comparisons of cancer incidence patterns. In this respect the ECR is doing rather well, with both high completeness and over 90% validity. For other items such as marital status and place of birth, the numbers reabstracted were too small to enable conclusions about validity in the ECR dataset.

Clinical information. For date of diagnosis, completeness was very high. As for validity, in case of incidence date, as many as about half of the study cases had discrepancies. This is very high proportion. It can affect the calculation of age at diagnosis when estimating age-specific cancer incidence. As mentioned above, incidence date for cancer is not recorded in the hospital notes as such and has to be

constructed by the clinicians reporting the cancer, following the ENCR guidelines (European Network of Cancer Registries website). In brief, the highest priority for the date of incidence is the date of first histological or cytological examination. In case this is not available, in declining order there are other events such as admission to the hospital etc. to be considered as incidence date. Also, if an event of the higher priority occurs within three months of the date initially chosen, the date of the higher priority event should take precedence. The brief summary of the guidelines shows that these are not easy to follow in a clinical setting, especially if a 'higher priority event' occurs and the cancer notification with the initial date of diagnosis has been forwarded to the ECR already. This may account for a number of differences in incidence dates in our study.

At the same time, the differences in the date of diagnosis were not big, with 95% of them falling within six weeks. A similar finding for the Scottish Cancer Registry has been reported (Brewster *et al.* 2002). Only 1.2% of all study cases were allocated a different year of incidence, and thus could have affected incidence statistics. The study by Brewster *et al.* (1994) which also took a single year worth of registrations, detected a 5% difference in the year of diagnosis for the Scottish Cancer Registry, which is bigger than the one detected by us.

There were discrepancies in diagnosis, first of all relating to cancer site. About one fifth of the diagnoses had some discrepancy. One half of these disagreements were cases where the specific subsite was recoded to subsite unspecified during reabstraction (10.7% of study population). It means that differences were at ICD–10 4–digit level. This lower precision in reabstraction could have resulted from the fact that the clinicians reporting on these cancer cases may record cancer site with higher precision on the notifications than is recorded in the case notes. This would have not affected cancer incidence statistics produced by the ECR as it only goes to 3–digit level. Yet in 55 (5.4%) cases discrepancy in cancer site at 3–digit level (ICD–10) occurred, which means that it could have affected the cancer incidence statistics to some extent. Considering that for statistical purposes, a number of sites (at 3–digit level) are grouped together, this percentage is perhaps smaller than 5.4% as a number of these discrepancies should fall into the same group. Another study (Brewster *et al*. 1994) has found 5.4% discrepancies in the first three digits of diagnosis code, which is very similar to the current study. The rest of the disagreements in cancer site were rare, each occurring in less than 2% of the cases, and all related to cancer subsites, thus not

affecting routine cancer statistics. Nevertheless, the differences in subsite level can affect the results of specific clinical and epidemiologic studies.

The differences in morphology of the studied cancers occurred in about a third of the study cases. Other studies have found 18.7% (Brewster *et al.* 2002), 28.3% (Brewster *et al.* 1994), which is also rather high. In the last mentioned study by Brewster, though, about a half of the discrepancies arose through inferences about morphology and allocation of morphology codes when there was no evidence of histological or cytological verification in the case notes.

As for specific discrepancies regarding morphology, most frequently (10.7%) a more specified morphology code (higher number) recorded in the ECR data was coded to a less specified morphology code (lower number) during reabstraction. This is a comparatively large group making up about a third of the discrepancies in morphology codes. To look into this issue in more detail, a random sample of 10% of those cases was checked against the original paper cancer notifications kept at the ECR to find out whether the original notifications contain more specific information on morphology allowing more specified morphology codes. It occurred for 90% of these cases that on the original paper notifications, a more specific morphology was actually recorded. This finding leads to the conclusion that we lacked the competency in recording the morphological diagnosis (written as text), and the differences detected by the study can not be related to the quality of the ECR data *per se.* Ideally the persons carrying out reabstraction would need to be experts (Parkin *et al.* 1994).

In a number of cases (8.3%), the morphology code was not allocated during reabstraction for cases that had a specific morphology code in the ECR dataset. This means that the ECR, for each of these cases, received and recorded information about morphology after receiving the original cancer notification. As for the case notes not holding this kind of information, the pathology reports containing information about morphology of the specific cancer could have been sent to the ECR directly from the pathology departments with copies not filed in the case notes.

A limitation of this study is that it was too small to provide good data on variation between the two groups of hospitals for some items where the difference between the information contained in the ECR files and obtained on reabstraction in was bigger than 95±2%. Yet its aim was to set a national picture of validity and completeness of cancer registrations.

4.2.3 Conclusions

Based on the findings of this study, it can be said that validity and completeness of most of the data items in the ECR files is very high.

The study was able to reveal that for some of the data items such as nationality, marital status, information is recorded not from the case notes, but some other source. Therefore these were not reproducible on reabstraction. This points to a problem with basic design of the reabstraction study. Namely, it assumes that all information needed for cancer reporting is present in the source documents, which is why the reabstracted notification is called the ’gold standard’. This is not always true as was shown by the current study. Therefore, introducing a standard pro forma for medical case notes for all hospitals in Estonia which would include all data items necessary for cancer registration, would be very useful.

In the future, when performing reabstraction studies for validating information on cancer registrations, it would be useful to review the source documents for cancer notifications for the availability of pro formas for all information detail under observation.

4.3 Completeness of data items

The third validation study was a survey to determine the completeness of personal and clinical information data items in the ECR files. It should be noted that this study simply looks at the completeness of data items within the ECR as distinct from the reabstraction study which compared a sample of the ECR cases with an external source.

4.3.1 Aims and methodology

The aim of this study was to get an overview of the completeness of data items recorded by the ECR, and be able to detect any changes over the most recent years.

To do this, I ordered a table of the main items registered, by year of recording. As major restructuring of the ECR data collection forms took place in 1994 (see Chapter 2 Section 2.3.1.4), I chose for this study the years starting from 1995, and going up to 2000 as the most recent year for which those data are available.

4.3.2 Results

The results for the completeness of personal and clinical information data items in the ECR files are presented in Table 4.9.

Table 4.9. Completeness of data items in the ECR in 1995-2000.

Data item	Year					
	1995	**1996**	**1997**	**1998**	**1999**	**2000**
Personal identification details						
ID code	78.4	92.2	95.1	98.4	99.2	99.9
Sex	100.0	100.0	100.0	100.0	100.0	100.0
Surname	100.0	100.0	100.0	100.0	100.0	100.0
Previous surname	4.3	4.6	5.5	4.4	2.5	2.0
First name	100.0	100.0	100.0	100.0	100.0	100.0
Day of birth	99.9	100.0	100.0	100.0	100.0	100.0
Month of birth	100.0	100.0	100.0	100.0	100.0	100.0
Year of birth	100.0	100.0	100.0	100.0	100.0	100.0
Marital status	79.1	77.8	76.9	64.7	58.0	54.8
Nationality	88.5	89.2	88.8	86.4	86.0	85.2
Place of birth	80.1	81.4	80.2	61.8	51.5	51.3
Area of residency	100.0	100.0	100.0	100.0	100.0	100.0
Residential address	100.0	100.0	100.0	100.0	100.0	100.0
Diagnostic information details						
Diagnosis	100.0	100.0	100.0	100.0	100.0	100.0
Year of diagnosis	100.0	100.0	100.0	100.0	100.0	100.0
Spread of cancer	99.0	98.9	99.1	97.4	95.4	95.2
Treatment	72.7	75.7	75.4	76.5	76.1	76.1

Personal information. For items of personal identification it is seen that completeness has been 100% throughout the years studied for a number of items such as gender, surname, first name, day (with the exception of 1995 data), month and year of birth, area of residency and residential address.

For national identification code, completeness of registration was only 78.4% in 1995, and has increased steadily, reaching as high as 99.9% in 2000.

For both marital status and place of birth, completeness of registration has fallen quite markedly, from about 80% to about 50%. Completeness of registering nationality of the cancer patients in the ECR files has decreased only a little over these years. Previous surname has been very rarely recorded in the ECR files and the frequency of recording has dropped from 5.5 in 1997 to 2.0 in 2000.

Diagnostic information. As for diagnostic information, the completeness of data items shows very high completeness over the years studied. Items of diagnostic information such as diagnosis and year of diagnosis have all been recorded 100% in all years studied. The spread of cancer is recorded for majority of patients, although the frequency of recording has decreased a bit. For treatment, completeness is in the range of 75%.

4.3.3 Discussion

Personal information. For items of personal identification completeness is very high. For other items of personal information, completeness is lower. This is also the case for recording national identification code for earlier years. These items with incomplete registration deserve some attention as they can possibly affect results of studies based on this kind of data.

The fact that the registration of national identification code around 1995 was not complete would have not affected the cancer registration process *per se* when searching for possible duplicate registrations during data entry. Namely, the national identification code was only introduced in Estonia in 1993, and could have been incompletely registered in source documents of cancer registration during first years. In cancer registration process, duplicate registrations are searched by name and date of birth, both

items which have been complete and sufficient for this purpose at the ECR. As the completeness of recording personal identification code has increased and reaches almost 100%, it can be used as a key variable in data linkage studies. For some other items of personal information, like marital status and place of birth, the data are not complete and the registration has become even less complete over the more recent years. There are several reasons for this decrease in the completeness of these items of personal data over time. As there is a staff shortage at the ECR, these items are not considered a priority. Although these items are not among the basic identification information, the missing values certainly limits the usefulness of such data in statistical overviews as well as in epidemiologic studies where linkages based on personal identification number might be used. However, it should be noted that the use of linkage studies in medical research is currently prohibited.

Diagnostic information. The completeness of recording diagnostic information in the ECR files is generally very good. Information regarding treatment has a bit lower completeness and is recorded in about three quarters of patients.

4.3.4 Conclusions

To summarize, the completeness of registration of basic personal and diagnostic details of information in the ECR files is very good.

Other items of both personal information marital status, nationality and place of birth that would be useful for purposes of in depth public health or clinical research, have deficiencies in recording that could affect the results of these studies. Regarding completeness of items of clinical information, it is certainly low for recording treatment. This would affect the results of clinical studies based on the ECR data.

The analysis focussed on all ages. However, the evidence presented inevitably relates mainly to cancers in adult life as these significantly outnumber cancers in childhood.

4.4 Summary

The three studies presented in this chapter were aimed at validating the data quality of ECR. They were designed so that they gave an overview of all the main data quality characteristics of cancer registration such as case completeness, validity of cancer registrations, and completeness of data items.

It would have been worthwhile to look at the quality of cancer registration data at the ECR over time, but for the case completeness and validity of registrations studies, it would have not been feasible for the following reasons. For case completeness study, there were no electronic databases available for data linkage beyond 1998. For validity of registrations, looking at changes over time would have lead to a very large number of reabstractions. As each reabstraction took about 10 minutes as an average, and considering time for travelling to hospitals, it was not possible to do more than in the range of 1000 reabstractions. However, the study of completeness of data items looked at data quality over time (1995–2000) as this simply involved making tabulation from the ECR.

As a summary of all these three studies, the following issues can be highlighted. Data quality in the ECR is good in general, and it does vary by specific quality characteristics.

As reported by the first study, completeness of case ascertainment at 90.8% was not remarkably high. Due to the study limitations the results are not generalisable to the whole ECR. It is of concern as it may affect the results of international comparisons. More work on this is a priority, looking at a much bigger number of reporting hospitals in order to get a more comprehensive picture.

Based on the results of the reabstraction study, the validity and completeness of cancer registrations at the ECR are high, being a little higher for personal and lower for clinical information. This study revealed that in case of some of the data items such as nationality and marital status, although the pro formas of the source documents do contain sections these variables, this information is still relatively complete in the ECR files.

Completeness of basic personal and diagnostic details of information in the ECR files is very good as detected by the third study.

Some of the cancer data from the ECR are presented and analysed in the following chapters. Chapter 5 gives an overview of the recent cancer incidence and mortality

trends in Estonia, while Chapter 6 compares cancer incidence and mortality rates in Estonia with some neighbouring countries.

Chapter 5. Cancer incidence and mortality in Estonia

In this chapter, an overview of cancer incidence and mortality rates and time trends in Estonia are presented, followed by a short description of factors influencing the rates and trends. Comparisons of incidence and mortality rates with some neighbouring countries are presented in the next chapter.

Data for the current analysis were obtained mainly from the EUROCIM software package, compiled by the European Network of Cancer Registries (2001). Data for cancer mortality for all ages as an average for 1993–97 were obtained from WHO Mortality Databank. In contrast to the data used in Chapter 4 that came directly from the ECR, in this chapter data were obtained from international databases such as EUROCIM and WHO Mortality Databank. The reason for choosing these databases instead of using data directly from ECR was ease of access using the built in tabulation facilities, and also the fact that in Chapter 6 cancer data from neighbouring countries was going to be used and it seemed reasonable to use the same databases for both chapters.

All rates were age-standardised to the European population, using five-year age groups, and expressed as incidence or mortality rates per 100 000. Five-year averages (1993–97) were used because of the small size of Estonian population. For the population size of Estonia, and in comparison with neighbouring countries, see Chapter 6 Table 6.1. Rates for individual years would have had too great a degree of random variation.

Throughout the study period, 1993-1997, coding at the ECR was performed using the first version of International Classification for Diseases in Oncology (ICD-O-1). Therefore changes in classification used for coding are not a concern. An overview of the classifications for coding used by the ECR over time were presented in Chapter 2 Section 2.3.1.4.

The ten cancer sites for men and women with the highest incidence rates in Estonia as an average for 1993–97 are presented, having excluded "other skin" referring to other

malignant neoplasms of the skin (all other excluding melanoma), leukaemia, and cancers of the brain and nerves as there are differences in completeness of registration for these cancers between time periods. For sites such as bladder, larynx, and oesophagus that feature among the ten leading sites for men only, the data for women are presented in some analyses for the purpose of completeness. For presenting mortality rates, the same sites as described above are used. The sites are presented according to their sequential order in the 10th revision of the ICD.

For presenting incidence and mortality time trends, data were obtained from EUROCIM and are shown as three years moving averages, covering the period from 1985 to 1997. For the year 1985, for example, this means the average of 1984–1986. For the last year, 1997, it includes average data for 1996–1997. For the first and last year under observation, 1985 and 1997, only two years' data were used, i.e. the averages for 1985-1986 and 1996-1997. This was done in order to obtain a longer time period for the trend analysis. A similar method is used for calculating the moving averages at the ECR (M. Mägi – 2004 – personal communication).

For cancer mortality in Estonia for some sites such as pancreas, corpus uteri, ovary, kidney and bladder, data were only available from 1994 (the rates used for this year are the averages for 1994–1995). For calculating p-values for time trends, Poisson regression was used. Age-specific numbers of cancer registrations or deaths were used for each individual registration year, sex and cancer site. Mid-year population was used for the denominator data. Registration year was entered into the model as a continuous variable while age group and sex were entered as categorical variables. P-value for the estimate of year parameter for trend was assessed by the Wald-test. Exact p-values are presented unless they were <0.001.

The ICD rubrics used for defining cancer sites are given in Table 5.1.

Table 5.1 ICD rubrics used for providing cancer sites in EUROCIM and WHO Mortality Databank.

Cancer	Incidence		Mortality	
	ICD–9	ICD–10	WHO ICD–8	WHO ICD–9
Oesophagus	150	C15	A046	B090
Stomach	151	C16	A047	B091
Colon	153	C18	153	B093
Rectum	154	C19–21	A049	B094
Pancreas	157	C25	157	B096
Larynx	161	C32	A050	B100
Lung	162	C33–34	A051	B101
Breast	174/175	C50	A054	B113
Cervix uteri	180	C53	A055	B120
Corpus uteri	182	C54	A056	182
Ovary	183	C56	183	B123
Prostate	185	C61	A057	B124
Kidney	189	C64–65	189	189
Bladder	188	C67	188	B126
All sites*	140–208	C00–97	A045–A058	B08–B149

*excluding “other skin”

It should be noted that ICD–9 was replaced by ICD–10 in Estonia for coding cancer incidence and mortality from 1998.

Analysis of survival rates based on primary data is beyond the scope of the current thesis. However, in order to assist with the interpretation of cancer mortality in relation to incidence, the five year relative survival rates for the major cancer sites, derived from published sources, are presented in Table 5.2.

Table 5.2. 5-year relative survival rates for the leading cancer sites in Estonia in 1985-89.

Source	**Cancer site**	**ICD -10**	**5-year relative survival (%)***		**95% CI**
Faivre *et al.* (1998a)	Oesophagus	C 15		3	0.5-1.3
Faivre *et al.* (1998a)	Stomach	C 16		16	14-18
Gatta *et al.* (1998a)	Colon	C 18	Men	37	30-44
			Women	38	33-43
Gatta *et al.* (1998a)	Rectum	C19-21	Men	34	29-41
			Women	36	31-41
Faivre *et al.* (1998b)	Pancreas	C25		1	0.1-5
Janssen-Hejinen *et al.* (1998)	Lung	C33-34	Men	5	–
			Women	14	–
Quinn *et al.* (1998)	Breast	C50		60	58-63
Gatta *et al.* (1998b)	Cervix uteri	C53		57	33-61
Gatta *et al.* (1998b)	Corpus uteri	C54		65	61-70
Gatta *et al.* (1998b)	Ovary	C56		26	22-29
Post *et al.* (1998)	Prostate	C61		39	–
Damhuis *et al.* (1998)	Kidney	C64-65		30	–
Micheli *et al.* (1998)	All sites	C00-97	Men	22	–
			Women	37	–

*where sex is not indicated, the combined survival for two sexes is presented.

It is seen from the table that 5-year relative survival rates vary considerably by site. While they are reasonable for some of the gynaecological cancer sites such as breast, cervix and corpus uteri, the 5-year relative survival rate is very low for cancer sites such as pancreas, oesophagus, and lung. These differences between sites are very similar to those seen in other populations. As discussed by Aareleid (Aareleid and Brenner 2002), in general it appears that cancer survival rates in Estonia are generally lower than in other European countries.

5.1 Incidence and mortality rates

5.1.1 Incidence rates

In 1993–97, the all ages cancer incidence rate for men in Estonia was 421.0 per 100 000 and for women 255.8 per 100 000.

The leading cancer sites for men and women are presented in Figures 5.1 and 5.2 respectively. For men, lung cancer is by far the most frequent cancer with an incidence rate of 104.4 per 100 000. The second most common cancer for men in Estonia for the period studied was cancer of the prostate with 56.5 per 100 000, which counts for about a half of the incidence of lung cancer and is rather closely followed by stomach cancer. The rest of the ten leading cancer sites for men have a considerably lower incidence than the first three cancer sites.

For women, the leading site is breast cancer (Figure 5.2) with an incidence rate of 56.0. This cancer site is followed by cancers of stomach, cervix uteri, corpus uteri, and colon, all with rates ranging between 21.6 and 19.1 per 100 000. Cancers of ovary, lung, kidney, rectum and pancreas lie in decreasing order in the bottom part of the leading ten sites for cancers in women.

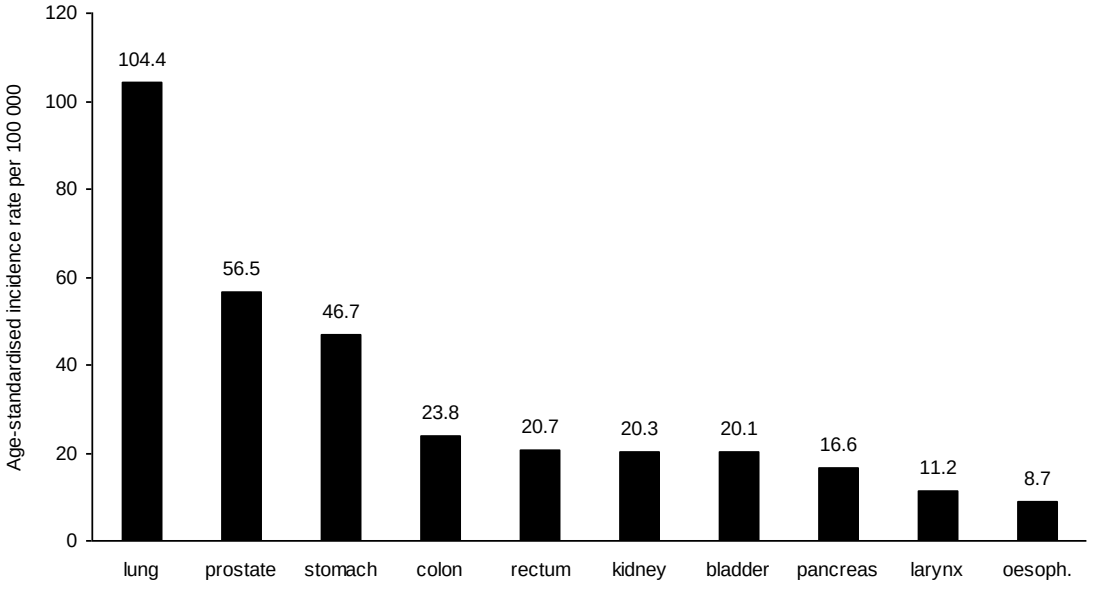

Figure 5.1. Age-standardised incidence rates per 100 000 per year, all ages, males, for ten leading sites of cancer incidence in Estonia, the average for 1993–97.
Source: EUROCIM

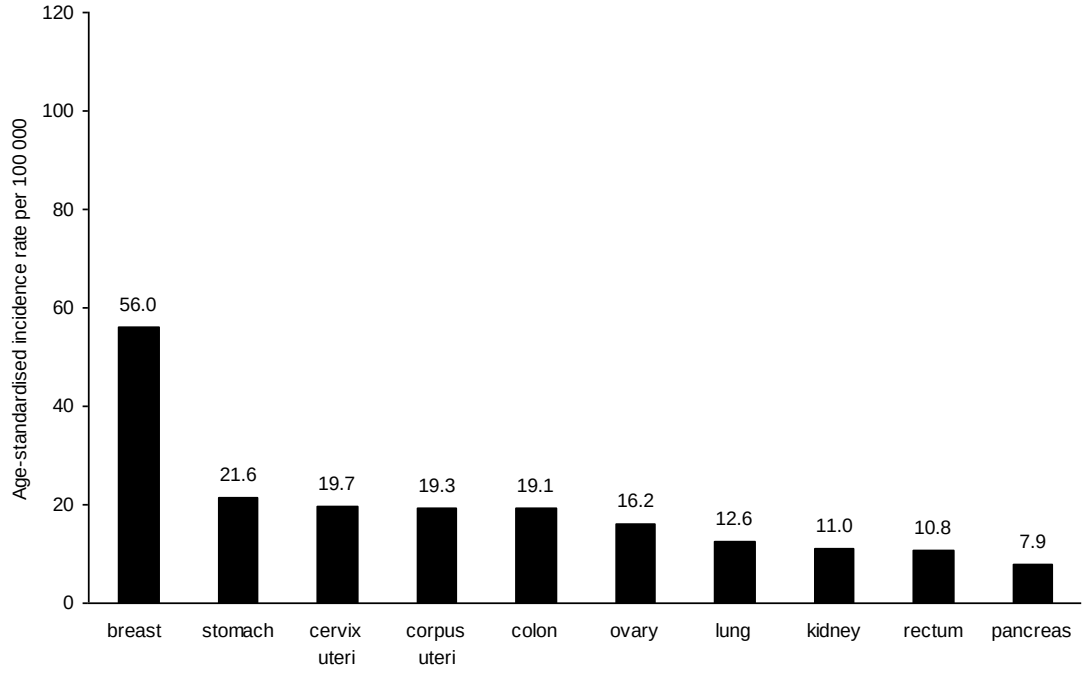

Figure 5.2. Age-standardised incidence rates per 100 000 per year, all ages, females, for ten leading sites of cancer incidence in Estonia, the average for 1993–97.
Source: EUROCIM

5.1.2 Mortality rates

The cancer mortality rate for men in Estonia was 299.8 per 100 00 and for women it was 146.6 per 100 00 as an average for 1993–97.

As can be seen from the graph in Figure 5.3, by far the leading site for cancer mortality in men is lung cancer, with a mortality rate of 94.2 per 100 000. This is followed by stomach cancer, which had a rate less than a half of the mortality from lung cancer. The third malignancy is prostate cancer, with a mortality rate just over a half of the rate for stomach cancer. The remaining seven cancers have considerably lower mortality.

For women (Figure 5.4), the leading site for cancer mortality is breast cancer with mortality rate of 24.7 per 100 000. This is followed by deaths from stomach cancer making up about two thirds of the mortality from breast cancer. Cancers of colon and lung have very similar rates and rank third and fourth respectively. The rest of the ten cancers in women are the cancers of cervix uteri, ovary, rectum, pancreas, cancer of kidney and corpus uteri.

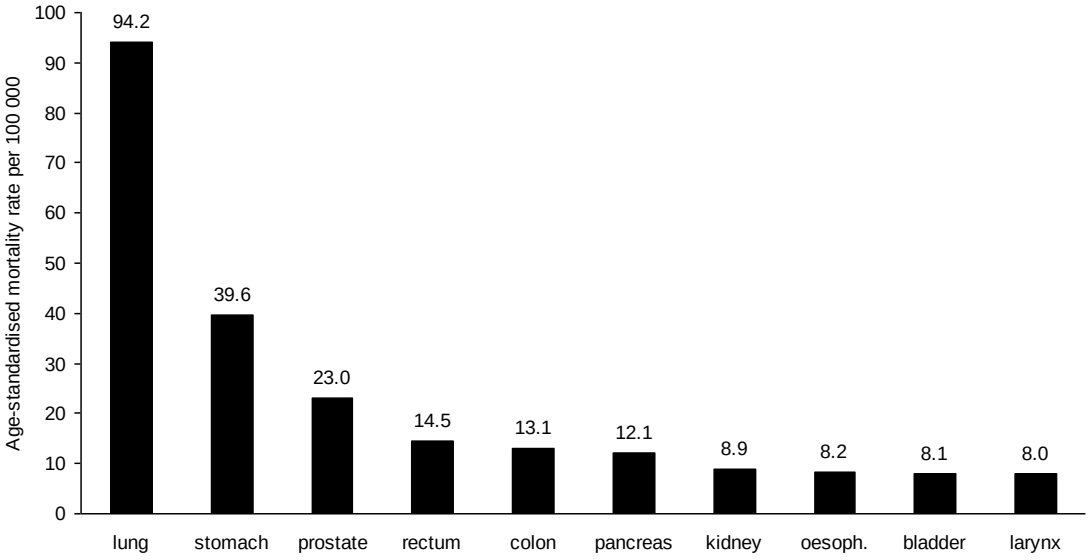

Figure 5.3. Age-standardised mortality rates per 100 000 per year, all ages, males, for ten leading sites of cancer incidence in Estonia, the average for 1993–97.
Source: WHO Mortality Databank

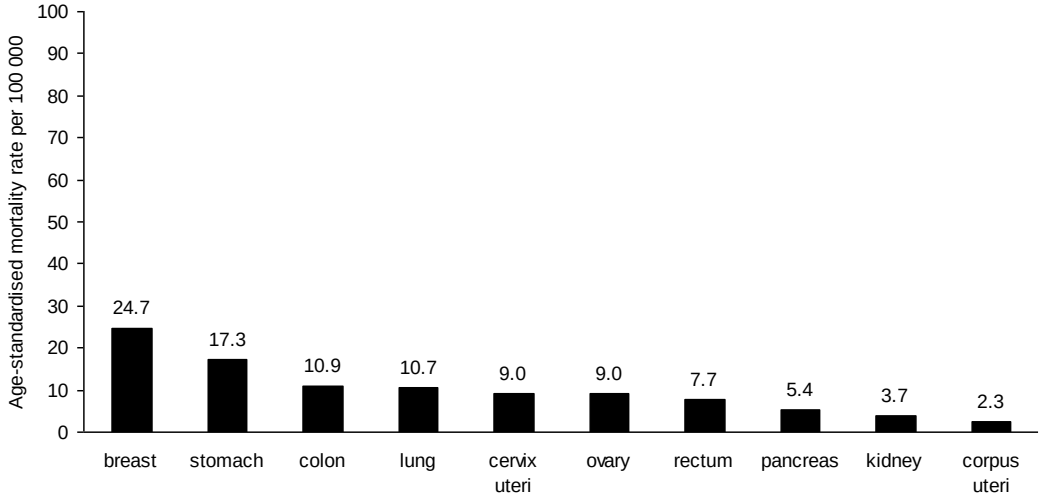

Figure 5.4. Age-standardised mortality rates per 100 000 per year, all ages, females, for ten leading sites of cancer incidence in Estonia, the average for 1993–97.
Source: WHO Mortality Databank

5.1.3 Incidence compared to mortality by site

It is of interest to compare cancer incidence and mortality rates between sites. This section presents a series of incidence/mortality scatter plots for the ten selected sites for men and women. A diagonal line is fitted for reference, denoting that incidence and mortality rates are equal.

Men. In Figure 5.5 the incidence/mortality scatter plots for men are presented. We can see that lung cancer lies at the upper right corner of the graph, indicating that incidence and mortality are both high. There is a clustering of cancer sites in the lower left-hand corner of the graph, indicating that these sites have relatively low incidence and mortality rates when compared to other sites. In this cluster, cancer sites such as oesophagus, larynx, pancreas and rectum are situated closer to the line than the other sites, indicating that mortality rates compared to incidence rates are relatively higher. Two sites such as stomach and prostate cancer are situated between the described cluster and lung cancer. The data point for stomach cancer lies to the right of prostate cancer and rather close to the diagonal line, indicating that mortality is relatively high when compared to incidence for this site. Prostate cancer, on the other hand, has rather low mortality when compared to incidence as it is situated well away from the line.

Women. In Figure 5.6 a similar graph for women is presented. For women all the rates are considerably lower than for men, and the range of the axes adjusted accordingly. Breast cancer lies in the upper right-hand corner of the graph. It has both mortality and especially incidence rates considerably higher than for the other cancer sites. Yet its mortality compared to incidence is relatively low. It is seen that for sites such as pancreas, rectum, lung and stomach, the respective data points lie rather close to the diagonal line, meaning that mortality rates are similar to incidence rates. For other cancer sites, the incidence rates are much higher than mortality rates. This is especially the case for cancer of corpus uteri, but also for cancer sites like kidney, breast, cervix uteri, colon and ovary.

The differences between cancer incidence and mortality for these cancer sites are discussed in the following section where the time trends are also presented.

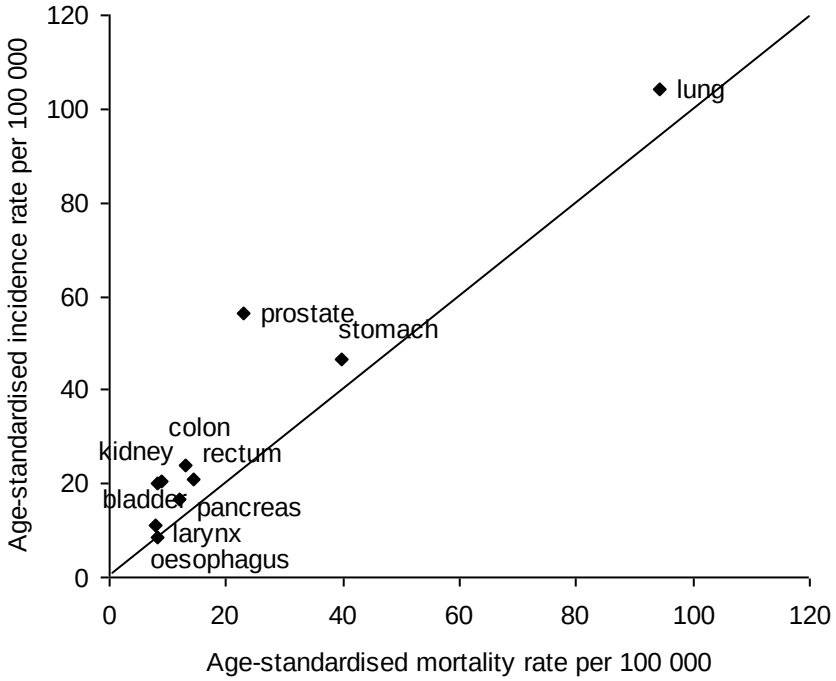

Figure 5.5. Incidence/mortality rates per 100 000, all ages, males, for ten leading sites of cancer incidence in Estonia, the average for 1993–97.
Source: EUROCIM and WHO Mortality Databank

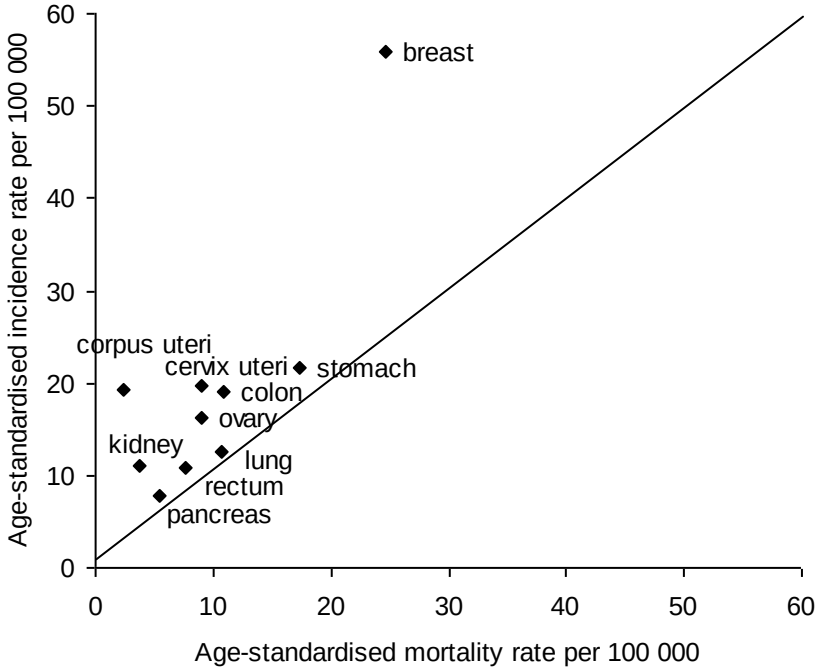

Figure 5.6. Incidence/mortality rates per 100 000, all ages, females, for ten leading sites of cancer incidence in Estonia, the average for 1993–97.
Source: EUROCIM and WHO Mortality Databank

5.2 Incidence and mortality trends

In this section time trends in age-standardised incidence and mortality rates are presented. Figures are presented showing time trends by sex and cancer site. The p-value for a linear trend is shown for each line, with the $p<0.05$ considered statistically significant.

5.2.1 Overall incidence and mortality trends

Overall cancer incidence and mortality trends in Estonia for men and women are presented on Figure 5.7 as three years moving averages.

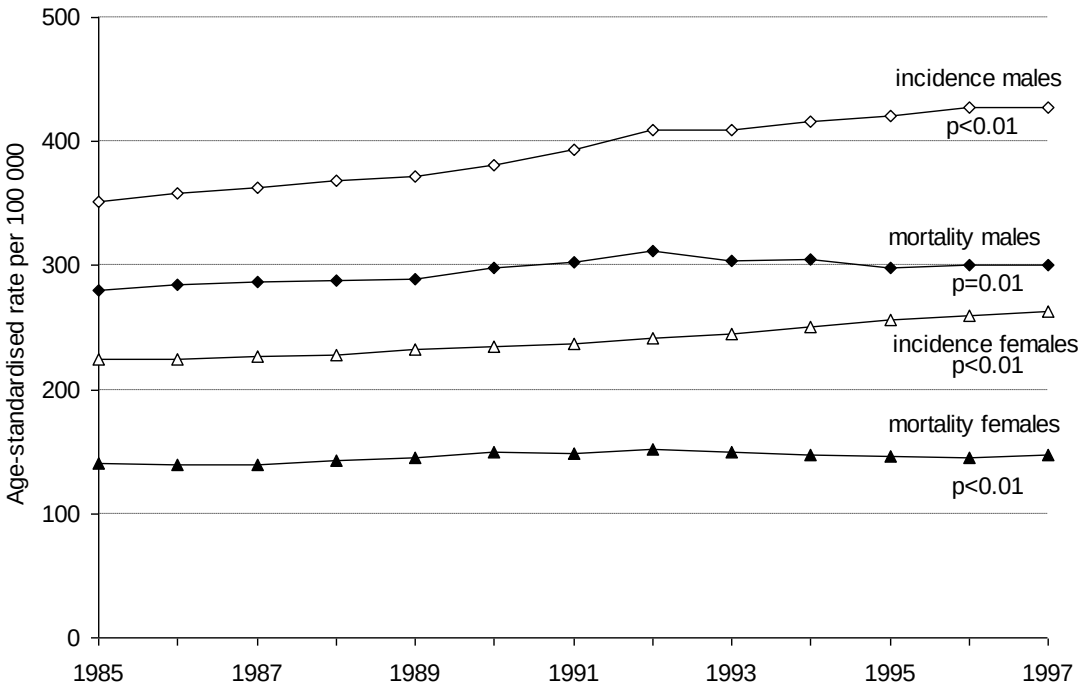

Figure 5.7.Trends in age-standardised incidence and mortality rates per 100 000, all malignant neoplasms, Estonia, in 1985–1997, all ages, three years moving averages. Source: EUROCIM.

It is seen from figure 5.7 that cancer incidence rates for men are about a third higher than for women. Also, the rates have steadily increased for both sexes over these years. This increase has been more marked at the beginning of 1990s and has continued for

both sexes for the whole second half of the time period studied. The total increase in cancer incidence for this period is 17.9% for men and 14.6% for women.

Cancer mortality again, is higher for men than for women. This sex difference is bigger than for incidence as the mortality rates for men are about twice as high as for women. For both sexes the mortality rates slowly increased until 1992. After 1992 the mortality rates for cancer in women have been relatively stable, while in men these have decreased a little. The total increase in cancer mortality over the period is 6.7% for men and 4.2% for women.

5.2.2 Incidence and mortality trends for ten leading sites

The following is a description of time trends in cancer incidence and mortality by sex for the selected sites. For each of the cancer sites, a brief mention of the etiologic factors is provided, as well as a short explanation of factors underlying of the time trends is provided.

5.2.2.1 Cancer of the oesophagus

In Figure 5.8 the incidence and mortality time trends for cancer of the oesophagus are presented.

As is seen from Figure 5.8, incidence trend for cancer of the oesophagus in men was quite stable from 1985 to 1991, then had a slightly higher rate around 1992 to 1995, after which it came down to its previous level and remained stable. Mortality trend for this cancer in men shows a steady increase until 1993, when the curve flattened off. Then it started going up again, passing the incidence curve in 1995. This may be due to the deaths from a higher number of cases diagnosed in early 1990–s.

For women both incidence and mortality rates are very low and the changes in rates should therefore be interpreted with caution even though three years moving averages are used for calculating the rates.

It is seen from Figure 5.8 that none of the time trends for this cancer are significant.

There is a positive association between heavy alcohol use, smoking, and the risk of oesophageal cancer (Nyren and Adami 2002a). This explains the higher rates in men compared to women in Estonia. A description of the smoking habits in Estonia will be given in Section 5.2.1.7.

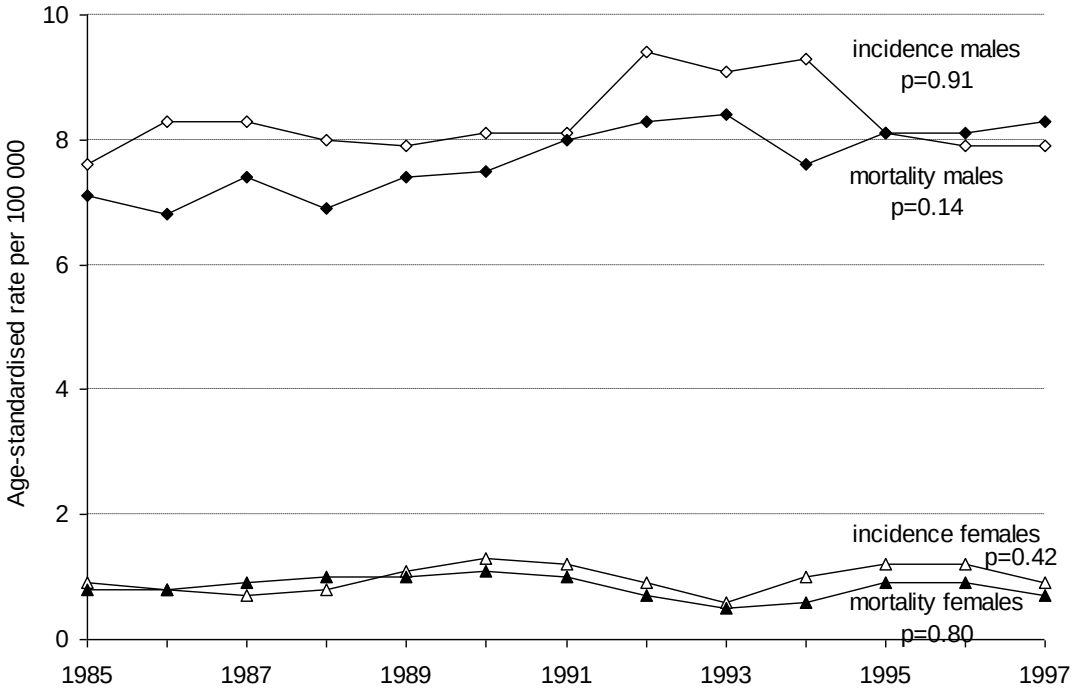

Figure 5.8. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the oesophagus, Estonia, in 1985–1997, all ages, three years moving averages. Source: EUROCIM.

In general, for both sexes the incidence and mortality curves for cancer of the oesophagus lie quite close together, which is an indication of poor survival. Survival rates for specific cancer sites are available from the EUROCARE II study (Berrino *et al.* 1998) for 1985–89, which compared cancer survival in 17 European countries. Overall survival rates for oesophageal cancer were poor (Faivre *et al.* 1998a) and in general the survival rates for men were slightly lower than the rates for women. The average European weighted survival was 10% at five years. The relative 5–year survival rate for oesophageal cancer in Estonia was 3% (relative survival rates according to sex were not calculated for Estonia because of small number of cases). According to the study there was a small overall improvement in overall 5–year survival rates between the two periods 1978–80 and 1987–89.

5.2.2.2 Cancer of the stomach

In Figure 5.9 incidence and mortality trends for stomach cancer in men and women are presented.

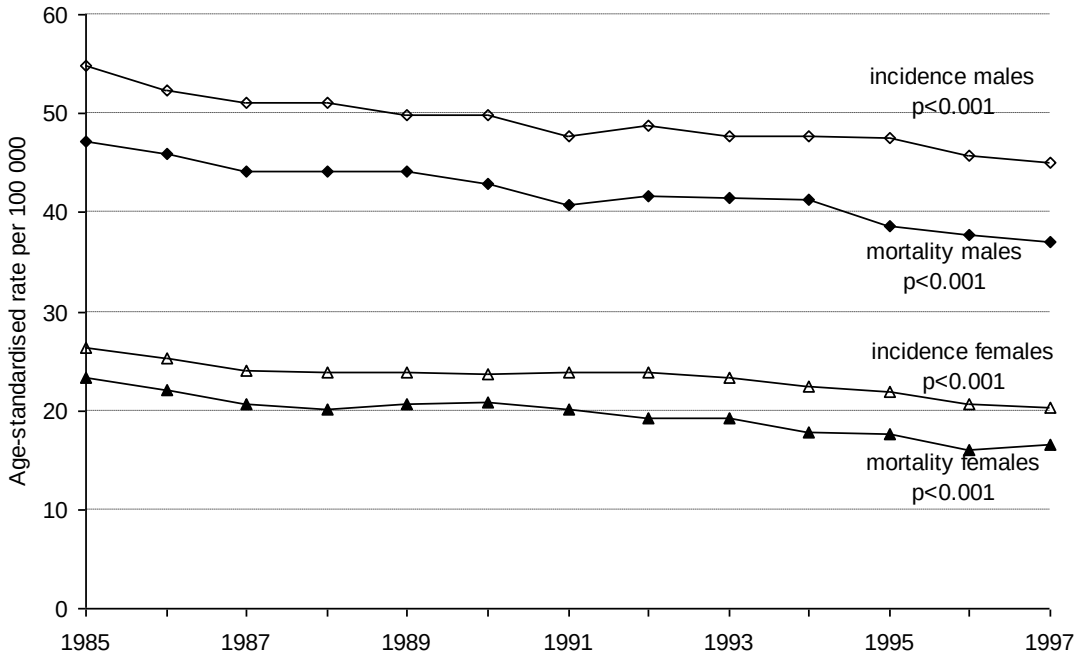

Figure 5.9. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the stomach, Estonia, in 1985–1997, all ages, three years moving averages. Source: EUROCIM.

It is seen that incidence is about twice as high for men than it is for women. Incidence rates for both sexes have steadily decreased over this period. In men the overall decrease in incidence rates is about 18 % and in women it is 26%. As for incidence, the trend for stomach cancer mortality is also downwards for both sexes for the whole time period. Mortality has also declined: for men by about 22% and for women 29%. All the time trends are highly significant.

Most countries with adequate statistical infrastructure have registered declines in stomach cancer incidence and mortality (Nyren and Adami 2002b). In Estonia, still, the incidence and mortality rates for stomach cancer remain quite high if compared to other countries in Europe. This is most probably explained by the high prevalence of *H. pylori* infection which is acquired in childhood and plays a significant role in the

aetiology of stomach cancer (Nyren and Adami 2002b) *H. pylori* infection is common in Estonia with a prevalence rate of around 80% (Maaroos 1995).

For both men and women, the level of the mortality rate is about 80% of the incidence rate level, reflecting the fact that cancer of the stomach has relatively poor survival. The five-year relative survival rate for stomach cancer in Estonia was 16% (Faivre et al. 1998a) for cancers diagnosed in 1985–89, which is considerably lower than the European average at 21%. According to EUROCARE II, survival rates for stomach cancer improved only slightly over time.

5.2.2.3 Cancer of the colon

Incidence and mortality trends for cancer of the colon are presented in Figure 5.10. It is seen that the incidence rate is somewhat higher (19–33%) for men than for women and that the rates are increasing for both sexes. The overall increase in incidence is quite considerable, about 43% in men and 33% in women. The time trends in colon cancer incidence are significant for both sexes.

Figure 5.10. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the colon, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

The mortality rates for both sexes have not changed substantially over this time period. Time trends in mortality are not significant. For men there has been a little more fluctuation in rates from year to year than for women.

Comparing the incidence and mortality trends it is seen that the gap between those for both sexes has widened during this time period. Calculating the mortality/incidence ratios gives us an estimation of the difference between the rates. For both men and women the M/I ratios range between 0.7 and 0.5, and have in general decreased over time.

Survival from cancer of the colon is relatively good and has improved. The Estonian 5–year relative survival rates for cancers diagnosed in 1978–80 *versus* 1987–89 increased from 23 to 39% in men and 30% to 40% in women (Gatta *et al.* 1998a). This is consistent with the widening gap between incidence and mortality. At the same time, the 5–year relative survival rates in Estonia still remained lower than the European average which was 47% in 1987–89 (Gatta *et al.* 1998a).

It is difficult to explain the increasing incidence of colon cancer in both sexes. Dietary differences have been proposed to be responsible for much of the incidence variation of colon cancer (Bray *et al.* 2002). Yet data about dietary habits in the past are very scarce. Sedentary lifesyle and lack of physical exercise can also possibly play a role in the increase of colon cancer incidence (Levi *et al.* 1999). Unfortunately in Estonia there is only very scarce information available on lifestyle related factors over time and systematic health surveys have been carried out only since the beginning of 1990–s.

5.2.2.4 Cancer of the rectum

Incidence and mortality trends for cancer of the rectum are presented in Figure 5.11.

It is seen that incidence rates for both sexes have been on decline during the first 4–5 years of the observed time period, then remained at the same level for 3–4 years, and diverged since 1991–1992, when the rate for women began declining, and the rate for men started increasing. The incidence rate for cancer of the rectum is much higher for men than it is for women and the difference has become bigger over the years. In 1985 male rates were 1.5 of the females rates, while by 1997 they were 2.1. The incidence trend in men is not significant, while in women the decreasing trend is significant.

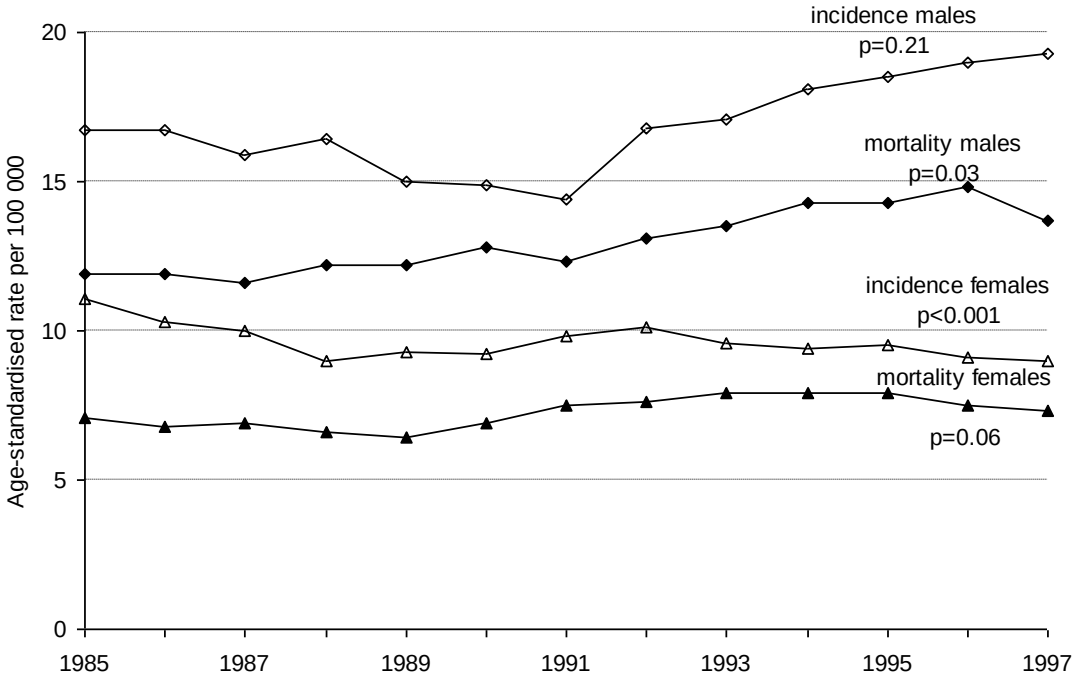

Figure 5.11. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the rectum, Estonia, in 1985–1997, all ages, three years moving averages. Source: EUROCIM.

A significant inverse relationship of total fiber intake and of its components with the risk of rectal cancer has been demonstrated (Levi *et al.* 2001a). According to Potter, there is good evidence of an elevated risk with higher red meat consumption and reduced risk with higher intake of plant foods and calcium (Potter and Hunter 2002). Therefore, higher incidence in men as compared to women for cancer of rectum may be due to different diet in men and women in Estonia. Data about diet habits in the past are difficult to find, but at least currently women in Estonia are reported to eat more fruit and vegetables (Kasmel *et al.* 2001).

For men it is seen that the mortality rates have been increasing almost over the whole time period, gaining its highest value in 1996 with an excess rate of 24% compared to its value in 1985. The time increasing trend in men is significant. For women the rate has shown only slight changes over the observed time with no overall change between 1985 and 1997. The mortality rate for cancer of the rectum is much higher for men than it is for women. This difference is around 40–50%, which reflects the difference in the

incidence rate. For this cancer site it is interesting to note that incidence and mortality trends between sexes are clearly different.

The difference in the level between incidence and mortality rates for rectal cancer has been around 20–50% for both men and women, showing that mortality rates are considerably lower than incidence rates. This is an indication that survival is rather good. Indeed, in Estonia for the rectal cancers diagnosed in 1987–89, relative survival at five years was 34% for men and 36% for women (Gatta *et al.* 1998a). This is still lower than the European average which was 43% at 5 years for patients diagnosed during the same time period (Gatta *et al.* 1998a).

5.2.2.5 Cancer of the pancreas

In Figure 5.12 time trends in the incidence and mortality of the cancer of pancreas for men and women are shown. For men, the rate has increased by 14% as a whole. At the same time, for the most recent years, there has been almost no change in incidence rate for men.

For women, the incidence trend appears different to that for men. Namely, the rates for women increased until 1992, and then, with some fluctuation, levelled off almost at the same position as at the beginning of the observed period. The difference in the incidence rates for men and women is around twofold for most of the time, and even bigger for the most recent years.

The incidence time trends for both sexes are not significant.

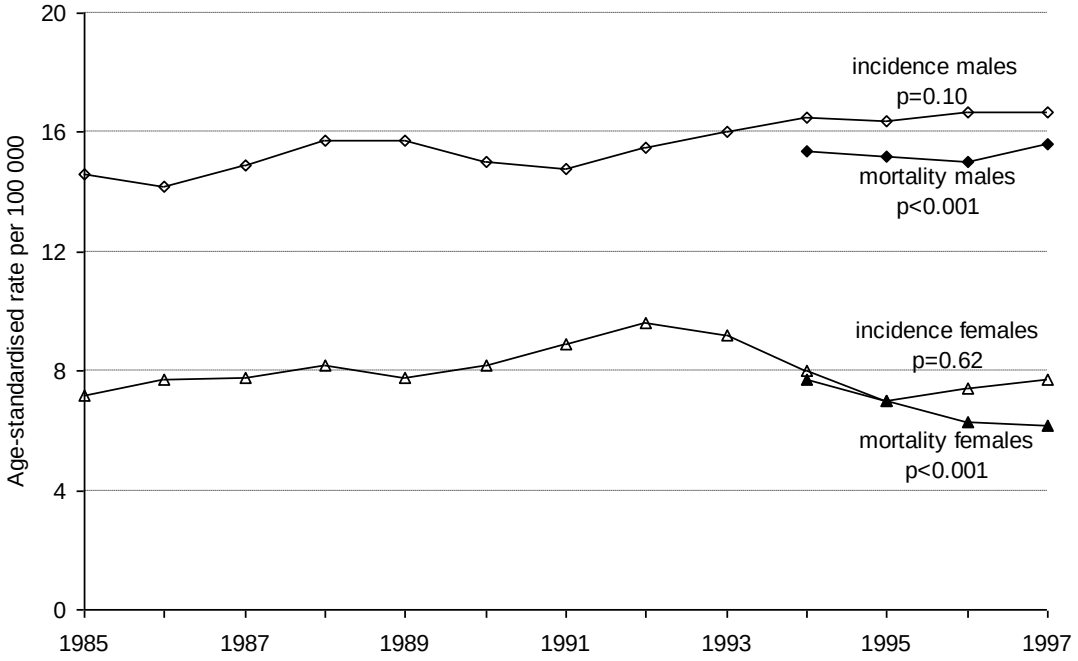

Figure 5.12. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the pancreas, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

Tobacco smoking is an established risk factor for cancer of the pancreas (Ekbom and Hunter 2002). The patterns in the past in smoking habits in Estonia will be described in section on lung cancer (5.2.1.7). Smoking certainly explains the higher incidence of pancreatic cancer in men compared to women in Estonia.

The role of other factors such as diet, alcohol and coffee consumption may also play a role in the risk of pancreatic cancer, but further evidence is required to confirm these associations (Weiderpass *et al.* 1998; Tavani and La Vecchia 2000). Diseases such as adult-onset diabetes mellitus and perhaps pernicious anemia increase the risk of pancreatic cancer (Ekbom and Hunter 2002).

Unfortunately, mortality data for cancer of the pancreas are available in EUROCIM from 1994 onwards only. For this reason only data for the four most recent years up to 1997 (as an average for 1996–1997) are presented. It is seen that for men the rates are increasing, while for women they are on decline. As cancer of the pancreas has very poor survival, this declining trend in women is most probably the reflection of declining incidence in 1993–95. Mortality from pancreatic cancer in men in Estonia is twice as high as mortality in women, reflecting the difference in incidence rates.

The median survival following diagnosis of pancreatic cancer is less than six months. It has in fact the worst survival among all forms of cancer (Ekbom and Hunter 2002). The results from EUROCARE II (Faivre *et al.* 1998b) showed that the 5–year survival rate in Estonia was only 1%, which was significantly lower than the 4% average for Europe.

5.2.2.6 Cancer of the larynx

Incidence and mortality trends for cancer of the larynx are shown in Figure 5.13.

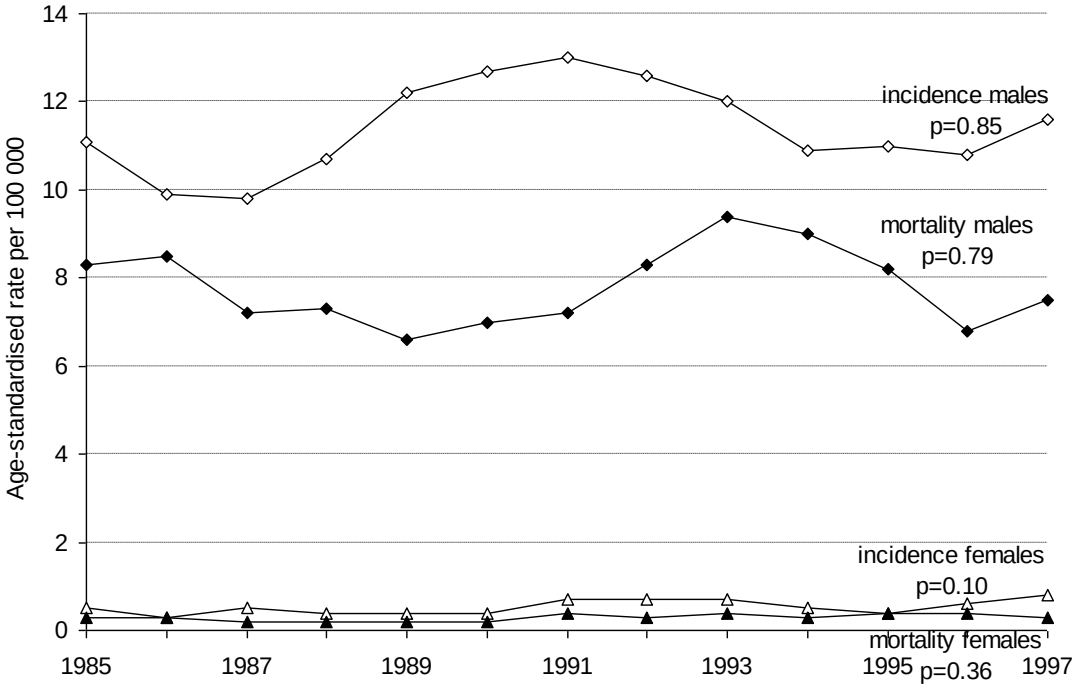

Figure 5.13. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the larynx, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

For men there is some variation in incidence rates over time, but at the end of the observed time period the rate is at the same level as it was in 1985. For women the rates are very low, and do not show any substantial absolute changes over time.

All the time trends are non-significant.

The main etiologic factors of cancers of the larynx are alcohol and tobacco (Cattaruzza *et al.* 1996; Riboli *et al.* 1996), and also diet, with a diet rich in fruit and

vegetables having a preventive effect against the risk of laryngeal cancer. In Estonian men, all those factors, especially alcohol and smoking, are very likely to play a role in the rather high incidence of laryngeal cancer. In contrast, the incidence rates for women in Estonia are small as the prevalence of smoking among women is low (see next section).

Mortality rates for cancer of the larynx in men have also varied over time, maintaining the initial value at the end of the observed time period. The most probable explanation for these fluctuations would be that they follow the changes in incidence with a 2–3 years time lag. However, because the rates are relatively small, this fluctuation in mortality rates similar to that of incidence may be due to chance. In women the mortality rates are very low and have been stable over this period.

Mortality rate is about one third lower than incidence rate for both sexes and the average M/I ratio is 0.7.

Survival of laryngeal cancer is good, with the five-year relative survival rate exceeding 60% in Europe (Bray *et al.* 2002), although it varies a lot according to the sub-site involved. In general poorer prognosis is characteristic of those populations where alcohol consumption is high and the upper part of the larynx is most affected (Bray *et al.* 2002). In this regard the survival of laryngeal cancer patients among men in Estonia seems to fit more with the pattern of lower survival in Eastern Europe when compared with Northern Europe when judged by the relatively small difference between the incidence and mortality rates. No data about survival rates for laryngeal cancer in Estonia are available.

5.2.2.7 Cancer of the lung

In Figures 5.14 and 5.15 incidence and mortality time trends for lung cancer for men and women are presented. For this cancer site the rates for men and women are presented on different graphs because of the big sex difference in rates.

The rates in men (Figure 5.14) increased until the end of 1980–s and levelled off after that until they started decreasing slightly in the early 1990–s. The net increase in the incidence rate in men from 1985 to 1997 was about 9%, with a significant time trend.

The lung cancer incidence rate for women (Figure 5.15) has been steadily increasing over these years. The total increase is nearly 26%, which is much more remarkable than

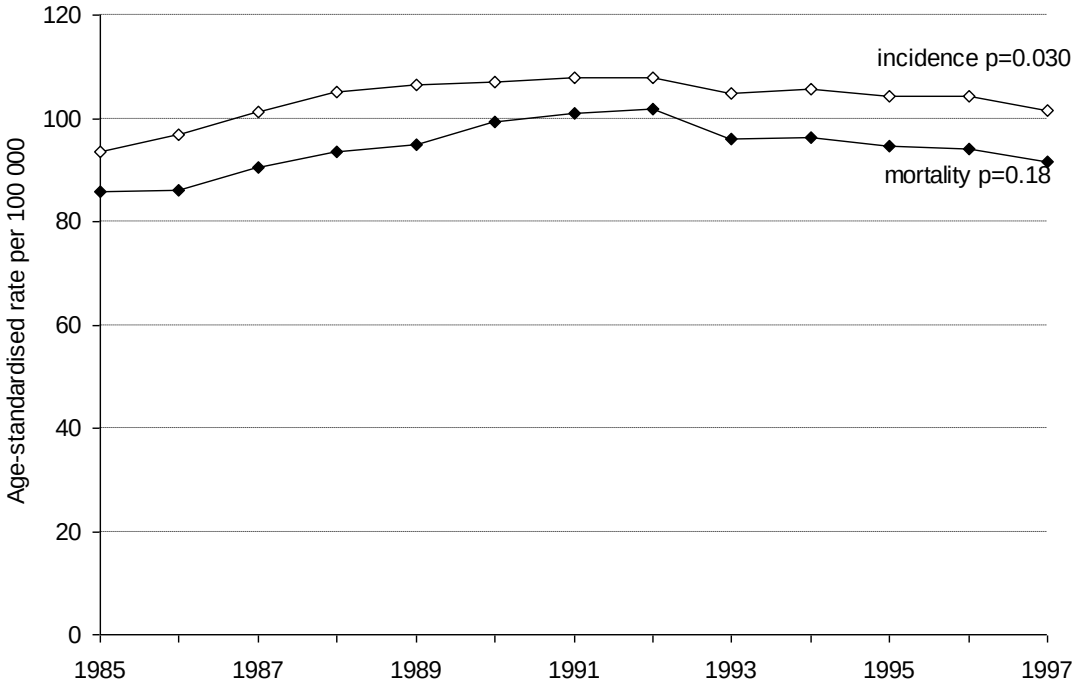

Figure 5.14. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the lung in men, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

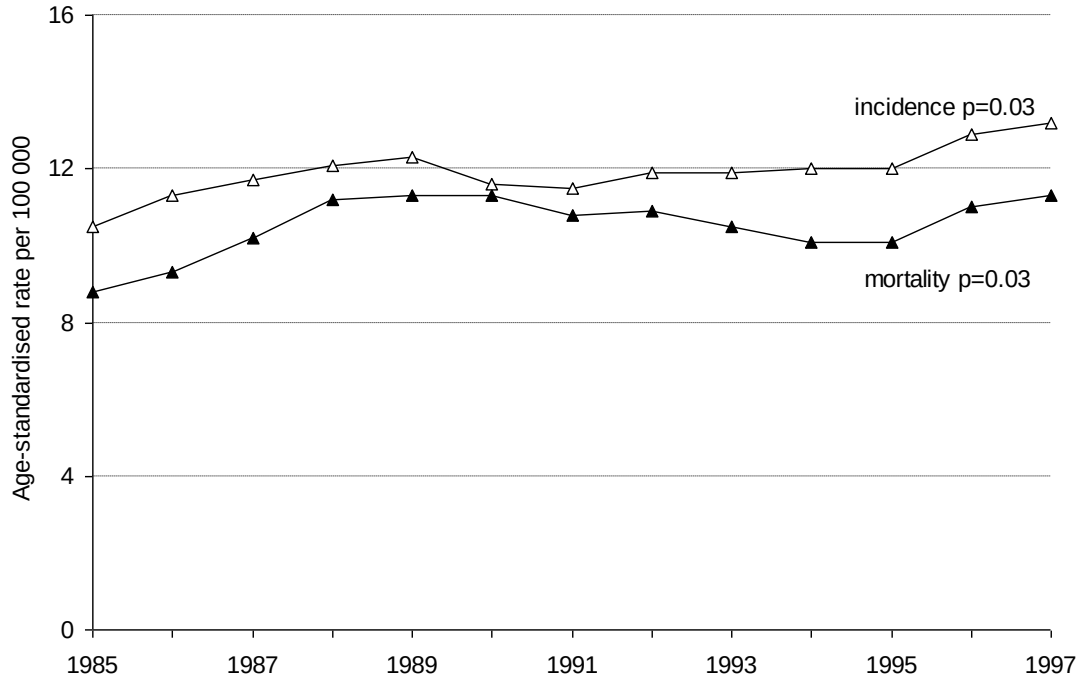

Figure 5.15. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the lung in women, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

the increase for men. However, in absolute terms, the incidence rate for lung cancer for women is about 8–9 times lower than for men.

Mortality trends follow the pattern of incidence trends very closely. Mortality rates are only slightly lower than incidence rates. The M/I ratio for lung cancer is close to one as survival is poor: for men it is 1.0 for men and for women it is between 0.8–1.0. Relative survival rates for lung cancers diagnosed in 1985–89 estimated at five years for men in Estonia (5%) were lower than the average for Europe (9%), while for women they were higher in Estonia (14%) than the average for Europe (10%) (Janssen-Heijnen *et al.* 1998). Aareleid and Brenner (2002) reported that 5–year relative survival rates for lung cancer ranged between 7–8% and showed only very little change over time for cancers diagnosed in 1969–98.

Tobacco smoking induces all major histologic types of lung cancer (Boffetta and Trichopoulos 2002). Research shows (Parkin *et al.* 1994b) that smoking in European populations accounts for some 90% of new cases of lung cancer in men, and some 73% (in Northern Europe) in women. Yet the given estimates may not be complete as they do not account for passive smoking, which has been shown to increase lung cancer risk (Boffetta *et al.* 1998, Hackshaw *et al.* 1997). For women in Estonia, the suggested attributable proportion of around 73 is probably not as high because lung cancer incidence for women in Estonia is rather low compared to, for example, the Nordic countries.

Direct estimates of the role of smoking in the occurrence of lung cancer in Estonia would require historical data on smoking, as the patterns of lung cancer incidence are largely determined by tobacco consumption patterns that took place two or more decades earlier (Kuper *et al.* 2002). However, data about smoking habits for those earlier decades are not representative of the whole population, but restricted to selected population groups such as teachers and doctors in Estonia. The results of these studies show that in 1977, among physicians, the proportion of current smokers was 42 % for men and 22 % for women (Väärt *et al.* 1979). The 1980 study of schoolteachers showed that 40 % of males and 11 % of females were current smokers (Raudsepp and Rahu 1984). In the WHO Health for All Database (2003d) the smoking prevalence data for Estonia go back as far as 1990 when the percentages for regular daily smokers aged 15 and over was 45.2 for men and 15.1 for women.

Based on the data from a large-scale national health survey carried out in 1996, the Estonian Health Interview Survey (Leinsalu *et al*. 1998a; 1998b), the smoking patterns that prevailed in the past can be described to some extent. The results of this survey show that the median age at the beginning of regular smoking is around 18 years for men and 21 years for women. It also gives estimates about percentage of men and women who have smoked regularly 10 or more years: 51.2 % of men and 14.5 % of women. As compared to men, a considerably smaller percentage of women have smoked in the past.

To conclude from the smoking figures presented above, high lung cancer rates over time for men in Estonia are attributable to smoking as the prevalence of smoking among men is and has been rather high. In women, the lung cancer rates for both incidence and mortality are rather low, and, again, are attributable to low prevalence of smoking. Unfortunately time-series data on smoking for representative samples of the whole Estonian population are not available and hence it is not possible to look in more detail at the relationship between lung cancer and smoking over time.

5.2.2.8 Cancer of the breast

In Figure 5.16 incidence and mortality trends for breast cancer in females are shown. It is seen that both rates show significant increasing trends. The relative rise is 30% for incidence and 32% for mortality. It is also seen that both rates stagnated in the early 1990s, and following that, the increase is especially marked for breast cancer incidence.

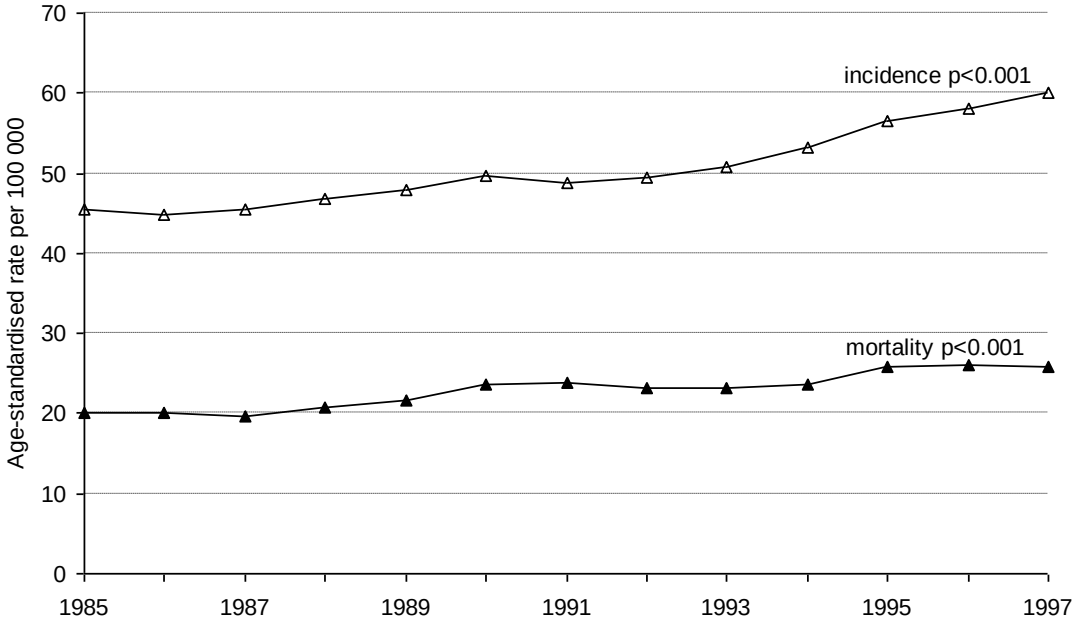

Figure 5.16. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the breast, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

Nulliparity, early age at menarche, late age at menopause, and late age at first full-term pregnancy have been known for many years to be associated with increased risk for breast cancer (Kelsey *et al.* 1993). Childbearing patterns have not been closely studied in Estonia, and there are no data available from the state statistics department about childbearing patterns such as parity and mothers' age at first birth beyond 1990. Thus at the moment it is difficult to find reasons for the increasing breast cancer rates in Estonia, and this is one of the areas for future research.

Hermon and Beral (1996) examined mortality rates for breast cancer for 20 countries in Europe, North America, Australia and New Zealand from 1950 to 1992. They concluded that for most countries the mortality rates have levelled of or begun to decline which appeared in part to be related to a reduction in childlessness and a reduction in age at birth. Breast cancer mortality is only about half of the incidence rate, which is constant with it having reasonable survival. The 5–year survival rate according to EUROCARE II study was 73% (Quinn *et al.* 1998) in Europe and 60% in Estonia. Aareleid and Brenner (2002) describe an increase in 5–year relative survival rates for breast cancer over time, reaching 65% in 1994–98. This is consistent with the widening gap between incidence and mortality rates seen in Figure 5.16.

5.2.2.9 Cancer of the cervix uteri

Figure 5.17 presents incidence and mortality rates for cancer of the cervix uteri. Incidence rates have increased by 9%, with most of the increase having taken place in the last five year period, and the time trend being not significant.

Mortality rates show more variability, which can be an artefact attributable to small numbers of deaths. No trend in mortality rates is apparent (p=0.94).

The mortality rate is about a half of the incidence rate and the difference between these rates has become wider over the years. The M/I ratio has been between 0.4 and 0.5 during this time period. The five year relative survival rate in Estonia (58%) is quite close to the European average (62%) (Gatta *et al.* 1998b).

Infection with specific high risk human papillomaviruses (HPV) is the most important risk factor for cervical cancer (Stuver and Adami 2002). Moreover, it may be in fact the causal agent in almost all occurrences of this cancer. A number of cofactors have also been identified which may act as possible modifiers of the cervical cancer, such as smoking, multiparity, oral contraceptive use, age at first intercourse, and other sexually transmitted infections.

Pap smear screening detects preclinical lesions of cervical cancer and is therefore recognised as an effective means of reducing its morbidity and mortality. No mass screening for cervical cancer has been carried out in Estonia, which may explain why the trends in mortality are not favourable compared to many western countries where screening programmes have been in place for some time (Lehtinen *et al.* 2000).

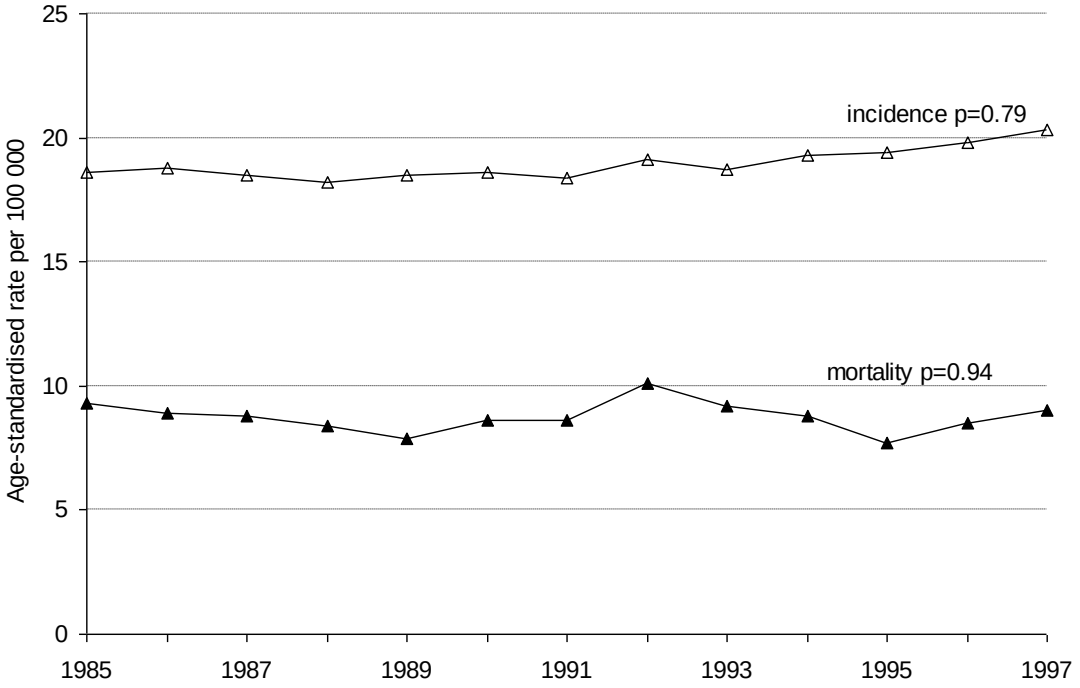

Figure 5.17. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the cervix uteri, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

5.2.2.10 Cancer of the corpus uteri

In Figure 5.18 incidence and mortality trends for cancer of the corpus uteri are shown. Again, unfortunately the mortality data for this cancer in the EUROCIM database are available from 1994 onwards only.

Incidence rates for this cancer show a stable significant increasing trend (p=0.01) and the rise accounts for 25%. Mortality rates are very low, and, also given the small number of years, no conclusions can be made about its changes. Compared to incidence, mortality is about 85% lower than incidence rate with M/I ratios ranging between 0.2 and 0.1. Relative survival rates in five years after diagnosis were 74% in Europe and 66% in Estonia. Relative survival rates at five years for endometrial cancer have been around 65% in Estonia during recent years with no consistent trends over time (Aareleid and Brenner 2002).

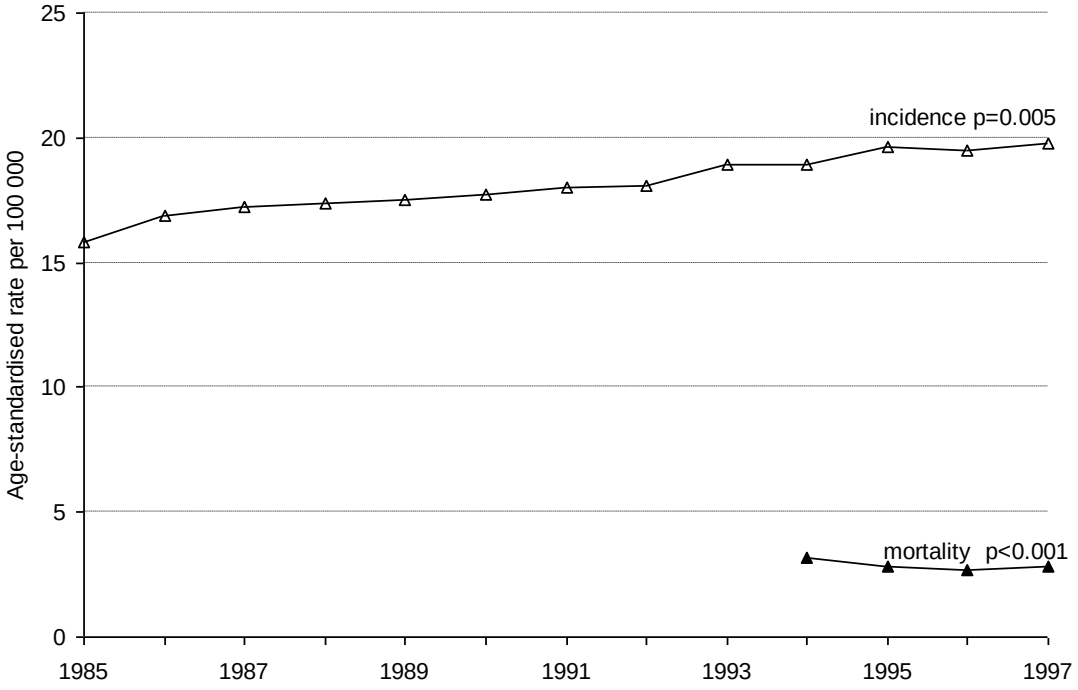

Figure 5.18. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the corpus uteri , Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

Overweight and obesity increase the risk of cancer of the endometrium, and the attributable proportion is 39% (Bergstrom *et al.* 2001).

5.2.2.11 Cancer of the ovary

In Figure 5.19 incidence and mortality data for cancer of the ovary are presented.

Incidence rate for this cancer has been rather stable over the years with a small not statistically significant overall decrease of about 7%. Mortality data are again only available for a few years and these do not show much variation either.

Cancer of the ovary has a fairly good prognosis, and relative survival is estimated at approximately 32% in women 5 years from diagnosis (Gatta *et al.* 1998b) as an average for Europe. The relative survival rate for Estonian women, which has had a modest increase (Aareleid and Brenner 2002) over time, was 25% according to EUROCARE II.

Figure 5.19. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the ovary, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

Hormonal and reproductive factors are shown to have a role in the aetiology of ovarian cancer (Gertig and Hunter 2002). Oral contraceptive use, increased parity and tubal ligation are inversely associated with risk.

5.2.2.12 Cancer of the prostate

In Figure 5.20 time trends in prostate cancer incidence and mortality are presented. The incidence rate for this cancer has risen sharply in early 1990–s, and this rise continues. The rate has doubled during the observed time and the time trend is significant.

The causes of prostate cancer remain poorly understood (Boyle *et al.* 2003; Gronberg 2003). Presently age, area of residence, ethinic background, and family history remain the only established risk factors for this cancer (Signorello and Adami 2002). Nutritional factors, but also hormonal influences may also have a role in the etiology of prostate cancer, but their definite role yet remains to be proved.

In contrast to changes in incidence rates, mortality from cancer of the prostate has been on the same level for most of the period, and started increasing only towards the very end of the studied time period. The time trend is significant (p=0.02). This increase may be due to increased incidence a few years earlier.

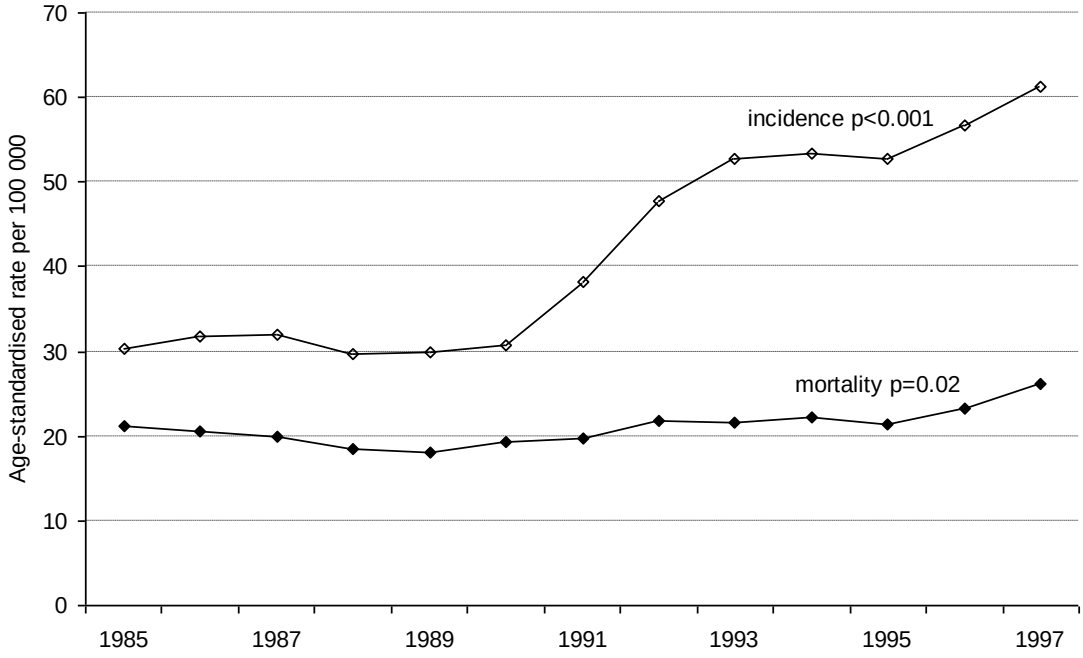

Figure 5.20. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the prostate, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

The difference between incidence and mortality rates has changed a lot, ranging from about 30% at the beginning of the observed period to about 60% at the end of the

period. The EUROCARE II study detected considerable variation of relative survival rates from prostate cancers in Europe for 1985–89 (Post *et al.* 1998). The lowest rates was in Estonia (39%), which was markedly lower than the average for Europe (55%). The gap between incidence and mortality rates in Estonia started widening in the early 1990–s as seen in Figure 5.20. The widening gap between incidence and mortality is consistent with recent improvements in prostate cancer survival as Aareleid and Brenner (2002) report an extraordinary big change over time, especially for prostate cancers diagnosed in 1994–98, where the survival rate reached about 60%.

The main reason for an increase both in incidence and survival is probably a change in the diagnostic activities (Aarelei and Brenner 2002). The introduction of the prostate specific antigen (PSA) determination and the increasing frequency of transurethral resections have led to discovering a number of asymptomatic prostate cancers. The PSA determination which was introduced in early 1990–s, became widely used in the world, including Estonia, by 1993 (Parkin *et al.* 2002). Some other factors leading to increased diagnosing should be mentioned (Timberg G 2004 – personal communication). During the recent years biopsies of the prostate tissue have become a routine method of diagnosing. The histologic diagnosing of prostate cancer has improved. Also, the awareness of men regarding the symptoms of prostate cancers has increased and they seek medical advice more often. Private clinics is a new development in Estonia, and men are more likely to seek medical consultation, going to these clinics. They prefer these for reasons of privacy and confidentiality. In case of suspicion of prostate malignancy, the patients are asked to attend check-ups in every three months, which also increases the chances of diagnosing prostate cancers.

The fact that mortality from this cancer, at the same time, has not increased much, suggests that there has been no increase in the risk for this cancer. This further supports the idea that the increase in incidence is due to more active diagnosing.

5.2.2.13 Cancer of the kidney

Figure 5.21 presents incidence and mortality trends for cancer of the kidney. Mortality data are again incomplete, as they are available only from 1994.

It is seen for both men and women that the incidence rates for this cancer have been constantly on the rise ($p<0.001$). For men the increase is especially marked for the more recent years. For both sexes the rates have doubled over this time period. The incidence

rate for men is twice as high as the rate for women for the whole time period, similar findings have been reported from the rest of Europe (Bray *et al.* 2002).

Cigarette smoking and obesity are the main risk factors for kidney cancer (Lindblad and Adami 2002). Genetic variations may explain the differences in incidence for this cancer among different populations, yet better understanding of genetic as well as molecular processes involved in the development of kidney cancer is needed.

Increase in the incidence rates for kidney cancer is related to the increase of smoking prevalence in the past, especially in men, and overweight (Bergstrom *et al.* 2001). As

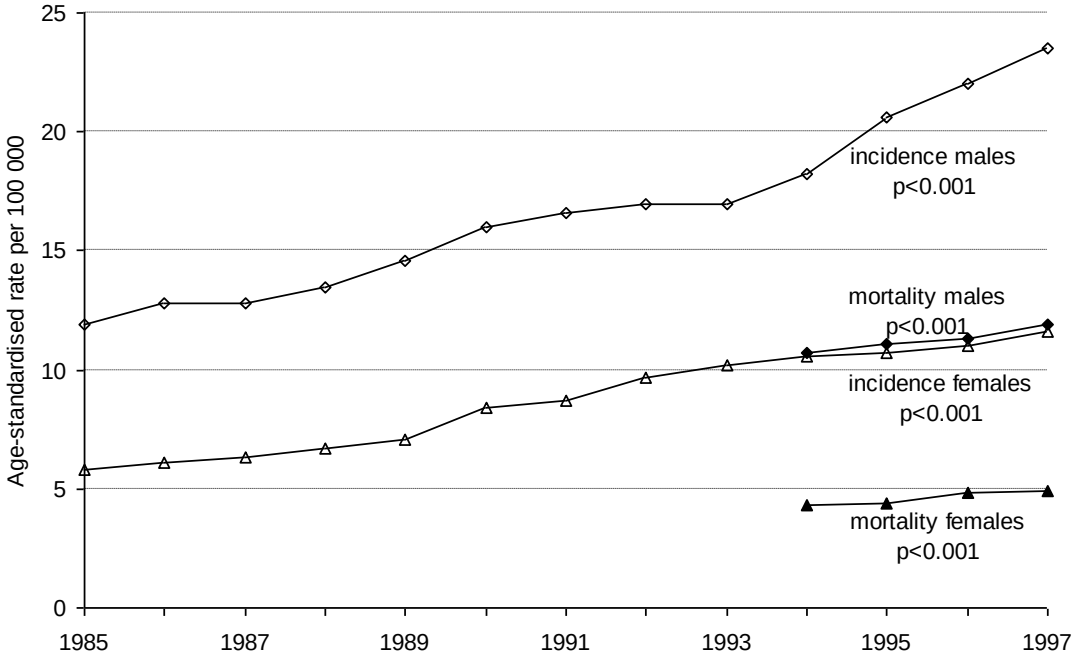

Figure 5.21. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the kidney, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

the lung cancer incidence rates are declining in Estonia, smoking is unlikely to play a role in the increase of kidney cancer rates, unless there is a considerably different latent period. This increase in incidence rate can be at least in part explained by diagnostic improvements. Modern imaging technologies such as ultrasonography and computer tomography markedly improved the diagnosing of renal tumours, especially small ones (Aareleid and Brenner 2002). These techniques became available in Estonia in the late 1980–s and early 1990–s respectively, and are now widely used (Aareleid 2004). Ultrasonography is practiced as a routine diagnostic method in all patients presenting

with symptoms characteristic to kidney cancer (Timberg G 2004 – personal communication).

In the mortality rates a small and steady rise is seen for both sexes. The relative difference between incidence and mortality is larger for women than it is for men, indicating better survival for women. The M/I ratios are between 0.5 and 0.6 for men and 0.4 for women.

The survival from kidney cancer in Estonia has improved vastly over the recent years (Aareleid and Brenner 2002) as is also reflected in Figure 5.21 by the widening gap between incidence and mortality rates. The 5–year relative survival rates have doubled over ten years, with the most recent estimate for cancers diagnosed in 1994–98 being around 50%. This rapid increase in survival rates may reflect an increasing proportion of small tumours as a result of diagnostic improvements. Also, advances in treatment and follow-up have contributed to higher survival (Timberg G 2004 – personal communication). Namely, a more radical method of surgery, laparotomy, has become a "gold standard" since early 1990–s, and six months after surgery, all patients are invited to undergo a computer tomography.

5.2.2.14 Cancer of the bladder

Figure 5.22 shows incidence trend and mortality rates for 1994–97 for cancer of the bladder. It is seen that the incidence for this cancer in men started to increase in late 1980–s and this increase accounts for about 36 %. In women, there is also an increase in incidence rates, but compared to men this is much smaller. Both incidence rates show a significant time trend.

Mortality rates for both sexes, available since 1994, show a slight increase. Compared to incidence rate, mortality is roughly a half of it, indicating rather good survival. The five year relative survival rate for bladder cancer in Estonia was close to 60% for cancers diagnosed in 1994–98 (Key *et al.* 2002).

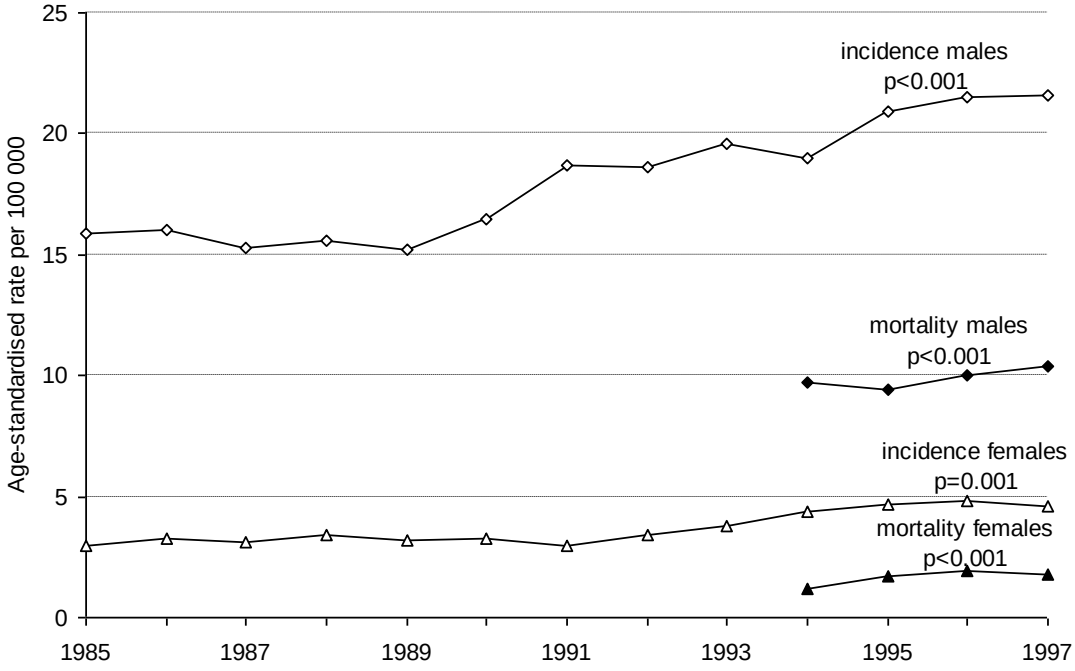

Figure 5.22. Trends in age-standardised incidence and mortality rates per 100 000 for cancer of the bladder, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

New diagnostic techniques that became available in the 1990–s, such as computer tomography scanners and techniques enabling more thorough investigation of the tumour tissue probably explain the increasing bladder cancer incidence. Early diagnosis is the main contributor to the improved outcomes for cancer of the urinary bladder.

5.2.3 Incidence trends in smoking related cancers

In this section time trends in smoking related cancers for men and women are presented (see Figures 5.23 and 5.24) and analysed. These include cancers of lung, larynx, oesophagus, pancreas, kidney and bladder. For all these cancers there is evidence for an established association with tobacco use (Kuper *et al.* 2002).

It is seen that for men all the observed incidence rates are a lot higher than for women. For men (Figure 5.23), the rates for lung cancer is decreasing. The male incidence rates are increasing for cancers of kidney and bladder, and also slightly increasing for cancer of the pancreas. For cancers of larynx and oesophagus the rates in men have fluctuated to some extent during the observed time period, but not changed at the end of the observed time period as compared to their initial value.

For women (Figure 5.24), the rates are increasing for cancers of lung, kidney and bladder. For cancer of pancreas in women, the rate has fluctuated to some extent during the observed time period, but retained its initial value at the end of the observed period. In the case of cancers of larynx and oesophagus, the female rates are based on very small numbers and fluctuations seen on the graph are most probably due to random variation.

In men the patterns of incidence time trends in smoking related cancers are very heterogeneous. Most importantly, the decreasing lung cancer rates should certainly be attributed to a recent decrease in smoking prevalence. The increase or stability in the rates for other smoking related cancers in men is probably the effect of other factors than smoking, such as differences in the latent periods for these cancers and/or the emergence or changes in prevalence of other causal factors. Improved diagnostic practices may count for increases in cancer incidence trends, certainly in the case of kidney bladder cancers as was discussed in Section 5.2.2.14.

In women, the incidence rate of lung cancer is increasing, which is consistent with the fact that Estonian women have been taking up smoking over the past years. The rates of other smoking related cancers in women are relatively small and thus difficult to interpret.

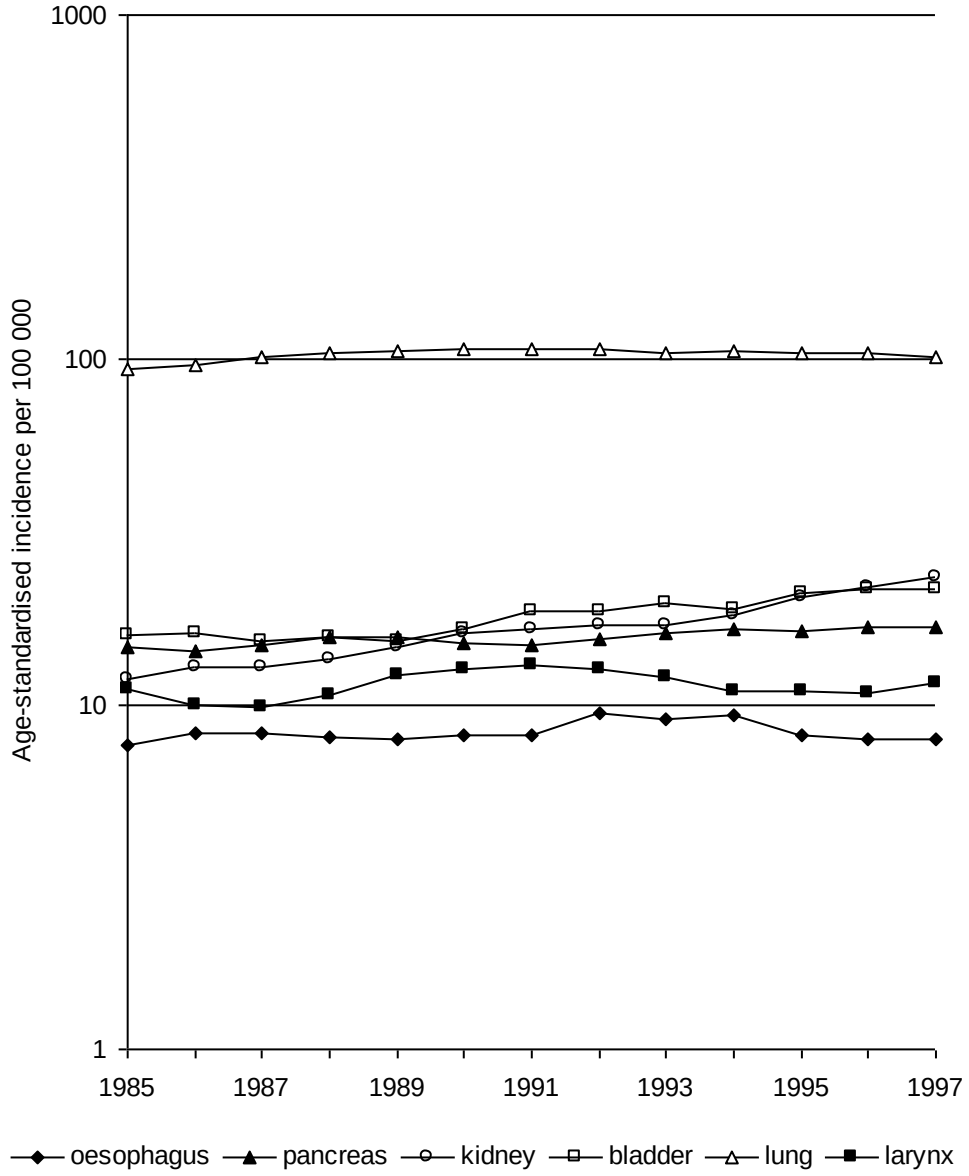

Figure 5.23. Trends in age-standardised incidence rates per 100 000 for smoking related cancers for men, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

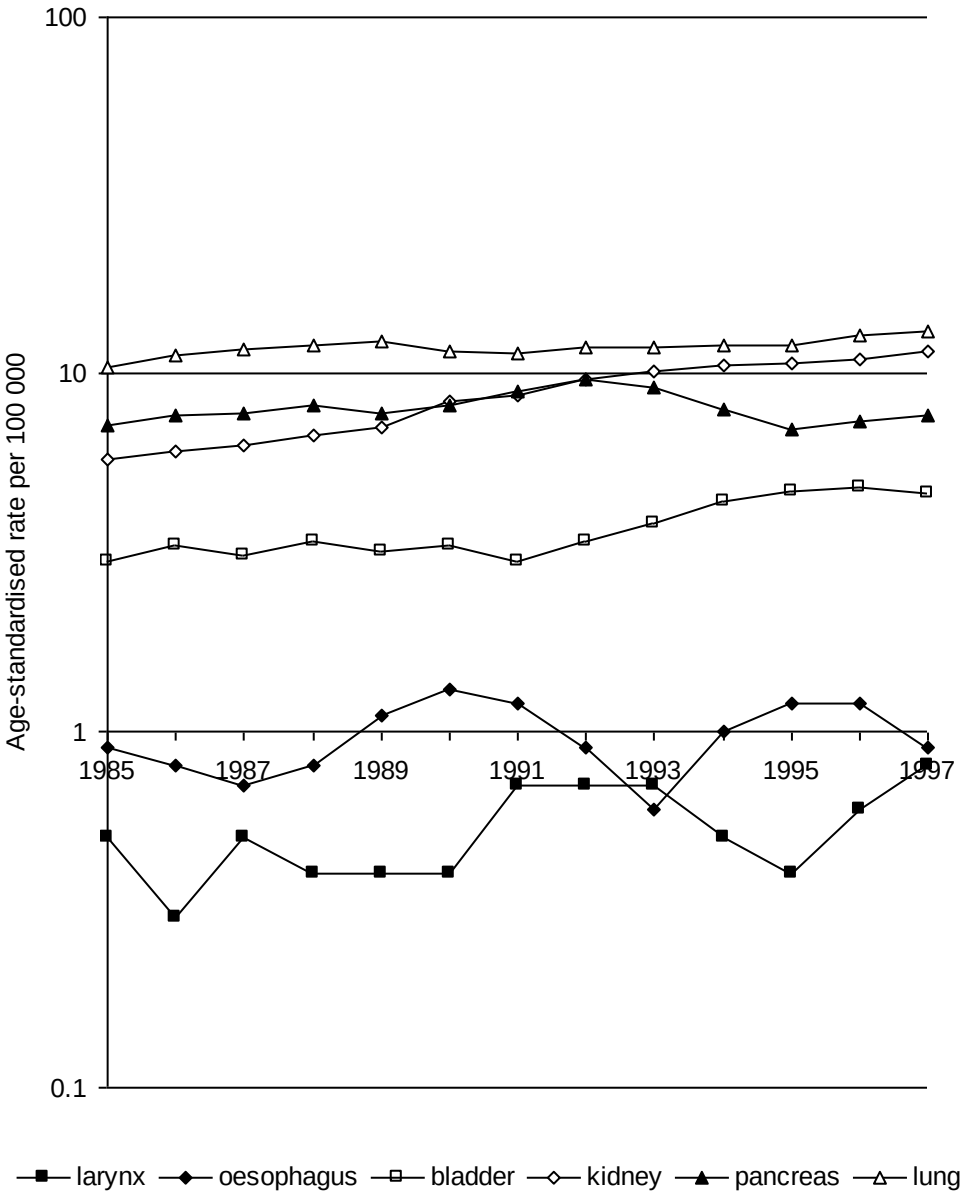

Figure 5.24. Trends in age-standardised incidence rates per 100 000 for smoking related cancers for women, Estonia, in 1985–1997, all ages, three years moving averages.
Source: EUROCIM.

5.3 Summary findings

Overall cancer incidence and mortality rates increased in Estonia in 1985–97.

Looking at specific sites, the incidence rates increased for a number of sites, such as lung, colon, breast, cervix and corpus uteri, and all the urological cancers (prostate, kidney, and bladder). For men they has also increased for cancers of rectum and pancreas. It should be noted that the incidence trends for these sites continue to go up

for all these sites with the exception of lung cancer for men, which started to decline in the second half of the period studied.

Incidence rates have remained stable for cancers of the oesophagus and larynx for both sexes, and ovary and pancreas for women. They have decreased consistently for stomach cancer for both sexes. For women they have also decreased for cancer of rectum.

In general mortality rates have increased proportionally less than incidence rates. As for specific sites, an increase is seen for cancers of lung and kidney for both sexes, and for gender specific sites such as breast and prostate. In men the increasing lung cancer mortality trend has reversed over the most recent years. In men the mortality rates also increased for cancers of oesophagus, rectum, and bladder, with the continuous upward trend. Mortality rates did not change overall for cancers of the colon and larynx for both sexes and and cancers of oesophagus and rectum and both cervix and corpus uteri in women.

The mortality rates decreased constantly for the cancer of stomach for both sexes.

5.4 Discussion

When interpreting cancer trends over time, some issues influencing these trends should be considered. Changes in cancer incidence can occur as a result of changes in underlying risk factors. But other issues such as developments in cancer registration practice, changes in diagnostic activities, including implementation of screening programmes also contribute to the changes in incidence over time. Mortality trends are influenced first of all by underlying incidence of disease, but in addition by earlier diagnosis and advances in treatment that reduce mortality. Other factors such as the validity of and changes in mortality registration etc. also have a role. Discussing the last mentioned ones, though, would be beyond the scope of this thesis as mortality data in EUROCIM are based on official mortality statistics from each country and WHO Mortality Databank, and thus do not reflect the validity of cancer mortality registration by the ECR.

In the following sections I discuss the likely contribution of the different factors to changes in incidence and mortality of the leading cancer sites in Estonia.

5.4.1 Risk factors

For cancer incidence trends, first of all, changes in the underlying known risk factors need to be studied to be able to find out their possible influence on the trends. This is difficult to do convincingly in Estonia as due to the long latent period for cancer, it would require time trend data on the occurrence of factors that may cause different malignancies. Such data are very scarce in Estonia.

Smoking certainly is the main risk factor responsible for changes in the incidence of a number of cancer sites, especially lung cancer. Some data on smoking were presented in Section 5.2.2.7. In addition, given the big burden of the smoking related cancers, the discussion the incidence trends of these cancers was given in Section 5.2.

Another example of changes in risk factors is the continuous decrease in stomach cancer incidence rates for both sexes seen in Estonia during recent decades. It must be attributable to improvements in living conditions and level of hygiene that cause a decrease in the prevalence of *H.pylori* infection that has a significant role in the aetiology of stomach cancer. There are no studies in the literature, however, that specifically address this issue in Estonia.

The increase in incidence of cancer of the cervix uteri must reflect an inrease in prevalence of infection with specific high risk HPV which is the most important risk factor for this cancer (Stuver and Adami 2002). Again, however, there are no time trend data for Estonia that can definitely show that this is the explanation. There is though some evidence of increased incidence of sexually transmitted diseases in Estonia at the beginning of 1990–s (Uuskula *et al.* 1997).

5.4.2 Diagnosing and screening

The emergence of new diagnostic methods or implementation of screening (as well as lack of screening) can also alter cancer incidence rates over time.

The reason for an increasing trend in prostate cancer incidence is very likely to be a change in the diagnostic activities, such as the introduction of the PSA determination and the increasing frequency of transurethral resections. Earlier diagnosis as a result of the implementation of new diagnostic methods also contributes to the widening gap between incidence and mortality trends for prostate cancer in Estonia.

In the case of other urologic cancers in Estonia, such as kidney and bladder cancers, recent developments in diagnosis such as ultrasonography and computer tomography have contributed to the increasing trend in incidence as well as the widening gap between the incidence and mortality trends.

The stagnation of mortality trend for cancer of the cervix uteri reflects the absence of a Pap smear screening programme in Estonia.

5.4.3 Registration artefact

Registration artefacts can occur, among other factors, due to changes in cancer registration process. It should be noted that by 1985, when the observation period started, the ECR had established its data collection process firmly and the changes in incidence rates over the next years can not be due to the well documented problems experienced by new cancer registries in completeness of cover in the first few years after they are established. Although there were some changes in the cancer registration process in Estonia over the period of 1985–97, when looking over time there are no obvious discontinuities in trends overall or by site that could relate to changes in the registration process.

Other registration artefacts would include misclassification of cancer sites or underascertainment of cancer cases. In case any of these existed, these were perhaps too small to be picked up in this comparison. As was shown by the results of the case completeness study in Chaper 4 Section 4.1.3, there may be some problems with underascertainment of cancer cases by the ECR. According to that study, cancers of the lung, thyroid, and prostate, and non-malignant neoplasms of the CNS were most frequently missed for various reasons (discussed in Section 4.1.4).

5.4.4 Treatment and survival

Advances of treatment have contributed to improvements in survival from breast cancer in Estonia over the recent years (Aareleid and Brenner 2002). This causes the mortality trend for breast cancer increase more slowly than the incidence trend and the gap between the two trends to widen.

Survival in Estonia has also increased for cancers of colon (Gatta *et al.* 1998a), ovary (Aareleid and Brenner 2002) (modest increase), urologic cancers (prostate, kidney and bladder) (Aareleid and Brenner 2002), causing the gap between incidence and mortality trends to widen.

5.4 Conclusions

It may be concluded that a lot of variation in the cancer incidence trends in Estonia is due to changes in underlying risk factors, most importantly smoking. For the great majority of these cases the time trends in incidence are upwards. This shows that the share of avoidable causes in the genesis of cancer among Estonian people is remarkable and the need for measures of public health intervention is urgent.

This comparison of cancer time trends in Estonia did not suggest major cancer registration artefacts. Advances in diagnostic methods account for some of the increase in incidence while improved survival explains some of the decrease in mortality. To see how cancer rates in Estonia match up to the respective rates of other countries, these will be presented in comparison with some neighbouring countries in the next chapter.

Chapter 6. Incidence and mortality in comparison with some neighbouring countries

In this chapter a description of Estonian cancer incidence and mortality in comparison with some neighbouring countries is given. The countries chosen for this comparison are the two other Baltic countries Latvia and Lithuania and the Nordic countries Sweden, Finland, Denmark and Norway. Iceland from the Nordic countries was excluded because of the very small population size (283 361 people). Therefore, in this chapter when referring to the Nordic countries, it includes Sweden, Finland, Denmark and Norway.

The population estimates for the countries studied are presented in Table 6.1.

Table 6.1. Population size as an average for 1993–1997 for the Baltic and Nordic countries. Source: Cancer Incidence in Five Continents vol. VIII (Parkin et al. 2002)

Country	**Population size**		
	Men	**Women**	**Total**
The Baltic countries			
Estonia	692 634	792 802	1 485 436
Latvia	1 161 593	1 345 473	2 507 066
Lithuania	1 754 769	1 960 682	3 715 451
The Nordic countries			
Denmark	2 585 044	2 652 693	5 237 737
Finland	2 490 660	2 623 907	5 114 567
Norway	2 161 250	2 209 117	4 370 367
Sweden	4 349 249	4 453 411	8 802 660

It is seen from Table 6.1 that Estonia has the smallest population of the countries included in the comparison. Latvia is nearly twice as large as Estonia Lithuania almost three times the size. All the Nordic countries have populations which are larger than the populations of the Baltic countries, the difference of the Estonian population to the Nordic countries is considerable. Among the Nordic countries, Sweden has the largest population size, which is about twice the size of the populations in every other Nordic country compared.

These differences in population size, especially the smaller population sizes of the Baltic as compared to the Nordic countries, and Estonia having the smallest population, affect the precision of comparisons between countries. Namely, the countries with smaller population size are more prone to random fluctuation of rates caused by small numbers of cancer cases. To minimize this error, five year average rates have been used.

The databases used for incidence and mortality data are the same as in Chapter 5. Some limitations apply: first, the incidence rates for Denmark are the averages for 1993–96 as no data for this country for 1997 were available from EUROCIM, and second, for cancer mortality in Estonia for some sites such as pancreas, corpus uteri, ovary, kidney and bladder, data were only available from 1994, not 1993.

The sites were selected according to their ranking of ten most frequent sites for cancer incidence in men and women in Estonia as an average for 1993–97. From this comparison the site named "other skin" referring to other malignant neoplasms of the skin (all other excluding melanoma), leukaemia, and cancers of the brain and nerves were left out as there are differences in classification and/or completeness of registration for these cancers between countries. For sites such as bladder, larynx, and oesophagus that feature among the ten leading sites for men only, the data for women are also presented for the purpose of completeness. The 'all sites' listing excludes non-melanoma skin cancer.

All rates were age-standardised to the European population, and expressed as incidence or mortality rates per 100 000. The sites are ordered by the ICD codes. The ICD rubrics used for defining cancer sites are given in Table 5.1.

In addition to the incidence and mortality rates by selected cancer sites between the countries, incidence rates for these sites are plotted against mortality rates by countries.

To examine the total total number of cases of the studied cancers registered for 1993–97 by the Baltic and Nordic cancer registries, the respective numbers are shown in Table 6.2.

Table 6.2. Total number of cases of cancers studied, registered for 1993–97 by the Baltic and Nordic cancer registries.
Source: EUROCIM.

Cancer site and ICD–10 code		Cancer registry						
		The Baltic countries			The Nordic countries			
		Estonia	Latvia	Lithuania	Denmark	Finland	Norway	Sweden
Oesophagus	M	261	415	629	1170	567	549	1187
C15	F	55	72	112	476	452	213	521
Stomach	M	1395	2103	3144	1755	2342	2188	3750
C16	F	1127	1685	2196	1052	2046	1454	2441
Colon	M	717	936	1251	4551	2647	4238	7649
C18	F	1017	1279	1501	5511	3384	5177	8206
Rectum	M	584	800	1415	3598	1950	2879	4967
C19–21	F	542	884	1304	2766	1845	2315	3803
Pancreas	M	499	892	1179	1525	1604	1390	2486
C25	F	439	792	921	1666	1914	1505	2733
Larynx	M	351	618	1011	1071	527	527	814
C32	F	26	26	55	224	55	104	123
Lung	M	3209	4769	6875	10128	8197	6215	8490
C33–34	F	665	847	1106	6669	2281	3021	5162
Breast C50	F	2527	4018	5258	17082	14974	10783	28371
Cervix uteri C53		860	897	1932	2351	811	1777	2427
Corpus uteri C54		913	1914	1970	3063	3176	2348	5882
Ovary C56		769	1367	1932	2841	2310	2293	493
Prostate C61		1597	1426	2885	7209	12000	12094	28920
Kidney	M	603	764	1049	1442	1910	1329	2840
C64–65	F	545	601	799	986	1505	937	2108
Bladder	M	577	958	1363	6090	2947	3947	7436
C 67	F	254	326	418	2069	932	1333	2549
All sites*	**M**	**12685**	**17812**	**27426**	**56779**	**47257**	**49394**	**97223**
C00–97	**F**	**12453**	**18667**	**25761**	**62496**	**49571**	**45728**	**96560**

* excluding “other skin”

It is seen that for Estonia, which has the smallest population, even for the five year period, the total number of cases for some sites is small. This is especially the case for cancer of the oesophagus, pancreas, larynx for both sexes and bladder in men, which all contribute less than five hundred cases over the five year period. For Latvia and Lithuania, the numbers for some cancer sites are also relatively small, with cancers of oesophagus, larynx and bladder for women for both countries and also cancer of oesophagus for men in Latvia contributing less than five hundred cases over the five year period. Among the Nordic countries, cancers of oesophagus and larynx in women have less than 500 cases. These two sites and also bladder cancer in women, for which the numbers of cases are reasonably large in the Nordic countries, do not figure among the ten leading sites for cancer incidence in women, but were added to the comparison

for the purpose of completeness as these sites are present among the ten leading sites for cancer incidence in men.

In Table 6.3 the numbers of cancer deaths in the comparison countries are presented.

Table 6.3. Total numbers of cancer deaths for 1993–97 by the Baltic and Nordic cancer registries.
Source: WHO.

Cancer site and ICD–10 code		Cancer registry						
		The Baltic countries			The Nordic countries			
		Estonia	Latvia	Lithuania	Denmark	Finland	Norway	Sweden
Oesophagus	M	244	416	586	1165	540	507	1177
C15	F	42	62	94	494	415	185	514
Stomach	M	1175	1965	2752	1425	1842	1773	3015
C16	F	913	1494	1831	996	1579	1185	2145
Colon	M	383	734	817	3294	1230	2328	3944
C18	F	599	993	1005	3791	1692	2486	4348
Rectum	M	409	643	1109	1955	983	1525	2199
C19–21	F	432	724	1032	1499	948	1258	1827
Pancreas	M	364	350	1081	1645	1558	1374	3246
C25	F	299	297	876	1839	1924	1513	3816
Larynx	M	252	486	752	500	170	185	243
C32	F	17	23	35	117	12	39	49
Lung	M	2902	4647	6395	10557	7488	5542	6611
C33–34	F	568	850	970	9023	1889	2643	5231
Breast C50	F	1169	1973	2759	6842	3916	3986	7564
Cervix uteri C53		426	505	1081	938	350	624	827
Corpus uteri C54		120	165	734	748	687	577	726
Ovary C56		445	370	1400	2308	1576	1593	3201
Prostate C61		623	947	1715	5141	3577	5525	11409
Kidney	M	270	214	797	1004	948	824	1973
C64–65	F	196	146	510	776	764	573	1509
Bladder	M	224	223	826	2154	740	1225	2055
C 67	F	87	88	218	856	345	551	869
All sites*	**M**	**8999**	**14994**	**21129**	**39159**	**25910**	**27567**	**53527**
C00–97	**F**	**7489**	**12416**	**16146**	**37492**	**23879**	**23625**	**48785**

* excluding “other skin”

It is seen from Table 6.3 that as was the case for numbers of incident cancers, some the numbers of cancer deaths tend to be small, especially in Estonia, for a number of sites such as oesophagus, larynx, and some of the gynaecological cancers.

6.1 Review of recent international comparisons

Introduction. The following is a survey of recent published work on cancer incidence and/or mortality rates and trends in Europe, looking at descriptive epidemiological

studies and reports. This analysis was restricted to all ages (not looking at childhood cancer or some other specific age groups separately) and common cancer sites.

There is a big literature comparing cancer incidence and mortality across countries, especially in Europe. The Nordic countries in particular are frequently included, having long standing cancer registries of high quality. However, Estonia and the other Baltic countries not very often feature in these comparisons. This review tries to find out to what extent these countries are included in European comparisons. It also aims to detect, where possible, for what reason the Baltic countries have been excluded from these comparisons.

This review also provides some insight into the methods of data collating for some of the studies, comparing these with the current study, as well as very briefly summarizes the findings for each study. All the studies are summarised in Table 6.4.

Some studies are confined to the European Union only (Aragones *et al.* 1997; Becker 1998; Black *et al.* 1997; Levi *et al.* 2000a; Levi *et al.* 200b; Levi *et al.* 2002; Levi *et al.* 2003a) and were not included in this survey.

Studies covering a number of sites. The most comprehensive piece of work is *Cancer Incidence in Five Continents*, a report issued at five year intervals by the IARC, that contains cancer incidence rates from a wide range of countries from all over the world. The most recent volume of *Cancer Incidence in Five Continents vol. VIII* (Parkin *et al.* 2002) includes cancer incidence data as an average for 1993–97, and covers amongst others all the countries chosen for my study. These data are collated by the IARC and subjected to strict quality control to maximise comparability between countries. Incidence rates are presented by country and cancer site for both sexes. In addition to incidence rates, this publication offers estimates for some data quality indicators and a short description of each participating cancer registry. Some of this information for the countries included in my study is presented in the next section. This publication does not discuss reasons for differences in incidence rates between countries and/or over time.

Table 6.4. Overview of recent studies in Europe looking at cancer incidence and/or mortality or survival.

Authors	**Publication year**	**Years covered**	**Cancer sites covered**	**Restrictions**	**Country**						
					The Baltic countries			***The Nordic countries***			
					Estonia	**Latvia**	**Lithuania**	**Finland**	**Denmark**	**Norway**	**Sweden**
Cancer Incidence in Five Continents vol. VIII (Parkin *et al.* 2002)	2002	1993–97	39 sites and all sites together		x	x	x	x	x	x	x
Bray *et al.* (2002)	2002	1995	25 common sites and all sites together	For Latvia and Lithuania, cancer incidence data not directly from cancer registries.	x	x	x	x	x	x	x
Dobrossy (2002)	2002	(1970)–97	all sites together	For time trend analysis (1970–97), the countries are grouped, and the Baltic countries are excluded.	x	x	x	x	x	x	x
Levi *et al*. (1999)	1999	1955–94	26 common sites and all sites together	In the time-trend analysis, the Baltic countries were excluded.	x	x	x	x	x	x	x
La Vecchia *et al*. (1998a)	1998	1955–92	19 common sites and all sites together					x	x		x
Aareleid *et al.* (1993)	1993	1982–1987	cervical cancer		x			x			
Ekbom and Akre (1998)	1998	1943 (1977)–89	testicular cancer		x	x	x	x	x	x	x
Levi *et al*. (2001b)	2001	1981–97	breast cancer		x		x	x	x	x	x
Botha *et al*. (2003)	2003	1950s (1980s)–2000	breast cancer		x			x	x	x	x
Tyczynski *et al*. (2003)	2003	2000	lung cancer		x	x	x	x	x	x	x
Levi *et al*. (2003b)	2003	1980–99	cancer of pancreas					x	x	x	x

Cancer incidence and mortality in Europe in 1995 has been studied by Bray *et al.* (2002). This review covers amongst others all the countries chosen for my study. It used reported incidence figures from the nationwide cancer registries and World Health Organization mortality data. In the case of Latvia and Lithuania, the recorded incidence data from national cancer registries were not used, because, according to the authors of this is study, they did not meet data quality standards for inclusion in *Cancer Incidence in Five Continents vol. VII* [*](Parkin *et al.* 1997). Indirect estimates of the numbers of new cancer cases for these countries were derived from national mortality data available from the WHO, assuming that there is a fixed ratio of incidence to mortality that can be estimated from other European countries. This method for deriving estimates deserves some criticism. First of all, it assumes that the difference between cancer mortality and incidence for different cancer sites is constant between countries, not allowing for differences in survival and/or in incidence and mortality time trends. Another concern would be that the mortality data are not very accurate as far as the mention of cancer on the death certificates is concerned. Consequently, this method lacks precision and this is an issue to be considered when interpreting the results. Commenting on the validity of this method, Bray *et al.* state that this procedure has been used in previous studies estimating the cancer burden in the European Union and that it has been shown to estimate incidence fairly accurately. As for the results, this article concludes that the general patterns of cancer emergence in Europe firmly establish the need for cancer control measures which target specific populations, especially the urgency to combat the ongoing tobacco epidemic.

Compared to the study carried out by Bray *et al.* that was described above, the current study has two advantages. Firstly, the cancer incidence rates recorded by the national registries, which were then collected and validated by the European Network of Cancer Registries, are used. Secondly, five-year average rates are used as opposed to one year rates used by Bray which are subjected to substantial random variations caused by small absolute number in rates for each year particularly for the Baltic countries.

[*] In fact the data for Latvia were included in the named publication, although with some concern about data quality. The data for Lithuania were omitted because of data processing error, and these data (1988-1992) were later included in the following volume of *Cancer Incidence in Five Continents* together with data for the next five-year period, 1993-1997, which is the period covered by this volume. Furthermore, *Cancer Incidence in Five Continents vol. VII* which the paper refes to, contains data for 1988-1992, thus 1995 data that were used in the paper were not included and could have not been used.

Dobrossy (2002) has published an interesting paper on cancer mortality in central-eastern Europe. He used the WHO Health for All Database to carry out mortality analysis for all sites together, as well as some selected sites such as lung, breast, and cervix uteri. He has presented cancer mortality rankings for 1997 for all the countries of Europe that belong to the European Region of WHO, which included all countries selected for the current study. For more sophisticated analysis, the countries were divided into regions and the Baltic countries were excluded. The presentation and discussion were concentrated on countries of central and eastern Europe, showing a much bigger cancer burden in this region compared to other regions such as the European Union and the Nordic region. It also pointed out major risk factors for cancer in central-eastern Europe, and measures to lower the high burden of cancer.

Levi *et al.* (1999) examined cancer mortality rates for 26 cancer sites or groups of sites in 35 European countries during the period 1990–1994 and trends in mortality for 24 major countries over the period of 1955–1994. For this study, mortality data, abstracted from the WHO database, were used. It included the mortality rates for all countries and most of the sites chosen for the current study. In the time-trend analysis, though, the Baltic countries were excluded because of missing data for several years. As a result the authors found that in most western European countries total cancer mortality was – for the first time – moderately downwards in the early 1990–s. However, cancer mortality was still upwards in a few southern and eastern European countries.

Some other studies, which also call themselves "European", do not include the Baltic countries in their analysis. An example of this would be a study by La Vecchia *et al.* (1998) which, using the WHO mortality database, looked at cancer mortality in Europe with regard to effects of age, cohort of birth, and period of death. It mentions some of the reasons why some of the countries were excluded such as small size (e.g. Ireland), countries whose national entities have changed (e.g. Yugoslavia, Czechoslovakia), and some which have substantial data missing (e.g. Romania, Bulgaria). The Baltic countries were perhaps, like Ireland, excluded for their small population size, as this study was looking at 16 major European countries. Norway was excluded without giving any reason.

Although not concerned with cancer incidence and/or mortality, but survival, it is interesting to take a look at the countries that participated in the EUROCARE II study (Berrino *et al.* 1998). Fourty five cancer registries in 17 countries contributed their data to this study, which were all included after validating by comparing with the numbers of

incident cancer cases for specific sites observed by a specific registry and those published in *Cancer Incidence in Five Continents vol. VII* (Parkin *et al.* 1997). Among the Nordic cancer registries, all but Norway participated in this study, while among the Baltic countries, only Estonia did so. For the Estonian Cancer Registry this shows not only that its data were of acceptable quality, but also that it was able to meet the challenge of participating in this big international project.

Studies of individual sites. The following studies were confined to a single cancer site such as cervical cancer (Aareleid *et al*. 1993), testicular cancer (Adami *et al.* 1994; Ekbom and Akre 1998), breast (Botha *et al.* 2003; Levi *et al.* 2001b), lung (Tyczynski *et al.* 2003) and pancreas (Levi *et al.* 2003). In the following paragraphs all these studies will be reviewed.

Long term incidence and mortality trends for cervical cancer in Estonia and Finland, going up to 1987, were analysed by Aareleid *et al.* (1993). The authors concluded that both incidence and mortality rates were considerably higher in Estonia, and the trends, although declining in both countries for incidence as well as mortality, were less marked for Estonia, and levelled off in the 1980–s. These differences were attributed mainly to the effective mass-screening programme introduced in Finland in the early 1960–s, but also to socioeconomic factors.

A collaborative study between ten population-based cancer registries in nine countries around the Baltic Sea was undertaken in order to analyze in detail geographic variations and temporal trends in the occurrence of testicular cancer (Adami *et al.* 1994; Ekbom and Akre 1998). All the Nordic and the Baltic countries were included. Testicular cancer incidence data were obtained from cancer registries in each country, starting from as early as 1943 for Denmark and more recently for the other countries. It examined 5–year average incidence rates for different time periods with the most recent being 1985–1989, and presented time trends. This analysis showed that an approximately tenfold geographical variation existed in testicular cancer incidence between the countries compared (Adami *et al.* 1994), and that birth cohort is a more important determinant of testicular cancer risk than year of diagnosis (Ekbom and Akre 1998).

A study to examine breast cancer in Europe with regard to mortality between 1981 and 1997, was performed by Levi *et al*.(2001b). It used tha data from the WHO mortality database, and included, among others, all countries that were chosen for the

current study, except Latvia. As this is a relatively short review, it does not give explantions on selection criteria for the countries. As for the results, the study concluded that a fall in breast cancer mortality below the age of 70 years was observed in all Western Europe, whereas the unfavourable trends persisted in Eastern Europe.

Breast cancer incidence and mortality trends in 16 European countries were analysed by Botha *et al*. (2003). Their analyses was based on the EUROCIM database (European Network of Cancer Registries 2001). This publication includes all the Nordic countries and Estonia from the Baltic countries. The reason for excluding some of the European registries from this analysis was that data had not been accepted for publication in *Cancer Incidence in Five Continents vol. VII* (Parkin *et al.* 1997), that was used as a proxy for the quality of registration, or the fact that they had contributed fewer than 10 consequtive years of data. The study concluded that incidence increased in all countries and that mortality trends for breast cancer differed between countries, with mortality declines that have emerged since the late 1980–s in some countries.

Lung cancer incidence and mortality rates for 38 European countries in the year 2000, including all countries in the current study, have been presented and discussed (Tyczynski *et al.* 2003). These estimates were based on the GLOBOCAN 2000 (Ferlay *et al.* 2001; Parkin *et al.* 2001b), which had derived cancer incidence data from cancer registries and mortality data from WHO Mortality Database. The study concluded that men in Eastern Europe have the highest lung cancer incidence and mortality rates, whereas men in Northern Europe have the lowest rates (with the exception of the Baltic States). In women, the study found very high lung cancer incidence in Northern Europe.

Levi *et al*. (2003b) described pancreatic cancer mortality in Europe between 1980 and 1999, using the WHO mortality database. They included all the four Nordic countries, but none of the Baltic countries. They were able to document a leveling of pancreatic cancer mortality in Europe.

To conclude, it should pointed out that there are only a few studies that have included the Baltic countries when looking at cancer occurrence in Europe. Compared to Latvia and Lithuania, Estonia is more often represented in these comparisons. There are only a few published studies that have compared the cancer rates between the Baltic and Nordic countries.

6.2 Brief overview of the cancer registries

For the incidence and mortality data to be comparable between countries, these need to be of high quality and use the same rules for coding cancer site and morphology. Data quality in each registry depends, among other factors, on the quality of cancer registration in each of the registries. The following is a short overview of some of the characteristics of the cancer registries in the countries studied. Table 6.5 summarizes the main characteristics and quality indicators of the registries involved.

The history of Estonian Cancer Registry is described in Chapter 2.3. It was founded in 1978 (see Table 6.5), but its population-based data* go back as far as 1968. The Latvian Cancer registry was established in 1980, two years later than ECR. In Lithuania, compulsory cancer registration was introduced as early as in 1957, but only in 1990 was the Lithuanian cancer Registry established as a discrete entity. Population based data for Lithuania are available from 1964 and thus it can be regarded as the Baltic country having the longest cancer registration history. Among the Nordic countries, the oldest registry is in Denmark, established in 1942. In all the Nordic countries the cancer registries started several decades earlier than in Estonia or Latvia, and about ten years earlier than in Lithuania. All the registries compared contain data for the whole country.

Indicators of data quality such as percentages of morphological verifications of tissue specimen (MV%), cases reported to the registry based on death certificate information only (DCO), and mortality incidence (M/I) ratios are presented in Table 6.5 for the countries studied. The definitions and interpretation of these data quality indicators and use was described in Chapter 3 Section 3.1.2.

In Table 6.5 it is seen that for both sexes the MV% are higher in the Nordic than in the Baltic countries, which is a positive indicator of data quality.

* Availability of population-based data means that the respective registry covers the whole population. When a registry is started, it usually takes some time to be able to include all incident cases occurring in a respective population. In the case of Estonia, when ECR was established in 1978, all cancer cases that had been diagnosed since 1968, covering the whole population, were incorporated.

Table 6.5. Main characteristics and quality indicators for all cancers in the Baltic and Nordic cancer registries.
Source: *Cancer Incidence in Five Continents vol. VIII.* (Parkin *et al.* 2002)

Cancer registry	Year registry started	Year population based data available	Indices of data quality (%)					
			Male			Female		
			MV	DCO	M/I	MV	DCO	M/I
The Baltic countries								
Estonia	1978	1968	81	2	71	86	1	60
Latvia	1980	1980	67	0	84	80	0	67
Lithuania	NA	1964	69	2	76	77	1	62
The Nordic countries								
Denmark	1942	1943	88	1	69	90	1	61
Finland	1952	1953	94	1	54	94	1	48
Norway	1952	1952	91	4	56	91	4	53
Sweden	1958	1958	98	–*	56	98	–*	51

(MV – morphological verification, DCO – death certificate only, M/I – mortality incidence ratio) NA – not applicable.
* The Swedish Cancer Registry does not use information on cancers based on death certificates

The percentages of DCO cases are very low in all countries studied. This fact can be considered as a positive indicator of data quality. Regarding reporting DCO cases by the Latvian Cancer Registry, it is the only Baltic cancer registry that does not give any information on the cancer registration process. Estonia and Lithuania, in contrast, mention the linkage to death certificates, as an additional source of information on new cases to the registry. It can be speculated, therefore, that the Latvian Cancer Registry does not perform this linkage and erroneously reports its percentage of DCO cases as zero instead of stating, if this is the case, that death certificate information is not used in cancer registration.

There are several aspects in the interpretation of M/I ratios that need to be considered, especially when dealing with aggretage data for all cancers and comparisons across countries. Firstly, the size of M/I ratios depends on the site-mix of cancers, i.e. the proportion of fatal cancers in any given country, being higher for countries that have a bigger proportion of fatal cancers. Secondly, the M/I ratios are sensitive to the linkage with mortality data from state statistical offices. Namely, when mortality data are used to complete the incidence rates, it may alter the M/I ratios rather unpredictably. If the countries for which cancer M/I ratios are compared differ in the practice of using

mortality data to complete the cancer incidence rates, it affects the conclusions based on the size of M/I ratios. Consequently, the value of aggregate M/I ratios in assessing data quality in cancer registries, is doubtful.

As is seen from Table 6.5, the M/I ratios are in general higher in the Baltic countries and lower in the Nordic countries. The most likely underlying cause for this difference is higher cancer survival rate for all cancers combined in the Nordic countries, which in fact may be due to differences in the site-mix. Higher survival leads to lower M/I ratios. Cancer survival is higher in the Nordic than in the Baltic countries as was demonstrated by the EUROCARE project (Sant *et al.* 2001). The study compared cancer survival trends from 20 cancer registries in 13 European countries and concluded that for most solid tumours, survival for cancer as a whole was highest in Northern Europe (as represented by Finland, Sweden and Iceland) and lowest in the Eastern Europe (Estonia and Poland), but also in the UK and Denmark. Lower cancer survival in Denmark, with its high proportion of lung cancer having very low survival, as compared to other Nordic countries is supported by the fact that its M/I ratios are higher for both sexes when compared to respective ratios in the other Nordic countries. It is not possible to find out in this situation whether the higher M/I ratios for the aggregate of all cancers in the Baltic countries could be explained by under-registration, different site-mix, or poorer survival.

Among the Baltic registries, the aggregate M/I ratios for Latvia for both sexes are higher than in Estonia or Lithuania. This is probably a sign of under-registration of cancer incidence in Latvia as there is no clear reason to expect large differences in cancer survival and/or incidence trends, or different site-mix between the Baltic countries, masking the effect of M/I ratios.

As an illustrative example of the quality indices for a selected cancer site, the corresponding figures for lung cancer are presented in Table 6.6. As for all cancers, the MV% for lung cancer are higher in the Nordic than in the Baltic countries. This means higher data quality in the Nordic registries because the availability of alternative diagnostic technologies reducing the necessity to carry out microscopical verification of lung cancer should not be more common in the Baltic than in the Nordic countries. The other finding is that the MV%-s among the Baltic countries vary, with Estonia having the highest and Latvia having the lowest percentage for both sexes.

Table 6.6. Main characteristics and quality indicators for lung cancer in the Baltic and Nordic cancer registries.
Source: *Cancer Incidence in Five Continents vol. VIII.* (Parkin *et al*. 2002)

Cancer registry	**Indices of data quality (%)**					
	Male			**Female**		
	MV	**DCO**	**M/I**	**MV**	**DCO**	**M/I**
The Baltic countries						
Estonia	73	2	90	62	2	82
Latvia	52	0	97	41	0	100
Lithuania	60	2	93	51	3	88
The Nordic countries						
Denmark	81	2	104	82	2	99
Finland	90	2	91	89	2	83
Norway	90	5	89	90	5	88
Sweden	98	–*	110	98	–*	104

(MV – morphological verification, DCO – death certificate only, M/I – mortality incidence ratio).
* The Swedish Cancer Registry does not use information on cancers based on death certificates

All the DCO percentages are low among all countries compared. Norway perhaps stands out for a slightly higher DCO percentage.

When looking at the M/I ratios, the assumption uderlying this comparison is that because lung cancer is highly fatal with no effective treatment, there should be no large differences in survival between the Baltic and the Nordic countries. Therefore the differences in the M/I ratios should be attributable to completeness of cancer registration unless there is some rapid change in incidence. The finding here is that in fact there is some variation in the M/I ratios between the registries. This is difficult to interpret even when assuming that there are no considerable differences in survival. The M/I are ratios above 100 for men in Denmark and both sexes in Sweden. This does not refer to under-registration but decrease in lung cancer incidence observed certainly for men in Denmark and Sweden, but also to a lesser extent for women in Sweden. For women in Denmark it is also close to 100, although no deacrease in incidence is observed.

As Latvia has higher M/I ratios for both sexes than the other Baltic countries, it could indicate underregistration of lung cancer cases in Latvia. This finding is in line with the fact that in Latvia there is apparently no linkage of cancer registry data with mortality

data, a procedure which in this case could contribute to the completeness of cancer incidence data.

Use of the data. *Cancer Incidence in Five continents vol. VIII* (Parkin et al. 2002) provides a summary of information about each registry regarding quality and use of the data. This is reproduced in Table 6.7 for the countries of interest.

Table 6.7. Uses of data and comments on data quality in the cancer registries included in the study.
Source: *Cancer Incidence in Five Continents vol. VIII.*(Parkin *et al.* 2002)

Cancer registry	Use of data	Comments on data quality
The Baltic countries		
Estonia	Annual reports since 1996. A number of descriptive and analytical studies, including international comparisons.	The quality of the data has not been formally evaluated; the first study on this subject is being carried out.*
Latvia	No comments on the use of data	All cancer data from this country are marked with an asterisk: the ratios of mortality to incidence are high for several sites, and the lack of cases based on death certificates alone, suggest a degree of under-reporting
Lithuania	Annual reports to the Ministry of Health. Registry report published at regular intervals. Studies on survival.	No comments on data quality
The Nordic countries		
Denmark	Routine staitistics, since 1978 published for each year separately. Studies of cancer prevention and control. Registry is used as an end-point in cohort studies.	Assessments by linkage to patient discharge registries, pathology registers and patient series registry have shown that the completeness of the registry is 95–97%.
Finland	Routine statistics, data for planning and health education purposes, as well as epidemiological, clinical, and pathological studies and follow-up data on cancer patients	No specific comments on data quality.
Norway	Several types of epidemiologic studies based on cancer registry data.	No specific comments on data quality.
Sweden	Annual reports. Many researchers in Sweden and in other parts of the world use the registry data.	No specific comments on data quality

* referring to the current study

It is seen that the extent of the use of data varies a lot between all registries compared, ranging from Latvian Registry with no comments on use of data to the registries of Finland and Denmark that probably use their data most. Among the Baltic registries, the ECR uses its data a lot more than the Latvian and Lithuanian registries.

The extent of the use of data may be considered as an indirect estimate of data quality as its validity tends to be enhanced as a result of its use in research.

As for data quality, several registries have commented on the quality of their own data. This is not the case for the Latvian Cancer registry. Moreover, all the Latvian cancer data are marked with an asterisk and provided with comments about caution to its data quality (see Table 6.5). This needs to be considered when interpreting the results. On the other hand, the Danish Cancer Registry most clearly gives its estimate on data completeness.

To conclude about the quality of data in the registries concerned, it seems to be generally better in the Nordic registries. Among the Baltic cancer registries Estonia seems to have the highest data quality. The high quality of the ECR data was revealed as a result of validation studies presented in Chapter 4. It is also supported by the fact that its data are rather extensively used in international comparisons (see Chapter 2 Section 2.3.2). In contrast, Latvian Cancer Registry seems to have problems with data quality such as under-reporting. These differences in the level of data quality of cancer registries concerned should be considered when interpreting the cancer incidence data produced by these registries.

6.3 Total cancer incidence and mortality

Introduction. The following is a description of cancer incidence and mortality for men and women in Estonia as an average for 1993–1997. In Tables 6.8–6.11 the rankings of cancer incidence and mortality rates by sex for all countries compared are presented for all cancers as well as the selected sites. The rates are presented with 95% confidence intervals that were calculated using the same method as described in Chapter 7 Section 7.5.2.

These tables illustrate very well the heterogeneity of Estonia's position for cancer incidence and mortality in comparison with other countries, and also the pattern of Baltic/Nordic divide in the case of some cancers, which is discussed as part of the description of rankings by each cancer site.

For cancer incidence in men, Estonia ranks first for such frequent cancers like lung and stomach, but also for cancers of kidney and oesophagus, as well as all cancers. For

seven sites out of ten it ranks among the leading three countries for cancer incidence in men.

For cancer incidence in women, the position of Estonia is more heterogenous than in men. Namely, it ranks first for cancers of stomach, cervix uteri, and kidney, but then falls below the three leading countries for all other cancer sites. The exception here is cancer of the larynx which ranks third.

For cancer mortality in men, Estonia ranks relatively high as for cancer incidence in men. It is in the top for the mortality from cancers of the stomach and lung, as well as total cancer mortality. Estonia ranks second for cancers of oesophagus, rectum, and kidney, and third for cancers of pancreas and larynx in men. In women, again, like for cancer incidence, Estonia's position among other countries varies more than for men. It ranks second for overall cancer mortality in women, and its position varies greatly between the cancer sites, from being the first for stomach cancer to ranking the sixth for cancers of pancreas and ovary.

Table 6.8. Comparison of cancer incidence rates for the Nordic and Baltic countries. Age-standardised incidence rates per 100 000, all sites together and selected sites of cancer in men, the average for 1993–97, all ages.*
Source: EUROCIM.

Rank	Oesophagus C15		Stomach C16		Colon C18		Rectum C19-21		Pancreas C25		Larynx C32	
	country	SIR (95%CI)	country	SIR (95%CI)	country	SIR (95%CI)	country	SIR (95%CI)	country	SIR (95%CI)	country	SIR (95%CI)
1.	**Estonia**	**8.7 (7.7-9.8)**	**Estonia**	**46.7 (44.3-49.3)**	Norway	33.5 (32.5-34.5)	Denmark	25.2 (24.3-26.2)	Latvia	17.4 (16.3-18.6)	Lithuania	13.6 (12.8-14.5)
2.	Lithuania	8.6 (7.9-9.3)	Lithuania	43.5 (42.0-45.0)	Denmark	30.9 (29.9-32.0)	Norway	23.9 (23.0-24.8)	**Estonia**	**16.6 (15.2-18.2)**	Latvia	11.5 (10.7-12.5)
3.	Denmark	8.1 (7.6-8.7)	Latvia	40.5 (38.8-42.3)	Sweden	27.3 (26.6-27.9)	**Estonia**	**20.7 (19.1-22.5)**	Lithuania	16.6 (15.3-17.2)	**Estonia**	**11.2 (10.1-12.4)**
4.	Latvia	7.9 (7.2-8.7)	Finland	19.4 (18.6-20.2)	**Estonia**	**23.8 (22.1-25.7)**	Lithuania	20.5 (19.5-21.6)	Finland	12.7 (12.1-13.4)	Denmark	8.2 (7.6-8.7)
5.	Finland	4.7 (4.3-5.1)	Norway	17.0 (16.3-17.8)	Finland	21.6 (20.8-22.5)	Sweden	19.0 (18.4-19.5)	Norway	10.9 (10.4-11.5)	Norway	4.6 (4.2-5.0)
6.	Norway	4.6 (4.2-5.0)	Sweden	13.3 (12.9-13.8)	Latvia	18.5 (17.3-19.7)	Latvia	16.9 (15.7-18.0)	Denmark	10.4 (9.8-11.0)	Finland	4.3 (3.9-4.7)
7.	Sweden	4.5 (4.3-4.8)	Denmark	12.4 (11.7-13.0)	Lithuania	17.5 (16.5-18.5)	Finland	16.4 (15.6-17.1)	Sweden	9.5 (9.2-9.9)	Sweden	3.2 (3.0-3.4)

* The ICD codes used to define cancer sites are summarised in Table 5.1.

continued

Table 6.8. Comparison of cancer incidence rates for the Nordic and Baltic countries. Age-standardised incidence rates per 100 000, all sites together and selected sites of cancer in men, the average for 1993–97, all ages.* (continued)
Source: EUROCIM.

Rank	Lung		Prostate		Kidney		Bladder		All sites excl. other skin	
	country	**SIR (95%CI)**	**country**	**SIR (95%CI)**	**country**	**SIR (95%CI)**	**country**	**SIR (95%CI)**	**country**	**SIR (95%CI)**
1.	**Estonia**	**104.4 (100.8-108.1)**	Finland	100.2 (98.4-102.1)	**Estonia**	**20.3 (18.8-22.0)**	Denmark	40.8 (39.6-42.0)	**Estonia**	**421.0 (413.6-428.6)**
2.	Lithuania	94.1 (91.8-96.3)	Sweden	99.4 (98.2-100.6)	Latvia	14.9 (13.9-16.0)	Norway	31.1 (30.1-32.1)	Denmark	407.8 (404.1-411.6)
3.	Latvia	90.3 (87.7-92.9)	Norway	91.9 (90.3-93.6)	Lithuania	14.5 (13.6-15.4)	Sweden	27.1 (26.4-27.7)	Norway	395.2 (391.6-398.7)
4.	Denmark	71.8 (70.3-73.4)	**Estonia**	**56.5 (53.8-59.4)**	Finland	13.4 (12.7-14.0)	Finland	25.2 (24.3-26.1)	Finland	388.7 (385.2-392.3)
5.	Finland	65.7 (64.3-67.2)	Denmark	44.6 (43.4-45.8)	Norway	12.6 (12.0-13.3)	**Estonia**	**20.1 (18.4-21.8)**	Lithuania	376.0 (371.5-380.6)
6.	Norway	51.0 (49.7-52.3)	Lithuania	41.8 (40.3-43.4)	Sweden	12.4 (11.9-12.8)	Lithuania	19.2 (18.2-20.3)	Sweden	364.9 (362.5-367.2)
7.	Sweden	32.2 (31.5-33.0)	Latvia	29.8 (28.2-31.4)	Denmark	11.6 (11.0-12.2)	Latvia	19.1 (17.9-20.3)	Latvia	343.0 (338.0-348.2)

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Table 6.9. Comparison of cancer incidence rates for the Nordic and Baltic countries. Age-standardised incidence rates per 100 000, all sites together and selected sites of cancer in women, the average for 1993–97, all ages.* Source: EUROCIM.

Rank	Oesophagus C15		Stomach C16		Colon C18		Rectum C19-21		Pancreas C25	
	country	SIR (95%CI)	country	SIR (95%CI)	country	SIR (95%CI)	country	SIR (95%CI)	country	SIR (95%CI)
1.	Denmark	2.5 (2.2-2.8)	**Estonia**	**21.6 (20.3-22.9)**	Norway	30.9 (29.9-31.8)	Denmark	16.0 (15.3-16.7)	Finland	9.5 (9.0-9.9)
2.	Finland	2.2 (2.0-2.4)	Latvia	18.7 (17.8-19.7)	Denmark	27.5 (26.6-28.3)	Norway	15.8 (15.1-16.5)	Denmark	8.8 (8.3-9.3)
3.	Sweden	1.5 (1.3-1.6)	Lithuania	18.5 (17.8-19.3)	Sweden	22.6 (22.0-23.1)	Sweden	12.3 (11.9-12.7)	Norway	8.5 (8.1-9.0)
4.	Norway	1.2 (1.1-1.4)	Finland	10.6 (10.1-11.1)	**Estonia**	**19.1 (18.0-20.4)**	Lithuania	11.6 (11.0-12.2)	Latvia	8.3 (7.7-8.9)
5.	**Estonia**	**1.0 (0.7-1.3)**	Norway	8.0 (7.6-8.5)	Finland	18.0 (17.3-18.6)	**Estonia**	**10.8 (9.9-11.7)**	Sweden	8.1 (7.8-8.5)
6.	Lithuania	0.9 (0.8-1.1)	Sweden	6.6 (6.3-6.9)	Latvia	14.1 (13.3-14.9)	Latvia	10.6 (9.9-11.3)	**Estonia**	**7.9 (7.2-8.7)**
7.	Latvia	0.8 (0.6-1.0)	Denmark	5.6 (5.2-6.0)	Lithuania	12.9 (12.3-13.6)	Finland	10.4 (9.9-10.9)	Lithuania	7.5 (7.0-8.0)

* The ICD codes used to define cancer sites are summarised in Table 5.1

continued

Table 6.9. Comparison of cancer incidence rates for the Nordic and Baltic countries. Age-standardised incidence rates per 100 000, all sites together and selected sites of cancer in women, the average for 1993–97, all ages.*
Source: EUROCIM.
(continued)

Rank	Larynx C32		Lung C33-34		Breast C50		Cervix uteri C53		Corpus uteri C54	
	country	**SIR (95%CI)**	**country**	**SIR (95%CI)**	**country**	**SIR (95%CI)**	**country**	**SIR (95%CI)**	**country**	**SIR (95%CI)**
1.	Denmark	1.5 (1.3-1.8)	Denmark	41.5 (40.3-42.7)	Denmark	110.5 (108.6-112.5)	**Estonia**	**19.7 (18.4-21.0)**	Latvia	23.8 (22.7-24.9)
2.	Norway	0.8 (0.7-1.0)	Norway	22.3 (21.4-23.1)	Sweden	104.8 (103.5-106.1)	Lithuania	19.0 (18.1-19.9)	Finland	20.0 (19.3-20.8)
3.	**Estonia**	**0.6 (0.4-0.9)**	Sweden	18.1 (17.6-18.7)	Finland	98.3 (96.6-99.9)	Denmark	17.5 (16.7-18.3)	Sweden	20.0 (19.5-20.6)
4.	Lithuania	0.5 (0.4-0.6)	Finland	12.6 (12.0-13.1)	Norway	82.4 (80.7-84.0)	Norway	14.6 (13.9-15.3)	Denmark	19.5 (18.7-20.3)
5.	Sweden	0.4 (0.3-0.5)	**Estonia**	**12.6 (11.6-13.6)**	**Estonia**	**56.0 (53.7-58.2)**	Latvia	12.1 (11.3-13.0)	**Estonia**	**19.3 (18.0-20.6)**
6.	Latvia	0.4 (0.2-0.5)	Lithuania	9.3 (8.7-9.8)	Latvia	52.3 (50.7-54.0)	Sweden	9.7 (9.3-10.1)	Lithuania	18.4 (17.6-19.3)
7.	Finland	0.3 (0.3-0.4)	Latvia	9.2 (8.6-9.9)	Lithuania	50.4 (49.2-52.0)	Finland	5.2 (4.8-5.6)	Norway	18.0 (17.3-18.8)

* The ICD codes used to define cancer sites are summarised in Table 5.1

continued

Table 6.9. Comparison of cancer incidence rates for the Nordic and Baltic countries. Age-standardised incidence rates per 100 000, all sites together and selected sites of cancer in women, the average for 1993–97, all ages.*
Source: EUROCIM.
(continued)

Rank	Ovary C56		Kidney C64-65		Bladder C67		All sites excl. other skin	
	country	**SIR (95% CI)**	**country**	**SIR (95%CI)**	**country**	**SIR (95% CI)**	**country**	**SIR (95% CI)**
1.	Denmark	20.0 (21.2-22.9)	**Estonia**	**11.0 (10.1-12.0)**	Denmark	11.5 (10.9-12.1)	Denmark	403.3 (399.7-406.9)
2.	Lithuania	18.1 (17.2-18.9)	Sweden	7.6 (7.2-7.9)	Norway	7.9 (7.5-8.4)	Sweden	331.2 (329.0-333.5)
3.	Latvia	17.4 (16.4-18.3)	Finland	7.5 (7.1-7.9)	Sweden	7.2 (6.9-7.5)	Norway	320.4 (317.2-323.6)
4.	Norway	17.3 (16.6-18.1)	Latvia	7.4 (6.8-8.0)	Finland	5.1 (4.7-5.4)	Finland	299.8 (297.1-302.6)
5.	Finland	16.8 (16.3-17.4)	Lithuania	7.3 (6.8-7.8)	**Estonia**	**4.5 (3.9-5.1)**	**Estonia**	**255.8 (251.2-260.5)**
6.	Sweden	16.4 (15.9-16.9)	Denmark	7.0 (6.6-7.5)	Latvia	3.4 (3.0-3.8)	Lithuania	233.8 (230.8-236.7)
7.	**Estonia**	**16.2 (15.2-17.6)**	Norway	7.0 (6.6-7.5)	Lithuania	3.3 (3.0-3.7)	Latvia	225.9 (222.5-229.3)

* The ICD codes used to define cancer sites are summarised in Table 5.1

Table 6.10. Comparison of cancer mortality rates for the Nordic and Baltic countries. Age-standardised mortality rates per 100 000, all sites together and selected sites of cancer in men, the average for 1993–97, all ages.*
Source: WHO Mortality Databank.

Rank	Oesophagus C15		Stomach C16		Colon C18		Rectum C19-21		Pancreas C25		Larynx C32	
	country	**SMR (95%CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95%CI)**
1.	Denmark	8.4 (7.9-8.9)	**Estonia**	**39.6 (37.4-42.0)**	Denmark	22.5 (21.7-23.3)	Lithuania	15.6 (14.6-16.5)	Lithuania	15.0 (14.1-15.9)	Lithuania	10.1 (9.4-10.9)
2.	**Estonia**	**8.2 (7.2-9.3)**	Latvia	38.5 (37.0-39.9)	Norway	18.8 (18.1-19.7)	**Estonia**	**14.5 (13.1-16.0)**	Finland	13.1 (12.5-13.8)	Latvia	9.1 (8.3-9.9)
3.	Lithuania	8.0 (7.4-8.7)	Lithuania	38.4 (36.8-40.2)	Latvia	15.0 (13.9-16.1)	Denmark	13.5 (12.9-14.1)	**Estonia**	**12.1 (10.9-13.4)**	**Estonia**	**8.0 (7.1-9.1)**
4.	Latvia	7.9 (7.2-8.7)	Finland	15.8 (15.0-16.5)	Sweden	13.7 (13.3-14.1)	Latvia	13.1 (12.1-14.2)	Sweden	11.9 (11.4-12.3)	Denmark	3.6 (3.3-3.9)
5.	Finland	4.6 (4.2-5.0)	Norway	14.3 (13.6-15.0)	**Estonia**	**13.1 (11.8-14.5)**	Norway	12.5 (11.9-13.2)	Denmark	11.5 (11.0-12.1)	Norway	1.5 (1.3-1.8)
6.	Sweden	4.4 (4.1-4.7)	Sweden	10.5 (10.1-10.9)	Lithuania	11.6 (10.9-12.5)	Finland	8.4 (7.9-9.0)	Norway	11.3 (10.7-11.9)	Finland	1.4 (1.2-1.7)
7.	Norway	4.4 (4.0-4.8)	Denmark	9.9 (9.4-10.5)	Finland	10.6 (10.0-11.3)	Sweden	7.9 (7.6-8.3)	Latvia	6.9 (6.2-7.7)	Sweden	0.9 (0.8-1.0)

* The ICD codes used to define cancer sites are summarised in Table 5.1

continued

Table 6.10. Comparison of cancer mortality rates for the Nordic and Baltic countries. Age-standardised mortality rates per 100 000, all sites together and selected sites of cancer in men, the average for 1993–97, all ages.*
Source: WHO Mortality Databank.
(continued)

Rank	Lung C33-34		Prostate 61		Kidney C64-65		Bladder C67		All sites excl. other skin	
	country	**SMR (95%CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95%CI)**
1.	**Estonia**	**94.2 (90.8-97.7)**	Norway	41.8 (40.7-43.0)	Lithuania	11.0 (10.3-11.8)	Denmark	14.6 (14.0-15.2)	**Estonia**	**299.8 (292.4-307.3)**
2.	Latvia	88.7 (86.2-96.3)	Sweden	37.1 (36.4-37.8)	**Estonia**	**8.9 (7.8-10.0)**	Lithuania	11.9 (11.1-12.8)	Latvia	292.1 (287.0-297.3)
3.	Lithuania	87.9 (85.7-90.1)	Denmark	33.8 (32.8-34.7)	Finland	8.0 (7.5-8.5)	Norway	9.5 (8.9-10.0)	Lithuania	290.6 (286.1-295.1)
4.	Denmark	74.0 (72.6-75.5)	Finland	31.8 (30.7-32.9)	Sweden	7.2 (6.9-7.5)	**Estonia**	**8.1 (7.1-9.3)**	Denmark	260.5 (256.8-264.3)
5.	Finland	62.3 (60.8-63.7)	Lithuania	24.9 (23.8-24.9)	Denmark	7.1 (6.7-7.6)	Sweden	6.9 (6.6-7.2)	Finland	221.0 (217.5-224.6)
6.	Norway	47.0 (45.8-48.3)	**Estonia**	**23.0 (21.2-24.9)**	Norway	6.8 (6.3-7.3)	Finland	6.5 (6.1-7.0)	Norway	216.9 (213.3-220.5)
7.	Sweden	39.7 (38.7-40.7)	Latvia	20.2 (18.9-21.6)	Latvia	4.1 (3.6-4.7)	Latvia	4.5 (4.0-5.2)	Sweden	191.3 (189.0-193.7)

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Table 6.11. Comparison of cancer mortality rates for the Nordic and Baltic countries. Age-standardised mortality rates per 100 000, all sites together and selected sites of cancer in women, the average for 1993–97, all ages.*
Source: WHO Mortality Databank.

Rank	Oesophagus C15		Stomach C16		Colon C18		Rectum C19-21		Pancreas C25	
	country	SMR (95%CI)	country	SMR (95%CI)	country	SMR (95%CI)	country	SMR (95%CI)	country	SMR (95%CI)
1.	Denmark	2.6 (2.3-2.8)	**Estonia**	**17.3 (16.1-18.5)**	Denmark	18.0 (17.3-18.6)	Lithuania	8.5 (8.0-9.1)	Sweden	10.2 (9.9-10.6)
2.	Finland	1.9 (1.7-2.1)	Latvia	16.0 (15.2-16.9)	Norway	15.8 (15.2-16.5)	**Estonia**	**7.7 (7.0-8.5)**	Finland	9.7 (9.7-10.2)
3.	Sweden	1.3 (1.2-1.5)	Lithuania	15.3 (14.6-16.1)	Sweden	11.1 (10.8-11.5)	Latvia	7.5 (7.0-8.1)	Denmark	9.4 (9.0-9.9)
4.	Norway	1.1 (0.9-1.3)	Finland	7.9 (7.5-8.3)	**Estonia**	**10.9 (10.0-11.8)**	Denmark	7.4 (7.0-7.8)	Norway	8.8 (8.3-9.3)
5.	Lithuania	0.8 (0.6-1.0)	Norway	6.6 (6.2-7.0)	Latvia	10.4 (9.8-11.1)	Norway	7.3 (6.8-7.7)	Lithuania	7.2 (6.7-7.7)
6.	**Estonia**	**0.7 (0.5-1.0)**	Sweden	5.5 (5.3-5.8)	Lithuania	8.4 (7.9-9.0)	Sweden	4.8 (4.5-5.2)	**Estonia**	**5.4 (4.8-6.1)**
7.	Latvia	0.6 (0.5-0.8)	Denmark	4.8 (4.5-5.1)	Finland	8.3 (7.9-8.7)	Finland	4.8 (4.5-5.0)	Latvia	3.1 (2.7-3.5)

* The ICD codes used to define cancer sites are summarised in Table 5.1

continued

Table 6.11. Comparison of cancer mortality rates for the Nordic and Baltic countries. Age-standardised mortality rates per 100 000, all sites together and selected sites of cancer in women, the average for 1993–97, all ages.*
Source: WHO Mortality Databank.
(continued)

Rank	Larynx C32		Lung C33-34		Breast C50		Cervix uteri C53		Corpus uteri C54	
	country	SMR (95%CI)	country	SMR (95%CI)	country	SMR (95%CI)	country	SMR (95%CI)	country	SMR (95%CI)
1.	Denmark	0.7 (0.6-0.9)	Denmark	33.4 (32.7-34.2)	Denmark	39.5 (38.5-40.5)	Lithuania	10.2 (9.6-10.9)	Lithuania	6.3 (5.9-6.8)
2.	**Estonia**	**0.4 (0.2-0.6)**	Norway	19.6 (18.8-20.4)	Norway	27.5 (26.6-28.4)	**Estonia**	**9.0 (8.1-9.9)**	Denmark	3.8 (3.5-4.1)
3.	Lithuania	0.3 (0.2-0.4)	Sweden	17.0 (16.5-17.5)	Lithuania	25.9 (25.0-27.0)	Latvia	6.2 (5.6-6.8)	Norway	3.6 (3.3-4.0)
4.	Latvia	0.3 (0.2-0.4)	**Estonia**	**10.7** (9.9-11.7)	**Estonia**	**24.7 (23.3-26.3)**	Denmark	5.5 (5.2-5.9)	Finland	3.5 (3.2-3.8)
5.	Norway	0.3 (0.2-0.4)	Finland	10.4 (9.9-10.9)	Latvia	24.1 (23.1-25.3)	Norway	4.6 (4.2-5.0)	**Estonia**	**2.3 (1.9-2.8)**
6.	Sweden	0.1 (0.1-0.2)	Latvia	9.0 (8.4-9.7)	Sweden	24.0 (23.4-24.6)	Sweden	2.7 (2.5-2.9)	Sweden	2.0 (1.9-2.2)
7.	Finland	0.1 (0.0-0.1)	Lithuania	8.2 (7.7-8.7)	Finland	23.7 (22.9-24.4)	Finland	1.9 (1.7-2.1)	Latvia	1.9 (1.6-2.2)

* The ICD codes used to define cancer sites are summarised in Table 5.1

continued

Table 6.11. Comparison of cancer mortality rates for the Nordic and Baltic countries. Age-standardised mortality rates per 100 000, all sites together and selected sites of cancer in women, the average for 1993–97, all ages.*
Source: WHO Mortality Databank.
(continued)

Rank	Ovary C56		Kidney C64-65		Bladder C67		All sites excl. other skin	
	country	**SMR (95% CI)**	**country**	**SMR (95%CI)**	**country**	**SMR (95% CI)**	**country**	**SMR (95% CI)**
1.	Denmark	13.7 (13.1-14.3)	Lithuania	4.4 (4.9-4.8)	Denmark	4.1 (3.8-4.4)	Denmark	201.1 (197.5-204.7)
2.	Lithuania	12.7 (12.0-13.4)	Sweden	4.2 (3.9-4.4)	Norway	2.8 (2.6-3.1)	**Estonia**	**146.6 (142.0-151.3)**
3.	Norway	11.5 (10.9-12.1)	Denmark	4.1 (3.8-4.5)	Sweden	1.9 (1.8-2.1)	Norway	145.8 (142.6-149.0)
4.	Sweden	10.5 (10.1-10.9)	Finland	3.9 (3.7-4.2)	Lithuania	1.7 (1.5-2.0)	Lithuania	141.0 (138.1-143.9)
5.	Finland	9.2 (8.7-9.7)	**Estonia**	**3.7 (3.2-4.2)**	Finland	1.5 (1.4-1.7)	Sweden	141.0 (138.8-143.2)
6.	**Estonia**	**9.0 (8.2-9.9)**	Norway	3.4 (3.1-3.7)	**Estonia**	**1.4 (1.2-1.8)**	Latvia	140.1 (136.7-143.4)
7.	Latvia	4.4 (3.9-4.9)	Latvia	1.5 (1.3-1.8)	Latvia	0.8 (0.6-1.0)	Finland	127.3 (124.5-130.1)

* The ICD codes used to define cancer sites are summarised in Table 5.1

Total cancer incidence and mortality. Rankings of the Baltic and Nordic countries for the total cancer incidence and mortality rates are presented in Table 6.12.

Incidence. For men Estonia has the highest total cancer incidence (see Table 6.12). Variations in incidence are rather considerable between the countries compared. As for the other Baltic countries, Lithuania ranks fifth and Latvia has the lowest rate. The difference between the Estonian and Latvian incidence rate is about 20%. Among the Nordic countries, Denmark has the highest rate and Sweden has the lowest rate. There is no Nordic/Baltic divide present in the comparison of incidence rates for men for all sites together.

For women the total cancer incidence in Estonia takes the fifth position after all the Nordic countries, with its rate being notably less than the rates in the Nordic countries. It is followed by the rates of Lithuania and Latvia, which have a bit lower total cancer incidence rate for women than Estonia.

For total cancer incidence in women, the fact that Nordic countries rank higher than the Baltic countries, is related to the high incidence of breast cancer in all Nordic countries and lung cancer especially in Denmark.

Table 6.12. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, all cancers (excl. other skin) in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence				Mortality			
	men		women		men		women	
	country	rate	country	rate	country	rate	country	rate
1.	**Estonia**	**421.0**	Denmark	403.3	**Estonia**	**299.8**	Denmark	201.1
2.	Denmark	407.8	Sweden	331.2	Latvia	292.1	**Estonia**	**146.6**
3.	Norway	395.2	Norway	320.4	Lithuania	290.6	Norway	145.8
4.	Finland	388.7	Finland	299.8	Denmark	260.5	Lithuania	141.0
5.	Lithuania	376.0	**Estonia**	**255.8**	Finland	221.0	Sweden	141.0
6.	Sweden	364.9	Lithuania	233.8	Norway	216.9	Latvia	140.1
7.	Latvia	343.0	Latvia	225.9	Sweden	191.3	Finland	127.3

*The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. The total cancer mortality for men Estonia ranks first. Total cancer mortality for men is very similar between the Baltic countries which rank as the leading three countries. Among the Nordic countries the mortality rates show more variability being the highest in Denmark and the lowest in Sweden.

Higher total cancer mortality rates for men in the Baltic countries result from high incidence and mortality of lung and stomach cancers in these countries, the lung mortality cancer rates making up about one third of the total mortality rate.

The total cancer mortality for women in Estonia is rather high and ranks second in this comparison of the neighbouring countries. Still, the mortality rate in Denmark which takes the first position in this ranking is much higher. At the same time, rates in the other countries are rather similar to those in Estonia.

Mortality in relation to incidence. In Figures 6.1 and 6.2 the incidence/mortality data are presented for all cancers for men and women. The diagonal lines are fitted for reference value of incidence rate being equal to mortality rate.

For men it is seen that Estonia is situated as the most upper right country with highest incidence and mortality rates. All the Baltic countries are more or less situated vertically above each other, indicating that they have very similar cancer mortality while the incidence varies, being the highest in Estonia and the lowest in Lithuania.

The Nordic countries are positioned to the left of the Baltic countries, indicating lower mortality. Cancer incidence in these countries, at the same time, is rather similar to the Baltic countries.

For women it is seen that all countries except Denmark are positioned vertically above each other, indicating that mortality is relatively similar, with no clear Baltic/Nordic difference. At the same time, incidence is more varied. It is lower and rather similar to one another in the Baltic countries as compared to Finland, Norway, and Sweden. Denmark lies at a relative distance from the rest of the countries, and shows higher incidence and mortality than in the rest of the countries.

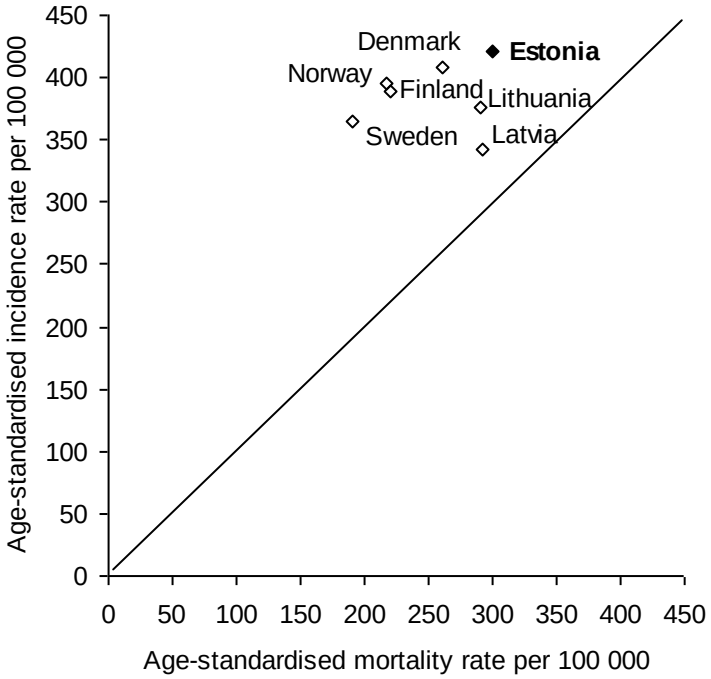

Figure 6.1. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, all cancers in men, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

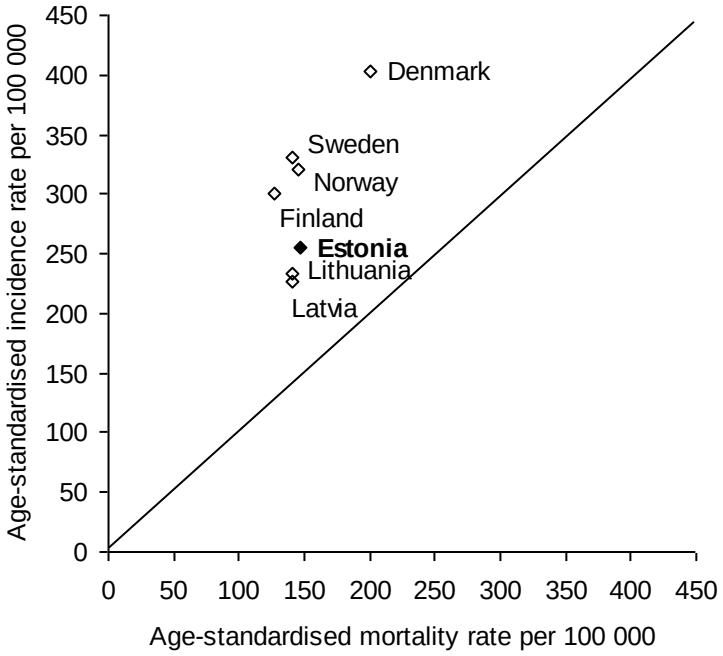

Figure 6.2. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, all cancers in women, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

6.4 Incidence and mortality comparisons by cancer site

The following is a description and some interpretation of cancer incidence and mortality rates for men and women by selected sites. The explanations in text are ordered by cancer site according to the sequential order of their ICD–10 codes. The text is illustrated with tables and figures. The tables are in fact replications of selected sections of Tables 6.7–6.10, presenting cancer incidence and mortality rankings by sex for each cancer site, which should give a better overview of the respective rankings.

In the description for each site, the ranking of Estonia and other countries for both sexes is outlined, and some explanations for the differences are offered. Also, differences between incidence and mortality rates between countries are discussed.

6.4.1 Cancer of the oesophagus

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the oesophagus for men and women are presented in Table 6.13.

Incidence. Estonia ranks first in this comparison of incidence rates for cancer of the oesophagus in men. With the exception of Denmark having a rate similar to the Baltic countries, the rates in the Baltics are almost twice as high as the incidence rates in Finland, Norway, and Sweden.

The incidence rates for women are based on very small numbers and therefore difficult to compare. The rates seem to be higher in the Nordic countries with Denmark having the highest rate.

The high in incidence seen for men in Estonia is probably explained by the positive association between heavy alcohol use, smoking, and the risk of oesophageal cancer (Nyren and Adami 2002a).

Table 6.13. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the oesophagus in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence				Mortality			
	men		women		men		women	
	country	rate	country	rate	country	rate	country	rate
1.	**Estonia**	**8.7**	Denmark	2.5	Denmark	8.4	Denmark	2.6
2.	Lithuania	8.6	Finland	2.2	**Estonia**	**8.2**	Finland	1.9
3.	Denmark	8.1	Sweden	1.5	Lithuania	8.0	Sweden	1.3
4.	Latvia	7.9	Norway	1.2	Latvia	7.9	Norway	1.1
5.	Finland	4.7	**Estonia**	**1.0**	Finland	4.6	Lithuania	0.8
6.	Norway	4.6	Lithuania	0.9	Sweden	4.4	**Estonia**	**0.7**
7.	Sweden	4.5	Latvia	0.8	Norway	4.4	Latvia	0.6

*The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. The mortality rate for men in Estonia ranks second for this cancer. The other two Baltic countries very closely follow Estonia. As for incidence, Denmark is an outlier among the Nordic countries with its rate ranking first and being very similar to those of the Baltic countries and nearly twice as high as the rates for the rest of the Nordic countries compared.

For women the rates are based on very small numbers and may be therefore affected by random fluctuation. Still, as for men, Denmark ranks first. The rates for the Baltic countries are at the bottom of this list with values very close to one another.

Mortality in relation to incidence. In Figures 6.3 and 6.4 the incidence rates plotted against mortality rates for cancer of the oesophagus in men and women are presented.

For men the graph (see Figure 6.4) shows two clusters of countries. In the upper right quadrant there is a cluster of the Baltic countries and Denmark, all showing relatively high incidence and mortality rates. The rest of the Nordic countries cluster very tightly in the middle part of the graph, with both incidence and mortality rates relatively lower than in the rest of the countries compared.

For women (see Figure 6.4), differently from men, there are no two clusters of countries. The incidence/mortality data points are rather spread along the diagonal line, with Denmark and to some extent Finland standing out with higher values of rates. Differently from men, the Baltic countries are situated at the bottom left quadrant of the graph. This is a very interesting finding. It shows that there is a big sex-difference in the incidence/mortality rates for the Baltic countries. This is rather due to differences in the prevalence patterns of underlying risk factors such as smoking and alcohol consumption, which are much higher for the Baltic men compared to women.

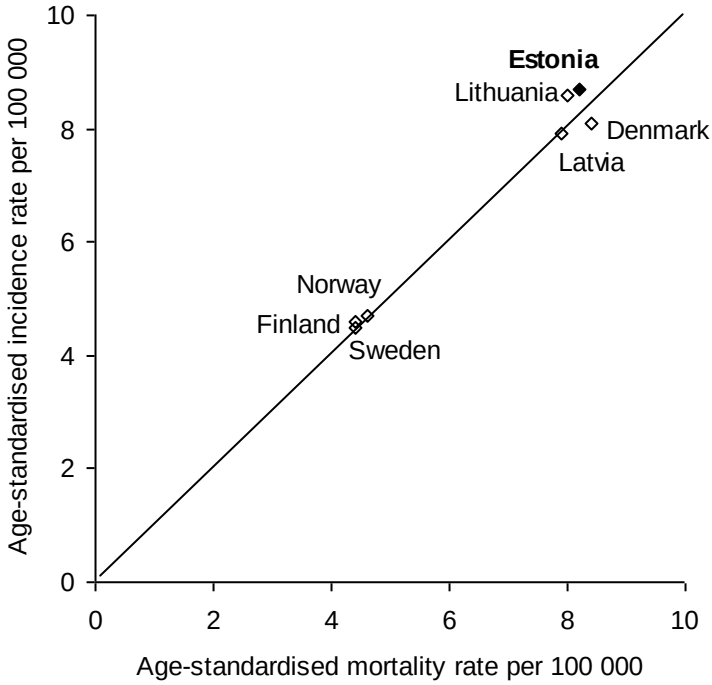

Figure 6.3. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the oesophagus in men, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

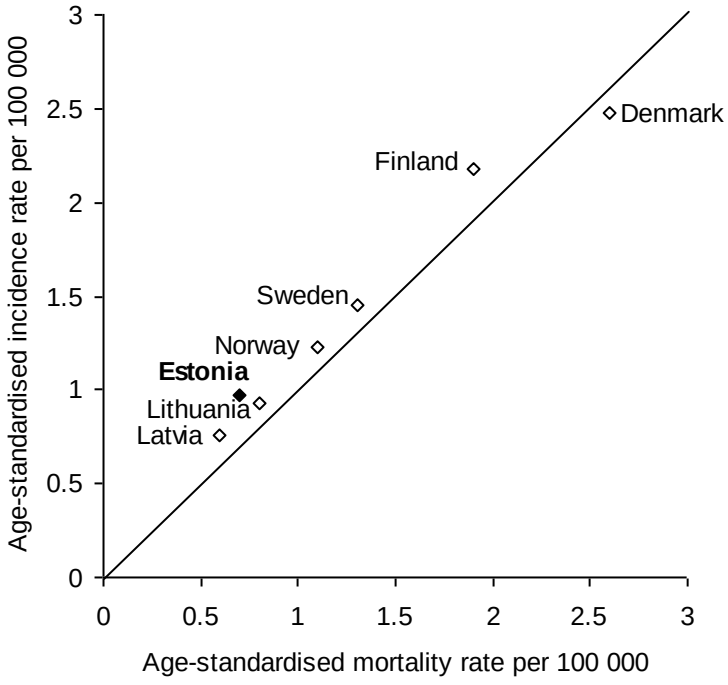

Figure 6.4. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the oesophagus in women, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

6.4.2 Cancer of the stomach

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the stomach for men and women are presented in Table 6.14.

Incidence. For this cancer Estonia ranks first in this comparison for both sexes and is rather closely followed by the rates of Latvia and Lithuania. For both men and women the rates in the Baltic countries are at least double the rates in the Nordic countries. The ranking for stomach cancer in the Nordic countries is the same for both sexes.

Table 6.14. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the stomach in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence				Mortality			
	men		women		men		women	
	country	rate	country	rate	country	rate	country	rate
1.	**Estonia**	**46.7**	**Estonia**	**21.6**	**Estonia**	**39.6**	**Estonia**	**17.3**
2.	Lithuania	43.5	Latvia	18.7	Latvia	38.5	Latvia	16.0
3.	Latvia	40.5	Lithuania	18.5	Lithuania	38.4	Lithuania	15.3
4.	Finland	19.4	Finland	10.6	Finland	15.8	Finland	7.9
5.	Norway	17.0	Norway	8.0	Norway	14.3	Norway	6.6
6.	Sweden	13.3	Sweden	6.6	Sweden	10.5	Sweden	5.5
7.	Denmark	12.4	Denmark	5.6	Denmark	9.9	Denmark	4.8

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. For this cancer site Estonia ranks first for both sexes. A Baltic/Nordic divide is present with all the Baltic countries having much higher rates than the Nordic countries. The ranking of the countries is the same for incidence and mortality rates and for both sexes.

Mortality in relation to incidence. In Figures 6.5 and 6.6 the stomach cancer incidence rates for men and women are plotted against the mortality rates. The pattern of stomach cancer mortality between countries is very similar to that for incidence for both men and women.

For both sexes two clusters of countries can be clearly distinguished, one is the Nordic and the other is the Baltic countries. The cluster of the Baltic countries is in the upper righ quadrant of the graph reflecting both high incidence and mortality. The Nordic countries, in contrast, are clustered in the lower left quadrant of the graph for relatively low incidence

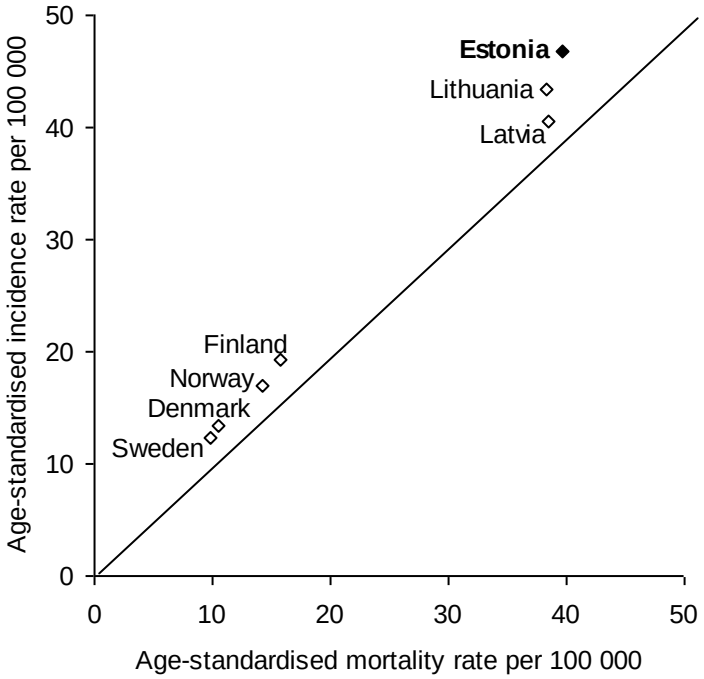

Figure 6.5. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the stomach in men, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

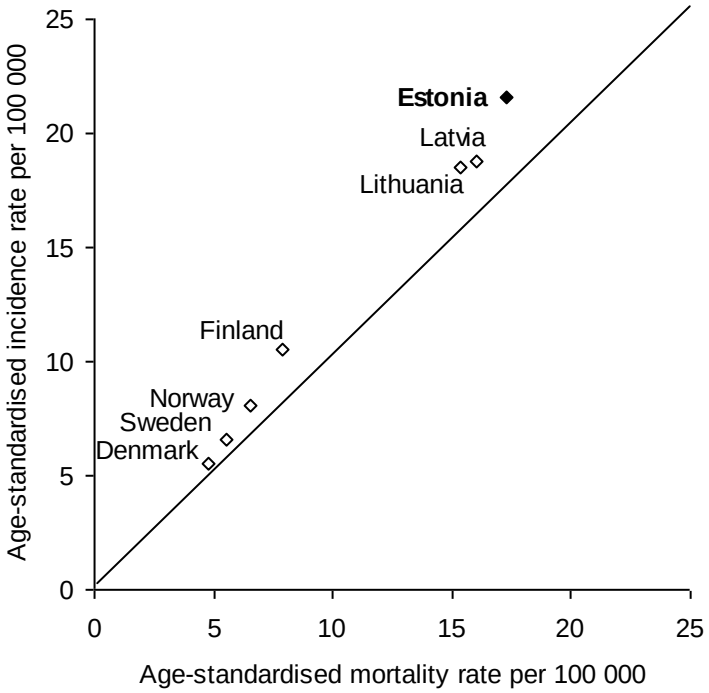

Figure 6.6. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the stomach in women, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

and mortality rates. The high stomach cancer rates in the Baltic countries are attributable to the high prevalence of *H.pylori* infection. According to Maaroos, the prevalence rate for this infection is around 80% in Estonia (Maaroos 1995). There are no published studies on the prevalence of *H.pylori* infection in Latvia and Lithuania. In fact the prevalence of this infection should be similar in the three Baltic countries as it is mainly acquired in early childhood (Logan and Walker 2001) and attributable to hygiene and sanitation conditions. All three countries were occupied by the Soviet Union from 1941–1991, and had rather similar standards of hygiene and living conditions.

In the Nordic countries, in contrast, the prevalence of *H.pylori* infection is much lower thanks to higher standards of hygiene. The prevalence of *H.pylori* infection ranges between 10–50% in the developed world (Rothenbacher and Brenner 2003). Prevalence data for Northern Europe are difficult to find in the literature, the closest finding is the one reported by EOROGAST Study Group (1993) from a study conducted in 1991, which identified a 15% prevalence of *H.pylori* infection for Denmark

6.4.3 Cancer of the colon

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the colon for men and women are presented in Table 6.15.

Incidence. For the cancer of the colon for both sexes, the incidence rate for Estonia is slightly lower than in most of the Nordic countries. Compared to Finland, the rate for Estonia is somewhat higher. Among the Baltic countries, the rate for the cancer of colon in Estonia is about a quarter higher than the rates in Latvia and Lithuania. In general, the rates in the Nordic countries are higher than the rates in the Baltic countries and a pattern of Baltic/Nordic divide, although not very clear, is present.

For women, the incidence rates for cancer of colon rank exactly the same order as the rates in men. The rates for women in all countries are slightly lower than the rates for men.

Some comments on the etiologic factors of cancer of the colon are summarised by the description of cancer of rectum in Section 6.4.4 as in the literature these two cancers are often grouped together.

Table 6.15. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the colon in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence				Mortality			
	men		women		men		women	
	country	rate	country	rate	country	rate	country	rate
1.	Norway	33.5	Norway	30.9	Denmark	22.5	Denmark	18.0
2.	Denmark	30.9	Denmark	27.5	Norway	18.8	Norway	15.8
3.	Sweden	27.3	Sweden	22.6	Latvia	15.0	Sweden	11.1
4.	**Estonia**	**23.8**	**Estonia**	**19.1**	Sweden	13.7	**Estonia**	**10.9**
5.	Finland	21.6	Finland	18.0	**Estonia**	**13.1**	Latvia	10.4
6.	Latvia	18.5	Latvia	14.1	Lithuania	11.6	Lithuania	8.4
7.	Lithuania	17.5	Lithuania	12.9	Finland	10.6	Finland	8.3

*The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. For this cancer site for men Estonia ranks fifth and for women it ranks fourth. The mortality rates for both sexes are much lower than incidence rates and show relatively large variation between countries. The mortality rates for women are lower than for men.

Mortality is higher, in general, among the Nordic countries for both sexes, with an exception of Finland having a relatively low mortality rate for cancer of the colon, ranking as the last country for both sexes. Higher mortality from this cancer in the Nordic countries as compared to the Baltic countries is a reflection of higher incidence rates in the Nordic countries.

Mortality in relation to incidence. The differences in incidence and mortality of colon cancer between different countries are illustrated in Figures 6.7 and 6.8. Looking at these graphs it is seen that the pattern of distribution of incidence/mortality rates data points is very similar between the sexes. Denmark and Norway lie in the upper right part of the graph and stand out for relatively high incidence and mortality rates. Estonia is grouped together with the rest of the countries. Some variation in both rates across countries is seen as the data points are not closely clustered.

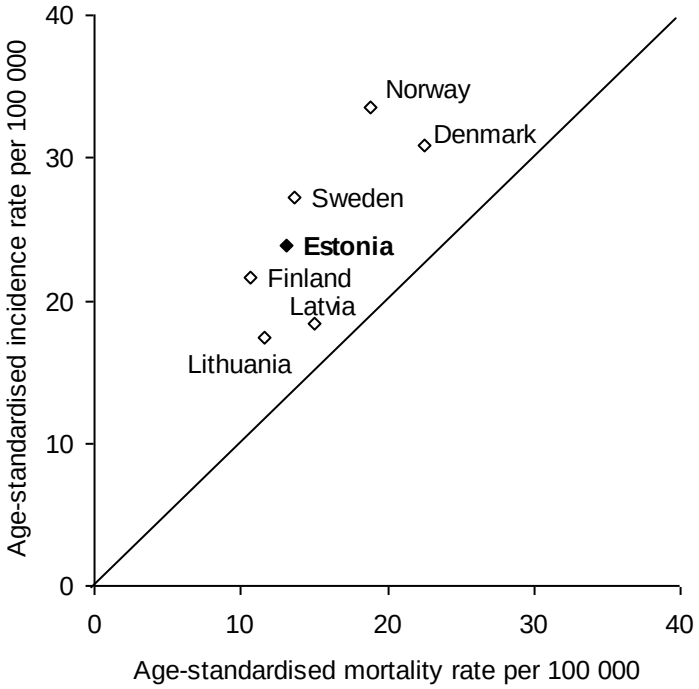

Figure 6.7. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the colon in men, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

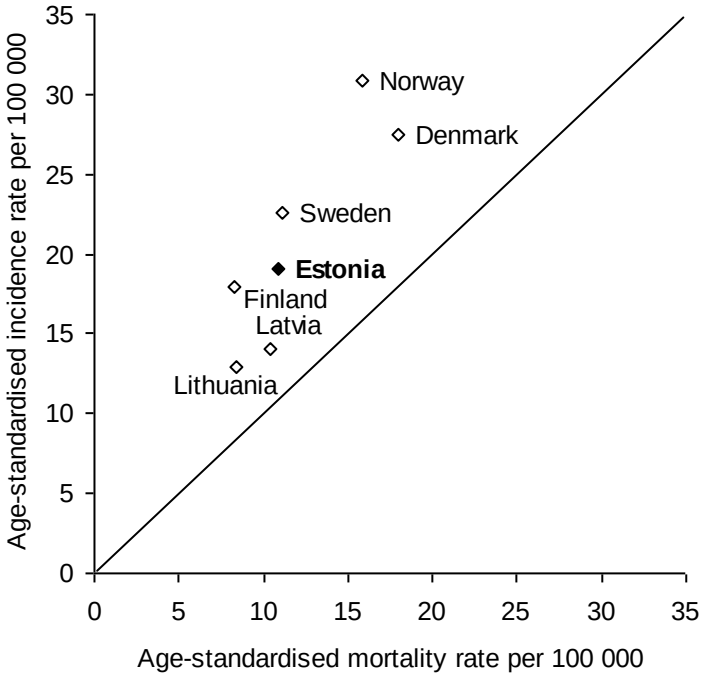

Figure 6.8. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the colon in women, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

6.4.4 Cancer of the rectum

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the rectum for men and women are presented in Table 6.16.

Incidence. For men Estonia ranks third in this comparison with the rates of Denmark and Norway being slightly higher. As Sweden has rather low incidence rate and Finland has the lowest rate for rectal cancer incidence for men, there is no Baltic/Nordic divide. Among the Baltic countries, the rate for rectal cancer incidence for men in Lithuania is very similar to that of Estonia while the rate for Latvia is somewhat lower.

For the incidence rate of rectal cancer in women, the rate for Estonia is relatively low, ranking in the fifth position and having very similar rate to Latvia and Finland ranking as the bottom two countries. The rates for all the Baltic countries are rather similar.

The rankings for rectal cancer incidence across the Nordic countries are rather similar between the sexes, with an exception of Swedish women ranking higher than men.

Dietary differences have been proposed to be responsible for much of the incidence variation of colorectal cancer (Bray *et al.* 2002). Yet there are no published data in relation to dietary differences or other known etiologic factors and differences in colorectal cancer incidence in the European countries, including the Nordic and the Baltic countries.

Table 6.16. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the rectum in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	**Incidence**				**Mortality**			
	men		**women**		**men**		**women**	
	country	**rate**	**country**	**rate**	**country**	**rate**	**country**	**rate**
1.	Denmark	25.2	Denmark	16.0	Lithuania	15.6	Lithuania	8.5
2.	Norway	23.9	Norway	15.8	**Estonia**	**14.5**	**Estonia**	**7.7**
3.	**Estonia**	**20.7**	Sweden	12.3	Denmark	13.5	Latvia	7.5
4.	Lithuania	20.5	Lithuania	11.6	Latvia	13.1	Denmark	7.4
5.	Sweden	19.0	**Estonia**	**10.8**	Norway	12.5	Norway	7.3
6.	Latvia	16.9	Latvia	10.6	Finland	8.4	Sweden	4.8
7.	Finland	16.4	Finland	10.4	Sweden	7.9	Finland	4.8

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. The mortality rates for cancer of the rectum for both sexes rank second in Estonia. Lithuania has the highest ranking for both sexes. With the rate for Latvia

ranking fourth and third for men and women, respectively, there is a Baltic/Nordic divide present. Denmark has the highest rate among the Nordic countries for both sexes, which is a reflection of its high incidence of rectal cancer, ranking first in the comparison for men and for women.

Mortality in relation to incidence. Figures 6.9 and 6.10 present incidence/mortality plots for cancer of the rectum in men and women.

The positions of the countries are are very similar for both sexes. The Nordic countries are divided into two groups with Denmark and Norway in the first group with relatively high both incidence and mortality rates. Sweden and Finland, on the other hand, have relatively low rates for both incidence and mortality. All the Baltic countries are clustered together, with relatively low incidence and high mortality. For men, Latvia perhaps stands out for a bit lower mortality and especially incidence rates compared to Estonia and Lithuania.

The fact that for cancers of both colon and rectum the incidence rates for both sexes follow the same pattern between countries indicates that these rates are real, i.e. a factor such as diet may cause these cancers as the dietary differences between sexes are minimal.

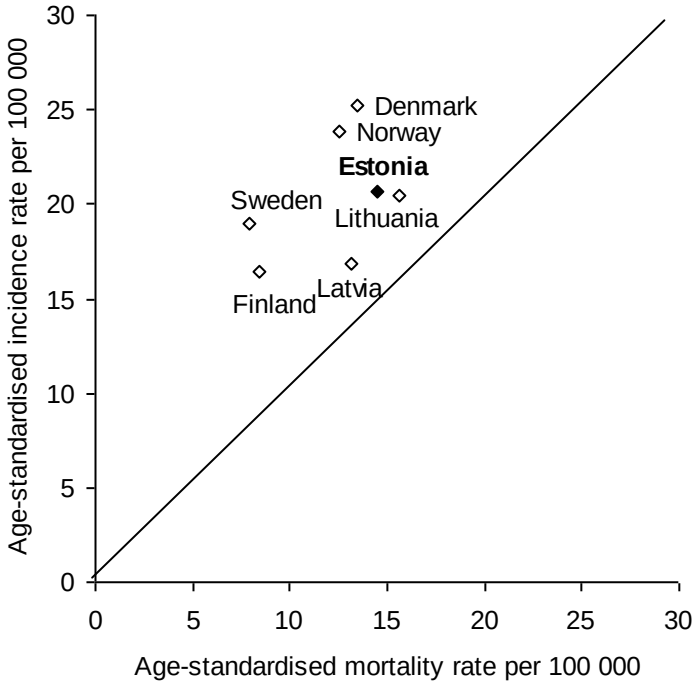

Figure 6.9. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the rectum in men, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

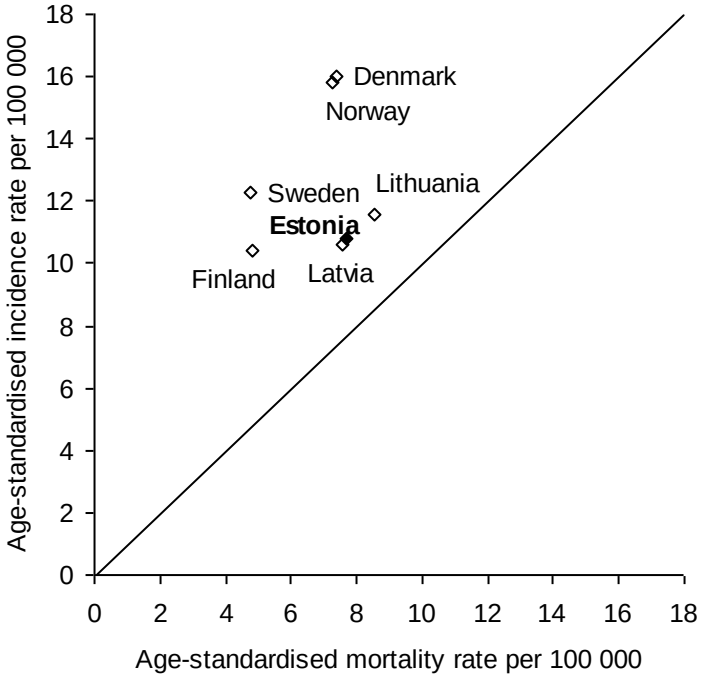

Figure 6.10. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the rectum in women, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

6.4.5 Cancer of the pancreas

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the pancreas for men and women are presented in Table 6.17.

Incidence. In men Estonia ranks second in the comparison for incidence rates of cancer of the pancreas. It has a slightly lower rate than Latvia and exactly the same rate as Lithuania. The Baltic countries rank the top three ones in this comparison with the rates for each country being about one third higher than the rates for the Nordic countries. Among the Nordic countries the rates for men are rather similar, with an exception of Finland for which the rates are somewhat higher than in the rest of the Nordic countries.

Tobacco smoking, which is the only established exogenous cause of the disease (Ekbom and Hunter 2002), explains the higher incidence of pancreatic cancer in men in the Baltic countries when compared to the Nordic countries.

The rates for cancer of the pancreas in women are lower than the rates in men and there is less variability bewteen the countries. The ranking of the countries is different from men. Estonia ranks sixth with only the rate for Lithuania being lower. The Nordic countries all have higher rates than the Baltic countries, except for Sweden having lower rate than Latvia, which ranks the highest among the Baltic countries.

The differences in pancreatic cancer incidence rates in women between the countries are difficult to interpret, especially as these are rather small. The relatively high rate in Finland compared to other Nordic countries can not be attributed to smoking as this is relatively low among women in Finland. Other risk factors such as genetic predisposition, diet, occupational factors, and diseases such as adult-onset diabetes mellitus and pernicious anemia may be responsible for this higher incidence, but the role of these factors in the etiology of pancreatic cancer yet remains to be clarified (Ekbom and Hunter 2002).

Table 6.17. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the pancreas in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence				Mortality			
	men		women		men		women	
	country	rate	country	rate	country	rate	country	rate
1.	Latvia	17.4	Finland	9.5	Lithuania	15.0	Sweden	10.2
2.	**Estonia**	**16.6**	Denmark	8.8	Finland	13.1	Finland	9.7
3.	Lithuania	16.6	Norway	8.5	**Estonia**	**12.1**	Denmark	9.4
4.	Finland	12.7	Latvia	8.3	Sweden	11.9	Norway	8.8
5.	Norway	10.9	Sweden	8.1	Denmark	11.5	Lithuania	7.2
6.	Denmark	10.4	**Estonia**	**7.9**	Norway	11.3	**Estonia**	**5.4**
7.	Sweden	9.5	Lithuania	7.5	Latvia	6.9	Latvia	3.1

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. For this cancer site Estonia ranks third for men and sixth for women. In men, among the Baltic states, which all have relatively high rates for pancreatic cancer incidence, ranking first three countries, Latvia has the lowest mortality for this cancer of all countries compared.

In women the mortality rates for cancer of the pancreas in the Baltic countries are lower than in the Nordic countries, a similar divide than the one seen for incidence rates. Interestingly, Latvia, which ranks fourth for pancreatic cancer incidence in women, ranks last for its mortality.

Comparison of incidence and mortality rates. In Figures 6.11 and 6.12 graphs for cancer of the pancreas in men and women are presented. Clustering of the Nordic countries is seen for both sexes. For men, the Nordic countries are positioned below the Baltic countries, indicating lower mortality than in the Baltic countries.

For women, it is seen that the Nordic countries are situated on a similar level for incidence of the Baltic countries. At the same time, they lie to the right of the Baltic countries, indicating higher mortality rates than in the Baltic countries.

Also, for the Nordic countries the data points lie below the diagonal line, indicating that the incidence rates are lower than mortality rates. This can have two explanations. First of all, it may refer to underregistration of incident cases of pancreatic cancer, wheras deaths from this malignancy are registered with great completeness, leading to an excess of death rate over incidence rate. Secondly, there may be a downwards timetrend in incidence. In this case the larger numbers of persons diagnosed

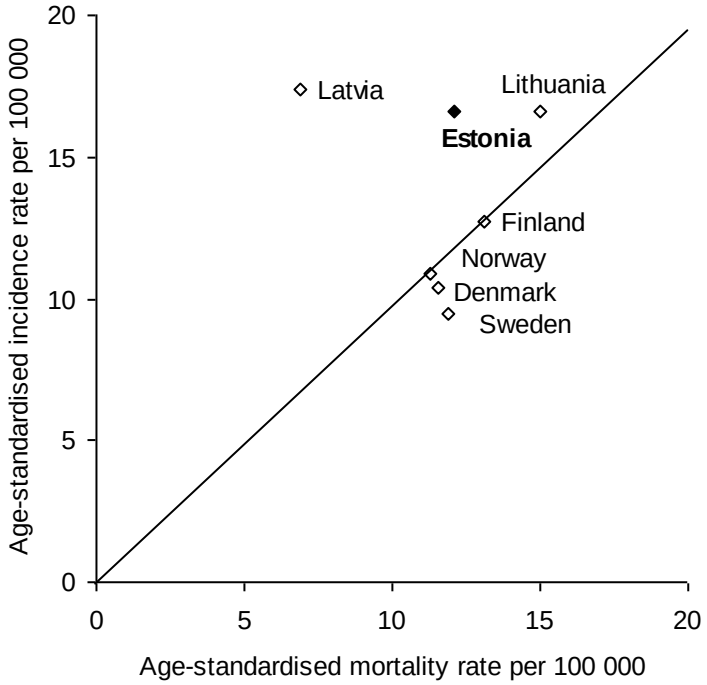

Figure 6.11. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the pancreas in men, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

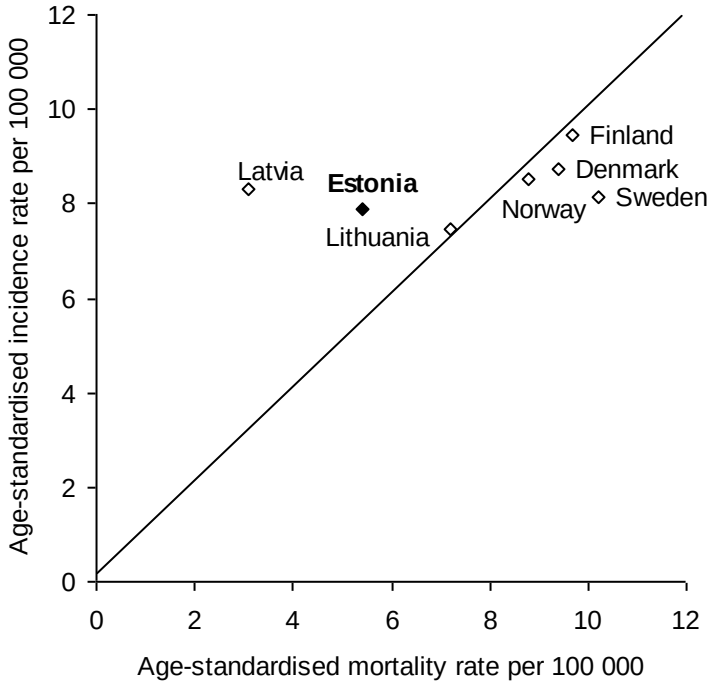

Figure 6.12. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the pancreas in women, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

with this cancer some time in the past die during this time period under observation, bringing mortality rate higher than the incidence rate at any point in time. The second explanation is more realistic in the case of the Nordic countries as trends in pancreatic cancer incidence are generally stable or slightly decreasing all over the world (Ekbom and Hunter 2002).

In the case of all the Baltic countries, no clustering is seen. The points are rather spread out horizontally, indicating that incidence for pancreatic cancer is rather simlar between those countries for both sexes.

For cancer of the pancreas one would expect that the the mortality are close to incidence rates as cancer of the pancreas is fatal, and very seldom patients survive longer than six months after diagnosis (Ekbom and Hunter 2002). This would mean incidence/mortality data points lying close to the diagonal line. In the case of the Baltic countries, this is not seen for Latvia and to some extent for Estonia and the respective data points are situated at some distance above the line. For Latvia for men as well as for women, the data point lies at a considerable distance from the line. This finding suggests that not all deaths from this cancer for both sexes are registered on the death certificates in Latvia. In the case of Estonia, there is also some distance between the incidence/mortality data points and the diagonal line for both sexes, indicating incompleteness in pancreatic cancer deaths' ascertainment.

6.4.6 Cancer of the larynx

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the larynx for men and women are presented in Table 6.18.

Incidence. For cancer of larynx in men, Estonia ranks third after Lithuania and Latvia. A clear Baltic/Nordic divide with all the Baltic countries ranking higher than the Nordic countries is seen. Among the Nordic countries, Denmark has a higher rate than any of the other Nordic countries and in is intermediate in position between the rates of the Baltic and the Nordic countries.

For women, the rates are based on very small numbers and due to random variation and should be interpreted with caution. It is seen, though, that the rate for Denmark stands out for a relatively high value which is double or higher than the rates in all of the other countries compared. This is probably due to relatively high smoking prevalence in Danish women.

Table 6.18. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the larynx in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	**Incidence**				**Mortality**			
	men		**women**		**men**		**women**	
	country	**rate**	**country**	**rate**	**country**	**rate**	**country**	**rate**
1.	Lithuania	13.6	Denmark	1.5	Lithuania	10.1	Denmark	0.7
2.	Latvia	11.5	Norway	0.8	Latvia	9.1	**Estonia**	**0.4**
3.	**Estonia**	**11.2**	**Estonia**	**0.6**	**Estonia**	**8.0**	Lithuania	0.3
4.	Denmark	8.2	Lithuania	0.5	Denmark	3.4	Latvia	0.3
5.	Norway	4.6	Sweden	0.4	Norway	1.5	Norway	0.3
6.	Finland	4.3	Latvia	0.4	Finland	1.4	Sweden	0.1
7.	Sweden	3.2	Finland	0.3	Sweden	0.9	Finland	0.1

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Cancer of the larynx is mostly caused by tobacco and alcohol use (Bofetta and Trichopoulos 2002; Cattaruzza *et al*. 1996).

Mortality. Looking at the mortality rates of laryngeal cancer in men, it is seen that the Baltic countries rank as first three countries, with the rates more than double the rates in the Nordic countries.

Among women, the rates are very small and no definite conclusions about the differences between countries can be drawn. Again, Denmark stands out for a higher rate than seen in the other countries. This is most probably attributable to high smoking prevalence among the Danish women.

Comparison of incidence and mortality rates. In Figures 6.13 and 6.14 incidence/ mortality graphs for cancer of the larynx in men and women are presented.

It is seen for men that the Baltic countries lie in the upper right part of the graph indicating higher incidence and mortality rates as compared to othe countries. Most of the Nordic countries, except Denmark, are clustered at the lower left end of the graph, showing that both incidence and mortality rates are relatively low. Denmark stands in between of these two groups of countries.

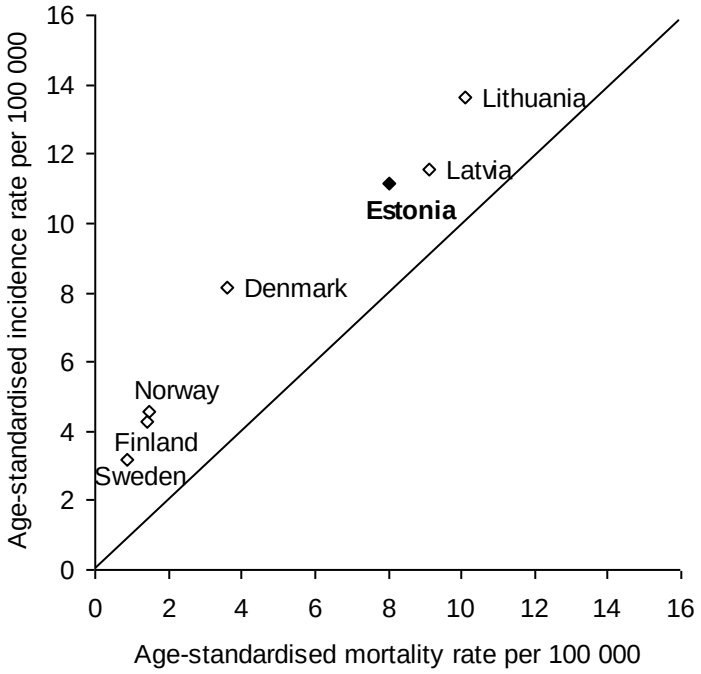

Figure 6.13. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the larynx in men, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

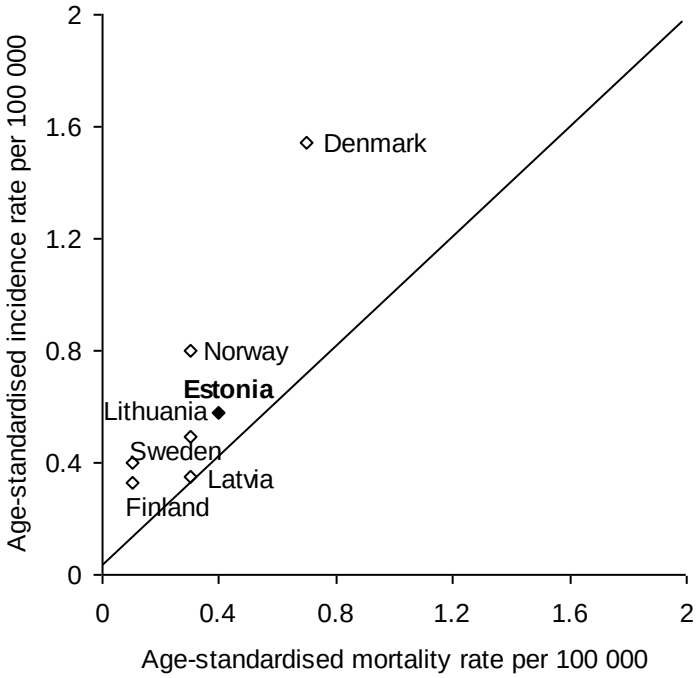

Figure 6.14. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the larynx in women, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank.

For women, all the incidence and mortality rates are relatively low, as this site was added to the analysis for the purpose of completeness, as it figures among the ten leading sites for men and not for women. For Denmark the incidence and mortality rates for cancer of the larynx in women are relatively high as compared to other countries. The rates for the other countries are clustered at the lower left quadrant of the graph.

Although the rates for cancer of the larynx in women are small, an observation sinilar to the distribution pattern of oesophageal cancer rates can be made. Namely, for men the Baltic countries have much higher rates than the Nordic countries. For women, the rates are small and rather similar across the countries except Denmark. The higher incidence rates for men for laryngeal cancer in the Baltic countries compared to Nordic countries is explained by higher smoking prevalence and alcohol use.

6.4.7 Cancer of the lung

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the lung for men and women are presented in Table 6.19.

Incidence. For this cancer in men, Estonia ranks first. The rates for the Baltic countries are relatively similar, and show about a quarter higher values than the rates for all of the Nordic countries studied. Thus a clear Baltic/Nordic divide is present. Among the Nordic countries, the rates show some variation. Denmark has the highest rate. It is more than double the rate for Sweden which has the lowest rate of the Nordic countries.

The incidence rates for lung cancer in women differ a lot from those for men as well as between the countries compared. Estonia has the highest lung cancer rate for women among the Baltic countries. Latvia and Lithuania have very similar to one another lung cancer incidence rate, which is about a quarter lower than the respective rate for Estonia. The Nordic countries except Finland all have higher rates than the Baltic countries, with Denmark having by far the highest rate. It is in fact twice as high as the rate for lung cancer incidence in Norway which ranks second. The other two Nordic countries compared have lower rates.

Table 6.19. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the lung in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence				Mortality			
	men		women		men		women	
	country	rate	country	rate	country	rate	country	rate
1.	**Estonia**	**104.4**	Denmark	41.5	**Estonia**	**94.2**	Denmark	39.7
2.	Lithuania	94.1	Norway	22.3	Latvia	88.7	Norway	19.6
3.	Latvia	90.3	Sweden	18.1	Lithuania	87.9	Sweden	17.0
4.	Denmark	71.8	Finland	12.6	Denmark	74.0	**Estonia**	**10.7**
5.	Finland	65.7	**Estonia**	**12.6**	Finland	62.3	Finland	10.4
6.	Norway	51.0	Lithuania	9.3	Norway	47.0	Latvia	9.0
7.	Sweden	32.2	Latvia	9.2	Sweden	39.7	Lithuania	8.2

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. For men, the rates are very high in the Baltic countries and a Baltic/Nordic divide similar to that for lung cancer incidence, is seen.

For women, Denmark stands out for extremely high rates in women compared to all other countries. In general the rates are lower in the Baltic than in the Nordic countries.

Mortality in relation to incidence. In Figures 6.15 and 6.16 incidence and mortality comparisons between countries for lung cancer for men and women are shown. For both sexes across the countries the data points are situated along the diagonal lines, indicating that the mortality rates are close to respective incidence rates. This is consistent with very poor survival for lung cancer (Janssen-Heijnen *et al.* 1998).

For men the data points for the Baltic countries are clustered in the upper right corner of the graph, indicating that both incidence and mortality rates are high. The rates for the Nordic countries show more variation with a common incidence/mortality ratio of around one as the points are situated very near or on the diagonal line.

For women the Baltic countries and Finland lie in the lower left corner of the graph with both incidence and mortality being low. Denmark, at the same time, stands out for extremely high values for both rates when compared to other countries.

This big sex-differences in the distribution of data points for the Baltic countries is attributable to differences in smoking patterns between sexes that are described in the following paragraphs.

The relatively high smoking prevalence for men in Estonia was described in Chapter 5 Section 5.2.3. In Latvia and Lithuania it has values similar to Estonia (World Health Organisation Health for All Database 2003), and this is consistent with the findings of lung cancer incidence rates for men in the Baltic countries.

The prevalence of smoking for men in all the Nordic countries has all the time been lower than in the Baltic countries in the 1990–s (World Health Organisation Health for All Database 2003), with Denmark having the highest rate among the Nordic countries. This is again consistent with the differences lung cancer incidence rates between the countries compared.

For women, smoking prevalence in the Nordic countries, especially in Denmark, has been in general higher than in the Baltic countries. Among the Nordic countries, the prevalence has been the lowest in Finland. These differences in smoking prevalence are reflected in the differences of lung cancer incidence rates for women.

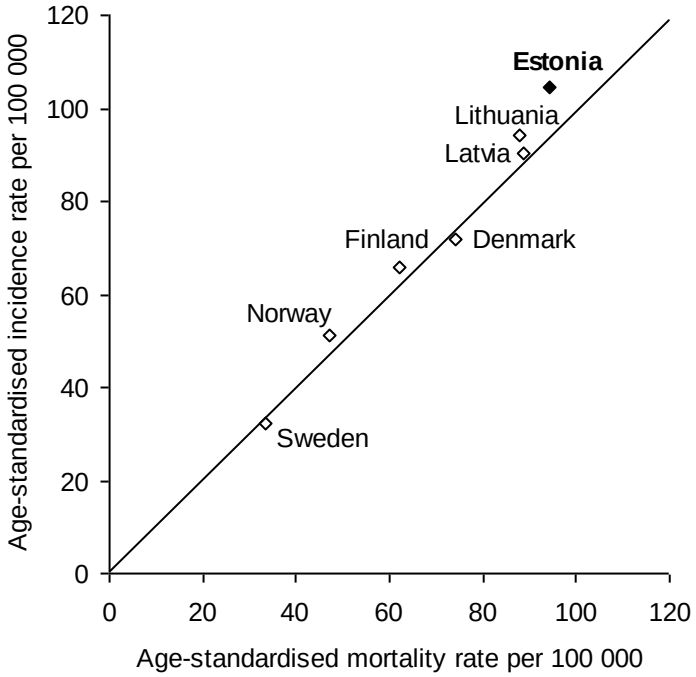

Figure 6.15. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the lung in men, the average for 1993–97, all ages. Source: EUROCIM and WHO Mortality Databank.

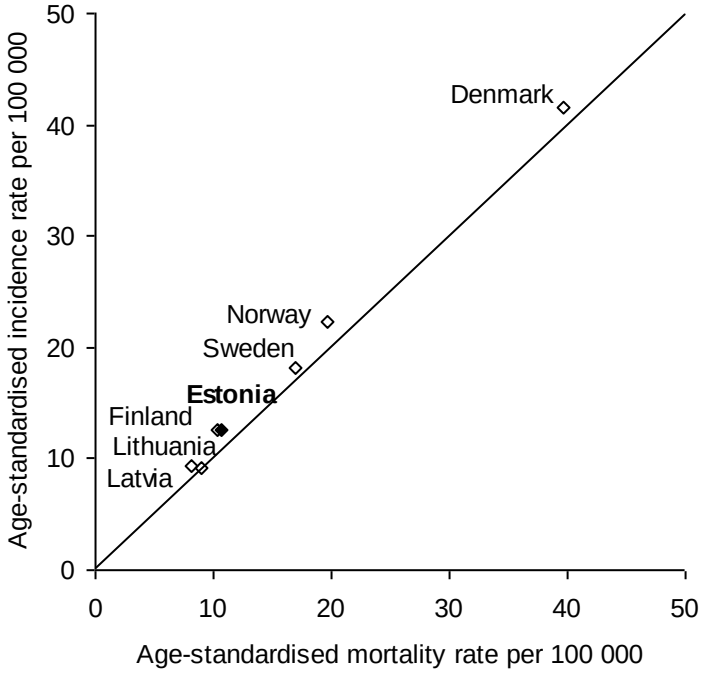

Figure 6.16. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the lung in women, the average for 1993–97, all ages. Source: EUROCIM and WHO Mortality Databank.

6.4.8 Cancer of the female breast

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the female breast are presented in Table 6.20.

Incidence. Estonia ranks fifth in the comparison of breast cancer rates for women. It is rather closely followed by the rates of Latvia and Lithuania. All the Baltic countries have rates below the Nordic countries, thus a clear Baltic/Nordic divide is evident. Among the Nordic countries, Denmark has the highest rate. The breast cancer incidence rates for Sweden and Finland quite closely follow the rate for Denmark, while Norway, which ranks fourth, has a bit lower rate.

The differences in the breast cancer incidence rates are attributable in part to differences in childbearing patterns that are known to be associated with breast cancer risk (Hermon and Beral 1996).

Table 6.20. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the female breast, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence		Mortality	
	country	**rate**	**country**	**rate**
1.	Denmark	110.5	Denmark	39.5
2.	Sweden	104.8	Norway	27.5
3.	Finland	98.3	Lithuania	25.9
4.	Norway	82.4	**Estonia**	**24.7**
5.	**Estonia**	**56.0**	Latvia	24.1
6.	Latvia	52.3	Sweden	24.0
7.	Lithuania	50.4	Finland	23.7

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. For mortality rates of breast cancer, Estonia ranks fourth and is surrounded by Lithuania and Latvia, ranking third and fifth, respectively. The rates for all countries show a lot of similarity with one another. The exception here is Denmark, which ranks first and has a relatively higher mortality rate than in the rest of the countries, a reflection of very high incidence rate.

Mortality in relation to incidence. Figure 6.17 shows incidence and mortality comparisons for breast cancer. It is seen that all countries have similar mortality rates except Denmark. The Baltic countries cluster closely together at the lower left corner of the graph, indicating that both incidence and mortality rates are relatively low. Between the Nordic countries, there is more variation in incidence and mortality rates. Compared to the Baltic countries, Norway, Finland and Sweden have similar mortality rates, while the incidence is much higher, especially in Sweden and Finland. Denmark stands out for

relatively high values for both rates, especially mortality when compared to the other countries.

As part of EUROCARE II study, Quin *et al.* (1998) estimated breast cancer survival. They concluded that, amongst other countries, survival was above the European average in Finland and Sweden, was average in Denmark and below average in Estonia. This finding is consistent with the distribution of the data points see in the graph.

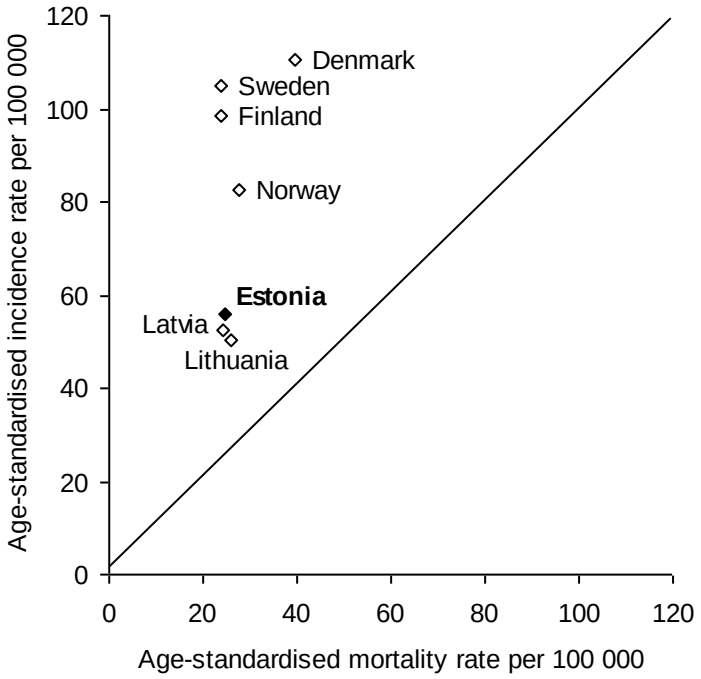

Figure 6.17. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the female breast, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank

6.4.9 Cancer of the cervix uteri

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the cervix uteri are presented in Table 6.21.

Incidence. The rates for cancer of the cervix uteri show considerable variation between the countries. Estonia ranks first, and is closely followed by the rate of Lithuania. Among the Baltic countries, Latvia has a somewhat lower rate and ranks fifth. Among the Nordic countries, Denmark ranks the highest and is followed by the rate for Norway, which is also relatively high. The rates in Sweden and especially Finland are much lower.

Cervical cancer screening can reduce the incidence of this cancer (excluding the *in situ* cases). In Finland, Norway, and Sweden, there exist mass–screening programmes for cancer of the cervix (Parkin *et al.* 2002). The lower incidence rates in the Nordic countries are attributable to screening.

The high incidence of cervical cancer incidence and mortality rates in Estonia as compared to Finland in 1968–87, and the less pronounced decrease in the rates in Estonia has been studied by Aareleid *et al.* (1993).The authors attribute this mainly to the difference in public health policies in the two countries, namely the lack of an effective mass screening programme in Estonia, whereas such a programme has been conducted in Finland. Unfortunately, almost two decades later the data that are being studied here are similar to the Estonian rates of cervical cancer from previous study and no mass screening programme has still been conducted in Estonia.

A relatively low incidence rate for Latvia is probably a result of misclassification of cervical cancers as cancers of corpus uteri and will be discussed in Section 6.4.10.

Table 6.21. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the cervix uteri, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	**Incidence**		**Mortality**	
	country	**rate**	**country**	**rate**
1.	**Estonia**	**19.7**	Lithuania	10.2
2.	Lithuania	19.0	**Estonia**	**9.0**
3.	Denmark	17.5	Latvia	6.2
4.	Norway	14.6	Denmark	5.5
5.	Latvia	12.1	Norway	4.6
6.	Sweden	9.7	Sweden	2.7
7.	Finland	5.2	Finland	1.9

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. For the mortality from this cancer, the Baltic countries rank as the leading ones in the comparison. Estonia ranks second. For all the Nordic countries, the mortality rates are lower than in the Baltic countries and are especially low in Sweden and Finland.

Mortality in relation to incidence. In Figure 6.18 the incidence/mortality graphs for cancer of cervix uteri are presented. It is seen that there is a big variation in both incidence and mortality rates across the countries. For all countries incidence rates are considerably higher than mortality rates and the incidence/mortality data points lie away from the diagonal line.

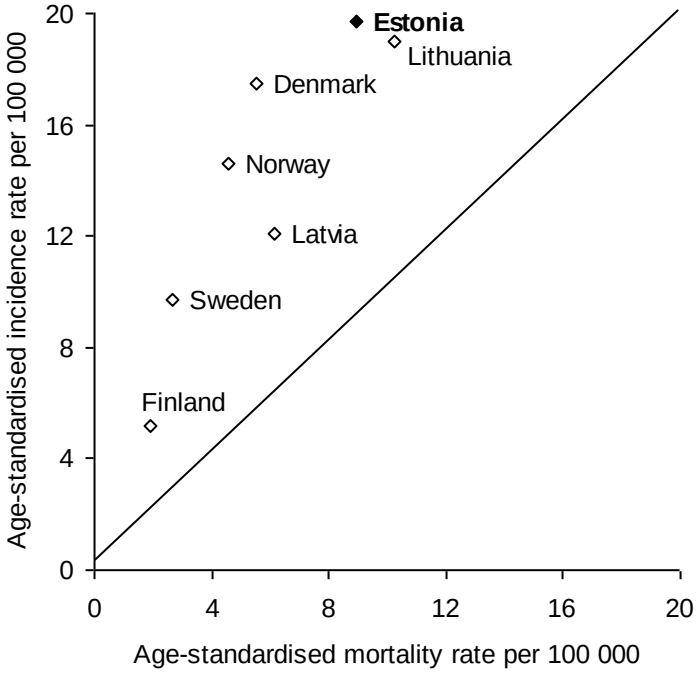

Figure 6.18. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the cervix uteri, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank

6.4.10 Cancer of the corpus uteri

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the corpus uteri are presented in Table 6.22.

Incidence. Estonia ranks fifth in this comparison. The rates for cancer of the corpus uteri are fairly similar between the countries except for Latvia, which is ranked first and stands out as having a relatively higher rate. There is no Baltic/Nordic divide seen for the incidence rates for this cancer.

The high incidence rate for cancer of the corpus uteri in Latvia seems to be caused by a misclassification problem where cervical cancers are classified as cancers of corpus uteri. If cancer registrations for uterine cancers do not specify whether the tumour is located in the cervix or corpus uteri, it may be wrongly recorded as corpus uteri cancers (Swerdlow *et al.* 1998). The incidence rate of the cancers of corpus uteri for Latvia is very high, and at the same time, the incidence of cancers of cervix uteri is very low in Latvia when compared to other Baltic countries.

Table 6.22. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the corpus uteri, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence		Mortality	
	country	rate	country	rate
1.	Latvia	23.8	Lithuania	6.3
2.	Finland	20.0	Denmark	3.8
3.	Sweden	20.0	Norway	3.6
4.	Denmark	19.5	Finland	3.5
5.	**Estonia**	**19.3**	**Estonia**	**2.3**
6.	Lithuania	18.4	Sweden	2.0
7.	Norway	18.0	Latvia	1.9

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. Mortality rates for all countries for this cancer are rather low, and there is about three-fold variation in the rates. The rate for Estonia ranks fifth. Lithuania stands out for a higher rate than in the other countries. This may be the result of more advanced stage distribution at diagnosis for cancer of the corpus uteri in Lithuania. Latvia, on the other hand, has the lowest mortality rate.

Mortality in relation to incidence. In Figure 6.19 incidence and mortality rates are presented for cancer of corpus uteri. It is seen that all the countries are situated in the upper left part of the graph, indicating that incidence compared to mortality is relatively

high. The outliers from the cluster are Latvia for a higher incidence rate than in the other countries and Lithuania for a higher mortality rate.

The fact that Latvia has the lowest mortality rate while the incidence rate for this cancer is the highest among the countries compared is a sign of incomplete cancer mortality registration.

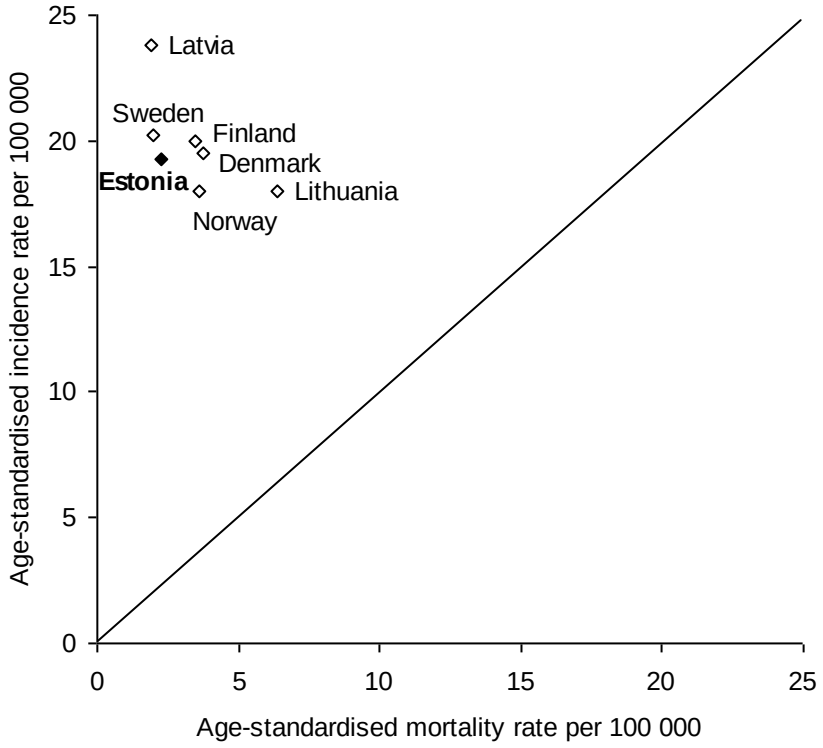

Figure 6.19. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the corpus uteri, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank

6.4.11 Cancer of the ovary

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the ovary are presented in Table 6.23.

Incidence. For cancer of the ovary the rate for Estonia is the lowest in this comparison. The rates do not show much variation between the countries. Denmark with its rate ranking first is somewhat an outlier with a relatively high rate. No Baltic/Nordic divide can be seen for the distribution of incidence rates for this cancer.

Table 6.23. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the ovary, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence		Mortality	
	country	rate	country	rate
1.	Denmark	20.0	Denmark	13.7
2.	Lithuania	18.1	Lithuania	12.7
3.	Latvia	17.4	Norway	11.5
4.	Norway	17.3	Sweden	10.5
5.	Finland	16.8	Finland	9.2
6.	Sweden	16.4	**Estonia**	**9.0**
7.	**Estonia**	**16.2**	Latvia	4.4

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. Estonia ranks sixth for the mortality rate for cancer of the ovary. As for incidence, the variation in the mortality rates is not large in general. The exception is Latvia with its lowest mortality rate that is only a half of that for Estonia only one rank up.

Mortality in relation to incidence. In Figure 6.20 the graphs for cancer of the ovary are presented.

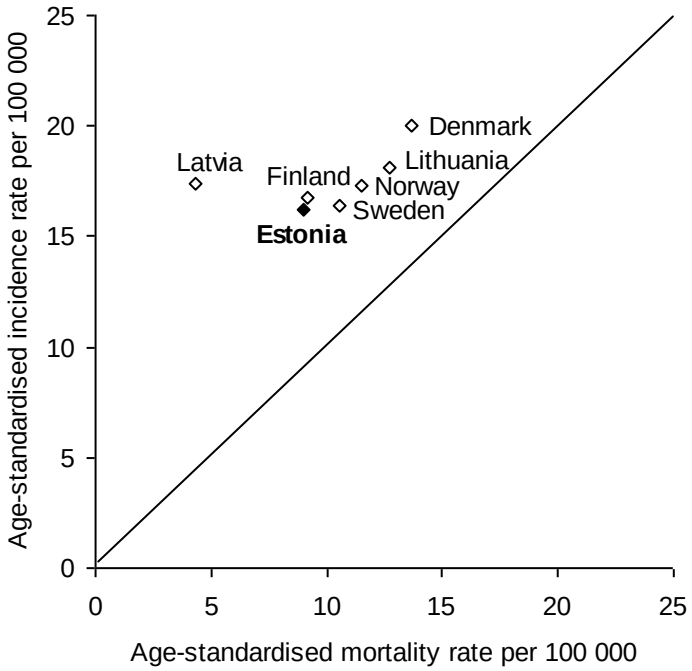

Figure 6.20. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the ovary, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank

It is seen from the graph that the data points for all countries except Latvia are clustered along the diagonal line. Estonia and Finland have a bit higher incidence/mortality ratios than the other countries in the cluster. Latvia stands out for a very low mortality compared to incidence. This finding, especially in the context of Latvia having one of the highest rates for incidence, refers to problems in mortality registration completeness.

6.4.12 Cancer of the prostate

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the prostate are presented in Table 6.24.

Incidence. For cancer of the prostate, Finland, Sweden, and Norway rank the first three countries with incidence rates being similar to one another and very high when compared to other contries. Estonia ranks fourth with a rate of slightly more than a half of the rates of each of the countries listed above and, at the same time, considerably higher than in the rest of the Baltic countries.

The differences in prostate cancer incidence may relate more to differing diagnostic practices between countries than to any variation in the underlying risk (Bray *et al.* 2002). An increased diagnosis of latent prostate tumours has been recently described and related to the use of transurethral prostatectomy and testing with prostate-specific antigen. These diagnostic techniques have been practiced in the Nordic countries for a couple of decades, and also in Estonia these have become available over the recent years (Aareleid 2004) The diagnosis of prostate cancer in Estonia has improved over the last decade (Timberg G 2004 – personal communication) and the diagnostic methods used are very similar to those used by the Nordic countries for some time already.

Mortality. For mortality rate of the prostate cancer, there is a Nordic/Baltic divide present. All the Baltic countries have lower rates than the Nordic countries. The rate for Estonia ranks fifth.

Table 6.24. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the prostate, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence		Mortality	
	country	rate	country	rate
1.	Finland	100.2	Norway	41.8

2.	Sweden	99.4	Sweden	37.1
3.	Norway	91.9	Denmark	33.8
4.	**Estonia**	**56.5**	Finland	31.8
5.	Denmark	44.6	Lithuania	24.9
6.	Lithuania	41.8	**Estonia**	**23.0**
7.	Latvia	29.8	Latvia	20.2

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality in relation to incidence. Figure 6.21 presents incidence/mortality graphs for prostate cancer. Two clusters of countries are seen. The first cluster is Finland, Sweden, and Norway, that are situated in the upper left quadrant of the graph indicating relatively high incidence and low mortality rates. The Baltic countries and Denmark are in the second cluster in the lower left quadrant of the graph and in fact are rather spread out along the mortality scale. The second cluster differs from the first one for much lower mortality rates,

while the differences in incidence rates are not so large.

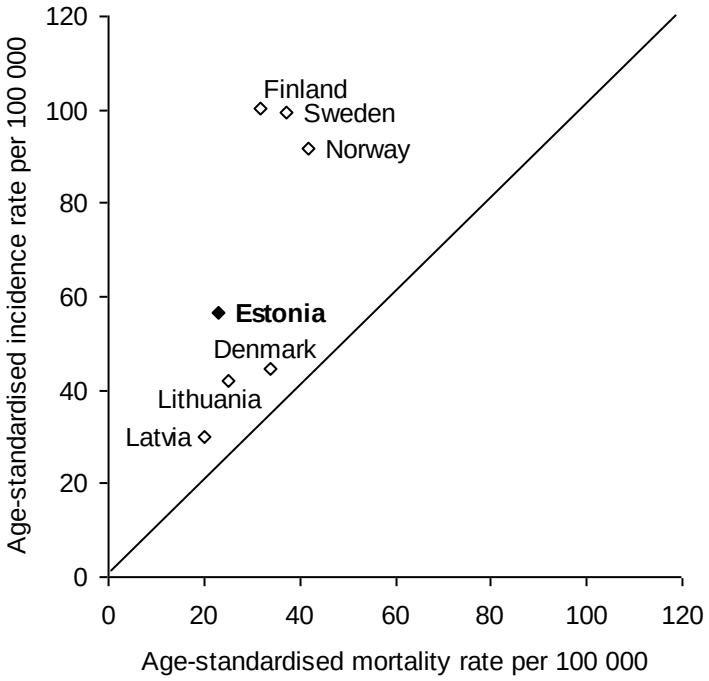

Figure 6.21. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the prostate, the average for 1993–97, all ages.
Source: EUROCIM and WHO Mortality Databank

6.4.13 Cancer of the kidney

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the kidney are presented in Table 6.25.

Incidence. For cancer of the kidney for both sexes, the rate for Estonia ranks first and stands out for a high rate compared to other countries.

In men it is followed by the other two Baltic countries. The rates Latvia and Lithuania are followed by the rates of the Nordic countries rather closely. Estonia stands out with about 25% higher rate than in the other two Baltic countries. There is a clear Baltic/Nordic divide present.

For women, Estonia also stands out for a rate which is considerably higher than in the other countries. The rest of the countries have the rates noticeably similar to one another. There is no pattern of Baltic/Nordic divide for this cancer in women.

The fact that for men the Baltic countries have higher incidence than the Nordic countries is most probably explained by smoking differences. Yet fact that Estonia has high incidence rates for both sexes, compared to all other countries, remains poorly understood. It may refer to more active diagnosing of kidney cancer by ultrasound, which is a routine diagnostic method in Estonia (Timberg G 2004 – personal communication).

Table 6.25. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the kidney in men and women, the average for 1993–97, all ages.*
Source: EUROCIM and WHO Mortality Databank.

Rank position	**Incidence**				**Mortality**			
	men		**women**		**men**		**women**	
	country	**rate**	**country**	**rate**	**country**	**rate**	**country**	**rate**
1.	**Estonia**	**20.3**	**Estonia**	**11.0**	Lithuania	11.0	Lithuania	4.4
2.	Latvia	14.9	Sweden	7.6	**Estonia**	**8.9**	Sweden	4.2
3.	Lithuania	14.5	Finland	7.5	Finland	8.0	Denmark	4.1
4.	Finland	13.4	Latvia	7.4	Sweden	7.2	Finland	3.9
5.	Norway	12.6	Lithuania	7.3	Denmark	7.1	**Estonia**	**3.7**
6.	Sweden	12.4	Denmark	7.0	Norway	6.8	Norway	3.4
7.	Denmark	11.6	Norway	7.0	Latvia	4.1	Latvia	1.5

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. Estonia ranks second for mortality from kidney cancer in men. The rates between the Baltic countries are very different with Lithuania having the highest rate of all countries compared and Latvia having the lowest rate with a very small value. The rates for the Nordic countries are very similar between each other.

For women Estonia ranks fifth. As for men, for women in the Baltic countries, the rate for Lithuania is a bit higher than that for Estonia, while the rate for Latvia ranks last in the whole comparison with its value being less than a half of any other country. The rates for the Nordic countries do not show much variation.

For Estonia, the relatively high mortality rates for kidney cancer reflect the huge increase in incidence over the recent years.

Mortality in relation to incidence. In Figures 6.22 and 6.23 the graphs for cancer of the kidney for men and women are presented. The positions of the countries on both graphs are rather similar. For both sexes, Estonia stands out for both high incidence and mortality rates. The other countries have fairly similar incidence rates, whereas mortality rates are quite different.

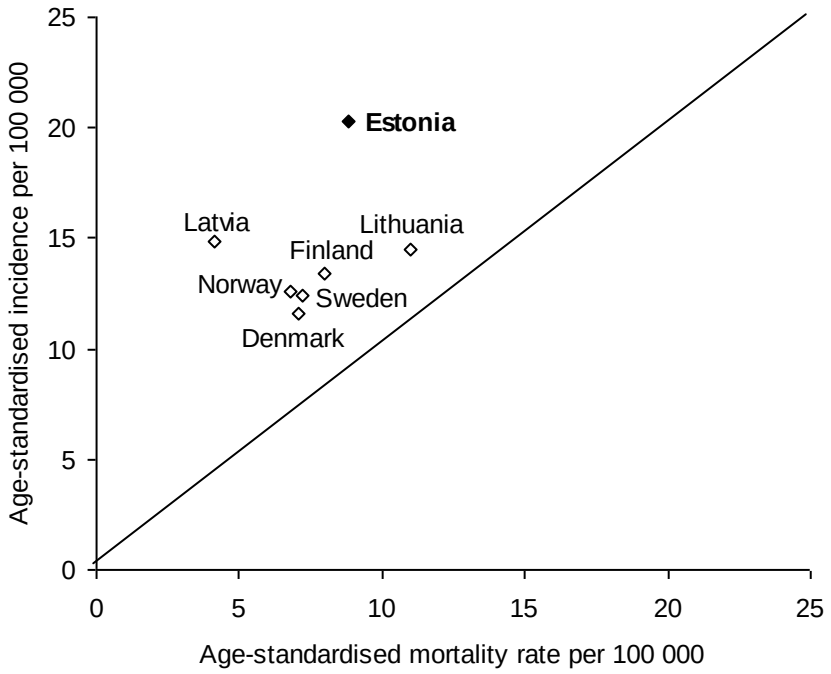

Figure 6.22. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the kidney in men, the average for 1993–97, all ages. Source: EUROCIM and WHO Mortality Databank

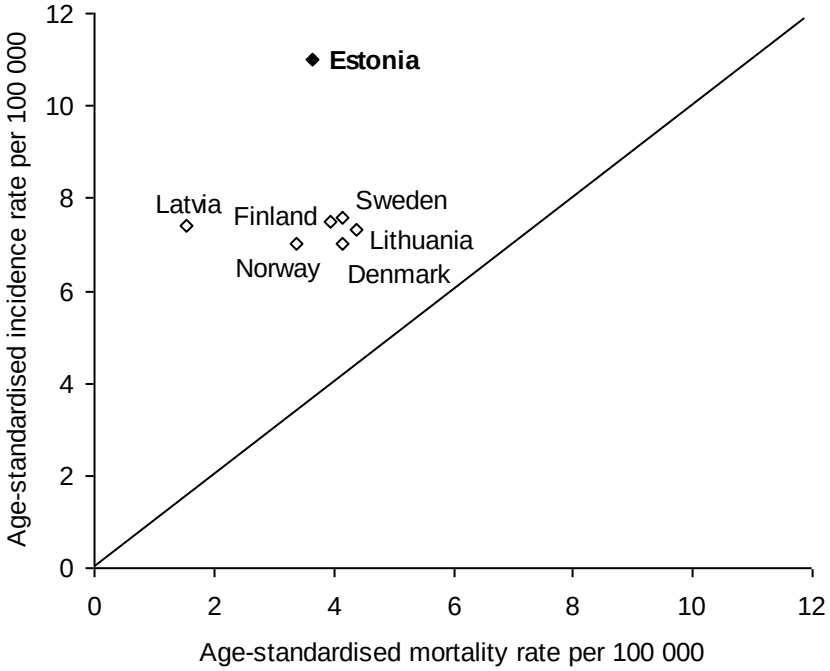

Figure 6.23. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the kidney in women, the average for 1993–97, all ages. Source: EUROCIM and WHO Mortality Databank

6.4.14 Cancer of the bladder

The rankings of the Nordic and Baltic countries for incidence and mortality rates for cancer of the bladder are presented in Table 6.26.

Incidence. The ranking of the countries for incidence rates of bladder cancer is very similar between the sexes. Estonia ranks fifth in this comparison for both sexes and is closely followed by the incidence rates for the other Baltic countries. The Nordic countries all have higher rates than the Baltic countries with Denmark having a considerably high rate for both sexes. The incidence rates for Denmark for both men and women are about a quarter higher than the rates of Norway which ranks second and twice as high as the rate of Estonia.

Smoking is by far the main known risk factor for bladder cancer. Yet it only explains some of the differences in incidence rates between those countries like the high incidence rates for Denmark for both men and women as compared to other Nordic countries. One would expect the incidence rates for this cancer in men in the Baltic countries to be higher than in the Nordic contries as smoking is more prevalent in the Baltic countries. As is seen from Table 6.25, this is not so. One explanation to this would be underdiagnosing of bladder cancer in Estonia and other Baltic countries. In the case of bladder cancer, borderline lesions are common and often underdiagnosed (Swerdlow *et al.* 2001). Patients presenting to the general practitioners with microhematuria are often not referred to specialists and thus can not be diagnosed with bladder cancer at an early stage (Timberg G 2004 – personal communication). A sign of underdiagnosing early bladder cancer is the fact that the *in situ* cancers are practically not diagnosed. It may be argued that bladder cancers are diagnosed later in their development, but the may remain undiagnosed especially in older patients.

It is difficult to see to what extent, if at all, this underdiagnosing affects the rates in women in the Baltic countries because all the rates for women in these countries are relatively small. The data points for all the Baltic countries are positioned below the Nordic countries as one would expect according to the smoking pattern of women in these countries.

Table 6.26. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Age-standardised rates per 100 000, cancer of the bladder in men and women, the average for 1993–97, all ages.*

Source: EUROCIM and WHO Mortality Databank.

Rank position	Incidence				Mortality			
	men		women		men		women	
	country	rate	country	rate	country	rate	country	rate
1.	Denmark	40.8	Denmark	11.5	Denmark	14.6	Denmark	4.1
2.	Norway	31.1	Norway	7.9	Lithuania	11.9	Norway	2.8
3.	Sweden	27.1	Sweden	7.2	Norway	9.5	Sweden	1.9
4.	Finland	25.2	Finland	5.1	**Estonia**	**8.1**	Lithuania	1.7
5.	**Estonia**	**20.1**	**Estonia**	**4.5**	Sweden	6.9	Finland	1.5
6.	Lithuania	19.2	Latvia	3.4	Finland	6.5	**Estonia**	**1.4**
7.	Latvia	19.1	Lithuania	3.3	Latvia	4.5	Latvia	0.8

* The ICD codes used to define cancer sites are summarised in Table 5.1.

Mortality. Estonia ranks fourth for bladder cancer mortality in men. The Baltic/Nordic divide that was seen for bladder cancer incidence in men, is not seen for mortality. The rates of the Baltic countries are scattered across the distribution with Lithuania having a rather high rate while the rate for Latvia is the lowest of all countries compared.

For women all the mortality rates for bladder cancer are very small, with an exception of Denmark having a rate that is considerably higher than in the other countries. Estonia ranks sixth.

Mortality in relation to incidence. In Figures 6.24 and 6.25 incidence and mortality rates are shown for cancer of the bladder in men and women. For men it is seen that the Baltic countries lie on a horizontal line, indicating that for a similar incidence the mortality rates are different with Latvia having the lowest and Lithuania having the highest rate. The Nordic countries except Denmark are situated above the Baltic countries which indicates that incidence is higher for these countries while mortality is rather similar. Differently from the rest of the Nordic countries Denmark stands out for a much higher incidence and mortality rate.

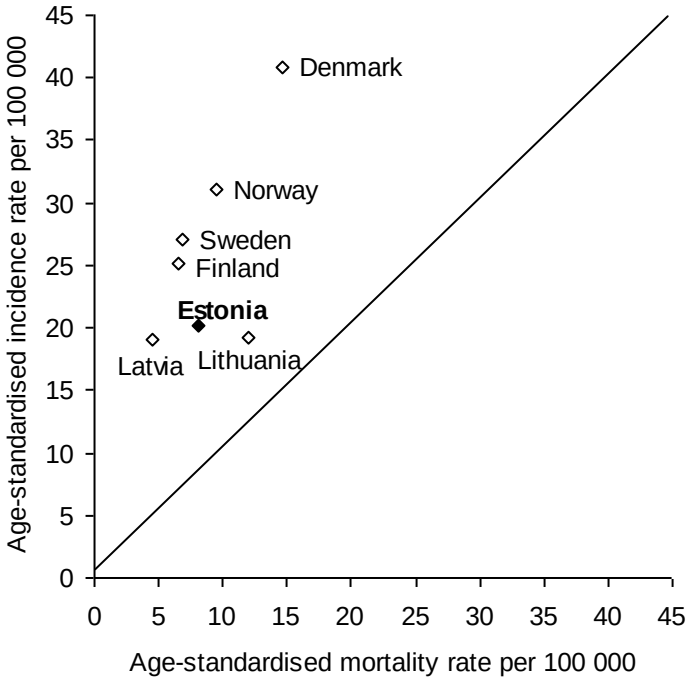

Figure 6.24. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the bladder in men, the average for 1993–97, all ages. Source: EUROCIM and WHO Mortality Databank

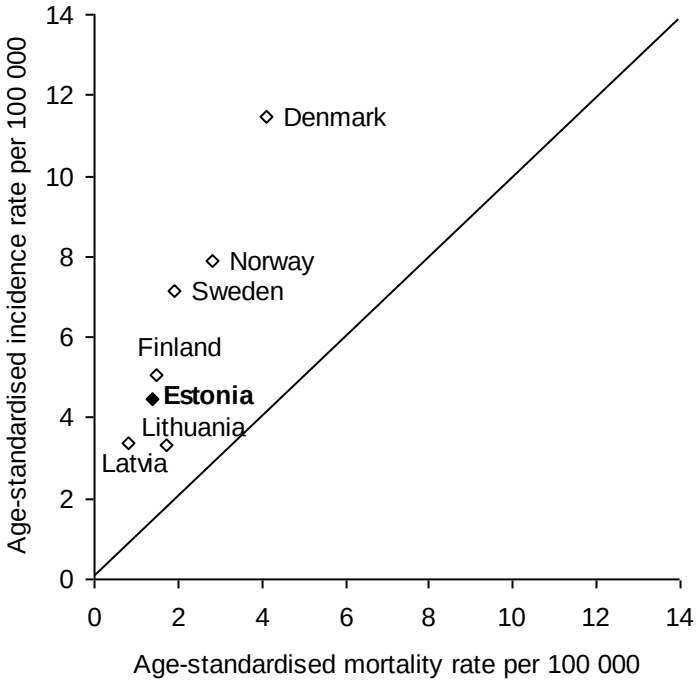

Figure 6.25. Comparison of cancer incidence and mortality rates for the Nordic and Baltic countries. Incidence/mortality rates per 100 000, cancer of the bladder in women, the average for 1993–97, all ages. Source: EUROCIM and WHO Mortality Databank

6.5 Discussion

In the following section some explanations for differences in the incidence and mortality of cancer in Estonia in comparison with other Baltic and the Nordic countries are presented for some specific cancer sites which stand out as having interesting distribution patterns. The discussion is focused on finding out how far the differences in cancer incidence rates are attributable to differences in etiologic risk factors, as distinct from differences in diagnosing or cancer registration process. In case of cancer mortality, issues like changes in the underlying incidence of cancer or advances in cancer treatment leading to higher survival, have a role.

6.5.1 Risk factors

According to Doll and Peto (1981), the share of modifiable risk factors for cancers is around 75-80 %, and possibly more. By modifiable risk factors both external and internal environmental factors are considered, the last mentioned ones containing factors such as endogenous hormones for example. The following is a discussion of the role of risk factors to the variation of cancer incidence rates between the countries compared.

Smoking is the most important risk factor for a number of cancers, such as lung, larynx, oesophagus, pancreas, kidney, and bladder. Therefore, differences in the smoking patterns of comparison countries should by large explain the variation in the incidence rates for the named cancers. Some insight into the patterns of smoking in Estonia, including the results from a recent health survey (Leinsalu *et al.* 1998), was given in Chapter 5 Section 5.2.2.7. The following section gives some information about the smoking patterns in the Nordic and the Baltic countries.

The comparisons of the past smoking habits between the Nordic and the Baltic countries are not easy as smoking data for the Baltic countries for the past decades are not available. As an indirect measure of smoking prevalence in the past, percentages of all cancer deaths attributable to smoking from all cancer deaths in the Baltic and the Nordic countries for 1990 are presented in Table 6.27. These figures were abstracted from the publication of the work performed by Peto *et al.* (1994), which used a method based on estimates of the fraction of particular causes of death attributable to smoking.

Table 6.27. Percentage of cancer deaths attributed to smoking from all cancer deaths in the Baltic and Nordic countries in 1990.
Source: *Mortality from smoking in the developed countries, 1950–2000* (Peto et al. 1994).

Country	Cancer deaths attributed to smoking (%)					
	Men			Women		
	35–69	70+	Total	35–69	70+	Total
The Baltic countries						
Estonia	55	35	**48**	4	4	**4**
Latvia	55	32	**47**	5	4	**4**
Lithuania	55	32	**46**	3	5	**3**
The Nordic countries						
Denmark	45	36	**39**	23	14	**18**
Finland	44	39	**41**	4	5	**5**
Norway	32	22	**25**	11	5	**7**
Sweden	26	18	**21**	9	5	**7**

Looking at the total percentages for men, it is seen that these are higher in the Baltic than in the Nordic countries. The proportion of deaths attributed to smoking is similar in each of the Baltic countries. Among the Nordic countries, Denmark and Finland stand out with a relatively higher percentage of deaths attributable to smoking as compared to Norway and Sweden.

Comparing the age groups in men between the two groups of countries, in the 35–69 age group the proportion of deaths is much bigger in the Baltic than in the Nordic countries. In the 70+ age group, this pattern is not seen. Interestingly, in the 35–69 age group the rankings for countries for smoking-related cancer deaths are exactly the same as the rankings for lung cancer incidence.

For women the proportion of cancer deaths attributable to smoking is very low in the Baltic countries in general and similar across these countries as well as age groups. In the Nordic countries, in contrast, it varies considerably. The percentage is relatively low and similar to the Baltic countries in Finland for both age groups. It is somewhat higher in Norway and Sweden in 35–69 age group. In Denmark it is considerably high in relation to other countries especially in the 35–69 age group, but also in the 70+ age group.

It can be concluded that smoking patterns between the Baltic and the Nordic countries have a big sex-difference. Men have a high smoking prevalence in the Baltic countries compared to the Nordic countries. For women this difference is in the

opposite direction. Smoking among women is less prevalent among the Baltic countries than among the Nordic countries, and although this difference is perhaps not so big as in men, Denmark stands out for an exceptionally high rate even compared to other Nordic countries.

Looking at the incidence of such frequent smoking-related cancers such as lung, larynx, oesophagus, pancreas, kidney, and bladder, one would expect these to be higher in the Baltic than in the Nordic countries. Indeed, Estonia together with the other Baltic countries stand out for high rates of all these cancers except bladder cancer. The rate for kidney cancer for men in Estonia deserves a special mention as this is considerably higher than in the other Baltic countries. Possible reasons for low incidence of bladder cancer in the Baltic countries as well as high incidence for kidney cancer in Estonia will be discussed below.

Thus the differences in cancer incidence rates of all but one smoking-related cancers in men between the Baltic and the Nordic countries are real, i.e. attributable to smoking differences, at least to a large extent, and not so much due to other factors influencing cancer incidence, such as listed in the introductory section of this discussion. In case of some of these malignancies such as cancers of larynx, oesophagus, and pancreas, alcohol consumption apparently causes an additional increase in incidence rates. Although the data on alcohol consumption for the Baltic countries for the last decades are very scarce, (World Health Organisation Health for All Database 2003) the greater use of alcohol by men in the Baltic countries as compared to the Nordic countries is evident.

Next I will take a look at the distribution patterns of smoking related cancers in women. First of all, for lung cancer, but also for other smoking related cancers, the incidence patterns of Estonia and the other Baltic compared to the Nordic countries reflect the differences in smoking patterns for women in these two groups of countries. That is, the cancer incidence rates are lower in the Baltic countries for most of the smoking-related cancers. This is not the case, though, for kidney cancer for which Estonia ranks first with a relatively high rate compared to all other countries, a similar finding to that in men. This can not be explained by smoking as a risk factor for kidney cancer and will be discussed below.

In the case of stomach cancer, very high incidence rates are seen for men and women in Estonia, but similarly in other Baltic countries. These are attributable to high prevalence of *H.pylori* infection as an underlying risk factor. The differences in the

prevalence rates for *H.pylori* infection between the Baltic and the Nordic countries with the Baltic countries having much higher rates were presented in Chapter 5 Section 5.2.2.2.

Among cancers of female genital organs, the incidence rate for cancer of the cervix uteri is high in Estonia and Lithuania. This is a reflection of the relatively high prevalence rate of specific high risk human papillomaviruses. HPV serology at the population level in the some of the Nordic and Baltic countries has only been studied for HPV type 16 seroprevalence (Lehtinen *et al.* 2000), that is present in about 50% of invasive cervical cancer. In Estonia the seroprevalence is 1.5 times higher than in Finland. Mass–screening programmes for this cancer exist in all Nordic countries, but not Baltic countries. A relatively low incidence rate for cervical cancer in Latvia is probably a result of misclassification of cervical cancers as cancers of corpus uteri as will be discussed in Section 6.5.3.

6.5.2 Diagnosing and screening

Differences in the diagnostic practices between the countries compared can lead to differences in cancer incidence rates. Most importantly, these differences can arise from differences in the availability of diagnostic facilities and technologies. The existence of a screening programme also alters the rates. In the following section, differences in diagnostic activities and screening between countries are discussed.

In the case of prostate cancer, screening and early detection can identify many of the silent tumours in the population (Hsing *et al.* 2000). For this tumour, the Nordic countries have very high values. This is a result of diagnosing latent tumours by more advanced diagnostic techniques such PSA determination and the increasing frequency of transurethral resections in these countries. In that respect Estonia, at least to some extent, also falls in line with the Nordic countries. In Estonia PSA determination and transurethral resections have become available over the recent years and are rather widely used (Aareleid 2004). As for the other two Baltic countries, it can be only speculated that these do not perhaps exercise such diagnostic activity, which is reflected in the lower rates of prostate cancer for these countries as compared to the others. Another explanation would be incomplete registration of prostate cancer by the Latvian and Lithuanian cancer registries.

The remarkably high rate for kidney cancer in case of Estonia, seen in both sexes, is difficult to interpret. Although smoking is an important known risk factor for this cancer, the rates for Estonia can not be explain by smoking entirely, especially the high rate in women in Estonia. There is some evidence that the excess of kidney cancer results from increase in diagnostic activities. The kidney cancer incidence trends in the Nordic countries in 1958–97 (data not shown), were rather stable for both sexes, with the rates similar to those of Estonia around 1985. In Latvia and Lithuania, an increase in incidence rates similar to that of Estonia, was seen. This gives further support to the role of modern diagnostic techniques increasing the kidney cancer incidence rates in Estonia, as these became available in the Baltic countries more recently than in the Nordic countries (Timberg G 2004 – personal communication). Perhaps the wider use of these in Estonia compared to Latvia and Lithuania explains Estonia's higher rates. Also, it may be speculated that lesions of borderline malignancy that would have never progressed to cancer are being detected and diagnosed as kidney cancers in Estonia.

As mentioned above, bladder cancer is an exception among the smoking-related cancers at least in men. Namely, all the Baltic countries have lower rates for bladder cancer in men than the Nordic countries. This may result from underdiagnosing the first symptoms of bladder cancer such as microhematuria are often misinterpreted by doctors in Estonia.

Finding out about the reasons for the differences of the incidence patterns for the urologic cancers in Estonia would certainly be a priority research area.

6.5.3 Registration artefact

Differences in registration of cancer cases between registries have to be of considerable size and not explained by other factors, to be detected. Knowing the main quality characteristics of all cancer registries involved in comparisons, but also problems with registration presented in the literature for any specific cancer site concerned, helps to uncover registration artefacts.

Registration problems for cervical cancer seem to be present in Latvia. Namely, a relatively low incidence rate for this malignancy in Latvia is most probably a result of misclassification of cervical cancers as cancers of corpus uteri because the incidence rate for this cancer in Latvia is the highest among the countries compared. This registration problem results from the fact that on some uterine cancer registrations it is

not specified, which part of the uterus is involved (Swerdlow *et al.* 1998) and these cases get registered as cancer of corpus uteri.

There seems to be an under registration of deaths from the cancers of pancreas and kidney for both sexes registered in Latvia, and to a smaller extent from cancer of the pancreas registered in Estonia as the mortality rates are relatively low when compared to respective incidence rates for those cancers that have a fairly short survival in general.

For cancer of the corpus uteri, Latvia has the lowest mortality rate (while the incidence rate for this cancer is the highest among the countries compared). This is a sign of incomplete cancer mortality registration.

For cancer of the ovary Latvia has the lowest mortality and this finding, especially in the context of Latvia having one of the highest rates for incidence, refers to problems in mortality registration completeness.

The deficits in mortality registration detected by this study were in great majority adherent to the Latvian cancer data. It is therefore possible to suggest that in addition to cancer registration problems in Latvia (Parkin *et al.* 2002), there are also problems in cancer mortality registration. No registration artefacts were detected in the cancer data provided by the Nordic countries, or Lithiuania. As for Estonia, these only became apparent for registration of mortality from cancer of the pancreas.

6.5.4 Treatment and survival

Advances in treatment of a specific cancer site can increase survival. An example of such situation from the current study would be breast cancer. The difference between incidence and mortality is much bigger in the Nordic countries (not so much in Denmark), as compared to the Baltic countries. This difference is attributed to differences in survival, which is higher in the Nordic countries than in the Baltic countries (Quinn *et al.* 1998).

6.6 Conclusions

This chapter presented the cancer incidence and mortality rates for men and women for Estonia and the neighbouring countries, showing Estonia's position in relation to other countries. It is seen that in men both cancer incidence and mortality are relatively high

in Estonia as it ranks first for all cancer sites combined as well as such frequent sites as stomach and lung. Some other smoking-related cancers also have rather high rates in men in Estonia. This finding reflects the uneven distrubution of underlying risk factors between the countries compared, with relatively high smoking (in men) and H. Pylori prevalence in Estonia.

Some of it can be attributed to other issues such as diagnosing, registration, or treatment.

Chapter 7. Ethnic differences of cancer incidence in Estonia

In this chapter a study looking at ethnic differences of cancer incidence between Estonians and Russians in Estonia is presented. These analyses illustrate how the ECR cancer data can be used in epidemiological research.

This chapter defines the term 'ethnicity' as used in epidemiological studies. It then looks at the ethnic composition of the population in Estonia. It presents data on differences in the health status and cancer incidence in the two main ethnic groups in Estonia: Estonians and Russians.

7.1. Defining ethnicity

Ethnicity is "a complex construct of, assured biology, but also culture, language, religion, and importantly for epidemiologists, distinct health beliefs and health behaviours" (Chaturvedi 2001). In contrast to ethnicity, the term "race" has been used in biomedical literature, which implies a distinction between genetic subgroups of people. However, unlike ethnicity, it does not take into account for cultural differences. The use of these two terms in biomedical literature is often blurred. However, ethnicity should be preferred.

It should be noted that ethnic differences in disease may at least in part be explained by socio-economic differences (Smith 2000). To be able to explore this, data on both are required.

It is important to study the effect of ethnicity on a disease as demonstration of ethnic differences can provide distinct aetiological clues (Chaturvedi 2001). Information on differences of cancer occurrence between ethnicities can help to identify new ways to reduce the burden of cancer (Parker 1998). Migrant studies of one ethnic group to a new location have also proved valuable in establishing disease etiology (Chaturvedi 2001; Muir 1996) as migrants bring their inherent disease risk to a new country.

Definition of ethnicity in Estonia. The concept of classifying the population of Estonia by ethnicity is one that partly reflects a Soviet tradition which is somewhat different to that used in the West. It is a complex construction that reflects perceived differences in culture and tradition. It is a self-referred entity that is first of all created in the families. Families themselves decide on the ethnicity of their family members. For example, in case the mixing of Estonians and Russians through marriage, the parents decide on the ethnicity of their offspring. This usually depends on the language spoken in the family as well as cultural tradition. Ethnicity is recorded in population Census as "nationality" although the true meaning is broader as explained by Chaturvedi (2001). The reason that it is not recorded as ethnicity, may be the problem of translation into Estonian as the word "ethnicity" is not really used in the Estonian language in the context of routine statistical data collection or epidemiology.

Estonian and Russian ethnic groups in Estonia differ from one another in several aspects such as historic and socio-economic background, language and culture. As most of the Russians in Estonia are migrants or children of migrants, the differences between Estonian and Russian ethnic groups derive from differences in these two countries in the past. In the following sections some more information of the ethnic distribution of the Estonian population is presented to help clarifying this issue.

7.2. Ethnic composition of Estonian population

Brief historical overview. Between 1918 and 1940, ethnic Estonians constituted almost 90% of the Estonian population. Russians have formed the second largest ethnic group over time (see Table 1.3). As described in Chapter 1 Section 1.2.2, after loosing its independence in 1940, in Estonia big waves of inward and outward migration occurred, changing the ethnic composition of its population considerably.

The ethnic composition of Estonia between 1959 and 2000 is presented in Table 7.1. It can be seen that the balance between the Estonian and Russian populations has changed over time. The proportion of Estonians in the population fell between 1959 and 1989 as the proportion of Russians increased following a big in-migration of the Russian population. In the early 1990s the situation reversed, as many Russians left after Estonia regained its independence in 1992.

Table 7.1. Ethnic composition of the population in 1959, 1970, 1979 and 1989 (%). Adapted from: Population of Estonia by population censuses (1995) and *Statistical yearbook of Estonia* (2003)

Nationality	**Year**				
	1959	**1970**	**1979**	**1989**	**2000**
Estonians	74.6	68.2	64.7	61.5	67.8
Russians	20.1	24.7	27.9	30.3	25.5
other	5.3	7.1	7.4	8.2	6.1
unknown	–	–	–	–	0.6

The distribution of Russians living in Estonia is distinct. The distribution of Russians living in Estonia is distinct. The geographical distribution is presented in Figure 7.1. It is seen that they are mainly situated in the North-Eastern areas of Estonia, adjacent to the border with Russia. The county of Kohtla-Järve in the North-East, as well as the towns of Narva and Kohtla-Järve, are predominantly inhabited by Russians. The majority of Russians live in the cities (93%) (*Population and Housing Census. Population de facto and usual resident population, population sex and age structure I.*), while among ethnic Estonians this percentage is much lower (56%). The two cities in the North-East, Narva and Kohtla-Järve, are predominantly inhabited by Russians.

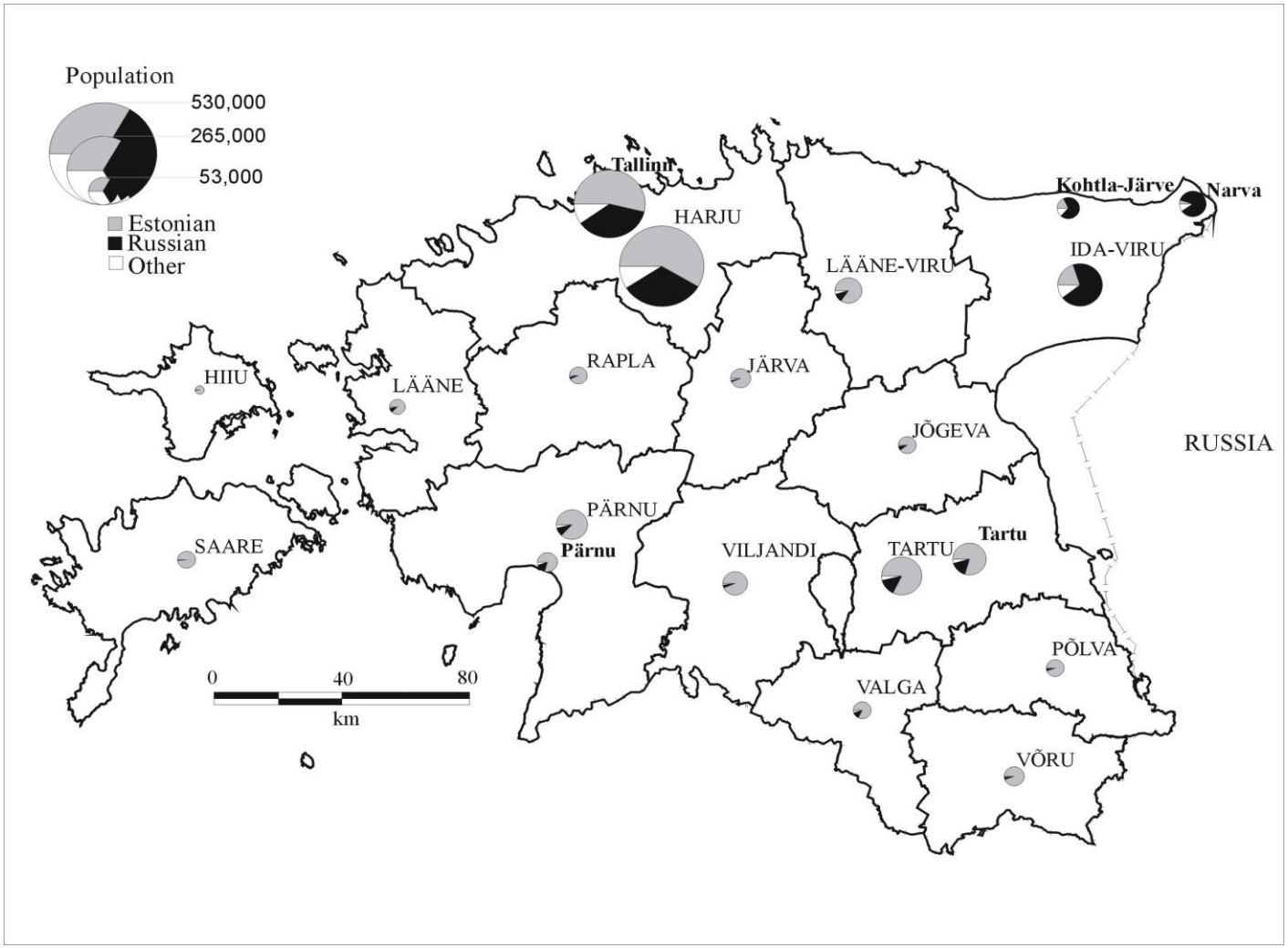

Figure 7.1. Map of main ethnic groups in Estonia by counties and five major cities.
Source: (Statistical Office of Estonia 2004)

The distribution of Estonian population in 2000 by main ethnic groups, age groups and sex is presented in Table 7.2. It is seen that the distributions of Estonians and Russians in each age group and sex are rather similar. However, in the oldest age group, the proportion of Russians is somewhat lower in both sexes than in younger age groups. This partly reflects the demographic situation before the World War II, where the Estonian population largely consisted of Estonians.

Table 7.2. Distribution of Estonian population by main ethnic groups, age groups and sex in the year 2000. Source: *Population and Housing Census. Population de facto and usual resident population, population sex and age structure I.*

Age group	Sex	Total population	Estonian		Russian		Other ethnic nationalities		Ethnic nationality unknown	
			number	%	number	%	number	%	number	%
Total	**M**	631 851	432 525	68.5	156 963	24.8	38 210	6.0	4 153	0.7
	F	738 201	497 694	67.4	194 215	26.3	42 526	5.8	3 766	0.5
0–19	**M**	812 194	562 866	69.3	200 693	24.7	43 815	5.4	4 820	0.6
	F	910 100	622 323	68.4	235 634	25.9	47 801	5.3	4 342	0.5
20–44	**M**	233 497	156 876	67.2	60 463	25.9	14 280	6.1	1 878	0.8
	F	240 977	159 432	66.2	65 850	27.3	14 323	5.9	1 372	0.6
45–64	**M**	150 714	98 036	65.0	38 439	25.5	13 084	8.7	1 155	0.8
	F	187 024	118 216	63.2	53 364	28.5	14 473	7.7	971	0.5
65+	**M**	67 032	47 219	70.4	14 251	21.3	5 209	7.8	353	0.5
	F	138 125	95 368	69.0	33 540	24.3	8 429	6.1	788	0.6

In Table 7.3 the distribution of the Estonian and Russian ethnic groups in the year 2000 by country of birth is presented. It is seen that the Estonian ethnic population was predominantly born in Estonia. In contrast, about half of the Russian population is born in Estonia, nearly a half in Russia, and about 5% in other countries. Looking at the sex distribution of the Russian ethnic group in Estonia by country of birth, it is seen that about two thirds of the Russian men are born in Estonia, while in women it is about a half. Unfortunately it is not known from which part of Russia the immigrants came from.

Data on the distribution of the population by ethnicity and country of birth by age is not available from the routine population census tabulations. However, it is very probable that the proportion of ethnic Russians born in Estonia is greater in the youngest age groups.

Table 7.3. Distribution of total population of Estonia, Estonian and Russian ethnic groups in Estonia by sex and country of birth in the year 2000. Source: *Population and Housing Census. Citizenship, nationality, mother tongue and command of foreign languages II*.

Ethnicity	Total	Country of birth					
		Estonia		Russia		other country	
		Number	%	Number	%	Number	%
Total population							
Estonian	930219	894499	96.2	28970	3.1	6750	0.7
Russian	351178	187046	53.3	146298	41.7	17834	5.1
Males							
Estonian	432525	418209	96.7	11172	2.6	3144	0.7
Russian	156963	92740	59.1	56031	35.7	8192	5.2
Females							
Estonian	497694	476290	95.7	17798	2.4	3606	1.9
Russian	194215	94306	48.6	90267	46.5	9642	5.0

7.3. Ethnic differences in health in Estonia

The following is an overview of published studies that have looked at ethnic differences in health and lifestyle in Estonia. The summary of findings is presented in Table 7.4.

During the Soviet time the issues of ethnicity in Estonia were little studied. There is only one study, published in Russian (Rahu 1977), which looked at cancer rates in Estonians and Russians, focussing on stomach cancer. It concluded that in 1968–1971, the Russian/Estonian ratio of age-adjusted incidence rates was 1.9–2.0 for the urban and 1.7 for the rural population.

In the monograph describing cancer incidence and mortality in Estonia (Thomson *et al.* 1996), the pattern of cancer incidence in Estonia by geographical areas is presented and characterised. Risk ratios with 95% confidence intervals were studied for fifteen counties and five towns. According to this publication, for a number of cancer sites geographical variation in Estonia was evident. For all cancers (excluding skin) the Estonian variation was 1.4–fold between the highest and the lowest of the twenty geographical locations studied. Among other findings in the regional variation of cancer incidence, for cancers of stomach, rectum, and lung, the rates were higher than the Estonian average in the North-Eastern cities.

Table 7.4. Studies of ethnic differences in health in Estonia

Author(s) and year of publication	Aspects of health/ lifestyle studied	Main findings
Rahu (1977)	stomach cancer	In 1968–1971 the Russian/Estonian ratio of

	incidence	age-adjusted incidence rates was 1.9–2.0 for urban and 1.7 for rural population.
Thomson *et al.* (1996)	cancer incidence and mortality	Cancer incidence in Estonia varies, being higher for a number of sites in areas that are predominantly inhabited by Russians.
Leinsalu (2002)	self-rated health	Russians have more self-rated poor health when compared to Estonians.
Pärna *et al.* (2002)	smoking patterns	No difference in smoking patterns of Estonians compared to non-Estonians aged 30–59.
Aluoja *et al.* (2004)	depression	Compared to Estonians, depressiveness was more common in Russians and other ethnic groups.
Koupilova *et al.* (2000)	birth weight and preterm birth	Birth weight of babies of non-Estonian mothers is lower and risk of preterm birth is higher compared to babies of Estonian mothers.
Kunst *et al.* (2002)	morbidity, mortality, and health-related behaviours	Russians more often report mental problems, have higher mortality, which is seen in nearly all causes, especially alcohol poisoning and homicide.
Leinsalu *et al.* (2004)	mortality and life expectancy	Mortality in Russians is higher than in Estonians. Ethnic differences between Estonians and Russians have increased from 1989 to 2000. The biggest differences were found for some alcohol related causes of death.

The Estonian Health Interview Survey (Leinsalu *et al.* 1998a) conducted in 1996, was the first large-scale survey about the health status of the population of Estonia. It consisted of a random sample of Estonian population aged 15−79, It serves as a comprehensive study looking at important aspects of health and lifestyle. Several research papers have been published that use data from this survey.

Using the data from the Estonian Health Interview Survey, an analysis was made of self-rated health by eight main dimensions of the social structure: urban/rural residence, marital status, education, ethnicity, economic activity, main occupation, and income (Leinsalu *et al.* 2002). The study revealed that, among other factors, Russian nationality was one of the most influential factors underlying poor health. In a logistic regression model, when controlled for all other dimensions of the social structure (urban/rural residence, marital status, education, economic activity, main occupation, and income) and age, Russian men had higher odds of reporting poor self-rated health than Estonian men, OR=1.49 (95%CI 1.16–1.92), and Russian women reported more poor self-rated health than did Estonian women OR=1.77 (95%CI 1.36–2.29). When expressed in terms of population attributable risk, Russian ethnicity was responsible for 19.1 % of "avoidable poor health" in men and 18.9% in women.

Using the Estonian Health Interview Survey, patterns of smoking in Estonia have been described and analysed (Pärna *et al.* 2002). This paper studied the subpopulation of respondents aged 30–59 and revealed, among other findings, that the smoking pattern was similar for non-Estonians compared to Estonians for men (prevalence odds ratio POR=1.01, 95% CI 0.68–0.50) as well as women (POR=0.76 95%CI 0.55–1.05) when adjusted for other social variables (age, residence, marital status, education, income, employment).

The prevalence and socio-demographic correlates of depression in Estonia have been investigated (Aluoja *et al.* 2004) based on the data from Estonian Health Interview Survey. Respondents completed a self-rating scale of depression and anxiety. The study found that depressiveness was more common in ethnic groups other than Estonian (majority of whom are Russian). Compared to Estonians, the odds ratio of depressive symptoms in Russians was 1.81 (95%CI 1.45–2.25) when mutually adjusted for sex, age, marital status, residence, education, income, economic activity and occupation.

Social variation in birth weight and length of gestation in Estonia in 1992–1997 has been studied by Koupilova *et al.* (2000). This study was based on the data of the Estonian Medical Birth Registry. Ethnicity along with maternal education and marital status were all independently related to the mean birth weight and the risk of preterm birth. Mothers of other than Estonian ethnicity (of whom the majority are Russians) had lighter babies (on average 77 grams (95%CI 71–84)) and slightly higher risk for preterm birth, OR=1.17 (95%CI 1.09–1.25) compared to Estonian mothers, when adjusted for gestational age, smoking, and other social variables such as mother's education and marital status.

A report on social inequalities in health in Estonia was jointly prepared by the Estonian Ministry of Social Affairs and the World Bank (Kunst *et al.* 2002). This was compiled as a result of a large study that utilised the data of several health surveys and health-related databases (mortality registry, mortality database, Health Insurance Fund database). Concerning morbidity, this study found that Russians more often report mental health problems, but they equally often report physical health problems as compared to Estonians. Russians also have higher mortality than Estonians, especially among men aged 15 to 39 years. Regarding causes of death, Russians were found to have higher mortality from nearly all causes of death, and especially from alcohol poisoning and homicide. The study also found that mortality differences between Estonians and Russians increased among both men and women and for nearly all causes

of death between 1987–1990 and 1999–2000. These findings were not adjusted for other social variables.

A recent study by Leinsalu *et al.* (2004) examined the change in ethnic differences in mortality in Estonia between 1989 and 2000. It compared two unlinked cross sectional census based analyses. Total and cause-specific mortality was analysed for ethnic Estonians and Russians, using the national mortality database. The study found that Russians have higher mortality in Estonia for almost all selected causes of death. In the period 1989–2000, ethnic differences in life expectancy increased from 0.4 years to 6.1 years among men and from 0.6 years to 3.5 years among women. The study found that the ethnic differences have increased over time. Regarding age, Russians had higher mortality than Estonians from age 40–45. As for cause of death, Russians had significantly higher mortality from stomach and lung cancer, chronic respiratory diseases, alcohol poisoning, and homicide, and significantly lower mortality from infectious diseases, ischaemic heart diseases (men only), and transport accidents (men only). The biggest differences were found for some alcohol related causes of death (alcoholic liver cirrhosis, alcohol poisoning, homicide, especially in 2000, with Russians having higher mortality than Estonians.

To conclude from the results of the studies that have looked at ethnic differences in health and lifestyle in Estonia, these exist for a number of conditions, with the Russian ethnic population often having worse outcome for the variables studied. When studies have adjusted for socio-economic, these differences still persist. This suggests that the differences in health are associated with some correlate of ethnicity unrelated to socioeconomic circumstances.

7.4 Cancer occurrence in Russia compared to Estonia

The focus of this chapter is on differences in cancer incidence and mortality between Estonians and Russians living in Estonia. However, to be able to better interpret the results of the current study, an overview of cancer incidence and mortality pattern in Russia is essential. It is difficult to obtain data for this kind of analysis, as for example, available data from EUROCIM (2001) and *Cancer Incidence in Five Continents volume VIII* (Parkin *et al.* 2002) contain Russian data as represented by only one cancer registry, the St. Petersburg Cancer Registry.

In the following sections an overview of cancer incidence and mortality is presented, comparing Estonia and Russia in 1995, based on the estimates for cancer incidence and mortality in Europe in 1995 (Bray *et al.* 2002). The cancer rates were standardised using the World population. Some comments on data quality should be made, particularly concerning cancer incidence data from Russia as there is no population-based cancer registration that covers the whole country. Bray *et al.* used indirect methods to estimate cancer incidence in Russia from national mortality data available from the WHO. This method was explained in Chapter 6 Section 6.1 and as commented in that section, it lacks precision. It also means that regrettably incidence and mortality rates are not really independent.

Resulting from the quality of these data, the mortality differences are more valid and I will start by looking at these. Cancer mortality rates in men between Estonia and Russia were very similar, with Estonia having a mortality rate of 302.8 and in Russia 308.8 per 100 000. The results for cancer mortality for specific sites in men are presented in Figure 7.2. It is seen that a number of sites have differences in mortality rates. Cancer mortality is higher in Russia for a number of sites such as oesophagus, stomach, larynx. In contrast, it is higher in Estonia for cancers of pancreas, prostate, and kidney.

For women the total cancer mortality is slightly higher in Estonia (148.3 per 100 000) than in Russia (139.2 per 100 000). The results for cancer mortality for specific sites in women are presented in Figure 7.3. It is seen that there is less variation between these two countries than there is for men. Cancer of stomach has higher mortality in Russia, while cancers of breast, cervix uteri, ovary and kidney have higher mortality in Estonia.

The total incidence rates for men in Estonia and Russia were rather similar, 420.4 and 432.6 per 100 000, respectively. The incidence rates for specific sites for men are presented in Figure 7.4. It is seen that the differences in incidence are similar to those in mortality, except for lung cancer which has higher incidence in Russia than in Estonia.

For women the total incidence of cancer is slightly higher in Estonia than in Russia, the respective rates being 256.2 and 239.5 per 100 000. The results for selected sites for incidence in women are presented in Figure 7.5. The difference as compared to cancer mortality is that no variation is seen in the incidence of breast and cervix uteri cancers between the two countries.

To conclude about cancer incidence and mortality in Estonia and Russia, although the overall rates are similar, there is some variation regarding specific sites. For stomach cancer, both mortality and incidence rates for both sexes are higher in Russia. Common urological cancers such as prostate and kidney, and also several gynaecological cancers have higher mortality in Russia. In men, lung cancer has slightly higher incidence in Russia when compared to Estonia.

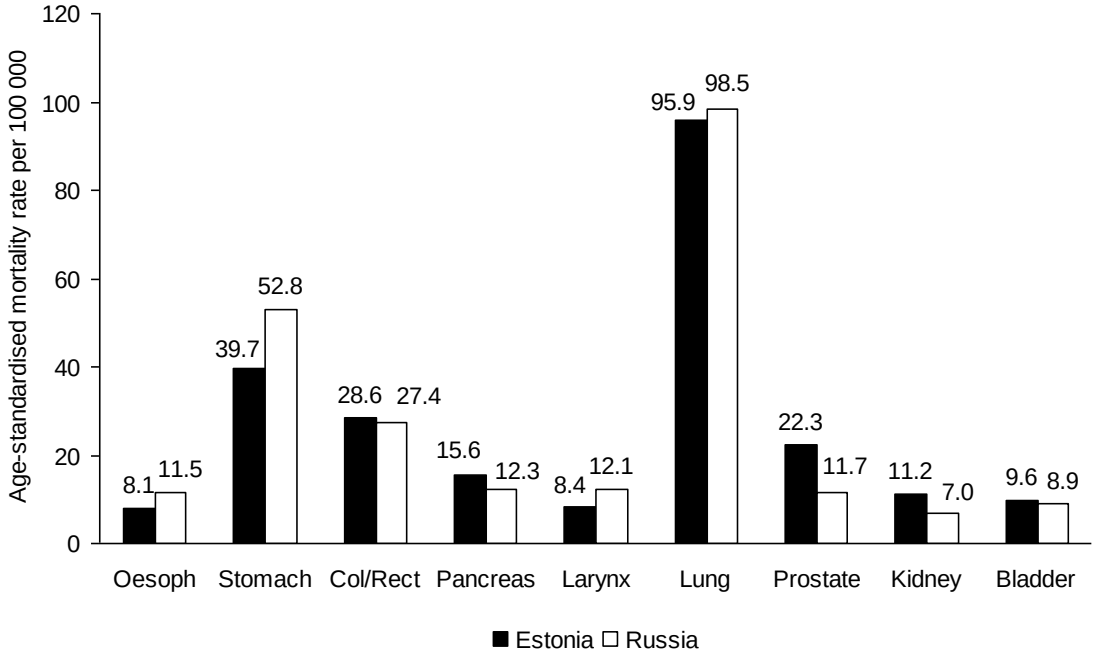

Figure 7.2. Comparison of cancer mortality rates between Estonia and Russia in 1995, men, selected sites. Mortality rates per 100 000, all ages. Source: Bray *et al*. 2002

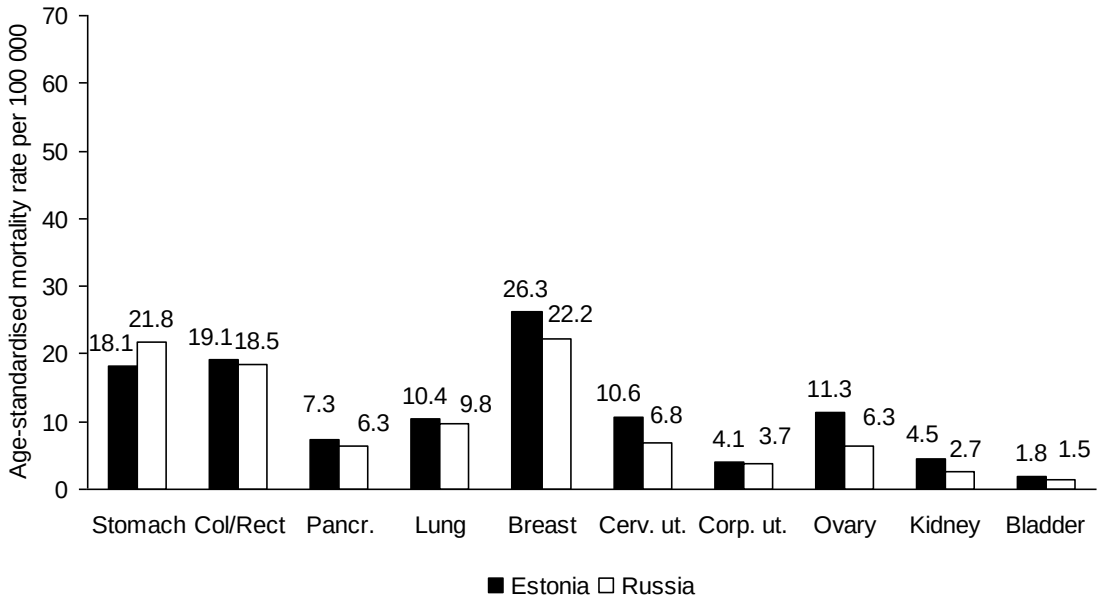

Figure 7.3. Comparison of cancer mortality rates between Estonia and Russia in 1995, women, selected sites. Mortality rates per 100 000, all ages. Source: Bray *et al*. 2002

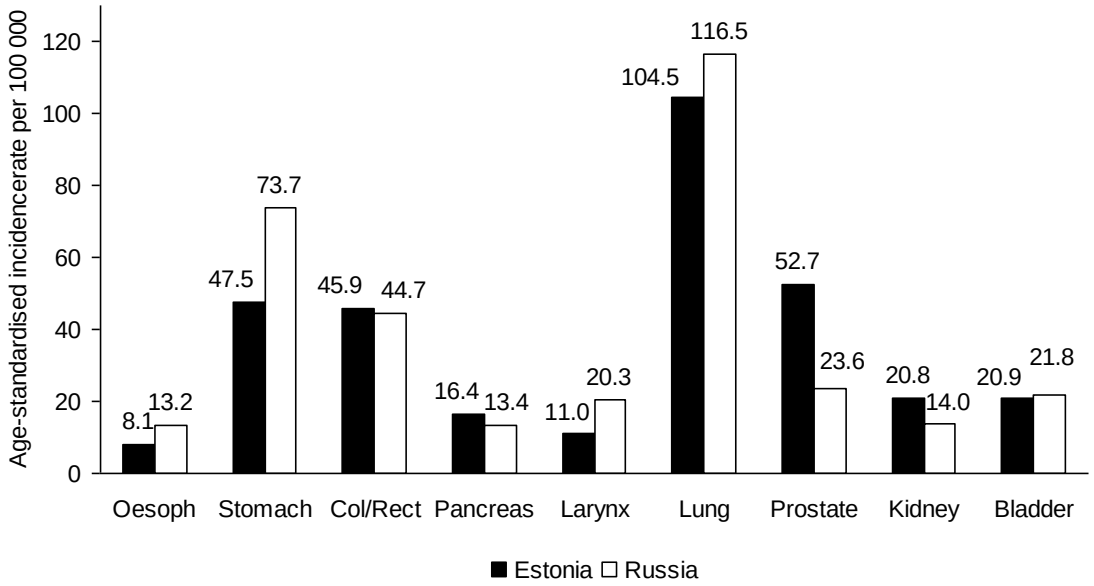

Figure 7.4. Comparison of cancer incidence rates between Estonia and Russia in 1995, men, selected sites. Incidence rates per 100 000, all ages. Source: Bray *et al*. 2002

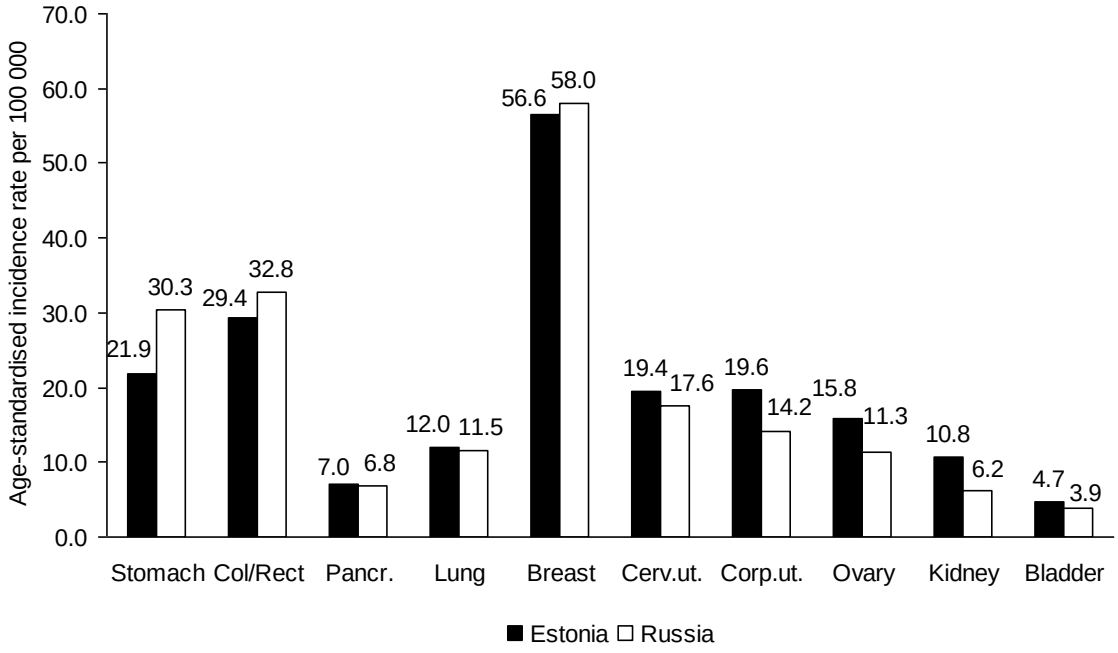

Figure 7.5. Comparison of cancer incidence rates between Estonia and Russia in 1995, women, selected sites. Incidence rates per 100 000, all ages. Source: Bray *et al*. 2002

7.5 Study of ethnic differences of cancer incidence in Estonia

7.5.1 Aims

To study ethnic differences in cancer incidence in Estonia, and to compare the situation before and after the profound political and economical changes in early 1990s.

7.5.2 Methods

Two cross-sectional unlinked census based cancer incidence analyses were performed. A similar approach has been used for studying ethnic differences in mortality in Estonia after the collapse of the Soviet Union (Leinsalu 2004). Cancer incidence data were obtained from the ECR in the form of individual level records, containing data on cancer diagnosis (ICD 4–digit code), year of diagnosis, patient's age in years, nationality, and sex. The ten selected cancer sites that were used in Chapters 5 and 6 of this thesis were also chosen for this study, as well as the aggregate of all cancer sites together excluding "other skin". Data were obtained for the years 1988–1990 and 1999–2000. The justification for selecting these years is that an attempt was made to obtain three years of cancer incidence data around both censuses under observation (1989 and 2000). At the time of the study the ECR did not have completed registration data for 2001 and for that reason it had to be excluded from the study.

Population denominators came from the population censuses of 1989 and 2000 (*Population and Housing Census. Population de facto and usual resident population, population sex and age structure I.*) The population denominators were available by year of age and were aggregated to form 5–year age groups.

Standardised cancer incidence rates (using European standard population, five–year age groups) were calculated for men and women for the aggregate periods 1988–1990 and 1999–2000, assuming that the ethnic distribution of the population at the census years was an unbiased estimate of the distribution for the peri–censal years. The absolute differences in standardised cancer incidence rates (SIR) for Estonians and Russians together with standard errors (SE) and p-values for SE-s in 1989 and 2000 were evaluated for both sexes. Also, differences in cancer incidence between Estonians and Russians in 1989 and 2000 were estimated for both sexes, using standardised rate ratios (SRR) with 95% confidence intervals. Data analysis was performed using STATA software. The statistical significance of the differences in SIR's was based on

calculating the standard error of each standardised rate, using the following formula (Breslow 1987):

$$SE(SIR) = \left(\sum_{j=1}^{J} w_j^2 d_j / n_j^2 \right)^{1/2}$$

A significance test of the absolute difference between SIR's was based on calculating a standard normal deviate in which the standard error of the difference was derived from the sum of the variance of the two individual SIR's. A p-value of <0.05 was considered statistically significant.

When comparing SRR's, the confidence intervals were based on the following formula (Breslow 1987):

$$SE \log SRR = \left\{ \frac{\sum_{j=1}^{J} w^2{}_j d_{1j} / n_{1j}^2}{\left(\sum_{j=1}^{J} w_j d_{1j} / n_{1j} \right)^2} + \frac{\sum_{j=1}^{J} w_j^2 d_{2j} / n_{2j}^2}{\left(\sum_{j=1}^{J} w_j d_{2j} / n_{2j} \right)^2} \right\}^{1/2}$$

where

w_j – standard weights in stratum
n_j – estimated population at risk in stratum
d_j – deaths observed in stratum
j – age-stratum

Data quality. The 1989 population census in Estonia was carried out in the framework of all-Union censuses and on the basis of all-Union programmes (*Population of Estonia by population censuses.*) No data about the coverage and/or data quality of this census is available. For the 2000 census, some quality estimates are available. For evaluating the coverage of the 2000 census and the quality of the census data, a post-enumeration sample survey was organised (*General information of 2000 Population and Housing Census in Estonia*.). It covered about 1% of the population and a stratified random sample of enumeration areas was drawn. Comparison of the census data and the data collected in the post-enumeration survey showed that the under-enumeration of the census was on an average 1.2%. Thus the coverage of the census was very high.

As for determining nationality, during the 1989 and 2000 censuses, it was recorded according to the statement of the person, i.e. self determined ethnic identity

(*Population of Estonia by population censuses*; *Population and Housing Census. Population de facto and usual resident population, population sex and age structure I*). If there was a dispute between parents of different nationality, then the mother's nationality was written as that of the child.

At the ECR, data about ethnicity have become less complete over the more recent years and are currently about 85% complete. As for the completeness and validity of registering nationality at ECR, it was shown by data quality studies in Chapter 4 Section 4.2.3.3 that nationality is recorded only in about one third of the medical case notes. However, according to the doctors filling in cancer notifications (Ole R 2004 – personal communication), if the respective pro forma about ethnicity is lacking or not completed in the medical case notes, they ask the patient about his/her ethnicity and record it on the cancer notification.

7.5.3. Results

There numbers of registered cancers that were studied are presented in Table 7.5, relating to all cancers registered at ECR in 1988–1990 and 1999–2000.

Table 7.5. Distribution by ethnicity of the numbers of registered cancers studied, 1988–1990 and 1999–2000.

Ethnicity	**1988–1990**		**1999–2000**	
	Number	**%**	**Number**	**%**
Estonian	9559	65.2	7331	61.7
Russian	3831	26.1	2620	22.1
Other	884	6.0	284	2.4
Missing	378	2.6	1632	13.8
Total	**14652**	**100.0**	**11867**	**100.0**

It is seen that the proportion of observations which have information about ethnicity missing has increased considerably between these two time periods. As for the later time period, 1999–2000, the finding of missing values for ethnicity of around 14% is consistent with the findings in Chapter 4 Section 4.3.2 where completeness of the data items at the ECR was presented for 1995–2000.

Numbers of cancers that the incidence rates are based on are provided in Tables 7.8 and 7.9.

The following is a description of changes of Estonian and Russian rates between 1988–1990 and 1999–2000.

Men. The respective changes for cancer incidence in men are presented in Table 7.6. It is seen that the total cancer incidence in Estonian men has increased while in Russian men it has decreased. These changes are statistically significant.

The rates for stomach and lung cancer have declined for both ethnic groups, whereas the decline for Russian men is larger compared to Estonian men, especially for lung cancer. Also, cancer of the pancreas has declined in Estonians, and cancer of the oesophagus has declined in Russians. The latter change is rather notable as in absolute values it has almost halved.

The increase of prostate cancer rates is seen for both Estonian and Russian men, whereas in Estonian men the increase is bigger. Small increases are also seen in the incidence of kidney and bladder cancers for both ethnic groups over time.

All the variations described for specific sites in men are statistically significant.

Women. Changes for cancer incidence in women between 1988–1990 and 1999–2000 are presented in Table 7.7. Cancer incidence in women has increased for both ethnic groups from 1988–1990 to 1999–2000, with both increases being statistically significant. Most importantly this change is caused by the increased incidence of breast cancer, which is more pronounced in Estonian women and yields statistical significance, while in Russian women it is smaller and not statistically significant.

Similarly to men, stomach cancer incidence is declining in both ethnic groups between 1988–1990 and 1999–2000, with the decline being statistically significant only
for Estonian women.

Table 7.6. Comparison of cancer incidence rates between 1988–1990 and 1999–2000, comparing Estonians and Russians. Age-standardised incidence rates (SIR) per 100 000 per year, all ages, men, for ten leading sites of cancer incidence in Estonia and all cancers.

Cancer	ICD–10	Estonians					Russians				
		1988–1990	1999–2000	Difference 1999–2000 to 1988–1990			1988–1990	1999–2000	Difference 1999–2000 to 1988–1990		
		SIR_1	SIR_2	$SIR_2–SIR_1$	SE	p-value	SIR_1	SIR_2	$SIR_2–SIR_1$	SE	p-value
Oesophagus	**C15**	7.1	7.2	0.1	1.22	0.940	13.1	7.3	-5.8	2.85	0.042
Stomach	**C16**	41.6	33.8	-7.8	2.78	0.005	72.2	55.3	-17.0	6.61	0.012
Colon	**C18**	16.6	23.6	7.0	2.07	0.001	24.6	23.4	-1.2	4.31	0.778
Rectum	**C19–21**	15.6	18.8	3.2	1.89	0.091	20.4	19.8	-0.6	3.77	0.872
Pancreas	**C25**	16.1	12.4	-3.7	1.71	0.031	17.2	17.3	0.1	3.97	0.976
Larynx	**C32**	11.7	11.6	-0.1	1.54	0.950	14.9	13.3	-1.6	2.92	0.582
Lung	**C33–34**	96.1	83.9	-12.2	4.27	0.005	137.6	108.8	-28.8	9.12	<0.001
Prostate	**C61**	29.4	50.3	20.9	2.96	<0.001	31.0	42.8	11.8	5.95	0.049
Kidney	**C64–65**	15.1	19.3	4.2	1.90	0.028	13.8	21.1	7.3	3.56	0.042
Bladder	**C67**	14.3	19.1	4.8	1.89	0.012	17.6	20.6	3.0	3.56	0.401
All sites*	**C00–97**	376.9	415.6	38.8	9.10	<0.001	476.7	439.3	-37.4	18.19	0.042

*excluding “other skin”

Table 7.7. Comparison of cancer incidence rates between 1988–1990 and 1999–2000, comparing Estonians and Russians. Age-standardised incidence rates (SIR) per 100 000 per year, all ages, women, for ten leading sites of cancer incidence in Estonia and all cancers.

Cancer	ICD–10	Estonians					Russians				
		1988–1990	1999–2000	Difference 1999–2000 to 1988–1990			1988–1990	1999–2000	Difference 1999–2000 to 1988–1990		
		SIR_1	SIR_2	SIR_2–SIR_1	SE	p-value	SIR_1	SIR_2	SIR_2–SIR_1	SE	p-value
Oesophagus	**C15**	0.8	0.8	0.0	0.31	1.000	1.7	0.8	-0.9	0.62	0.148
Stomach	**C16**	21.9	17.3	-4.6	1.61	0.005	30.8	25.1	-5.7	3.12	0.068
Colon	**C18**	15.2	16.6	1.4	1.42	0.322	17.5	21.9	4.4	2.61	0.092
Rectum	**C19–21**	9.1	12.6	3.5	1.20	0.004	15.4	14.0	-1.4	2.26	0.536
Pancreas	**C25**	8.4	7.1	-1.3	0.99	0.190	7.2	9.9	2.7	1.76	0.126
Larynx	**C32**	0.4	0.6	0.2	0.29	0.490	0.6	0.5	-0.1	0.45	0.826
Lung	**C33–34**	12.2	12.9	0.7	1.31	0.596	12.9	12.6	-0.3	2.13	0.888
Breast	**C50**	48.7	59.3	10.6	2.95	<0.001	45.0	51.5	6.5	4.19	0.122
Cervix uteri	**C53**	21.1	20.5	-0.6	1.86	0.750	15.1	15.7	0.6	2.42	0.802
Corpus ut.	**C54**	18.0	19.2	1.2	1.67	0.472	17.5	18.7	1.2	2.57	0.638
Ovary	**C56**	18.3	17.1	-1.2	1.62	0.944	16.0	16.6	0.6	2.49	0.810
Kidney	**C64–65**	7.7	7.8	0.1	1.04	0.920	6.1	8.7	2.6	1.63	0.110
Bladder	**C67**	3.6	4.3	0.7	0.69	0.312	1.7	2.7	1.0	0.90	0.268
All sites*	**C00–97**	262.6	301.6	39.0	6.42	<0.001	252.5	281.7	29.2	9.90	0.003

*excluding “other skin”

An alternative way to look at these data is to compare the size of the relative ethnic differences in the two time periods. The following is a comparison of cancer incidence between Estonians and Russians between two time periods: 1988–1990 and 1999–2000. Standardised incidence rates are presented together with the numbers of cancers that these rates are based on and standardised rate ratios with 95% confidence intervals.

Total cancer incidence. In Tables 7.8 and 7.9 cancer incidence rates between Estonians and Russians in 1988–1990 and 1999–2000 for men and women are presented.

1988–1990. In men for the period of 1988–1990, the total cancer incidence in Russians was higher than in Estonians. As for specific sites, a number of cancer sites such as oesophagus, stomach, colon, rectum, larynx and lung had higher values. The rest of the cancer sites showed similar values between the two ethnic groups.

In women in 1988–1990 the total cancer incidence was similar for the two ethnic groups. According to specific sites, some variation was seen, with cancers of oesophagus, stomach and rectum having higher rates in Russian women and cancer of cervix uteri and bladder having lower rates in Russian women.

1999–2000. During the period 1999–2000, the total cancer incidence in men showed similar estimates in Russian and Estonian men. Higher incidence in Russians was seen in cancers of stomach, pancreas, and lung, while the rest of the malignancies showed similar incidence rates between the two ethnic groups.

In women for the period of 1999–2000, total cancer incidence showed no difference between the two ethnic groups. Cancers of stomach, colon and pancreas had higher rates in Russian women, while cancers of cervix uteri and bladder had somewhat lower rates in Russian women when compared to Estonian women.

For both Estonians and Russians the total cancer incidence was higher in men than in women during both the observed time periods.

Summary. Comparing the incidence rate ratios of 1988–1990 with that in the years 1999–2000, it is seen that these have become smaller for nearly all cancer sites.

In men the differences in rates for cancers of the oesophagus and colon have disappeared. As in 1988–1990, in 1999–2000 the Russian men had still higher than Estonian men incidence of cancers of stomach and lung.

Compared to men, the differences in cancer incidence rates between Estonian and Russian women are smaller in general for 1988–1990 as well as for 1999–2000. The

higher rates of stomach cancer and lower rates for cervix uteri cancer in Russian women were seen in both time periods. The Russian women developed an excess rate of cancers of colon and pancreas for 1999–2000.

However, it should be noted that these changes in the magnitude of the ethnic differences in cancer incidence between the two periods could be due to chance, as can be

judged by the overlap in all cases of the 95% confidence intervals.

Table 7.8. Comparison of cancer incidence rates between Estonians and Russians in 1988–1990 and 1999–2000. Age-standardised incidence rates per 100 000 per year, all ages, men, for ten leading sites of cancer incidence in Estonia and all cancers.

Cancer	ICD–10	1989						2000					
		Estonian		Russian		SRR Rus/Est	95% CI	Estonian		Russian		SRR Rus/Est	95% CI
		SIR	no**	SIR	no**			SIR	no**	SIR	no**		
Oesophagus	**C15**	7.1	84	13.1	48	1.85	1.22–2.82	7.2	58	7.3	24	1.01	0.63–1.65
Stomach	**C16**	41.6	494	72.2	294	1.73	1.49–2.02	33.8	281	55.3	156	1.64	1.33–2.01
Colon	**C18**	16.6	199	24.6	90	1.48	1.11–1.96	23.6	198	23.4	66	0.99	0.74–1.33
Rectum	**C19–21**	15.7	189	20.4	74	1.30	0.98–1.73	18.8	161	19.8	56	1.05	0.77–1.44
Pancreas	**C25**	16.1	188	17.2	56	1.07	0.76–1.51	12.4	103	17.3	49	1.40	0.96–2.04
Larynx	**C32**	11.7	141	14.9	68	1.27	0.95–1.73	11.6	98	13.3	39	1.15	0.78–1.68
Lung	**C33–34**	96.1	1146	137.6	571	1.43	1.29–1.60	83.9	713	108.8	304	1.30	1.13–1.49
Prostate	**C61**	29.4	353	31.0	100	1.05	0.83–1.35	50.3	418	42.8	103	0.85	0.67–1.08
Kidney	**C64–65**	15.1	181	13.8	60	0.91	0.67–1.25	19.3	162	21.1	60	1.09	0.80–1.50
Bladder	**C67**	14.3	171	17.6	70	1.23	0.92–1.65	19.1	160	20.6	60	1.08	0.80–1.46
All sites*	**C00–97**	376.9	4520	476.7	1947	1.26	1.19–1.34	415.6	3472	439.3	1225	1.06	0.99–1.32

*excluding “other skin”
**no – number of cancers

Table 7.9. Comparison of cancer incidence rates between Estonians and Russians in 1988–1990 and 1999–2000. Age-standardised incidence rates per 100 000 per year, all ages, women, for ten leading sites of cancer incidence in Estonia and all cancers.

Cancer	ICD–10	1989						2000					
		Estonian		Russian		SRR Rus/Est	95% CI	Estonian		Russian		SRR Rus/Est	95% CI
		SIR	no**	SIR	no**			SIR	no**	SIR	no**		
Oesophagus	**C15**	0.8	19	1.7	13	2.13	1.00–4.36	0.8	13	0.8	5	1.00	0.35–2.87
Stomach	**C16**	21.9	459	30.8	227	1.41	1.19–1.66	17.3	236	25.1	129	1.45	1.15–1.81
Colon	**C18**	15.2	332	17.5	130	1.15	0.94–1.42	16.6	246	21.9	120	1.32	1.05–1.66
Rectum	**C19–21**	9.1	200	15.4	113	1.69	1.33–2.14	12.6	182	14.0	74	1.11	0.84–1.48
Pancreas	**C25**	8.4	182	7.2	52	0.86	0.63–1.18	7.1	102	9.9	52	1.39	0.98–1.99
Larynx	**C32**	0.4	7	0.6	5	1.50	0.46–4.67	0.6	6	0.5	2	0.83	0.17–4.58
Lung	**C33–34**	12.2	243	12.9	97	1.06	0.83–1.34	12.9	178	12.6	65	0.98	0.72–1.32
Breast	**C50**	48.7	837	45.0	338	0.92	0.81–1.05	59.3	684	51.5	253	0.87	0.75–1.01
Cervix uteri	**C53**	21.1	351	15.1	112	0.72	0.59–0.89	20.5	211	15.7	70	0.77	0.58–1.01
Corpus ut.	**C54**	18.0	334	17.5	136	0.97	0.79–1.19	19.2	233	18.7	91	0.97	0.76–1.26
Ovary	**C56**	18.3	336	16.0	117	0.87	0.70–1.09	17.1	208	16.6	77	0.97	0.74–1.27
Kidney	**C64–65**	7.7	145	6.1	45	0.79	0.56–1.12	7.8	106	8.7	46	1.12	0.77–1.60
Bladder	**C67**	3.6	88	1.7	12	0.47	0.26–0.89	4.3	66	2.7	15	0.63	0.35–1.15
All sites*	**C00–97**	262.6	5039	252.5	1884	0.96	0.92–1.02	301.6	3859	281.7	1395	0.93	0.88–1.00

*excluding “other skin

**no – number of cancers

7.5.4 Discussion

Some of the limitations of the current study should be mentioned. This study does not account for socio-economic or urban-rural differences as these variables did not exist in the data that were used. Socio-economic conditions could have an effect on ethnic differences in cancer incidence. As stated in the methods section the validity of recording ethnicity at ECR is rather low. Data about nationality are rather often based on "informal" decisions during the cancer registration process and this may also affect the results of the current study. Also, differential reporting of ethnicity at population census and at cancer reporting (which is very unlikely) could bias the result of the current study. Another limitation would be differential migration of the Russians to Russia, which may have caused changes in the Estonian/Russian cancer incidence rates over time.

It was seen in Table 7.5 that the percentage with missing ethnicity increased from 2.6 to 13.8 between the two periods studied. This could have affected the results of the current study if missing ethnicity was predominantly on account of one of the main ethnic groups. This is unlikely, as there has been an overall decrease in the completeness of reporting personal identification items in the ECR over the recent years. This was discussed in Chapter 4.3.3.

The studies on ethnicity and health in Estonia by Leinsalu *et al.* have shown that Russian nationality is the most influential factor underlying poor health (Leinsalu *et al.* 2002) and that mortality differences between Estonians and Russians exist (Leinsalu *et al.* 2004) with Russians having higher mortality. The current study adds a new aspect to this kind of knowledge by showing that there are differences in cancer incidence between the two main ethnic groups in Estonia.

The following is a discussion of some important differences in the Estonian and Russian cancer incidence rates in Estonia.

The fact that Russian men had much higher total cancer incidence in 1988–1990 than the Estonian men, is possibly explained by higher incidence of lung and stomach cancer rates in Russian men in 1988–1990. Comparing these rates between the two ethnic groups over time, it is seen that in Russian men the decline in these rates was larger than that in Estonian men. Although the rates of lung and stomach cancer incidence in Russian men in 1999–2000 remain higher than in Estonian men, the decline in these rates between the two time periods brings the total cancer incidence in

Russian men rather close to that of the Estonian men, and the difference that existed in total cancer incidence in 1988–1990 is no longer seen.

As for the two cancer sites mentioned in the previous paragraph, lung and stomach, these deserve special attention. As described in the results section, the decline in lung cancer incidence in Russian men is considerable, and more pronounced than in Estonian men. This finding is difficult to explain. It may have to do with age–specific lung cancer rates and the age group of Russian men (mainly young and middle–aged) who moved to Russia between the 1989 and 2000 population census. When Estonia and Russia are compared as countries, lung cancer incidence in Russia is also higher than in Estonia.

Relatively high stomach cancer rates in Estonia may be explained by high prevalence of *H.Pylori* infection (see Chapter 5 Section 5.2.2.2). According to the current study, the stomach cancer rates are higher in Russians than in Estonians. This is consistent with the findings of Rahu (1977). Still, when comparing the incidence rates for this malignancy with respective rates in Russia, it is seen that those are higher. This points to a higher prevalence of *H. Pylori* infection in Russia that is related to poorer sanitary conditions compared to Estonia at least in the past. According to Reshetnikov (2001), the sero–prevalence of *H.Pylori* infection in Siberian populations is 71–92%. The Russian population in Estonia may have higher prevalence of *H.Pylori* infection inherent to their country of origin as this infection is mainly acquired in childhood and about a half of the Russian population in Estonia is born in Russia.

The stomach cancer rates are declining for both ethnic groups and both sexes. This is consistent with recent declines in stomach cancer incidence which have been registered in a number of countries (Nyren and Adami 2002b).

It should be noted that the potential effect of different lag-periods for *H.Pylori* and smoking in causing cancer may also explain the differences in the occurrence of stomach and lung cancers between Estonians and Russians in Estonia between 1988–1990 and 1999–2000.

The rest of the digestive tracts malignancies (larynx, oesophagus, colon and rectum) showed only a little variation between Estonians and Russians. The findings such as the increase in colon cancer rates in Estonian men and the decrease in the rates of the oesophageal cancer in Russian men are difficult to explain.

The decline in pancreatic cancer incidence in Estonian men is not seen in Russian men. As smoking and alcohol consumption are risk factors for pancreatic cancer, this

may be explained by differences in lifestyle such as higher use of strong spirits and more prevalent daily smoking by Russian men (Kunst *et al.* 2002) for 1990–2000.

Studying the incidence patterns of common urologic cancers between the main ethnic groups in Estonia and making comparisons with Russia, the following observations can be made. In Estonia the two main ethnic groups have similar incidence for cancers of kidney, bladder and prostate, and increase in the incidence of these malignancies is seen over time. This finding supports the fact that the diagnosis of urologic cancers has increased in Estonia over the recent years due to diagnostic improvements, discussed more in detail in Chapter 5 Sections 5.2.2.13 and 5.2.2.14. It should be noted though, that in women the incidence of bladder cancer has low estimates and the changes are difficult to estimate, and no change in kidney cancer incidence is seen in women.

As for the gynaecological cancers, the following observations can be made. The incidence of cancer of cervix uteri in Estonia is lower in Russians. The explanation for this finding may be that as there is no mass–screening for cervical cancer in Estonia, the higher incidence rate in Estonians may refer to higher knowledge about this cancer in Estonian women who refer themselves for Pap–smears. The fact that breast cancer incidence in Estonian women is increasing more rapidly than in Russian women may have to do with differences in childbearing pattern (Kelsey 1993).

7.5.5 Conclusions

This study looked at cancer incidence patterns of ethnic Estonians and Russians in Estonia in 1988–1990 and 1999–2000. The Russians in Estonia have an excess cancer rate for a number of sites, and the differences are more pronounced in men. A constant finding is the excess of stomach cancer in Russians for both sexes.

As already mentioned it would have been good to be able to examine the extent to which ethnic differences may in part reflect socio–economic differences. However this was not possible.

Some of the differences in cancer rates between the Estonians and Russians in Estonia are likely to be attributable to variation in exposure to specific etiologic factors that are caused by differences in lifestyle, such as diet, smoking and drinking habits. However some of changes over time may be due to differential migration. Further research to understand these ethnic differences in cancer incidence is warranted.

Chapter 8. Conclusions

In this thesis, the history and present status of the Estonian Cancer Registry were reviewed. A literature review of registry data validation studies was presented along with three *ad hoc* studies to validate the quality of cancer data collected by the Estonian Cancer Registry. Also, this study presented an overview of cancer incidence and mortality trends for the leading sites in Estonia for 1985–97 and comparisons of cancer incidence and mortality rates with the Nordic and the Baltic countries.

Based on this work, the following conclusions can be made:

First, the overview of the Estonian Cancer Registry history and present status demonstrated that it has undergone vast development since it was established in 1978. Although cancer registration in Estonia initially adhered to principles of cancer registration in the Soviet Union, from the late 1970–s it started to diverge and soon after the dissolution of the Soviet Union, there was a definitive break with the Soviet cancer registration principles.

Over the recent years, the Estonian Cancer Registry has established itself as a high standard cancer registry with a rather extensive use of data. This is reflected by its participation in several international projects as well as numerous studies based on the Estonian Cancer Registry data. Some of the limitations should be noted, such as underutilisation of data for the formulation of health policies or for clinical studies.

Second, as revealed by the *ad hoc* data validation studies carried out as part of this study, data quality in the Estonian Cancer Registry is good in general. These studies demonstrated that the validity and completeness of cancer registrations are high in the Estonian Cancer Registry, being a little higher for personal and lower for clinical information. Completeness of case ascertainment was not very high, although the result may be affected by the limitations that the study suffered from.

Third, cancer incidence and mortality in Estonia has increased in recent years. Cancer incidence trends for specific sites are increasing in a large number of cases. It should be noted that the decline in lung cancer incidence rates for men is an encouraging development, showing that smoking has become less prevalent among men. Unfortunately, this is not the case for women in Estonia. The continuing decrease in the incidence rates of stomach cancer is also encouraging, as it indicates the decreasing prevalence of *H. pylori* infection. The implementation of new diagnostic methods contributes to the increasing incidence and mortality of all urologic cancers in Estonia.

The increase in cancer mortality over recent years has been proportionally less than that in incidence. As for specific sites, the stagnation of the mortality trend for cancer of the cervix uteri is worrying because it reflects the absence of a screening programme in Estonia.

Fourth, comparing cancer incidence and mortality in Estonia with that of its neighbouring countries revealed that Estonia is positioned rather high for the incidence of all smoking related cancers as well as stomach cancer, especially when compared with the Nordic countries. The rather big excess of kidney cancer in Estonia when compared to all other countries most probably results from the increase in diagnostic activities. This also seems to be the case for prostate cancer, which has higher incidence in Estonia than in the rest of the Baltic countries. The deficit of bladder cancer is likely to be due to underdiagnosing of this malignancy in Estonia.

Fifth, the comparison of cancer incidence rates between the two main ethnic groups – Estonians and Russians – showed that the ethnic differences exist. A constant finding is the excess of stomach cancer in Russians for both sexes. Some of the differences in cancer rates between the Estonians and Russians in Estonia are likely to be attributable to variation in exposure to specific etiologic factors that are caused by differences in lifestyle, such as diet, smoking and drinking habits.

Chapter 9. Recommendations

In this chapter recommendations based on the findings of the studies are presented.

Recommendations for the Estonian Cancer Registry:

General

- Raising doctors' awareness of the high value of population based cancer data and getting them to co-operate in cancer registration process. One of the ways to do this would be systematic presentations or written summaries of the studies performed with the Estonian Cancer Registry data.
- Linkage with mortality data from the Statistical Office for Estonia needs to be re-established. This would be a high priority undertaking as the lack of cancer mortality data not only causes problems in case completeness, but also makes it not possible to calculate cancer survival.
- Completeness of case ascertainment can be enhanced the making more use of other sources such as histopathology departments and performing linkage of the Estonian Cancer Registry data with the databases from these departments.

For the cancer registration process

- Care is needed when entering some details such as source of notification to the Estonian Cancer Registry electronic database. Errors of this kind alter the statistics of cancer rates between medical centres. Also it makes not possible to carry out reabstraction exercises as the cancer patients can not be traced back to the medical institution.
- Processing the cancer notifications from the hospitals to the Estonian Cancer Registry needs more attention and supervision. Training of the staff at the medical records departments of cancer notifying hospitals need to be carried out.

- The completeness of recording cancer treatment by the Estonian Cancer Registry needs to be enhanced.
- Ethnicity is an important variable of personal information and needs to be recorded by the Estonian Cancer Registry.

Recommendations on further studies

- Completeness of case ascertainment of the Estonian Cancer Registry should be studied more thoroughly, involving all major cancer reporting centres. An alternative would be a study of linking the Estonian Cancer Registry data with the Central Sickness Fund data and carrying out active retrieval of missing cases.
- Studies on the quality of registration of childhood cancers should be undertaken.
- Finding out about the reasons for the differences of the incidence patterns for the urologic cancers in Estonia would certainly be a priority research area.
- Studies of cancer incidence and ethnicity, accounting for socio-economic differences, should be undertaken.

Recommendations for the Estonian health care system

- Recognizing the role of the Estonian Cancer Registry as a resource of data for formulating health policies.
- Establishing a nationwide hospital discharge registry. This development would help to increase the completeness of the Estonian Cancer Registry data.
- Developing and implementing standard pro formas for medical case notes to be used in all medical centres.

Recommendations for public health

- Take measures to reduce the prevalence of smoking
- Introduce Pap–smear screening for cervical cancer

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Appendix 1. Published research paper

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