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LETTER TO THE EDITOR

The Estonian Cancer Registry: foundation and further history

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The year 2018 marks the 40th anniversary of the creation of the Estonian Cancer Registry (ECR). This population-based registry covers the entire population of Estonia, which is currently 1.3 million.

The foundation of the registry and its existence over a period of 40 years are quite remarkable for this country and could serve as an interesting precedent in the history of cancer registration worldwide. The purpose of this study is to describe the circumstances leading to the establishment of the ECR and the challenges that have been met in the registry's work afterwards.

Cancer registration in the USSR

Compulsory cancer registration in the USSR started in 1953. Registration progress and specificities have been documented with sufficient clarity [1–3] and will be therefore treated only briefly here.

The Soviet cancer registration was based on the system of cancer dispensaries responsible for diagnosis, treatment and life-long follow-up of the patients. In the dispensaries one department, most often an organization and methodology department, dealt with cancer statistics at a regional level. The dispensaries compiled annual statistical reports, including the number of new cancer cases, and presented them to the USSR Ministry of Health six weeks after the end of the year. As cancer registration was a manual process and statistical reports were prepared manually, the tabulated numbers were final, i.e., official reports have never been corrected over time.

Annual statistical reports provided information on cancer cases by gender for six age groups and for 12 individual sites or groups of sites. During several decades, a Soviet disease classification or Soviet modification of the ICD was used for the coding of diagnosis.

Cancer registration was governed by ideological prejudices that prized the superiority of the Soviet system. For example, it was announced that 'in capitalist countries, within the system of private physicians, it is impossible to have complete registration of diseases, but in our country and in other socialist countries there are all possibilities for complete registration of malignant tumours' [4, page 4].

In addition to using non-standard age groups and disease classification, an area of concern in cancer registration in the USSR was also the completeness and quality of data. Many researchers took a pragmatic approach to make cancer incidence data comparable with those available from the countries with an advanced cancer registration system. Most often, the students working on a candidate or doctoral degree collected case by case incidence data in their study region and presented incidence statistics in internationally accepted formats. In this way, in some territories official cancer incidence data were temporarily replaced by a set of more accurate and comparable data. In other words, cancer epidemiology research in the USSR concentrated mainly on replacing official incomplete statistical data with revised and updated ones [2].

The birth of a cancer registry in Estonia

Several prerequisites made the ECR possible [5]. First, by the middle of 1960s, cancer notifications covering the whole country had been centralized in the Tallinn Cancer Dispensary. The staff of the dispensary, who wanted to overcome the limitations of the manual cancer registration, were ready for computerization to facilitate the preparation of annual reports. Second, the country's most advanced data processing system, in which the technology of module programing was applied, was developed for the Razdan-3 mainframe computer (Data Processing Centre of the Estonian Radio) in 1969–1972.

Third, Pavel Bogovski, the director of the Institute of Experimental and Clinical Medicine (IECM), was a staff member of the International Agency for Research on Cancer (IARC) in 1968–1974. Working in the agency gave him a good idea of the importance of cancer registries in cancer control. Fourth, within a tiny group of cancer epidemiologists at the IECM a firm belief was achieved that a different kind of cancer registration should be applied in Estonia. Otherwise the prospects for epidemiological research would be dim. In 1969 and 1974 two informational papers on the need to create a cancer registry were prepared by one of us (MR) and presented to the administration of the dispensary and the institute.

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Fifth, the WHO started to express the need for standardization of data collected by cancer registries [6] and it had a certain impact on Soviet health authorities. Sixth, it was announced that a local initiative to modify cancer registration documents for computerization would be welcomed, if it does not interrupt timely submission of mandatory annual statistical reports to the Ministry of Health in Moscow. Moreover, we had collaboration with colleagues at Moscow Cancer Research Centre that partially involved cancer registration activities in the USSR. And, finally, in Estonia, Väino Rätsep, a cancer surgeon, was appointed Minister of Health in 1975.

In summary, in the middle of 1970s, three institutions in Estonia – the central cancer dispensary, research institute and the Ministry of Health – were interested in acting hand in hand to improve cancer registration. This process was aided by the existence of an effective data processing system in Estonia, WHO's initiative to standardize cancer registry procedures worldwide, and the positive attitude of relevant authorities and persons in Moscow toward constructive changes in cancer registration.

Advances and obstacles

The ECR was established on January 16, 1978 by an Order of the Ministry of Health (Table 1). In the beginning, the ECR consisted of two parts: the Team of Cancer Registry in the Department of Clinical Oncology at the IECM, and the Unit of Cancer Statistics at the Tallinn Cancer Dispensary. In 1993, the ECR became a part of the Estonian Cancer Centre. Six years later, by a Regulation of the Minister of Social Affairs, the ECR 'was converted into a database of the Ministry of Social Affairs'. In accordance with legislation in force, the 'controller' of the ECR is the Ministry of Social Affairs and the 'processor' is the National Institute of Health Development (NIHD). Currently, the staff of the registry and cancer database are located at the NIHD. The development of the specific legal basis of the ECR's activities has been largely

Table 1. Highlights in the activity of the ECR and associated research,[a] since 1978.

Date/Year	Event
1978	On Jan. 16 the ECR is founded (Order of the Ministry of Health No. 14). The registry introduces the morphology section of the ICD-O (1976).
1980	At the initiative of the ECR the 3rd edition of TNM Classification of Malignant Tumours (1978) is translated into Estonian and published.
1983	The registry introduces the topography section of the ICD-O (1976), that was translated into Estonian and published in the previous year.
1985	At the initiative of the ECR the classification of hematopoietic and lymphoid malignancies in the morphology section of ICD-O (1976) is translated into Estonian and published.
1986	The East-German Cancer Registry and the ECR conclude a bilateral agreement on scientific cooperation for the years of 1986–1990.
1989	The ECR becomes a voting member of the International Association of Cancer Registries (IACR).
1990	At the initiative of the ECR the 4th edition of TNM Classification of Malignant Tumours (1987) is translated into Estonian and published.
1991	The Finnish Cancer Registry and the ECR conclude a bilateral agreement on scientific cooperation for the years of 1991–1996.
1992	Incidence data from the ECR are published in the *Cancer Incidence in Five Continents* series [7] for the first time.
1994	Work reorganization in the ECR, updating of database structure, new cancer notification forms introduced. The ECR becomes a member of the European Network of Cancer Registries (ENCR).
1995	Survival data from the ECR are published in the frames of the EUROCARE study for the first time [8].
1997	The National Science Award of the Republic of Estonia is given to the four authors of the statistical compendium *Cancer in Estonia 1968–1992: incidence, mortality, prevalence, survival* [9]. *Atlas of cancer incidence in Estonia* is published [10].
1998	Childhood cancer incidence data from the ECR are published in the *International incidence of childhood cancer* [11] for the first time.
2001	IARC, IACR and ENCR awarded the Diploma of International Appreciation to the ECR.[b]
2007	IACR Honorary Membership is awarded to the 1st and 5th Head of the ECR.
2011	The new Public Health Act (March 10) contains a special chapter on databases, including the ECR.[c]

[a]The ECR's staff as of February 2018 consists of five persons who ensure functioning of the registry. Research using registry data is conducted predominantly at the Department of Epidemiology and Biostatistics, National Institute for Health Development (before 2003 the IECM) on the basis of a competitive grant evaluation process.

[b]This international moral support was provided to the cancer registry in a very tough time when, e.g., a high public health official had expressed an opinion that medical registries in Estonia are 'golden eggs whose laying is a waste of money' and that the ECR is a useless abstract database [12].

[c]The ECR is defined as 'a database belonging into the state information system which is maintained for analyzing the occurrence of cancer and survival of cancer patients, organizing health services, planning cancer control methods and evaluating the efficiency thereof as well as for organizing statistics on morbidity and for epidemiological research' [13].

dependent upon the speed and quality of modernization of the justice system in Estonia after the restoration of independence in 1991.

The ECR was the first institution in the USSR whose name contained the words 'cancer registry'. In 1986, we announced with full conviction that this registry is unique in the USSR and its experience may be used in founding other registries in different regions of the country [14]. The ECR went forward step-by-step, starting with introducing in Estonia international classifications, and continuing with international collaboration, including data provision for global cancer surveillance (Table 1). Thanks to the presence of the ECR and to the participation of researchers in the shaping of it, modern epidemiology has landed on its feet in Estonia. It is evidenced, e.g., by cohort studies measuring cancer risk among furniture workers [15], physicians [16] and Chernobyl cleanup workers [17]. And it means simultaneously the creation and usage of Estonian terms of epidemiology [18].

Progress in cancer registration has been intertwined with numerous other processes and events. Now, several decades later, it is hard to accept that during many of the early years of the ECR the processing power of a mainframe computer was so low that a data set size of 50–100 MB caused a serious problem. For some unknown reason, incident cases for two years had disappeared from the database and the archived paper cancer notifications for the period of 1963 to 1967 had been destroyed (Figure 1). In the early 1990s, the ECR was at the edge of extinction because of outdated hard- and software.

In the 1990s, a new generation of public health officials suddenly faced a harsh reality: the ECR, created in the era of Soviet stagnation, is still alive and needs financing. A rapidly changing staff of officials, who had control over the existence of the ECR, did not know what else to do than to criticize registry practice and make it suffer from constant underfunding [12].

The Personal Data Protection Acts of 1997 and 2003 did not contain exemptions for the processing of personal data for historical, statistical or scientific purposes provided by the EU Directive 95/46/EC. This kind of legislative act in combination with slow legislation of related laws led to a series of consequences, paralyzing the work of all medical registries and register-based epidemiological research (Figure 1). It was a real disaster when the linkage of cancer registry files with death certificate database was prohibited from 2001 to 2010. Moreover, the Data Protection Inspectorate declared that a medical death certificate is an illegal document and made the Statistics Estonia stop entering death cases into the database for 15 months [19].

During the period considered, the officials attempted twice to encourage making files anonymous in medical registries on the grounds that it is a valid approach to personal data protection. Fortunately, no changes were undertaken, and it is our sincere hope that there will be no fatal deviation from Nordic legislation principles [20] and data quality standards set by the Nordic cancer registries [21].

The most recent prohibition of transfer of data for research purposes from October 14 to November 15, 2016 was caused by the fact that the controller of the ECR had forgotten to renew a data processing license.

Both during good and difficult times the staff of the ECR and collaborating epidemiologists have received help and support from their foreign colleagues. A deep act of international solidarity took place in November–December 1998 when at least 17 individuals or institutions followed our plea and sent a letter of protest to the President, Prime Minister, and Ministry of Social Affairs regarding a recent request to discontinue sending data to medical registries.

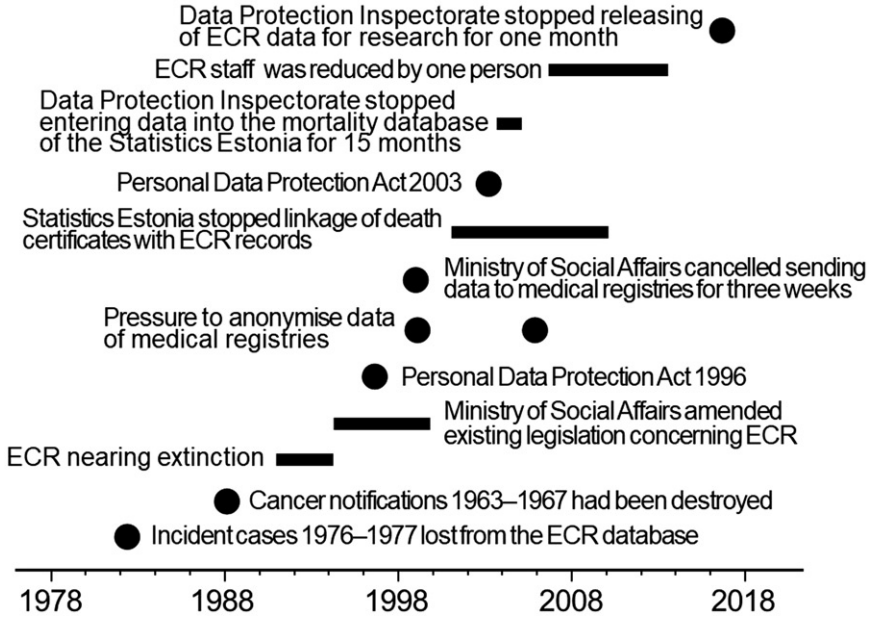

Figure 1. Challenges in the activity of the ECR and associated research, since 1978.

Although the current state of health of the ECR is satisfactory, we should remember that the registry is a fragile organism. It could not survive if turned into an experimental playground of IT solutions, if overloaded with data items collected for whatever purpose and of unknown quality, if having no scientific output.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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LETTER TO THE EDITOR

Incidence and survival of head and neck squamous cell carcinoma in children and young adults in Denmark: a nationwide study from 1980 to 2014

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Introduction

Head and neck squamous cell carcinoma (HNSCC) is exceedingly rare among children and young adults. When observed, there is often association to predisposing factors such as DNA repair defects (Fanconi anemia, Bloom syndrome), prior irradiation of the head and neck among cancer survivors, oral graft versus host disease or oncogenic virus infection [1–4].

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