

## **The Regional Registry of Gastro-Intestinal Cancer North Baden (2.2 Million Inhabitants)**

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**Summary.** The advantages of a population-based registry are discussed. It is shown that a registry for gastro-intestinal cancer in a district with expert medical care based upon histo-pathological diagnosis, has the principal advantage that it limits the sites of material collection to a few effective contributors, thus providing highly accurate data. The disadvantage of collecting data by two separate steps should be tolerated. The geographic situation and the organization of the regional registry for gastro-intestinal cancer in North Baden are described and the incidences for these cancers for the years 1971–1975 are given for the population of 2.2 million.

**Key words:** Cancer registry — Gastro-intestinal cancer — Histo-pathologic diagnoses.

**Zusammenfassung.** Die Vorzüge eines bevölkerungsbezogenen patho-anatomischen Registers werden diskutiert. In einem Gebiet mit einer guten medizinischen Versorgung hat ein Organregister für Magen/Darm-Tumoren, das sich auf histologisch-pathologische Diagnosen stützt, folgenden Vorteil: Es reduziert die Stellen, an denen die Daten erhoben werden, auf einige wenige und erreicht dadurch eine sehr hohe Zuverlässigkeit. Als Nachteil muß in Kauf genommen werden, daß die histologisch-pathologischen und die klinischen Daten in zwei verschiedenen Arbeitsgängen erhoben werden müssen. Die Organisation und die geographische Situation des regionalen Registers für gastro-intestinale Tumoren in Nord-Baden werden beschrieben. Die Inzidenzen der Magen/Darm-Tumoren für die Jahre 1971 und 1975 in Nord-Baden (2.2 Millionen Einwohner) werden angegeben.

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## 1. General Considerations

The basis for recognizing a malignant growth is morphological. It may therefore be assumed that, whenever there is a suspicion of cancer, a histopathological examination will have been performed to confirm the findings of cancer. Cancer registries in Scandinavia indicate that more than 90% of reported cancer cases—with the exception of cancer of the lungs—are based upon histopathological findings and that than 95% of cancer cases are verified by biopsies.

The histopathological findings are, therefore, the most reliable source for oncologic and epidemiologic studies. Additional information may be obtained for each patient at the time of investigation such as; personal data, health records and social, economic, and clinical data.

Since it is not mandatory in the Federal Republic of Germany to report any cancer diagnosed—as it is, for example, in Scandinavia—the DFG approved the project of establishing a population-based regional registry for gastrointestinal cancer on a histopathological basis in 1975. To our knowledge there is no registry in the developed countries which is organized this way; the existing registries (Hamburg, Saarland, England, Connecticut etc.) are based upon clinical data or upon mandatory reporting (Scandinavia, GDR). In the Federal Republic of Germany there are, at present, two cancer registries (Hamburg and Saarbrücken); one is located in a city-state area and the other in an area with heavy industry and both are based upon clinical data. In this paper the advantages, disadvantages and the experience gained from a registry based upon histopathological data only (i.e. Patho-anatomic Institutes) are discussed.

The cancer registry of North Baden is located in an area of variable demography with cities, rural and industrial areas having either a low or high population, having various social classes and various groups of professions.

As the registry functions on the basis of histopathological findings it is possible to attain precise and differentiated scientific and epidemiological results. In addition to the ability of securing the frequency of histopathological findings statistically, the regional cancer registry may be used for the following:

1. Morphological, ecological and psycho-social data may be stored and used for studies.
2. Statistical analyses of morphological appearances in light-microscopy and electron-microscopy result in more detailed findings on the morphological characteristics of a tumor.
3. The regional population-based registry may be utilized for follow-up and catamnestic studies.

## 2. The Purpose of a Population-Based Registry

In a highly industrialized country knowledge of absolute and relative incidences of certain diseases is very important in the medical care of the people. In Western countries the two main causes of death, cardio-vascular diseases and cancer seem to depend in part upon external factors, correlated with living

habits and/or environmental factors. Statistical mortality studies cannot determine risk factors or the risk population and Preventive Medical Care and the assesment of costs, delivers of service etc. require a sound statistical basis.

Because of the different systems of medical care in different countries, different standarization etc., the international comparison of morbid statistics only can be accomplished by taking into account a high percentage of errors and many difficulties. Follow-up studies, such as specialized prospective studies, are impossible.

### **3. Organisation of a Population-Based Registry**

The efficiency of data collection depends upon the disease which is to be considered and this also holds true for various sites at which cancer occurs. Certain types of carcinoma are almost invariably diagnosed by histo-pathological examinations (for example cancer of the rectum or oesophagus) while others are recognized by other techniques, such as X-rays, clinical pictures etc. It seemed appropriate that the collection of cases of gastro-intestinal cancer should be commenced in histo-pathological institutes. In addition to hospital cases, those referred from private physicians are also available in these institutes. Working in this way gives the following advantages:

1. Limiting the places where cases of cancer are collected to a few pathoanatomical institutes rather than dealing with a great number of private physicians and hospitals.

2. Close contact can be maintained with members of institutes where cases are collected.

3. Based upon this personal contact a much better motivation for forwarding in appropriate data of cancer patients is achieved.

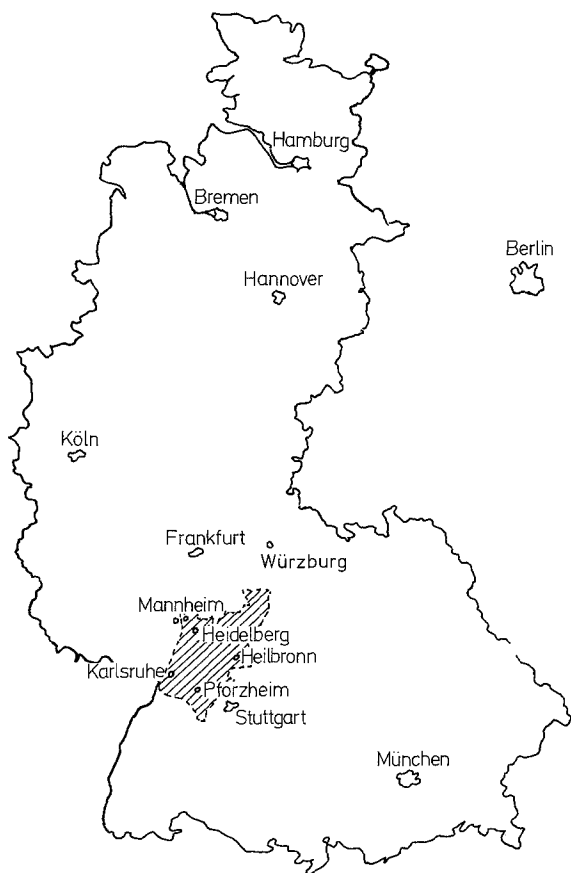
In our registry collecting *all* cases of cancer is the highest goal. Only positively proven cancer cases, i.e. cases diagnosed by histo-pathological examination are considered and in this way false positive cases are not considered. Although the two main errors of every registry, false positive and false negative (missing) cases are antagonistic in effect, it is felt that it is better to delete one possibility of error and to define the lower limit of the incidence of a certain tumor. Naturally, this is only possible in cancers with a high percentage of histo-pathological verification, as with cancer of the gastro-intestinal tract.

A disadvantage of our registry is the fact that we cannot collect the histo-pathological and clinical data in one step.

### **4. Determination of the Regional Area Covered by a Registry**

Epidemiological research work must consider external variables, which are:

1. The borders of countries, districts, villages,
2. the geographic units for official statistics (population, age, distribution of countries, districts, federal state),
3. the living habits of the population (rural, urban) etc.



**Fig. 1.** The geographic situation of the regional cancer registry North Baden

Additional internal factors innate to the registry are, for example, the financial situation determining the number of registry personnel, the possibility of computer access etc. For all these reasons and because of the experience of already existing registries in West Germany (Hamburg, Saarland), the best choice for our registry seemed to be to cover the district of North Baden with a total population of approximately 2.2 million inhabitants.

With regard to the underlying age distribution of the population, a total number of about 2.000 newly detected cases per year would be expected, a number which is very close to the reality. A detailed discussion of the data obtained (incidences, age distribution etc.) is in preparation (Kayser and Burkhardt, 1978). A great advantage of our registry is the fact that the entire population is covered by only six pathological institutes, a fact which allows a very limited number of registry personnel.

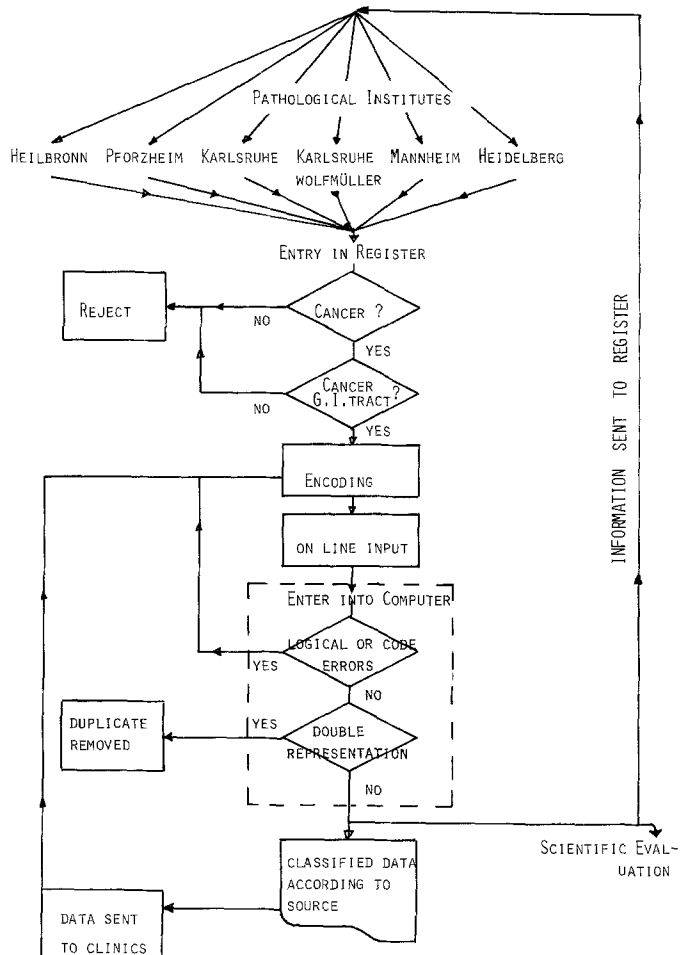
The geographic situation including the location of the pathological institutes is shown in Figure 1. About 40% of the total population live in the urban centers (Mannheim, Heidelberg, Karlsruhe, Heilbronn, and Pforzheim); the remaining 60% live in the rural areas of the Southern Odenwald and Northern

Schwarzwald (1970 census). The degree of industrialization is very variable and while the Rhine valley is one of the most polluted areas in West Germany (Mannheim, Ludwigshafen), as are Karlsruhe and Heilbronn, most of the Odenwald district is covered with woods and its pollution may be considered to be low compared to the densely populated areas.

## 5. Collection of Data

The scheme of collecting our data is shown in Figure 2.

*The first step* is to collect and send confirmed cases of gastro-intestinal cancer to the registry. Because of the different set-up in the pathological institutes concerned, it is not possible to receive the cases of gastro-intestinal cancer from all institutes automatically. While four institutes send their material, the data from the two remaining ones must be collected by personnel of the registry.



**Fig. 2.** Flow chart showing the working method of the regional cancer registry

Before we started collecting the material we interviewed the bigger hospitals in our district to determine to which Institute of Pathology they are sending their material for examination. It was found that only one medium-sized hospital was sending its material to an Institute of Pathology located outside of our area. The data of this hospital is collected separately, but it consists of only a few cases a year (less than 1%).

*The second step* is to codify and store the collected cases.

We consider all malignancies of the gastro-intestinal tract (oesophagus, stomach, small intestines, colon, rectum, including anus) and include local carcinomas in colonic polyps (dysplasia III).

In addition to the personal data, the following data are codified by a conventional (manual) method:

1. The medical procedure for recognizing the tumor (i.e. whether the first diagnosis was by biopsy, resection, or autopsy).
2. The localization of the tumor according to the ICD-topography-code.
3. The morphology of the tumor according to an extended ICD/O-code (Grimm, 1978):

1st extension: malignancy, extension of the tumor in accordance with the 5th digit of the ICD/O.

2nd extension: the development of the tumor, i.e. epithelial, mesenchymal, lymphomatous etc.

*The third step* is to collect the clinical data.

A form for each case is printed by our small computer, DIETZ mincal 621 (48 k-Bytes, 2 exchangeable disks, 2.4 million Bytes, 1 magnetic tape, 1 printer, 2 displays). This form contains the previously available data and a preprinted scheme for collecting the missing clinical information. Medical students complete the forms by reading the clinical histories in the appropriate hospitals.

*The fourth and last step* is to codify and store clinical and histo-pathological information.

## 6. Conclusion

The registry has been fully operational since the middle of 1976. In addition to the collection of present data, all data are collected retrospectively for the years 1971 to 1975. Presently available data for the years 1971 to 1975, especially the incidences and the age distributions of gastric cancer, cancer of the oesophagus, small intestines, rectum, and colon, are presented and discussed separately (Kayser and Burkhardt, 1978). The collection of clinical information is not yet completed.

In Table 1 the incidences of gastro-intestinal according to the different main locations are shown for the years 1971 to 1975. For comparison, the incidences obtained by Clinical Registries of Hamburg and Saarland are included. These data are closely comparable to each other and indicate the high accuracy of a registry based upon patho-anatomical institutes. The differences of the incidences of stomach and rectal cancer must be examined in a second step (for example age and sex distribution of the population, different risk factors etc.)

**Table 1.** Incidences of gastro-intestinal cancer in Hamburg, Saarland and North Baden

Tumor localization	Oesophagus (150)	Stomach (151)	Intestines (152)	Colon (153)	Rectum (154)
1971 Cases	61	650	29	412	631
Inc/10 <sup>5</sup>	2.8	29.5	1.3	18.7	28.6
1972 Cases	51	758	27	455	632
Inc/10 <sup>5</sup>	2.3	34.5	1.2	20.6	29.7
1973 Cases	88	754	28	491	667
Inc/10 <sup>5</sup>	4.0	34.2	1.3	22.3	30.3
1974 Cases	81	799	23	542	674
Inc/10 <sup>5</sup>	3.7	36.2	1.0	24.6	30.5
1975 Cases	88	759	29	554	617
Inc/10 <sup>5</sup>	4.0	34.4	1.3	25.1	29.9
<i>Saarland</i>					
1971 Cases	46	347	15	270	213
Inc/10 <sup>5</sup>	4.1	30.9	1.3	24.1	19.0
<i>Hamburg (1960-1962)</i>					
Cases	250	2698	44	1204	857
Inc/10 <sup>5</sup>	4.5	49.0	0.8	21.9	15.6

German law concerning the prevention of misuse of personal data that has recently become effective, endangers the existence of the registries located in Saarbrücken und Hamburg. Indeed Saarbrücken has already been closed down. Institutes of Pathology may establish histopathological population-based registries, for the information stored by these registries does not leave the area of professional security of the physicians and thus the law of protection of personal data is observed. The histo-pathological and population-based registry at Heidelberg demonstrates that it may be utilized for various purposes.

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