INTRODUCTION

HISTORICAL DEVELOPMENT OF THE REGISTRY

1955 Start data collection
1967 Appointment of registration officer
1973 Introduction Megavoltage Equipment
1974 New cancer control policy in the Netherlands
1979 Foundation of SOOZ (= regional cancer care organization)
1981-1983 Evaluation of registry
1983 Foundation of Comprehensive Cancer Centre South
1985 Epidemiological data available from 1976-1983

This regional cancer registry was founded in Eindhoven, in the southeastern part of the Netherlands. It gradually expanded through decentralised procedures of data collection in hospitals together with the extension of consultative services of the centralised radiotherapy department in Eindhoven. It continued to function in 1974 when the other three Dutch registration projects were terminated. Evaluation of completeness of the registry and validity of the data started together with the introduction of electronic data processing. Completeness of the registry appeared to exist for most tumour sites in a large part (± 85%) of the registration area from 1975. Additional data could be found in specialised centers such as for childhood cancer, haematology oncology, neuro oncology and head and neck tumours. Data of this population based cancer registry are now used in descriptive and comparative epidemiological studies, clinical documentation projects and planning services for cancer patients.

AGE

85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0

From: CBS population statistics

Age distribution of the population of the "core" of the registration area in 1980

POPULATION CHARACTERISTICS

- 1 million inhabitants, 6% of the Dutch population
- population data from Central Bureau of Statistics: accurate and easily available
- Core: 830,000 inhabitants (1980)
- population density 400/km²
- ± 80% Roman Catholic; since 1970 considerable secularization
- declining birthrate by more than 30% in period 1970-1980
- considerable ageing of population: ±
  2% annual increase of number of older
  people
- prevalence of smoking: high in males
  and low in females until mid-seventies
- relatively low participation of females
  in labour market, especially in
  industry, until the mid-seventies

H • Hospital
• • "Core"
■ • "Peel"

CORE AND PEEL OF SOOZ-REGISTRATION
AREA

MAJOR CHARACTERISTICS OF THE REGION:
- 2500 km², 20-50 m. above sea level
- intensive agricultural activities
  industries (electronic, cars, textile,
  tobacco)
- considerable environmental pollution
  (air, soil)
- includes a part of the Kempen, which
  is considerably polluted with heavy
  metals
- surrounded by heavily industrialised
  regions (Ruhrgebiet, Limburg, Antwerp)

MEDICAL CARE IN RELATION TO CANCER
CONTROL
- hardly any financial barriers
- general practitioner as entry to spe-
  cialised care
- one radiotherapy department
  (Eindhoven)
- comprehensive cancer centre in deve-
  lopment
- neuro surgery mainly in Tilburg
- 4 hospital beds per 1000 inhabitants
- 9 co-operating hospitals, mostly new
  built

- university hospitals only outside the
  region (Nijmegen)
- 1 pathology laboratories
- cervical cancer screening starting
  from 1977
- oncology consultants' service in all
  hospitals
- deaths in period data available from
  the Central Bureau of Statistics (CBS)

REGISTRATION PROCEDURES
 Coding: - topography ICD-9
  since 1978
  morphology ICD-O

Routine notification: - 3 depts.of Pathology
  - 1 dept.of Radiotherapy

Multiple sources of data: - medical records of
  in-patients
  - radiotherapy files
  - pathology reports
  - out-patient depart-
  ments(dermatology)

Additional searches in: - specialised oncolo-
  gical clinics
  - Dutch Childhood
    Leukemia Study Group
  - neuro-oncology in
    Tilburg

Quality control through:
  manual filing system
  by patient name and
  tumoursite
  - multiple sources of
    data
  - specific studies

Follow-up: - not complete

Electronic data processing:
  main frame:IBM 4361
  software:SAS/SEER
  terminal:IBM-PC/XT

TEN MOST FREQUENT TUMOUR SITES IN
SOOZ REGION IN 1978-1982

<table>
<thead>
<tr>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>site</td>
<td>% or-</td>
</tr>
<tr>
<td>Lung</td>
<td>32,0</td>
</tr>
<tr>
<td>Prostate</td>
<td>10,0</td>
</tr>
<tr>
<td>Stomach</td>
<td>7,2</td>
</tr>
<tr>
<td>Colon</td>
<td>7,1</td>
</tr>
<tr>
<td>Bladder</td>
<td>6,7</td>
</tr>
<tr>
<td>Rectum</td>
<td>5,1</td>
</tr>
<tr>
<td>Kidney</td>
<td>3,1</td>
</tr>
<tr>
<td>Leukemia</td>
<td>2,7</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>2,5</td>
</tr>
<tr>
<td>Larynx</td>
<td>2,5</td>
</tr>
<tr>
<td>Pancreas</td>
<td>2,3</td>
</tr>
</tbody>
</table>
| Nervous sys-
  tem         | 1,9 | 12  | Lymphoma| 2,0  |

464
ELECTRONIC DATA PROCESSING FOR THE IKZ/SOZO CANCER REGISTRY

HISTORY

1955: Start of manual data collection, coding, archiving and retrieval including simple statistics: annual number of new cancer cases by sex, primary site and age.


1980-1983: Computer assisted evaluation of population based data on:
- completeness of number of reported cases: analysis per municipality
- validity of data: checks on histology, analysis per tumour site
- comparison of age-adjusted incidence rates per tumour site with data from foreign registries
- checks on incidence/mortality ratio's

1985: Extension of items per patient according to the recommendations of working party on national cancer registry: introduction of new registration forms and patient identification.

1986: Implementation of dedicated software for validity and consistency checking (conversion of some modules from the SEER program NCI, USA).

FUTURE: Research oriented facilities needed.

HARDWARE

1980-1983 DEC 20/60 (time sharing)
1983-1984 IBM 4331 (time sharing)
1985- IBM 4361 (host)
        IBM PC/XT remote terminal

FUTURE IBM 4361 host with IBM PC/XT

SOFTWARE

RTL/2. sequential file
COBOL, sequential file
SAS-BASIC for multi purpose data management, report writing and statistical analysis.
SAS-FSP for full screen data entry and editing functions.
Local research facilities with SAS-PC?

APPLICATIONS OF CANCER REGISTRY DATA

CO-OPERATION IN COHORT STUDIES

R = routine; core data adequate
O = optional; additional data collection required

CLINICAL STUDIES PROSPECTIVE & RETROSPECTIVE

ANALYTIC EPIDEMIOLOGIC RESEARCH: POPULATION BASED CASE-REFERENT STUDIES

ESTIMATION OF POPULATION BASED "RELATIVE" SURVIVAL RATES AND PREVALENCE RATES

DESCRIPTIVE EPIDEMIOLOGY: MONITORING OF CANCER RISE AND MORTALITY ECOCLOGICAL STUDIES

CANCER REGISTRY (CORE DATA)
EXPERIENCE WITH SAS-SOFTWARE AND ANTICIPATED POTENTIALS

Shortly after the evaluation of the cancer registry data on completeness and validity was finished, we decided to implement SAS-base and SAS-FSP software in order to improve data management facilities compared with the sequential file handling (RTL/2 and COBOL) previously in use.

This choice was made on recommendations from colleagues, working in cancer registries abroad and judgement of the local situation and possibilities on the other hand.

Conversion to SAS went very prosperously and we soon experienced to our satisfaction the considerable improvement in data management facilities.

Besides, as a SAS-user we expect to be able to join hands easily with colleagues from research institutes, e.g. universities - as SAS products diffused widely in that field - to help us to develop the cancer registry in the service of the community by carrying out the projects displayed in figure 4.

The development and recent release of PC-SAS also has great potentials in our field for setting up distributed data management with adequate uniformity and quality coupled with flexibility and we think this approach will stimulate collaboration.

Reference: