The inflammatory bowel diseases (IBD), Crohn’s disease (CD) and ulcerative colitis (UC) are characterized by chronic intestinal inflammation with periodic exacerbation and a variety of local and systemic complications. The incidence rates, particularly of CD, have probably increased in the last decades. The incidence of IBD in the Scandinavian countries is considered to be among the highest in Europe, with peak incidence rates in younger adults. In the county of Copenhagen, which represents 10% of the Danish population, the estimated prevalence in 1987 for CD and UC was 54 and 160 per 100 000 inhabitants, respectively. The diseases are relatively rare, making it expensive and time consuming to estimate incidence in follow-up studies since they have to be large; furthermore it is difficult to continue prospective registration for many years, and surveillance bias may be a problem if attention varies from region to region and over time. Therefore it would be of value if existing registers could provide data of acceptable quality for surveillance of IBD.

The aims of this study were (i) to estimate incidence rates of CD and UC by using the Danish National Registry of Patients from 1981 to 1992, and (ii) to compare the estimated rates with existing epidemiological data from primary data collection.
MATERIALS AND METHODS
All inpatients with CD and UC are treated free of charge in public hospitals in Denmark. Since 1977, all patients are registered in the National Registry of Patients (NRP) when they are discharged from Danish public hospitals. Coding takes place at the department in charge of treatment when the discharge summaries are written. The registration includes the patient’s personal identification number (given to all citizens in Denmark at birth), discharge diagnoses and operations performed. The population of Denmark was about 5.1 million inhabitants in the study period.

We used the Danish version of the Eighth Edition of the International Classification of Diseases (ICD-8) during the entire period. All the patients who were discharged with affirmative CD (563.01) or UC (563.19 or 569.04) were identified in the Danish NRP from 1 January 1977 to 31 December 1992.

The annual incidence rates for each of the two diseases and for each sex were estimated as the number of patients entered in the NRP for the first time, divided by the number of inhabitants in the middle of the same calendar year. Some of the patients were registered as CD at one discharge and as UC at another. In order to compare changes in the incidence rate over time, patients registered as having both CD and UC were included under the first disease registration in the NRP. The incidence rates were directly standardized to the 1992 Danish population using 15-year age groups. Since prevalent cases would be registered for the first time in the years after the start of the registry in 1977, data from 1977 to 1980 were excluded.

Figure 1 shows the age-standardized rates of the first registered admission for CD. When the registry started in 1977, the estimated rate was about 9 per 100 000 person years for women and 5 per 100 000 person years for men, decreasing rapidly during the following years to 5.0 per 100 000 person years for women and 3.5 per 100 000 person years for men. From 1983 and up to 1992 the rate for both men and women tended to increase. The mean incidence rate during the study period was 4.6 per 100 000 per year (5.4 per 100 000 per year for women and 3.7 per 100 000 per year for men). Table 2 summarizes the age-adjusted incidence rates in three time periods and shows an increasing incidence.

Table 3 gives the mean incidence rate and the relative change in incidence rate per year. There was a peak incidence rate in the 15–29 year olds. The incidence rate increased in most age groups, with the highest increase in women between 15 and 29 and women older than 75. For the last group the relative change in incidence rate
The incidence rate of Crohn’s disease using the first admission in the National Registry of Patients, 1977–1992

The incidence rate was directly standardized to the 1992 Danish population by 15-year age groups.

**Table 2** Mean incidence rate for Crohn’s disease in three time periods using the National Registry of Patients (NRP), 1981–1992

<table>
<thead>
<tr>
<th>Time period</th>
<th>Total number of patients</th>
<th>Mean incidence rate per 100 000 person years (95% confidence interval [CI])a</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>1981–1984</td>
<td>453</td>
<td>321</td>
</tr>
<tr>
<td>1985–1988</td>
<td>581</td>
<td>395</td>
</tr>
<tr>
<td>1989–1992</td>
<td>645</td>
<td>411</td>
</tr>
</tbody>
</table>

a The incidence rate was directly standardized to the 1992 population by 15-year age groups. The 95% confidence intervals were based on assumption of the Poisson distribution.

**Table 3** Mean incidence rates of Crohn’s disease in different age groups and the changes in incidence over time, 1981–1992, estimated by the Poisson regression model

<table>
<thead>
<tr>
<th>Age groupa</th>
<th>Total no. of patients</th>
<th>Mean incidence rate per 100 000 person years</th>
<th>Relative change in incidence rate per year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>&lt;15 years</td>
<td>31</td>
<td>52</td>
<td>0.6</td>
</tr>
<tr>
<td>15–29 years</td>
<td>615</td>
<td>381</td>
<td>9.1</td>
</tr>
<tr>
<td>30–44 years</td>
<td>419</td>
<td>294</td>
<td>6.2</td>
</tr>
<tr>
<td>45–59 years</td>
<td>255</td>
<td>192</td>
<td>5.0</td>
</tr>
<tr>
<td>60–74 years</td>
<td>242</td>
<td>156</td>
<td>5.3</td>
</tr>
<tr>
<td>≥75 years</td>
<td>117</td>
<td>52</td>
<td>4.6</td>
</tr>
</tbody>
</table>

a Age at first admission.
was 1.08 per year, resulting in a doubling of the incidence rate in 10 years.

Figure 2 shows the age-standardized rates of the first registered admission for UC. In 1977 the estimated rates were 25 per 100,000 person years for women and 23 per 100,000 person years for men, but decreased to about 15 per 100,000 person years for both women and men in 1980. From 1981 to 1992 a slower decrease was found. The mean incidence rate in the study period was 13.2 per 100,000 per year (13.4 per 100,000 per year for women and 13.0 per 100,000 per year for men). Table 4 summarizes the age-adjusted incidence rates in three time periods and a decreasing tendency was found.

Table 5 shows the mean incidence rate and relative change in incidence rate per year. The incidence rate was low in children, higher in younger adults, and especially high in men over 60. The rate decreased in most age groups.

**DISCUSSION**

Hospital discharge data were used to estimate incidence rates over a 12-year time span. The incidence rate increased for CD but was rather stable, with a tendency to decrease, for UC.

The present study supports previous findings of high incidence rates for both CD and UC in Denmark.²,³
There are genetic factors in the aetiology of IBD, but environmental causes are probably more important.\textsuperscript{2,23,24} The rapid and continuing increase in the incidence of CD points to an increase in an environmental factor or lack of comparability over time.

Various aspects must be considered when evaluating the results. The study was based on discharge diagnoses which may vary in quality between different hospitals and over time. If discharge diagnoses have reduced validity (i.e. the predictive value of a positive registration is low) the incidence rate would be overestimated, and if the completeness (an estimate of the sensitivity) is reduced this would give an underestimation of the underlying incidence rate. Even with misclassification it may still be possible to detect variations in the incidence rates, given that the type and magnitude of the misclassification do not change over time.\textsuperscript{18}

We validated the diagnoses of CD and UC in the NRP in the County of North Jutland in order to estimate the magnitude of misclassification. The completeness of the NRP, using a pathology information system as a reference standard, was 94\% for both diseases, and the validities (i.e. the percentage of patients registered under the disease code fulfilling the criteria of CD and UC) were 97\% and 90\% for CD and UC, respectively.\textsuperscript{25} This could indicate that the incidence rate for CD is slightly underestimated and for UC slightly overestimated, but nothing is known about changes in the misclassification over time.\textsuperscript{18}

The study indicated that it is possible to get reliable estimates of the incidence rates, especially for CD. The estimates of the incidence rates based on the Danish NRP will probably be even more complete in the future because from 1994 outpatients are also included.

### Table 5: Mean incidence rates of ulcerative colitis in different age groups and the changes in incidence over time, 1981–1992, estimated by the Poisson regression model

<table>
<thead>
<tr>
<th>Age group\textsuperscript{a}</th>
<th>Total no. of patients</th>
<th>Mean incidence rate per 100 000 person years</th>
<th>Relative change in incidence rate per year (95% confidence intervals [CI])</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>&lt;15 years</td>
<td>159</td>
<td>123</td>
<td>2.9</td>
</tr>
<tr>
<td>15–29 years</td>
<td>1103</td>
<td>908</td>
<td>16.3</td>
</tr>
<tr>
<td>30–44 years</td>
<td>1043</td>
<td>1010</td>
<td>15.6</td>
</tr>
<tr>
<td>45–59 years</td>
<td>674</td>
<td>744</td>
<td>13.1</td>
</tr>
<tr>
<td>60–74 years</td>
<td>751</td>
<td>783</td>
<td>16.5</td>
</tr>
<tr>
<td>&gt;75 years</td>
<td>451</td>
<td>376</td>
<td>18.1</td>
</tr>
</tbody>
</table>

\textsuperscript{a} Age at first admission.
to make links to several data sources, e.g. registers of cancer, births, and causes of deaths making clinical and epidemiological research based on the whole population possible. It will be important to follow the development of IBD, especially to see if the differences in Europe persist.

ACKNOWLEDGEMENTS
The study was supported by the Beckett Foundation, the North Jutland Research Foundation, the Foundation of Director Jacob Madsen and his wife Olga Madsen, and the memorial grant of John M Klein and his wife. The activities of The Danish Epidemiology Science Centre are financed by a grant from The Danish National Research Foundation.

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(Revised version received January 1997)