



Original Research

# Underestimation of pancreatic cancer in the national cancer registry – Reconsidering the incidence and survival rates



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## KEYWORDS

Cancer registration;  
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**Abstract Background:** In the Netherlands, like in many other European countries, pancreatic cancer mortality was found to be systematically higher than the incidence. This suggests that there is an underestimation of the reported incidence of pancreatic cancer.

**Aim:** We aimed to study the incidence of pancreatic cancer in the Rotterdam area and to compare this with the national level.

**Methods:** This study is embedded in the Rotterdam Study (RS), an ongoing population-based prospective cohort study of people aged 45 years and above, enrolled between 1989 till 2006. Details on incident pancreatic cancer cases were available until 2013. Age-specific incidence rates were calculated and compared with data available in the Netherlands Cancer Registry.

**Results:** At baseline 14,922 participants were at risk of developing pancreatic cancer. Median follow-up time was 16.4 person years per person. In total, 113 participants developed pancreatic cancer. Rates increased with age with an incidence rate of 109.9 (95% confidence interval [CI]; 85.7–138.8) per 100,000 person years for people older than 75. This is higher than the currently reported 55.9–89.2 per 100,000 person year. Of the 113 cases identified in the RS, only 67.3% was reported as pancreatic cancer in the Netherlands Cancer Registry. Cases that were not registered were significantly older and had significantly poorer survival.

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**Conclusion:** The incidence of pancreatic cancer, as registered by the Netherlands Cancer Registry, is an underestimation. Patients, not registered by the cancer registry, have a significantly poorer survival. Consequently, we probably overestimate the already poor survival of pancreatic cancer.

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## 1. Introduction

Pancreatic cancer is currently one of the most lethal types of cancer in Europe and has a 5-year survival of around 5% [1]. Due to ageing of populations, the incidence of pancreatic cancer has increased over the past few decades in Europe [1,2]. In the past decade some improvement in survival has been reported, but still [3] it is expected to become the second deadliest cancer by the end of 2020 [2,4].

In line with this European trend, the incidence rate of pancreatic cancer has increased in the Netherlands as well. The estimated incidence rate varies from 0.5 to 3.6 per 100,000 person years for persons younger than 50 years to 55.9 to 89.2 per 100,000 person years for persons older than 75 years [5].

In the Netherlands, cancer incidence is registered nationwide by the Netherlands Comprehensive Cancer Registration (IKNL). Cause of death, however, is registered by a different body: Statistics Netherlands (CBS). They collect death certificates from the Municipal Personal Records Database (BRP) with date and cause of death as assigned by treating physicians.

Between 2010 and 2014, the number of new cases diagnosed ranged from 2198 to 2326 [6]. Interestingly, in those same years, fewer patients were diagnosed with pancreatic cancer than those died of this cancer (2481–2682) [7]. In fact, the rate of pancreatic cancer mortality has been systematically higher than the incidence rate, since the start of the Netherlands Cancer Registry (NKR) in 1989 [6]. Above numbers suggest an underestimation of the true incidence of pancreatic cancer or an overestimation of pancreatic cancer mortality, which could be important for several reasons. Firstly, because these numbers are supposed to inform clinicians and their patients. Secondly because incidence and mortality rates largely influence the way we prioritise our focus in studying different diseases and lastly because these numbers are used to advise health care and insurance company policy makers.

The objectives of this study were to establish the incidence rate of pancreatic cancer and its mortality in a large and long-standing population-based prospective cohort study and to extrapolate this number to a national level to get insight into this discrepancy in figures from national registries.

## 2. Patients and methods

### 2.1. Study population

The study was embedded in the Rotterdam Study (RS), an ongoing population-based prospective cohort study in the Netherlands. The rationale and design have been described extensively previously [8,9]. Briefly, in 1989 inhabitants of the suburb Ommoord, aged 55 years and older, were invited to participate. The original cohort was enrolled between 1989 and 1993. Of 10,275 invited subjects, 7983 entered the study (78%). A second cohort of 3011 persons (67% response) was enrolled between 2000 and 2001. In 2006, a third cohort with 3932 persons of 45 years and older were enrolled (65% response). This resulted in an overall study population of 14,926 individuals aged 45 years and above.

The RS has been approved by the institutional review board (Medical Ethics Committee) of the Erasmus Medical Center and by the review board of The Netherlands Ministry of Health, Welfare and Sports.

### 2.2. Assessment of cancer cases

#### 2.2.1. Rotterdam Study

In this study, cases of pancreatic cancer were identified through follow-up of medical records of the general practitioners, by hospital discharge letters and furthermore through linkage with the Dutch Hospital Data (Landelijke Basisregistratie Ziekenhuiszorg, previously Landelijke Medische Registratie) and registries of histology and cytopathology. Cases were classified according to the International Statistical Classification of Diseases, 10th revision (ICD-10) and the International Classification of Primary Care, 2nd edition (ICPC-2) [10,11].

All potential cases of pancreatic cancer and level of certainty, thereof, were independently adjudicated by two physicians (JF, RR). In case of disagreement, consensus was sought through consultation of an experienced pancreatic surgeon (CvE).

Level of certainty of diagnosis was established as: certain (pathology confirmed), probable (clinical diagnosis based on a mass in the pancreas and/or liver metastases on CT-scan, ultrasound or endoscopic ultrasonography and/or increased levels of CA19.9), or possible (e.g. an uncircumscribed mass by physical

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