



UMEÅ UNIVERSITET

Umeå University Medical Dissertations, New Series No 1945

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# Data quality in the National Prostate Cancer Register (NPCR) of Sweden

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## Akademisk avhandling

som med vederbörligt tillstånd av Rektor vid Umeå universitet för avläggande av medicine doktorsexamen framläggs till offentligt försvar i Hörsal E04 i Farmakologihuset, Norrlands Universitetssjukhus fredagen den 2 mars 2018, kl. 09:00.  
Avhandlingen kommer att försvaras på svenska.

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**Organization**

Umeå University  
Department of Surgical and  
Perioperative Sciences,  
Urology and Andrology

**Document type**

Doctoral thesis

**Date of publication**

9 February 2018

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**Title**

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**Abstract**

**Background:** Data in quality registers are increasingly used for quality assurance of health care, benchmarking, and research. If valid conclusions are to be drawn from such studies, it is vital that register data have high quality. The aim of this thesis was to assess data quality in the National Prostate Cancer Register (NPCR) of Sweden, a nationwide register that since 1998 captures 98% of all cases of Prostate cancer (Pca) in Sweden. The proportion and characteristics of Pca cases not registered in NPCR was investigated in paper I. Four dimensions of data quality were evaluated for NPCR in paper II: completeness, timeliness, comparability, and validity. Proportion and characteristics of Pca cases registered in NPCR but with unknown risk category were investigated in paper III. Finally, the association between Socioeconomic Status (SES) and Pca diagnosis, treatment, and mortality was studied in paper IV.

**Material and methods:** Data quality of NPCR was studied by cross-linkages between NPCR and other health care registers and demographical databases by use of the Swedish personal identity number. Validity was further studied by re-abstraction of patient health care records, followed by comparison of re-abstracted and original register data.

**Results:** Men not registered in NPCR, who constituted around 2% of all cases in the Swedish Cancer Register, differed only modestly in characteristics from cases in NPCR, indicating that NPCR is generalizable for all men with Pca in Sweden. Data quality in NPCR was high overall, with high completeness compared to the Swedish Cancer Register with registration mandated by law and few Pca cases were detected by use of death certificates. There was timely registration, and good comparability with registration forms and coding routines that were compliant with international guidelines. Data validity was high with high agreement and correlation for key variables. Men with unknown risk category had, compared to men with known risk category, more often concomitant bladder cancer, higher comorbidity, and lower Pca mortality. Men with high SES had, compared to men with low SES, higher probability of Pca detected during health checkup, shorter waiting times for prostatectomy, and higher probability of curative treatment for intermediate and high-risk cancer. Pca mortality was lower in men with high SES than in men with low SES for high-risk cancer.

**Conclusion:** These results indicate that data quality in NPCR is high and that NPCR is population-based. There were consistent differences in diagnostic and therapeutic activity according to SES despite an equal access tax-financed healthcare system in Sweden.

**Keywords**

Prostate cancer, Cancer quality register, Data quality, Evaluation, Validity

**Language**

English

**ISBN**

978-91-7601-831-6

**ISSN**

0346-6612

**Number of pages**

44 + 4 papers