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Evaluation of data quality in the National Prostate Cancer Register of Sweden

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Abstract ***Background:*** Data in cancer quality registers are increasingly used for quality assurance, benchmarking, and research.
Materials and methods: Data in the National Prostate Cancer Register (NPCR) of Sweden were evaluated for completeness, timeliness, comparability and validity. Completeness and timeliness were assessed by cross-linkage to the Swedish Cancer Register, comparability was examined by comparing registration routines in NPCR with national and international guidelines, and validity was assessed by re-abstraction of data from medical charts for 731 men diagnosed with prostate cancer (Pca) in 2009. Furthermore, data on treatment were validated by record linkage to the Swedish Patient Register and The Prescribed Drug Register.
Results: NPCR captured 98% of Pca cases in the Cancer Register and the mean value for completeness of the 48 evaluated variables was 90% (range 64–100%). Timeliness increased substantially from 2008 to 2012 with 95% of cases reported within 12 months after diagnosis in 2012. NPCR complied with national and international coding routines. Overall, the agreement between original data and re-abstracted data from 731 charts was high. For example, the correlation between original and re-abstracted data was 1.00 for date of surgery, and 0.97 for serum levels of prostate specific antigen and exact agreement was 97% for Gleason score at biopsy, 83% for clinical local T stage and more than 95% of the androgen deprivation therapies registered in NPCR had a corresponding filled prescription.

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Conclusion: Record linkages with other data sources and re-abstraction of data showed that data quality in NPCR is high.

1. Introduction

Data in cancer quality registers are increasingly used for quality assurance, benchmarking and in research [1,2]. Thus, high data quality is crucial if valid conclusions are to be based on information available in such registers [3–6]. Guidelines on evaluation of data quality have been published by the International Agency for Research on Cancer (IARC) [7], including methods for assessing completeness, timeliness, comparability and validity [8,9]. These four dimensions represent key aspects of register data quality and the aim of this study was to assess these aspects of data quality in the National Prostate Cancer Register (NPCR) of Sweden, the largest cancer quality register in Sweden [10].

2. Materials and methods

The structure and development of NPCR has recently been comprehensively described [10]. In brief, NPCR is nation-wide since 1998, and registers data on diagnostic work up, tumour characteristics and primary treatment in men with incident prostate cancer (Pca). Tumour characteristics are reported according to tumour, node and metastases classification (TNM) by use of the Union Internationale Contre le Cancer (UICC) classification of 2009 – 7th edition with some modifications [11,12]. From 2000, tumour differentiation is registered according to the Gleason classification system, and since 2007 data on prostate volume, number of biopsies positive for cancer and linear extent of cancer on diagnostic biopsies are also registered. Prostate adenocarcinomas are included in NPCR according to the International Classification of Diseases by The World Health Organisation (ICD-10 C619). The corresponding systemised nomenclature of medicine (SNOMED) codes used for detailed histology-topology classification of tumours [13] is as follows: adenocarcinomas (81403), ductal adenocarcinoma (85003), signet ring cell adenocarcinoma (84903), mucinous adenocarcinoma (84803) and small cell neuroendocrine cancer (82463). Clinically diagnosed Pca (80003) is also reported. Registration is performed by designated staff using three forms on the web based platform INCA (Information Network for Cancer care) [14]. The recording staff is employed by each department and there is an annual workshop for this staff on data extraction organised by NPCR with the aim of increasing data quality. The registration forms contain a brief definition of each variable with a more comprehensive user guide available on the NPCR web site [12]. The diagnostic form also serves as the clinical report to the Cancer Register, to which reporting is mandated. Before final entry to the NPCR database, data are checked for completeness by a monitor at each respective Regional Cancer Centre. The INCA platform has been in use since 2007 and is currently used by 31 national cancer quality registers and contains data on more than 400,000 cancer cases.

To assess completeness and timeliness, registration status and date of registration in NPCR were compared to data in the Swedish Cancer Register that are based on two independent sources of information, from the diagnostic pathology department and from the treating clinical department. Reporting to the Cancer Register is compulsory and mandated by law [15].

Comparability was examined by a review of the NPCR manuals and reporting forms, comparing the routines in NPCR with national and international guidelines [16].

Validity of reported data was assessed by re-abstraction of data from medical charts for 735 randomly selected men diagnosed with Pca in 2009. Re-abstraction was performed by two nurses with extensive experience in monitoring of clinical trials as well as registration at the INCA platform who had no current affiliation with the reporting units or NPCR. Data were re-abstracted at 12 hospitals and five private health care providers selected to ensure a wide geographical distribution with inclusion of both public and private health care providers of different size and case mix (Fig. A1 Appendix). The re-abstracted data were registered in a separate specific form on the INCA platform and compared with data from the original registration.

In addition, data in NPCR were assessed by record linkages between NPCR, the Patient Register, and the Prescribed Drug Register. The Patient Register provided information on radical prostatectomy (KEC00, KEC01, KEC10, and KEC20) and surgical castration (bilateral orchiectomy) (KFC00, KFC10, and KFC15). Primary androgen deprivation therapy with GnRH analogues (ATC L02AE) and anti-androgens (ATC L02BB) was assessed by comparing data in NPCR with filled prescriptions in the Prescribed Drug Register which includes all filled prescriptions in Sweden since July 2005. Data include the prescribed drug, amount and dose, and date of prescription and date of filling [17]. A separate linkage was performed in order to identify men with prostate cancer in the Cancer Register and