

## COHORT PROFILE

# Cohort Profile: The National Prostate Cancer Register of Sweden and Prostate Cancer data Base Sweden 2.0

Mieke Van Hemelrijck,<sup>1\*</sup> Annette Wigertz,<sup>2</sup> Fredrik Sandin,<sup>2</sup> Hans Garmo,<sup>1,2</sup> Karin Hellström,<sup>2</sup> Per Fransson,<sup>3</sup> Anders Widmark,<sup>4</sup> Mats Lambe,<sup>2,5</sup> Jan Adolfsson,<sup>6</sup> Eberhard Varenhorst,<sup>7</sup> Jan-Erik Johansson,<sup>8</sup> and Pär Stattin<sup>9,10</sup> for NPCR and PCBaSe Sweden<sup>†</sup>

<sup>1</sup>King's College London, School of Medicine, Division of Cancer Studies, Cancer Epidemiology Group, London, UK, <sup>2</sup>Regional Cancer Centre, Uppsala University Hospital, Uppsala, Sweden, <sup>3</sup>Department of Nursing, Umeå University, Umeå, Sweden, <sup>4</sup>Department of Radiation Sciences, Oncology, Umeå University, Umeå, Sweden, <sup>5</sup>Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Stockholm, Sweden, <sup>6</sup>Oncological Centre, CLINTEC Department, Karolinska Institutet, Stockholm, Sweden, <sup>7</sup>Department of Urology, Linköping University Hospital, Linköping, Sweden, <sup>8</sup>Department of Urology, Örebro University Hospital and Örebro University, <sup>9</sup>Department of Surgical and Perioperative Sciences, Urology and Andrology, Umeå University, Umeå, Sweden and <sup>10</sup>Department of Surgery, Urology Service, Memorial Sloan-Kettering Cancer Center, New York, NY, USA

\*Corresponding author. King's College London, School of Medicine, Division of Cancer Studies, Cancer Epidemiology Group, Research Oncology, 3rd Floor, Bermondsey Wing, Guy's Hospital, London SE1 9RT, UK.

E-mail: mieke.vanhemelijck@kcl.ac.uk

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In 1987, the first Regional Prostate Cancer Register was set up in the South-East health-care region of Sweden. Other health-care regions joined and since 1998 virtually all prostate cancer (PCa) cases are registered in the National Prostate Cancer Register (NPCR) of Sweden to provide data for quality assurance, benchmarking and clinical research. NPCR includes data on tumour stage, Gleason score, serum level of prostate-specific antigen (PSA) and primary treatment. In 2008, the NPCR was linked to a number of other population-based registers by use of the personal identity number. This database named Prostate Cancer data Base Sweden (PCBaSe) has now been extended with more cases, longer follow-up and a selection of two control series of men free of PCa at the time of sampling, as well as information on brothers of men diagnosed with PCa, resulting in PCBaSe 2.0. This extension allows for studies with case-control, cohort or longitudinal case-only design on aetiological factors, pharmaceutical prescriptions and assessment of long-term outcomes. The NPCR covers >96% of all incident PCa cases registered by the Swedish Cancer Register, which has an underreporting of <3.7%. The NPCR is used to assess trends in incidence, treatment and outcome of men with PCa. Since the national registers linked to PCBaSe are complete, studies from PCBaSe 2.0 are truly population based.

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## Why was the cohort set up?

In January 1987, the first Regional Prostate Cancer Register was set up in the South-East health-care region of Sweden to enable epidemiological surveillance in terms of stage-specific incidence and treatment outcomes. In 1992, a similar register was set up in the Northern Sweden region, followed by similar initiatives in the Southern and Uppsala–Örebro region. These registers then formed the National Prostate Cancer Register (NPCR) of Sweden in 1996. The Western region joined in 1997, followed by the Stockholm–Gotland region in 1998 and since then virtually all incident cases of prostate cancer (PCa) in Sweden have been registered in the NPCR (Figure 1).<sup>1</sup> The primary aim of the NPCR is to provide data for quality assurance, bench marking of patient care and clinical research.

## Who is in the cohort and how often have they been followed up?

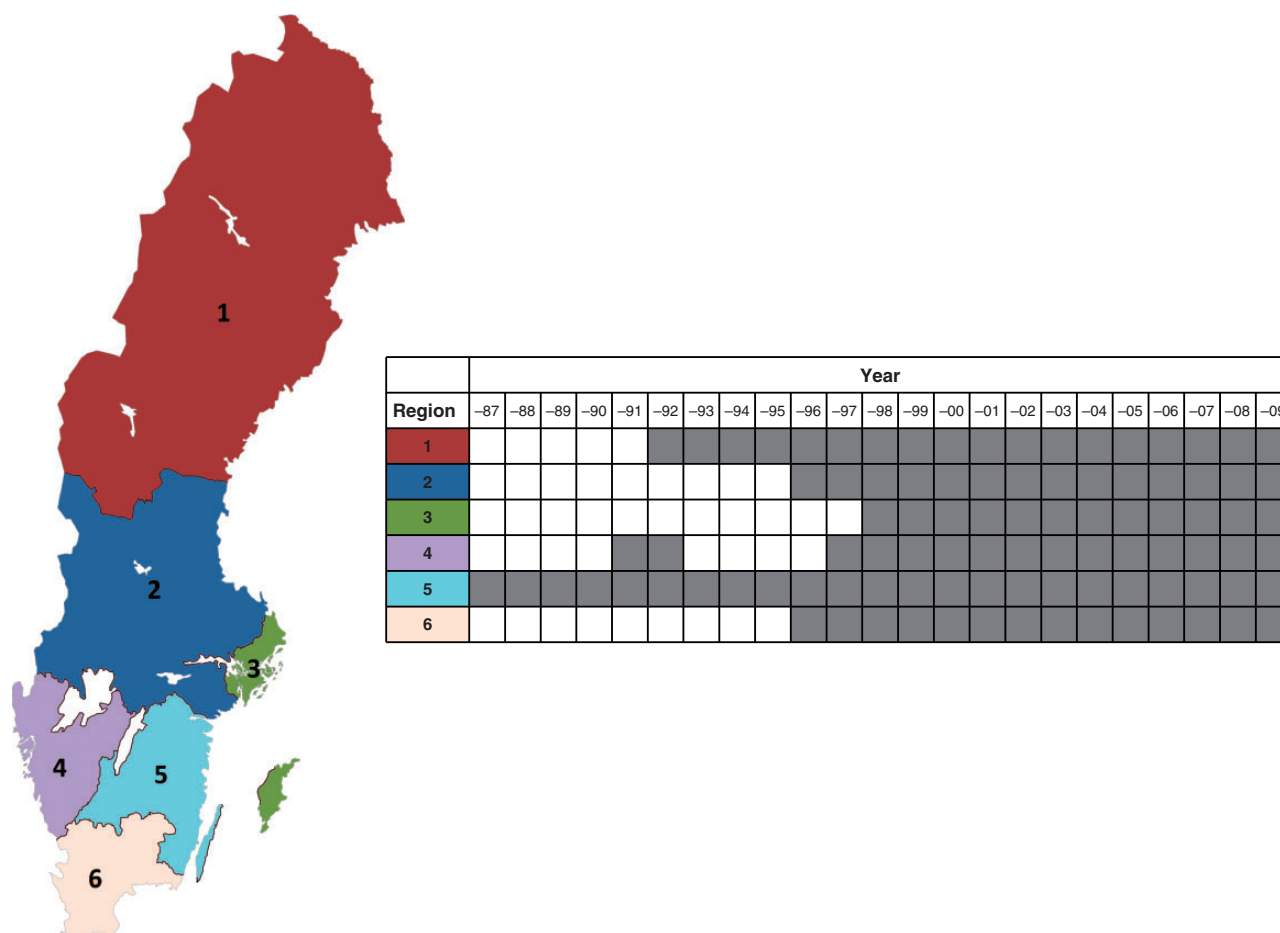
NPCR captures >96% of all newly diagnosed, biopsy-confirmed PCas registered in the Swedish National

Cancer Register, to which registration is compulsory and mandated by law.<sup>2,3</sup> Reports to the Cancer Register are obtained from the treating clinician and the pathology department that made morphological diagnosis.<sup>4</sup>

All new incident cases of prostate adenocarcinomas are reported to the respective regional register, which are also regularly linked to each Regional Cancer Register, and data on cases not reported to NPCR are requested from each reporting clinical unit.<sup>5</sup> Data are validated and checked for completeness at each Regional Cancer Centre before being entered to the online IT platform Information Network for Cancer care (INCA).<sup>6</sup> Updates and corrections of previous years are made continuously. Until 2006, personal identity numbers (PINs) were not included in the central database of the NPCR, which meant that patients could only be followed up in regional databases. However, as of January 2007, PINs for all cases in NPCR diagnosed before and after that date have been added to the NPCR.

### Attrition

NPCR covers >96% of all newly diagnosed, biopsy-confirmed PCas registered by the Swedish Cancer



**Figure 1** The six regions in Sweden registering information on prostate cancer diagnoses for the NPCR and the year the registration was introduced

Register,<sup>2</sup> which has an underreporting for PCa of <3.7%.<sup>4,7</sup> Validity of data on primary treatment is estimated to be >90% for curative treatment and surveillance, and >95% for endocrine treatment (unpublished data). [Supplementary Appendix Tables 1–4](#), available as [Supplementary data at IJE online](#), illustrate capture ratios for all variables registered in NPCR.

## What has been measured?

Prostate adenocarcinomas are registered in NPCR, but no other forms of neoplasia of the prostate. The variables registered at present (2011) are demonstrated in [Supplementary Appendix Tables 1–4](#), available as [Supplementary data at IJE online](#). Since the start of NPCR, new variables have been added. For instance, cause of the medical examination leading to diagnosis of PCa was added in 2000, i.e. whether diagnosis followed from assessment of a symptomatic man or from PSA-testing of an asymptomatic man. In the late 1990s, a decision was made by the NPCR steering committee to recommend use of the Gleason grading system instead of the previously used WHO grading, a change which was completed in all Swedish health-care regions in 2000. In parallel, a tutorial was provided among Swedish pathologists to achieve a more standardized use of the Gleason score.<sup>8</sup> Recently, we also started using PCa risk categories based on a modification of the guidelines of the National Comprehensive Cancer Network (NCCN).<sup>9</sup> The NCCN does not distinguish between regionally metastatic and distant metastatic disease and since outcomes differ between these categories, we have divided the NCCN category ‘disseminated PCa’ accordingly. An overview of these risk categories is provided in [Table 1](#) and their incidence is presented in [Figure 2](#).

As of 2007, more detailed data on biopsy procedure and surgical treatment are registered. Conservative management is reported as active surveillance (with intention of curative treatment when progression occurs) or watchful waiting (with intention of endocrine therapy at time of progression in men with short life expectancy). Oncologists have been registering

information on primary curative radiotherapy since 2008 ([Supplementary Appendix Table 3](#), available as [Supplementary data at IJE online](#)).

In a separate effort, men aged <70 years with T1–2 tumours and serum PSA level <20 ng/ml at time of diagnosis and with no signs of disseminated disease who were diagnosed between 1997 and 2002 were followed up at a mean time of 4 years after diagnosis in a research project.<sup>2</sup> Subsequently, a 5-year follow-up of the same category of cases has been integrated into the regular NPCR. The variables that are recorded in this follow-up are depicted in [Supplementary Appendix Table 4](#), available as [Supplementary data at IJE online](#).

In 2008, the NPCR started to assess patient outcomes such as urinary incontinence and erectile dysfunction by use of questionnaires with Patient-Reported Outcome Measures (PROMs).<sup>10</sup> These questionnaires are intended to be distributed among patients prior to curative treatment, with a follow-up questionnaires provided 1 and 5 years after treatment (see [Appendix available as Supplementary data at IJE online](#)). An overview of all information collected in NPCR since 1998 is shown in [Figure 3](#).

For some men in NPCR data from lifestyle and health-care questionnaires as well as cryopreserved plasma and buffy coat are available as these men have participated in prospective cohort studies<sup>11–13</sup> or in a large case–control study, Cancer Prostate Sweden (CAPS), focusing on genetic association studies.<sup>14,15</sup> These settings create an ideal design for nested case–control studies with plasma available for biochemical analysis, DNA for genetic analyses and tumour characteristics from NPCR.

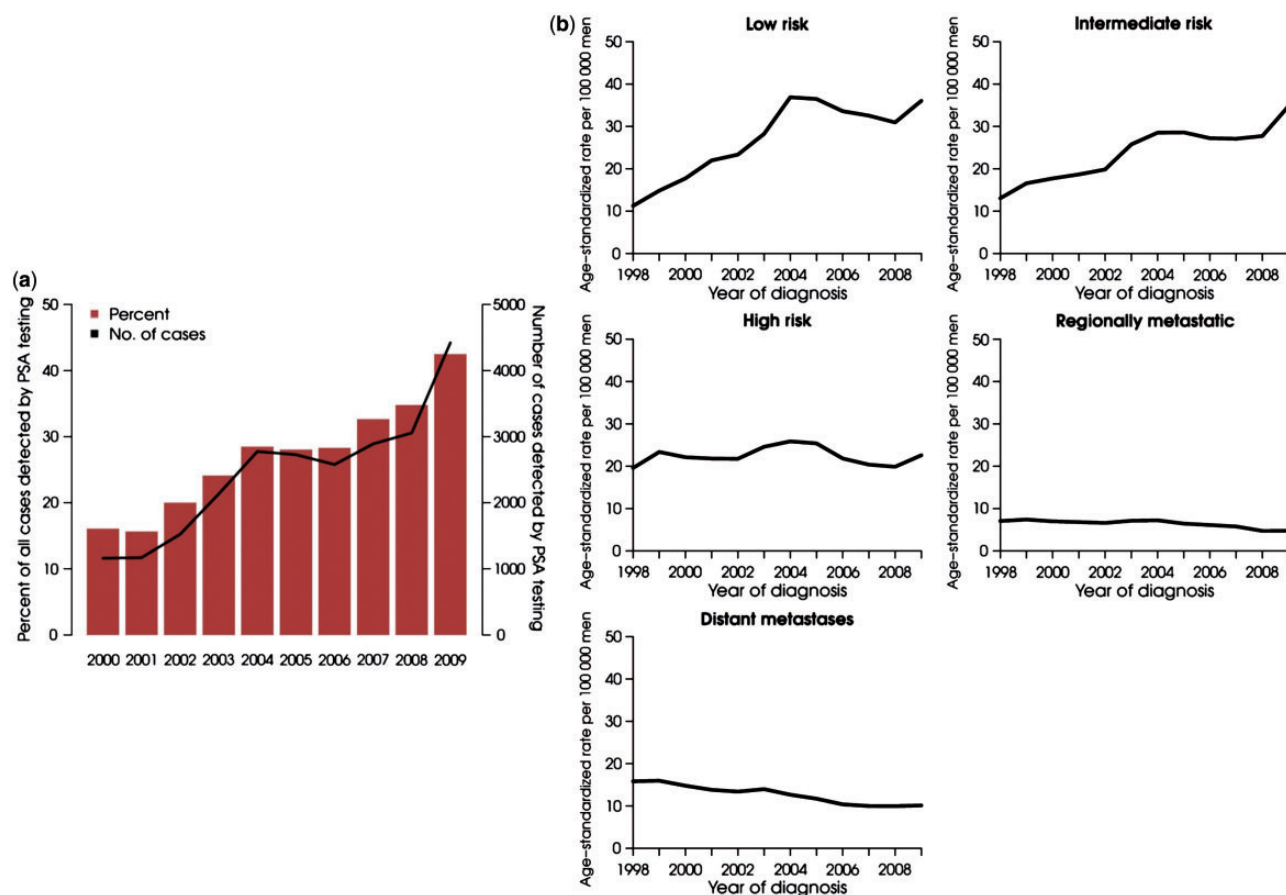
## PCBaSe

In 2008, NPCR was linked to a number of other population-based registers via the use of the PIN ([Table 2](#) and [Figure 4](#)). The aim of this linkage, named Prostate Cancer data Base Sweden (PCBaSe), was to create a database with extensive longitudinal data for a population-based, nation-wide cohort of men diagnosed with PCa.<sup>16</sup> This database has now been extended with more cases, longer follow-up and a selection of two control series of men free of

**Table 1** Definition of prostate cancer risk categories currently used in the NPCR

	Definition
<b>Risk categories<sup>a</sup></b>	
Localized prostate cancer	
Low risk	T1–2, Gleason score 2–6 and PSA <10 ng/ml
Intermediate risk	T1–2, Gleason score 7 and/or PSA 10 to <20 ng/ml
High risk	T3 and/or Gleason score 8–10 and/or PSA 20 to <50 ng/ml
Regionally metastatic/Locally advanced	T4 and/or N1 and/or PSA 50 to <100 ng/ml in the absence of distant metastases (M0 or Mx)
Distant metastases	M1 and/or PSA ≥100 ng/ml

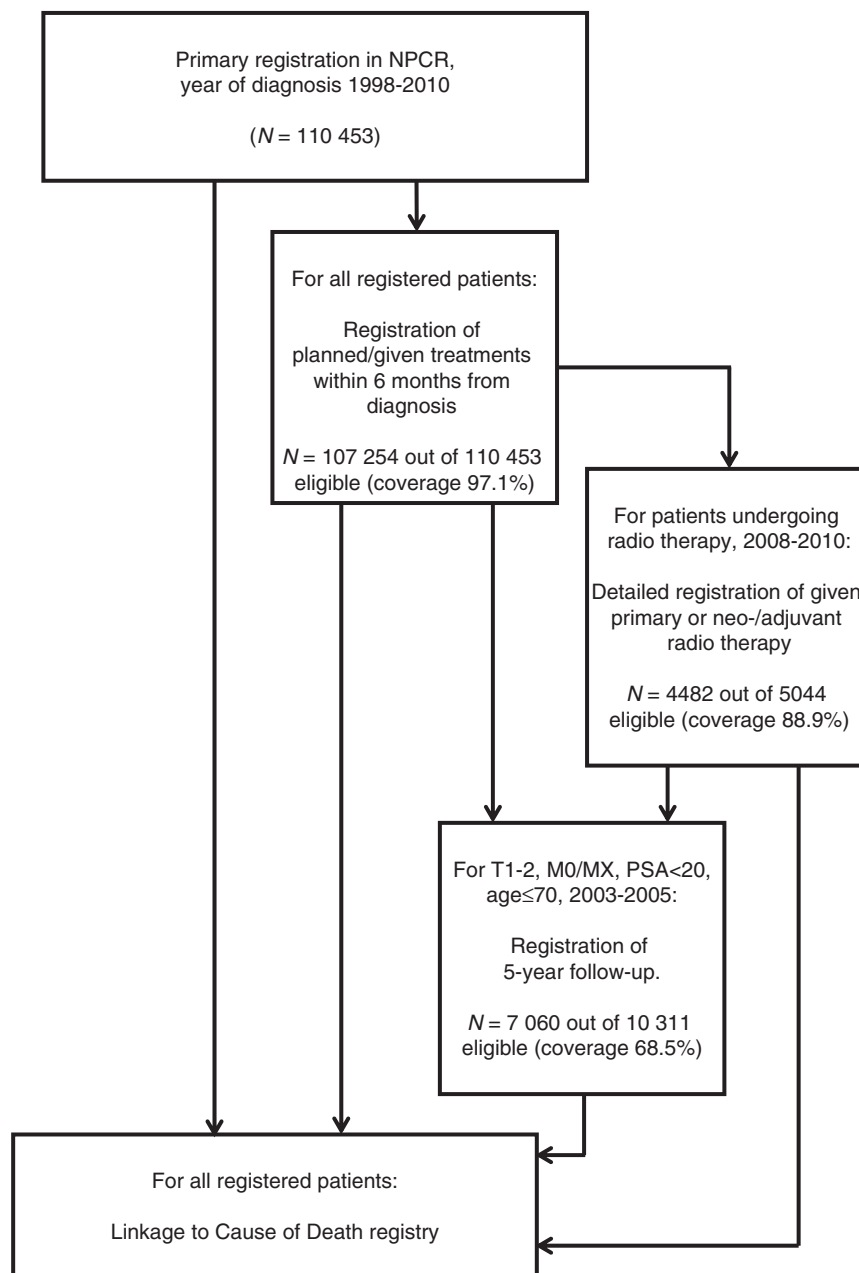
<sup>a</sup>Risk groups according to modification of the National Comprehensive Cancer Network Practice Guidelines in Oncology-Version 1.2010: prostate cancer.<sup>9</sup>



**Figure 2** (a) Proportion (percentage and number of cases) of prostate cancer patients diagnosed via PSA testing of asymptomatic men during the period 2000–09; (b) age-standardized incidence rates of prostate cancer by risk categories during the period 1998–2009 as defined in Table 1

**Table 2** Registers queried for information on subjects in PCBaSe 2.0 by linkage via PIN of cases in the NPCR of Sweden and their control series

Register	Data content
Swedish Cancer Register	Notification of cancer diagnosis, site and date. Reporting mandated by law from clinician and pathology department
Patient Register	In-patient and Out-patient Registers, with diagnostic and surgical codes
Cause of Death Register	Date and underlying and contributing causes of death coded according to ICD-10
Register of the Total Population and Changes	PIN for all Swedish residents, country of birth, marital status
Registers of Immigration and Emigration	Date of immigration and emigration
Sweden Household Census	Demographics collected 1960–90 including e.g. profession
Longitudinal database on socio-economic factors (LISA)	Extensive set of socio-economic factors with annual update including data on annual income, marital status, profession and income
The Prescribed Drug Register	All prescribed and dispensed drugs for all Swedish residents since July 2005
The Multi-Generation Register	Data on all residents born after 1932 with information on identity for father, mother, brothers, sisters and offspring
National Diabetes Register	Details on diabetes diagnosis and metabolic factors for ~50% of adults with diabetes in Sweden
Hernia Register	>95% of all hernia surgeries performed since 1992
Riks-HIA/Swede Heart	Details on infarct diagnoses and drugs on discharge since 1995, cardiac surgeries, etc.



**Figure 3** Flow diagram of data collection in NPCR since 1998, from that year NPCR is nationwide

PCa at the time of sampling, resulting in PCBaSe 2.0. This extension allows for observational studies with case-control, cohort or longitudinal case-only design that can be used for studies of pertinent clinical epidemiological issues.

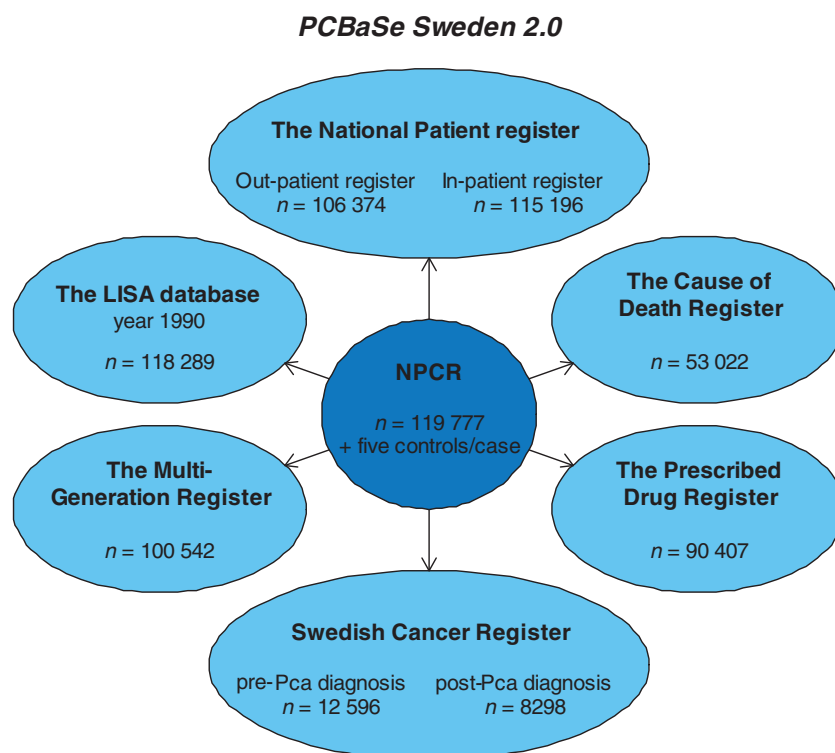
PCBaSe 2.0 includes data on 119 777 cases and data from up to 11 national registers. Besides all PCa cases in NPCR, it also contains two control series of men without PCa, denoted below as comparison cohorts, as well as information on brothers of men diagnosed with PCa (Supplementary Appendix Tables 5 and 6, available as Supplementary data at *IJE* online). More specifically, PCBaSe 2.0 contains one selection of

controls for case-control studies and one selection of a comparison cohort for prospective cohort studies. Some men without PCa may have been eligible for both comparison cohorts.

#### Controls for case-control studies

For each case of PCa, a set of controls was chosen in a ratio of 2:1 for the period of 1987–95 and in a ratio of 5:1 for the period of 1996–2009. Eligible controls were all men free of PCa at the end of the year of diagnosis of the index case, who lived in the same county as the case and were born in the same year. Cases and





**Figure 4** PCBaSe Sweden 2.0: linkage of NPCR to other national demographic and health-care registers

controls were thus matched by year of birth and county of residence. For men diagnosed with PCa at age  $\geq 90$  years, controls were only matched by year of birth due to the smaller available sample size of putative controls. Because of the above selection criteria, the same men may have been selected as controls for different cases (as long as the cases were diagnosed in a different year). A control was also allowed to become a case after the date of the index case.

#### Comparison cohort for prospective cohort studies

Follow-up started at time of PCa diagnosis for men with PCa (index cases) and ended at time of death, emigration or study closing date (31 December 2009), whichever came first. In studies where cause of death is of no interest, closing date was 1 June 2010. The comparison cohort for these men consists of men free of PCa who were randomly selected according to the eligibility criteria as described for the controls in the case-control studies (see above). For all men with PCa registered between 1987 and 1995, we selected two men free of PCa from the same county and birth year, and for those registered between 1996 and 2009 we selected five men free of PCa from the same county and birth year. Thus, for each man with PCa, PCBaSe 2.0 contains two or five matched men without PCa. Each man with PCa has a unique set of men without PCa in the comparison cohort. However, those without PCa were allowed to become an index

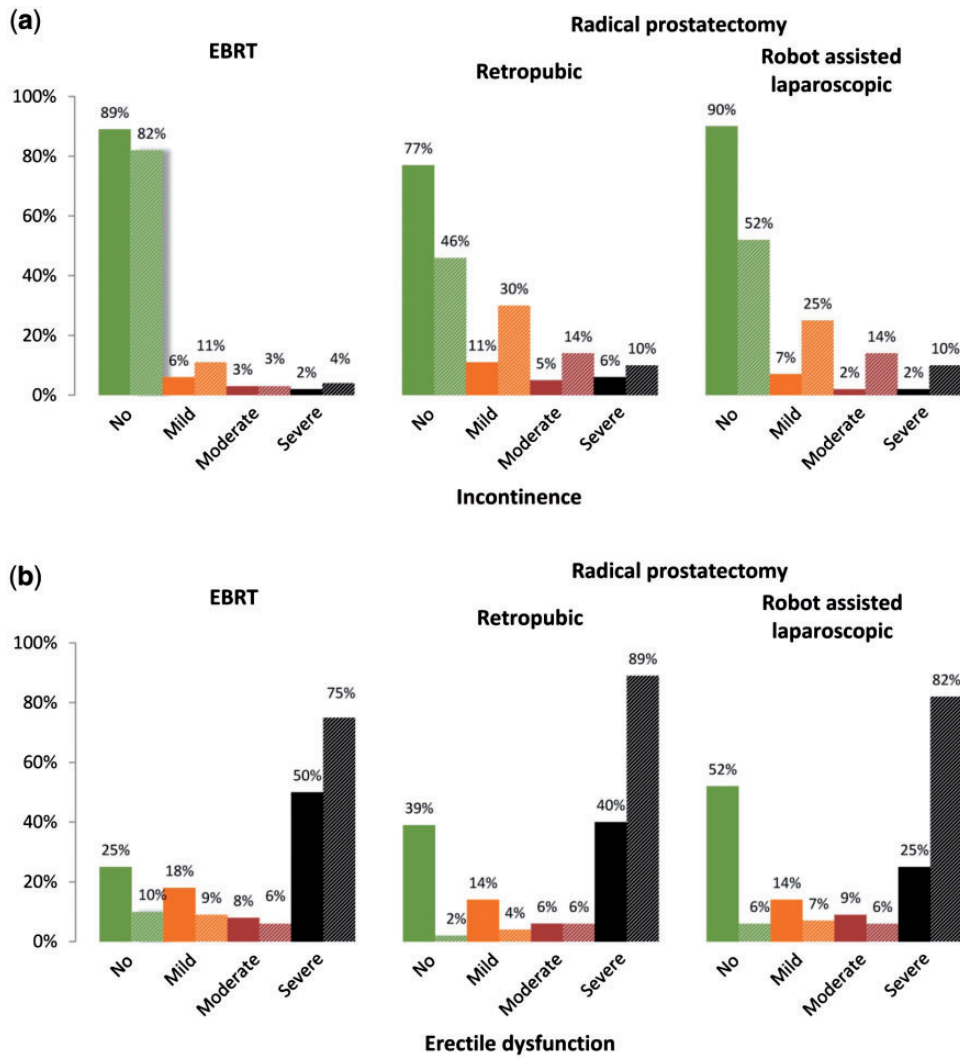
case themselves when diagnosed with PCa after the date of the original index case. Therefore, follow-up of men in the comparison cohort started at time of diagnosis of the index case and ended at time of PCa diagnosis, death, emigration or study closing date (31 December 2010), whichever came first.

Furthermore, PCBaSe 2.0 contains information on a variety of demographic, socio-economic and clinical components through the linkage of NPCR with a number of national registers (Supplementary Appendix Table 5, available as Supplementary data at *IJE* online, Figure 4). A more detailed description of the content of these registers has been published,<sup>16</sup> but a brief overview is listed below.

#### The Patient Register

As of 1987, the National Patient Register collects information regarding in-patient care nationwide. Each record contains medical information on surgical procedures, hospital department and discharge diagnoses coded according to International Classification of Diseases (ICD-9 or ICD-10).<sup>17</sup> For heart diseases, primary diagnoses have been shown to be correct for  $\sim 95\%$  as judged by the European Society of Cardiology diagnosis guidelines.<sup>18–20</sup>

From the National Patient Register, we calculated the Charlson Comorbidity Index to assess the burden of concomitant disease for each man with and without PCa in PCBaSe 2.0.<sup>21,22</sup> This index consists of 18 groups of diseases with a specific weight



**Figure 5** (a) Urinary incontinence and (b) erectile dysfunction (ED) before (solid bars) and 1 year (dotted bars) after external beam radiotherapy (EBRT), retropubic prostatectomy or robotic assisted laparoscopic radical prostatectomy in 218, 466 and 693 men, respectively

assigned to each disease category (1, 2, 3 and 6). The weights are then summed to obtain an overall score, resulting in the three comorbidity levels of the index: 0 for no comorbidity, 1 for mild and  $\geq 2$  for severe comorbidity<sup>23</sup> (Supplementary Appendix Tables 5 and 6, available as Supplementary data at *IJE* online).

**The Cancer Register**

The Swedish National Cancer Register, which is managed by the National Board of Health and Welfare, was founded in 1958.<sup>24</sup> All incident cases of cancer in Sweden must be separately reported to the cancer register by the responsible clinician as well as the respective pathologist/cytologist. All cancers are thus histologically or cytologically confirmed and record linkage by

means of the PIN ensures that each tumour is only registered once.<sup>25,26.</sup>

**The Cause of Death Register**

As of 1953, the National Board of Health and Welfare administers a database containing cause of death data.<sup>17</sup> It shows underlying cause of death coded according to ICD-10 and this has been shown to be accurately defined, in particular for men with PCa.<sup>27,28</sup>

**Population and housing census and labour market studies**

From 1960 until 1990, the Total Population Register, maintained by Statistics Sweden, conducted a 5-yearly census, which collected information from questionnaires and nationwide registers. The censuses provide information on the individual, their

**Table 3** Publications based on data in PCBaSe Sweden

Reference	Journal	Year	Topic	Main findings
Thorstenson <i>et al.</i> (2012) <sup>50</sup>	<i>Eur J Cancer</i>	2012	Risk of fractures	GnRH agonists or orchiectomy were associated with increased risk of fractures requiring hospitalization, whereas anti-androgen monotherapy had no increase in such fractures
Van Hemelrijck (2012) <sup>51</sup>	<i>Eur Urol</i>	2012	Patterns of multiple adverse events	One-third of PCa patients with an adverse event after treatment subsequently experienced another adverse event
Bill-Axelsson <i>et al.</i> (2011) <sup>52</sup>	<i>Eur J Cancer</i>	2011	Risk of psychiatric treatment	Men with PCa had increased risk of psychiatric treatment for depression, post-traumatic stress disorder and use of antidepressants
Robinson <i>et al.</i> (2011) <sup>53</sup>	<i>Int J Cancer</i>	2011	Risk of ischaemic heart disease and stroke after endocrine treatment	Regardless of treatment, men with prostate cancer had a small increase in risk of Ischaemic Heart Disease (IHD) and stroke and initiation of endocrine treatment was associated with a further increase in risk of IHD
Akre <i>et al.</i> (2011) <sup>54</sup>	<i>Eur Urol</i>	2011	Outcomes among men with locally advanced prostate cancer managed with non-curative intent	We assessed cumulative incidence of prostate cancer-specific death within 8 years of diagnosis and found that PCa-specific mortality was high suggesting under-treatment, particularly among older men
Berglund <i>et al.</i> (2011) <sup>55</sup>	<i>J Urol</i>	2011	Comorbidity, socio-economic factors and treatment decisions and mortality	Comorbidity affected treatment choices, and was associated with all cause, competing causes and conditional prostate cancer-specific mortality
Bill-Axelsson <i>et al.</i> (2010) <sup>56</sup>	<i>Eur Urol</i>	2010	Risk of suicide in men with PCa	Suicide risk was twice as high among men with locally advanced or metastatic disease, compared with an age-matched male population free of PCa
Stattin <i>et al.</i> (2010) <sup>57</sup>	<i>J Natl Cancer Inst</i>	2010	Socio-economic characteristic in relation to PCa death	Socio-economic disparities in the management and mortality in men with high risk PCa were observed within the setting of a national health-care system aiming to provide care on equal terms to all residents
Van Hemelrijck <i>et al.</i> (2010) <sup>58</sup>	<i>J Clin Oncol</i>	2010	Risk of circulatory diseases	Men with PCa were found to have an increased risk of circulatory diseases compared with men in the general population, with the highest risk for those on endocrine therapy
Van Hemelrijck <i>et al.</i> (2010) <sup>59</sup>	<i>Lancet Oncol</i>	2010	Risk of thromboembolic diseases	Men with PCa were found to have an increased risk of thromboembolic diseases compared with men in the general population, with the highest risk for those on endocrine therapy
Bratt <i>et al.</i> (2010) <sup>38</sup>	<i>J Natl Cancer Inst</i>	2010	Risk of PCa among brothers of men with PCa	Brothers of index patients with PCa were at increased risk of a diagnosis of PCa, in particular in the first year after the index brother's date of diagnosis

household and housing, such as demographics, occupation, earnings, number of people per household, etc.<sup>29</sup> In PCBaSe 2.0, socio-economic characteristics were determined by record linkages to the 1960–90 5-yearly Census Databases by use of the Swedish Socio-economic Index.<sup>30,31</sup> The original census consisted of 18 categories defining the economically active population, primarily based on self-reported

occupation. In subsequent censuses, information on occupation was retrieved from the statement of earnings to the Swedish Tax Office. For PCBaSe, a socio-economic index can be aggregated into five categories based on occupation: blue-collar workers, farmers, self-employed, lower white-collar workers and higher white-collar workers. This index is commonly used in epidemiological studies.<sup>32,33</sup> We used



the last registered occupation since many men were retired by the date of PCa diagnosis.

The Total Population Register<sup>34</sup> also provides information on country of origin and emigration as this register is daily updated in terms of migration (Supplementary Appendix Tables 5 and 6, available as Supplementary data at *IJE* online).

Moreover, socio-economic characteristics in PCBaSe 2.0 can be defined by information on education level, annual family income and marital status, available from linkage with the Longitudinal integration database for health insurance and labour market studies (LISA by its Swedish acronym) (Supplementary Appendix Tables 5 and 6, available as Supplementary data at *IJE* online).<sup>35</sup> This database holds annual registers since 1990 and includes all individuals aged  $\geq 16$  years who were registered in Sweden as of December 31 for each year. The database integrates existing data from the labour market and educational and social sectors, and is updated each year with a new annual register. The individual is the primary object in LISA, but connections to family, companies and places of employment are also available.<sup>35</sup>

#### **The Prescribed Drug Register**

The Swedish Prescribed Drug Register<sup>36</sup> includes all prescriptions dispensed in Swedish pharmacies from July 2005. For instance, it contains data on the prescribed item, amount and dose, and age, sex and place of residence of the patient, as well as date of prescribing and dispensing. Drugs administered in hospital are not recorded.

#### **Multi-Generation Register**

The Swedish Multi-Generation Register is held by Statistics Sweden and includes family information for all persons born in Sweden since 1932 who were still residents in Sweden from 1961 onwards.<sup>37</sup> In 2007, there were approximately 8 million persons in the register who can be linked to biological parents, siblings and children. For those alive after 1990, the register is virtually complete with respect to parents and offspring.<sup>37</sup> For the linkage with PCBaSe, an index patient is defined as a man with PCa registered in the NPCR for whom one or more brothers were identified in the Multi-Generation Register. The index patient and his brother(s) were denoted as a family. If only one of the brothers had a PCa diagnosis, he was the index patient. If more than one brother was identified in NPCR, the brother with the earliest date of diagnosis of PCa was the index patient. Families in which a brother of the index patient was diagnosed with PCa before 1 January 1996 were identified by linkage to the Swedish Cancer Register and were excluded as no detailed information (from NPCR) of the first PCa in this family was then available. Brothers who had died

or emigrated before the date of diagnosis of the index patient were also excluded.<sup>38</sup>

#### **Linkage to other quality registers**

PCBaSe 2.0 has also been also linked to other national quality registers including the Swedish Hernia Register,<sup>39</sup> the Swedish National Diabetes Register<sup>40</sup> and Swedeheart.<sup>41</sup>

To maximize patient confidentiality, all data received from Statistics Sweden and Swedish Board of Health and Welfare underwent pseudo-anonymization, for which the key is kept exclusively by the National Board of Health and Welfare. All data held by the research group are thus pseudo-anonymized, but an annual update can still be conducted. All data analysis is performed at one of the regional oncological centres, and the Research Ethics Board at Umeå University has approved of PCBaSe 2.0.

## **What has it found? Key findings and publications**

### **NPCR**

The NPCR has been used to assess trends in incidence, treatment and survival of men with PCa in Sweden.<sup>1,2,42–46</sup> Annual reports of the NPCR (in Swedish) are publicly available<sup>47</sup> and a number of research papers have been published (Supplementary Appendix Tables 3 and Table 7, available as Supplementary data at *IJE* online).

For instance, we assessed outcomes in 6879 patients with localized prostate cancer and found that prostate cancer-specific mortality at 10 years was 2.4% among patients with low-risk prostate cancer in the surveillance group, indicating that surveillance may be a suitable treatment option for many low-risk patients.<sup>42</sup> The following example illustrates how the NPCR can inform and influence urological practice. Despite the national and regional guidelines stating that bone scans are usually not indicated for men with localized, well-differentiated tumours with PSA levels  $< 20$  ng/ml, data from NPCR indicated an extensive use of bone scans in men with low-risk prostate cancer before 2003. These findings were presented and discussed at regional urological meetings, and as a result one can now observe a strong decrease in the use of bone scans for these men (Supplementary Figure 1, available as Supplementary data at *IJE* online).

In a pilot study of 1377 men, we assessed urinary incontinence and erectile dysfunction using the PROM questionnaire in men who underwent curatively intended procedures both before and 1 year after the procedure took place. There was a modest increase in the frequency of urinary incontinence and a strong increase in the frequency of erectile dysfunction, especially for men who underwent prostatectomy (Figure 5).

## PCBaSe

A number of studies on diverse topics such as psychological distress after PCa diagnosis, adverse effects of endocrine treatment and association of comorbidity and socio-economic status to selection of treatment and outcomes have been published based on data in PCBaSe (Table 3).

## What are the main strengths and weaknesses?

NPCR captures virtually all men diagnosed with PCa in Sweden since 1998. Including more than 110 000 cases, NPCR is the world's largest clinical database on PCa with data available on clinical stage, specific tumour differentiation according to the Gleason grading and serum PSA levels in an unselected patient population from an entire nation. Since many of the registers linked to NPCR are also known to be complete, we can confidently state that studies from PCBaSe 2.0 are population based. Addition of a control population for case-control studies and a comparison group for cohort studies allows for adjustment for all potential confounding factors recorded in the registers. In addition, linkage to the Multi-Generation Register allows for analyses of familial risk of PCa for a large part of the study population.<sup>37</sup>

No information is available about proportion of men with PCa not registered in NPCR (<4%). Another limitation is that treatment >6 months after date of PCa diagnosis is not registered in NPCR for all men. For instance, it is known that a proportion of men curatively treated, on surveillance, or on anti-androgens will subsequently receive other treatments. As of 2003, a chart review is performed 5 years after treatment for men aged <70 years with a localized PCa at time of diagnosis in order to capture secondary treatment and adverse effects of primary treatment. Information on surgical treatment is available from the Hospital Discharge Register<sup>48</sup> and the National Day-Surgery Register.<sup>49</sup> No information is available about smoking habits, BMI, diabetes, hypertension or other medical conditions not requiring in-hospital care. However, as of July 2005, we can assess some of these comorbidities by use of relevant drug prescriptions in the Prescribed Drug Register. All data in NPCR are collected based on routine clinical work with no central review of biopsies or radical prostatectomy specimens, but all data are monitored by designated register nurses and database monitors at each regional cancer centre before final entry into

INCA.<sup>6</sup> However, new strategies are in place to further strengthen the data captured in the NPCR. A retrospective collection of radiotherapy data from all radiotherapy departments will be performed for the period 1996–2008. This will provide detailed information on post-operative radiotherapy as well as curative radiotherapy received >6 months after initial diagnosis of PCa.

## Can I get hold of the data? Where can I find out more?

The steering groups of NPCR and PCBaSe welcome collaboration and the interest of national and international colleagues. For more information, please contact: par.stattin@urologi.umu.se

## Supplementary Data

Supplementary Data are available at *IJE* online.

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Contributors for NPCR and PCBaSe Sweden: Linda Drevin (Regional Cancer Centre, Uppsala University Hospital, Uppsala, Sweden), Anna Bill-Axelsson (Department of Urology, Uppsala University, Uppsala, Sweden), David Robinson (Department of Surgery, Höglund Hospital, Eksjö, Sweden; Department of Surgical and Perioperative Sciences, Urology and Andrology, Umeå University, Umeå, Sweden), Olof Akre (Clinical Epidemiology Unit, Department of Medicine Solna, Karolinska Institutet, Stockholm, Sweden).

**Conflict of interest:** None declared.

## KEY MESSAGES

- With more than 110 000 registered cases since 1998, NPCR represents the world's largest clinical database on prostate cancer.
- A number of studies on outcomes, psychological distress, adverse events and other comorbidities have been published based on data in NPCR and PCBaSe and many more studies are ongoing.
- In a subgroup of 6879 patients with localized prostate cancer, prostate cancer-specific mortality at 10 years was 2.4% among patients with low-risk prostate cancer in the surveillance group, indicating that surveillance may be a suitable treatment option for many low-risk patients.
- In another pilot study of 1377 men, we could assess urinary incontinence and erectile dysfunction, and found a modest increase in the frequency of urinary incontinence and a strong increase in the frequency of erectile dysfunction, especially for men who underwent prostatectomy.

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