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ORIGINAL RESEARCH ARTICLE

Improved adherence to prostate cancer guidelines concomitant with public reporting. Nationwide population-based study

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ABSTRACT

Background: Swedish national guidelines provide evidence-based recommendations for standard of care; however, little is known about adherence to them. The aim of this study was to assess adherence to management guidelines for prostate cancer (PCa).

Materials and methods: Data in the National Prostate Cancer Register (NPCR), that includes 98% of all incident PCa cases in Sweden, were used to analyse adherence to national PCa guidelines for men diagnosed between 2010 and 2023. A selection of quality indicators displayed on the public web page of NPCR were assessed.

Results: Active surveillance in men with low-risk PCa and an estimated life expectancy >10 years increased from 44% in 2010 to 88% in 2023. Radical treatment for men with localised high-risk PCa and life expectancy >10 years increased from 60% in 2010 to 86% in 2023 and for men with locally advanced PCa and life expectancy >5 years from 37% in 2010 to 64% in 2023. The proportion of radical prostatectomies for low- or intermediate-risk PCa performed with nerve-sparing technique increased from 61% in 2015 to 87% in 2023. Use of adjuvant androgen deprivation therapy after radiotherapy for men with high-risk or locally advanced PCa increased five-fold from 14% in 2010 to 73% in 2022.

Conclusion: Adherence to recommendations in national guidelines improved in Sweden between 2010 and 2023. Public, open reporting of NPCR data on adherence to guidelines down to department level is likely to have contributed to these improvements.

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KEYWORDS
Prostate cancer; adherence to guidelines; trend analysis; treatment

Background

Clinical guidelines provide recommendations for evidence-based health care with the aim to improve quality of care [1]. The first Swedish national guidelines for prostate cancer (PCa) care were published in 2014, and have been updated multiple times [2–4].

To achieve high standard and equal quality of care, it is important to continuously monitor and evaluate adherence to guidelines. For this purpose, the steering group of the National Prostate Cancer Register (NPCR) of Sweden selected 20 variables in NPCR as quality indicators in 2014 [5]. Of these, 10 indicators were selected among variables on activities performed in urological departments and 10 variables for oncological departments. These quality indicators were selected to mirror different aspects of PCa care. The level of adherence is measured with defined target levels for low, intermediate and high adherence, and displayed by use of a dashboard panel (Figure 1). The result for each individual hospital is reported back within 24 h of registration in NPCR on a secured online platform that can be accessed only by staff at each department [7]. For the purpose of benchmarking, the report displays results from other hospitals in the same health care region as well as the national average. Performance of previous years can also be visualised and compared to the current year. Surgeon identity is blinded in the NPCR data, where name is substituted with a code. Each department has the code key for their surgeons; therefore, individual-level feedback is possible.

Data on the results for these indicators down to department level are also posted and updated twice yearly at RATTEN, a public website where data are displayed in an interactive online reporting system in Swedish and in English [5, 8] (Figure 2).

The aim of this study was to assess temporal trends in adherence to a selection of quality indicators that have been reported by NPCR between 2010 and 2023.

Material and methods

The aim of NPCR of Sweden is to ensure quality of care for men with PCa and to assess adherence to national guidelines for PCa [3, 4]. The completeness of the NPCR is high, including 98% of all incident PCa cases as compared with the Cancer Register, to which reporting is mandated by law [10]. The NPCR records information on cancer characteristics, diagnosis, work-up, and primary treatment of men with PCa. In Prostate Cancer Data

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Figure 1. Reporting on adherence to each urological department in Sweden based on data from National Prostate Cancer Register of Sweden at a secured server.

Adherence levels are categorised as high, intermediate, or low, and include data from specific department, from the healthcare region and the entire nation, and previous years [6].

MRI: Magnetic Resonance Imaging; RP: Radical Prostatectomy; PROM: Patient-reported outcome measures.

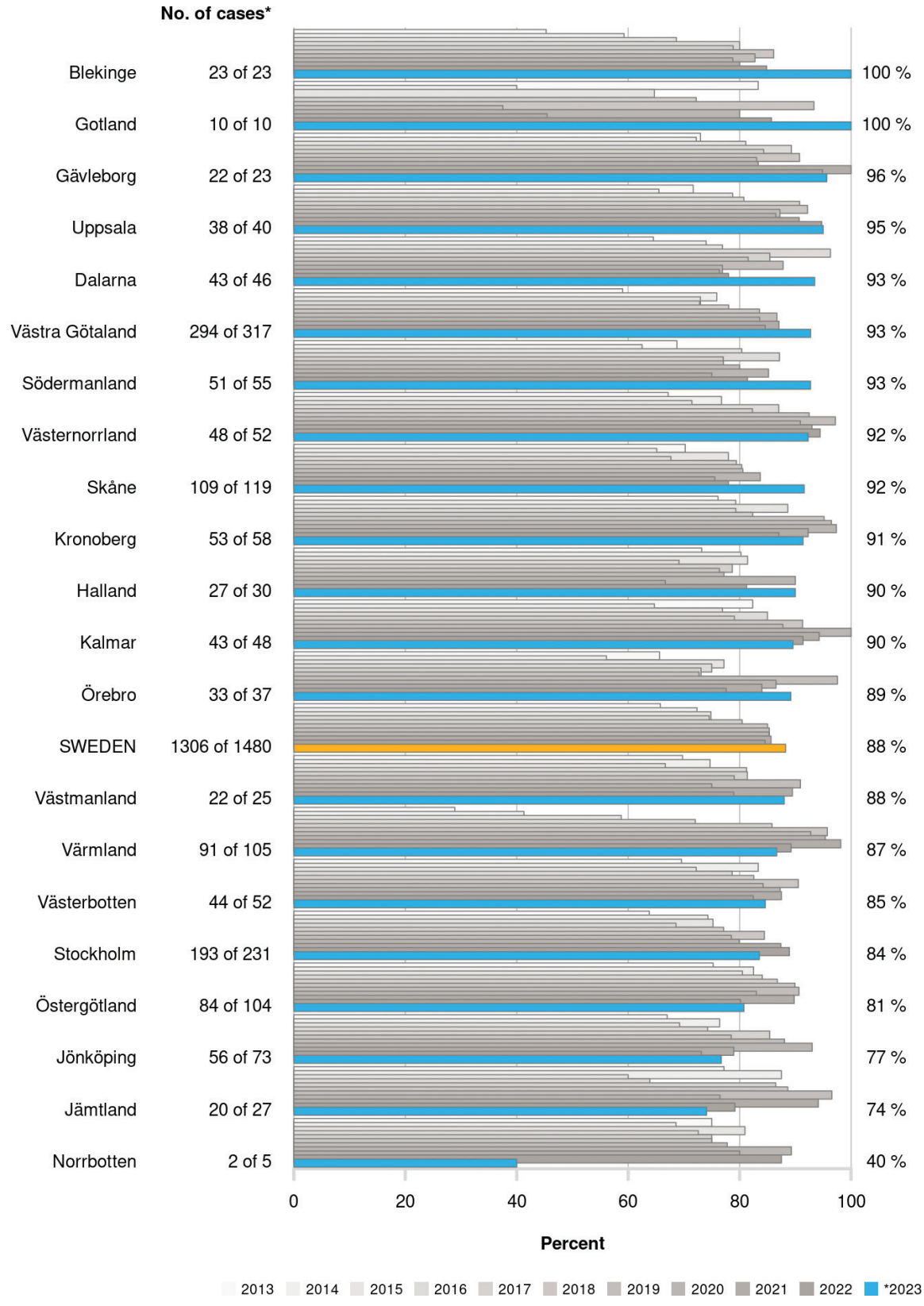

Figure 2. Report on the proportion of men with low-risk prostate cancer managed by active surveillance as presented on RATTEN, a public interactive online reporting system.
Results are displayed for each year from 2013 to 2023 across all 21 regions, along with the national average [9].

Base of Sweden (PCaBaSe) RAPID, information in NPCR has been enriched by individual level record linkages to other health care registers including The Prescribed Drug Register, The Patient Register, The Cause of Death Register, The Emigration Register, and The longitudinal integrated database for health insurance and labour market studies (LISA), a socioeconomic database.

Study population

All men with PCa registered in the NPCR between 2010 and 2023 were included for analysis. Risk category at diagnosis was defined according to a modification of the National Comprehensive Cancer Network (NCCN) categorisation [11]. On the online reporting system RATTEN, the indicators can be stratified by patient age. In this study, we use life expectancy as a metric to better align with established guideline recommendations since it is biological age and not chronological age that should be considered when selecting treatment. Life expectancy was estimated based on age, and two recently created comorbidity indices — the Drug Comorbidity Index (DCI) based on filled prescriptions a year prior to diagnosis, and the Multidimensional diagnosis-based comorbidity index (MDCI), based on detailed data on diagnoses in The Patient Register [12–15]. Public Swedish health care is provided by six health care regions that are divided into 21 regions.

Quality indicators

Quality indicators were selected among variables registered in NPCR to assess different aspects of PCa care including quality of work-up and treatment. These variables included the proportion of men with low-risk PCa and a life expectancy of more than 10 years who received active surveillance, the proportion of men with high-risk PCa and a life expectancy of more than 10 years who received radical treatment, and the proportion of men with locally advanced PCa and a life expectancy of more than 5 years who received radical treatment. The use of magnetic resonance imaging (MRI) to define the target for primary radiotherapy was investigated as well as the use of multidisciplinary conference for treatment planning in men with high-risk or locally advanced PCa. Furthermore, the proportion of nerve-sparing prostatectomies in men with low- or intermediate-risk PCa who underwent radical prostatectomy, and the proportion of prostatectomy specimens with negative resection margins following radical prostatectomy in men with pT2 and pT3 tumours was investigated. The proportion of men who received adjuvant androgen deprivation therapy (ADT) after radiotherapy for high-risk or locally advanced PCa was also assessed.

A detailed description, inclusion criteria and evidence basis behind each quality indicator are shown in Supplementary Table 1 and Supplementary Document 1.

Study design and analysis

The proportion of adherence to each quality indicator was assessed separately for each of the six health care regions in Sweden and over time for each consecutive year. Crude temporal trends in binary quality indicators were assessed by computing annual proportions.

Results

A total of 143,772 men were diagnosed with PCa and registered in NPCR in 2010–2023 (Table 1). Median life expectancy was 16 years (Interquartile Range [IQR] (Q1–Q3): 11–20). The largest risk

Table 1. Baseline characteristics of 143,772 men in the National Prostate Cancer Register of Sweden diagnosed between 2010 and 2023.

Variable	*N* 143,772	% 100
Age at diagnosis (years)		
Median (Q1–Q3)	70 (64–76)	
< 60	15,019	10
60–69	49,803	35
70–79	55,798	39
80+	23,152	16
Life expectancy[a] (years)		
Median (Q1–Q3)	16 (11–20)	
< 5	6,989	5
5–10	24,228	17
10–15	36,199	25
15+	76,356	53
Year of diagnosis		
2010–2014	38,029	26
2015–2023	105,743	74
Health care region		
Central	30,987	22
North	14,299	10
Capital	29,456	20
South	26,312	18
Southeast	17,071	12
West	25,647	18
Risk category		
Low-risk	33,926	23
Intermediate-risk	50,730	35
High-risk	20,703	14
Locally advanced	10,589	7
Regional metastases	6,095	4
Distant metastases	16,982	12
Unknown	4,747	3
Primary treatment		
Active surveillance	35,433	25
Watchful waiting or unknown	8,834	6
Radical prostatectomy	29,933	21
Intended radical prostatectomy[b]	5,051	4
Radical radiotherapy	23,184	16
Intended radical radiotherapy[b]	4,811	3
Unknown radical treatment	1,330	1
Androgen deprivation therapy	29,454	20
Unknown	5,454	4

[a]Life expectancy was calculated based on age and comorbidity indices: the Drug Comorbidity Index (DCI) and the Multi-dimensional Diagnosis-based Comorbidity Index (MDCI) instead of the Charlson Comorbidity Index as previously described [12, 13, 16].

[b]Intended procedures are men who were assigned to the procedure but who did not undergo the procedure.

category was intermediate-risk PCa, 35% of men were in that category ($n = 50,730$). Active surveillance was the most common treatment strategy, accounting for 25% ($n = 35,433$), while radical prostatectomy represented the most common radical treatment, 21% ($n = 29,933$).

Active surveillance

The use of active surveillance in men with low-risk PCa with a life expectancy >10 years increased markedly during the study period, from 44% in 2010 to 88% in 2023, with small variations between regions (Figure 3A).

Radical treatment

The use of radical treatment increased from 60% in 2010 to 86% in 2023 for men with localised high-risk PCa who had a life expectancy of 10 years or more, and from 37% to 64% for men with locally advanced PCa and a life expectancy of 5 years or more (Figures 3B and 3C). There were large differences between health care regions in the proportion of men who received radical treatment for locally advanced PCa, from 46% to 82% in bottom and top health care region.

Nerve-sparing

The use of nerve-sparing resection in men who underwent radical prostatectomy for low or intermediate-risk PCa increased from 61% in 2015 to 87% in 2023, varying from 70% to 96% in 2023 in the healthcare regions with lowest and highest rate (Figure 3D).

Negative resection margins

The proportion of negative resection margins after radical prostatectomy for pT2 cancer in 2023 was 80% and remained constant during the study period with small differences between regions (Figure 3E), whereas the proportion of negative resection margins for pT3 cancer increased from 47% in 2010 to 61% in 2023, with larger differences between health care regions (Figure 3F).

Magnetic Resonance Imaging and multidisciplinary conferences

The use of MRI to define target prior to primary radical radiotherapy increased more than two-fold from 44% in 2010 to 94% in 2023, with large differences between health care regions (Figure 4A). Furthermore, the use of multidisciplinary conference to plan treatment for high-risk or locally advanced PCa increased from 27% to 81% between 2012 and 2023 (Figure 4B).

Adjuvant Androgen Deprivation Therapy

The use of adjuvant ADT after radiotherapy of high-risk or locally advanced PCa increased five-fold, from 14% to 73% between 2010 and 2022 (Figure 4C).

Discussion

Summary of main findings

In this nationwide, population-based register study, adherence to guidelines improved between 2010 and 2023. For most indicators, differences in adherence between health care regions decreased; indicating a more uniform management of PCa.

Strengths and limitations

The NPCR of Sweden has a 98% completeness compared to the Cancer Register, to which reporting is mandated by law. We assessed the adherence to a wide range of guideline recommendations, selected to reflect various aspects of cancer care, in a nationwide population-based cohort. Data quality in the NPCR has previously been shown to be high when compared to re-abstracted data from medical charts [17]. Treatment decisions should be governed by biological age and not chronological age, and guideline recommendations are therefore based on life expectancy and not age. In this study, we were able to assess life expectancy by use of not only age, but also optimised register-based measures of comorbidity [18].

The study has some limitations. Information on some indicators was limited, for example registration of use of multidisciplinary conferences started in 2012 and information on nerve-sparing procedures was recorded from 2015. Of note, for the majority of men registered in the NPCR, there is no follow-up after primary treatment in NPCR, except for a small group of men with advanced PCa registered in Patient-overview PCa [19]. Furthermore, due to the observational nature of the study, a causal relationship between the implementation of an open reporting system and improvements in guideline adherence cannot be inferred.

Interpretation of findings

We assessed the adherence to guideline recommendations for a wide range of quality indicators. Active surveillance was implemented in Sweden between 2006 and 2007 for men diagnosed with low-risk PCa and a life expectancy of 10–15 years or more, aiming to mitigate overtreatment and treatment-related complications [20]. Our findings indicate that the use of active surveillance in this group doubled between 2010 and 2023.

We observed a gradual increase in use of radical treatment in men with high-risk and locally advanced PCa over the past decade, including in older men. Radical treatment has been recommended in guidelines after the publication of the Scandinavian Prostate Cancer Group-**7** (SPCG-7) trial in 2009 [21]. Nevertheless, in 2023, only three out of five men with locally advanced PCa and a life expectancy of 5 years or more underwent radical treatment. Although clinical trials rarely include men above age 75 years, both European Association of Urology (EAU) and Swedish guidelines recommend radical treatment for men with high-risk PCa and a life expectancy of 5–10 years or more [4, 5, 21, 22]. Adherence to guideline recommendations among older men was also poor in a recent

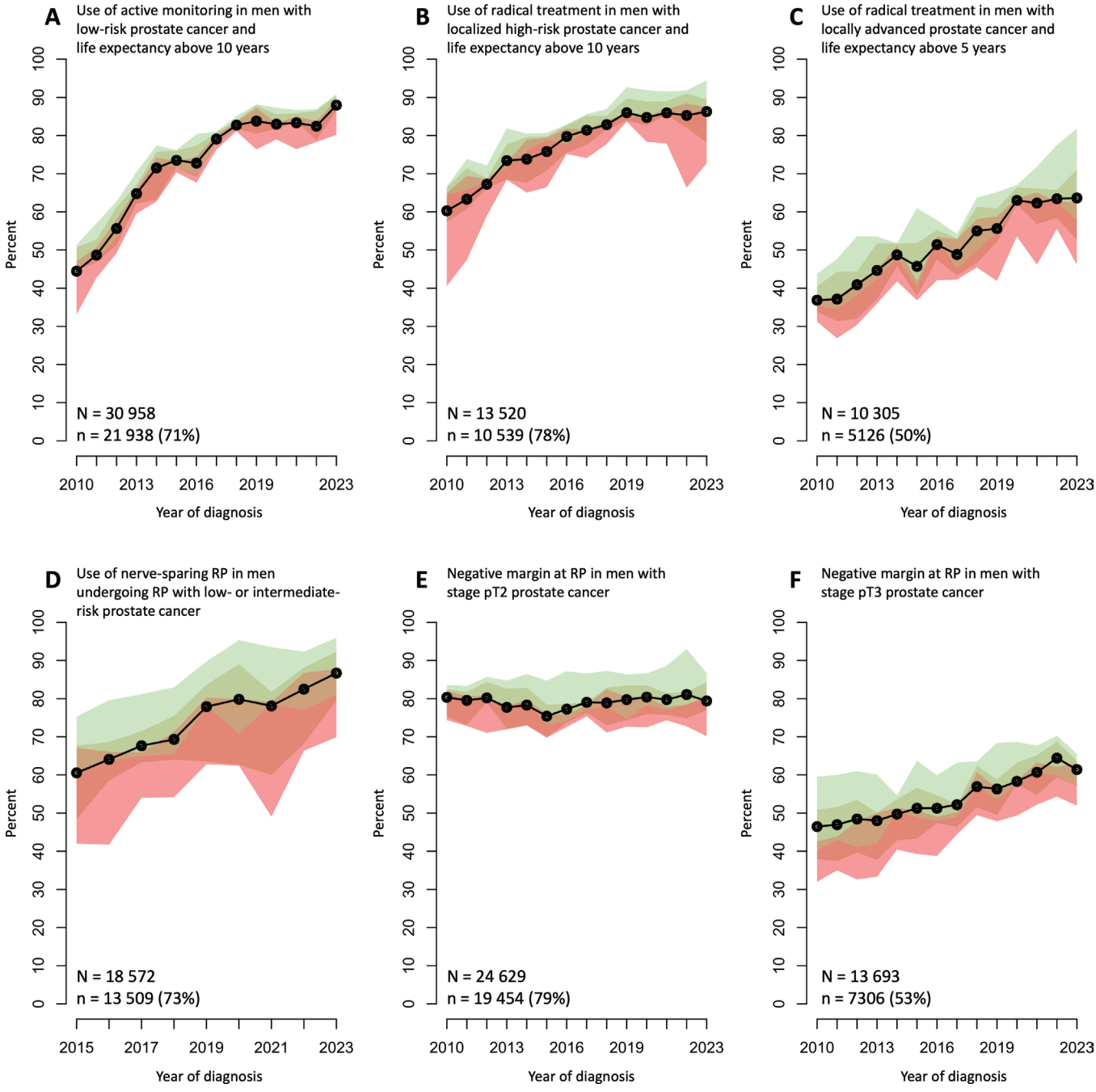

Figure 3. Temporal trends in binary quality indicators registered in urological departments.

Study period from 2010 to 2023 except for nerve sparing resection available from 2015. Data on radical treatment were available until April 2023. The black dotted line represents the national average whereas the different coloured shades represent the six health care regions of Sweden.

N = total number of men, *n* = treated men.

French prospective multicentre study, in which only half of men aged 70 years or older received treatment recommended by guidelines [23].

The use of nerve-sparing resection in men who underwent radical prostatectomy for low or intermediate-risk PCa has overall increased during the study period, but regional differences persist. Sparing the neurovascular bundle is essential for preserving erectile function, and evidence also suggests that it plays an important role in maintaining urinary continence [24]. However, the benefits of nerve-sparing need to be balanced against the risk of incomplete cancer removal. Our results show a relatively stable rate of negative surgical margins for men with pT2 cancer, despite increased use of nerve-sparing surgery during the study period.

There was a slight increase observed in the proportion of negative resection margins for men with pT3 cancer. This increase could potentially be attributed to increased use of multiparametric MRI, which has been shown to improve the surgical management of high-risk tumours [25]. MRI-based dose planning with image-guided radiotherapy has been recommended in guidelines since

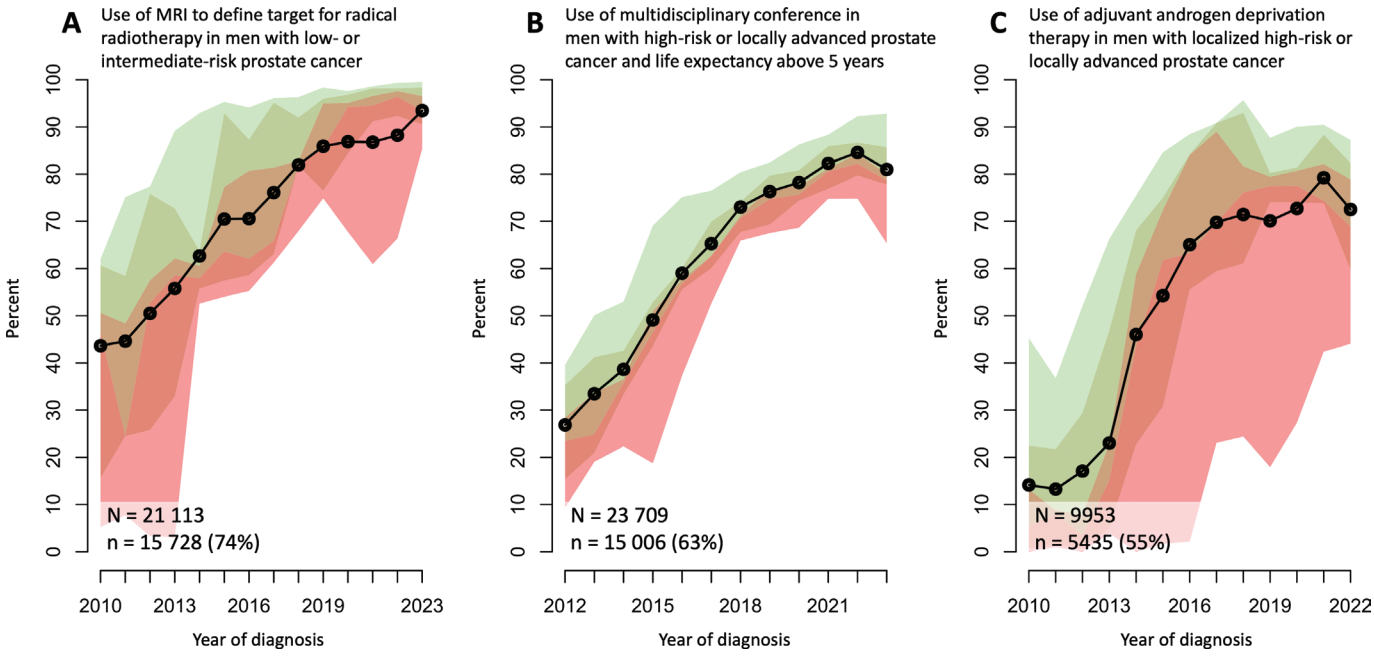

Figure 4. Temporal trends in binary quality indicators registered in oncological departments.

Study period from 2010 to 2023 except for data on use of multidisciplinary conference available from 2012. Data on adjuvant androgen deprivation therapy (ADT) was available until April 2022. The black dotted line represents the national average whereas the different coloured shades represent the six health care regions of Sweden.

N = total number of men, *n* = treated men.

2016 as standard of care [26]. We observed increased adherence to this recommendation in all health care regions. Similarly, the use of adjuvant ADT for men treated with radiotherapy for high-risk or locally advanced PCa increased substantially in line with recommendations in national guidelines since 2014 [4], albeit with some differences between regions.

The large differences in adherence between health care regions observed for most variables are a cause of concern and highlight the need of benchmarking between health care providers

Importance of evaluating adherence to guideline recommendations

Clinical guidelines provide evidence-based recommendations for best standard of care and are intended to promote standardised, clinically appropriate, and cost-effective care while also preventing overtreatment and use of potentially harmful practices [27].

However, surprisingly little is known about the uptake and adherence to guidelines for PCa care. To date, only a few studies have investigated adherence to PCa guidelines for a few specific variables, using databases that do not offer the same population coverage as provided by the NPCR (e.g., SEER–Medicare database) [28, 29]. In other areas for example cardiology, several studies have investigated adherence to guideline-recommendations on cardiac arrest, rehabilitation after myocardial infarction, and medical treatment for heart failure [30–32]. Furthermore, the Swedish Total Hip Replacement Register, has enabled ongoing monitoring of implant performance and surgical techniques [33]. By providing real-time feedback to healthcare providers, it has contributed to a reduction in revision rates and improved the long-term survival of hip replacements.

The initial step toward improving adherence to guidelines is to assess adherence and openly report these measures [34]. Effective implementation of guidelines then relies on the requirements of health care authorities on physicians as well as healthcare professionals' willingness to learn from these reports and adapt patient care to evidence-based knowledge. Awareness of being observed leads to changes in behaviour, known as the Hawthorne effect [35]. Future qualitative studies are needed to address physicians' awareness of guidelines, when and how they use them, and what conflicts that may occur in daily practice related to their use.

The quality indicators in this study are process indicators, i.e. they measure delivery. However, for a comprehensive quality assessment, structural indicators (resources and capacity) and outcome indicators are also important. For benchmarking purposes, process indicators are the most suitable and enable meaningful comparisons across institutions and regions [36].

As guidelines evolve mirroring new evidence for best practice, the NPCR steering group updates the selection of quality indicators in order to assess newly added recommendations and to stop reporting data for indicators on recommendations for which adherence has become high.

Conclusion

Adherence to Swedish national PCa guidelines improved between 2010 and 2023 in Sweden according to quality indicators in the NPCR. Public, open reporting of NPCR data on

adherence to guidelines, down to department level, is likely to have contributed to the improvement.

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Conflicts of interest

The authors report no conflicts of interest.

Disclaimer

Rolf Gedeborg is also employed by the Medical Products Agency (MPA) in Sweden. The MPA is a Swedish Government Agency. The views expressed in this article may not represent the views of the MPA.

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