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TRUE NORTH GLOBAL REGISTRY PROGRAM REPORT 2025

Prostate Cancer Outcomes (PCO) Study 2016–2024
Patterns of care and patient-reported outcomes

DKG GERMAN CANCER SOCIETY · MOVEMBER TRUE NORTH · PCOStudy

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PCOStudy

BPS®
Bundesverband Prostatakrebs Selbsthilfe e.V.

LIST OF ABBREVIATIONS

ADT
Androgen deprivation therapy

AS
Active surveillance

BPS
Bundesverband Prostatakrebs Selbsthilfe e.V. (German patient support and advocacy group)

cT
Clinical tumour stage

DKG
Deutsche Krebsgesellschaft (German Cancer Society)

EBRT
External beam radiation therapy

EPIC-26
Expanded Prostate Cancer Index Composite-26

HDR
High dose rate

ICHOM
International Consortium for Health Outcomes Measurement

IQR
Inter-quartile range

LDC
Local data centre

LDR
Low dose rate

MID
Minimally important difference

NCCN
National Comprehensive Cancer Network

OMOP
Observational Medical Outcomes Partnership

PCO
Prostate Cancer Outcomes

PCOR-ANZ
Australian and New Zealand Prostate Cancer Outcomes Registry

PROMs
Patient-reported outcome measures

PSA
Prostate-specific antigen

RPE
Radical prostatectomy

RT
Radiation therapy

SD
Standard deviation

TNGR
True North Global Registry

TNM
“Tumour node metastasis” staging system developed by the Union for International Cancer Control (UICC)

UICC
Union of International Cancer Control (UICC)

WW
Watchful waiting

MESSAGE FROM THE BPS

Written by Günter Feick and Günther Carl, BPS

THE PROSTATE CANCER OUTCOMES STUDY – PATIENT SUPPORT AND ADVOCACY, AND PUTTING PATIENT-REPORTED OUTCOMES ON THE AGENDA

By 2012 the prostate cancer patient support and advocacy organisation of Germany (Bundesverband Prostatakrebs Selbsthilfe e.V. [BPS]) concluded that the measurement of patient-reported outcomes and conducting relevant comparative analyses were important steps that should be implemented to support the advancement of prostate cancer care.

We are accustomed to measuring and comparing outcomes in our professional lives, when trading goods and products for example; or in our personal lives for entertainment, such as when following the soccer league rankings. So why then, would we forgo the opportunity to apply outcomes measurement and comparison in prostate cancer care, when it is available?

With this mindset, and realising the internationally renowned Urologist, and founder of Martini-Klinik, Prof. Hartwig Huland also strongly supported the outcomes measurement concept of the International Consortium of Health Outcomes Measurement (ICHOM), we got on the train to visit him in the Martini-Klinik Hamburg. There, Dr Jens Deerberg-Wittram joined our conversation, who was the ICHOM founding president at this time.

At this meeting, the opportunity emerged that we had pursued for some time.

ICHOM agreed to organise an international group of clinician leaders, registry leaders and patient representatives for defining outcomes that are important to patients. And Movember agreed to support and finance this project for improving prostate cancer care.

With the help of 28 individuals from 9 countries, who dedicated their time, expertise and lived experience in a working group, we developed the ICHOM Standard Set for Localized Prostate Cancer.[1,2] In partnership with ICHOM, under the leadership of Prof. Huland, we completed our task within 12 months; defining the recommended outcomes and the intervals of measurement, and creating and distributing the first publication of these parameters.[1]

Shortly after this, the BPS solicited the interest of the German Cancer Society (Deutsche Krebsgesellschaft [DKG]) and the OnkoZert for initiating the Prostate Cancer Outcomes (PCO) Study utilising the ICHOM standard set. Movember also developed the international True North Global Registry (TNGR) for men with localised prostate cancer. Our instantaneous desire to join the TNGR project was honoured by Movember, and we became a contributing partner thereafter.

With this privilege, and our determination to make TNGR and the PCO Study a success, we started our public promotional activities. A widely disseminated film production featuring a BPS board member and a Urologist, together with a renowned narrator brilliantly served our goal – maximum participation for optimum study results. The effects of our promotional activities soon became obvious, with increasing numbers of patients joining the PCO Study, an impetus which is still carrying us forward today.

Looking back at when the BPS first started investigations to define a system that measures, compares and improves outcomes; we patient representatives are still stunned about the speed of development of the TNGR and the PCO Study.

Outstanding levels of cooperation among all the inspiring individuals, their organisations and our common goals, accelerated the speed of implementation. We knew that what we were doing matters to patients' lives, and we were poised to deliver on our promises as soon as possible.

Now with 9 years of the PCO Study completed, and with over 150 excellent PCO Study centres getting close to 100,000 patients registered, we can take comfort in the feeling of a job well done. Of all patients diagnosed with low- and intermediate-risk localised prostate cancer in 2024 in Germany, 33% were registered in the PCO Study.

We extend our heartfelt thanks to all registered patients for sharing their data with us. You have chosen to become part of a group of men who care for others who will be coming after them, and will benefit from your engagement.

Congratulations and thanks are also extended to all who are working diligently on the TNGR registry and the PCO Study. We hope you all share this positive feeling about the project you are carrying forward for better outcomes for men and their significant others.

"

Let us soon talk now about the degree of transparency we want to realise for the PCO data.

If we want patients to know where the best outcomes are achieved, we probably could find ourselves between a rock and a hard place.

Yet, we should not refrain from providing this important additional quality to all patients and caregivers.

Let us tackle this in the spirit of good cooperation and commitment to our goals as we did so well in the past.

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MESSAGE FROM THE PRESIDENT OF THE GERMAN CANCER SOCIETY (DKG)

The German Cancer Society (DKG) takes great pride in reflecting on nine successful years of the PCO Study – the German branch of the Movember-funded True North Global Registry. This initiative has become a global example of how to combine clinical excellence with the lived experiences of patients.

First and foremost, my sincere thanks go to the Bundesverband Prostatakrebs Selbsthilfe e.V. (BPS). From the very beginning, their unwavering commitment has ensured that the patient perspective truly drives this project. We are equally grateful to Movember, whose long-standing support and vision have made the study possible. A special acknowledgment goes to the Certification Institute OnkoZert: without their outstanding work in integrating the registry into certified centres from Day One, none of this would have been achievable.

Today, more than 150 centres across Germany, Austria, and Switzerland contribute to the PCO Study. Their sustained dedication – often far beyond what is formally required – has been instrumental in building and maintaining a prostate cancer cohort of significant size and quality. Behind this achievement stand not only highly committed physicians, but also the many skilled professionals who meticulously document data, ensure completeness, and safeguard accuracy; making an essential contribution to the study's success and international reputation.

The PCO Study proves that research is strongest when built on partnership: between patients and clinicians, between science and care, and between vision and consistent effort. It has set new standards for evaluating cancer treatment – not only by looking at clinical quality indicators, but also by investigating what truly matters to patients: quality of life.

To everyone involved over the past nine years – patients, BPS, Movember, OnkoZert, participating centres, and the dedicated individuals working behind the scenes – thank you for shaping a model of patient-centred research that inspires far beyond our borders.

PROFESSOR MICHAEL P. GHADIMI MD
President, German Cancer Society (DKG)

MESSAGE FROM MOVEMBER

Since 2016, Movember has been proud to invest in an ambitious global effort to improve outcomes for men with prostate cancer: the True North Global Registry. What began as a groundbreaking idea nine years ago to create the world's first international prostate cancer registry capturing both clinical data and the lived experiences of men has grown into a powerful tool for driving quality of cancer care.

Movember's investment of AUD $20.3 million globally, including €991,344 in Germany for the PCO Study has been fundamental to this success. Today, the registry holds data on 149,000 patients worldwide, making it an indispensable resource for shaping evidence-based, patient-centred care.

Movember has a clear mission with prostate cancer: to reduce the number of men dying from the disease, and to improve quality of life in men globally who are living with or beyond a prostate cancer diagnosis. Central to achieving this is ensuring that every man regardless of where he lives, his background, or where he receives treatment has access to high-quality care informed by robust data and the voices of patients themselves, through Patient Reported Outcome Measures (PROMs). The True North Global Registry and its German component, the PCO Study, have been instrumental in advancing this goal by shining a light on variations in care and outcomes and highlighting opportunities for improvement to enable more equitable care.

PROMs captured by the PCO Study reveal the true, lived-experience impact of prostate cancer treatment. Data from the German cohort make clear the profound consequences of surgery on sexual function with three in four men impacted by a decline in sexual function. The picture is similarly stark for urinary control with nearly two in three men impacted. These data underscore why PROMs are valuable and the importance of the Movember mission with prostate cancer.

Movember is pleased to see the plans for the registry's continued operation in Germany, a testament to its demonstrated value. Under the leadership of OnkoZert as the Coordinating Data Centre, and with participating centres now self-funding their involvement, the initiative is firmly embedded in the prostate cancer care sector. This ongoing commitment will ensure data-driven insights will continue to drive quality of care and provide critical insight into the impact of treatment on men's quality of life. Their insights will enable informed, patient-centred consultations and ensure that critical functional outcomes are recognised as a core component of cancer care.

The PCO Study has set a high standard for integrating clinical excellence and research. It has generated a substantial research output through peer-reviewed publications, deepening our real-world evidence for diagnosis, treatment and outcomes for prostate cancer care to help reduce disparities and elevate standards of care.

This would not have been possible without the participation of men with prostate cancer contributing their data and reported outcomes to the PCO Study. We are also grateful for the dedication of the German Cancer Society, BPS, OnkoZert, ClarData, and each of the participating sites. We hope they are as proud as we are to see their contributions transforming the future of men's prostate cancer care in Germany.

SARAH WELLER MSc, BAppSci (ExSci)
Global Director, Prostate Cancer
Movember

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EXECUTIVE SUMMARY AND KEY FINDINGS

OVERVIEW OF THE PCO STUDY

The Prostate Cancer Outcomes (PCO) Study was initiated in 2016 as part of the larger Movember-funded True North Global Registry (TNGR). The PCO established the uniform collection of patient-reported outcomes in prostate cancer centres certified according to the criteria of the German Cancer Society (DKG)[1] in Germany, Austria and Switzerland. It is a joint effort of the patient advocacy group BPS (Bundesverband Prostatakrebs Selbsthilfe), the German Cancer Society (DKG), the certification institute OnkoZert and their data partner ClarData as well over 160 prostate cancer centres. As of November 2025, nearly 100,000 prostate cancer patients have participated in the study. Patients complete a standardised survey before the beginning of treatment/observational management in a centre (known as the T0 questionnaire), and then complete a second survey 12 months later (the T1 questionnaire). Questionnaire data are linked to patients' clinical data and annual benchmark reports are issued, providing centres with data on their performance regarding functional outcomes (e.g., urinary incontinence, sexual function) compared to other centres. This report contains an overview of the outcomes achieved in these centres, and how these relate to the clinical and socio-demographic characteristics of the patients. We also describe how the PCO data were used to shape research initiatives and quality requirements across Germany, Austria and Switzerland.

POPULATION CHARACTERISTICS AND DIAGNOSIS

This report includes data from 47,466 patients (median age 67 [IQR, 62,72]) enrolled between 2016 and 2024, who had completed both their enrolment and their 12-month survey (T0 and T1; **Figure 1**). Data stem from 162 certified centres, 148 in Germany, 3 in Austria, and 11 in Switzerland. Half of the centres were located in cities with 100,000–1,000,000 inhabitants, and their ownership was mixed, with 53% of centres being in the public domain and the remainder being private or run by a charity. All but two were teaching/academic hospitals. Data on education and insurance status were only available for German patients in the PCO Study (N=43,479). Among these German men, overall, 42% had a school-leaving certificate that allowed access to a university/university of applied sciences. Privately insured patients make up 27% of the sample, which overrepresents this patient group compared with the general German population, which is approximately 10% privately insured.

KEY FINDINGS

Over 2016–2024, approximately 50% of patients had localised, intermediate-risk disease at enrolment (**Figure 4**), with d'Amico risk group[2] at enrolment generally being higher in higher age groups (**Figure 5**). Risk group at diagnosis varied little by enrolment year among the whole group, or by level of school-leaving certificate or insurance status among German men (**Figures 6–7**). Around 6 out of 7 patients (40,570/47,466; see **Table 5a**) received surgery as their primary management strategy, with 2% of those (N=917) receiving additional radiation therapy (RT) within 1 year. RT was the initial management strategy for approximately 10% of men (N=4,973); fewer than 2% of men had active surveillance (AS; N=714); and fewer than a half percent had watchful waiting (WW, N=188). Men in higher age groups more often received RT or observational management (AS/WW) compared with surgery (**Table 5b**). Overall, among patients with low-risk disease, over 80% (N=6,359/7,800) received surgery (**Table 5a**), with little variation according to school-leaving certificate or insurance status seen among the German men in the study (**Tables 5c and 5d**). Over time, among all surgically treated patients, the proportion of robotic surgeries increased from approximately half to nearly three quarters of the PCO cohort, mainly at the expense of open surgery (**Figure 13**). Nerve-sparing surgery remained stable over time at around 70% (**Figure 18**), and was more frequent in low-risk groups (85% [N=5,380 men with localised low-risk disease], **Figure 19**) and younger age groups (85% [N=6,126 men under 60 years] **Figure 19**). Among German study participants, nerve-sparing surgery was more common in the privately insured (77% [N=7,625 men] **Figure 22**).

When considering patient-reported outcome measures (PROMs), the proportion of patients who completed both questionnaires (among those who completed the baseline one), remained stable over time at around 75% (**Figure 2**). Use of online compared with paper questionnaire completion hardly increased over time, occurring in 23% of patients younger than 60 years, and 11% among those 80 years and older in the 2022–2023 cohort (**Figure 25**, N=3,029).

Changes in patient-reported function following treatment are at the heart of PCO, and these data reveal relevant impairments, especially regarding sexual and urinary function. Pad use increased from 4% at baseline to 45% after surgery alone (at least one pad per day, N=40,570), and from 7% to 13% after radiotherapy (RT +/–ADT; N=4,973; see **Table 7**). The proportion of patients with erections firm enough for intercourse declined from 51% before, to 9% after surgery alone and from 27% before, to 13% after radiotherapy.

The EPIC-26 summary score[3] was used as an international quasi-standard to score functional outcomes over 5 domains from 0–100, with higher scores indicating better results. Minimally important differences (MIDs) in these domains are recognised in the literature as being changes of:

6–9 points for urinary incontinence; 5–7 points for urinary irritation/obstruction; 4–6 points in the bowel and the vitality/hormonal domains; and a change of 10–12 points in the sexual domain.[4,5] This highlights how significant the changes in PROMs that we see in the PCO Study are to the men who are experiencing them.

Overall, the urinary incontinence domain score decreased from 92 to 74 points between the T0 baseline questionnaire and the 12-month post-treatment/enrolment (T1) questionnaire (**Table 8**). With declines of 20 points following surgery alone and 3 points after RT (+/–ADT) being reported. The urinary irritation/obstruction score improved by 5 points after surgery alone and declined by 2 points in the RT group. Bowel function declined by 2 points in the surgery-alone group and 8 in the RT group, and vitality/hormonal function declined by 5 points after surgery alone and by 9 after RT (+/–ADT). Sexual function was scored as 60 at enrolment and 28 one year later overall (N=47,466), with declines of 35 points after surgery alone and 14 points after RT (+/–ADT). In patients managed with AS and WW, function remained mostly stable between T0 and T1 for bowel, sexual and hormonal domains, but improved for both urinary domain scores. Examining single-item PROMs responses via Sankey plots helps further in bringing to life the impact of the changes seen in some of these items. For example, of the 20,206 men who underwent surgery and reported adequate erections at baseline (T0), only 3,091 (15%) retained adequate sexual function at the 12-month T1 questionnaire (**Figure 33**); and in men undergoing RT alone, 50% (N=416/828) who had erections firm enough for intercourse before therapy reported at least some loss in function at 12 months (**Figure 45**). Noting that some men included in the analysis may have used sexual aids (e.g. devices, pills). Nevertheless, these data emphasise that this substantial risk of decline in sexual function is something patients should be made aware of during consultations for any kind of active management of their prostate cancer.

GERMAN PROGRAM ACTIVITIES

What made the situation special in the three countries covered in this report, compared with the larger TNGR, was that functional outcome collection had already been established in several specialised centres with a high caseload – particularly the Martini Clinic in Hamburg. From an early stage, the Martini Clinic served as an informal benchmark for many other centres that wanted a standard with which to compare themselves. One of the aims of PCO therefore was to facilitate these comparisons. To avoid language and reporting style becoming barriers, the local data centre (LDC) established additional reporting in German using the long-established reporting style of the German Cancer Society (DKG)'s certification program. Reporting was accompanied by in-person workshops and, later, by online meetings during and after the pandemic to present and discuss results. Results were also reported at an individual patient level, with centres able to access individual patient results and use them for patient management.

In an effort to discuss results beyond those directly involved in TNGR, the legislative branch of the centre certification system commissioned the so-called 'Reduce Working Group' in September 2021. The group was tasked with developing measures to reduce variation in outcomes between centres and improve overall quality. Over the following 12 months, a group of 15 experts, including patients, formed and met four times. One of the results was after finding that a probably excessive proportion of low-risk patients were being treated with surgery – causing unnecessary functional impairment in many patients – the group recommended the addition of an indicator to the certification criteria to report the rate at which low-risk patients were being managed with AS. The indicator was implemented in certification reporting.

Centres were encouraged to work with their own data, and some published their work in scientific journals. Additionally, the German Cancer Society (DKG) coordinated publications that covered Germany, Austria and Switzerland.[6–14] Besides numerous publications, engaging with the results led to the initiation of several well-funded studies aimed at improving functional outcomes for prostate cancer patients, which are currently in progress.[15–17]

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ZUSAMMENFASSUNG UND WICHTIGSTE ERGEBNISSE

ÜBERBLICK ÜBER DIE PCO-STUDIE

Die Prostate Cancer Outcomes Studie (PCO-Studie) wurde 2016 als Teil des größeren, von der Movember Foundation finanzierten True North Global Registry (TNGR) ins Leben gerufen. Die PCO-Studie etablierte die einheitliche Erfassung von Patient-Reported Outcomes (PROs) in Prostatakrebszentren, die nach den Kriterien der Deutschen Krebsgesellschaft (DKG)[1] in Deutschland, Österreich und der Schweiz zertifiziert sind. Es handelt sich um eine gemeinsame Initiative der Patientenvertretung BPS (Bundesverband Prostatakrebs Selbsthilfe), der Deutschen Krebsgesellschaft (DKG), des Zertifizierungsinstituts OnkoZert und ihres Datenpartners ClarData sowie über 160 Prostatakrebszentren. Bis November 2025 haben fast 100.000 Prostatakrebspatienten an der Studie teilgenommen. Die Patienten füllen vor Beginn der Behandlung bzw. zu Beginn der Aktiven Überwachung/Watchful Waiting in einem Zentrum einen standardisierten Fragebogen aus (den sogenannten T0-Fragebogen) und 12 Monate später einen zweiten Fragebogen (den T1-Fragebogen). Die Fragebogendaten werden mit den klinischen Daten der Patienten verknüpft und es werden jährliche Benchmark-Berichte erstellt, die den Zentren Daten zu ihrer Leistung in Bezug auf funktionelle Ergebnisse (z. B. Harninkontinenz, Sexualfunktion) im Vergleich zu anderen Zentren liefern.

Dieser Bericht enthält einen Überblick über die in diesen Zentren erzielten Ergebnisse und deren Zusammenhang mit den klinischen und soziodemografischen Merkmalen der Patienten. Zusätzlich wird in diesem Bericht beschrieben, wie die PCO-Daten genutzt werden, um Forschungsinitiativen und Qualitätsanforderungen zu gestalten.

BEVÖLKERUNGSMERKMALE UND DIAGNOSE

Dieser Bericht berücksichtigt Daten von 47.466 Patienten (Medianalter 67, Interquartilsabstand 62-72), die zwischen 2016 und 2024 in die PCO-Studie eingeschlossen wurden und Fragebogen sowohl zu T0 als auch zu T1 (**Figure 1**) ausgefüllt haben. Die Daten stammen aus 162 zertifizierten Zentren, davon 148 in Deutschland, 3 in Österreich und 11 in der Schweiz. Die Hälfte der Zentren befand sich in Städten mit 100.000 bis 1.000.000 Einwohnern, und ihre Trägerschaft war gemischt: 53 % der Zentren waren öffentlich, die übrigen privat oder freigemeinnützig. Bis auf zwei Ausnahmen handelte es sich um Lehr-/Universitätskliniken. Daten zum Bildungs- und Versicherungsstatus lagen nur für deutsche Patienten in der PCO-Studie vor (N = 43.479). Von diesen deutschen Männern hatten insgesamt 42 % einen Schulabschluss, der ihnen den Zugang zu einer Universität/ Fachhochschule erlaubte. Privatversicherte Patienten machen 27 % der Stichprobe aus, wodurch diese Patientengruppe im Vergleich zur deutschen Gesamtbevölkerung, in der etwa 10 % privat versichert sind, überrepräsentiert ist.

WICHTIGSTE ERGEBNISSE

Im Zeitraum 2016–2024 hatten etwa 50 % der Patienten bei der Aufnahme in die Studie eine lokalisierte Erkrankung mit mittlerem Risiko (**Figure 4**), wobei die d'Amico-Risikogruppe[2] bei der Aufnahme in die Studie in der Regel in den höheren Altersgruppen höher war (**Figure 5**). Die Risikogruppe bei der Diagnose variierte innerhalb der gesamten Gruppe nur geringfügig nach Jahr der Aufnahme oder nach Schulabschluss oder Versicherungsstatus (**Figure 6–7**). Etwa 6 von 7 Patienten (40.570/47.466; siehe **Table 5a**) wurden nach Einschluss in die Studie zunächst operiert, wobei 2 % von ihnen (N = 917) innerhalb eines Jahres zusätzlich eine Strahlentherapie (Radiotherapie, RT) erhielten. Bei etwa 10 % der Männer (N = 4.973) war die RT die erste Behandlungsstrategie; weniger als 2 % der Männer wurden aktiv überwacht (Active Surveillance, AS; N = 714) und weniger als ein halbes Prozent wurden beobachtet (Watchful Waiting, WW, N = 188). Männer in höheren Altersgruppen erhielten häufiger eine RT oder wurden aktiv überwacht/ beobachtet (AS/WW) (**Table 5b**). Insgesamt wurden über 80 % (n = 6.359/7.800) der Patienten mit einer Erkrankung mit geringem Risiko operiert (**Table 5a**), wobei es kaum Unterschiede hinsichtlich des Schulabschlusses oder des Versicherungsstatus gab (**Table 5c und 5d**). Im Laufe der Zeit stieg der Anteil der robotergestützten Operationen bei allen chirurgisch behandelten Patienten von etwa der Hälfte auf fast drei Viertel der PCO-Kohorte, hauptsächlich auf Kosten der offenen Chirurgie (**Figure 13**). Die nervenschonende Chirurgie blieb im Laufe der Zeit mit etwa 70 % stabil (**Figure 18**) und war in Gruppen mit geringem Risiko (85 % [n = 5.380 Männer mit lokalisierter Erkrankung mit geringem Risiko], **Figure 19**) und jüngeren Altersgruppen (85 % [n = 6.126 Männer unter 60 Jahren], **Figure 19**) häufiger. Unter den deutschen Studienteilnehmern wurden Privatversicherte besonders häufig nervenschonend operiert (77 % [n = 7.625 Männer], **Figure 22**).

Bei Betrachtung der patientenberichteten Ergebnisse (PROs) blieb der Anteil der Patienten, die beide Fragebögen ausgefüllt hatten (unter denjenigen, die den T0-Fragebogen ausgefüllt hatten), im Laufe der Zeit mit etwa 75 % stabil (**Figure 2**). Die Nutzung von Online-Fragebögen im Vergleich zu Papierfragebögen nahm im Laufe der Zeit nur geringfügig zu und lag in der Kohorte 2022–2023 bei 23 % der Patienten unter 60 Jahren und bei 11 % der Patienten über 80 Jahren (**Figure 25**, n = 3.029).

Veränderungen der von den Patienten angegebenen Funktion nach der Behandlung stehen im Mittelpunkt der PCO-Studie, und diese Daten zeigen relevante Beeinträchtigungen, insbesondere in Bezug auf die sexuelle und die Harnkontinenzfunktion. Die Verwendung von mindestens einer Einlage stieg von 4 % zu T0 auf 45 % zu T1 nach einer alleinigen Operation (N = 40.570) und von 7 % auf 13 % nach einer Strahlentherapie mit oder ohne Androgendeprivationstherapie (RT +/– ADT; N=4.973; siehe **Table 7**). Der Anteil der Patienten mit einer für den Geschlechtsverkehr ausreichenden Erektion sank von 51 % vor der Operation auf 9 % nach der Operation allein und von 27 % vor der Strahlentherapie auf 13 % nach der Strahlentherapie.

Die Summenscores des international gebräuchlichen EPIC-26-Fragebogens[3] wurde als internationaler Quasi-Standard verwendet,

um die funktionellen Ergebnisse in fünf für die Prostatakrebstherapie besonders relevanten Bereichen auf einer Skala von 0 bis 100 zu bewerten, wobei höhere Werte bessere Ergebnisse anzeigen. Als minimal wichtige Unterschiede (MIDs) in diesen Bereichen werden in der Literatur folgende Veränderungen betrachtet: 6–9 Punkte für Harninkontinenz; 5–7 Punkte für Harnwegsreizungen/Harnverhalt; 4–6 Punkte in den Bereichen Darm und Vitalität/ Hormonelle Beschwerden; und eine Veränderung von 10–12 Punkten im Bereich Sexualität.[4,5]

Insgesamt sank der Wert für den Bereich Harninkontinenz zwischen dem Fragebogen zum Ausgangswert T0 und dem Fragebogen 12 Monate nach der Behandlung/Studieneinschluss (T1) von 92 auf 74 Punkte (**Table 8**). Dabei wurden durchschnittliche Verschlechterungen von 20 Punkten nach der Operation allein und von 3 Punkten nach RT (+/–ADT) festgestellt. Der Score für Harnwegsreizungen/Harnverhalt verbesserte sich nach Operation allein um 5 Punkte und sank in der Strahlentherapie-Gruppe um 2 Punkte. Die Darmfunktion verschlechterte sich in der Gruppe mit alleiniger Operation um 2 Punkte und in der Strahlentherapie-Gruppe um 8 Punkte, während die Vitalität/Hormonfunktion nach der Operation allein um 5 Punkte und nach RT (+/–ADT) um 9 Punkte abnahm. Die sexuelle Funktion wurde bei der Aufnahme mit 60 Punkten und ein Jahr später insgesamt mit 28 Punkten bewertet (N = 47.466), mit einem Rückgang von 35 Punkten nach einer alleinigen Operation und 14 Punkten nach einer Strahlentherapie (+/–ADT). Bei Patienten, die mit AS und WW versorgt wurden, blieb die Funktion zwischen T0 und T1 in den Bereichen Darm, Sexualität und Hormone weitgehend stabil, und verbesserte sich in beiden Scores zur Harnfunktion leicht. Die Untersuchung der Antworten auf einzelne PRO-Fragen mithilfe von Sankey-Diagrammen kann dabei helfen, die Auswirkungen der bei einigen dieser Fragen festgestellten Veränderungen besser zu veranschaulichen: Von den 20.206 Männern, die sich einer Operation unterzogen hatten und zu Beginn der Studie (T0) eine für den Geschlechtsverkehr ausreichende Erektionsfähigkeit angaben, hatten beispielsweise nur 3.091 (15 %) bei der Befragung nach 12 Monaten (T1) eine für Geschlechtsverkehr ausreichende sexuelle Funktion (**Figure 33**). Bei Männern, die sich ausschließlich einer Strahlentherapie unterzogen hatten, gaben 50 % (n = 416/828), die vor der Therapie Erektionen hatten, die für den Geschlechtsverkehr ausreichend waren, nach 12 Monaten einen Funktionsverlust an (**Figure 45**). Dabei ist zu beachten, dass einige der in die Analyse einbezogenen Männer möglicherweise sexuelle Hilfsmittel (z. B. Geräte, Arzneimittel) verwendet haben, was in den Auswertungen nicht berücksichtigt wurde. Dennoch unterstreichen diese Daten, dass Patienten bei Konsultationen zu jeder Art der aktiven Behandlung ihres Prostatakrebses auf dieses erhebliche Risiko einer Abnahme der Sexualfunktion hingewiesen werden sollten.

AKTIVITÄTEN DES DEUTSCHEN PROGRAMMS

Was die Situation in den drei in diesem Bericht behandelten Ländern im Vergleich zum größeren TNGR besonders machte, war, dass die Erfassung der funktionellen Ergebnisse in mehreren spezialisierten fallzahlstarken Zentren bereits vor Start der PCO-Studie etabliert war – beispielsweise in der Martini-Klinik in Hamburg. Von Anfang an diente die Martini-Klinik einigen Zentren als informeller Maßstab, um sich zu vergleichen. Eines der Ziele von PCO war es daher, diese Vergleiche zu ermöglichen und speziell einem deutschsprachigen Publikum leichter zu machen. Um Sprach- und Stilbarrieren zu vermeiden, wurde für die DKG-zertifizierten Zentren neben den TNGR-Berichten eine zusätzliche Berichterstattung in deutscher Sprache eingeführt, die sich an dem lange etablierten Format des Zertifizierungsprogramms der DKG orientierte. Die Berichterstattung wurde durch persönliche Workshops und während und nach der Pandemie durch Online-Meetings begleitet, um die Ergebnisse vorzustellen und zu diskutieren. Die Ergebnisse werden auch auf individueller Patientenebene berichtet, wobei die Zentren auf die individuellen Patientenergebnisse zugreifen und diese für das Patientenmanagement nutzen können.

Um die Ergebnisse über die direkt an PCO Beteiligten hinaus zu diskutieren, rief die Zertifizierungskommission (also die Legislative des Zentrumszertifizierungssystems) im September 2021 die sogenannte „AG Reduce " ins Leben. Die Gruppe hatte die Aufgabe, Maßnahmen zu entwickeln, um die Unterschiede in den Ergebnissen zwischen den Zentren zu verringern

und die Gesamtqualität zu verbessern. In den folgenden 12 Monaten bildete sich eine Gruppe von 15 Expertinnen und Experten, darunter auch Patienten, die sich viermal traf. Eines der Ergebnisse war, dass die Gruppe, nachdem sie festgestellt hatte, dass ein erheblicher Anteil von Patienten mit niedrigem Risiko operativ behandelt wurde – was vielfach zu wahrscheinlich unnötigen Funktionseinschränkungen führte – empfahl, die Zertifizierungskriterien um Indikatoren zu ergänzen, um die Rate der mit AS behandelten Patienten mit geringem Risiko zu erfassen, mit dem Ziel, mehr Niedrigrisikopatienten aktiv zu überwachen.

Die Zentren wurden außerdem ermutigt, mit ihren eigenen Daten zu arbeiten, und einige veröffentlichten ihre Arbeiten in wissenschaftlichen Fachzeitschriften. Darüber hinaus koordinierte die Deutsche Krebsgesellschaft (DKG) Veröffentlichungen, die Deutschland, Österreich und die Schweiz abdeckten.[6–14] Neben diesen zahlreichen Veröffentlichungen führte die Auseinandersetzung mit den Ergebnissen zur Initiierung mehrerer drittmittelgeförderter Studien, die auf die Verbesserung der funktionellen Ergebnisse für Prostatakrebspatienten abzielen und derzeit laufen.[15–17]

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INTRODUCTION

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Welcome to, and thank you for reading, the 2025 report on the PCO Study conducted in prostate cancer centres certified according to the criteria of the German Cancer Society (DKG). This report is based on data collected from patients who have been treated in one of the over 160 participating centres in Germany, Austria and Switzerland between the years 2016–2024. Since its establishment in 2016, the PCO Study has been a lighthouse project of the German Cancer Society. It started as the first research project of the certification department, and soon became an example for similar endeavours, such as the EDIUM study,[1] which replicated the same quality-indicator reporting model in colorectal cancer, involving 100 colorectal cancer centres. Furthermore, PCO has been, and still is, a training ground that led to the development of many more studies in certified centres. These included not only observational, but also interventional studies, which have expanded from examining prostate cancer to also look at breast, colorectal and lung cancer. Over time, these research projects, and the staff associated with them, became so numerous that a new health services research department grew out of the original certification department.

In the beginning, for the DKG, the PCO Study was a logical extension of its certification initiative; adding 'outcomes provided directly by the patients' to the clinical-quality measures that had already long been established in existing reports; including such measures as surgical resection margins, complication rates or provision of psychosocial care. With the establishment of PCO, we started collecting PROs at scale, and included them into the quality-assurance program. This allowed PROs to become part of the outcome discussion, which previously was mostly limited to clinical outcomes; effectively sidelining the hugely impactful side effects that may come with prostate cancer treatment. The introduction of PROs was novel at that time, and actually still is unusual in many parts of the world. It is also still very unusual in many other diseases, particularly many other cancers where we would hope for a stronger recognition of PROs in routine care.

What drove the establishment of PCO was the simple idea of measuring what matters to patients. It was the patient advocacy group BPS (Bundesverband Prostatakrebs Selbsthilfe) that convinced the DKG to participate in the Movember

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All this would not have been possible without the vision and foresight of the Movember Foundation, which not only funded the study with a substantial amount of Australian Dollars but also made all those contributors part of the Movember family.

initiative that was issued in July 2015, and that finally resulted in the PCO Study and its parent study the True North Global Registry, or TNGR.

Part of the call was the restriction to 3–5 sites – which we respectfully ignored! Instead, we asked all the DKG-certified prostate cancer centres whether they wanted to embark on this journey with us. And in the summer of 2016, we started with 24 centres.

Setting up PCO was a team effort from the beginning. We had a strong patient group, who guided the idea and acted as our compass regarding what was important to patients and what was not. Our other key collaborators included the certification institute OnkoZert and the data experts from ClarData with their innovative technical and organisational solutions; the DKG as the scientific lead; and over 160 individual cancer centres, who brought their will to improve overall prostate cancer care. And of course, the thousands of people working in those centres who have helped us develop PCO over the past 9 years.

All this would not have been possible without the vision and foresight of the Movember Foundation, which not only funded the study with a substantial amount of Australian Dollars but also made all those contributors part of the Movember family. It was, and still is, fun to be associated with Movember, be a Mo-Bro or Mo-Sis, have a Moustache grown in November and make it easier to talk about Men’s Health issues. Speaking of Australian Dollars: it sometimes needs a push from someone else to get things moving. Movember has helped establish PRO collection as a standard of care in German prostate cancer management, which would not have been possible without them. Meaning that each of the individual Movember donors who might be reading this helped us with this push to get PROs into routine care, and we are grateful to you! Have fun reviewing this report!

ABOUT THIS REPORT

This report is the result of the first nine years of data collection for the PCO Study; using data supplied by prostate cancer centres that are certified according to the criteria set out by the German Cancer Society, and which contribute to the TNGR. The information is collected in centres from Germany, Austria and Switzerland and presents analyses of diagnostic, clinical and patient-reported outcomes data.

While our international readership may be more familiar with the 'True North Global registry' (TNGR), in Germany, this project has run for many years under the name PCO Study, short for Prostate Cancer Outcomes Study. When the registry was first formed, prostate cancer centres that were certified by the German Cancer Society came together to run the project under the title 'Prostate Cancer Outcomes – Compare and Reduce Variation'. To maintain visibility and understanding in Germany, we now use the title 'PCO Study' – a slightly simpler version of this original name. ClarData, our data infrastructure partner, also developed a PCO Study website that served as a tool for participating patients to complete questionnaires; as an information source for the general audience to inform themselves about the study and its progress; and as a portal for the participating centres to access study material and databases.

What makes the PCO Study particularly special, is that our patient support and advocacy organisations were not only consulted throughout the study, but they were the ones who convinced the German Cancer Society (DKG), the certification institute OnkoZert, and the participating centres to conduct the study in the first place. The result is an established structure for the collection of these valuable patient-reported outcomes, to which almost 100,000 patients have contributed so far. This report marks an important milestone, at which we should pause and reflect on all that we have achieved so far, as well as considering what remains to be done.

HOW TO READ THIS REPORT

The report contains content and analyses similar to those published by other Movember-funded projects. Those familiar with the Prostate Cancer Outcomes of Australia and New Zealand (PCOR-ANZ) Annual Reports for example, will see the similarities in scope and style.

The first part of the report explains the methods used to collect the data. In contrast to the PCOR-ANZ report, the PCO Study is not derived from a population-based registry. Instead, patients are recruited in certified centres; with the aim to complement clinical indicators – long established in certified centres – with Patient-Reported Outcomes (PROs). This needs to be kept in mind when reading and interpreting the findings of the report.

Bearing in mind that report tables and figures should be self-explanatory, we decided to present descriptive data only and forego complex statistics. We refer those interested in more detailed analyses to the annual reports that include case-mix-adjusted centre comparisons, or to the many publications in scientific journals that resulted from the data in the previous years.[2,3]

All figures and tables are briefly commented on when we thought this was necessary or helpful. Often, reasons are given for why we did the analyses, caveats are highlighted or the most striking findings briefly pointed out. Following sample descriptions and clinical characteristics, the focus of the report are symptoms and function

in persons living with, and beyond, localised prostate cancer. Together with Movember, the authors decided to pay particular attention to potential differences according to risk group – a determining factor for treatment planning – as well as potential differences according to sociodemographic characteristics. These include age, education, and insurance status.

The latter is very specific to Germany with roughly 90% of the population being insured in the statutory insurance system. It covers interventions that are 'sufficient, appropriate, and economical'. While 10% of patients in Germany are privately insured, they are overrepresented in the PCO Study population (representing 27% [11,121/43,479]). They are typically persons of higher socioeconomic status and often are civil servants or self-employed. Few analyses look into outcome differences by insurance status, but with the PCO Study data we can do this to some extent.

The report also incorporates elements that reflect how data is being used to report trends in diagnosis, management and patient outcomes, alongside how data is used to change practice through certification requirements.

METHODS

PCO DATASET

Overview

PCO data are exclusively collected in centres certified according to the German Cancer Society (DKG). The study is restricted to DKG-certified centres, as these centres routinely maintain the documentation on most necessary components of the study data (primarily clinical indicators). This allows the linking of the tumour documentation system to the OncoBox. The OncoBox is a software used by the DKG-certified centres to transform their data into a homogenous format and to make it eligible for trials or cohort studies such as TNGR. To be awarded the DKG certification, centres have to fulfil requirements set out by a multidisciplinary commission that includes doctors, nurses, social workers, psycho-oncologists, and many other professional representatives, as well as patient representatives. Requirements include, among other things, fulfilment of guideline recommendations and minimum case numbers. For more information on the cancer centre certification programme of the German Cancer Society (DKG), please see Kowalski C *et al.* 2017.[4] Currently over 170 centres are certified in Germany, Austria, Luxemburg, Switzerland who treated 45,000 centre cases (see eligibility criteria below) prostate cancer patients with an average of 270 primary cases per centre in 2023.[5]

Study design

This is a prospective, multicentre observational cohort study, in which participating certified centres are asked to consecutively enrol all patients.

Patient eligibility criteria

Included in the PCO Study are patient cases from participating centres – 'Centre cases' – who have locally treated prostate cancer and have given their informed consent to participate in the study (see **Supplementary Table 1** for patient characteristics). Centre cases, as defined in Section 1.2.1 of the prostate cancer centre survey for certification are:

> *"all patients with a diagnosis of prostate cancer, localised and/or metastasised, primary diagnosis or recurrence or metastasis, who have been admitted to the centre or the tumour conference and received significant portions of their treatment there (surgery, radiotherapy, systemic therapy, watchful waiting, active surveillance or similar); a patient can be counted as a centre case for one centre only; second-opinion patients are not counted; interdisciplinary treatment plans must exist; time of counting is their (initial) presentation in the centre; coverage in the tumour documentation system must be complete".*

The study protocol of the PCO Study was approved by the Ethics Committee of the Medical Association of Berlin and, subsequently, by local committees. The study was registered in the German Clinical Trials Register (ID: DRKS00010774).[6] Patients are approached to give written informed consent early enough to allow for the completion of a questionnaire prior to the start of treatment. Patients with M1 disease at baseline were not included in the study. The protocol does allow the recruitment of N1 patients, but these patients were not considered for this report. Instead, the analytic sample was restricted to patients with localised and locally advanced disease, in accordance with the certification criteria.

Scope of data included in this report

The dataset consists of questionnaire data completed by the patients and clinical data completed by the centre. Both datasets are combined in the centre, pseudonymised, and sent to the certification institute OnkoZert/ClarData, where quality assurance of the data is done, and then transferred to the DKG where they are analysed.

Data from certified prostate cancer centres in Germany, Austria and Switzerland from the years 2016–2024 are included in this report. Since data transfer from the centres takes place every year in spring, patients from 2024 are excluded from some of the analyses where complete calendar years are required. Patients had to answer a baseline (T0) and a post-therapeutic (T1) questionnaire 12 months after treatment or enrolment to be included in most of the analyses presented in this report. Although 12-month PRO data are not required for all analyses, we restricted the analytic sample to those with 12-month PROs, for consistency between samples. For drop-out analyses, those with no 12-month questionnaire were also considered.

PROMs

Tracking and analysing patient-reported outcomes (PROs) is the key focus of the PCO Study, with the aim of comparing relevant outcomes across treatment centres after men receive local treatment for prostate cancer, or after they have been under observation through active surveillance (AS) or watchful waiting (WW) protocols. PRO measures (PROMs) are captured using the standardised, validated and patient-completed Expanded Prostate Cancer Index Composite (EPIC-26) questionnaire,[7] the Utilisation of Sexual Devices Questionnaire[8] and the libido question assessing interest in sex from the EORTC-QLQ-PR25,[9] as outlined by the International Consortium for Health Outcomes Management (ICHOM).[10] Patient questionnaires are completed both before treatment begins, and at least once, 12 months after treatment has started (or 12 months after diagnosis in those on active surveillance or watchful waiting). PROMs are collected by filling out a paper questionnaire or on the PCO Study website, depending on the patient's preference.

TABLE 1: **DESCRIPTION OF PROMS QUESTIONS EXAMINED IN CHAPTER 3**

Variable	Definition
Urinary Domain	
Use of one or more pads per day	Over the last 4 weeks: use of pads or adult diapers to control leakage reported as 'Used one or more pads per day' **Scale:** none, 1 pad per day, 2 pads per day, 3 or more pads per day
Sexual Domain	
Erections are firm enough for intercourse	Over the last 4 weeks: quality of erections reported as 'firm enough for intercourse' **Scale:** None at all, not firm enough for any sexual activity, firm enough for masturbation and foreplay only, firm enough for intercourse

For a complete list of questions in the EPIC-26 instrument, and corresponding responses from PCO Study participants, see Supplementary Table 2.

PROMs 'completion' was defined as completion of at least one question from the PRO questionnaire. Two of the PRO questions have been focused on in Chapter 3, and are presented in **Table 1**. The answers to the full range of EPIC-26 questions as answered by patients in the PCO Study can be found in **Supplementary Table 2**.

AGE STANDARDISATION

This report presents the results of descriptive statistics, and results are generally not adjusted for potentially influential factors. Disease characteristics and treatment patterns, however, often vary systematically with age. Furthermore, we assume that the distribution of age varies between groups defined by education and health insurance. When comparing groups that differ in their age structure, rough estimates can be misleading. Age standardisation eliminates the confounding effect of age, resulting in adjusted rates that are comparable between groups. We therefore report age-adjusted results where we consider this particularly relevant, and mention this specifically in the table/figure caption when we do so.

For direct age standardisation, age-specific rates for groups by education/health insurance are calculated and weighted by a fixed reference age distribution of a standard population. The weighted average of these age-specific rates yields the age-standardised rate.

In this study, the internal population—the combined age distribution of all individuals included in the analysis—was used as the standard. This approach ensures that the standard weights reflect the actual age structure of the population under study. We assume that the study population reflects the age structure of prostate cancer patients in general more precisely than external populations (e.g., WHO world standard).

DROP-OUT ANALYSIS

A drop-out analysis was performed in order to explore whether the patient population investigated in this report (i.e. patients who have answered a baseline and a post-therapeutic questionnaire 12 months after treatment or enrolment) differs from the total PCO Study population; which additionally includes patients who have only answered a baseline questionnaire but no post-therapeutic questionnaire 12 months after treatment or enrolment. For drop-out analysis, descriptive analyses of sociodemographic and clinical characteristics, as well as of the management strategy, were performed (see **Supplementary Table 1**).

DATA AGGREGATIONS AND ANALYSIS OVERVIEW

Grouping was performed according to the following categories:

- Year of completion of the pre-therapeutic (T0) questionnaire ('study entry').

- Age group at diagnosis:
  - Under 60 years of age (<60),
  - Over 60 and less than 70 years of age (≥60 and <70),
  - Over 70 and less than 80 years of age (≥70 and <80),
  - 80 years of age or older (≥80).

- Highest school-leaving certificate.
  - This information was collected alongside PROMs in the patient baseline questionnaire, and is only available for German participants.

The German education system offers different levels of school-leaving certificate determined by the amount or level of high-school education attained as listed below. These certificates are evidence of the level of high-school education attained but do not designate whether an individual went on to attend a higher-education institute; that is, they do not necessarily represent the final overall level of education attained by a given individual. These certificates are:

- **Lower secondary school** certificate (Hauptschule/Volksschule), equivalent to Grade 9 (or 8/9 years of schooling, sometimes 10 years)
- **Intermediate secondary school** certificate (Mittlere Reife/Realschule) equivalent to Grade 10 (or 10 years of schooling depending on the Bundesland and birth cohort)
- **Comprehensive school** certificate (Polytechnische Oberschule) equivalent to Grade 10 (or 10 years of schooling)
- **Technical college or university of applied science** entrance certificate (Fachhochschulreife)
- **University entrance certificate** (Abitur), equivalent to 12–13 years of schooling allowing access to university-level education.
- Other/none.

- Insurance (statutory/private) available for German participants only. This information was collected alongside PROMs in the patient baseline questionnaire. Patients categorised as having an insurance of type other or none were excluded from analyses by type of health insurance as this group is small and very diverse.

- Risk group at diagnosis according to d'Amico (see below and **Table 2** for more detail).

- Management strategy:
  - surgery (with or without radiation therapy [RT] within 12 months),
  - radiation therapy (RT; with or without androgen-deprivation therapy [ADT]),
  - Active surveillance (AS),
  - Watchful waiting (WW).

Since insurance and educational systems are different in Austria, Switzerland, these are only reported for Germany.

SUBGROUP ANALYSIS

Subgroup analyses were performed by restricting the patient data to patients of centres that have been participating in the PCO since at least (1) 2018 or (2) 2019. This is important to track if changes over time might be due to differences in participating centre composition in contrast to reflecting real changes over time.

RISK CLASSIFICATION ACCORDING TO D'AMICO

The d'Amico risk classification system was first proposed in 1998,[11] and has long been a standard of care used to help identify appropriate management plans for patients with prostate cancer.[12] It classifies patients into low-, intermediate-, and high-risk groups based on prostate-specific antigen (PSA) level, clinical tumour stage (cT), and Gleason score at diagnosis; and is the currently accepted national standard for prostate cancer risk stratification according to the German Clinical Guidelines.[13] The d'Amico system forms the basis of several other internationally recognised systems such as those recommended by European Association of Urology (EAU), National Institute for Health and Care Excellence (NICE), and National Comprehensive Cancer Network (NCCN).[14]

TABLE 2: **D'AMICO RISK CLASSIFICATION (ACCORDING TO GERMAN CLINICAL GUIDELINES CERTIFICATION CRITERIA)**

Localised, low risk	PSA ≤10 ng/mL and Gleason 6 and cT1c or cT2a
Localised, intermediate risk	PSA >10–20 ng/mL or Gleason 7 or cT2b
Localised, high risk	PSA >20 ng/mL or Gleason ≥8 or cT2c
Locally advanced	T3–4 N0 M0

MANAGEMENT STRATEGIES

This report focuses on broad categories of different initial management modalities after first diagnosis:

- surgery (with or without radiation therapy [RT] within 12 months),
- radiation therapy (RT; with or without androgen-deprivation therapy [ADT]),
- Active surveillance (AS),
- Watchful waiting (WW).

Analyses throughout the report are separated according to type of initial management.

MINIMAL IMPORTANT DIFFERENCE

Minimal important differences (MID, sometimes referred to as minimal clinically important changes, MIC) are used in some analyses. MIDs are defined as *"the smallest difference in score in the domain of interest which patients [or clinicians] perceive as beneficial and which would mandate […] a change in the patient's management," (Jaeschke et al., 1989).*[15] In our analyses, MIDs refer to changes in EPIC-26 domain scores reported by patients between the pre-therapeutic (i.e. baseline; T0) and the post-therapeutic (i.e. 12 months after treatment or enrolment; T1) time point, among patients who have answered both a baseline (T0) and at a post-therapeutic (T1) questionnaire.

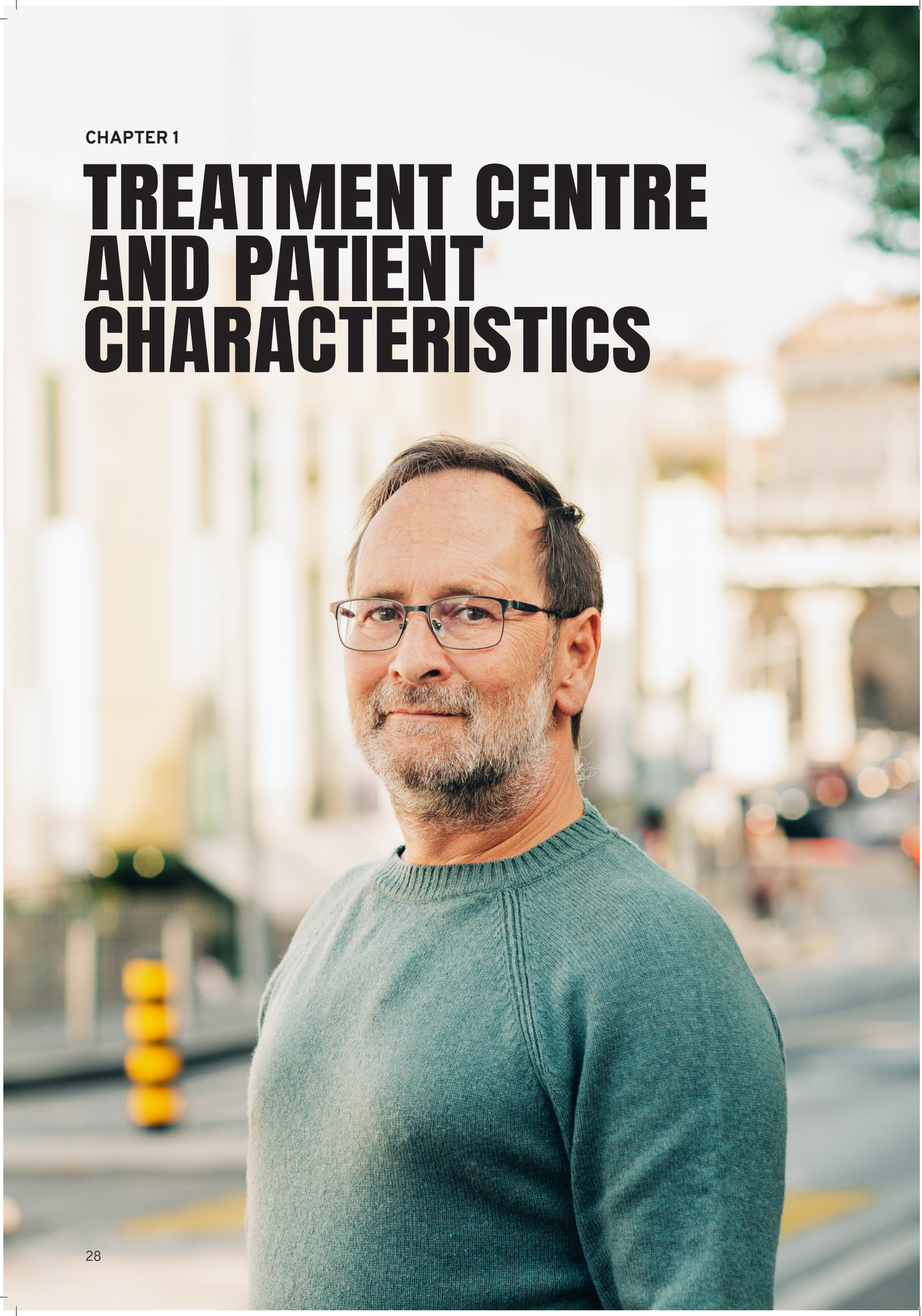
For the EPIC-26, Skolarus (2015)[16] reported the following ranges of MID estimates by domain:

- Bowel domain: change of 4–6 points
- Vitality/hormonal domain: change of 4–6 points
- Sexual domain: change of 10–12 points
- Urinary incontinence: change of 6–9 points
- Urinary irritation/obstruction: change of 5–7 points

We use the lower bound of the ranges, i.e. the absolute value of the post-score to pre-score difference, provided by Skolarus to define a deterioration as being at least a 'MID', i.e. the absolute value of the post-score to pre-score difference is equal to, or greater than, the difference defined as the MID.

CHAPTER 1

TREATMENT CENTRE AND PATIENT CHARACTERISTICS



TREATMENT CENTRE CHARACTERISTICS

Data from 162 prostate cancer centres have been included in this report (see **Table 3**). Currently, 167 centres participate in the PCO Study. Those contributing data to this report are mostly publicly owned and almost all are teaching hospitals, which is a good reflection of the certified centre landscape.

Patient characteristics

Patients for the PCO Study are recruited in certified centres that are a selection of prostate cancer treating units. They represent hospitals with higher caseloads (minimum case numbers are one of the requirements). Outcomes are better on average in certified centres,[17] which treat roughly 55% of newly diagnosed prostate cancer patients

TABLE 3: **CHARACTERISTICS OF CERTIFIED CENTRES PARTICIPATING IN THE PCO STUDY BY COUNTRY, AS OF DECEMBER 2024**

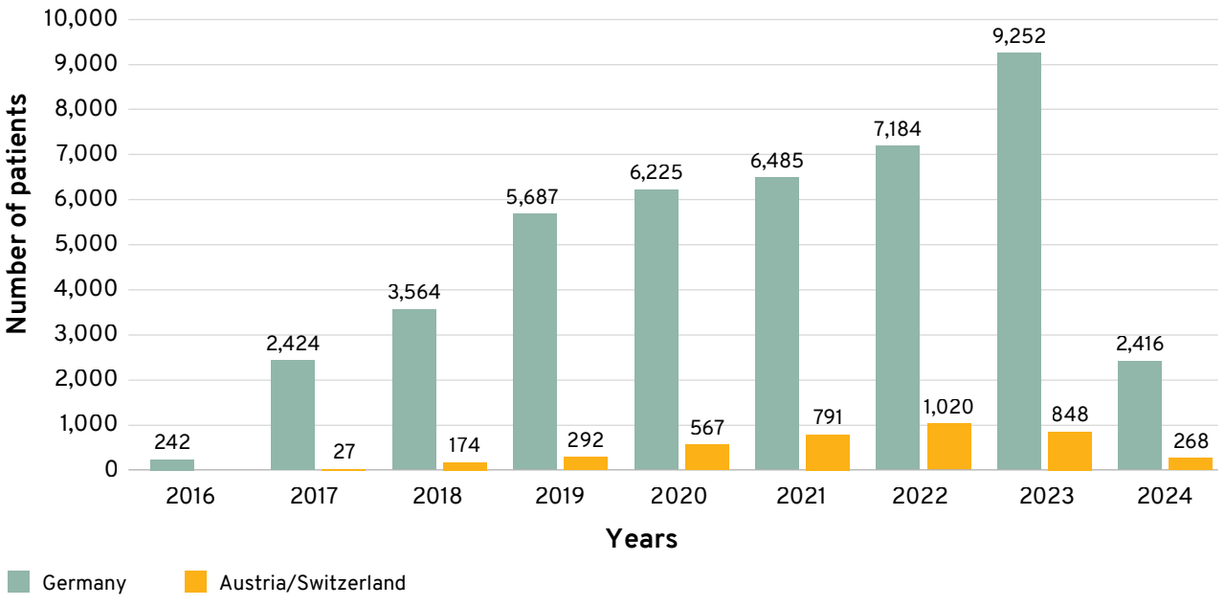
Characteristic, reported as n (%)	N	Germany (N = 148)	Austria (N = 3)	Switzerland (N = 11)	Overall (N = 162)
Urbanisation	**162**				
Small-sized town [>20K]		3 (2.0%)	0 (0%)	1 (9.1%)	4 (2.5%)
Medium-sized town [20K-100K]		63 (43%)	1 (33%)	4 (36%)	68 (42%)
Large city [>100K-1M]		74 (50%)	1 (33%)	6 (55%)	81 (50%)
Metropolitan city [>1M]		8 (5.4%)	1 (33%)	0 (0%)	9 (5.6%)
Ownership	**161**				
Private		18 (12%)	0 (0%)	5 (50%)	23 (14%)
Charitable		49 (33%)	3 (100%)	1 (10%)	53 (33%)
Public		81 (55%)	0 (0%)	4 (40%)	85 (53%)
Unknown		0	0	1	1
Teaching status	**162**				
Non-teaching hospital		1 (0.7%)	0 (0%)	1 (9.1%)	2 (1.2%)
Teaching hospital		123 (83%)	3 (100%)	9 (82%)	135 (83%)
University hospital		24 (16%)	0 (0%)	1 (9.1%)	25 (15%)

in Germany.[5,18] In addition, German population-based registry data only report data on Union of International Cancer Control (UICC) stage,[19] not on d'Amico/National Comprehensive Cancer Network (NCCN) risk groups,[12] making stage comparisons and treatment pattern comparisons difficult. In general, it can be said that, in certified centres, patients on AS/WW are underrepresented because these patients often remain under the care of their office-based specialists.

The patient population investigated in this report includes patients who have answered a pre-therapeutic baseline questionnaire (designated T0) as well as a post-therapeutic questionnaire that is administered 12 months after treatment or enrolment (designated T1). This population encompasses a total of 47,466 patients; 43,479 patients of whom are from Germany, and 3,987 of whom are from Austria and Switzerland combined (see **Figure 1**). However, the total PCO Study population additionally includes patients who have answered a T0 baseline questionnaire, but no T1 12-month post-therapeutic questionnaire (see **Figure 2** for T1 completion rates over time). When comparing these two patient populations, the drop-out analysis shows that patients do not differ substantially with respect to sociodemographic and clinical characteristics (see **Supplementary Table 1**).

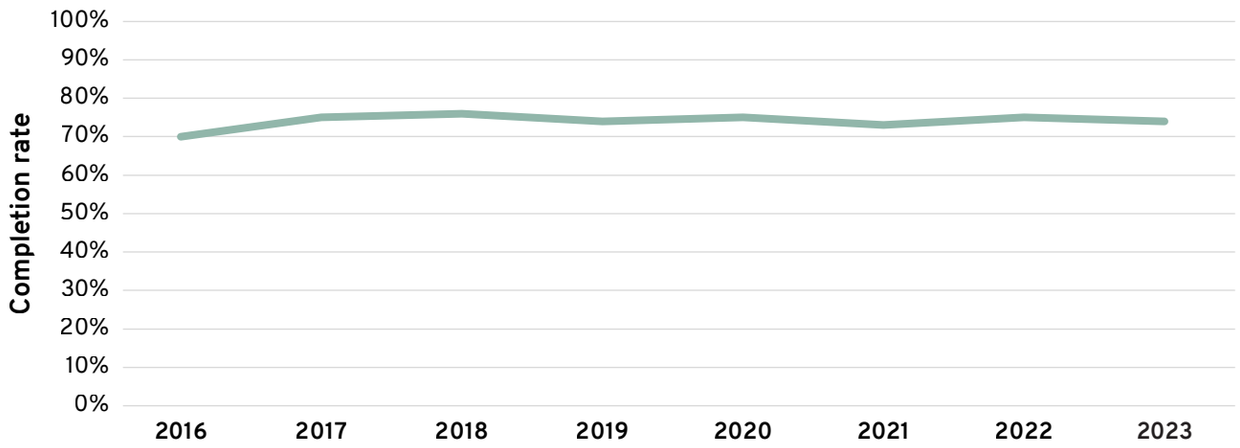
When analysing data related to completion of the T1 12-month post-therapeutic questionnaire, only patients recruited through 2023 are considered. This is because, for the patient group with a 2024 study-entry date, there was not sufficient time for everyone to complete their questionnaires as well as undertake the associated data-gathering processes before the cut-off date for data transfer in May 2025.

FIGURE 1: **NUMBER OF PATIENTS DIAGNOSED WITH PROSTATE CANCER AND INCLUDED IN THIS PCO STUDY REPORT (ANSWERED BOTH T0 AND T1 QUESTIONNAIRES) BY COUNTRY, PER YEAR (N=47,466)**



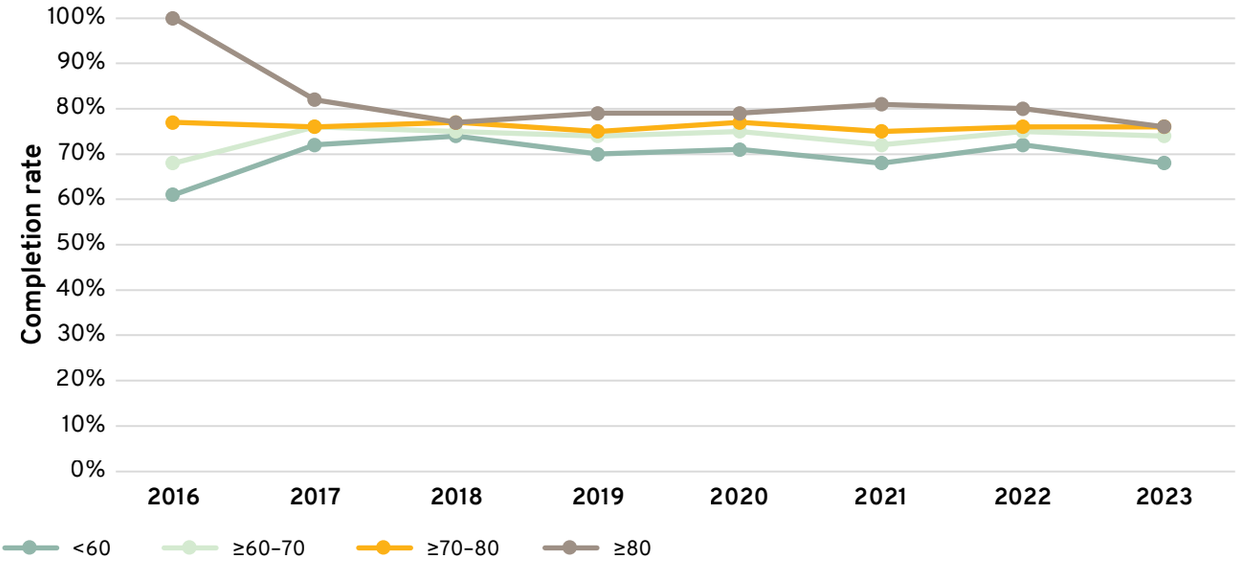
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- A total of ~4,000 patients from Austria and Switzerland are included; they were not included in all subsequent analyses since e.g. information on highest school-leaving certificate and type of health insurance was only available for patients from Germany.
- See Supplementary Figures 55 and 56 for sensitivity analyses restricted to patients of centres that have been participating in the PCO Study since at least (1) 2018 or (2) 2019.

FIGURE 2: **COMPLETION RATE FOR THE 12-MONTH POST-THERAPEUTIC (T1) QUESTIONNAIRE IN THIS PCO STUDY REPORT, BY YEAR (2016–2023, N=60,378)**



- Year of study entry/registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire (T0).
- All patients registered with the PCO Study who completed a T0 questionnaire 2016–2023 (N=60,378), are included in this figure.
- Patients with a PCO Study registration date of 2024 are not included as there was not sufficient time (15 months is required) for T1 questionnaire completion and associated data gathering before the data transfer cut off in May 2025.

FIGURE 3: **COMPLETION RATES FOR THE 12-MONTH POST-THERAPEUTIC (T1) QUESTIONNAIRE IN THIS PCO STUDY REPORT, BY AGE GROUP (2016–2023; N=60,378)**



- Year of study entry/registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire (T0).
- All patients registered with the PCO Study who had a T0 questionnaire completed between 2016 and 2023 (N=60,378) are included in this figure.
- Patients with a PCO Study registration date of 2024 are not included as there was not sufficient time (15 months is required) for T1 questionnaire completion and associated data gathering before the data transfer cut off in May 2025.
- Supplementary Figures 67 and 68 display completion rates for post-therapeutic (T1) questionnaires in the PCO Study from 2016 to 2023 (year of pre-therapeutic questionnaire) by age group - restricted to patients of centres that have been participating in the PCO since at least (1) 2018 or (2) 2019, respectively.

TABLE 4A: **NUMBER AND PROPORTION OF PATIENTS PER YEAR, BY AGE GROUP AT DIAGNOSIS (ALL PATIENTS)**

Characteristic, reported as n (%)	2016 (n=242)	2017 (n=2,451)	2018 (n=3,738)	2019 (n=5,979)	2020 (n=6,792)	2021 (n=7,276)	2022 (n=8,204)	2023 (n=10,100)	2024 (n=2,684)	Overall (n=47,466)
<60	48 (20%)	508 (21%)	697 (19%)	1,026 (17%)	1,102 (16%)	1,188 (16%)	1,282 (16%)	1,492 (15%)	401 (15%)	7,744 (16%)
≥60 and <70	108 (45%)	1,117 (46%)	1,696 (45%)	2,748 (46%)	3,120 (46%)	3,319 (46%)	3,797 (46%)	4,747 (47%)	1,279 (48%)	21,931 (46%)
≥70 and <80	85 (35%)	789 (32%)	1259 (34%)	2042 (34%)	2,376 (35%)	2,534 (35%)	2,858 (35%)	3,552 (35%)	942 (35%)	16,437 (35%)
≥80	1 (0.4%)	37 (1.5%)	86 (2.3%)	163 (2.7%)	194 (2.9%)	235 (3.2%)	267 (3.3%)	309 (3.1%)	62 (2.3%)	1,354 (2.9%)
Unknown	0	0	0	0	0	0	0	0	0	0

TABLE 4B: **NUMBER AND PROPORTION OF PATIENTS PER YEAR, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY)**

	2016 (n=242)	2017 (n=2,424)	2018 (n=3,564)	2019 (n=5,687)	2020 (n=6,225)	2021 (n=6,485)	2022 (n=7,184)	2023 (n=9,252)	2024 (n=2,416)	Overall (n=43,479)
Lower secondary school or equivalent (8/9 years of schooling)	82 (34%)	806 (34%)	1,231 (35%)	1,843 (34%)	1,883 (32%)	1,839 (30%)	1,908 (28%)	2,343 (27%)	648 (29%)	12,583 (30%)
Intermediate secondary school (10 years of schooling)	56 (23%)	466 (19%)	663 (19%)	1,004 (18%)	1,153 (19%)	1,227 (20%)	1,307 (19%)	1,750 (20%)	449 (20%)	8,075 (19%)
Comprehensive school	7 (2.9%)	91 (3.8%)	187 (5.3%)	363 (6.6%)	413 (6.9%)	452 (7.3%)	552 (8.2%)	698 (8.0%)	172 (7.6%)	2,935 (7.1%)
Entrance certificate for a higher technical college/university of applied science	33 (14%)	323 (13%)	421 (12%)	739 (13%)	815 (14%)	862 (14%)	928 (14%)	1,235 (14%)	291 (13%)	5,647 (14%)
University entrance certificate	56 (23%)	665 (28%)	941 (27%)	1,419 (26%)	1,589 (27%)	1,667 (27%)	1,929 (29%)	2,520 (29%)	666 (29%)	11,452 (28%)
Other	4 (1.7%)	32 (1.3%)	53 (1.5%)	98 (1.8%)	76 (1.3%)	86 (1.4%)	120 (1.8%)	101 (1.2%)	27 (1.2%)	597 (1.4%)
None	3 (1.2%)	13 (0.5%)	13 (0.4%)	16 (0.3%)	18 (0.3%)	22 (0.4%)	19 (0.3%)	31 (0.4%)	7 (0.3%)	142 (0.3%)
Unknown	1	28	55	205	278	330	421	574	156	2,048

Data on school-leaving certificates are restricted to patients from centres in Germany.

In comparison with similar endeavours like the PCOR-ANZ registry,[20] patients are only enrolled in the PCO Study when they complete the T0 baseline questionnaire. **Figure 2** is an analysis of the patients who participated in the PCO Study between 2016 and 2023 and completed the pre-therapeutic questionnaire (N=60,378).

The figure shows the proportion of patients who were registered with the PCO Study (answered the T0 questionnaire) and also completed the T1 12-month post-therapeutic questionnaire. Completion rates for T1 have remained relatively stable over time at 73–76%, except for the first year (70%), when the study was still being established. Notably, very little dropout was seen (73% completion) in the COVID-19 pandemic year of 2021. When analysed by age group (**Figure 3**), from 2017 onwards, there is a slight trend towards higher responses in the older age groups (76–81% completion in men aged ≥80) vs the younger age groups (68–72% completion in men aged <60).

When considering potential trends over time in the PCO Study patient population (**Table 4a–c**), it should be noted that collection of data in 2024 was still ongoing at time of reporting and only patients who had 12-month follow-up data are included (i.e. answered the T1 12-month post-therapeutic questionnaire; N=47,466).

By and large, the proportions of patients per age group remained stable over time across the PCO Study, with only a small decrease in the proportion of men under 60 years notable over time (20% [N=242] in 2016; to 15% [N=2,684] in 2024; **Table 4a**). Information on school-leaving certificate and type of health insurance is only available for German patients. In this group, the distribution among most 'highest school-leaving certificate' groups also remained stable over time (**Table 4b**). The proportions of statutory versus private health insurance also remained stable over time (**Table 4c**), but the proportion of privately insured patients is high (27%; 11,121/43,479) compared with the general German population (which is only approximately 10%).

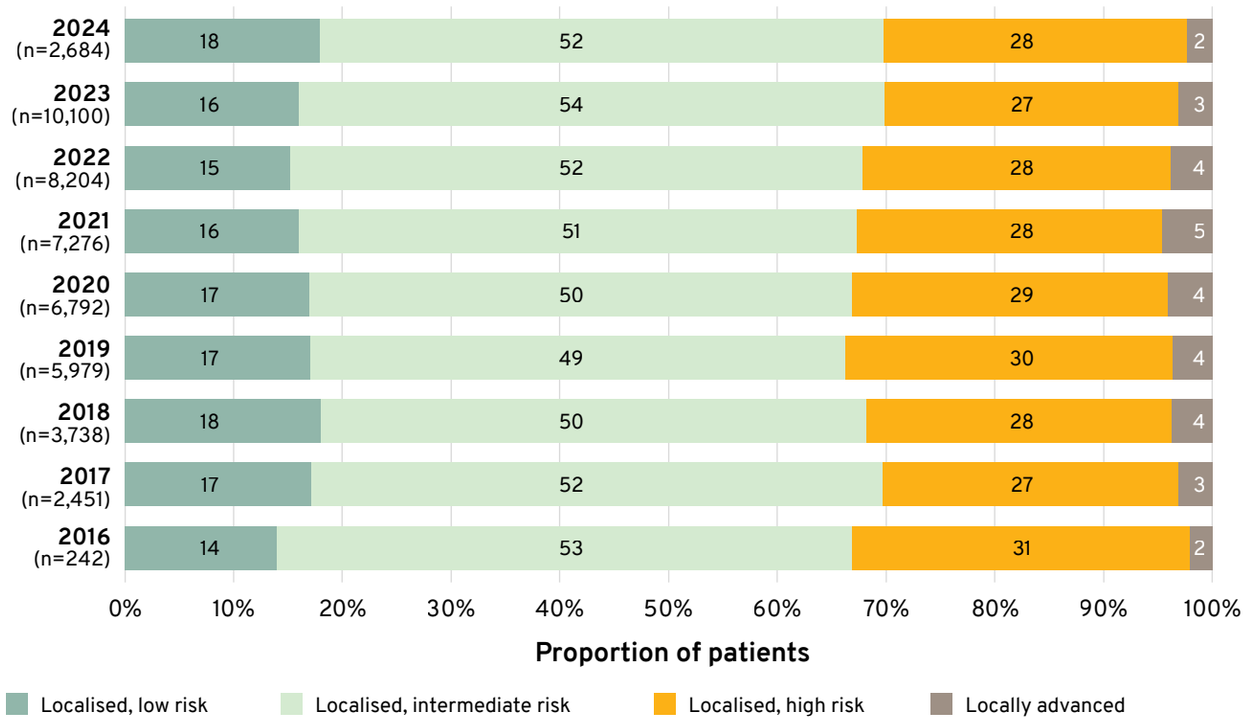
For corresponding results on sensitivity analyses restricted to centres that have been participating in the PCO Study since at least (1) 2018 or (2) 2019 see **Supplementary Tables 3 and 4**.

TABLE 4C: **NUMBER AND PROPORTION OF PATIENTS PER YEAR, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY)**

	2016 (n=242)	**2017** (n=2,424)	**2018** (n=3,564)	**2019** (n=5,687)	**2020** (n=6,225)	**2021** (n=6,485)	**2022** (n=7,184)	**2023** (n=9,252)	**2024** (n=2,416)	**Overall** (n=43,479)
Statutory health insurance	167 (70%)	1,669 (70%)	2,518 (72%)	4,035 (73%)	4,368 (73%)	4,503 (73%)	4,943 (73%)	6,364 (73%)	1,684 (74%)	30,251 (73%)
Private health insurance	72 (30%)	719 (30%)	978 (28%)	1,423 (26%)	1,571 (26%)	1,642 (27%)	1,831 (27%)	2,318 (27%)	567 (25%)	11,121 (27%)
Other / none	1 (0.4%)	11 (0.5%)	18 (0.5%)	32 (0.6%)	34 (0.6%)	28 (0.5%)	24 (0.4%)	31 (0.4%)	11 (0.5%)	190 (0.5%)
Unknown	2	25	50	197	252	312	386	539	154	1,917

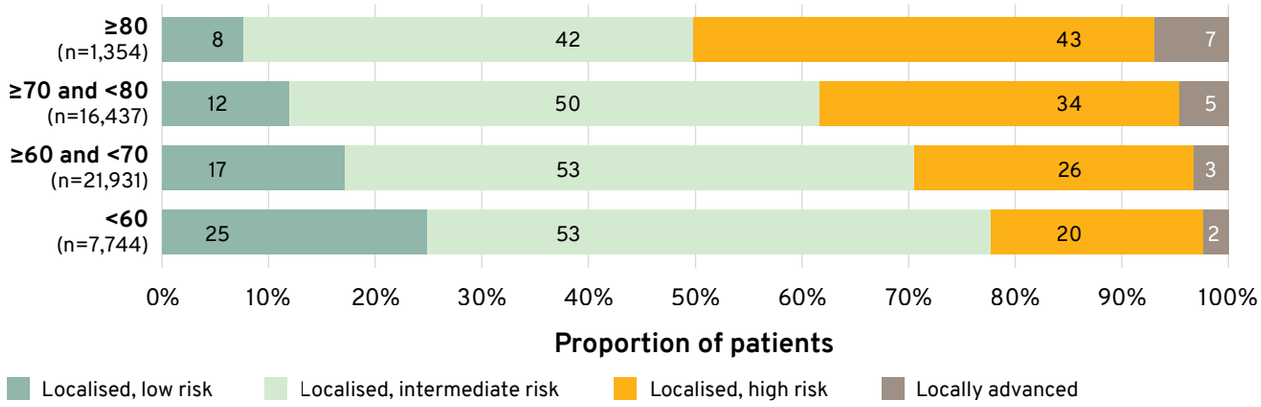
Data on type of health insurance are restricted to patients from centres in Germany.

FIGURE 4: **PROPORTION OF PATIENTS PER D'AMICO RISK GROUP AT DIAGNOSIS PER YEAR (N=47,466)**



- Proportions per risk group are calculated as a percentage of total patients registered per year.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- See Table 2 for details on d'Amico risk groups.
- See Supplementary Figures 57 and 58 for sensitivity analyses restricted to patients of centres that have been participating in the PCO Study since at least (1) 2018 or (2) 2019.

FIGURE 5: **PROPORTION OF PATIENTS PER D'AMICO RISK GROUP AT DIAGNOSIS, BY AGE GROUP AT DIAGNOSIS (N=47,466)**



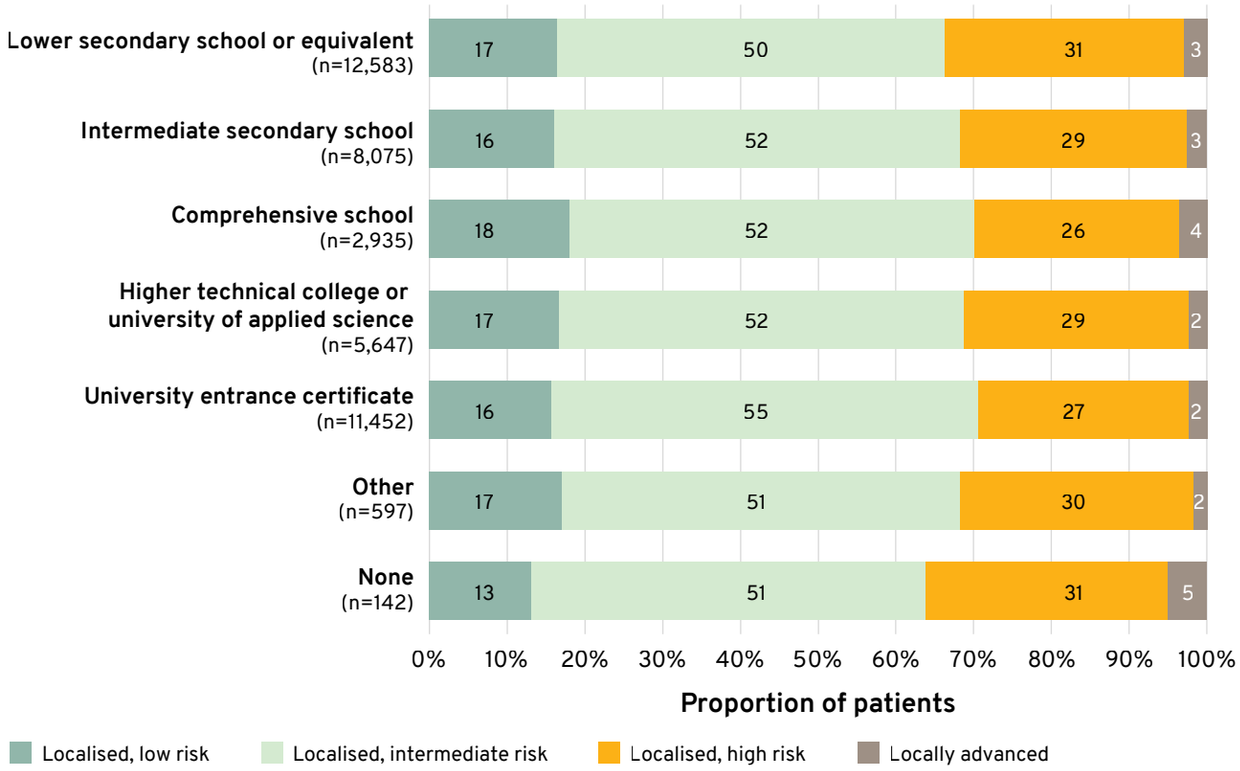
- Proportions per d'Amico risk group are calculated as a percentage of total patients per age group at diagnosis.
- See Table 2 for details on d'Amico risk groups.

Risk classification according to d'Amico

The distribution of patients among prostate cancer risk groups (defined according to d'Amico, see **Figure 4**) remained relatively stable over time, with the majority of patients (49–54%) having localised, intermediate-risk cancer, followed by localised, high-risk cancer (27–31%).

In general, according to the reported d'Amico risk groups, older patients tend to have higher-risk cancer (see **Figure 5**). Localised, high-risk and locally advanced disease was seen in 43% and 7% of men aged 80 or older (N=1,354) respectively. Whereas in men younger than sixty years (N=7,744) 20% of men had high-risk localised disease and 2% of men had locally advanced disease. In part, this is likely due to older patients being diagnosed at later cancer stages; but it may also be because older, lower-risk patients remain under the care of their office-based urologist, rather than being referred to a high-throughput centre (and therefore not being included in the PCO Study).

FIGURE 6 : **PROPORTION OF PATIENTS PER D'AMICO RISK GROUP AT DIAGNOSIS BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY, N=41,431)**

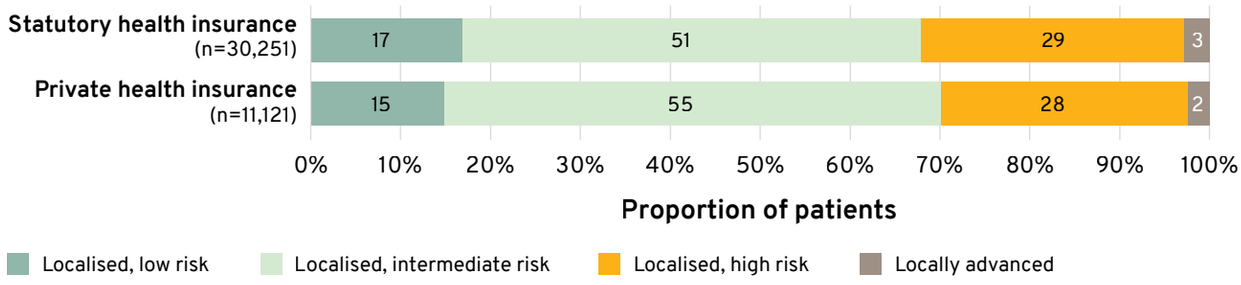


- Proportions per d'Amico risk group are calculated as a percentage of total patients registered per 'highest school-leaving certificate' grouping (data only available for Germany).
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by school leaving certificates, thereby making the groups comparable in terms of age.
- See Methods for more information on school-leaving certificates, and Table 2 for details on d'Amico risk groups.

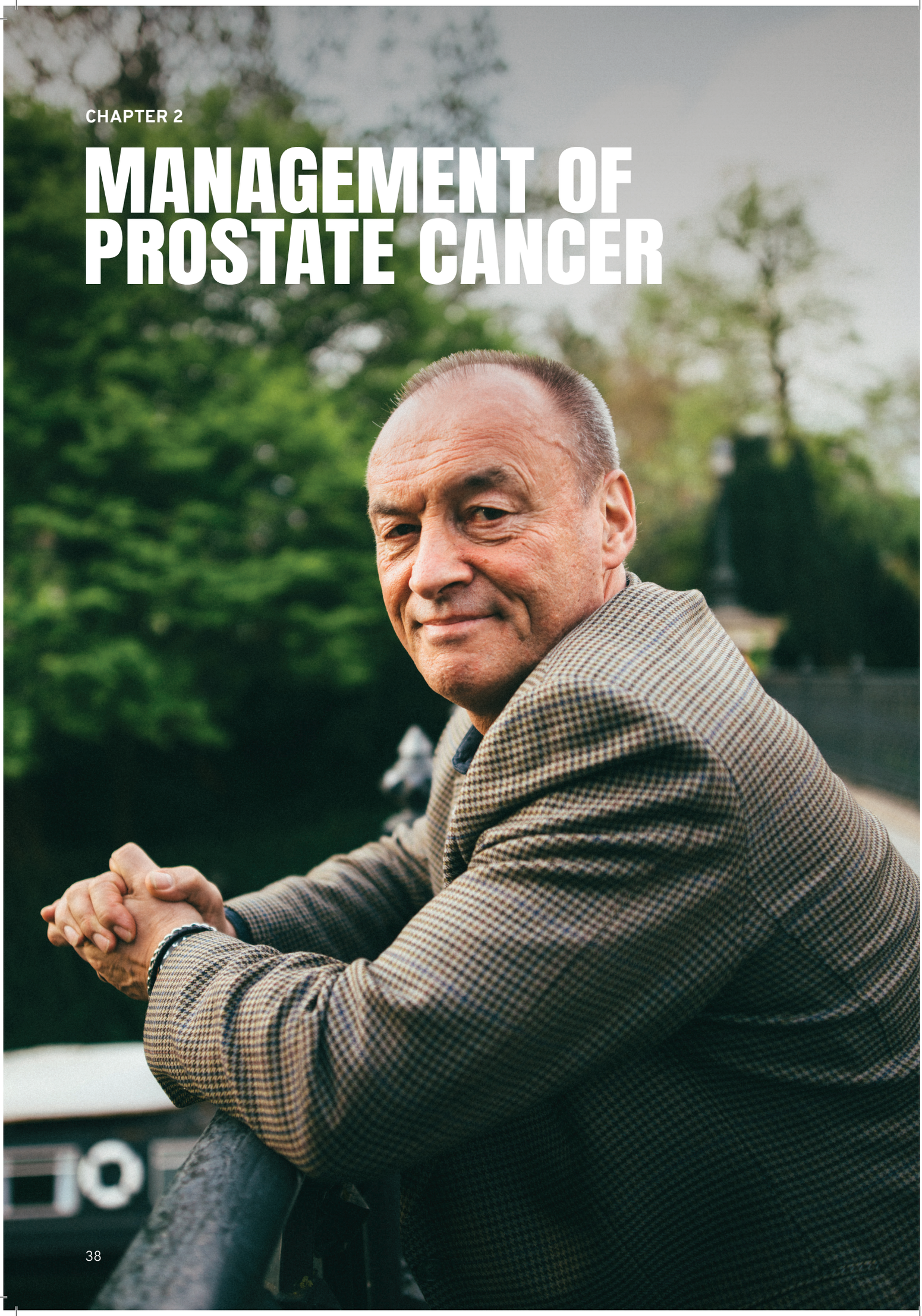
In German patients, there appears to be a slight trend towards being diagnosed with higher-risk cancer in those who have had lower levels of education (see **Figure 6**). Among patients with a lower secondary school (or equivalent) certificate (N=12,583) 31% had localised high-risk cancer and 3% had locally advanced cancer; whereas among those with a university entrance certificate (N=11,452) 27% were diagnosed with localised high-risk cancer and 2% had locally advanced cancer.

When considering cancer risk at diagnosis per type of health insurance in the German patients in the sample (**Figure 7**), slightly less localised, low-risk disease was seen in the privately insured population (15% of N=11,121) compared with the statutory insurance population (17% of N=30,251). The privately insured population also had slightly higher levels of intermediate-risk disease (55% vs 51%) and slightly lower levels of localised, high-risk or locally advanced disease (30% vs 32%) versus the statutory health insurance population.

FIGURE 7: **PROPORTION OF PATIENTS PER D'AMICO RISK GROUP AT DIAGNOSIS, BY TYPE OF HEALTH INSURANCE AT DIAGNOSIS (GERMANY ONLY, N=41,372)**



- Proportions per d'Amico risk group are calculated as a percentage of total patients registered per type of health insurance (data only available for Germany).
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by type of health insurance, thereby making the groups comparable in terms of age.
- See Table 2 for details on d'Amico risk groups.



CHAPTER 2

MANAGEMENT OF PROSTATE CANCER

Treatment decision making is always a hot topic among patients and clinicians alike. Different treatments can come with very different side effect profiles, and the risk of decision regret if patients do not fully understand these choices. Although recent data suggests less 'patient regret' was seen when shared decision making was observed, as documented in the Europa Uomo *"Shared Decision Making Study"*.[21] There is also considerable variation across guideline recommendations, between countries, and among treatment centres – not to mention differences in outcomes across both countries and providers. For example, many guidelines have been recommending AS for low-risk disease for a long time;[22,23] but, in Germany, this only happened in the 2024 guideline update.[13]

What we see in the PCO Study in general, is that around 6 out of 7 patients (40,570/47,466; see **Table 5a**) receive surgery i.e. radical prostatectomy (RPE) as their primary treatment (referred to just as 'surgery' throughout this report). This is in part due to the role of our participating centres as referral centres – as noted previously, patients who are initially managed by AS/WW often remain under the care of their office-based urologist. Also, many urology departments in the PCO Study centres are likely to recruit more effectively than their radiotherapy counterparts. In DKG centres overall, from 2019–2023, around 60% of patients (including patients with advanced disease) received surgery, 18% received RT, and around 10% were managed with AS/WW.[5]

TABLE 5A: **NUMBER AND PROPORTION OF PATIENTS PER TREATMENT GROUP, BY D'AMICO RISK GROUP AT DIAGNOSIS (ALL PATIENTS)**

Characteristic, reported as n (%)	Surgery alone (n=40,570)	Radiation (+/– ADT) (n=4,973)	Surgery + radiation (n=917)	AS (n=714)	WW (n=188)	Others (n=104)	Overall (n=47,466)
Localised, low risk	6,359 (16%)	728 (15%)	23 (2.5%)	572 (80%)	82 (44%)	36 (35%)	7,800 (16%)
Localised, intermediate risk	21,758 (54%)	2,235 (45%)	232 (25%)	124 (17%)	87 (46%)	58 (56%)	24,494 (52%)
Localised, high risk	11,176 (28%)	1,639 (33%)	573 (62%)	15 (2.1%)	17 (9.0%)	10 (9.6%)	13,430 (28%)
Locally advanced	1,277 (3.1%)	371 (7.5%)	89 (9.7%)	3 (0.4%)	2 (1.1%)	0 (0%)	1,742 (3.7%)
Unknown	0	0	0	0	0	0	0

TABLE 5B: **NUMBER AND PROPORTION OF PATIENTS PER TREATMENT GROUP, BY AGE GROUP AT DIAGNOSIS (ALL PATIENTS)**

Characteristic, reported as n (%)	Surgery alone (n=40,570)	Radiation (+/– ADT) (n=4,973)	Surgery + radiation (n=917)	AS (n=714)	WW (n=188)	Others (n=104)	Overall (n=47,466)
<60	7,249 (18%)	222 (4.5%)	145 (16%)	109 (15%)	1 (0.5%)	18 (17%)	7,744 (16%)
≥60 and <70	19,944 (49%)	1,196 (24%)	444 (48%)	291 (41%)	13 (6.9%)	43 (41%)	21,931 (46%)
≥70 and <80	12,957 (32%)	2,748 (55%)	320 (35%)	288 (40%)	88 (47%)	36 (35%)	16,437 (35%)
≥80	420 (1.0%)	807 (16%)	8 (0.9%)	26 (3.6%)	86 (46%)	7 (6.7%)	1,354 (2.9%)
Unknown	0	0	0	0	0	0	0

TABLE 5C: **NUMBER AND PROPORTION OF PATIENTS PER TREATMENT GROUP, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY)**

	Surgery alone (n=37,495)	**Radiation (+/– ADT)** (n=4,395)	**Surgery + radiation** (n=890)	**AS** (n=459)	**WW** (n=148)	**Others** (n=92)	**Overall** (n=43479)
Highest level of education							
Lower secondary school or equivalent (8/9 years of schooling)	10,371 (29%)	1,714 (42%)	289 (34%)	121 (29%)	64 (49%)	24 (26%)	12,583 (30%)
Intermediate secondary school (10 years of schooling)	7,063 (20%)	735 (18%)	166 (20%)	72 (17%)	22 (17%)	17 (19%)	8,075 (19%)
Comprehensive school	2,579 (7.2%)	238 (5.8%)	80 (9.4%)	34 (8.2%)	0 (0%)	4 (4.4%)	2,935 (7.1%)
Entrance certificate for a higher technical college/university of applied science	4,927 (14%)	525 (13%)	95 (11%)	70 (17%)	19 (15%)	11 (12%)	5,647 (14%)
University entrance certificate	10,268 (29%)	820 (20%)	198 (23%)	112 (27%)	19 (15%)	35 (38%)	11,452 (28%)
Other	495 (1.4%)	75 (1.8%)	14 (1.6%)	7 (1.7%)	6 (4.6%)	0 (0%)	597 (1.4%)
None	118 (0.3%)	14 (0.3%)	8 (0.9%)	1 (0.2%)	1 (0.8%)	0 (0%)	142 (0.3%)
Unknown	1,674	274	40	42	17	1	2,048

*Data on school-leaving certificates are restricted to patients from centres in Germany

TABLE 5D: **NUMBER AND PROPORTION OF PATIENTS PER TREATMENT GROUP, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY)**

	Surgery alone (n=37,495)	**Radiation (+/– ADT)** (n=4,395)	**Surgery + radiation** (n=890)	**AS** (n=459)	**WW** (n=148)	**Others** (n=92)	**Overall** (n=43479)
Statutory health insurance	25,852 (72%)	3,235 (78%)	679 (79%)	325 (78%)	102 (77%)	58 (64%)	30,251 (73%)
Private health insurance	9,901 (28%)	890 (22%)	178 (21%)	90 (21%)	30 (23%)	32 (35%)	11,121 (27%)
Other/none	172 (0.5%)	11 (0.3%)	1 (0.1%)	4 (1.0%)	1 (0.8%)	1 (1.1%)	190 (0.5%)
Unknown	1,570	259	32	40	15	1	1,917

*Data on type of health insurance are restricted to patients from centres in Germany.

We also see many patterns in this PCO Study, that would be expected due to guideline-recommended decision making, or based on sociodemographic factors. For example, WW is practically only seen in patients who are 70 years of age or older (**Table 5b**); and more surgery compared with RT is conducted in the younger versus older age groups (18% surgery [7,249/40,570] vs 4.5% RT [222/4,973] in men <60; compared with 32% surgery [12,957/40,570] vs 55% RT [2,748/4,973] in men aged 70–79; see **Table 5b**).

When considering treatment by d'Amico risk group (**Table 5a**), there is a tendency towards higher-risk patients being treated with radiation therapy compared with surgery (33% RT [1,639/4,973] vs 28% surgery [11,176/40,570] in high-risk disease, compared with 45% RT [2,235/4,973] vs 54% surgery [21,758/40,570] in intermediate-risk disease). There are very few patients with high-risk or locally advanced disease who are being managed with AS (2.1% [N=15/714; and 0.4% [N=3/714] respectively), and these patients may, in part, be misclassified. Nevertheless, many patients with low-risk disease still receive surgery 16% (6,359/40,570). While details on the management provided for patients with localised, low-risk disease are provided in the next section, details on the management provided for patients of remaining risk groups are provided in **Supplementary Figures 1-12**.

In the German PCO patients, more men with a lower secondary school certificate (42%, 1,714/4,395) and fewer men with a university entrance certificate (20%, 820/4,395; see **Table 5c**) received RT than might be expected based on the overall populational distribution of school-leaving certificates (lower secondary school, 30% [12,583/43,479]; university entrance certificate 28% [11,452/43,479]). Similarly, WW was received by more men with a lower secondary school or equivalent certificate (49%, 64/164) and fewer men with a university entrance certificate (19%, 19/148) than might be expected based on the general PCO Study population.

When analysing management groups by type of health insurance (**Table 5d**) there was a trend towards more men with statutory health insurance receiving both RT (78%, 3,235/4,395) and surgery + RT (79%, 679/890) compared with the general population (73% statutory insurance [30,251/43,479]). Mirrored by fewer men with private health insurance receiving RT (22% (890/4,395) and Surgery + RT (21% [178/890]) versus the 27% (11,121/43,479) private insurance that was seen in the population as a whole.

When considering changes in treatment over time across the whole PCO Study group (**Figure 8**), most striking is the increase in the proportion of RT patients between 2017 and 2018. This may in part reflect an overall change in treatment decision making due to a 2016 clinical guideline update, and may also be due to better recruitment by radio-oncologists from 2018 onwards. In 2016, there were fewer treatment centres included in the study, which likely explains the lack of recruitment of men to AS/WW in that year. Notably, the proportion of patients who receive surgery followed by RT is declining (halving over time, from 7% of N=242 in 2016, to 1% of N=2,684 in 2014). This is similar to other datasets like PCOR-ANZ.[20]

MANAGEMENT PROVIDED FOR PATIENTS WITH LOCALISED, LOW-RISK DISEASE ACCORDING TO D'AMICO

AS has long been the recommended standard of care for low-risk disease internationally,[22,23] and has recently also been recommended as management of choice in the German guidelines from 2024 onwards.[13] Before that, patients should have been "informed" about AS.[24] Therefore, we have chosen to look at this specific patient group in depth. Results of analyses on patients in other risk groups are presented in **Supplementary Figures 1 to 12**.

The only notable change over time (**Figure 9**) is a trend towards lower proportions of radiation therapy, but this may be partly due to recruitment. The proportions of patients being managed by AS in this PCO Study sample remain low across

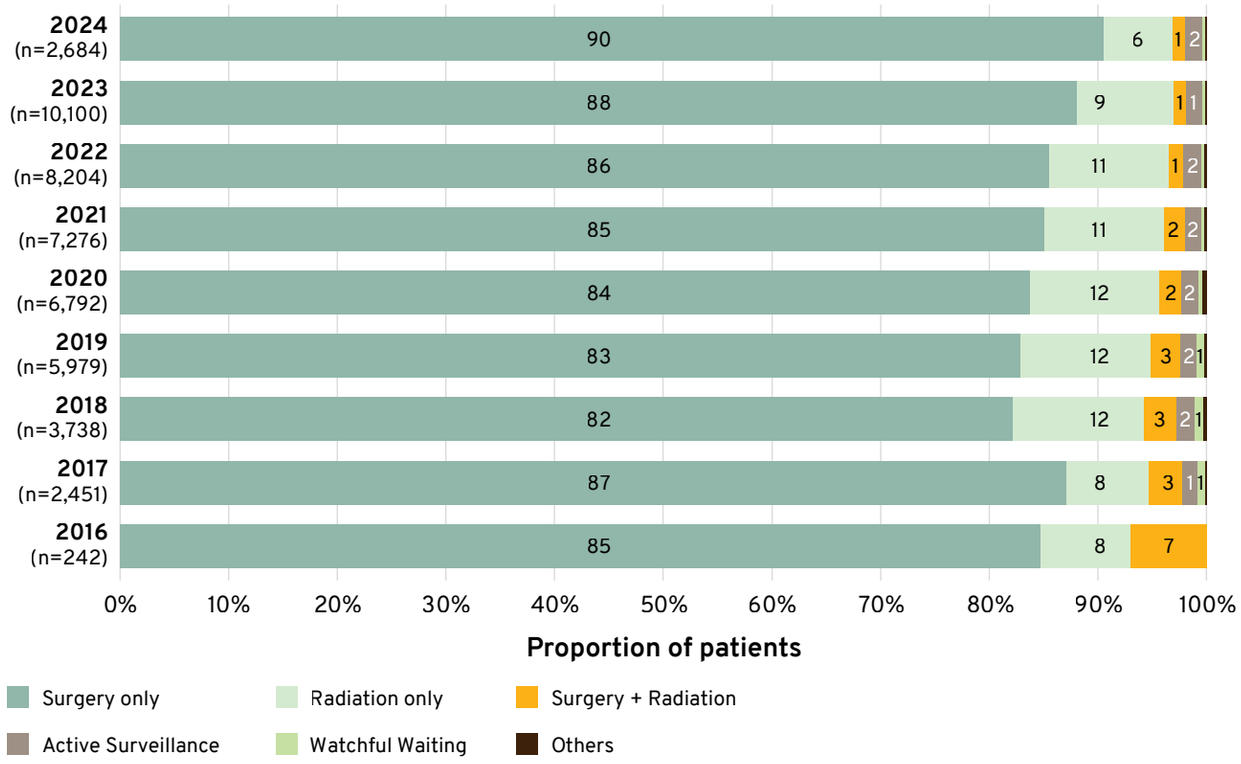
all years (≤8%), despite a steep increase in observational management strategies in the general centre population, as reported by DKG, with 18% of patients undergoing AS or WW in 2013 (849/4,646), and 41% in 2023 (3,080/7,484).[5,25] Participating PCO Study centres report difficulties recruiting AS patients because they typically are seen only briefly in these referral centres and then their cases are handled by office-based urologists.

As is expected, surgery is reported in lower proportions of patients with low-risk disease as age group increases (**Figure 10**); being seen in 89% of patients who were 60 years of age or younger (N=1,938), compared with 18% of patients who were 80 years or older, across 2016–2024 (N=103). The proportions of RT, AS and WW increase correspondingly with increasing age groups.

When examining management types across the different school-leaving-certificate groups (Germany only), very few differences are seen (**Figure 11**). Although, in patients with a university entrance certificate (N=1,843), there was a slightly higher proportion of surgery (85% vs 80-83%) and a slightly lower proportion of RT (8% vs 10-13%) reported compared with the other groups.

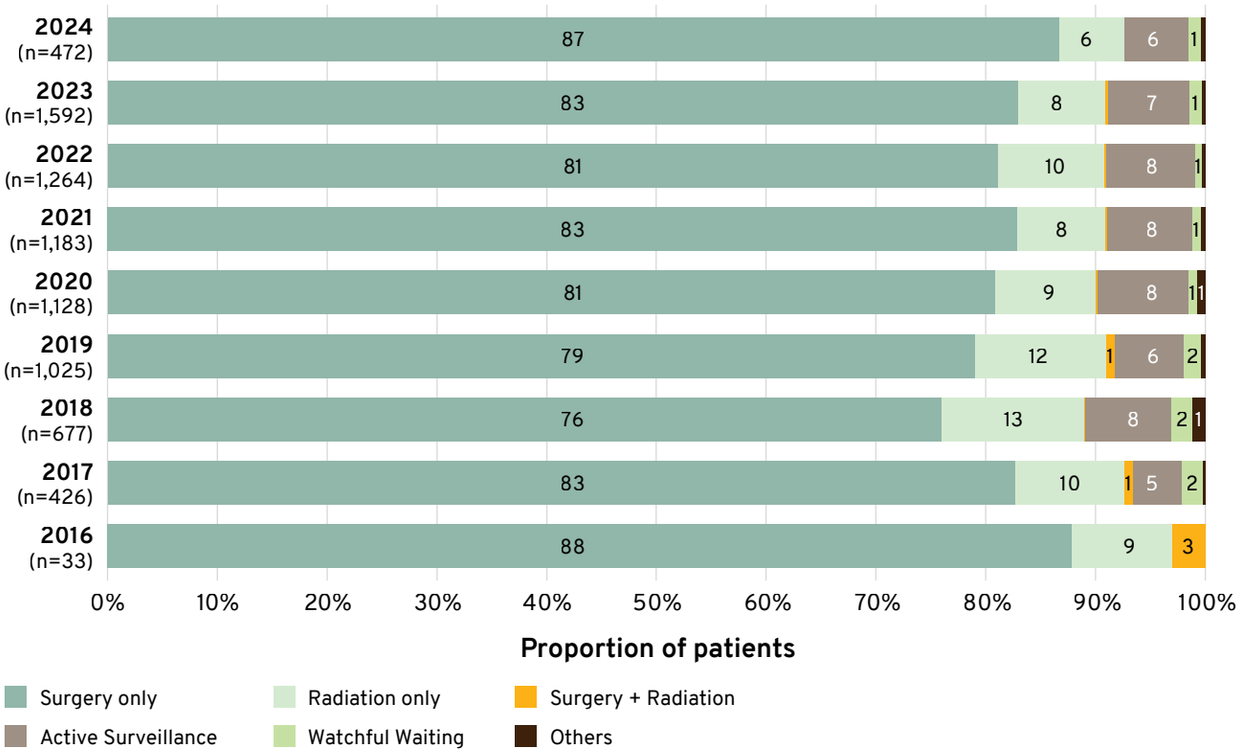
In terms of differences by type of health insurance (**Figure 12**), a higher proportion of privately insured patients received surgery alone (85% of N=1,605) compared with patients who had statutory health insurance 80% of N=5,192), with a corresponding difference seen in the rates of RT alone (8% vs 12%, respectively). This is probably due to there being a few specialised, high-volume referral centres that are included in the PCO Study, where patients with private insurance may choose to go for surgery, even when their disease is low risk.

FIGURE 8: **PROPORTION OF PATIENTS PER MANAGEMENT GROUP, BY YEAR OF STUDY ENTRY (N=47,466)**



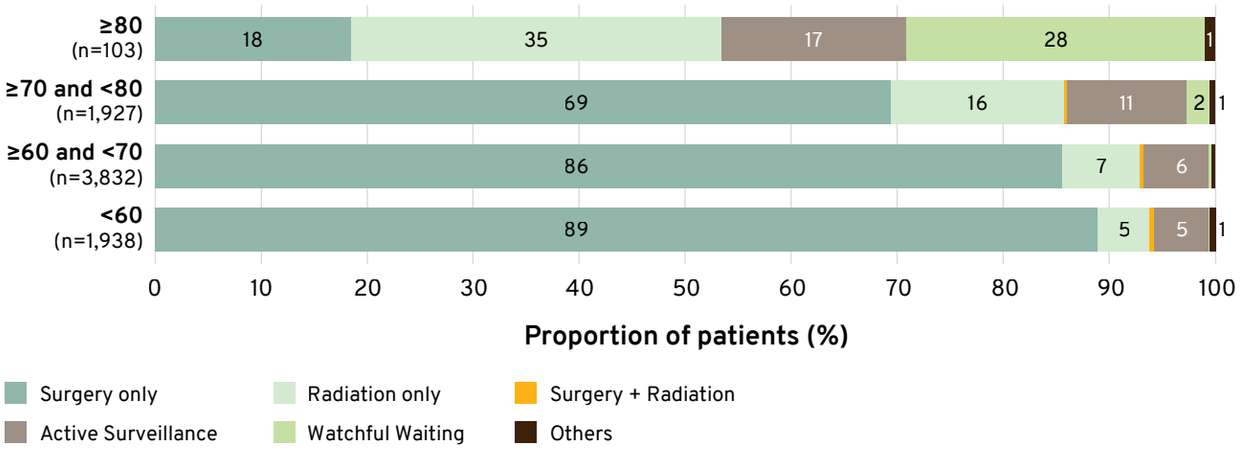
- Proportions per management group are calculated as a percentage of total patients registered per year of study entry.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- See Supplementary Figures 59 and 60 for sensitivity analyses restricted to patients of centres that have been participating in the PCO since at least (1) 2018 or (2) 2019.

FIGURE 9: **PROPORTION OF PATIENTS PER MANAGEMENT GROUP, AMONG PATIENTS WITH LOCALISED, LOW-RISK DISEASE, PER YEAR OF STUDY ENTRY (N=7,800)**



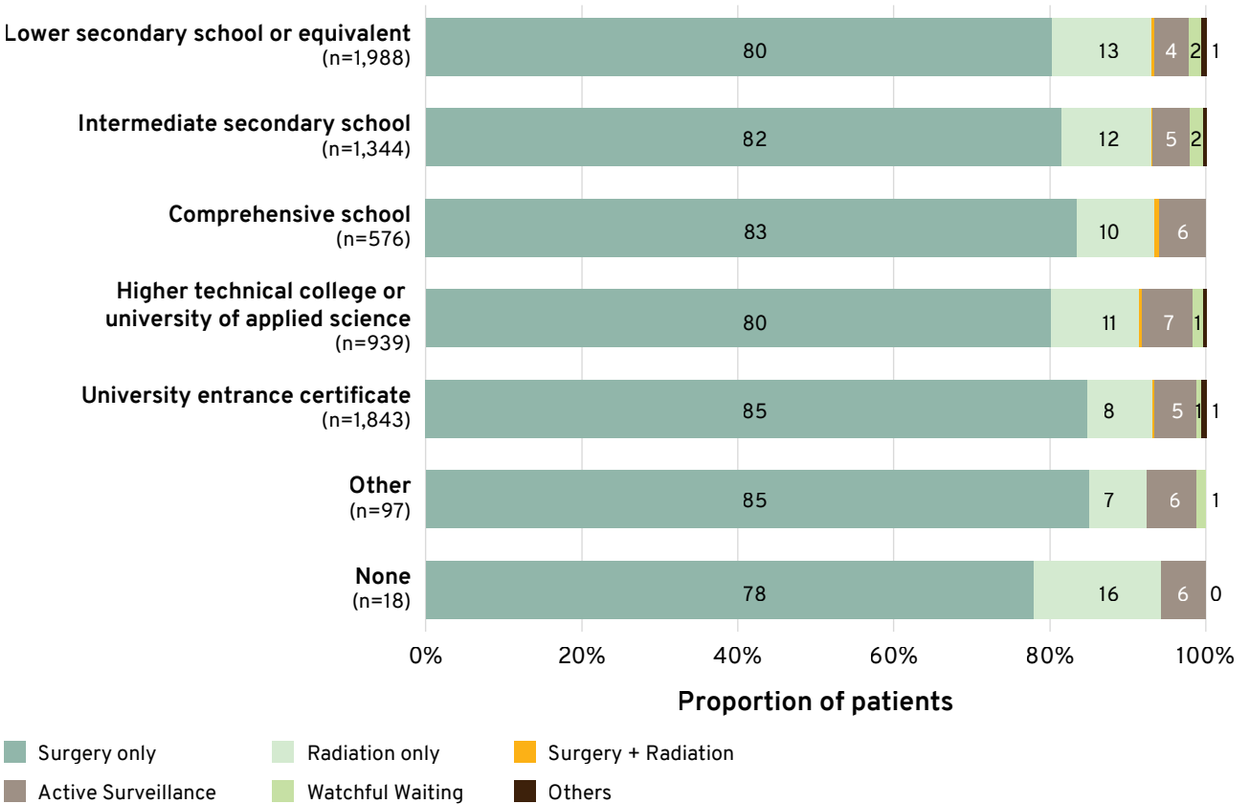
- Proportions per management group are calculated as a percentage of total patients who had localised, low-risk disease, per year of study entry.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- See Supplementary Figures 61 and 62 for sensitivity analyses restricted to patients of centres that have been participating in the PCO Study since at least (1) 2018 or (2) 2019.

FIGURE 10: **PROPORTION OF PATIENTS PER MANAGEMENT GROUP, AMONG PATIENTS WITH LOCALISED, LOW-RISK DISEASE, BY AGE GROUP AT DIAGNOSIS (N=7,800)**



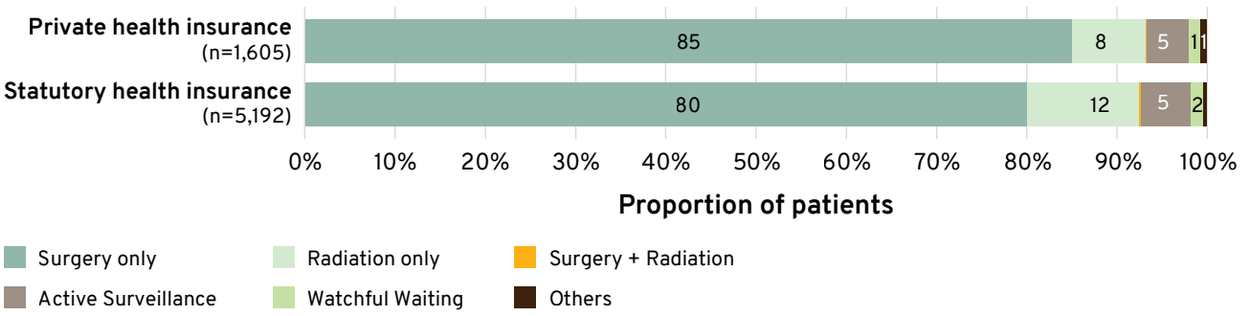
- Proportions per management group are calculated as a percentage of total patients who had localised low-risk disease per age group at diagnosis.

FIGURE 11: **PROPORTION OF PATIENTS PER MANAGEMENT GROUP, AMONG PATIENTS WITH LOCALISED, LOW-RISK DISEASE, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY, N=6,805)**



- Proportions per management group are calculated as a percentage of total patients per 'highest school-leaving certificate' grouping (available for Germany only).
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by school-leaving certificates, thereby making the groups comparable in terms of age.

FIGURE 12: **PROPORTION OF PATIENTS PER MANAGEMENT GROUP, AMONG PATIENTS WITH LOCALISED, LOW-RISK DISEASE, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY, N=6,797)**



- Proportions per management group are calculated as a percentage of total patients who had localised, low-risk disease, per type of health insurance.
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by type of health insurance, thereby making the groups comparable in terms of age.

SURGERY

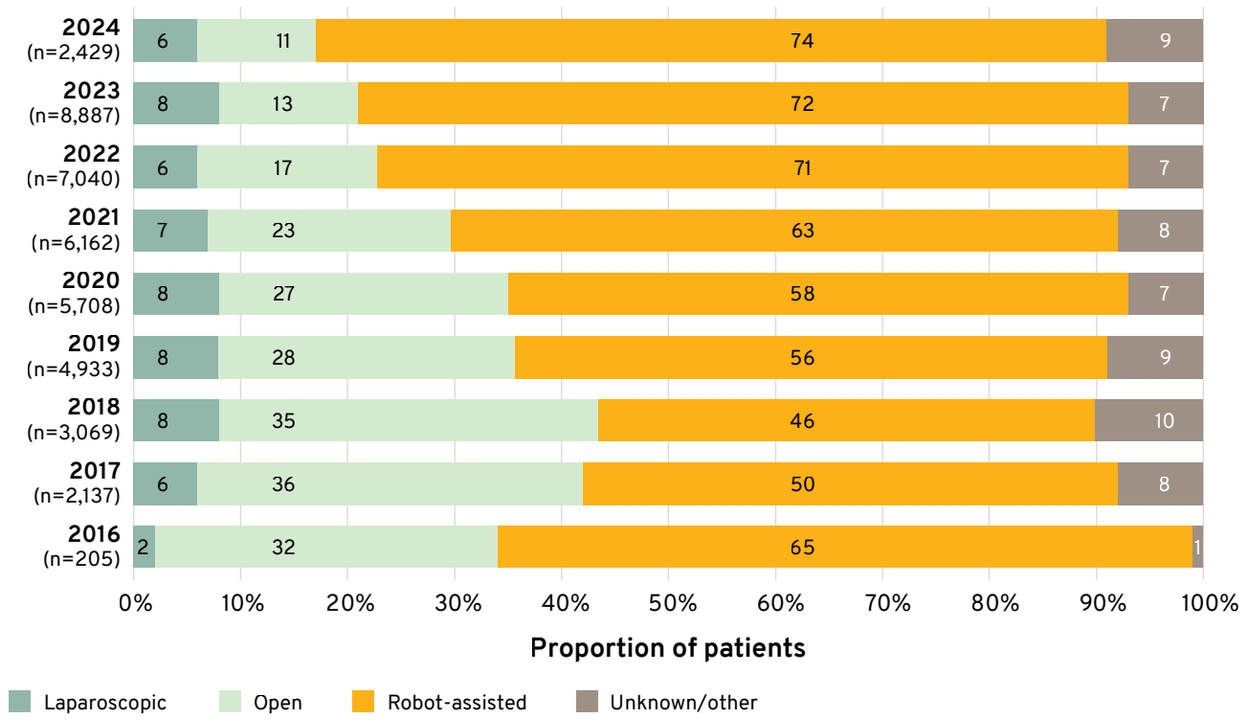
Given that, in general, over 80% of PCO Study patients have been receiving surgery as their initial management type over the years (see **Figure 8**), we have taken an in-depth look into the different types of surgery that were performed. Globally, the use of robot-assisted surgery is on the rise,[26] and in this analysis we compare the proportion of robotic surgery with open and laparoscopic approaches, as well as examining the proportion of nerve-sparing surgeries that were undertaken. All analyses for surgery, except for those on surgical margins, are restricted to the patient group who had surgery without radiation between the T0 baseline questionnaire and the T1 12-month post-treatment questionnaire (N=40,570): this group accounts for 98% of surgical patients in the PCO Study (N=40,570/41,487).

Surgical approach in patients who had surgery with no radiation within 12 months of T0

In line with the general change in practise that favours the use of minimally invasive and robot-assisted surgical techniques,[26] a steep decrease in the proportion of open surgery is seen in the PCO Study over time (see **Figure 13**); from >30% at the start of the study to only 11% (N=2,429) in 2024. This is mirrored by a corresponding increase in the proportion of robot-assisted surgery that is carried out, which rose from 50–65% in 2016–2017 to 74% of surgical procedures in 2024 (in men who did not have RT within 12 months of surgery).

There were no notable differences in type of surgical technique used when analysed by d'Amico risk group at diagnosis (**Figure 14**), but a trend

FIGURE 13: **PROPORTION OF PATIENTS PER TYPE OF SURGERY, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY YEAR OF STUDY ENTRY (N=40,570)**

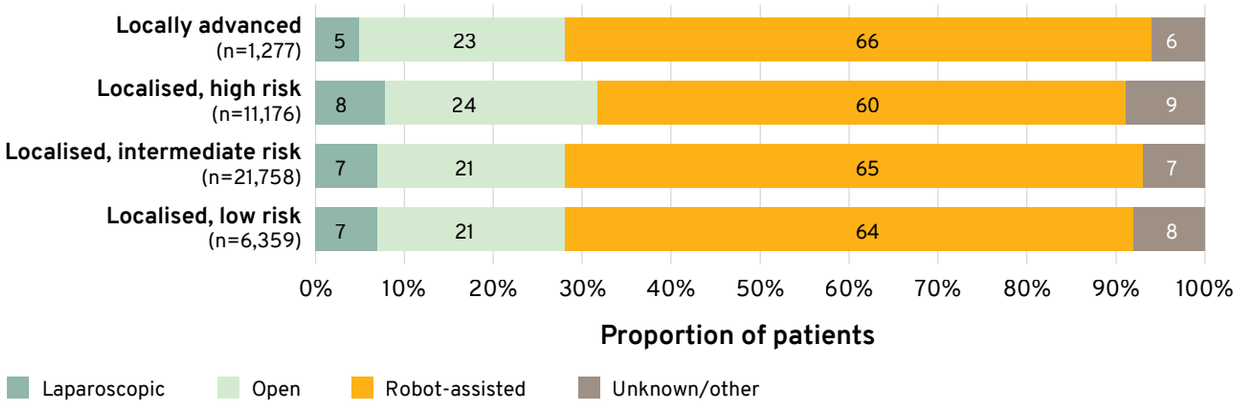


- Proportions per type of surgery are calculated as a percentage of total patients who had surgery without radiation, per year of study entry.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- See Supplementary Figures 63 and 64 for sensitivity analyses restricted to patients of centres that have been participating in the PCO Study since at least (1) 2018 or (2) 2019.

towards slightly more laparoscopic or open surgeries and fewer robot-assisted surgeries was seen with increased age (**Figure 15**). In men under 60 years of age (N=7,249) laparoscopic and open surgery accounted for 7% and 19% of cases respectively; with robot-assisted surgery undertaken in 68% of cases. But in the majority of men – those between 60 and 79 years of age – the laparoscopic approach was provided to 22–23% of men, and the robot-assisted approach was provided to 61–64% of men.

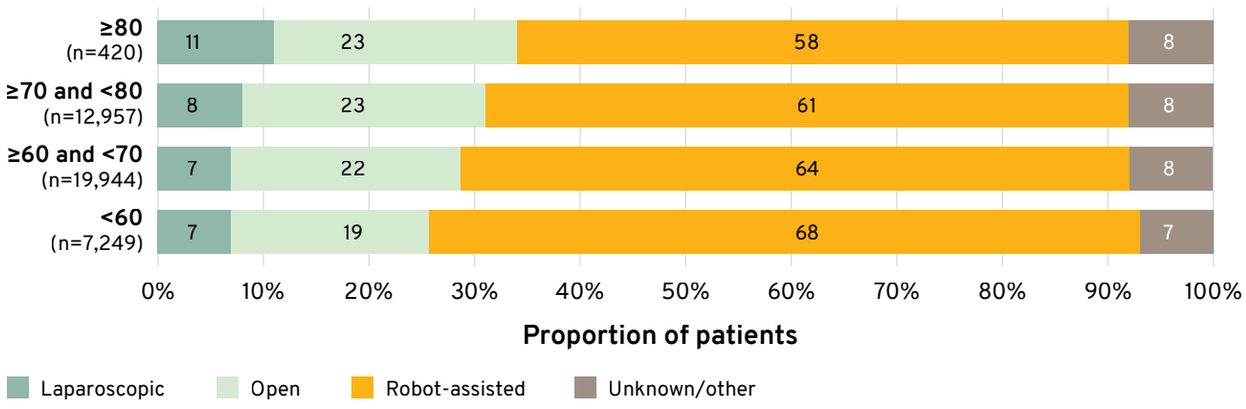
In terms of differences by highest-school-leaving certificate (examined in German patients only, **Figure 16**), the proportion of robot-assisted surgery is relatively consistent across the mid-range groups at approximately 60%, with slight differences seen in both the 'lower secondary school or equivalent' group (57% of N=10,371) and the 'university entrance certificate' group (65% of N=10,268). The proportion of open surgeries undertaken remains relatively stable across all groups.

FIGURE 14: **PROPORTION OF PATIENTS PER TYPE OF SURGERY, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY D'AMICO RISK GROUP (N=40,570)**



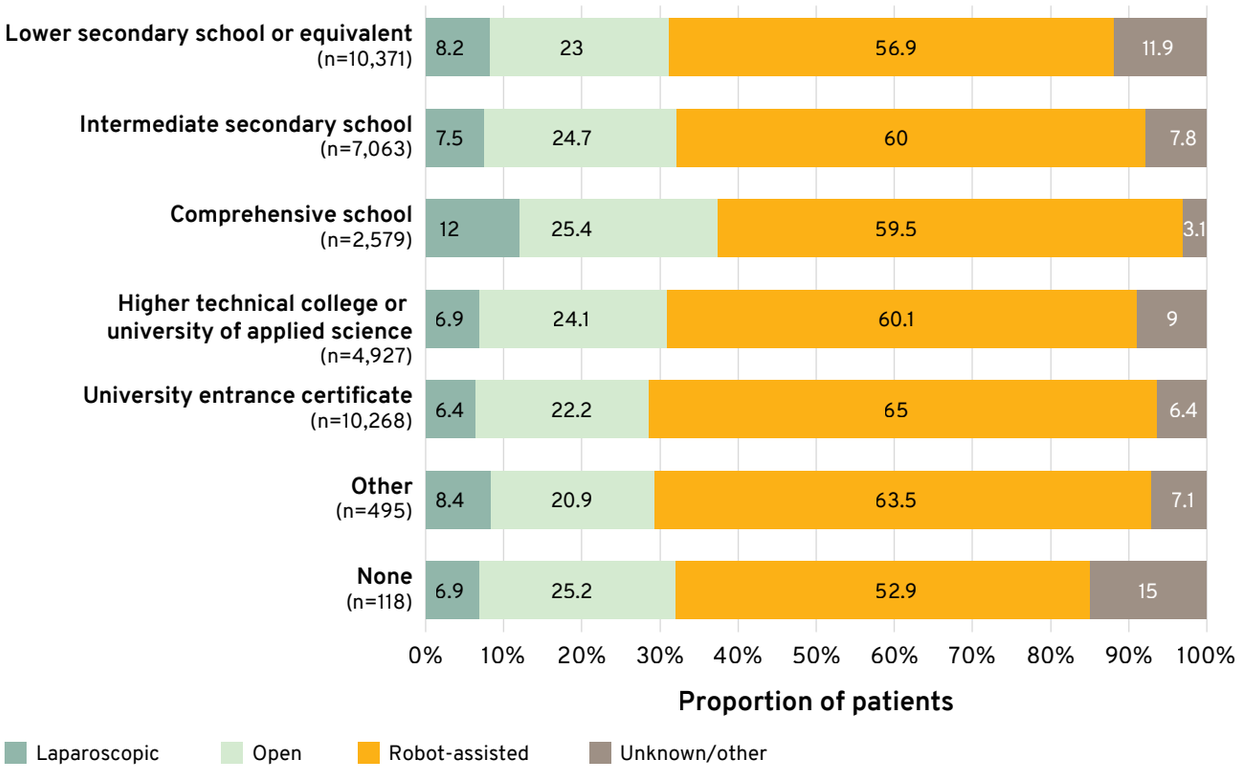
- Percentages are calculated as a percentage of total patients who had surgery without radiation per d'Amico risk group at study diagnosis.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- See Table 2 for details on d'Amico risk groups.

FIGURE 15: **PROPORTION OF PATIENTS PER TYPE OF SURGERY, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY AGE GROUP AT DIAGNOSIS (N=40,570)**



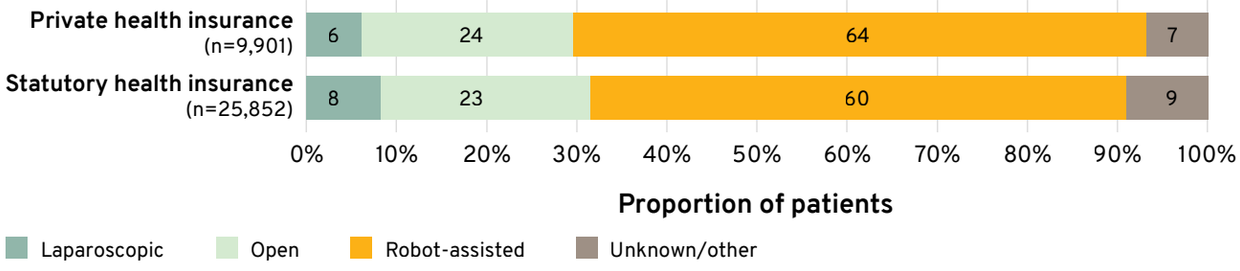
- Proportions per type of surgery are calculated as a percentage of total patients who had surgery without radiation, per age group at diagnosis.
- 'Without radiation' is defined as no radiation within 12 months of surgery.

FIGURE 16: **PROPORTION OF PATIENTS PER TYPE OF SURGERY, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY, N=35,821)**



- Proportions per type of surgery are calculated as a percentage of total patients who had surgery without radiation, per 'highest school-leaving certificate' grouping (available for Germany only).
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by school-leaving certificates, thereby making the groups comparable in terms of age.

FIGURE 17: **PROPORTION OF PATIENTS PER TYPE OF SURGERY, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY, N=35,753)**



- Proportions per type of surgery are calculated as a percentage of total patients who had surgery without radiation, per type of health insurance.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by type of health insurance, thereby making the groups comparable in terms of age.

Also in Germany (see **Figure 17**), men with statutory health insurance (N=25,852) had slightly lower levels of robot-assisted surgery (60% vs 64%) and marginally higher levels of laparoscopic surgery (8% vs 6%) compared with those who had private health insurance (N=9,901).

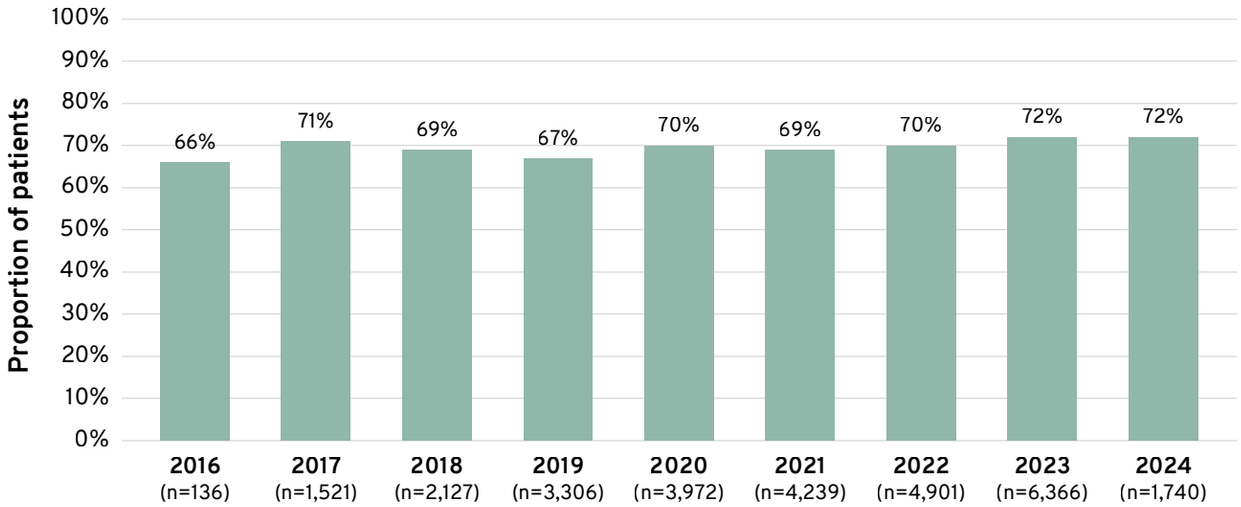
Nerve-sparing surgery in patients who had surgery with no radiation within 12 months of T0

Nerve-sparing surgery is essential for preserving erectile function and is reported to help preserve adequate erections in 50–70% of men who had normal function prior to surgery.[26]

However, different surgical approaches to nerve-sparing surgery may be used (e.g. interfascial or 'partial' nerve sparing or intrafascial or 'aggressive' nerve sparing) and when considering the PCO data, it should be noted that the documentation available to the PCO Study does not differentiate between techniques used.

A nerve-sparing approach to surgery was taken in the majority of cases (66–72%, N=40,570) across the PCO Study, with no notable trends observable over time (**Figure 18**). As expected in patients with localised disease, nerve-sparing surgery was more prevalent in men in the lower d'Amico risk groups (76–85%) versus

FIGURE 18: **PROPORTION OF PATIENTS WHOSE SURGERY WAS NERVE-SPARING, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY YEAR OF STUDY ENTRY (N=40,570)**

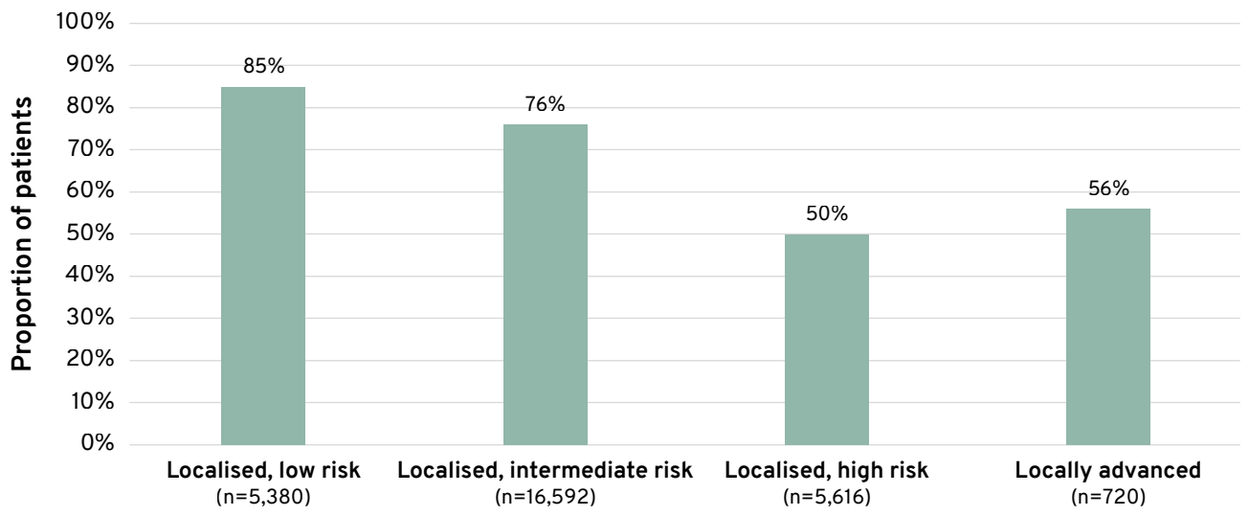


- Among all patients who had surgery without radiation (N=40,570), a total of N=28,308 patients (70%) had nerve-sparing surgery.
- The proportion of patients who had nerve-sparing surgery is calculated as a percentage of total patients who had surgery without radiation, per year of study entry.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- See Supplementary Figures 65 and 66 for sensitivity analyses restricted to patients of centres that have been participating in the PCO Study since at least (1) 2018 or (2) 2019.
- The numbers below the bars indicate the number of patients who underwent nerve-sparing surgery in each group.

the higher risk groups (50–56%; see **Figure 19**). Although the locally advanced group had a higher proportion of nerve-sparing surgery (56%, N=720) compared with the localised, high-risk group (50%, N=5,616) this should not be overinterpreted, as the high-risk group is comparatively small. This may also be due to patient self-selection for treatment centres that are known to specialise in nerve-spring surgery.

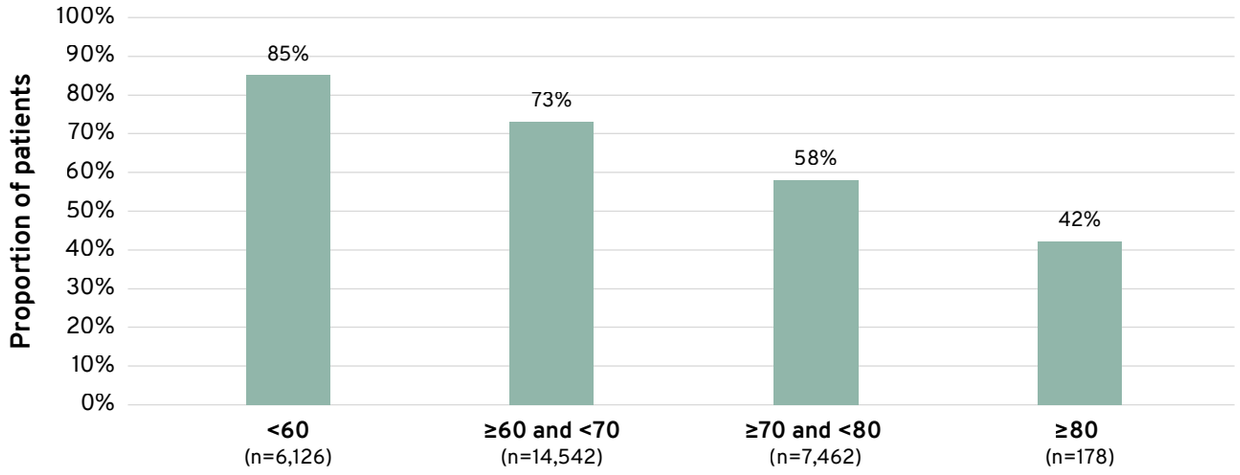
Similarly, as expected, larger proportions of nerve-sparing surgery are undertaken in men of younger age; 85% in men <60 years (N=6,126) vs 42% in men ≥79 years (N=178) (see **Figure 20**). In Germany, there is also a trend towards higher proportions of nerve-sparing surgery in those with higher school-leaving certificates; 61% (N=6,273) in the 'lower secondary school' group vs 76% (N=7,926) in the 'university entrance certificate' group (see **Figure 21**). The 'comprehensive school' group slightly deviates from this trend again, at 60% (N=1,665). Also in Germany, there is a clearly higher proportion of nerve-sparing surgery undertaken in the privately insured (77%, N=7,625) vs those with statutory insurance (66%, N=17,149; see **Figure 22**).

FIGURE 19: **PROPORTION OF PATIENTS WHOSE SURGERY WAS NERVE-SPARING, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY D'AMICO RISK GROUP AT DIAGNOSIS (N=40,570)**



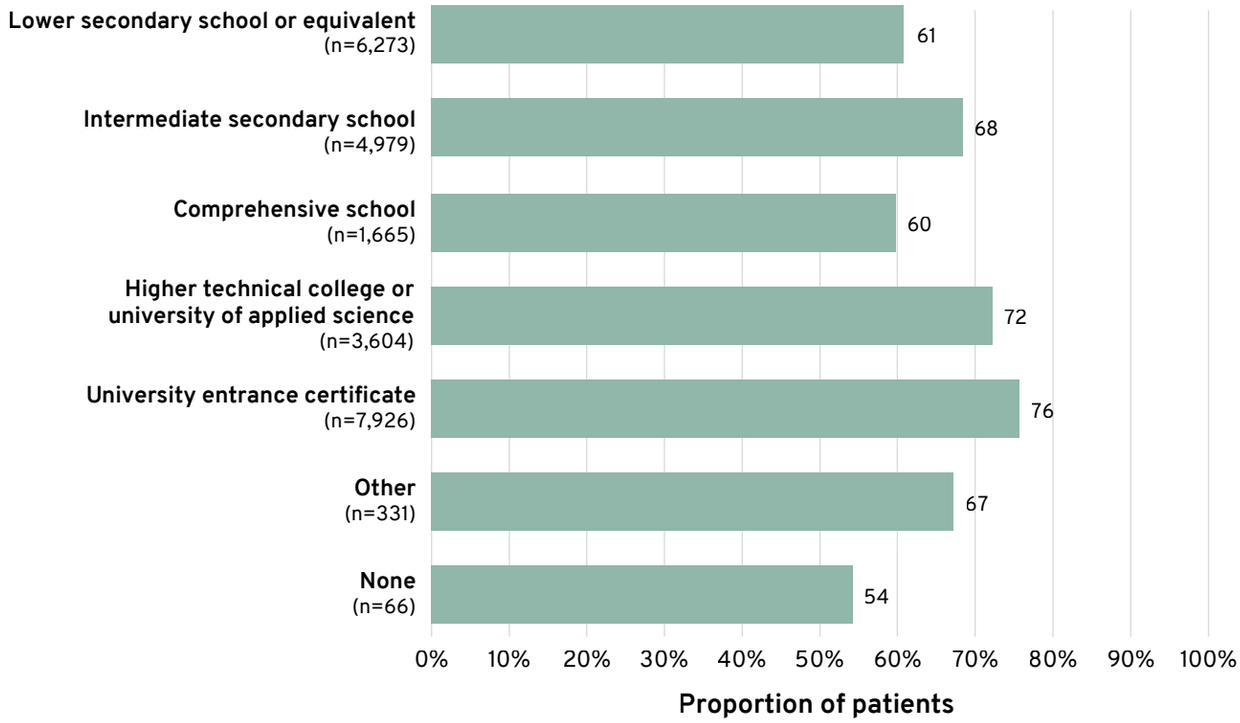
- Among all patients who had surgery without radiation (N=40,570), a total of N=28,308 patients (70%) had nerve-sparing surgery.
- The proportion of patients who had nerve-sparing surgery is calculated as a percentage of total patients who had surgery without radiation, per d'Amico risk group at diagnosis.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- See Table 2 for details on d'Amico risk groups.
- The numbers below the bars indicate the number of patients who underwent nerve-sparing surgery in each group.

FIGURE 20: **PROPORTION OF PATIENTS WHOSE SURGERY WAS NERVE-SPARING, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY AGE GROUP AT DIAGNOSIS (N=40,570)**



- Among all patients who had surgery without radiation (N=40,570), a total of N=28,308 patients (70%) had nerve-sparing surgery.
- The proportion of patients who had nerve-sparing surgery per age group, is calculated as a percentage of total patients who had surgery without radiation, per age group at diagnosis.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- The numbers below the bars indicate the number of patients who underwent nerve-sparing surgery in each group.

FIGURE 21: **PROPORTION OF PATIENTS WHOSE SURGERY WAS NERVE-SPARING, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY, N=35,821)**



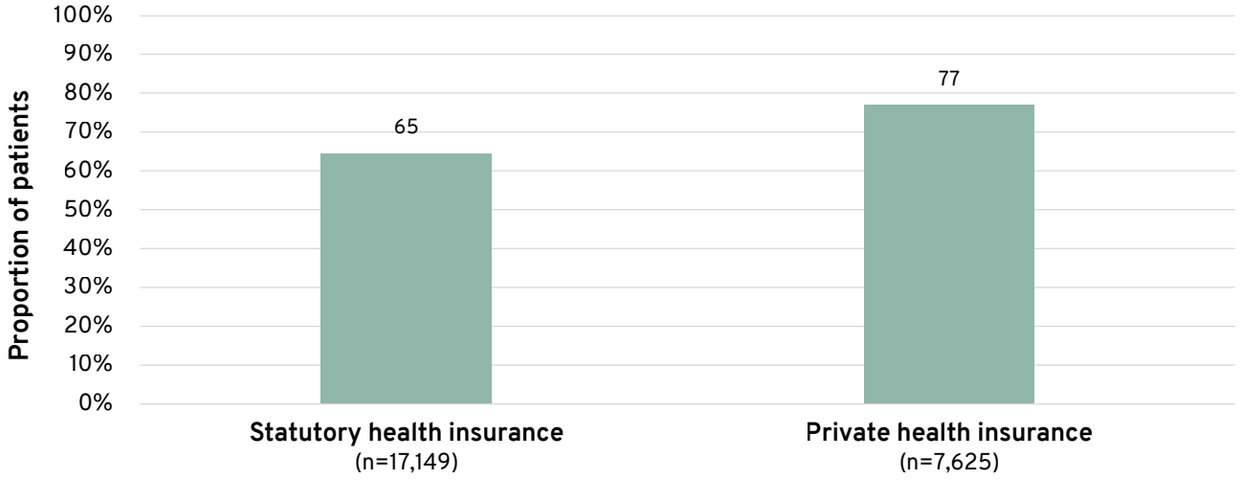
- Among all patients who had surgery without radiation and had data available on their highest school-leaving certificate (N=35,821), a total of N=24,844 patients (69%) had nerve-sparing surgery.
- The proportion of patients who had nerve-sparing surgery is calculated as a percentage of total patients with education data available who had surgery without radiation, per 'highest school-leaving certificate' grouping.
- Data on school-leaving certificates is available for Germany only.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by school-leaving certificates, thereby making the groups comparable in terms of age.
- The numbers next to the bars indicate the number of patients who underwent nerve-sparing surgery in each group.

Surgical margins

Positive surgical margins post prostatectomy are associated with an increased risk of biochemical recurrence and cancer relapse. These margins are identified by a pathologist after the procedure, and there is ongoing debate about whether the surgical approach – open, robotic, or laparoscopic prostatectomy – affects the likelihood of margin positivity.[27] In cases of organ-confined disease (pT2), a positive margin is considered a proxy indicator of surgical technique and proficiency.[28] Maintaining a low rate of positive surgical margins continues to be considered a key clinical quality benchmark internationally,[29] and is one of several clinical quality indicators that are considered by DKG. To obtain DKG certification, cancer centres must demonstrate that they are sticking to a range of clinical guidelines through providing quality indicators such as these in their annual reports.

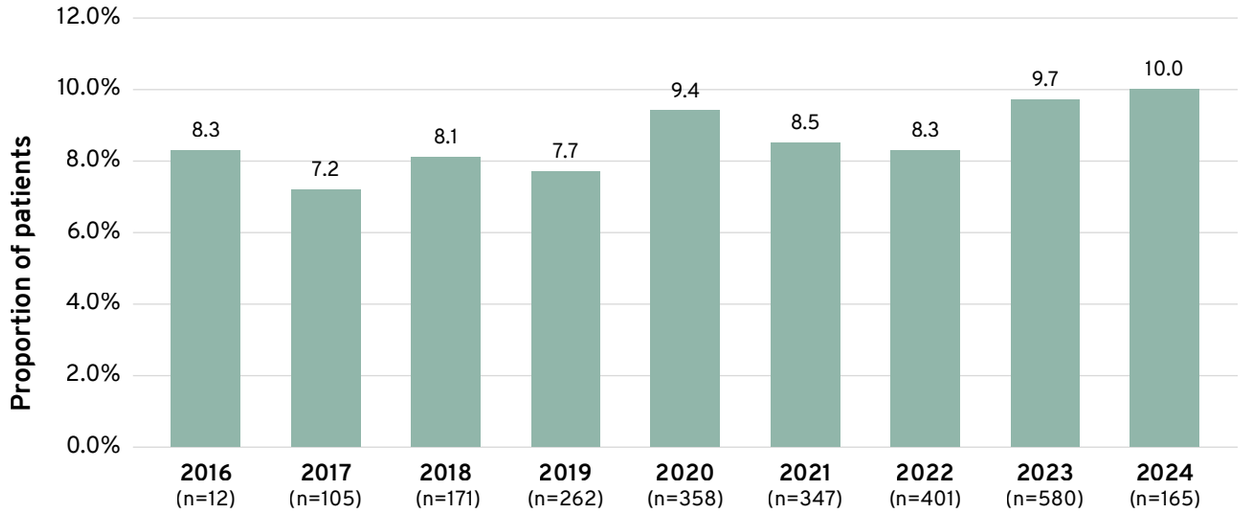
The following analyses on surgical-margin positivity are based on the group of men who had surgery, both with and without radiation, between the T0 baseline questionnaire and the T1 12-month post-treatment questionnaire (N=41,487).

FIGURE 22: **PROPORTION OF PATIENTS WHOSE SURGERY WAS NERVE-SPARING, AMONG PATIENTS WHO HAD SURGERY WITHOUT RADIATION, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY, N=35,753)**



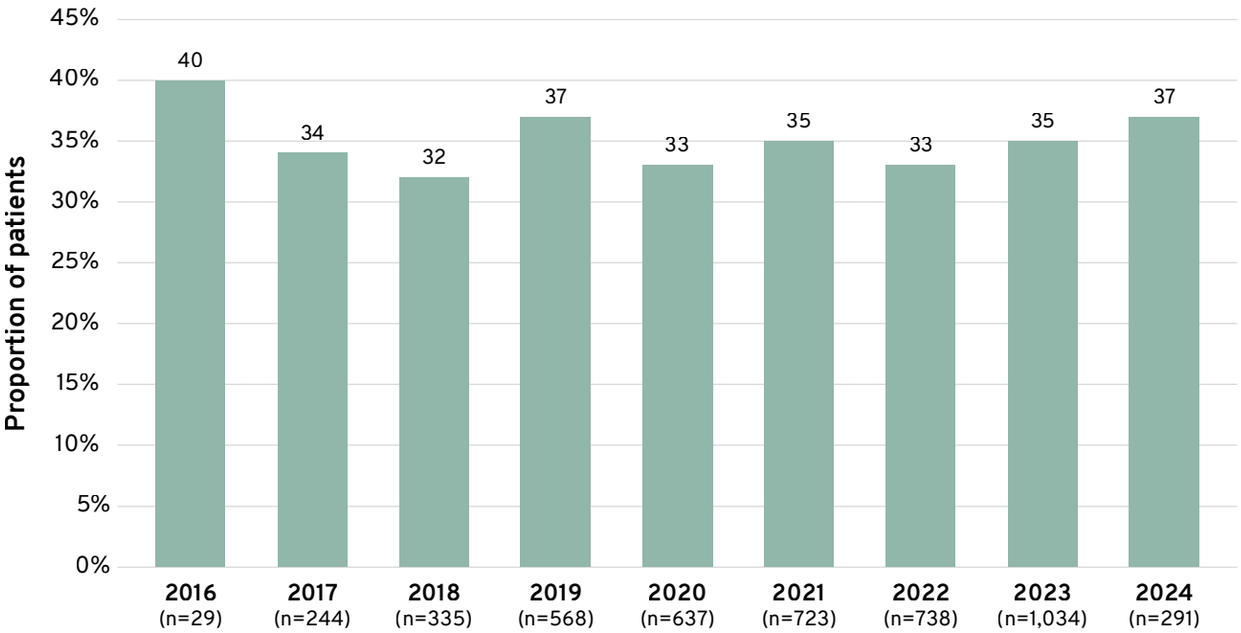
- Among all patients who had surgery without radiation and had data available on their type of health insurance (N=35,753), a total of N=24,774 patients (69%) had nerve-sparing surgery.
- The proportion of patients who had nerve-sparing surgery is calculated as a percentage of total patients with health insurance data available who had surgery without radiation, per type of health insurance.
- Data on type of health insurance is available for Germany only.
- 'Without radiation' is defined as no radiation within 12 months of surgery.
- Direct age standardisation was performed to account for any differences in age structure among the groups defined by type of health insurance, thereby making the groups comparable in terms of age.
- The numbers below the bars indicate the number of patients who underwent nerve-sparing surgery in each group.

FIGURE 23: **PROPORTION OF PT2-PATIENTS WITH POSITIVE SURGICAL MARGINS (R1/R2) BY YEAR OF STUDY ENTRY (N=27,456)**



- The proportion of pT2 patients who had positive surgical margins (R1/R2) is calculated as a percentage of total pT2 patients who had data available on surgical margin status (N=27,456).
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- The numbers below the bars indicate the number of patients with positive surgical margins in each group.

FIGURE 24: **PROPORTION OF PT3/4-PATIENTS WITH POSITIVE SURGICAL MARGINS (R1/R2) BY YEAR OF STUDY ENTRY (N=13,338)**



- The proportion of pT3/4 patients who had positive surgical margins (R1/R2) is calculated as a percentage of total pT3/4 patients who had data available on surgical margin status (N=13,338).
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic questionnaire.
- The numbers below the bars indicate the number of patients with positive surgical margins in each group.

In this report, there were N=27,456 men with organ-confined (pT2) disease who had data available on their surgical margin status (see **Figure 23**). The rate of pT2 positive surgical margins has remained relatively stable, at or below 10%, across all years included in the report. This is a relatively low rate compared with other cohorts such as that covered by the PCOR-ANZ Annual report, which reports positive surgical margin rates between 12% and 18% (N=9,226) depending on type of institute or type of surgery.[20]

When considering positive surgical margins in locally advanced (pT3/4) disease, as has been previously reported by the PCOR-ANZ, the picture is somewhat different from that in pT2 disease, with comparatively much higher margin-positivity rates.[30] Once the PCO Study was fully established in 2017, rates of pT3/4 margin positivity consistently ranged between 32% and 37% up to 2024 (**Figure 24**). Similarly, an overall risk-adjusted pT3/4 margin positivity rate of 37.4% (95% CI, 36.33–38.45%) was seen in the most recent PCOR-ANZ annual report, which covered the years 2020–2022 (N=8,496).[20]

RADIATION THERAPY

In this PCO Study report N=4,973 men received RT as part of their treatment plan (see **Table 6a**). Within this group, the majority (94%; 4,515/4,793) received external-beam radiation therapy (EBRT), with only N=82 patients receiving high-dose-rate (HDR) brachytherapy and N=376 men receiving low-dose-rate (LDR) brachytherapy.

TABLE 6A: **NUMBER AND PROPORTION OF PATIENTS UNDERGOING RT BY TYPE OF RT (+/-ADT) AND D'AMICO RISK GROUP AT DIAGNOSIS (ALL PATIENTS)**

	Overall radiation therapy			EBRT					Brachytherapy	
Characteristic, reported as n (%)	**All RT** (n=4,973)	**–ADT** (n=2,517)	**+ADT** (n=2,248)	**All EBRT** (n=4,515)	**–ADT preT1** (n=2,106)	**+ADT preT0 only** (n=130)	**+ADT preT0 +ADT T0 to T1** (n=1,400)	**–ADT preT0 +ADT T0 to T1** (n=622)	**HDR** (n=82)	**LDR** (n=376)
Localised, low risk	728 (15%)	670 (27%)	51 (2.3%)	485 (11%)	431 (20%)	7 (5.4%)	27 (1.9%)	12 (1.9%)	3 (3.7%)	240 (64%)
Localised, intermediate risk	2,235 (45%)	1,389 (55%)	764 (34%)	2,089 (46%)	1,249 (59%)	43 (33%)	475 (34%)	228 (37%)	23 (28%)	123 (33%)
Localised, high risk	1,639 (33%)	380 (15%)	1,160 (52%)	1,578 (35%)	351 (17%)	72 (55%)	696 (50%)	328 (53%)	48 (59%)	13 (3.5%)
Locally advanced	371 (7.5%)	78 (3.1%)	273 (12%)	363 (8.0%)	75 (3.6%)	8 (6.2%)	202 (14%)	54 (8.7%)	8 (9.8%)	0 (0%)
Unknown	0	0	0	0	0	0	0	0	0	0

T0 = pre-therapeutic questionnaire was answered.

T1= 12-month post-therapeutic questionnaire was answered.

Among all patients undergoing radiation therapy (N=4,973), there were n=208 with missing information on ADT; and among patients undergoing EBRT (n=4,515), there were n=257 with missing information on ADT and/or timing of ADT.

Among patients receiving RT overall (see **Table 6a**) in whom receipt/non-receipt of ADT was documented (N=4,765), ADT was received by 47% (2,248/4,765). In men who had EBRT, the PCO Study was also able to document when they began their ADT in relation to the pre- (T0) and post- (T1) therapeutic questionnaires. Of the N=2,152 men who received EBRT plus ADT, most started it before recruitment (i.e. before answering the pre-therapeutic questionnaire [T0]), and kept taking it between baseline and 12 months (65%, 1,400/2,152 [+ADT preT0, +ADT T0 to T1]). There were comparatively few men who had EBRT and received their ADT only after recruitment (29%, 622/2,152 [–ADT preT0; +ADT T0 to T1]) and very few who received ADT but stopped it before study recruitment (6%, 130/2,152 [+ADT pre T0 only]). This is notable in that, among the overall group of men receiving RT+ADT, a large proportion of them (at least 62% [1,400/2,248] overall) will have answered the pre-therapeutic PROMs questionnaire while taking ADT, meaning that their T0 PROMs may have been influenced by the side-effect profile of their hormone therapy.

TABLE 6B: **NUMBER AND PROPORTION OF PATIENTS UNDERGOING RT BY TYPE OF RT (+/-ADT) AND BY AGE GROUP AT DIAGNOSIS (ALL PATIENTS)**

	Overall radiation therapy			EBRT					Brachytherapy	
Characteristic, reported as n (%)	**All RT** (n=4,973)	**–ADT** (n=2,517)	**+ADT** (n=2,248)	**All EBRT** (n=4,515)	**–ADT preT1** (n=2,106)	**+ADT preT0 only** (n=130)	**+ADT preT0 +ADT T0 to T1** (n=1,400)	**–ADT preT0 +ADT T0 to T1** (n=622)	**HDR** (n=82)	**LDR** (n=376)
<60	222 (4.5%)	169 (6.7%)	44 (2.0%)	163 (3.6%)	113 (5.4%)	2 (1.5%)	27 (1.9%)	10 (1.6%)	3 (3.7%)	56 (15%)
≥60 and <70	1,196 (24%)	733 (29%)	410 (18%)	985 (22%)	540 (26%)	25 (19%)	249 (18%)	115 (18%)	28 (34%)	183 (49%)
≥70 and <80	2,748 (55%)	1,285 (51%)	1,349 (60%)	2,582 (57%)	1,138 (54%)	76 (58%)	854 (61%)	368 (59%)	43 (52%)	123 (33%)
≥80	807 (16%)	330 (13%)	445 (20%)	785 (17%)	315 (15%)	27 (21%)	270 (19%)	129 (21%)	8 (9.8%)	14 (3.7%)
Unknown	0	0	0	0	0	0	0	0	0	0

T0 = pre-therapeutic questionnaire was answered.

T1= 12-month post-therapeutic questionnaire was answered.

Among all patients undergoing radiation therapy (N=4,973), there were n=208 with missing information on ADT; and among patients undergoing EBRT (n=4,515), there were n=257 with missing information on ADT and/or timing of ADT.

TABLE 6C: **NUMBER AND PROPORTION OF PATIENTS UNDERGOING RT BY TYPE OF RT (+/-ADT) AND BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY)**

	Overall radiation therapy			EBRT					Brachytherapy	
Characteristic, reported as n (%)	**All RT** (n=4,395)	**–ADT** (n=2,333)	**+ADT** (n=1,859)	**All EBRT** (n=3,938)	**–ADT preT1** (n=1,923)	**+ADT preT0 only** (n=109)	**+ADT preT0 +ADT T0 to T1** (n=1,158)	**–ADT preT0 +ADT T0 to T1** (n=496)	**HDR** (n=82)	**LDR** (n=375)
Lower secondary school or equivalent (8/9 years of schooling)	1,714 (42%)	890 (40%)	745 (43%)	1,586 (43%)	777 (43%)	48 (46%)	480 (43%)	176 (41%)	30 (37%)	98 (27%)
Intermediate secondary school (10 years of schooling)	735 (18%)	387 (18%)	306 (18%)	655 (18%)	314 (17%)	12 (11%)	201 (18%)	74 (17%)	13 (16%)	67 (19%)
Comprehensive school	238 (5.8%)	137 (6.2%)	91 (5.3%)	200 (5.4%)	101 (5.6%)	7 (6.7%)	57 (5.2%)	25 (5.9%)	1 (1.2%)	37 (10%)
Entrance certificate for a higher technical college or university of applied science	525 (13%)	284 (13%)	216 (13%)	455 (12%)	222 (12%)	13 (12%)	129 (12%)	66 (15%)	16 (20%)	54 (15%)
University entrance certificate	820 (20%)	466 (21%)	327 (19%)	700 (19%)	361 (20%)	25 (24%)	208 (19%)	76 (18%)	22 (27%)	98 (27%)
Other	75 (1.8%)	40 (1.8%)	32 (1.9%)	70 (1.9%)	35 (1.9%)	0 (0%)	25 (2.3%)	7 (1.6%)	0 (0%)	5 (1.4%)
None	14 (0.3%)	7 (0.3%)	6 (0.3%)	13 (0.4%)	6 (0.3%)	0 (0%)	4 (0.4%)	2 (0.5%)	0 (0%)	1 (0.3%)
Unknown	274	122	136	259	107	4	54	70	0	15

Data on school leaving certificates are restricted to patients from centres in Germany.

T0 = pre-therapeutic questionnaire was answered.

T1= 12-month post-therapeutic questionnaire was answered.

Among all patients from German centres undergoing radiation therapy (N=4,395), there were n=203 with missing information on ADT; and among patients from German centres undergoing EBRT (N=3,938), there were n=252 with missing information on ADT and/or timing of ADT.

Patients who did receive RT+ADT tended to have higher-risk disease and were older (64% [1,433/2,248] had high-risk disease or greater, **Table 6a**; 80% were ≥70 years [1,794/2,248] **Table 6b**) compared with patients who did receive RT-ADT (18% with higher-risk disease, 64% ≥70 years). However, receipt of ADT did not vary much by highest school-leaving certificate (**Table 6c**), or by type of health insurance (**Table 6d**) when considering the bivariate findings. Further, the timing of ADT hardly varied with disease risk, age, or – among German participants – highest school-leaving certificate or type of health insurance (**Tables 6a–d** respectively).

As expected, LDR brachytherapy is more common in younger men (64% [239/376] were <70 years, **Table 6b**), and men with lower-risk disease (64% [240/376] had localised, low-risk disease **Table 6a**). Correspondingly, HDR brachytherapy is more prevalent in older men (62% [51/82] were ≥70 years, **Table 6b**), and men with higher-risk disease (68% [56/82] had localised, high-risk or locally advanced disease, **Table 6a**). No obvious association was seen with the distribution of LDR or HDR brachytherapy by highest school-leaving certificate or by type of health insurance among German men (**Tables 6c and 6d** respectively).

TABLE 6D: **NUMBER AND PROPORTION OF PATIENTS UNDERGOING RT BY TYPE OF RT (+/-ADT) AND BY TYPE OF HEALTH INSURANCE (GERMANY ONLY)**

	Overall radiation therapy			EBRT					Brachytherapy	
Characteristic, reported as n (%)	**All RT** (n=4,395)	**–ADT** (n=2,333)	**+ADT** (n=1,859)	**All EBRT** (n=3,938)	**–ADT preT1** (n=1,923)	**+ADT preT0 only** (n=109)	**+ADT preT0 +ADT T0 to T1** (n=1,158)	**–ADT preT0 +ADT T0 to T1** (n=496)	**HDR** (n=82)	**LDR** (n=375)
Statutory health insurance	3235 (78%)	1,753 (79%)	1,342 (78%)	2,909 (79%)	1,461 (80%)	80 (76%)	856 (77%)	334 (79%)	58 (71%)	268 (75%)
Private health insurance	890 (22%)	461 (21%)	383 (22%)	780 (21%)	363 (20%)	25 (24%)	249 (22%)	91 (21%)	21 (26%)	89 (25%)
Other / none	11 (0.3%)	7 (0.3%)	4 (0.2%)	6 (0.2%)	3 (0.2%)	0 (0%)	3 (0.3%)	0 (0%)	3 (3.7%)	2 (0.6%)
Unknown	259	112	130	243	96	4	50	71	0	16

Data on type of health insurance are restricted to patients from centres in Germany.

T0 = pre-therapeutic questionnaire was answered.

T1= 12-month post-therapeutic questionnaire was answered.

Among all patients from German centres undergoing radiation therapy (N=4,395), there were n=203 with missing information on ADT; and among patients from German centres undergoing EBRT (N=3,938), there were n=252 with missing information on ADT and/or timing of ADT.

CHAPTER 3

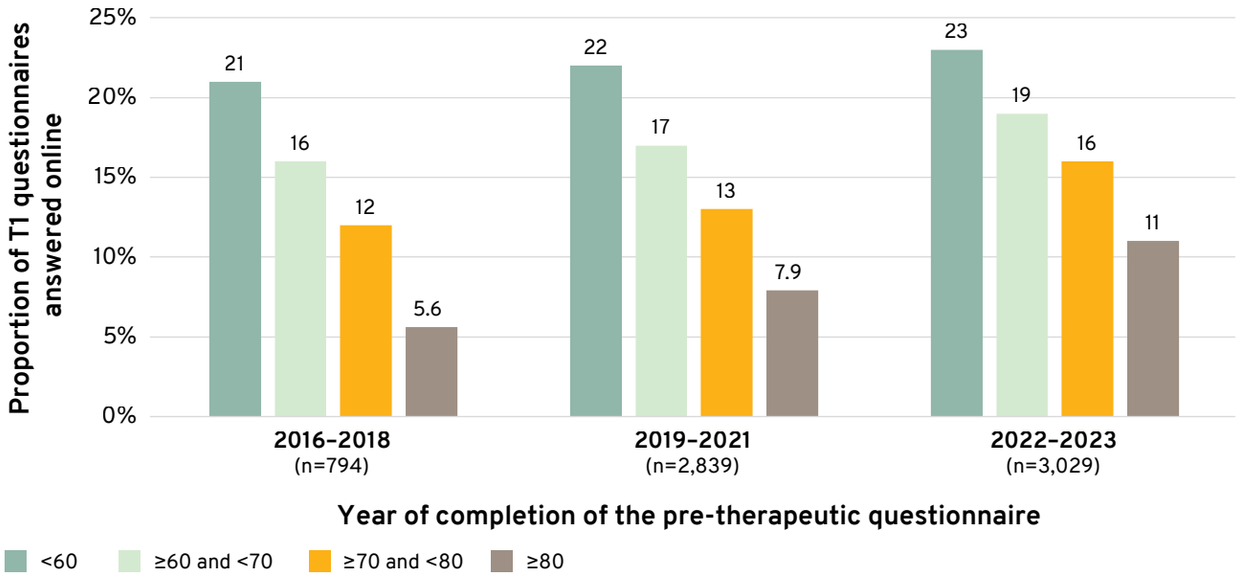
PATIENT-REPORTED OUTCOME MEASURES (PROMs)

PREFERRED METHOD OF ANSWERING THE POST-THERAPEUTIC QUESTIONNAIRE

In order to provide input for potential ways to improve delivery of our PROMs questionnaire, we have analysed the preferred method (online or paper) chosen by patients for answering the questionnaire over the years. To provide a fair comparison, this analysis covers the years 2016 to 2023 only, because PROMs collection for the 2024 cohort was not 'complete' by the cut-off point for data analysis in May 2025. Further, to simplify this analysis we have aggregated the years into 3 overall cohorts of men who answered their T0 questionnaire in 2016–2018, 2019–2021 and 2022–2023.

Since 2016–2018, there has been a small but consistent increase in online completion of the PROMs questionnaire across all age groups (see **Figure 25**); although interestingly, the increase has been most prominent in the oldest age group, doubling in rate from 5.6% (7/124) in 2016–2018 to 11% [62/569] in 2022–2023. Nevertheless, only approximately 1 in 6 questionnaires [7,321/41,987) are answered online overall.

FIGURE 25: **PROPORTION OF ONLINE VS PAPER RESPONSES TO POST-THERAPEUTIC (T1) QUESTIONNAIRES BY YEAR OF STUDY ENTRY AND AGE GROUP (2016–2023)**

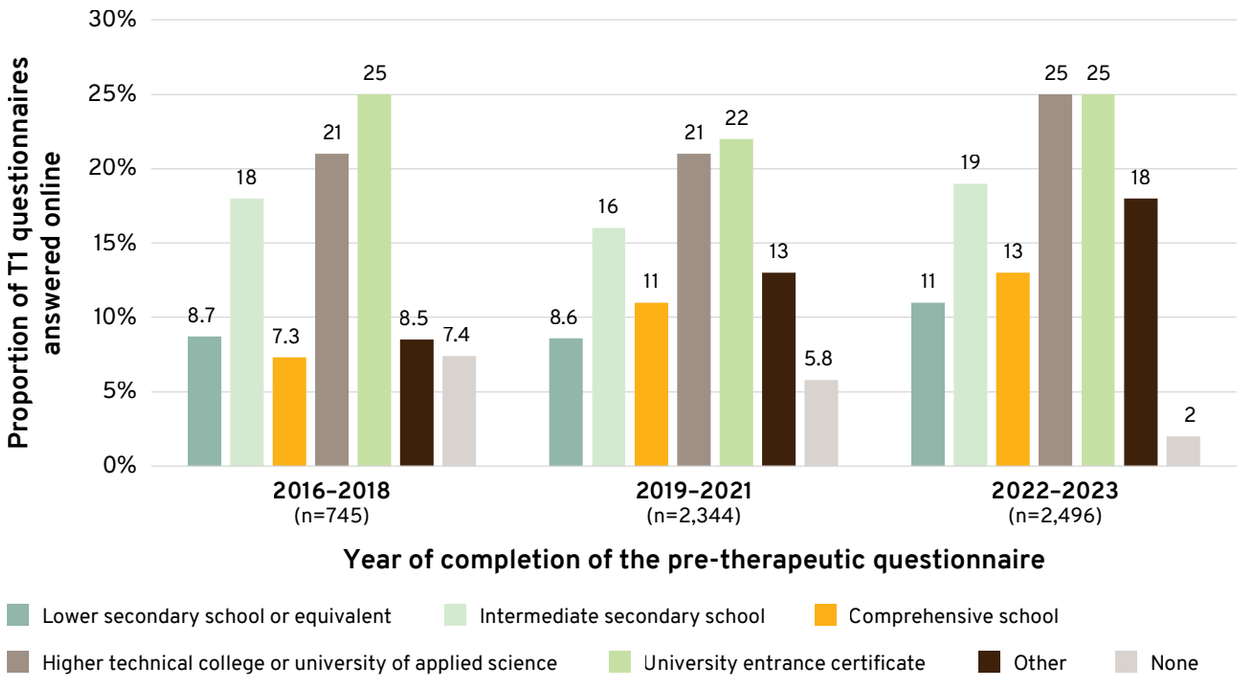


- For simplicity, this analysis was divided into three cohorts based on combining the year of PCO Study entry into larger groups: 2016–2018, 2019–2021 and 2022–2023.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic (T0) questionnaire.
- Percentages are calculated as a percentage of patients per age group at diagnosis who answered their T1 questionnaire online, versus the total patients per age group who had T1 data and information on online versus paper responses available.
- Two centres use their own data collection systems and do not document whether questionnaires were answered online or on paper and are not included in this analysis: for n=41,987 (88%) of all patients who answered questionnaires at T0 and T1 (n=47,466), information on online versus paper responses was provided.
- See Supplementary Figures S69 and S70 for sensitivity analyses restricted to patients of centres that have been participating in the PCO since at least (1) 2018 or (2) 2019.
- The numbers below the bars indicate the numbers of patients who answered their T1 questionnaire online and had information on age available.

In German men who had data available on PROMs responses and education (N=33,927), the proportion of those answering online was consistently higher across all years in those who had an intermediate secondary school certificate (16–19%); a higher technical college or university of applied science certificate (21–25%), and those who had a university entrance certificate (22–25%). Responses among men with known lower levels of school-leaving certificate ranged between 8.7% and 11% (see **Figure 26**).

Online responses are also comparatively more popular in German men with private health insurance (20–23% over the years;) compared with those who have statutory insurance (13–17% over the years; see **Figure 27**, N=34,077). However, in our digital-focused age, it is perhaps still surprising that the proportion of online versus paper responses does not climb above approximately 1 in 4 across any demographic stratum.

FIGURE 26: **PROPORTION OF ONLINE VS PAPER RESPONSES TO POST-THERAPEUTIC (T1) QUESTIONNAIRES BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY, 2016–2023)**

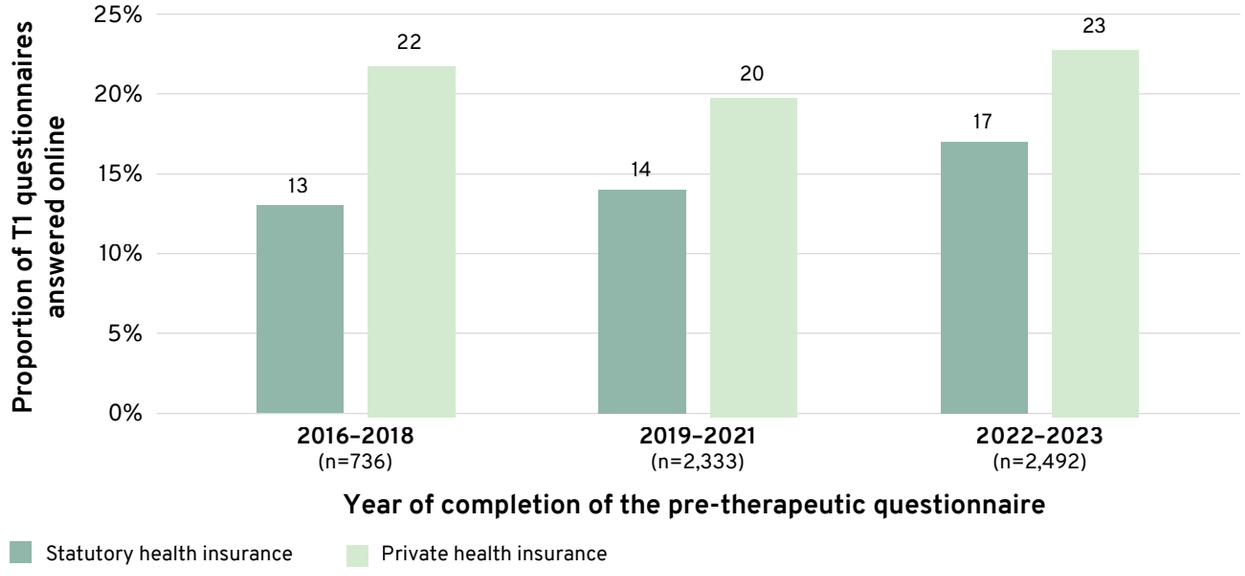


- For simplicity, this analysis was divided into three cohorts based on combining the year of PCO Study entry into larger groups: 2016–2018, 2019–2012 and 2022–2023.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic (T0) questionnaire.
- Percentages are calculated as a percentage of patients in Germany per school-leaving certificate group who answered their T1 questionnaire online, versus the total patients per school-leaving certificate group who had T1 data and information on online versus paper responses available.
- Two centres use their own data collection systems and do not document whether questionnaires were answered online or on paper and are not included in this analysis: for n=41,987 (88%) of all patients who answered questionnaires at T0 and T1 (n=47,466), information on online versus paper responses was provided.
- See Supplementary Figures S71 and S72 for sensitivity analyses restricted to patients of centres that have been participating in the PCO since at least (1) 2018 or (2) 2019.
- The numbers below the bars indicate the number of patients in Germany who answered their T1 questionnaire online and had information on highest school-leaving certificate available.

OVERALL PROMS BY MANAGEMENT STRATEGY

For the purpose of brevity, we have focused this report on the urinary incontinence and sexual function domains of the EPIC-26 questionnaire (see **Table 7**), which were the domains that were most impacted overall according to the EPIC-26 summary scores (see **Table 8**): with T0-to-T1 changes of –18 for urinary incontinence and –32 for sexual function reported. Notably, a clinically relevant deterioration (T1-score minus T0-score) was defined as a minimally important difference (MID) of at least 6 points in the urinary incontinence domain score and a change of 10 points in the overall Sexual Domain score.[15,16] However, it should also be noted that, when considering the sexual-domain data, use of aids (e.g. devices or pills) to improve sexual function was not taken into account. The response data for 2016–2024 across all remaining questions on the EPIC-26 questionnaire can be found in **Supplementary Table 2**.

FIGURE 27: **PROPORTION OF ONLINE VS PAPER RESPONSES TO POST-THERAPEUTIC (T1) QUESTIONNAIRES BY YEAR OF STUDY ENTRY AND TYPE OF HEALTH INSURANCE (GERMANY ONLY, 2016–2013)**



- For simplicity, this analysis was divided into three cohorts based on combining the year of PCO Study entry into larger groups: 2016–2018, 2019–2012 and 2022–2023.
- Year of registration in the PCO Study is defined by year of completion of the pre-therapeutic (T0) questionnaire.
- Percentages are calculated as a percentage of patients in Germany per type of health insurance who answered their T1 questionnaire online, versus the total patients per type of health insurance who had T1 data and information on online versus paper responses available.
- Two centres use their own data collection systems and do not document whether questionnaires were answered online or on paper and are not included in this analysis: for n=41,987 (88%) of all patients who answered questionnaires at T0 and T1 (n=47,466), information on online versus paper responses was provided.
- See Supplementary Figures S73 and S74 for sensitivity analyses restricted to patients of centres that have been participating in the PCO since at least (1) 2018 or (2) 2019.
- The numbers below the bars indicate the number of patients in Germany who answered their T1 questionnaire online and had information on type of health insurance available.

TABLE 7: **PRE- (T0) AND POST- (T1) THERAPEUTIC RESPONSES TO KEY QUESTIONS FROM THE URINARY AND SEXUAL DOMAINS OF THE EPIC-26 QUESTIONNAIRE, ANALYSED BY MANAGEMENT GROUP**

Item	Response, reported as n (%)	Surgery alone (n=40,570)	Radiation (+/– ADT) (n=4,973)	Surgery + radiation (n=917)	AS (n=714)	WW (n=188)	Others (n=104)	Overall (n=47,466)
Urinary domain								
How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks? **(T0)**	None	38,775 (96%)	4,587 (93%)	864 (96%)	615 (86%)	114 (62%)	98 (97%)	45,053 (96%)
	1 pad per day	1,099 (2.7%)	278 (5.6%)	25 (2.8%)	64 (9.0%)	52 (28%)	0 (0%)	1,518 (3.2%)
	2 pads per day	216 (0.5%)	48 (1.0%)	7 (0.8%)	21 (2.9%)	11 (6.0%)	1 (1.0%)	304 (0.6%)
	3 or more pads per day	116 (0.3%)	26 (0.5%)	7 (0.8%)	12 (1.7%)	7 (3.8%)	2 (2.0%)	170 (0.4%)
	Unknown	364	34	14	2	4	3	421
How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks? **(T1)**	None	21,981 (55%)	4,288 (87%)	379 (42%)	650 (91%)	142 (76%)	92 (89%)	27,532 (58%)
	1 pad per day	12,368 (31%)	492 (10.0%)	308 (34%)	48 (6.7%)	40 (21%)	9 (8.7%)	13,265 (28%)
	2 pads per day	3,594 (8.9%)	100 (2.0%)	118 (13%)	8 (1.1%)	3 (1.6%)	1 (1.0%)	3,824 (8.1%)
	3 or more pads per day	2,322 (5.8%)	63 (1.3%)	100 (11%)	7 (1.0%)	2 (1.1%)	1 (1.0%)	2,495 (5.3%)
	Unknown	305	30	12	1	1	1	350
Sexual domain								
How would you describe the usual QUALITY of your erections during the last 4 weeks? **(T0)**	None at all	5,854 (15%)	1,813 (38%)	204 (23%)	120 (17%)	99 (55%)	12 (12%)	8,102 (18%)
	Not firm enough for any sexual activity	5,067 (13%)	852 (18%)	146 (16%)	104 (15%)	31 (17%)	11 (11%)	6,211 (13%)
	Firm enough for masturbation and foreplay only	8,320 (21%)	831 (17%)	169 (19%)	143 (21%)	26 (15%)	26 (26%)	9,515 (21%)
	Firm enough for intercourse	20,206 (51%)	1,273 (27%)	370 (42%)	323 (47%)	23 (13%)	52 (51%)	22,247 (48%)
	Unknown	1,123	204	28	24	9	3	1,391
How would you describe the usual QUALITY of your erections during the last 4 weeks? **(T1)**	None at all	20,498 (51%)	2,577 (53%)	727 (81%)	120 (17%)	82 (46%)	20 (19%)	24,024 (51%)
	Not firm enough for any sexual activity	7,844 (20%)	915 (19%)	93 (10%)	101 (15%)	39 (22%)	17 (16%)	9,009 (19%)
	Firm enough for masturbation and foreplay only	8,286 (21%)	717 (15%)	64 (7.1%)	182 (26%)	38 (21%)	35 (34%)	9,322 (20%)
	Firm enough for intercourse	3,403 (8.5%)	630 (13%)	14 (1.6%)	293 (42%)	20 (11%)	32 (31%)	4,392 (9.4%)
	Unknown	539	134	19	18	9	0	719

TABLE 8: **COMPARISON OF THE PRE- (T0) AND POST- (T1) THERAPEUTIC EPIC-26 SUMMARY SCORES BY TYPE OF MANAGEMENT RECEIVED**

EPIC-26 domain	Reported as mean **Score** (SD)	**Surgery alone** (n=40,570)	**Radiation (+/– ADT)** (n=4,973)	**Surgery + radiation** (n=917)	**AS** (n=714)	**WW** (n=188)	**Others** (n=104)	**Overall** (n=47,466)
Urinary incontinence	Pre	**93** (14)	**90** (16)	**91** (16)	**87** (21)	**75** (27)	**94** (12)	**92** (14)
	Unknown	2,078	331	75	28	16	9	2,537
	Post	**73** (28)	**87** (20)	**64** (30)	**89** (17)	**84** (22)	**89** (19)	**74** (27)
	Unknown	1,083	314	34	34	10	6	1,481
	Post-pre-difference	**-20** (27)	**-3** (17)	**-27** (30)	**3** (19)	**10** (24)	**-3** (12)	**-18** (27)
	Unknown	3,022	579	105	55	25	14	3,800
Urinary irritation/ obstruction	Pre	**86** (15)	**86** (15)	**82** (18)	**79** (20)	**73** (23)	**89** (11)	**85** (15)
	Unknown	2,734	495	87	40	21	7	3,384
	Post	**90** (12)	**84** (16)	**87** (14)	**86** (14)	**88** (14)	**89** (13)	**90** (13)
	Unknown	2,181	484	65	41	19	12	2,802
	Post-pre-difference	**5** (16)	**-2** (17)	**5** (21)	**7** (21)	**15** (23)	1 (13)	**4** (17)
	Unknown	4,495	850	140	71	36	17	5,609
Bowel function	Pre	**96** (9)	**95** (10)	**95** (9)	**94** (12)	**92** (13)	**96** (10)	**96** (9)
	Unknown	2,677	591	65	41	23	3	3,400
	Post	**94** (11)	**87** (18)	**88** (16)	**94** (11)	**93** (12)	**95** (11)	**93** (12)
	Unknown	2,040	554	60	33	25	6	2,718
	Post-pre-difference	**-2** (11)	**-8** (17)	**-7** (17)	**0** (12)	**1** (16)	**-1** (10)	**-2** (12)
	Unknown	4,279	983	113	63	40	8	5,486
Sexual function	Pre	**62** (28)	**44** (29)	**54** (30)	**59** (29)	**31** (25)	**64** (28)	**60** (29)
	Unknown	1,566	305	39	32	17	2	1,961
	Post	**27** (25)	**30** (25)	**15** (16)	**56** (29)	**32** (25)	**47** (29)	**28** (25)
	Unknown	826	206	31	22	13	0	1,098
	Post-pre-difference	**-35** (29)	**-14** (24)	**-39** (30)	**-3** (19)	**0** (22)	**-16** (24)	**-32** (29)
	Unknown	2,251	441	67	46	23	2	2,830
Vitality/ hormonal function	Pre	**90** (14)	**88** (16)	**89** (15)	**89** (13)	**86** (15)	**91** (14)	**90** (14)
	Unknown	2,121	409	47	35	27	3	2,642
	Post	**85** (17)	**79** (21)	**73** (24)	**89** (15)	**85** (15)	**89** (14)	**85** (18)
	Unknown	1,367	364	41	33	24	5	1,834
	Post-pre-difference	**-5** (16)	**-9** (19)	**-16** (22)	**-1** (13)	**-2** (15)	**-1** (11)	**-5** (16)
	Unknown	3,188	669	82	59	39	7	4,044

Overall domain scores: urinary and sexual domains

When considering changes in summary scores by type of management received (**Table 8**) men who had surgery followed by RT experienced the largest impact on both urinary and sexual function.

Urinary function scores declined by –27 (SD 30) points for surgery +RT (N=917) and by –20 (SD 27) points for surgery alone (N=40,570) which is clinically relevant; and sexual function scores declined by –39 (SD 30) points for surgery +RT (N=917) and by –35 (SD 29) points for surgery alone (N=40,570), i.e. a clinically relevant decline was observed.

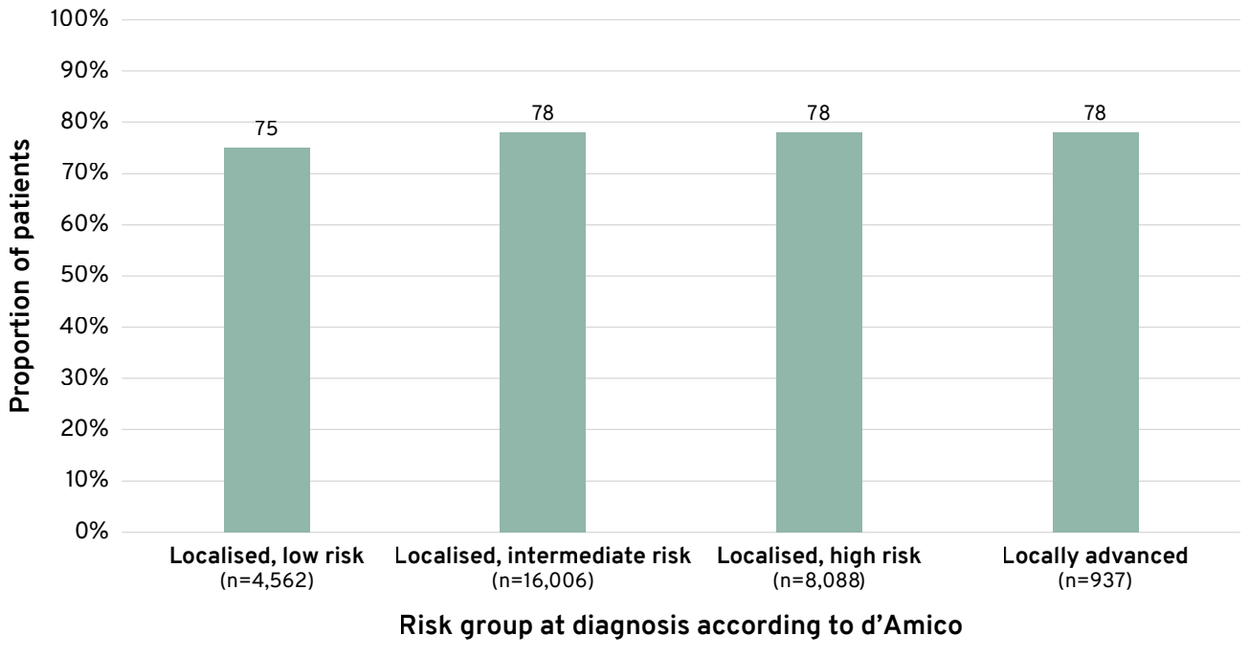
The decline in overall domain score seen in men receiving RT (+/–ADT) was far less pronounced and not clinically relevant for urinary function (-3 [SD 17], N=4,973) compared with the surgery-based types of active management, and notably, these domain scores were roughly equivalent across active management types at baseline (ranging from 91–93 points).

However, the picture is a little more complicated for the sexual domain in men receiving RT (+/–ADT). The reported decline in sexual function was –14 (SD 24) points overall for these men (N=4,973), which is comparatively far less of a change between T0 and T1 compared with the decline after surgical management options. But when considering this data, it is important to note that the baseline (T0) scores for men receiving RT (+/–ADT) were already much lower than their surgery-alone counterparts at 44 (SD 29) versus 62 (SD 28) points. As previously noted, a substantial portion of men who received RT overall were already receiving ADT when they answered their T0 questionnaires (at least 62% [1,400/2,248] overall, see **Table 6a**). But regardless of which intervention (ADT or RT) may have been responsible for the impact on sexual function, or at what timepoint the majority of that impact occurred, it is clear that, overall, men receiving RT (+/–ADT) do experience a substantial and clinically relevant impact on their sexual function after 12 months.

Overall domain scores: bowel and hormonal domains

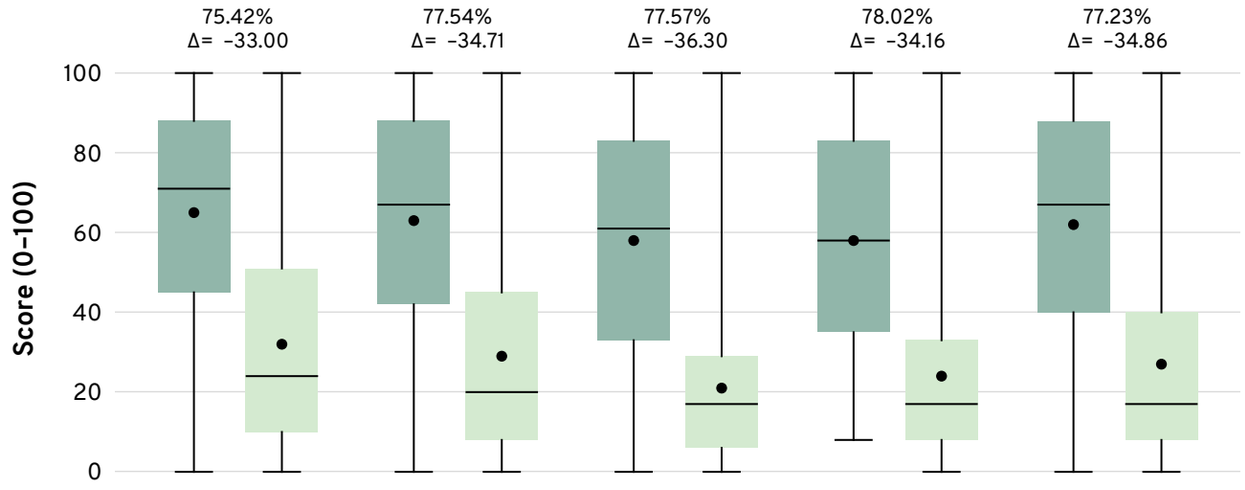
In terms of overall bowel function, summary scores only changed by at least an MID (–4 points)[16] when RT was involved in the treatment plan; reducing by –8 (SD 17) points for RT (+/–ADT) at T1; and by –7 (SD 17) for Surgery +RT at T1 (compared with a change of only –2 [SD 11] for surgery alone; see **Table 8**). However for the vitality/hormonal function domain, a clinically relevant decline of at least 4 points was reported by men across all active management plans; with the largest impact seen by those having surgery followed by RT (–16 [SD 22] points) followed by RT (+/–ADT; –9 [SD 19] points) and surgery alone (–5 [SD 16] points). While men on observational management plans reported little impact (1–2 points drop in overall score across AS and WW).

FIGURE 28: **PROPORTION OF PATIENTS WITH A CLINICALLY RELEVANT DETERIORATION IN THE EPIC-26 SEXUAL DOMAIN SCORE, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY D'AMICO RISK GROUP AT DIAGNOSIS**



- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A clinically relevant deterioration was defined as a minimally important difference (MID) of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Percentages are calculated as a percentage of patients whose Sexual Domain score decreased by at least 10 points between the T0 and the T1 questionnaire, versus the total number of patients with T0 and T1 Sexual Domain scores available.
- The numbers below the bars indicate the number of patients with a clinically relevant deterioration.

FIGURE 29: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY D'AMICO RISK GROUP**



	Localised, low risk	Localised, intermediate risk	Localised, high risk	Locally advanced	Overall
T0	n=6,152	n=20,969	n=10,654	n=1,229	n=39,004
T1	n=6,236	n=21,363	n=10,902	n=1,243	n=39,744

- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

PROMS ANALYSIS FOR PATIENTS RECEIVING ACTIVE MANAGEMENT

PROMs for patients treated with surgery alone

To keep this report manageable in size and stay relevant to the largest number of men possible, we report here, and in the following sections, on the single largest treatment group in each key active management category. Among men having surgery as part of their management plan, that is those who had surgery alone (85% of the total group; N=40,570/47,466) and among those having RT as part of their management plan that is those having RT (+/-ADT; 10.5%, N=4,973/47,466).

Throughout this chapter, we use the previously established minimal important differences (MIDs) for the relevant EPIC-26 domains as the measure of a notable decline in function. For the sexual function domain of EPIC-26 that is a decline of –10 points,[16] and for the urinary function domain that is a decline of –6 points.

For more information, see **Supplementary Figure 13** for an overview of the distribution of pre- and post-score values of patients treated with surgery without radiation by domain. Analyses of the PROMs submitted by patients treated with surgery followed by RT within twelve months can be found in **Supplementary Figures 14 to 26**.

Surgery alone: focus on the sexual domain

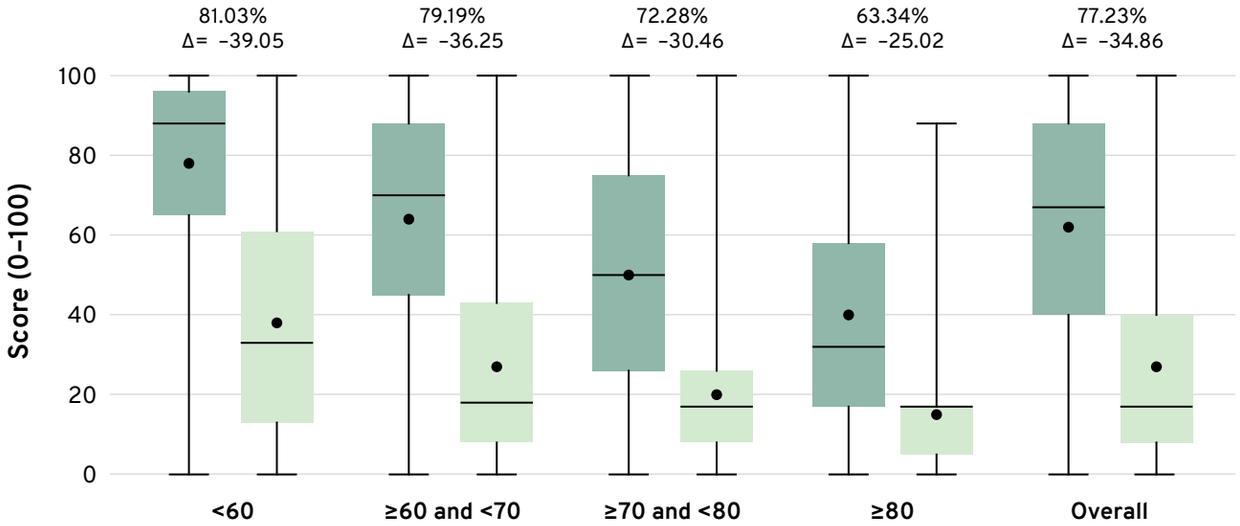
Among men having surgery alone, roughly three in four people experience a decline in sexual function of at least one MID, with no notable difference in these rates seen between d'Amico risk groups (**Figure 28**). The magnitude of the average change in sexual function (Δ, as shown in **Figure 29**) shows a steep decline over the 12 months between the T0 and T1 questionnaires of around –33 to –36 points across the risk groups, with no notable differences between groups.

When analysed according to age group (**Figure 30**), as might be expected, the distribution of sexual function scores at T0 decreases across age groups, with the highest baseline sexual function scores seen in the youngest age group (<60). After the T1 post-therapeutic questionnaire this group who have the most to lose (N=7,182), report the largest change in sexual function: an average drop of –39 points, with 81% of the group reporting greater than an MID decline. Although the magnitude of the decline decreases gradually across the age groups, all age groups still report a steep decline in sexual function with the least change reported in men ≥80 years; among whom 63% (N=405) still report a change of at least the MID, with an average drop in sexual function score of –25 points.

In patients from Germany, similar steep declines in sexual function score are seen across all groups when analysed by highest school-leaving certificate (**Figure 31**), with 75–79% of men across the different groups reporting at least the MID change. The largest average decrease in score (–37) was seen in the University certificate group (N=10,090) and the largest proportion of men reporting the MID was seen in the technical college/university of applied science (UAS) group (79%, N=4,840); although no groups differ hugely from the average overall parameters of 78% (N=36,709) reporting a change ≥MID, and an average change in score of –35 points. Analysis of sexual function scores by type of health insurance among German patients showed very little variation between the two groups (**Figure 32**).

The single EPIC-26 item on 'quality of erections', when examined in a Sankey plot (**Figure 33**), particularly illustrates the massive decline in sexual function seen after radical prostatectomy. Of the 20,206 men who reported adequate erections at baseline (T0), only 3,091 (15%) retained adequate sexual function at the 12-month T1 questionnaire; and >50% (11,272/20,206) reported they had either erections that were not firm enough for intercourse, or none at all. Notably, this analysis does not account for the use/non-use of sexual aids (e.g. devices, pills).

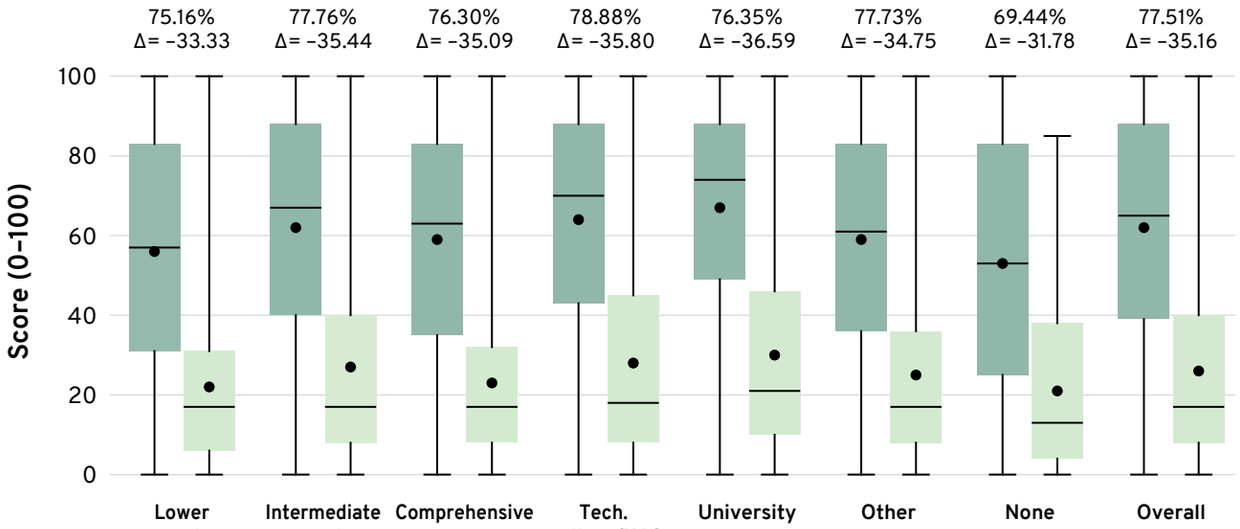
FIGURE 30: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY AGE GROUP AT DIAGNOSIS**



	<60	≥60 and <70	≥70 and <80	≥80	Overall
T0	n=7,116	n=19,270	n=12,239	n=379	n=39,004
T1	n=7,182	n=19,616	n=12,541	n=405	n=39,744

- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

FIGURE 31: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY)**



	Lower secondary	Intermediate secondary	Comprehensive	Tech. college/UAS	University	Other	None	Overall
T0	n=9,906	n=6,823	n=2,476	n=4,782	n=9,968	n=468	n=111	n=39,004
T1	n=10,125	n=6,921	n=2,515	n=4,840	n=10,090	n=482	n=114	n=36,709

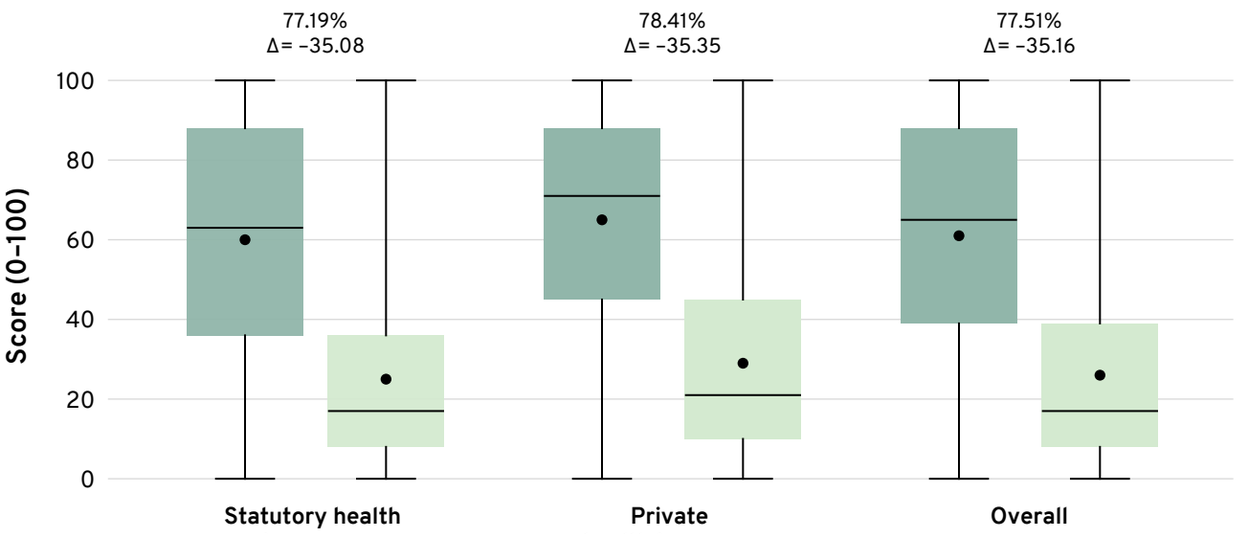
- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

Surgery alone: focus on the urinary incontinence domain

When considering the urinary incontinence domain, approximately 2 in 3 men (59–66% across d'Amico risk groups, see **Figure 34**) report a clinically relevant change in urinary incontinence (≥MID, or more than –6 points) at the 12-month T1 questionnaire, with relatively small differences seen between risk groups.

The magnitude of the average change (Δ) in urinary incontinence ranged from –18 points in men with localised, low-risk disease (N=6,198) to –23 points in men with localised high-risk disease (N=10,833), closely followed by men with locally advanced disease (N=1,231), who had a –21 point average decline in urinary incontinence (see **Figure 35**). Overall, 62% of men reported a change ≥MID, with the proportions notably a little higher for the localised high-risk disease group (66%, N=10,833) and the locally advanced disease group (65%, N=1,231).

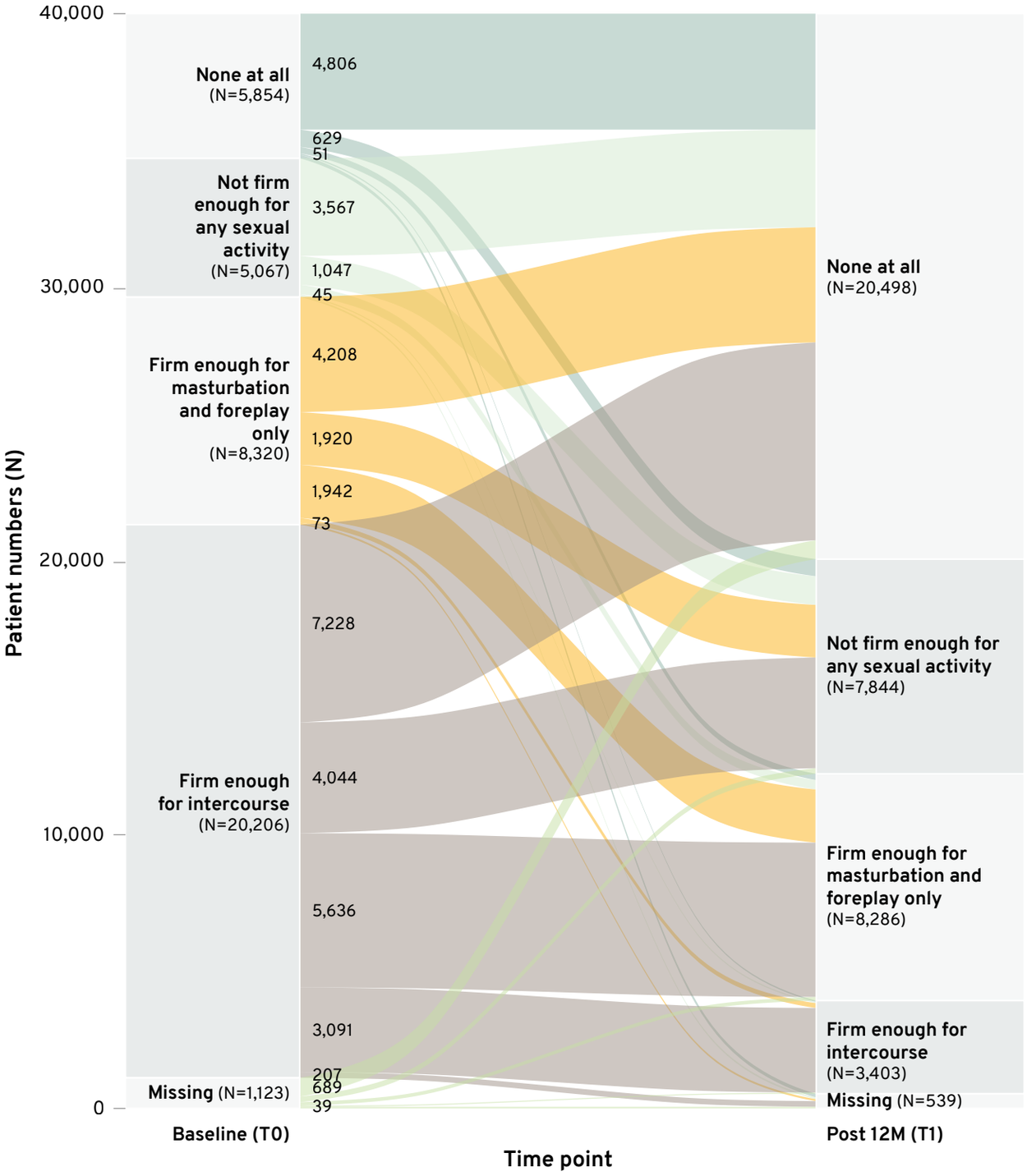
FIGURE 32: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY)**



	Statutory health insurance	Private health insurance	Overall
T0	n=24,838	n=9,606	n=39,004
T1	n=25,288	n=9,727	n=39,744

- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

FIGURE 33: **PATTERN OF CHANGES IN RESPONSES TO THE 'QUALITY OF ERECTIONS' EPIC-26 ITEM, BETWEEN THE PRE-(T0) AND POST-(T1) THERAPEUTIC QUESTIONNAIRE, AMONG PATIENTS RECEIVING SURGERY ALONE**



Item: How would you describe the usual QUALITY of your erections during the last 4 weeks?

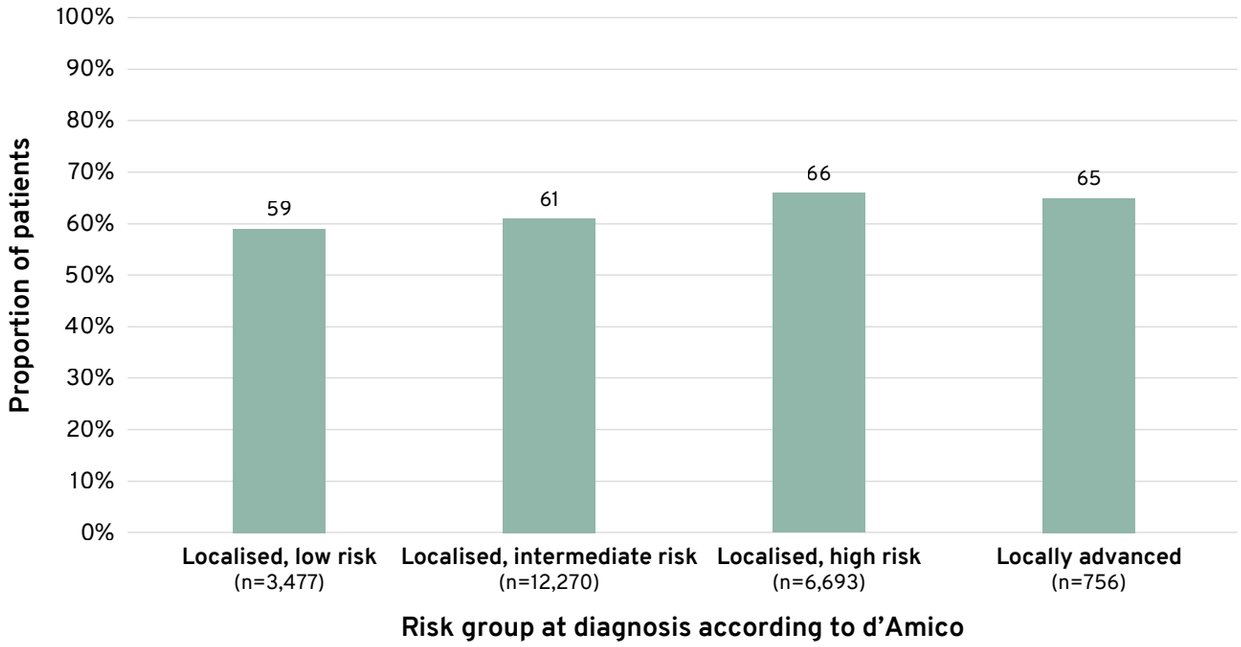
None at all | Not firm enough for any sexual activity | Firm enough for masturbation and foreplay only | Firm enough for intercourse | Missing

- Surgery alone is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- The figures given for the transition from T0 to T1 are patient numbers.

As expected, men in older age groups had a greater tendency towards having lower urinary incontinence scores at baseline (T0; **Figure 36**) and following this trend, the older the age group, the larger was the reported decline at the 12-month T1 questionnaire. Those in the oldest age bracket (≥80 years) reported the greatest magnitude of decline in urinary incontinence; with 73% of men reporting a change ≥MID, and an average change of –27 points. Those in the youngest age group reported the least decline; 58% had a ≥MID change, with an average decline of –17 points.

Among German patients, no pattern was seen when analysed according to highest school-leaving certificate (**Figure 37**). But there was a notable difference when analysed by type of health insurance (**Figure 38**) with 64% of men who had statutory insurance (N=25,056) reporting a change ≥MID, compared with 58% for those with private

FIGURE 34: **PROPORTION OF PATIENTS WITH A CLINICALLY RELEVANT DETERIORATION IN THE EPIC-26 URINARY DOMAIN SCORE, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY D'AMICO RISK GROUP AT DIAGNOSIS**

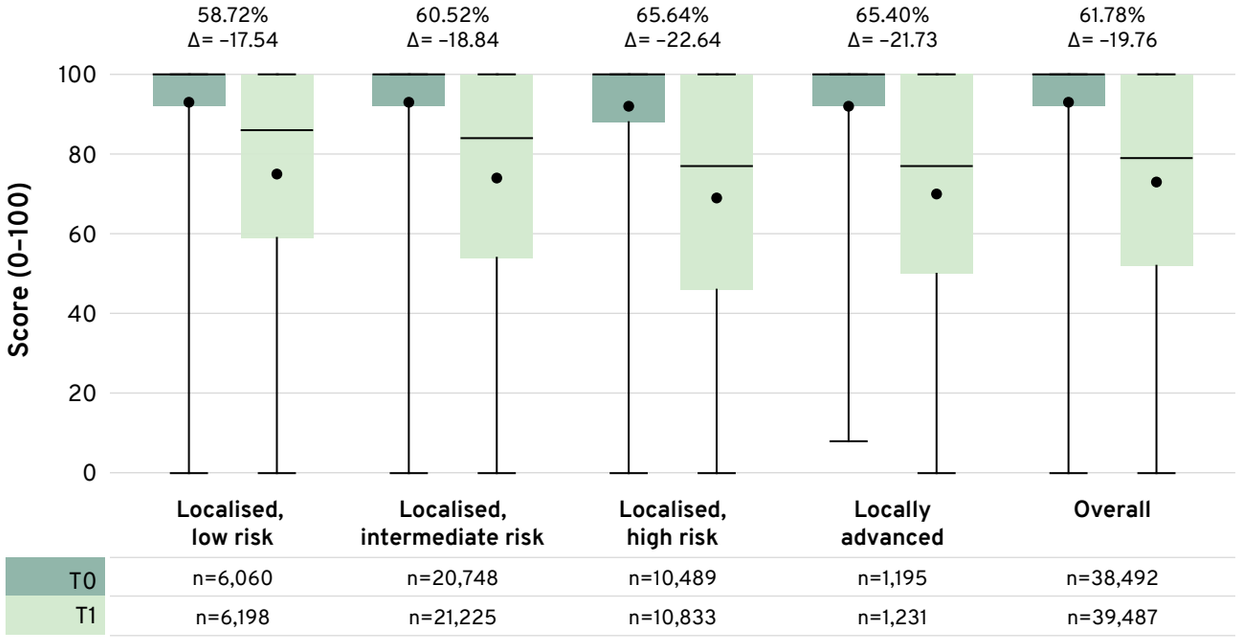


- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A clinically relevant deterioration was defined as a minimally important difference of at least –6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Percentages are calculated as a percentage of patients whose Urinary Domain score decreased by at least 6 points between the T0 and T1 questionnaire, versus the total number of patients with T0 and T1 Urinary Domain scores available.
- The numbers below the bars indicate the number of patients with a clinically relevant deterioration.

insurance (N=9,731). Similarly, the magnitude of the average change in incontinence was greater in the statutory insurance group at –21 points compared with –17 points for those who were privately insured.

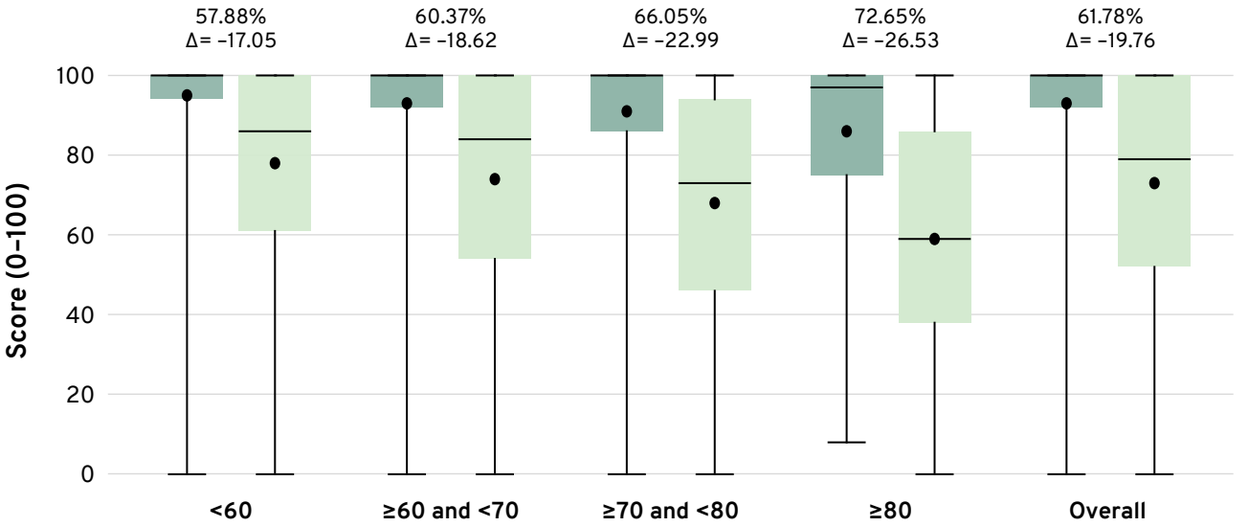
Analysis of the single EPIC-26 item on incontinence ('use of pads or adult diapers per day') evaluated in a Sankey plot, again underscores the magnitude of the impact of radical prostatectomy on urinary function (**Figure 39**). Over 40% (N=16,901/38,775) of men who were previously pad-free, were using at least 1 pad per day 12 months later – a topic that the PCO Study has also published on recently in more detail (Kowalski *et al.* 2024.).[31]

FIGURE 35: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY D'AMICO RISK GROUP**



- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least –6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

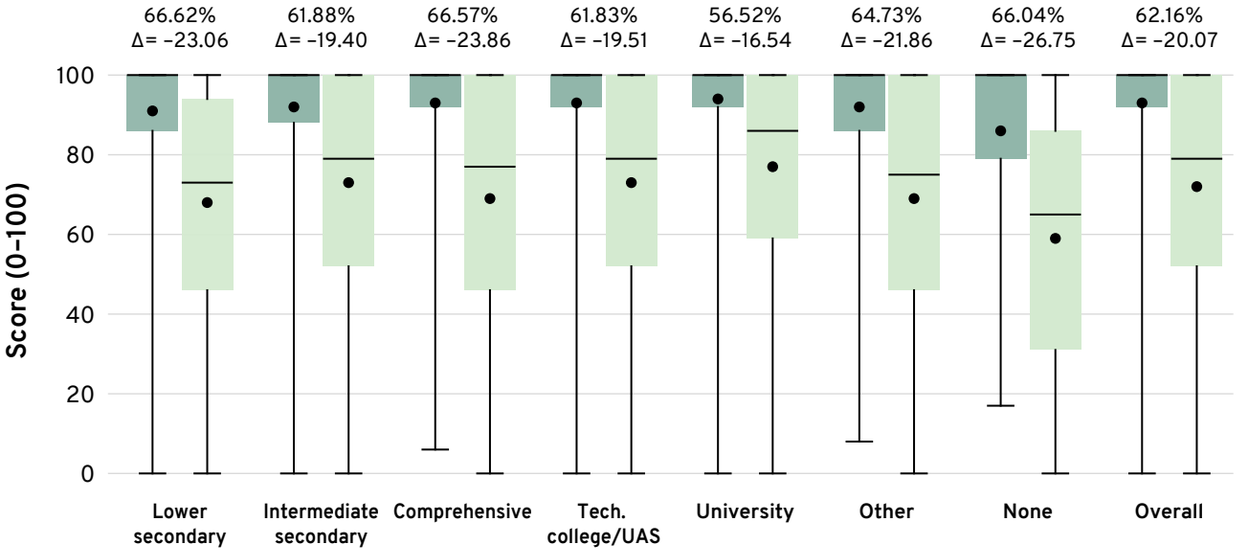
FIGURE 36: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY AGE GROUP AT DIAGNOSIS**



	<60	≥60 and <70	≥70 and <80	≥80	Overall
T0	n=7,067	n=19,078	n=11,973	n=374	n=38,492
T1	n=7,130	n=19,464	n=12,487	n=406	n=39,487

- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least −6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

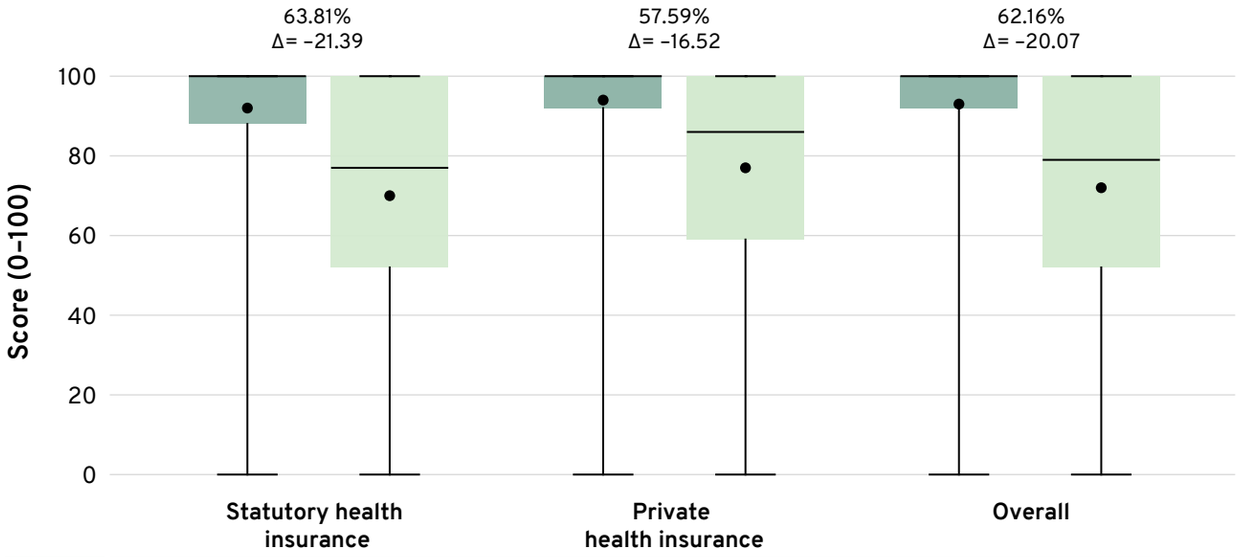
FIGURE 37: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY)**



	Lower secondary	Intermediate secondary	Comprehensive	Tech. college/UAS	University	Other	None	Overall
T0	n=9,582	n=6,750	n=2,430	n=4,762	n=9,983	n=461	n=109	n=35,524
T1	n=9,988	n=6,881	n=2,481	n=4,825	n=10,091	n=480	n=113	n=36,473

- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least −6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

FIGURE 38: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH SURGERY ALONE, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY)**

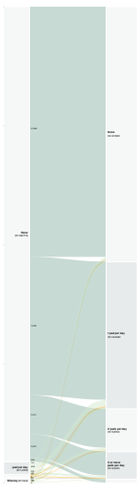


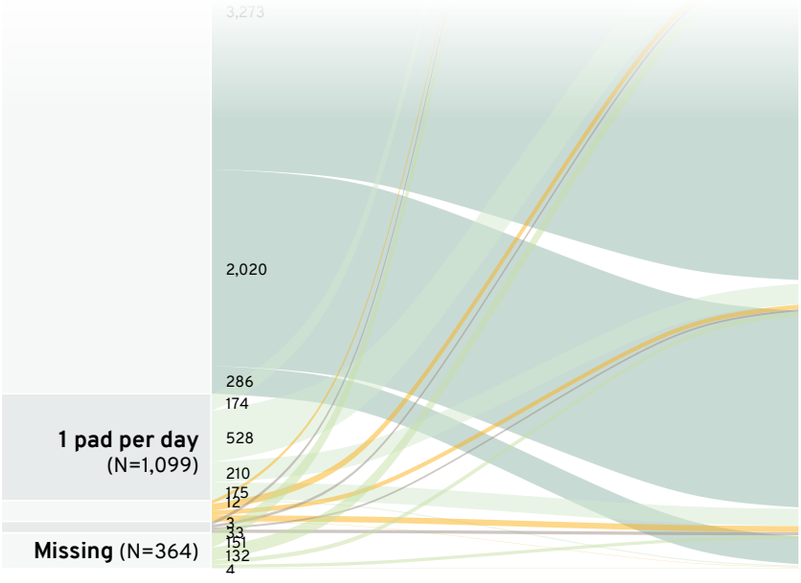
	Statutory health insurance	Private health insurance	Overall
T0	n=24,390	n=9,605	n=35,524
T1	n=25,056	n=9,731	n=36,473

- Surgery alone, is defined as having surgery but no radiation therapy within 12 months of surgical intervention.
- A minimally important difference (MID) was defined as a change of at least −6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

FIGURE 39: **PATTERN OF CHANGES IN RESPONSES TO THE 'USE OF PADS OR ADULT DIAPERS PER DAY' EPIC-26 ITEM, BETWEEN THE PRE-(T0) AND POST-(T1) THERAPEUTIC QUESTIONNAIRE, AMONG PATIENTS RECEIVING SURGERY ALONE**

Please note: This figure isn't viewable within the format of this report. To view Figure 39 in full online, click on the QR code below.





PROMs for patients treated with radiation therapy

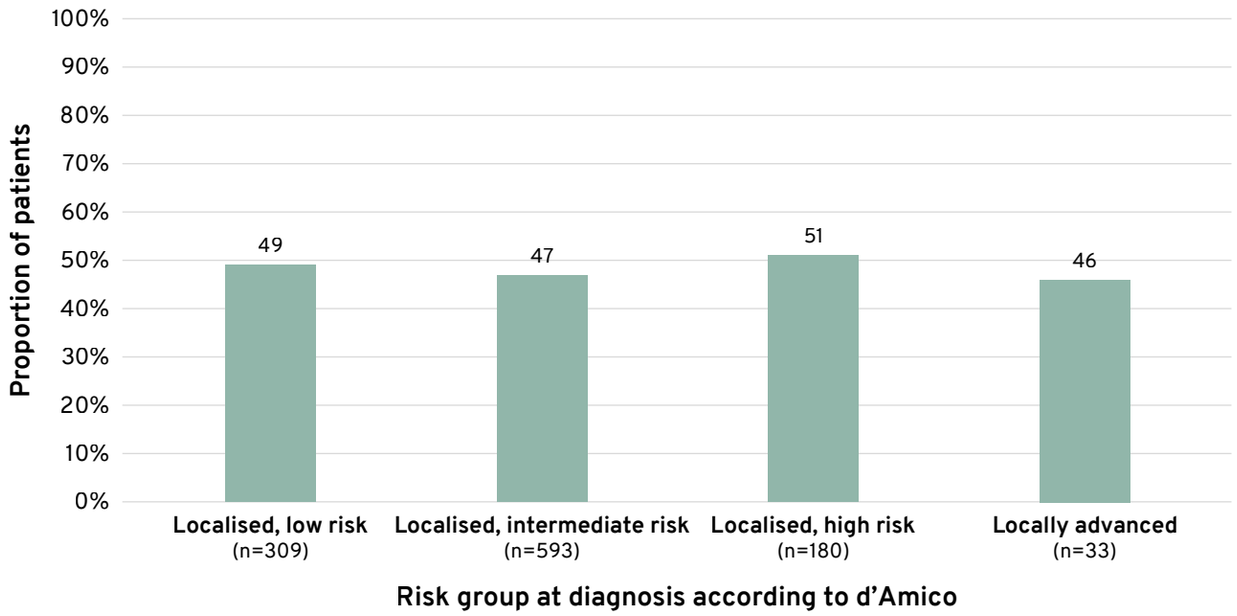
Often, RT is accompanied by ADT, and the timing of ADT is pivotal for the interpretation of the results of any PROMs. The PCO Study allows the inclusion of men who are already using ADT, these men typically already have impaired function across several domains when completing the T0 baseline questionnaire. Then, whether men start their ADT before or after their RT (but before the 12-month T1 questionnaire) may also have an impact. However, the largest individual RT-receiving group, according to the timing of ADT, is that of men who had no ADT at all (any type of RT, and no ADT before T1; N=2,517). The following results will only depict this patient group.

PROMs analysis for patients treated with RT for the remaining RT+ADT groups – as defined by the timing of their ADT use – can be found in **Supplementary Figures 27 to 54**.

RT alone (no ADT before T1): focus on sexual domain

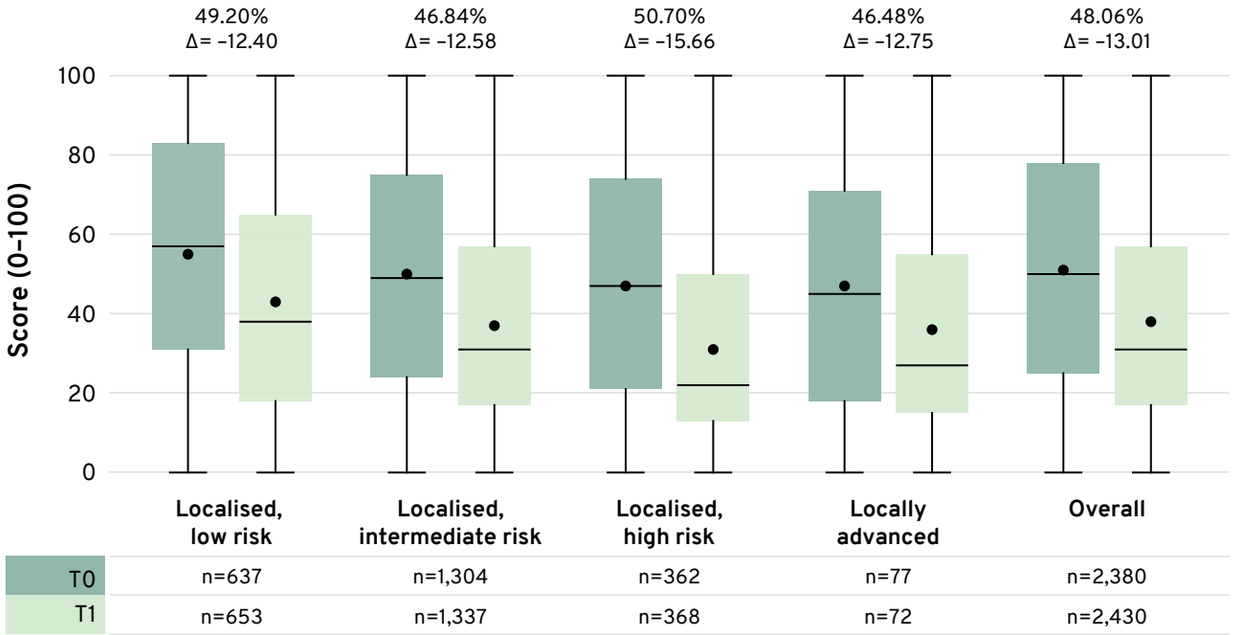
Among men having RT alone, approximately half the PCO PROMs responders reported a decline in sexual function of at least one MID (46–51% across groups), with no substantial difference seen between the d'Amico risk groups (**Figure 40**).

FIGURE 40: **PROPORTION OF PATIENTS WITH A CLINICALLY RELEVANT DETERIORATION IN THE EPIC-26 SEXUAL DOMAIN SCORE, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY D'AMICO RISK GROUP AT DIAGNOSIS**



- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A clinically relevant deterioration was defined as a minimally important difference of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Percentages are calculated as a percentage of patients whose Sexual Domain score decreased by at least 10 points between the T0 and T1 questionnaire, versus the total number of patients with T0 and T1 Sexual Domain scores available.
- The numbers below the bars indicate the number of patients with a clinically relevant deterioration.

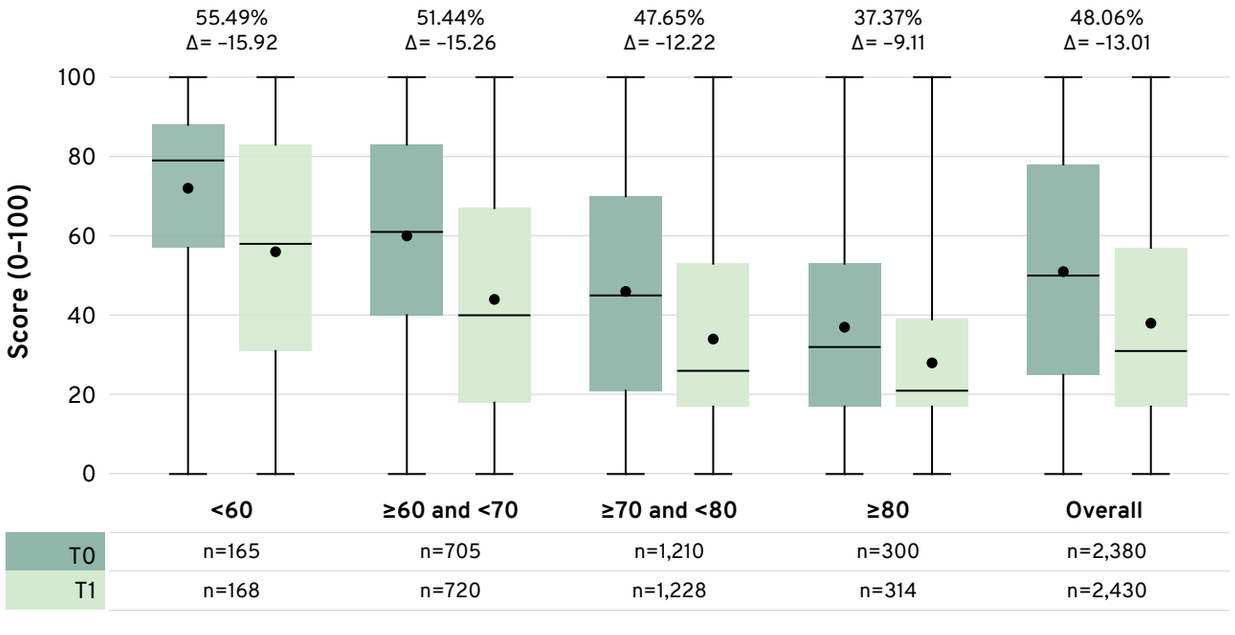
FIGURE 41: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY D'AMICO RISK GROUP**



	Localised, low risk	Localised, intermediate risk	Localised, high risk	Locally advanced	Overall
T0	n=637	n=1,304	n=362	n=77	n=2,380
T1	n=653	n=1,337	n=368	n=72	n=2,430

- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

FIGURE 42: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY AGE GROUP AT DIAGNOSIS**



	<60	≥60 and <70	≥70 and <80	≥80	Overall
T0	n=165	n=705	n=1,210	n=300	n=2,380
T1	n=168	n=720	n=1,228	n=314	n=2,430

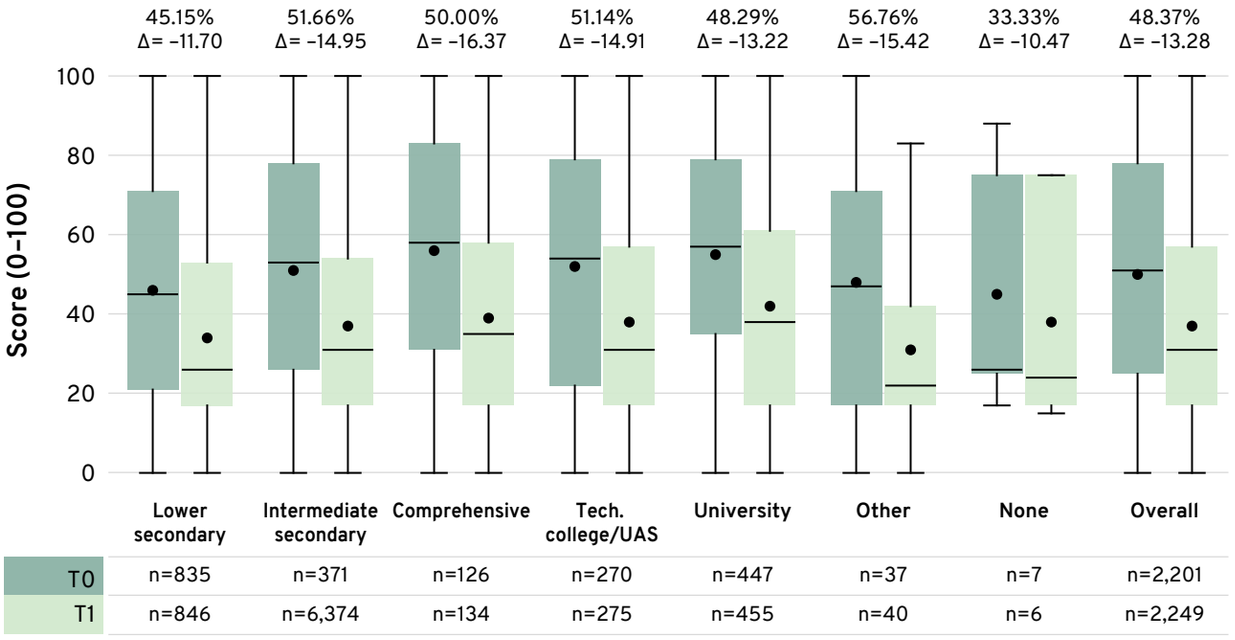
- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

Analysis of the magnitude of the average change (Δ) in sexual function by d'Amico risk group showed a steep decline across all risk groups after RT (**Figure 41**); the largest change, a drop of –16 points, was seen in men with localised high-risk disease, while all other risk groups reported a drop of between –12 to –13 points at the 12-month questionnaire (T1).

Similar to the picture seen in men who had surgery, a gradually declining distribution of baseline (T0) scores for sexual function was seen in the older age groups (**Figure 42**). The change in post-RT sexual function scores at the 12-month T1 questionnaire similarly declined in magnitude as the age group increased: the largest decrease (–16 points) was seen in youngest age group (<60, N=168) who started from the highest range of baseline sexual function scores; and the lowest decline (–9 points) was seen in the oldest age group (≥80, N=314) who started from the lowest range of baseline sexual function scores.

In German patients, analysis by highest school-leaving certificate (**Figure 43**) showed similar levels of steep decline in post-RT sexual function scores across groups, with no clear notable pattern. However, some differences were seen when analysed by type of health insurance (**Figure 44**), with 51% (N=449) of

FIGURE 43: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY)**

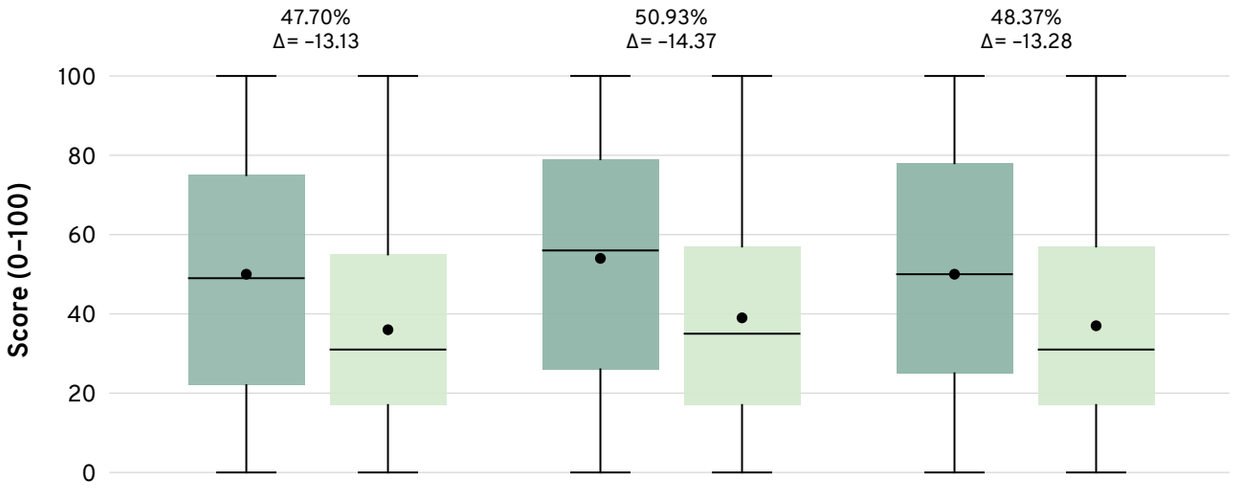


- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

men who had private insurance reporting a decline of at least the MID, compared with 48% of men with statutory insurance. The magnitude of the average change in score was only slightly lower for men with private insurance compared with those with statutory insurance (–14 points versus –13 points) which is less of a discrepancy than was reported by surgical patients across health-insurance types.

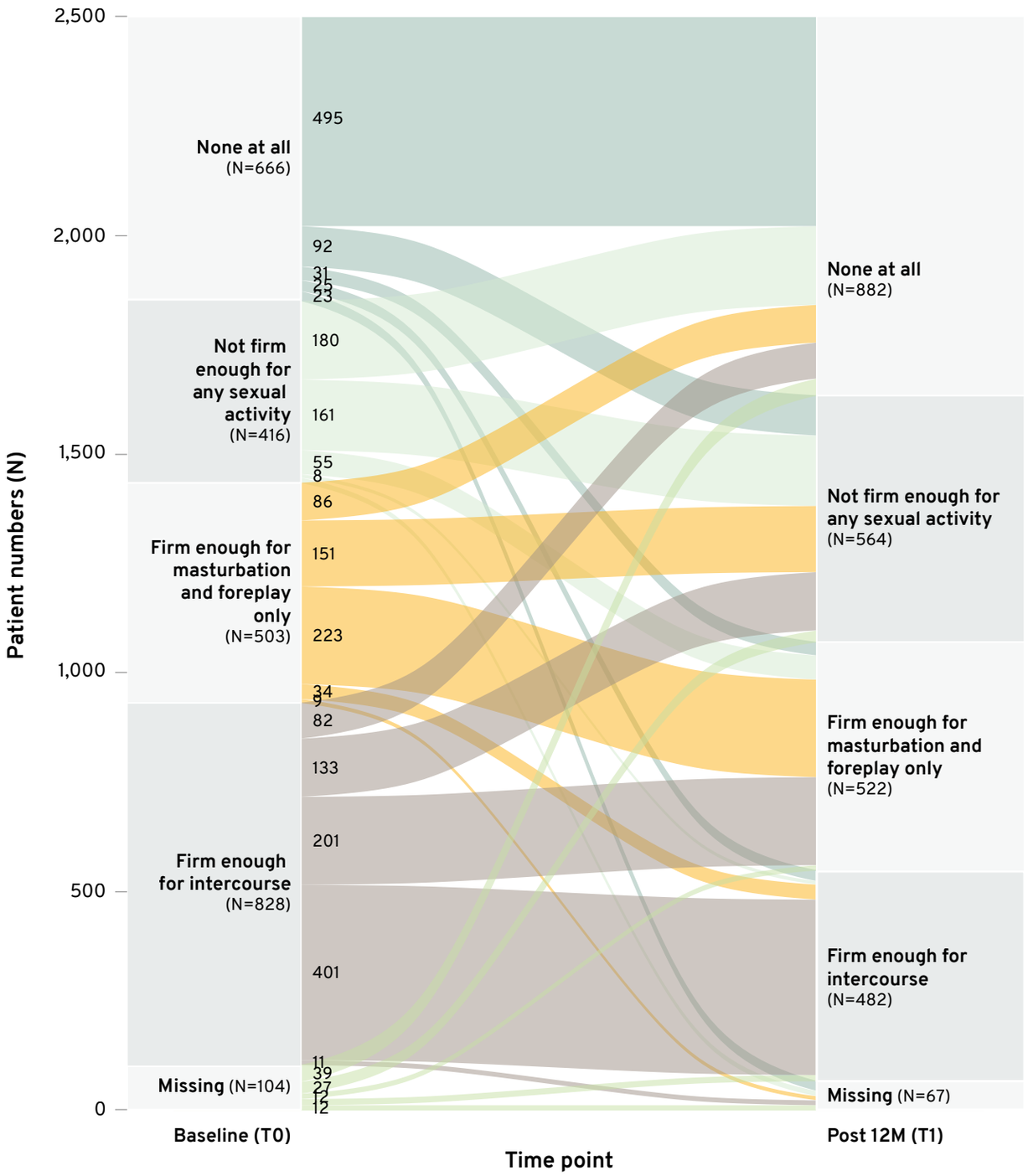
Analysis of the single item on 'quality of erections' via a Sankey plot (**Figure 45**) again illustrates the scope of the decline in sexual function after RT: 50% (N=416/828) of patients who had erections firm enough for intercourse before RT reported at least some loss in function at 12 months; with 26% (N=215/828) of the group who started with adequate function reporting either no erectile function at all, or erections not firm enough for sexual activity at 12 months. Compared with men who had surgery (**Figure 29**), RT patients generally tended to have a slightly lower distribution of baseline sexual function scores (**Figure 41**). Although again, patients included in the analysis may have used sexual aids (e.g. devices, pills). Nevertheless, these data underline that, as with surgery, this substantial risk of decline in sexual function is something patients should be made aware of during consultations.

FIGURE 44: **DISTRIBUTION OF EPIC-26 SEXUAL DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION WITHOUT ADT, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY)**



- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least –10 points (T1-score minus T0-score) in the overall Sexual Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

FIGURE 45: **PATTERN OF CHANGES IN RESPONSES TO THE 'QUALITY OF ERECTIONS' EPIC-26 ITEM, BETWEEN THE PRE-(T0) AND POST-(T1) THERAPEUTIC QUESTIONNAIRE, AMONG PATIENTS RECEIVING RADIATION WITHOUT ADT**

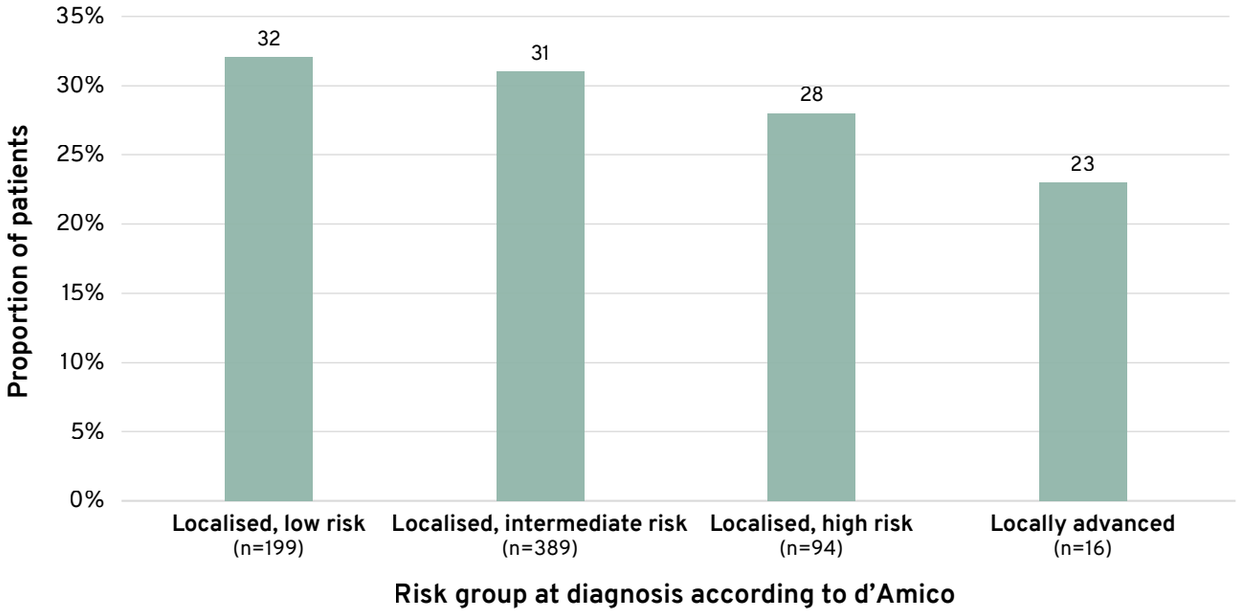


Item: How would you describe the usual QUALITY of your erections during the last 4 weeks?

None at all · Not firm enough for any sexual activity · Firm enough for masturbation and foreplay only · Firm enough for intercourse · Missing

- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- The figures given for the transition from T0 to T1 are patient numbers.

FIGURE 46: **PROPORTION OF PATIENTS WITH A CLINICALLY RELEVANT DETERIORATION IN THE EPIC-26 URINARY DOMAIN SCORE, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY D'AMICO RISK GROUP AT DIAGNOSIS**



- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A clinically relevant deterioration was defined as a minimally important difference of at least –6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Percentages are calculated as a percentage of patients whose Urinary Domain score decreased by at least 6 points between the T0 and T1 questionnaire, versus the total number of patients with T0 and T1 Urinary Domain scores available.
- The numbers below the bars indicate the number of patients with a clinically relevant deterioration.

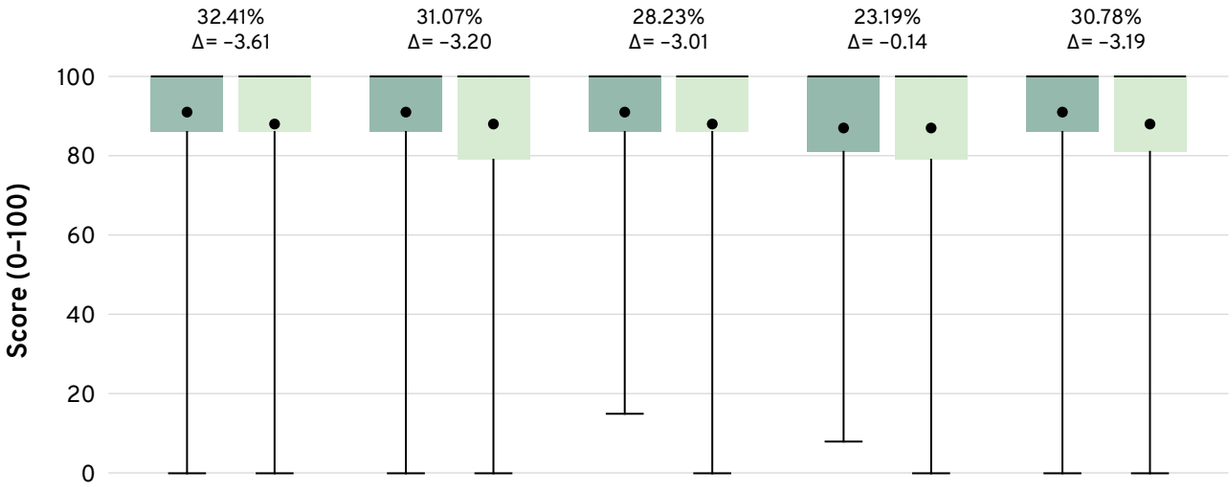
RT alone (no ADT before T1): focus on the urinary domain

The proportion of men who had RT without ADT and who experienced clinically relevant declines in urinary function at 12 months (≥MID of –6 points on T1) was roughly 30% overall (see **Figures 46 and 47**). Lower-risk patients experienced more decline, with rates of 32% (N=199) and 31% (N=389) among those with localised low-risk disease and localised intermediate-risk disease respectively. A rate of 23% of men reaching ≥MID was reported for locally advanced patients, but there were comparatively few patients in this group (N=16).

Although 30% of men experienced a clinically relevant decline overall, the average decline between T0 and T1 is only 3 points on a domain score that ranges from 0–100 (**Figure 47**) – substantially lower than the average decline of –20 points reported by men who had surgery alone.

Again, with increasing age, increasingly larger proportions of lower urinary function scores were reported by men having RT at the T0 questionnaire (**Figure 48**). With the youngest men tending to experience the largest decline in function: an average change of approximately –4 points was reported by men <60 (N=168) and by men ≥60 and <70 (N=718); but declines of just over –2.5 points were reported by both older age groups.

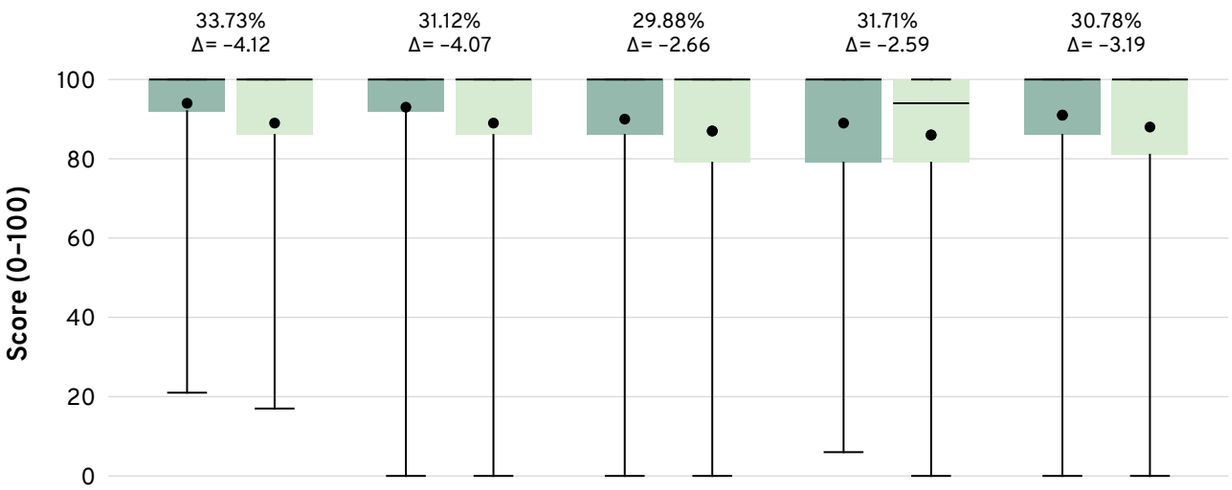
FIGURE 47: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY D'AMICO RISK GROUP**



	Localised, low risk	Localised, intermediate risk	Localised, high risk	Locally advanced	Overall
T0	n=636	n=1,306	n=351	n=72	n=2,365
T1	n=646	n=1,312	n=358	n=73	n=2,389

- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least −6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

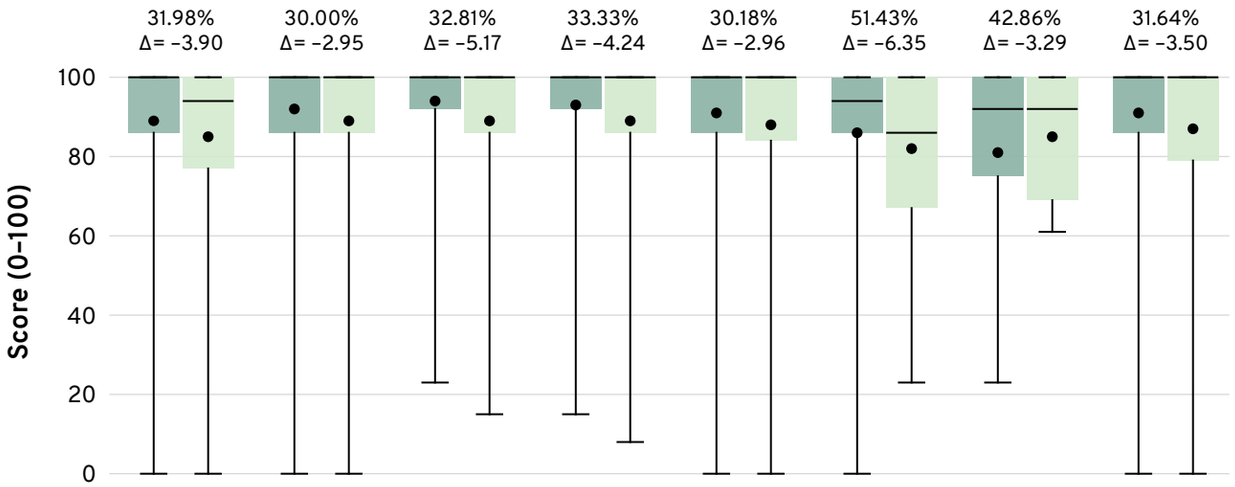
FIGURE 48: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY AGE GROUP AT DIAGNOSIS**



	<60	≥60 and <70	≥70 and <80	≥80	Overall
T0	n=167	n=708	n=1,185	n=305	n=2,365
T1	n=168	n=718	n=1,197	n=306	n=2,389

- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least −6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

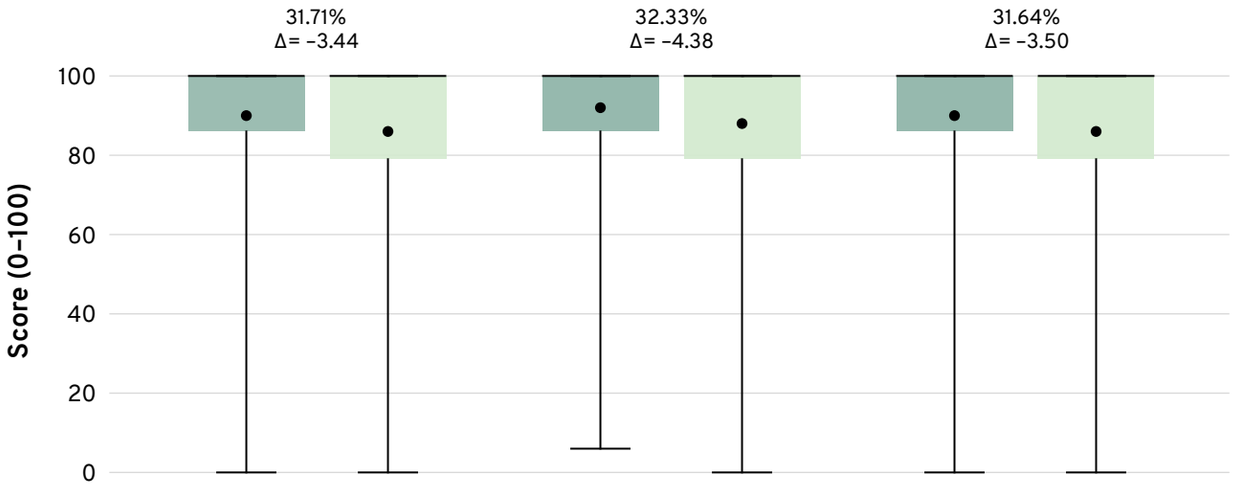
FIGURE 49: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY HIGHEST SCHOOL-LEAVING CERTIFICATE (GERMANY ONLY)**



	Lower secondary	Intermediate secondary	Comprehensive	Tech. college/UAS	University	Other	None	Overall
T0	n=816	n=368	n=131	n=271	n=452	n=37	n=7	n=2,190
T1	n=817	n=375	n=133	n=270	n=457	n=38	n=7	n=2,215

- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least–6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

FIGURE 50: **DISTRIBUTION OF EPIC-26 URINARY DOMAIN SCORES, FOR PRE- (T0) AND POST- (T1) THERAPEUTIC QUESTIONNAIRES, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT, BY TYPE OF HEALTH INSURANCE (GERMANY ONLY)**



	Statutory health insurance	Private health insurance	Overall
T0	n=1,638	n=444	n=2,082
T1	n=1,653	n=447	n=2,100

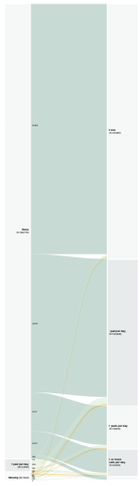
- Radiation therapy without ADT, is defined as having radiation therapy without ADT within 12 months of treatment or before treatment.
- A minimally important difference (MID) was defined as a change of at least –6 points (T1-score minus T0-score) in the overall Urinary Domain score.
- Average change (Δ) and proportion of patients with a decrease of at least one MID (%) are calculated based on patients with both valid T0 and T1 domain score, boxplots are based on patients who have a valid domain score for the respective time point.

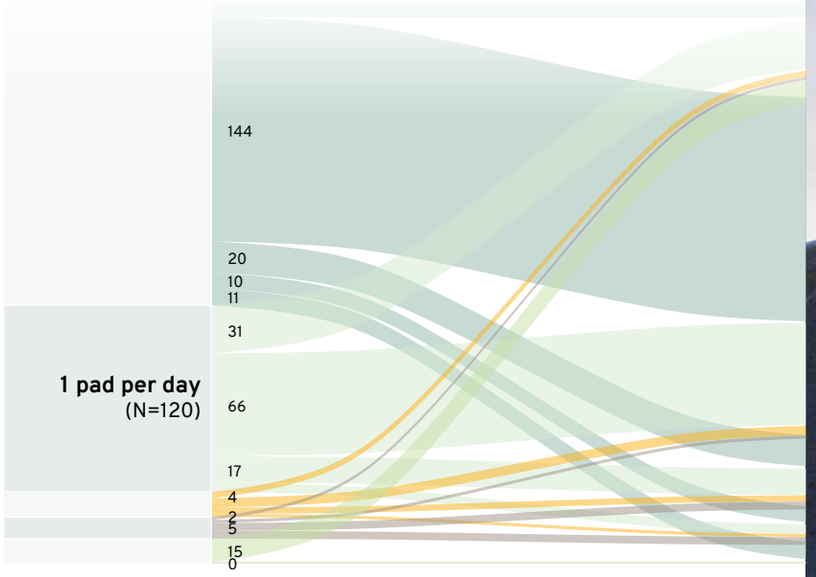
In German men, similar to other educational-certificate analyses, very little variation in the magnitude of the average change (Δ) in urinary function was seen across the different school-leaving certificate groups (**Figure 49**). However, in this analysis, the 'Other' group (N=38) reported a distinctly larger Δ of –6; but this is hard to interpret as we do not have information on the characteristics of this group, and it contained only 38 men at the T1 questionnaire. Analysis by type of health insurance in German men (**Figure 50**) also revealed only small differences; the average change in urinary function score was –3 for men with statutory insurance (N=1,653) and –4 for men with private health insurance (N=447), while the proportion reporting an MID change was approximately 32% for both groups.

By contrast with the data for men having surgery only, the single-item analysis of the incontinence question ('use of pads or adult diapers per day') by Sankey plot, revealed that relatively few men who have RT alone commence pad use 12 months after treatment. Only 7% of this management group (N=185/2,351) were using one or more pads per day by the 12-month T1 questionnaire (**Figure 51**).

FIGURE 51: **PATTERN OF CHANGES IN RESPONSES TO THE 'USE OF PADS OR ADULT DIAPERS PER DAY' EPIC-26 ITEM, BETWEEN THE PRE-(T0) AND POST-(T1) THERAPEUTIC QUESTIONNAIRE, AMONG PATIENTS TREATED WITH RADIATION THERAPY WITHOUT ADT**

Please note: This figure isn't viewable within the format of this report. To view Figure 51 in full online, click on the QR code below.





CHAPTER 4

LOCAL GERMAN PROGRAM ACTIVITIES

GERMAN PROGRAM ACTIVITIES: ANNUAL REPORTS

What made the situation special in the three countries contributing to the PCO Study was that the collection of functional outcomes had already been established in several specialised centres that had a high caseload; particularly the Martini Clinic in Hamburg. From an early stage, the Martini Clinic served as an informal benchmark for many other centres that wanted to begin similar initiatives and needed a standard of best practice for comparison.

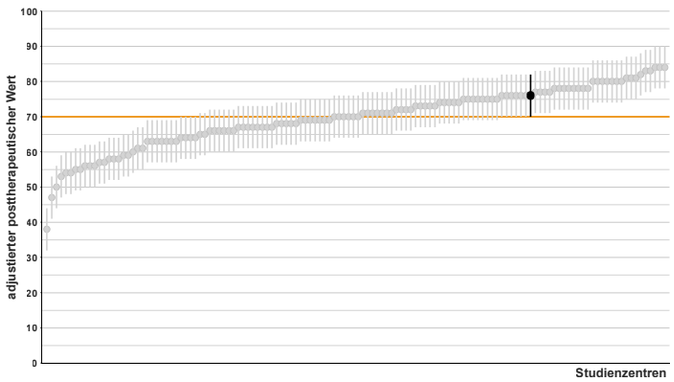
One of the aims of the local data centre (LDC) in Germany, Austria and Switzerland was therefore to facilitate comparisons between centres. To avoid language and reporting style becoming barriers, the German Cancer Society – together with OnkoZert and the BPS – established additional reporting standards in German, using the long-established reporting style of the German Cancer Society's certification program to produce annual reports. By contrast with the annual reports issued by the global TNGR data centre in Melbourne, these German LDC reports were limited to functional outcomes; because clinical-quality indicators had already been reported to the centres before.

One key objective was to make the reports as reliable as possible, and avoid the concerns of practitioners that we were comparing apples

FIGURE 52: **EXAMPLE OF A TYPICAL ANALYSIS FROM THE ANNUAL PCO REPORT FROM DKG CENTRES (IN GERMAN), SHOWING THE OUTCOMES DISTRIBUTION FOR POST-SURGICAL INCONTINENCE**

Prostate Cancer Outcomes-Studie (PCO) Ergebnisbericht
Ergebnisbericht für die Verwendung in Ihrem Studienzentrum
Casemix-adjustierte EPIC-26-Scores: Inkontinenz (nur RPE)

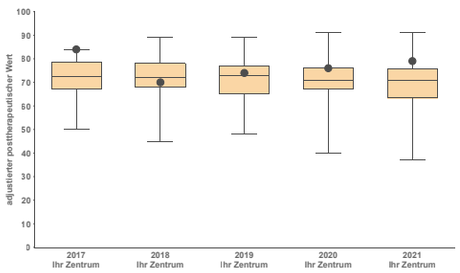
DKG KREBSGESELLSCHAFT

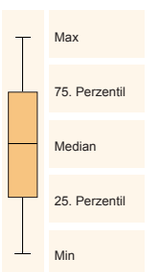


Ihr Zentrum (adjustiert)	76
Rang Ihres Zentrums[1]	29 von 130

Ihr Zentrum (adjustiert)	Alle Zentren
Median (orangene Linie)[2]	70,0
Durchschnitt[3]	69,6
Interquartilsabstand[4]	11,0

[1] Der Rang Ihres Zentrums bezieht sich auf die adjustierten Werte.
[2] Der Median ist ein Lagemaß und entspricht dem Wert, der in einer sortierten Stichprobe genau in der Mitte liegt.
[3] Durchschnitt (arithmetische Mittel) der adjustierten posttherapeutischen Werte aller Zentren.
[4] Der Interquartilsabstand ist ein Streuungsmaß und gibt die Breite des Intervalls an, in dem bei einer sortierten Stichprobe die mittleren 50% der Werte liegen (25. und 75. Perzentil) – in diesem Fall der adjustierten posttherapeutischen Werte.





Interpretationshinweise:

Sie finden oben abgebildet die adjustierten posttherapeutischen Ergebnisse für die EPIC-26 Dimension „Inkontinenz" für Zentren mit Daten von mindestens 10 Patienten im Zeitraum 2017-2021 zusammen mit den dazugehörigen MID-Intervallen.
Für die Dimension „Inkontinenz" ist die MID 6.

Für die EPIC-26-Scores gilt: je höher der Wert, desto besser geht es den Patienten in Ihrem Zentrum 12 Monate nach Behandlung. EPIC-26-Scores können Werte zwischen 0 und 100 annehmen.

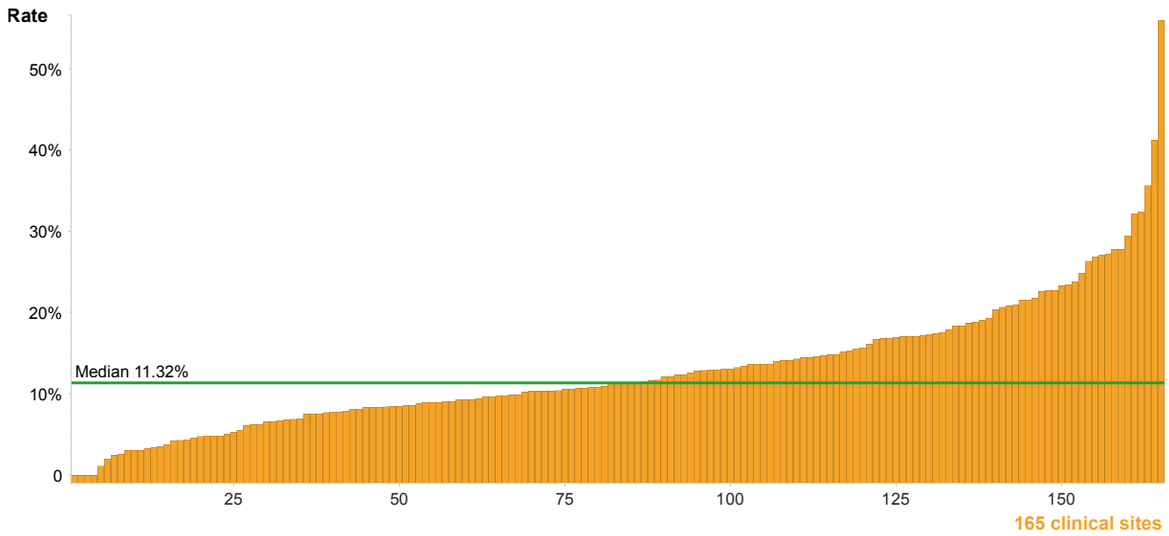
Unten links finden Sie die adjustierten posttherapeutischen Werte aller Zentren im Zeitverlauf als Boxplots abgebildet. Der jeweilige Wert Ihres eigenen Zentrums ist durch einen Punkt gekennzeichnet.

FIGURE 53: **EXAMPLE FROM THE 2024 DKG ANNUAL REPORT – PROPORTION OF PATIENTS WITH LOCALISED LOW-RISK DISEASE AMONG ALL PATIENTS WHO RECEIVE SURGERY (ENGLISH TRANSLATION)**

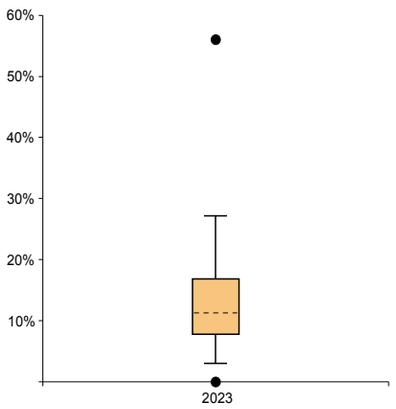
Annual Report Prostate 2025 (Audit year 2024 / Indicator year 2023)

22. Rate of locally confined Prostate Cancer and low risk with RPE/RCE (GL QI)

DKG KREBSGESELLSCHAFT Certification



	Definition of indicator	All clinical sites 2023		
		Median	Range	Patients Total
Numerator	Primary cases of the denominator with locally confined prostate carcinoma and low risk	13*	0 – 361	3,450
Denominator	Primary cases with RPE + RCE	102*	33 – 2,492	26,921
Rate	No target value	11.32%	0.00% – 56.00%	12.82%**



		2019	2020	2021	2022	2023
	Max	—	—	—	—	56.00%
	95th percentile	—	—	—	—	27.17%
	75th percentile	—	—	—	—	16.84%
	Median	—	—	—	—	11.32%
	25th percentile	—	—	—	—	7.87%
	5th percentile	—	—	—	—	3.01%
	Min	—	—	—	—	0.00%

Clinical sites with evaluable data		Clinical sites meeting the target value	
Number	%	Number	%
165	100.00%	—	—

Comments:
The proportion of patients with locally confined prostate cancer and low risk classification in the total number of primary cases with radical prostatectomy/cystectomy was calculated for the first time in the indicator year 2023. 12.8% of all primary cases with RPE/RCE (median 11.3%) had such low-risk prostate cancer (range 0–56%).

Adapted from Indicator Analysis 2025 of the Certified Prostate Cancer Centres. Audit year 2024, Indicator year 2023.
RPE/RCE, radical prostatectomy/radical cystoprostatectomy; GL QI, Guideline Quality Indicator.

with oranges, due to potential differences in the case-mix between populations of different centres. We therefore paid attention to rigidly adjusting for case-mix differences. Therefore, a standard, adjusted case-mix schematic, with a graphical illustration that uses minimal important differences (MIDs) was developed for the annual reports;[3] resulting in the characteristic plots, as shown in **Figure 52**.

The case-mix adjustment was based on a rigorous review of the literature, and particularly on methods developed by the UK National Health System (NHS). This method of case-mix adjustment has been used in all the German-language annual reports,[2] and has also been applied to the TNGR dataset, with results also reported in several journal publications.[3,32,33]

Reporting was accompanied by in-person workshops and, later, during and after the pandemic, by online meetings to present and discuss results. The purpose was to make the centres aware of the novel tool they have at hand to improve care for patients. Therefore, and in addition to the aggregated results in the annual reports, centres can review every patient's data individually as well as follow up their patients.

GERMAN PROGRAM ACTIVITIES: THE REDUCE WORKING GROUP ('AG REDUCE')

The German Cancer Society's certification program is built upon the division of powers: the certification commission (legislative branch) develops the requirements, the independent auditors (the executive branch) review whether candidate centres fulfil the requirements, and the certificate awarding committee (judiciary branch) decides whether a centre receives a certificate based on the documentation provided by the auditors.

The PCO Study is embedded in these structures. While the initiation of the PCO Study was not based on a certification commission decision, shortly after the initial success of the PCO, use of the EPIC-26 outcomes questionnaire was made mandatory for all prostate cancer centres that were applying for a certificate (as of 2020). DKG-certified centres can still decide, though, whether to use the EPIC-26 as a participant of the PCO Study, or to use their own routine for EPIC-26 functional outcomes collection; but the large majority of DKG-certified centres now participate in the PCO Study.

In an effort to discuss results beyond those directly involved in the PCO Study, this same certification commission decided in 2021, to task a group of dedicated individuals – including patients, clinicians, researchers, and quality experts – with developing measures to reduce the variation in outcomes between centres, and improve overall clinical quality, based on the PCO Study results. This so-called 'Reduce Working Group' was formed in September 2021. Over the following 12 months, this group of 16 experts met four times. They issued a number of recommendations referring to the presentation of data, encouragement of mutual learning activities, and most notably, to acknowledge the high number of patients with localised low-risk disease who received surgery; causing unnecessary functional impairment in many men.

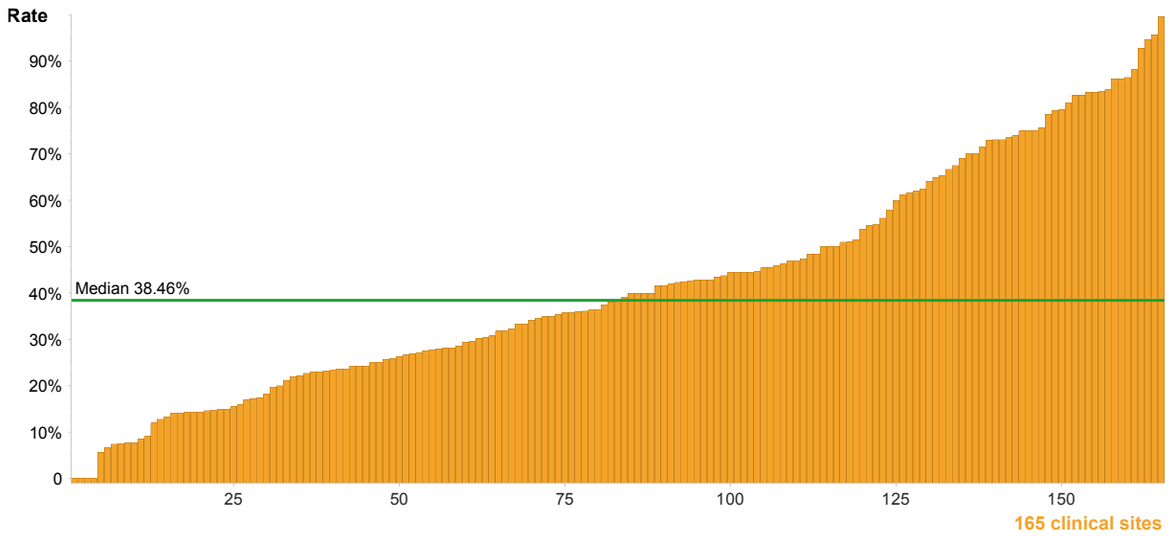
The working group therefore recommended the addition of quality indicators to the certification criteria to report on the management of patients with low-risk disease. Quality-indicator reporting has long been established in cancer centres, and is used to make processes and outcomes comparable, and to provide guidance on where there might be room for improvement.[34] Following the working group recommendations, two new quality indicators were implemented in the certification reporting system: one that tracks the proportion of patients with localised low-risk disease among all patients who receive surgery (see **Figure 53** for an example from the 2024 DKG annual report); and one that tracks the proportion of patients with localised low-risk disease who are receiving surgery overall (see **Figure 54** for an example from the 2024 DKG annual report). These indicators are intended to make management behaviour transparent, and to ultimately lead to fewer unnecessary surgeries in patients with low-risk disease.

FIGURE 54: **EXAMPLE FROM THE 2024 DKG ANNUAL REPORT – PROPORTION OF PATIENTS RECEIVING SURGERY AMONG ALL PATIENTS WITH LOCALISED LOW-RISK DISEASE (ENGLISH TRANSLATION)**

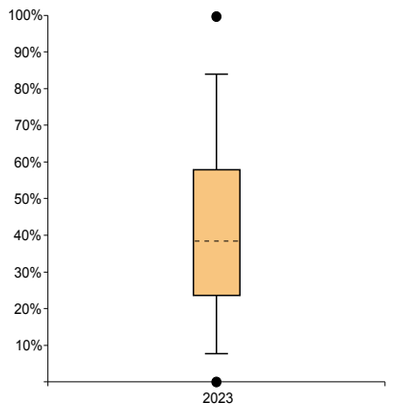
Annual Report Prostate 2025 (Audit year 2024 / Indicator year 2023)

23. RPE/RCE in primary cases with locally confined Prostate Cancer and low risk (GL QI)

DKG KREBSGESELLSCHAFT Certification



	Definition of indicator	All clinical sites 2023		
		Median	Range	Patients Total
Numerator	Primary cases with locally confined prostate carcinoma and low risk and RPE/RCE	13*	0 – 361	3,450
Denominator	Primary cases with locally confined prostate carcinoma and low risk	36*	4 – 377	7,484
Rate	No target value	38.46%	0.00% – 99.63%	46.10%**



		2019	2020	2021	2022	2023
	Max	—	—	—	—	99.63%
	95th percentile	—	—	—	—	83.91%
	75th percentile	—	—	—	—	57.89%
	Median	—	—	—	—	38.46%
	25th percentile	—	—	—	—	23.71%
	5th percentile	—	—	—	—	7.71%
	Min	—	—	—	—	0.00%

Clinical sites with evaluable data		Clinical sites meeting the target value	
Number	%	Number	%
165	100.00%	—	—

Comments:
The proportion of primary cases requiring surgery (RPE/RCE) among primary cases with locally limited, low-risk carcinoma is also reported for the first time: 46% of this patient group underwent surgical treatment. Here, too, there is a wide range of treatments, from 0 to 100% (median 38.5%).

Adapted from Indicator Analysis 2025 of the Certified Prostate Cancer Centres. Audit year 2024, Indicator year 2023.
RPE/RCE, radical prostatectomy/radical cystoprostatectomy; GL QI, Guideline Quality Indicator.

GERMAN PROGRAM ACTIVITIES: PUBLICATIONS AND STUDIES BUILDING ON THE PCO

The PCO was planned as a research study that can contribute to quality development in prostate cancer care. In addition to the reports issued annually, data are discussed with the participating centres and ideas for publications are regularly developed. These publications are coordinated by the German Cancer Society team with input from all centres that were interested in a specific topic. Publications that evolved from PCO so far include, for instance, a study description, the validation of the German version of the EPIC-26, prediction analyses of baseline and post-treatment function, prediction of psychosocial support utilisation, incontinence prevalence after surgery, and outcome variation across centres. These publications were also part of dissertations, for example those of Drs Clara Breidenbach and Nora Tabea Sibert, who worked extensively with the data.

Involving centres in working with the results and contributing to publications has been one means to, not only add to research, but to also give relevance to patients' functional outcomes.[3,31,35–41] In addition, centres were encouraged to work with their own data, and some published their work in scientific journals, often by extending PCO Study data with data additionally collected in the originating centre.[42–46]

Besides numerous publications, engaging with the results led to the initiation of several novel studies, many of which are very well-funded, and aimed at improving functional outcomes for prostate cancer patients. All these studies were ongoing during the writing of this report. The following provides just the gist of some these efforts.

The 'Pro-P Trial' initiated by the Urology Department of the University Hospital Düsseldorf,[47] evaluates the effect of an electronic system for monitoring patient-reported outcome measures. Prostate cancer patients treated surgically in the intervention group of the randomised-controlled trial are asked to complete electronic PRO questionnaires, including the EPIC-26, on a regular basis. In case of symptoms or functional impairment, an alert is triggered to initiate a consultation with the relevant centre. The aim is to improve continence. The control group receives usual care. The PCO infrastructure, including the OncoBox, is used to facilitate the running of this study.

Similarly, the randomised-controlled trial 'ProKontinenz',[48] initiated by the Urology Department of the Technical University of Dresden is also aimed at improving continence. The PCO cohort is used to identify patients with relevant change in continence after surgery for prostate cancer. Here, controls receive usual care, while patients in the intervention group receive specific online information on surgeries and other measures to improve continence; with the key aims of helping more patients benefit from such measures and, ultimately decreasing functional impairment.

The 'MID-EPIC-D' study,[49] funded by the German Cancer Aid, and initiated by the DKG, BPS, OnkoZert and Würzburg University, is an extension of the PCO Study that is aiming to develop MIDs specific for the German, Swiss and Austrian prostate cancer patient population. Currently, MIDs from America are used in the PCO Study, but the literature is clear that population-specific MIDs are preferred.[50] Therefore, a subsample of the PCO cohort is re-surveyed after 24 months, with a questionnaire including an item that is suitable as the anchor for deriving MIDs. This 24-month survey also allows for the observation of changes in functional outcomes over time.

DATA COMPLETENESS

This section provides data on the completeness of the variables used in this report to provide additional context about the reliability of the data, and therefore the findings.

Data completion for variables included in this report is for the 47,466 participants with both T0/T1 questionnaires, or subsets, according to country or type of treatment. It should be read in addition to the drop-out analysis that informs about those that completed a T0 but no T1 questionnaire.

Overall, the amount of missing information is very small. This is in part due to the study design: patients submit their consent together with their baseline questionnaire, and only patients with a completed baseline questionnaire are considered study participants, leading to high completeness of the EPIC-26 scores for example. Regarding the PROs, we find the highest proportion of missing information in the irritative/obstructive and bowel function scores. Among German men, information on school-leaving certificate and insurance status are collected together with the PRO data and are of similar completeness. The high completeness of the clinical information is due to the fact that they are part of the routine data collection for certification. That is, centres submit their data in as complete a format as possible for the calculation of the quality indicators. Incomplete data typically have to be revised before being accepted for publication resulting in a mostly complete dataset. The comparably high number of missing data seen in questionnaires, is due to some centres using their own survey infrastructure, meaning this information is not part of the PCO data set.

TABLE 9: **DATA COMPLETENESS FOR INCLUDED VARIABLES**

Variable	Definition	Percent
Year of completion of the Item -therapeutic questionnaire ('study entry')	47,466/47,466	100
Age	47,466/47,466	100
Risk classification according to d'Amico	47,466/47,466	100
Treatment	47,466/47,466	100
ADT Item T1	47,185/47,466	99.4
ADT Item (T0) only	47,466/47,466	100
ADT Item (T0), ADT (T0) to T1	47,466/47,466	100
No ADT Item (T0), ADT (T0) to T1	47,092/47,466	99.2
Item operative/pathologic T-status*	40,570/40,570	100
Surgical method*	40,570/40,570	100
Nerve-sparing surgery*	40,570/40,570	100
Positive surgical margin*	39,949/40,570	98.5
Leading radiation therapy†	4,973/4,973	100
Highest school-leaving certificate#	41,431/43,479	95.3
Type of health insurance#	41,562/43,479	95.6
T1 questionnaire completed	74,413/74,413	100
Questionnaire mode (paper vs. online)	41,987/47,466	88.5

*Among patients with surgery. †Among patients with radiotherapy. #Among patients treated in German centres.

TABLE 10: **DATA COMPLETENESS FOR EPIC-26 DOMAINS AND ITEMS, AT T0 AND T1**

T0			T1		
EPIC-26 DOMAIN	**COUNT**	**%**	**EPIC-26 DOMAIN**	**COUNT**	**%**
Sexual function (T0)	45,505/47,466	95.9	**Sexual function (T1)**	46,368/47,466	97.7
Urinary incontinence (T0)	44,929/47,466	94.7	**Urinary incontinence (T1)**	45,985/47,466	96.9
Urinary irritation / obstruction (T0)	44,082/47,466	92.9	**Urinary irritation / obstruction (T1)**	44,664/47,466	94.1
Vitality / hormonal function (T0)	44,824/47,466	94.4	**Vitality / hormonal function (T1)**	45,632/47,466	96.1
Bowel function (T0)	44,066/47,466	92.8	**Bowel function (T1)**	44,748/47,466	94.3
EPIC-26 ITEM	**COUNT**	**%**	**EPIC-26 ITEM**	**COUNT**	**%**
Item 1 (T0)	47,042/47,466	99.1	**Item Q1 (T1)**	47,177/47,466	99.4
Item Q2 (T0)	46,994/47,466	99	**Item Q2 (T1)**	47,155/47,466	99.3
Item Q3 (T0)	47,045/47,466	99.1	**Item Q3 (T1)**	47,116/47,466	99.3
Item Q4a (T0)	45,470/47,466	95.8	**Item Q4a (T1)**	46,376/47,466	97.7
Item Q4b (T0)	45,112/47,466	95	**Item Q4b (T1)**	45,352/47,466	95.5
Item Q4c (T0)	44,831/47,466	94.4	**Item Q4c (T1)**	45,180/47,466	95.2
Item Q4d (T0)	45,567/47,466	96	**Item Q4d (T1)**	45,410/47,466	95.7
Item Q4e (T0)	45,968/47,466	96.8	**Item Q4e (T1)**	45,898/47,466	96.7
Item Q5 (T0)	46,901/47,466	98.8	**Item Q5 (T1)**	47,137/47,466	99.3
Item Q6a (T0)	46,597/47,466	98.2	**Item Q6a (T1)**	46,213/47,466	97.4
Item Q6b (T0)	44,403/47,466	93.5	**Item Q6b (T1)**	45,096/47,466	95
Item Q6c (T0)	44,172/47,466	93.1	**Item Q6c (T1)**	44,880/47,466	94.6
Item Q6d (T0)	44,142/47,466	93	**Item Q6d (T1)**	44,858/47,466	94.5
Item Q6e (T0)	44,325/47,466	93.4	**Item Q6e (T1)**	45,090/47,466	95
Item Q7 (T0)	46,563/47,466	98.1	**Item Q7 (T1)**	46,545/47,466	98.1
Item Q8a (T0)	46,164/47,466	97.3	**Item Q8a (T1)**	46,702/47,466	98.4
Item Q8b (T0)	45,335/47,466	95.5	**Item Q8b (T1)**	45,693/47,466	96.3
Item Q9 (T0)	46,075/47,466	97.1	**Item Q9 (T1)**	46,747/47,466	98.5
Item Q10 (T0)	45,419/47,466	95.7	**Item Q10 (T1)**	46,425/47,466	97.8
Item Q11 (T0)	45,942/47,466	96.8	**Item Q11 (T1)**	46,608/47,466	98.2
Item Q12 (T0)	46,079/47,466	97.1	**Item Q12 (T1)**	46,602/47,466	98.2
Item Q13a (T0)	45,721/47,466	96.3	**Item Q13a (T1)**	46,238/47,466	97.4
Item Q13b (T0)	40,965/47,466	86.3	**Item Q13b (T1)**	43,909/47,466	92.5
Item Q13c (T0)	45,224/47,466	95.3	**Item Q13c (T1)**	45,965/47,466	96.8
Item Q13d (T0)	45,528/47,466	95.9	**Item Q13d (T1)**	46,221/47,466	97.4
Item Q13e (T0)	45,293/47,466	95.4	**Item Q13e (T1)**	45,998/47,466	96.9

DISCUSSION AND FUTURE DIRECTIONS

The PCO Study is an outstanding success, and will have included 100,000 patients by spring 2026. Over 150 prostate cancer centres from Germany, Austria and Switzerland are taking part in the PCO. These centres cover 80% of patients from all certified centres. The PCO Study makes sure patients' reports are part of every centres' quality assessment, and has put PROs on the agenda in prostate cancer care at scale. It has inspired interventional studies to improve patient functioning, and has released a substantial research output already. It has also inspired similar studies that follow the PCO model for other cancers, for example, EDIUM for colorectal cancer has been established since 2018.[1] When the partners involved first embarked on this adventure, no one would have thought this would work out the way it did. Overall, we feel that the PCO Study could not have started off any better. Of course, there are always things that can be improved: the overall response rate could be closer to 100%, and patients managed with RT, AS and WW are less well-recruited than patients who are managed with surgery. Nevertheless, the PCO group is willing and able to continue working on improving the study into the future.

What might future developments look like? Certainly, we are aiming to support the extended use of PRO data for directly intervening in patients with impaired function. The ongoing trials Pro-P47 and ProKontinenz48 are developing and testing routines for this and we are eagerly awaiting the study results. PRO monitoring has previously shown positive effects in large randomised trials.[51–53] These were mostly limited to patients being treated with systemic therapy; but when functional impairments go undertreated – as is often the case after surgery for prostate cancer – simple monitoring systems may be able to show high-value results at relatively low costs. The PCO Study can serve as a basis for helping establish this as a national standard of care.

Then of course there is the technical sphere. Since the establishment of the PCO Study, there have been many developments, some of which we have assessed and taken on board. For example, we have transformed the PCO Study data into the common data model known as the Observational Medical Outcomes Partnership (OMOP),[41] which allows us to take part in larger-scale collaborative projects with other similar databases; yet the overall appearance of the PCO Study has hardly changed. By contrast, we haven't, for example, transferred the PCO Study to an app – even when, a couple of years ago, health-app funding in Germany peaked – and we are happy today that we haven't. Instead, careful changes were made only to the online portal and the way it functioned, resulting in a very stable online environment. We look forward to evaluating future technical developments, and implementing any innovations that we believe will help us improve the PCO Study over time.

> "
>
> What else may the future bring? It may, and should, include the implementation of PROMs collection beyond prostate and colorectal cancer.

What else may the future bring? It may, and should, include the implementation of PROMs collection beyond prostate and colorectal cancer. There are many cancers, if not all, that deserve the systematic collection of PROs to depict outcomes and improve quality. Short-, medium- and long-term side effects alike make lives harder for hundreds of millions of cancer survivors globally; and systematic follow-ups, which deploy well-developed PROs on a regular basis, may identify the most significant hardships, and lead to measures being taken to improve the quality of life of millions. This is the spirit of the PCO Study, reflecting that of its parent study, the True North Global Registry (TNGR).

PCO PUBLICATIONS

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INDEX OF TABLES AND FIGURES

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