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Prostate Cancer Care for Men with an Intellectual Disability: A Population-based Cohort Study of Symptoms, Diagnosis, Treatment, and Survival

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Abstract

Background and objective: Intellectual disability (ID) is increasingly recognised as a hidden driver of cancer mortality. However, evidence on prostate cancer (PC) care in this population is limited.

Methods: The study population comprised 29 554 men with an ID and 518 739 comparators from the Clinical Practice Research Datalink Aurum database, which is linked to hospital, mortality, and cancer registry data. Poisson and Cox regression analyses were used to estimate incidence rate ratios (IRRs), risk ratios (RRs), and hazard ratios (HRs) with 95% confidence intervals (CIs) for outcomes related to PC presentation, diagnosis, treatment, and survival.

Key findings and limitations: The ID group presented more frequently with symptoms suggestive of PC (IRR 1.35, 95% CI 1.28–1.43) but were less likely to have a prostate-specific antigen (PSA) test within 90 d (RR 0.66, 95% CI 0.63–0.70). Following detection of elevated PSA, the ID group had fewer referrals (RR 0.83, 95% CI 0.72–0.96), biopsies (RR 0.54, 95% CI 0.41–0.71), and PC diagnoses (RR 0.51, 95% CI 0.41–0.65). The ID group were also more likely to be diagnosed on the date of death (RR 5.96, 95% CI 2.70–11.77), have missing Gleason scores (RR 1.61, 95% CI 1.27–2.01), and present with de novo metastatic PC (RR 1.79, 95% CI 1.15–2.77). Among those with Gleason scores, the rate of clinically significant PC (Gleason $\geq$7) was comparable between the ID and control groups, while receipt of radical treatment for nonmetastatic PC was slightly lower in the ID group (RR 0.73, 95% CI 0.51–1.00). Men with an ID had twofold higher risk of death from PC following diagnosis (HR 2.11, 95% CI 1.64–2.73).

Conclusions and clinical implications: Men with an ID face disparities across the PC care pathway from investigation of relevant symptoms to survival after diagnosis. Targeted interventions are needed to address these inequities.

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ADVANCING PRACTICE

What does this study add?
This study provides comprehensive evidence highlighting disparities in prostate cancer care for men with intellectual disabilities, including a lower frequency of prostate-specific antigen (PSA) testing following symptoms, lower referral rates, and fewer biopsies following detection of elevated PSA. These men are more likely to have metastatic disease at diagnosis, have an almost sixfold higher risk of being diagnosed on their date of death, and have twofold higher risk of dying from prostate cancer following diagnosis. There is an urgent need for targeted interventions to improve care in this group.

Clinical Relevance
In this large population-based study from the United Kingdom, men with an intellectual disability face significant disparities in prostate cancer care, from delayed diagnosis to poorer survival outcomes. These findings highlight an urgent need for targeted interventions to address systemic barriers, such as lower rates of PSA testing and biopsies, and ensure equitable, high-quality care for this vulnerable population. Associate Editor: Alicia K Morgans.

Patient Summary
We looked at prostate cancer care for men with an intellectual disability. We found that these men are less likely to receive appropriate investigations after presenting with symptoms suggestive of prostate cancer. They are also more likely to be diagnosed after the cancer has spread and are more likely to die from prostate cancer in comparison to men without an intellectual disability.

1. Introduction

Intellectual disability (ID) is defined as a lifelong neurodevelopmental condition characterised by significant impairments in intellectual functioning and adaptive behaviour, with onset in childhood [1]. Globally, approximately 200 million individuals have an ID [2,3]. This population frequently encounters systemic barriers in health care services, including communication difficulties, insufficient provision of reasonable adjustments, and diagnostic overshadowing [3]. Life expectancy for adults with an ID is on average 19–23 yr shorter than for the general population, with nearly half of deaths considered preventable [4]. Addressing these health disparities has been recognised as a priority by the National Health Service (NHS) long-term plan, National Institute for Health and Care Excellence guidance, and the Learning from Lives and Deaths programme in the UK [5,6].

ID is increasingly recognised as a hidden driver of cancer mortality [7–10]. This is partly because of lower participation in national screening programmes, such as those for breast, bowel, and cervical cancers [11,12], and diagnosis of cancer at a more advanced stage, when treatments are less effective [10,13]. However, evidence concerning prostate cancer (PC), which is the cancer most frequently diagnosed among men, is lacking. Although studies generally report lower PC incidence in the ID population [14], it is unclear whether this reflects a genuinely lower risk or is primarily because of lower use of diagnostic investigations such as prostate-specific antigen (PSA) testing. Data are also limited regarding follow-up after an elevated PSA result, as well as treatment patterns and survival outcomes following a PC diagnosis in this population.

The aim of this study was to examine the impact of ID on all aspects of PC care using a large, population-based matched cohort. Parameters investigated included PSA testing (both overall and when used to investigate symptoms potentially indicative of PC), urgent suspected PC referrals, diagnostic investigations, treatments received, and survival.

2. Patients and methods

2.1. Data source and study population

The study population was derived from anonymised primary care electronic health records from the Clinical Practice Research Datalink (CPRD) Aurum database [15], which is linked to data from the Office for National Statistics (ONS) mortality records, National Cancer Registration Analysis Service (NCRAS), and Hospital Episode Statistics (HES). Further linked data were obtained from CPRD for ethnicity [16] and Index of Multiple Deprivation. CPRD Aurum comprises routinely collected health data from general practices across England using the Egton Medical Information Systems (EMIS) web-based clinical system. In the UK, registration with a general practice is a prerequisite for accessing NHS care, and nearly the entire population is registered with a general practice. The CPRD database is considered broadly representative of the UK population. At the time of data extraction, CPRD Aurum included records for ~50 million patients, with ~25% of the UK population and ~20% of general practices currently contributing data.

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2.2. Eligibility and exclusion criteria

Eligible participants were men diagnosed with an ID between January 1, 2000 and December 31, 2018. The date of diagnosis was used as the index date for matching. ID was identified using Read, Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT), and EMIS codes derived from previous studies and manual searches of the CPRD data dictionary [17–25]. Codes were included both for specific diagnostic terms and for conditions associated with ID to account for ID under-recording in primary care. To reflect the use of terms in UK legislation and NHS guidance, "learning difficulty" was treated as synonymous with ID [26]. The complete code set was reviewed and verified by two clinicians (O.J.K. and U.C.) according to previously established methods (Supplementary material) [27].

For each individual with an ID, up to 20 matched comparators were identified using incidence density sampling, with matching by the index date, sex, and age (±2 yr). Comparators had no ID diagnosis recorded before the index date, and entered follow-up on the same date as the corresponding individual with an ID. Only individuals eligible for linkage to the NCRAS, ONS, and HES data sets were included. Follow-up commenced at the later of the index date or the individual's 40th birthday, given the low risk of PC before the age of 40 yr. Exclusion criteria were a cancer diagnosis recorded before the start of follow-up and continuous registration with a general practice of <6 mo before the index date. Follow-up ended on December 31, 2018, the latest date for which linked data were available. Cohort entry is illustrated in Fig. 1 using a standardised graphical framework [28].

2.3. Outcomes and statistical analysis

Diagnostic and prediagnostic outcomes included symptoms suggestive of PC [29] and PSA testing; Supplementary Tables 2 and 3 provide the relevant code lists. For these analyses, follow-up for each comparator was limited to the end of follow-up for the matched individual with an ID to ensure comparable observation periods. Outcomes also included PSA testing within 90 d of each new symptomatic presentation for cases in which no PSA test had been recorded in the preceding 12 mo. For the first PSA result above the relevant age-specific threshold [29], outcomes included urgent suspected PC referral within 28 d, prostate biopsy within 56 d, and PC diagnosis within 56 d. PC diagnosis within 6 mo was also included, given the lack of recommended timeframe throughout the whole study period.

Outcomes for patients diagnosed with PC included Gleason score completeness, clinically significant disease (Gleason score ≥7), and PC-specific mortality and survival. PC-specific mortality and survival were based on the ONS-derived data for the underlying cause of death, determined from death certificate information using prespecified rules to identify the condition initiating the sequence of events leading directly to death [30]. Radical treatment (surgery or radiotherapy) within 6 mo was included for clinically significant nonmetastatic disease from 2009 onwards, which reflects the availability of radiotherapy data. Diagnoses were ascertained from NCRAS tumour registry records. A sensitivity analysis was performed for Gleason score completeness after 2010 [31] following changes to national reporting guidelines after that date.

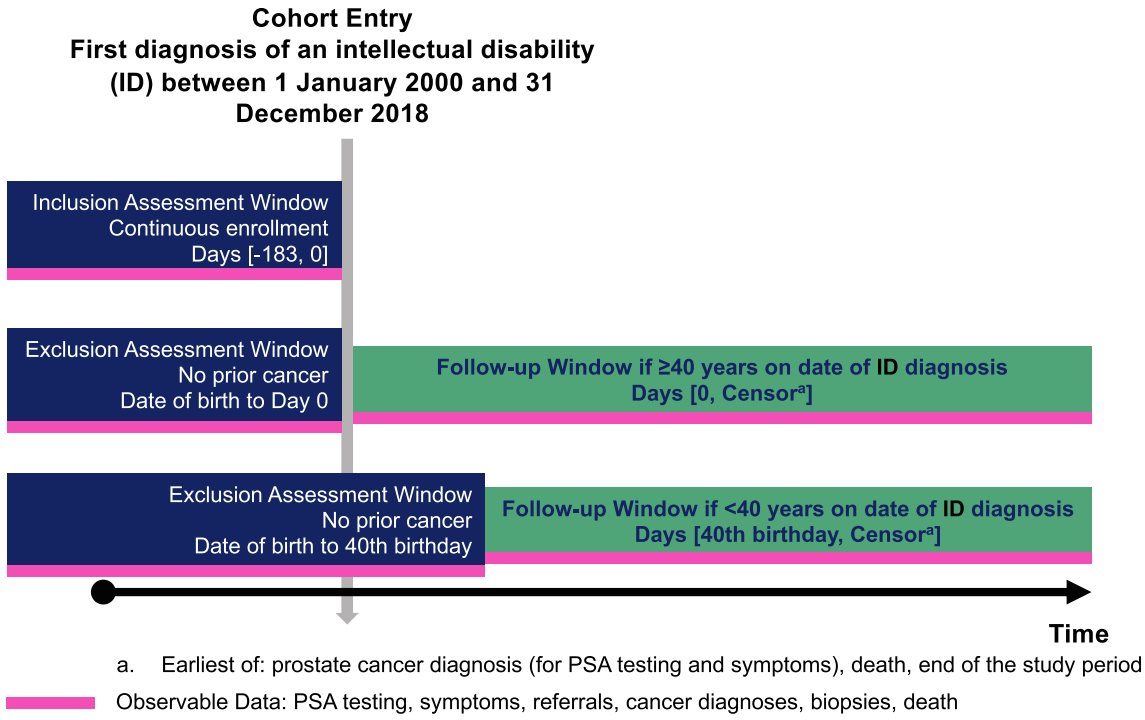

Fig. 1 – Cohort selection and availability of data for assessment of inclusion criteria, exclusion criteria, and outcomes. PSA = prostate-specific antigen.

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Crude proportions were calculated for each outcome by ID status. Poisson regression with an offset for follow-up time was used to estimate incidence rate ratios (IRRs), and modified Poisson regression with inverse probability-of-censoring weights was used to estimate risk ratios (RRs). Cox proportional-hazards regression was applied to estimate hazard ratios (HRs) for PC-specific mortality. All regression models (Poisson, modified Poisson, and Cox) were adjusted for age, ethnicity, and deprivation, and 95% confidence intervals (CIs) were calculated. Analyses of events from baseline (eg, symptom and PSA testing rates) used matched-set fixed effects with robust standard errors clustered by matched set and patient. Analyses of outcomes occurring after baseline (eg, PC-specific survival; outcomes following elevated PSA) used unmatched, event-anchored models to mitigate collider bias. PC-specific survival was also estimated using the Kaplan-Meier method. Subgroup analyses were performed by ID severity (mild, moderate, and severe; Supplementary Table 1) for subgroups not precluded by reporting restrictions for cells with a count <5. Analyses were conducted in R version 4.0.0 (R Foundation for Statistical Computing, Vienna, Austria). The study adhered to the recommendations of the REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) statement [32].

3. Results

The study population comprised 29 554 men with an ID, and 518 739 men without an ID in the control group. Counts of individual diagnostic codes for ID are shown in Supplementary Table 4; the code most frequently recorded was "On learning disability register" (n = 17 864, 60.4%). Median age at the start of follow-up was 52.0 yr (interquartile range 18.2 yr). Men with an ID were more likely to live in an area of higher deprivation (Table 1), and a greater proportion of this group were of White ethnicity (91.0% vs 85.9%), while the proportions of men of Asian (3.2% vs 5.1%) and unknown ethnicity (2.1% vs 4.8%) were lower than in the control group. The proportions of men of Black ethnicity, who are at higher risk of PC, were similar in the ID and control groups (3.0% vs 3.2%). Median follow-up was 5.4 yr overall, and was shorter in the ID group than in the control group (4.5 vs 5.5 yr) owing to higher all-cause mortality for the ID cohort.

A greater proportion of men with an ID experienced at least one symptom suggestive of PC in comparison to the control group (20.6% vs 13.1%; Table 2), while similar proportions had at least one PSA test (22.0% vs 19.2%). After accounting for follow-up duration and the possibility of multiple events per individual, ID was associated with a higher incidence rate of symptoms (IRR 1.35, 95% CI 1.28–1.43) and a similar incidence rate of PSA testing (IRR 0.99, 95% CI 0.95–1.02). PSA testing within 90 d of a new symptom suggestive of PC was markedly less frequent in the ID group (15.8% vs 25.5%; RR 0.66, 95% CI 0.63–0.70).

A total of 879 men with an ID and 19 128 men without an ID had at least one elevated PSA result recorded during follow-up. Referral within 28 d was less frequent for men with an ID (18.2% vs 21.6%; RR 0.83, 95% CI 0.72–0.96), as was biopsy within 56 d (5.5% vs 9.3%; RR 0.54, 95% CI 0.41–0.71). Similarly, the proportions of men diagnosed with PC were lower in the ID group both within 56 d (7.7% vs 15.1%; RR 0.51, 95% CI 0.41–0.65) and within 6 mo (11.6% vs 22.1%; RR 0.53, 95% CI 0.44–0.64) of the first elevated PSA.

A total of 241 men with an ID and 8929 without an ID were diagnosed with PC during follow-up. Recording of a PC diagnosis on the same date as death was significantly more common in the ID group (RR 5.96, 95% CI 2.70–

Table 1 – Baseline characteristics of the study population

Parameter	Intellectual disability status				
	No ID	Any ID	Mild ID	Moderate ID	Severe ID
Patients (N)	518 739	29 554	4267	4473	2891
Age, n (%)					
40–50 yr	227 154 (43.8)	13 840 (46.8)	2304 (54.0)	2465 (55.1)	1597 (55.2)
50–60 yr	139 203 (26.8)	7525 (25.5)	1182 (27.7)	1116 (24.9)	755 (26.1)
60–70 yr	86 042 (16.6)	4599 (15.6)	574 (13.5)	620 (13.9)	377 (13.0)
>70 yr	66 340 (12.8)	3590 (12.1)	207 (4.9)	272 (6.1)	162 (5.6)
Ethnicity, n (%)y					
White	445 697 (85.9)	26 885 (91.0)	3951 (92.6)	4137 (92.5)	2672 (92.4)
Asian	26 711 (5.1)	954 (3.2)	136 (3.2)	149 (3.3)	93 (3.2)
Black	16 490 (3.2)	877 (3.0)	152 (3.6)	146 (3.3)	95 (3.3)
Mixed/multiple	3757 (0.7)	186 (0.6)	– [a]	– [a]	– [a]
Other	1440 (0.3)	26 (0.1)	28 (0.7)	41 (0.9)	31 (1.1)
Unknown	24 644 (4.8)	626 (2.1)	– [b]	– [b]	– [b]
IMD quintile, n (%)					
1 (least deprived)	97 162 (18.7)	3737 (12.6)	459 (10.8)	536 (12.0)	443 (15.3)
2	101 308 (19.5)	5219 (17.7)	665 (15.6)	840 (18.8)	616 (21.3)
3	104 088 (20.1)	6043 (20.4)	825 (19.3)	1,008 (22.5)	635 (22.0)
4	106 408 (20.5)	6809 (23)	1054 (24.7)	934 (20.9)	587 (20.3)
5 (most deprived)	109 076 (21)	7712 (26.1)	1264 (29.6)	1155 (25.8)	610 (21.1)
Unknown	697 (0.1)	34 (0.1)	– [b]	– [b]	– [b]

ID = intellectual disability; IMD = Index of Multiple Deprivation.
[a] Owing to reporting restrictions for cell counts <5, this value was included in the "Other" category.
[b] Owing to reporting restrictions for cell counts <5, imputed values were used.

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Table 2 – Differences in PC presentation, investigation, treatment, and outcomes between groups with and without an ID

Parameter	Patients, *n*/*N* (%)		Effect estimate
	No ID	ID	(95% CI)
Symptoms potentially indicative of PC	67 749/518 739 (13.1)	6093/29 554 (20.6)	1.35 (1.28–1.43) [a]
PSA testing	99 736/518 739 (19.2)	6516/29 554 (22.0)	0.99 (0.96–1.02) [a]
PSA testing within 90 d of symptoms	34 203/133 966 (25.5)	1522/9661 (15.8)	0.66 (0.63–0.70) [b]
Referral within 28 d of first elevated PSA	4138/19 128 (21.6)	160/879 (18.2)	0.83 (0.72–0.96) [b]
Biopsy within 56 d of first elevated PSA	1778/19 128 (9.3)	48/879 (5.5)	0.54 (0.41–0.71) [b]
Diagnosis within 56 d of first elevated PSA	2881/19 128 (15.1)	68/879 (7.7)	0.51 (0.41–0.65) [b]
Missing Gleason score after diagnosis	1607/8929 (18)	77/241 (32)	1.61 (1.27–2.01) [b]
Clinically significant PC (Gleason ≥7)	5462/7322 (74.6)	117/164 (71.3)	0.96 (0.80–1.15) [b]
Surgery or RT within 6 mo of nmPC diagnosis	2248/3561 (63.1)	35/75 (46.7)	0.73 (0.51–1.00) [b]
De novo mPC	475/5395 (8.8)	21/139 (15.1)	1.79 (1.15–2.77) [b]
PC-specific mortality	1378/8929 (15)	62/241 (26)	2.11 (1.64–2.73) [c]

ID = intellectual disability; PC = prostate cancer; PSA = prostate-specific antigen; RT = radiotherapy; nmPC = nonmetastatic PC; mPC = metastatic PC.
[a] Incidence rate ratio estimate.
[b] Risk ratio estimate.
[c] Hazard ratio estimate.

11.77). In these instances, PC was almost always recorded as the underlying cause of death (nine of nine , 100% in the ID group, and 42/44, 95% in the control group). Men with an ID were more likely to have missing Gleason scores (32.0% vs 18.0%; RR 1.61, 95% CI 1.27–2.01) and de novo metastatic disease (15.1% vs 8.8%; RR 1.79, 95% CI 1.15–2.77). Among men with a Gleason score recorded, 71.3% of those with an ID and 74.6% of those without an ID had clinically significant (Gleason score ≥7) PC (RR 0.96, 95% CI 0.80–1.15). Among men with Gleason score ≥7 and nonmetastatic PC, fewer men with an ID received radical treatment within 6 mo (46.7% vs. 63.1%), although the difference was only of borderline significance (RR 0.73, 95% CI 0.51–1.00). Following diagnosis, PC-specific mortality was markedly worse in the ID group, in both absolute (26.0% vs 15.0% died during follow-up) and relative (HR 2.11, 95% CI 1.64–2.73) terms. Fig. 2 shows PC-specific survival curves for the two groups.

Among men for whom ID severity was recorded, 4267 (36.7%) had a mild ID, 4473 (38.4%) a moderate ID, and 2891 (24.9%) a severe ID (Table 1). Men with an ID of any severity were more likely to present with symptoms suggestive of PC (Table 3). PSA testing rates were similar across groups, except in the severe ID group, who were less likely to be tested (IRR 0.82, 95% CI 0.74–0.90). Follow-up investigations were less frequent across all ID severity groups, with the lowest rates in the severe ID group for PSA testing within 90 d of symptom presentation (RR 0.42, 95% CI 0.34–0.52) and for biopsy (RR 0.13, 95% CI 0.02–0.91) and PC diagnosis (RR 0.09, 95% CI 0.01–0.66) following first elevated PSA. Men with a severe ID were also the most likely to have de novo metastatic PC (RR 13.03, 95% CI 1.29–131.46). PC-specific survival declined progressively with increasing ID severity, with HRs for PC mortality of 2.79 (95% CI 1.01–7.73) for mild ID, 3.19 (95% CI 1.56–6.55) for moderate ID, and 5.10 (95% CI 1.19–21.74) for severe ID.

4. Discussion

In this large population-based matched cohort study involving >540 000 men, we examined the impact of ID on various aspects of the PC care pathway. Men with an ID experienced a higher burden of symptoms potentially indicative of PC and were less likely to receive a PSA test in a timely manner after presentation with symptoms. On detection of elevated PSA, men with an ID were referred for investigations less often, underwent fewer biopsies, and were diagnosed with PC at a rate approximately half that for the control group. Among men diagnosed with PC, ID was associated with twofold higher risk of death from PC, almost sixfold higher risk of diagnosis being first recorded at death, a higher likelihood of missing Gleason scores, and higher risk of de novo metastatic PC. Among men with Gleason scores, the rate of radical treatment for clinically significant nonmetastatic PC was lower in the ID group, although the difference was only of borderline statistical significance.

This is the first study to identify specific points along the PC diagnostic and treatment pathway that may contribute to poorer outcomes for patients with an ID. The first major disparity identified was a lower rate of PSA testing to investigate symptoms potentially indicative of PC. This may reflect a higher baseline prevalence of such symptoms in the ID population, misattribution of symptoms to non–PC-related causes, or failure to appropriately reassess persistent or recurring symptoms. Our results indicate that a lower testing rate may have led to detection of fewer cases of aggressive PC, as indicated by the higher frequency of de novo metastatic presentation, as well as diagnosis on the date of death in cases for which PC was also recorded as the cause of death. Further investigation is needed to clarify the reasons for lower PSA testing and to inform targeted strategies that promote its equitable use in primary care.

Another key divergence occurred after detection of elevated PSA. Men with an ID were less likely to be referred for urgent suspected PC investigations. Prostate biopsies were performed less frequently in the ID group, which may contribute to a lower rate of PC diagnosis and a higher proportion of missing Gleason scores. Plausible explanations for these observations include elevated PSA being attributed to benign causes and concerns about obtaining informed consent for biopsy. Clinicians may be less likely to pursue a diagnosis if they consider a patient unfit for treatment. However, radical radiotherapy is generally well tolerated, even among individuals with significant comorbidities. In addition, newer techniques such as stereotactic ablative radiotherapy can deliver curative treatment in five

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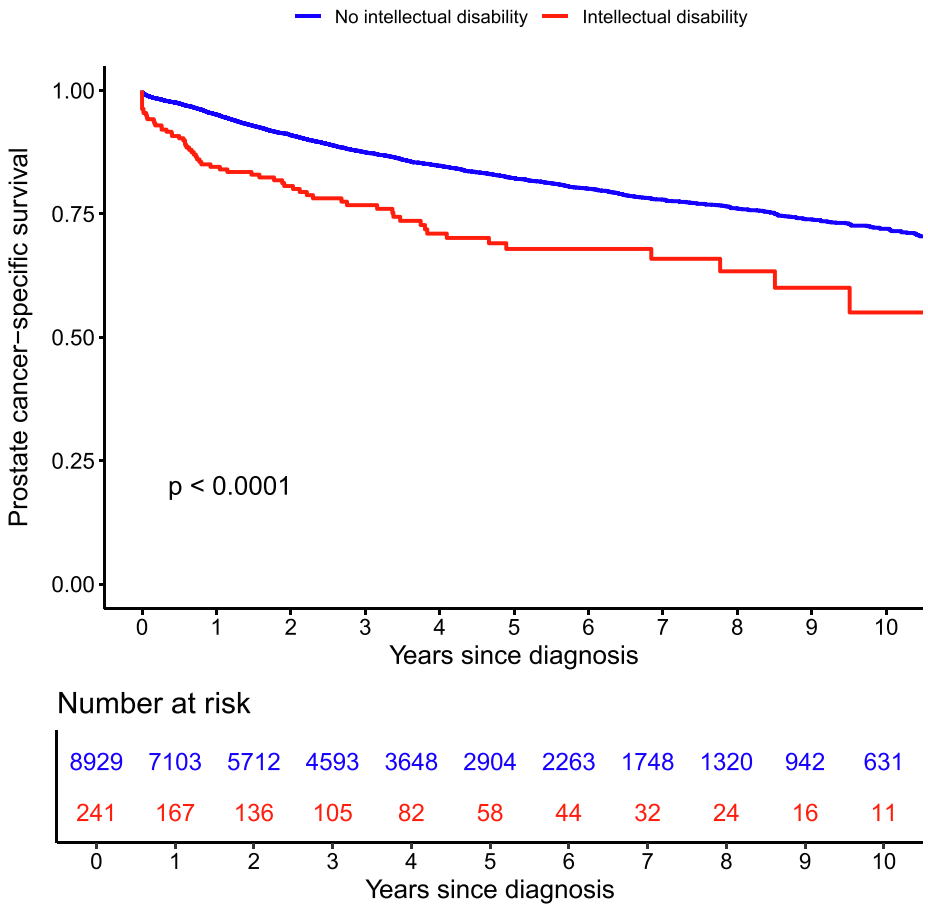

Fig. 2 – Prostate cancer–specific survival following diagnosis for men with or without an intellectual disability.

sessions rather than the 20 fractions typically required with conventional radical radiotherapy.

The lack of histological confirmation from less frequent biopsies has important clinical implications, particularly for treatment planning. In early-stage PC, management is guided by risk stratification, which depends on Gleason score, PSA level, and clinical stage. Low-risk disease may be safely monitored, while treatment is recommended for intermediate- or high-risk disease to reduce the risk of distant metastases [33]. When metastases are present at diagnosis or develop later, access to the most effective and well-tolerated treatments, such as androgen receptor pathway inhibitors, often requires histological confirmation (or a very high PSA level). Without a biopsy-confirmed PC diagnosis, men with an ID may face barriers not only to timely diagnosis but also to appropriate treatment access in both early and advanced disease stages. Together, these factors may contribute to the substantially shorter PC-specific survival observed in this study.

Our results also show that adverse PC outcomes among men with an ID were evident across all ID severity levels, which indicates that the findings were not driven solely by the most severe cases. However, there was evidence that outcomes worsened with increasing ID severity. The group with a severe ID had the lowest rates of follow-up investigations after symptom onset, were more likely to present with metastatic PC, and had fivefold higher risk of PC-specific death. These findings suggest that while disparities in PC investigation and management may affect all men with an ID, those with a more severe ID may experience the greatest barriers to timely diagnosis and optimal care.

A limited number of previous studies have examined PC care for men with an ID. A Scottish record-linkage study showed that the PC incidence was lower for men with an ID (standardised incidence ratio 0.37) [14]. By contrast, a population-based cohort study in Sweden found similar PC rates for groups with and without an ID, although the study included mostly younger men, among whom overall PC incidence was low [34]. A 2012 UK primary care cohort study by Osborn et al [35] revealed that men with an ID were 13% less likely to undergo PSA testing than age-matched control subjects. A Netherlands study found no significant differences in PC-specific mortality [36].

Several limitations of our study should be acknowledged. Relatively few patients in the cohort were aged >70 yr, the age group most commonly diagnosed with PC. Although matching and adjustment for age help to mitigate confounding, residual confounding may still have influenced the results. The analyses by ID severity were limited by underuse of codes specifying severity, which resulted in small subgroup sizes. While the study identified specific gaps in care, such as lower rates of prostate biopsy, it lacked

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Table 3 – Differences in PC presentation, investigation, treatment, and outcomes between groups with and without a mild, moderate, or severe ID

Parameter	Patients, *n*/*N* (%)		Effect estimate
	Without ID of the severity indicated	With ID of the severity indicated	(95% CI)
Symptoms potentially indicative of PC			
Mild ID	10 311/74 717 (13.8)	1072/4267 (25.1)	1.42 (1.27–1.59) [a]
Moderate ID	11 246/77 299 (14.5)	1162/4473 (26)	1.40 (1.27–1.55) [a]
Severe ID	7243/50 113 (14.5)	660/2891 (22.8)	1.32 (1.07–1.63) [a]
PSA testing			
Mild ID	14 248/74 717 (19.1)	929/4267 (21.8)	0.99 (0.91–1.08) [a]
Moderate ID	15 853/77 299 (20.5)	1137/4473 (25.4)	1.03 (0.95–1.11) [a]
Severe ID	10 071/50 113 (20.1)	577/2891 (20)	0.82 (0.74–0.90) [a]
PSA testing within 90 d of symptoms			
Mild ID	4626/17 755 (26.1)	242/1731 (14)	0.60 (0.53–0.69) [b]
Moderate ID	5049/19 595 (25.8)	264/1851 (14.3)	0.60 (0.53–0.68) [b]
Severe ID	3463/13 922 (24.9)	111/1124 (9.9)	0.42 (0.34–0.52) [b]
Referral within 28 d of first elevated PSA			
Mild ID	532/2219 (24)	21/111 (18.9)	0.78 (0.53–1.15) [b]
Moderate ID	575/2491 (23.1)	17/125 (13.6)	0.59 (0.38–0.93) [b]
Severe ID	350/1696 (20.6)	9/75 (12)	0.59 (0.31–1.11) [b]
Biopsy within 56 d of first elevated PSA			
Mild ID	201/2219 (9.1)	5/111 (4.5)	0.45 (0.19–1.09) [b]
Moderate ID	210/2491 (8.4)	6/125 (4.8)	0.50 (0.23–1.10) [b]
Severe ID	154/1696 (9.1)	1/75 (1.3)	0.13 (0.02–0.91) [b]
Diagnosis within 56 d of first elevated PSA			
Mild ID	307/2219 (13.8)	5/111 (4.5)	0.35 (0.15–0.82) [b]
Moderate ID	371/2491 (14.9)	4/125 (3.2)	0.23 (0.09–0.61) [b]
Severe ID	1 696/248 (14.6)	1/75 (1.3)	0.09 (0.01–0.66) [b]
PC-specific mortality			
Mild ID	97/953 (10)	<5/22	2.79 (1.01–7.73) [c]
Moderate ID	146/1095 146 (13)	8/24 (33)	3.19 (1.56–6.55) [c]
Severe ID	95/770 (12)	<5/5	5.10 (1.19–21.74) [c]

ID = intellectual disability; PC = prostate cancer; PSA = prostate-specific antigen; RT = radiotherapy; nmPC = nonmetastatic PC; mPC = metastatic PC.
[a] Incidence rate ratio estimate.
[b] Risk ratio estimate.
[c] Hazard ratio estimate.

the detailed clinical information needed to explore the underlying reasons for these disparities. In particular, the absence of paired clinical data prevented assessment of whether patients appropriately received PSA testing or follow-up investigations according to the wider clinical context. Rates of missing Gleason scores may have been influenced by gaps in reporting practices rather than biopsies not being performed, although it would be expected that reporting practices should not differ with respect to ID [31]. Treatment for advanced-stage disease was also not examined because of limitations in the data available. Inaccuracies in cause-of-death recording on death certificates, particularly if they differed between men with and without an ID, could have led to ascertainment bias and misestimation of the association with PC-specific mortality. Despite these limitations, our study represents the most comprehensive analysis to date of the PC care pathway for men with an ID.

5. Conclusions

In conclusion, this large, population-based study highlights substantial inequities in the PC care pathway for men with an ID. Men with an ID were significantly less likely to receive timely investigations following symptom presentation, less likely to undergo prostate biopsy after an elevated PSA result, and more likely to be diagnosed with PC at death or without key diagnostic information such as Gleason score. Targeted efforts to understand and address these gaps in PC care are urgently needed to improve outcomes in this underserved population.

Author contributions: Oliver John Kennedy had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Kennedy, Chauhan, Gorman, Lorigan, Merriel, Van Staa, Wright, Ashcroft.
Acquisition of data: Wright, Kennedy.
Analysis and interpretation of data: Kennedy.
Drafting of the manuscript: Kennedy.
Critical revision of the manuscript for important intellectual content: Kennedy, Chauhan, Gorman, Lorigan, Merriel, Van Staa, Wright, Ashcroft.
Statistical analysis: Kennedy, Ashcroft.
Obtaining funding: Ashcroft.
Administrative, technical, or material support: Ashcroft.
Supervision: Lorigan, Ashcroft.
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Ethics statement: This study was approved by the Clinical Practice Research Datalink (CPRD) independent scientific advisory committee (23_003009). CPRD also has ethical approval from the Health Research Authority to support research using anonymised patient data (research ethics committee reference 21/EM/0265). Individual patient consent was not required, as all data were deidentified.

***Data sharing statement*:** Electronic health records are, by definition, considered sensitive data in the UK under the Data Protection Act and cannot be shared via public deposition because of information governance restrictions to protect patient confidentiality. Access to Clinical Practice Research Datalink (CPRD) data is subject to protocol approval via the CPRD research data governance process. For more information see https://cprd.com/data-access. Linked secondary care data from Hospital Episodes Statistics, mortality data from the Office for National Statistics, cancer data from the National Cancer Registration and Analysis Service, and Index of Multiple Deprivation data can also be requested from CPRD.

Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.euo.2026.01.004.

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