Vulval squamous cell carcinoma is an under-reported cancer associated with poor outcomes: a national retrospective cohort study of the incidence and trends in England, 2013–2022

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Dear Editor, Vulval squamous cell carcinoma (VSCC) accounts for ~90% of vulval cancers in England.[1] Diagnosis is often delayed due to nonspecific presentations, limited screening, poor awareness and reluctance to undergo intimate examinations.[1] Other than sentinel lymph node biopsies, management advances have been scarce. This national retrospective cohort study describes epidemiological trends, diagnostic stage, referral routes, treatment and survival in England (2013–2022) among self-identifying women.

National data were extracted from the National Disease Registration Service 'Get Data Out – Skin' dataset. Crude incidence rates (CIRs) and European age-standardized rates (EASRs) were reported per 100 000 person years (PY), standardized to the European Standard Population 2013. Temporal trends were assessed using Surveillance, Epidemiology, and End Results (SEER) Joinpoint regression analysis [v5.2.0© (National Cancer Institute, USA, 2024)] and annual percentage change (APC). Incidence rate ratios (IRRs) with Poisson regression analysis evaluated the impact of the COVID-19 pandemic (2020–2022) compared with pre-pandemic rates (2019). Data were stratified by ethnicity, stage at diagnosis, deprivation quintile, referral route and treatment. CIRs by ethnicity were calculated using data from the Office for National Statistics 2013–2022, and deprivation quintiles from English Indices of Multiple Deprivation (IMD) 2019. Five-year net survival was reported for 2014–2016 diagnoses.

Between 2013 and 2022, 8930 VSCC cases were registered [mean (SD)/year 893 (63.36)], CIR 3.15 PY [95% confidence interval (CI) 3.09–3.22]. APC was 1.07% (95% CI −0.37 to 2.57; $P = 0.142$) for CIR, and 0.34% (95% CI −1.02 to 1.72; $P = 0.612$) for EASR. VSCCs were diagnosed at the following stages: 58.6% at stage 1–2, 22.1% at stage 3–4, and 19.3% at unknown stage. Age-specific incidence increased with age, peaking at 80–90 years. There was no age-specific temporal change (Table 1).

Compared with pre-pandemic rates (2019), a nonsignificant fall occurred in 2020 [IRR 0.92 (95% CI 0.83–1.01); $P = 0.067$], followed by a significant rebound in 2021 [IRR 1.13 (95% CI 1.03–1.23); $P = 0.009$].

VSCC was the most common cutaneous SCC (cSCC) location among the Black ethnic group, accounting for 25.27% (115 of 455) of cSCCs, compared with 2.84% (8273 of 291 105) in the White ethnic group. Yet, White women accounted for 92.24% of VSCC cases (8237 of 8930), whereas Black women accounted for 1.29% (115 of 8930).

Diagnoses were made through an urgent suspected cancer referral in 48.0% of stage 1–2 cases and 55.1% of stage 3–4 cases. There were 487 VSCCs (of 6939; 7.02%) diagnosed through emergency presentation, compared with 6086 nongenital cSCCs (of 329 474; 1.85%) – a significant difference of 5.17% (95% CI 4.59–5.80%; $P < 0.0001$). There were 182 stage 3–4 VSCC diagnoses (of 1544; 11.79%) made through emergency presentation from 2013 to 2020, with 34 (of 211; 16.11%) in 2020.

Incidence was higher in the most deprived quintile [CIR = 3.67 (95% CI 3.51–3.83)] than in the least deprived quintile [CIR = 2.72 (95% 2.59–2.86)].

Excision surgery was the primary treatment in 59.26% of cases, and 77.21% of stage 1–2 lesions. Diagnostic biopsies were excluded from these counts, even if the lesion was fully excised. Stage 3–4 VSCC was often managed with multimodal treatment: surgery with radiotherapy was most common (26.86%); followed by surgery, radiotherapy and chemotherapy (19.31%); surgery only (18.52%); chemotherapy with radiotherapy (12.39%); and radiotherapy alone (11.71%).

Five-year net survival (adjusted for background mortality) for stage 1–2 VSCC was 78.2% (95% CI 74.9–81.4) and 33.1% (95% CI 28.5–37.8) for stage 3–4.

Globally, this is the first and largest national dataset, establishing the incidence and survival of VSCC cases in England. A nonsignificant upward incidence trend reflects the ageing population in which chronic inflammatory conditions such as lichen sclerosus are common, with a high prevalence of high-risk human papillomavirus (HPV) genotypes, and incidental detection through cervical screening. A nonsignificant downward trend in incidence was observed during the first year of the COVID-19 pandemic, when dermatology outpatient appointments fell to 58% of pre-lockdown values,[2] with a rebound the following year.

Table 1 Incidence, survival, ethnicity, route to diagnosis, deprivation quintile and treatment trends of all stages of vulval squamous cell carcinoma (VSCC)

Variable	Output	Variable	Output
CIR	*PY (95% CI)*	*EASR*	*PY (95% CI)*
2013–2022	3.15 (3.09–3.22)	2013–2022	3.18 (3.11–3.25)
2013	3.02 (2.82–3.24)	2013	3.13 (2.92–3.35)
2014	3.07 (2.86–3.28)	2014	3.13 (2.92–3.35)
2015	3.16 (2.96–3.38)	2015	3.22 (3.01–3.44)
2016	2.99 (2.79–3.20)	2016	3.04 (2.83–3.25)
2017	3.06 (2.86–3.27)	2017	3.09 (2.89–3.31)
2018	3.34 (3.13–3.56)	2018	3.36 (3.15–3.58)
2019	3.14 (2.94–3.35)	2019	3.16 (2.95–3.37)
2020	2.87 (2.68–3.07)	2020	2.85 (2.66–3.05)
2021	3.54 (3.23–3.76)	2021	3.48 (3.27–3.70)
2022	3.33 (3.12–3.55)	2022	3.17 (2.97–3.38)
APC (95% CI; *P*-value)	1.07% (–0.37 to 2.57; 0.142)	APC (95% CI; *P*-value)	0.34% (–1.02 to 1.72; 0.612)
Age-specific incidence rate of VSCC by 5-year age band, PY (95% CI)			
Age group (years)	2013–2015	2016–2018	2019–2021
0–19	0	0	0
20–24	0.02 (–0.01–0.05)	0.04 (–0.01–0.09)	0
25–29	0.27 (0.13–0.40)	0.14 (0.04–0.23)	0.12 (0.03–0.21)
30–34	0.32 (0.17–0.46)	0.45 (0.27–0.62)	0.61 (0.41–0.81)
35–39	0.63 (0.42–0.85)	0.68 (0.46–0.89)	1.18 (0.90–1.46)
40–44	1.64 (1.31–1.98)	1.62 (1.28–1.97)	1.73 (1.38–2.08)
45–49	2.68 (2.26–3.09)	2.35 (1.96–2.74)	2.20 (1.81–2.59)
50–54	3.33 (2.85–3.81)	3.61 (3.13–4.09)	3.54 (3.06–4.01)
55–59	4.57 (3.96–5.17)	4.05 (3.51–4.60)	4.16 (3.63–4.69)
60–64	4.90 (4.25–5.55)	5.36 (4.69–6.03)	5.35 (4.70–6.00)
65–69	5.91 (5.21–6.62)	6.10 (5.38–6.83)	6.05 (5.32–6.79)
70–74	8.04 (7.10–8.99)	8.03 (7.15–8.91)	8.91 (8.03–9.80)
75–79	10.65 (9.46–11.84)	10.34 (9.18–11.51)	10.80 (9.66–11.93)
80–84	15.42 (13.80–17.05)	15.03 (13.45–16.61)	12.68 (11.26–14.11)
85–89	15.42 (13.43–17.41)	17.23 (15.16–19.30)	17.15 (15.10–19.20)
90+	18.31 (15.65–20.98)	17.51 (14.93–20.09)	13.61 (11.36–15.87)
Survival	Net (95% CI)	Survival	K–M (95% CI)
1 year	83.9% (82.3–85.5)	1 year	81.3% (79.8–82.8)
3 years	70.5% (68.4–72.7)	3 years	64.8% (62.8–66.6)
5 years	64.3% (61.7–66.9)	5 years	56.5% (54.6–58.5)
Ethnicity	*n* (%)	Route to diagnosis	*n* (%) (2013–2020)
White	8237 (92.24)	Urgent suspected cancer	3260 (46.98)
Asian	166 (1.86)	GP referral	2318 (33.41)
Black	115 (1.29)	Other outpatient	707 (10.19)
Mixed	36 (0.40)	Emergency presentation	487 (7.02)
Other	67 (0.75)	Inpatient elective	30 (0.43)
Unknown	309 (3.46)	Unknown or route not classified	137 (1.97)
Deprivation quintile	CIR PY (95% CI)	Treatment	*n* (%) (2013–2021)
1, most deprived	3.67 (3.51–3.83)	Surgery only	4708 (59.26)
		Surgery and RT	1001 (12.60)
2	3.34 (3.10–3.39)	Surgery, RT and CT	555 (6.99)
3	3.11 (2.97–3.26)	CT and RT	478 (6.02)
		RT only	440 (5.54)
4	3.03 (2.88–3.17)	Surgery and CT	67 (0.84)
		CT only	33 (0.42)
5, least deprived	2.72 (2.59–2.86)	Other	663 (8.34)

APC, annual percentage change; CI, confidence interval; CIR, crude incidence rate (per PY); CT, chemotherapy; EASR, European age-standardized rate (per PY); GP, general practitioner; K–M, Kaplan–Meier; PY, 100 000 person years; RT, radiotherapy.

Higher VSCC rates in deprived populations aligned with other HPV-related malignancies, reflecting higher prevalences of smoking and obesity, lower HPV vaccination uptake, and poorer healthcare access.[3,4] The latter may contribute to delayed lichen sclerosus diagnosis and management. Incomplete data collection, particularly regarding surgical procedure codes, may account for lower-than-expected surgical excision proportions.

High rates of emergency presentation of late-stage VSCC with distant metastasis, are linked with poor prognoses. Emergency presentations of cancer are associated with a greater risk of 12-month mortality, compared with other referral routes.[5]

The Netherlands Cancer Registry reported an increasing VSCC APC, of 5.0% (95% CI 2.7–7.7)[6] from 2002 to 2010, while Italian registries reported a decreasing APC of –0.1% (95% CI −1.4 to −0.5)[7] from 1990 to 2015.

HPV vaccination has reduced genital warts, and cervical and anal precancer rates,[8] but has not yet impacted VSCC incidence. Although artificial intelligence and virtual consultations show promise in skin cancer triage, they present challenges in VSCC. Promoting awareness and early detection of vulval changes mitigate physical and psychosexual sequelae of late-stage management of this under-reported cancer.

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Data availability: The data of UK incidence rate, survival and route of administration are openly available at: https://nhsd-ndrs.shinyapps.io/get_data_out.

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Patient consent: Not applicable.

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Co-primary endpoints PASI 90 and IGA 0/1 at Week 16 were met.**Secondary endpoints. †N= mNRI, missing data were imputed with mNRI (patients with missing data following treatment discontinuation due to lack of efficacy or a TRAE were counted as non-responders; multiple imputation methodology was used for other missing data). ‡43.9% (n=189/431), and 43.4% (n=116/267) of biologic-naïve and TNFi-IR PsA patients achieved the primary endpoint of ACR 50 at Week 16 in BE OPTIMAL and BE COMPLETE, respectively (vs 10.0% [n=28/281] and 6.8% [n=9/133] placebo, p<0.0001); 54.5% (n=235/431) and 51.7% (n=138/267) maintained it at Week 52 (NRI).[4–6]

ACR 50, ≥50% response in the American College of Rheumatology criteria; **AS**, ankylosing spondylitis; **CRP**, C-reactive protein; **DMARD**, disease-modifying antirheumatic drug; **HS**, hidradenitis suppurativa; **IGA**, Investigator's Global Assessment; **(m)NRI**, (modified) non-responder imputation; **MRI**, magnetic resonance imaging; **nr-axSpA**, non-radiographic axial spondyloarthritis; **NSAID**, non-steroidal anti-inflammatory drug; **PASI 75/90/100**, ≥75/90/100% improvement from baseline in Psoriasis Area and Severity Index; **PsA**, psoriatic arthritis; **PsD**, psoriatic disease; **PsO**, psoriasis; **TNFi-IR**, tumour necrosis factor-α inhibitor – inadequate responder; **TRAE**, treatment-related adverse event.

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