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# 'Get Data Out' Skin: national cancer registry incidence and survival rates for all registered skin tumour groups for 2013–2019 in England

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## Abstract

**Background** Providing detailed skin cancer statistics, including incidence and survival, by tumour type and patient characteristics is important for up-to-date epidemiological information.

**Objectives** To create a new clinically relevant consensus-based classification for registered skin tumours using tumour type and patient characteristics and to describe its application to all registered tumours in England between 2013 and 2019.

**Methods** Tumours with skin topographical codes (ICD-10) and morphology and behaviour (ICD-O3) were grouped together in an iterative process creating a hierarchical tree structure. The primary-level grouping partitioned skin tumours into skin cancer, melanoma *in situ*, extramammary Paget disease (EMPD) and tumours of uncertain malignant potential. Second-level groups split skin cancer into keratinocyte cancer (KC), melanoma and rare cancers. The third-level group split KC into basal cell carcinoma (BCC) and squamous cell carcinoma (cSCC). Further groups were split into genital or non-genital, first or subsequent tumour, age, gender, stage, or National Health Service (NHS) region. Incidence counts, Kaplan–Meier and net survival estimates and referral routes [two-week wait (TWW), general practitioner (GP), outpatient] categorisations were calculated for each grouping across all years.

**Results** A total of 1 445 377 skin cancers and 49 123 precancerous lesions and undefined entities were registered in England between 2013 and 2019. Skin tumours and skin cancer incidence rates are increasing for most tumour types. The most common type of skin cancer was BCC with an incidence rate of 282.36 per 100 000 person-years (PYs) [$n=158\,934$, 95% confidence interval (CI) 280.98–283.76] in 2019, followed by cSCC with an incidence rate of 85.24 per 100 000 PYs ($n=47\,977$, 95% CI 84.48–86.00) and melanoma with 27.24 ($n=15\,332$, 95% CI 26.81–27.67) per 100 000 PYs. Each year approximately 1800 rare skin cancers, 1500 genital cSCCs and 100 cases of EMPD are registered. Of 15 000 melanoma cases, 120 cases of melanoma occur in individuals aged < 25 years annually. One-year and five-year overall net survival varies by tumour type. cSCC 5-year net survival (89.8%, 95% CI 88.8–90.9) was comparable to the net survival of all melanomas (89.6%, 95% CI 88.7–90.6). BCC had excellent survival (overall net survival > 100%). Patients with late-stage melanoma, Merkel cell carcinoma and genital cSCC have a 5-year net survival < 60%. Older patients received fewer TWW referrals than their younger counterparts with the same tumour type at the same location. Patients with acral lentiginous melanoma had fewer TWW referrals and more standard GP referrals than patients with common melanomas.

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**Conclusions** 'Get Data Out' Skin provides detailed and up-to-date statistics on all registrable skin tumours in England, including for the first time precancerous lesions and rare subtypes of common cancers. These data can be used by clinicians, researchers and commissioners to better understand skin cancer and improve resource allocation.

**What is already known about this topic?**

- Skin cancer is the most common cancer diagnosed annually; however, published national statistics in England are often limited to melanoma and non-melanoma skin cancer (NMSC) with no breakdown by tumour types.

**What does this study add?**

- 'Get Data Out' (GDO) Skin provides new up-to-date statistics on the most recent years of cancer registry data, incidence, survival and referral routes, on groups of similar patients and tumours.
- These data cover all registerable skin tumours in England, are publicly available and will be routinely updated.
- GDO Skin outputs can be used by clinicians, the public, charities, researchers and commissioners to support evidence-based practice, healthcare and research planning.
- The standardised groups of tumours can be analysed to identify trends and improve understanding of skin cancer epidemiology.

Skin cancer is the most common type of cancer diagnosed annually in the UK and worldwide,[1,2] with approximately one in five people currently estimated to experience skin cancer in their lifetime in England.[3] The highest incidence rates are seen in predominantly white populations in locations where ultraviolet (UV) exposure is high, notably Oceania and parts of the USA.[1]

Historically, most national cancer registries have not routinely reported on subsets of rarer skin cancers. Keratinocyte cancers (KCs), the grouped term for basal cell carcinoma (BCC) and cutaneous squamous cell carcinoma (cSCC), have either never been recorded or only registered as one BCC and one cSCC per patient.[4,5]

Additionally, the traditional grouping of skin cancer is International Classification of Disease (ICD v10) C43 (melanoma) and C44 [non-melanoma skin cancer (NMSC)], which excludes skin cancer diagnosed on the cutaneous lip (C00.x) and genitals [male: C60.x (penis)/C63.2 (scrotum); female: C51.x (vulva)]. This definition has historically been used for the publication of national cancer statistics in the UK.[6–9]

Venables *et al.*[10] proposed a new counting method where individual patients can contribute one BCC or cSCC tumour each year (first per patient per annum) to provide a more accurate estimate of annual skin cancer diagnoses. Although this method has been formally approved by the UK and Ireland Association of Cancer Registries, it has not yet been included in routine publications.

The objective of this study was to create a new and clinically relevant consensus-based classification for all registered skin tumours using tumour type and patient characteristics, and to describe its application to cancer registry data for registrable skin tumours diagnosed in England between 2013 and 2019.

These data are openly available and will be routinely updated by the English cancer registry to provide relevant statistics that can be used to better understand the burden of skin cancer, to increase awareness among patients, clinicians, charities and the public, to inform workforce planning and to support research.

## Patients and methods

### Study design and cohort selection

This cancer registry retrospective cohort study used data provided by the National Health Service (NHS) Digital's National Disease Registration Service (NDRS).[11] NDRS cancer registrations are created using NHS data feeds, pathology reports submitted by NHS and private pathology laboratories when a patient receives a histopathological diagnosis of cancer, Patient Administration System, mortality data from the Office for National Statistics (ONS) and the Cancer Outcomes and Services Dataset provided by multidisciplinary team meetings. These registrations can then be linked to other datasets such as Hospital Episode Statistics (HES) and Cancer Waiting Times. Follow-up takes place throughout the rest of the patient's life through data linkage with NHS dataflow. 'Get Data Out' (GDO) is an NDRS programme that produces key statistics, including incidence and survival, for clinically relevant groups of similar patients with cancer in England. A skin tumour partition was created following the GDO framework.

All tumours diagnosed between 2013 and 2019 that were recorded with skin, scrotal, cutaneous lip, vulval and penile cancer ICD-10 codes were included (Appendix S1; see Supporting Information). One national cancer registration service for England was created in 2013, which is a commonly used start date for consistent data quality. Tumours were grouped using International Classification of Diseases for Oncology, 3rd Edition (ICD-O3) morphology and behaviour codes (Appendix S2; see Supporting Information). Malignant (behaviour codes 3, 6 and 9) and non-malignant, *in situ* and uncertain malignant potential (behaviour codes 1 and 2) skin tumours were included in the cohort. Actinic keratoses, Bowen disease/*in situ* cSCC and all benign skin tumours are not registerable tumours in NDRS and were therefore excluded. All ICD-O3 skin groupings were created with input from the GDO working group which included dermatologists, oncologists, pathologists and data analysts.

BCC and cSCC tumours are registered via an autoprocessor. The first BCC or cSCC is fully registered and all subsequent BCCs or cSCCs are linked to the first BCC or cSCC record. BCC and cSCC tumours are categorised as either a 'first ever' or a 'subsequent' tumour, with only one BCC or cSCC tumour counted per year, with a look-back period until 1 January 1995, following methodology previously described by Venables *et al.*[10]

The following covariates were included: diagnosis date, gender, age, body site location of tumour, stage [American Joint Committee on Cancer staging system version 7 (2013–2017 diagnoses) and version 8 (2018–2019 diagnoses)] and NHS region (2019 definitions) (Appendix S3; see Supporting Information). Missing data were designated as unknown, apart from scrotal cSCC which were designated 'stage not applicable' when grouped in the male genital cSCC group because these tumours are staged using a different staging system from that used for penile cSCC and represented a minority of cases. The diagnosis date for tumours with a histopathological diagnosis is derived from the pathology report as the first 'not missing' date when the sample was taken, received or reported. For tumours without histopathology, the diagnosis date was the incidence date reported in the NHS dataflow that informed NDRS of the tumour. Further tumour type classifications were created through a consensus exercise involving the GDO working group using additional tumour subtypes and patient characteristics to create clinically meaningful groups. This created a hierarchical tree structure where tumours with similar characteristics were grouped together (Figure 1).

All skin tumours were initially grouped by diagnosis year. The structure of the tree is the same for each year of data included. The primary-level grouping partitions all skin tumours into four branches: skin cancer, melanoma *in situ*, skin tumours of uncertain malignant potential and extramammary Paget disease (EMPD). Although the World Health Organization defines EMPD as invasive, our working group designated EMPD as precancerous as it usually presents as an intraepithelial tumour without invasive disease.[12]

The second-level grouping split skin cancers into KC, melanoma and rare skin cancers. The third level splits KC tumours into BCC and cSCC, while rare tumours were split into appendageal (adnexal), cutaneous sarcoma, Merkel cell carcinoma, malignant neoplasm of skin not otherwise specified and other rare skin cancers. All splits mentioned above were made using ICD-O3 morphology and behaviour codes.

Melanoma was further classified as genital or non-genital based on ICD-10 codes, as were BCC and cSCC tumours. Further details on the hierarchical tree structure, including how tumours are defined and split, can be found in the grouping document (Appendix S4; see Supporting Information). The label 'common melanoma' is used here to denote common cutaneous melanoma types, such as superficial spreading melanoma, lentigo maligna melanoma, and nodular melanoma (see Appendix S2 for details). Acral lentiginous melanoma is presented separately from 'common melanoma'. Further partitions were on tumour site, age, geography, stage or gender, with final group sizes between 19 and 1607 depending on the tree branch and the diagnosis year.

### *Statistical analysis*

All analyses were performed at tumour level. Patients were able to contribute multiple tumours in multiple tumour type groups. Statistics were calculated for each group along the tree branch. Crude incidence rates were calculated using the incidence count and population estimates derived from the 2019 normalised ONS data, and 95% confidence intervals (CIs) for the incidence estimate, which capture the natural and random imprecision that occurs in the real world, were calculated using Byar's approximation method.[13]

Overall survival was calculated using the Kaplan–Meier method and Pohar-Perme net survival estimates at 3, 6, 9, 12, 24, 36, 48, 60 and 72 months. Kaplan–Meier analyses used the time between diagnosis and last known vital status date as the survival time and estimated variance using Greenwood's formula.[14] The 95% CIs for the survival estimates were obtained using log–log transformation.[15] Net survival was calculated using the cohort approach with the

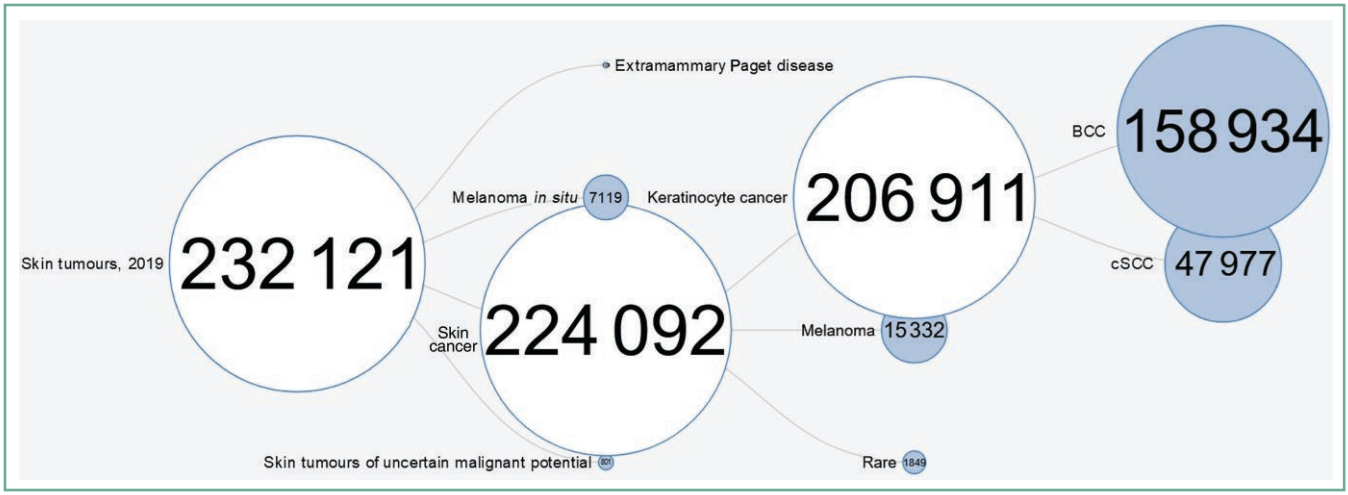


**Figure 1** A visualisation of the hierarchical structure of skin tumour groups partitioned by tumour type (www.cancerdata.nhs.uk/getdataout/skin). BCC, basal cell carcinoma; cSCC, cutaneous squamous cell carcinoma.

Pohar-Perme estimator used to create an estimate which is more robust against informative censoring bias.[16,17] Lifetables to measure background mortality using age (0–99 years), gender, population weighted quintile of the index of multiple deprivation (IMD) and region were created by NDRS. These tables provide the expected estimate of mortality in the general population and of dying from other causes (e.g. heart attack). Comparing the survival of patients with cancer with the expected survival provides the net survival estimate. A survival greater than 100% is possible, as this indicates that survival for patients with cancer is better than the expected survival based on age, sex, IMD and region. All groups were subject to the following data-quality criteria: (i) at least 10 patients must be alive at that particular survival period; (ii) at least two patients need to have died; (iii) the standard error of the survival estimate should be $<20\%$; and (iv) the survival estimate should not increase with duration.[18] In groups where these statistical tests were not met, the estimate was supressed.

Standard NDRS survival methodology aims to calculate survival of the patient after their first diagnosed tumour of a given tumour type. 'Skin cancer' is a broad group containing multiple tumour types, and excluding a patient from melanoma survival analysis because they had a BCC 10 years earlier was deemed inappropriate. Instead, six survival groups were created (BCC, cSCC, melanoma invasive, melanoma *in situ*, rare invasive and EMPD, or rare uncertain malignant potential) to identify and exclude individuals with a previous tumour within that survival group, between 1995 and the diagnosis year of interest (2013–2018), from the survival analysis. For example, this meant that a patient with two melanomas, one in 1999 and one in 2015, was excluded from the 2015 cohort survival calculation. Survival groups were defined using ICD-O3 codes (see Appendix S2 for details). Groups containing subsequent BCC/cSCC tumours had no survival estimated. Groups containing a mix of tumour types, e.g. the 'skin cancer' group, which contained melanoma, BCC, cSCC and rare tumours, also had no survival estimated, as the 'previous tumour' restriction cannot be defined in a meaningful way.

'Routes to diagnosis' statistics categorises a patient diagnostic pathway into one of eight routes following the methodology previously described by Elliss-Brookes *et al*.[19] Categorisations were made using HES data and cancer waiting times data. Eight standard diagnostic routes were used: two-week wait (TWW), general practitioner (GP) referral, screening, other outpatient, inpatient elective, emergency presentation, death certificate only and unknown, in addition to a 'not classified' group. The 'not classified' group was used for tumour groups that had no route assessed, which mostly contained subsequent tumours, as these are identified algorithmically and not fully registered. 'Routes to diagnoses' were presented as the absolute count and percentages of tumours that met the criteria for that category.

Analyses were performed in SQL developer (Oracle, Santa Clara, CA, USA), Stata, R and RStudio. No sensitivity analyses were performed. B.v.B., S.V., C.E., B.R. and Z.C.V. had full access to the database used to extract the study population and data linkage. Published data were required to meet the anonymisation standard for publishing health and social care data (2013, version 1.0), including satisfying k-anonymity requirements and approval from a Caldicott Guardian. Some outputs were withheld to reduce the risk of identification of patients in small groups. No further ethical approval or informed consent was required.

## Results

A total of 1 445 377 skin cancers were diagnosed between 2013 and 2019 in England. Additionally, during the same period 49 123 precancerous lesions or tumours of unknown malignant potential were registered.

### Incidence

The overall incidence of registered skin tumours in 2013 was 340.6 per 100 000 person-years (PYs) (95% CI 339.1–342.2), rising to 412.4 per 100 000 PYs (95% CI 410.7–414.1) in 2019. These rates represent a crude count increase from 183 477 tumours in 2013 to 232 121 tumours in 2019.

Most skin tumours registered were skin cancers (2019; $n=224\,092$, 96.5%). The most common type of skin cancer was BCC with an incidence rate of 282.4 per 100 000 PYs ($n=158\,934$, 95% CI 281.0–283.8) in 2019, followed by cSCC with 85.2 per 100 000 PYs ($n=47\,977$, 95% CI 84.5–86.0). The least common cancer type group reported was acral lentiginous melanoma *in situ* with a crude count of 46 cases in 2019 [incidence rate 0.05 per 100 000 PYs (95% CI 0.03–0.07)]. Increases in crude counts and incidence rates were seen for almost all tumour types included in this analysis across the diagnosis years (2013–2019).

### Survival

One-year net survival estimates were calculated for diagnosis years 2013–2019 and 5-year estimates were calculated for diagnosis years 2013–2014. Survival proportions varied with tumour type and diagnoses year (Table 1). The highest 5-year net survival estimates were seen for melanoma *in situ* – lentigo maligna subgroup at 103.6% (95% CI 101.6–106.1) and melanoma *in situ* – other melanoma *in situ* subgroup at 101.2% (95% CI 99.8–102.6).

Net survival for BCC was excellent ($>100\%$), although the estimate increased over the follow-up time and did not pass quality requirements; therefore, a precise estimate is not available. BCC subgroups by site at the eyelid, ear, lip and lower limb sites all had 5-year survival greater than 100%.

The lowest 5-year net survival estimates were observed for genital cSCC and Merkel cell carcinoma. While genital cSCC diagnosed at any stage had a 5-year survival of 66.9% (95% CI 63.4–70.4), survival for stage III–IV tumours fell to under 35% for both men and women (2014 diagnoses; men: 34.6%, 95% CI 21.7–47.5; women: 33.4%, 95% CI 24.7–42.1). Genital cSCC had similarly poor survival as genital melanoma (2014 diagnoses; Kaplan–Meier: 31.1%, 95% CI 18.4–44.7). However, 5-year net survival for genital BCC was better, but remained lower than non-genital BCC, ranging from 77.6% (2013 diagnoses, 95% CI 59.6–95.5) to 94.7% (2014 diagnoses, 95% CI 79.6–109.9). The 5-year net survival estimate of Merkel cell carcinoma diagnosed at any stage was 49.4% (2013 diagnoses, 95% CI 40.2–58.7), with case numbers too small to provide net survival estimates by stage.

**Table 1** Incidence, survival and diagnostic route statistics for main skin tumour types (melanoma, BCC, cSCC, rare). Statistics are derived from the most recently available year. Incidence rates are taken from 2019 diagnoses, and survival rates are taken from 2014 and 2018 diagnoses for 5-year and 1-year survival, respectively. The diagnostic route data are from 2018 diagnoses. Data for other years and tumour types are available as part of the full 'Get Data Out' Skin tumours release available at www.cancerdata.nhs.uk/getdataout/Skin

| Tumour type | 2019 incidence count | Incidence rate per 100 000 PYs (95% CI) | 5-year net survival, % (95% CI) | 5-year Kaplan–Meier survival, % (95% CI) | Two-week wait route, % (95% CI) | GP referral route, % (95% CI) | Other route, % (95% CI)* | Route unknown/not classified, % (95% CI) |
|---|---|---|---|---|---|---|---|---|
| All skin tumours | 232 121 | 412.39 (410.71–414.07) | [i] | [i] | 12.2 (12–12.3) | 31.6 (31.4–31.8) | 12.0 (11.7–12.2) | 44.3 (44.0–44.6) |
| All skin cancers | 224 092 | 398.12 (396.48–399.78) | [i] | [i] | 12.3 (12.2–12.4) | 30.3 (30.1–30.5) | 12.0 (11.7–12.2) | 45.4 (45.1–45.7) |
| BCC first PPPA | 158 934 | 282.36 (280.98–283.76) | [i] | [i] | 0.7 (0.7–0.8) | 33.3 (33.1–33.5) | 13.1 (12.8–13.4) | 52.9 (52.5–53.3) |
| BCC first ever | 92 308 | 164.00 (162.94–165.06) | >100[h] | 83.2 (82.9–83.4) | 1.1 (1.1–1.2) | 53.7 (53.4–54.0) | 21.7 (21.3–22.2) | 23.4 (23.1–23.7) |
| Genital BCC | 89 | 0.16 (0.13–0.20) | 94.7 (79.6–109.9) | 76.5 (64.5–84.9) | 22.7 (15.5–32.0) | 54.6 (44.7–64.2) | 14.4 (6.4–36.6) | 8.2 (4.2–19.2) |
| cSCC first PPPA | 47 977 | 85.24 (84.48–86.00) | [i] | [i] | 34.9 (34.5–35.4) | 22.3 (22.0–22.7) | 9.1 (8.7–9.6) | 33.6 (33.0–34.2) |
| cSCC first ever | 32 606 | 57.93 (57.30–58.56) | 89.8 (88.8–90.9) | 63.7 (63.1–64.3) | 48.6 (48.0–49.1) | 30.6 (30.1–31.1) | 12.0 (11.4–12.7) | 8.9 (8.5–9.3) |
| Genital cSCC (female patients) | 892 | 3.13 (2.93–3.35) | 63.0 (58.5–67.5) | 56.8 (53.3–60.1) | 47.8 (44.7–51.0) | 31.0 (28.2–34.0) | 17.8 (13.9–23.1) | 3.4 (2.2–5.3) |
| Genital cSCC (male patients) | 632 | 2.27 (2.10–2.46) | 73.9 (68.4–79.3) | 64.4 (60.0–68.5) | 35.5 (31.8–39.5) | 29.4 (25.9–33.2) | 31.1 (24.7–39.7) | 3.9 (2.5–6.5) |
| Common melanoma | 15 065 | 26.77 (26.34–27.20) | 90.0 (89.0–90.9) | 80.2 (79.5–80.9) | 62.9 (62.2–63.7) | 22.7 (22.0–23.3) | 7.3 (6.6–8.1) | 7.1 (6.6–7.6) |
| Acral lentiginous melanoma | 196 | 0.35 (0.30–0.40) | 76.0 (66.1–85.8) | 65.4 (57.5–72.2) | 56.0 (49.5–62.3) | 28.9 (23.4–35.1) | 10.7 (6.0–21.7) | 4.4 (2.2–9.9) |
| Genital melanoma | 71 | 0.13 (0.10–0.16) | [g] | 31.1 (18.4–44.7) | 50.8 (38.8–62.7) | 31.7 (21.6–44.0) | 12.7 (4.4–42.5) | 4.8 (1.2–19.3) |
| Melanoma *in situ* | 7119 | 12.65 (12.36–12.95) | >100[h] | 88.4 (87.6–89.3) | [b] | [b] | [b] | [b] |
| Cutaneous sarcoma | 585 | 1.04 (0.96–1.13) | 93.3 (86.1–100.4) | 76.3 (71.3–80.6) | 28.5 (24.7–32.5) | 40.7 (36.5–45.0) | 17.8 (12.6–25.7) | 13.0 (9.9–17.5) |
| Appendageal (adnexal) | 545 | 0.97 (0.89–1.05) | 80.7 (72.9–88.5) | 57.4 (52.6–61.8) | 25.3 (21.7–29.2) | 42.3 (38.1–46.6) | 22.2 (16.5–30.6) | 10.2 (7.3–14.5) |
| Merkel cell carcinoma | 359 | 0.64 (0.57–0.71) | 58.6 (48.2–68.9) | 40.9 (35.1–46.7) | 40.9 (35.8–46.2) | 36.2 (31.3–41.4) | 17.4 (11.4–27.4) | 5.6 (3.2–10.1) |
| Extramammary Paget disease | 109 | 0.19 (0.16 -0.23) | 91.3 (76.6–106.0) | 67.8 (56.9–76.5) | 6.5 (3.0–13.4) | 52.7 (42.6–62.5) | 23.7 (12.6–48.7) | 17.2 (9.8–31.2) |
| Skin tumours of uncertain malignant potential | 801 | 1.42 (1.33–1.53) | 90.6 (83.5–97.7) | 70.2 (66.0–74.0) | 22.5 (19.6–25.7) | 48.8 (45.2–52.5) | 14 (10.1–19.9) | 14.6 (11.5–18.6) |

BCC, basal cell carcinoma; cSCC, cutaneous squamous cell carcinoma; PPPA, per patient per annum. *'Other route' combined the following categories: other outpatient, inpatient elective, emergency presentation, death certificate only, unknown route, and route not classified. Some data are not available as the estimate failed quality requirements and has been suppressed. [b]Data are not available as the data quality is too poor to release this statistic. [g]The standard error of the survival estimate was greater than 20%. [h]Precise estimate is not available as the net survival estimate has increased with duration. [i]Data are not available as the methodology is under review. Data codes (e.g. [b]) are in alignment with standard 'Get Data Out' missing data codes.

Five-year net survival for stage I common melanoma and the subgroup 'limbs not known' increased over time and did not meet quality criteria. However, stage I melanoma of the trunk and head, face and scalp were 99.3% (95% CI 98.0–100.6) and 100.4% (95% CI 96.8–104.0) for 2014 diagnoses, respectively. Common melanoma (excluding genital and acral lentiginous melanoma) 5-year net survival for a tumour diagnosed in 2014 deteriorated with stage from 77.1% (95% CI 74.4–79.9) for a stage II tumour to 22.4% (95% CI 16.7–28.1) for a stage IV tumour.

Five-year net survival for cSCC was 89.8% (95% CI 88.8–90.9). Other skin cancer types with poor 5-year net survival were acral lentiginous melanoma (2014 diagnoses; 76.0%, 95% CI 66.1–85.8) and appendageal (skin adnexal) carcinoma (2014 diagnoses; 80.7%, 95% CI 72.9–88.5).

### Routes to diagnosis

For each group, the proportion categorised as being diagnosed via different diagnostic routes (e.g. TWW or standard GP referral) was calculated for diagnosis years 2013–2018 (Table S1; see Supporting Information). All tumour types had a proportion categorised in the 'unknown' referral pathway, ranging from 3.2 (95% CI 0.9–10.9) for genital melanoma to 23.2% (95% CI 22.9–23.4) for BCC.

Common melanoma had the highest proportion of TWW referrals (63.0%, 95% CI 62.2–63.7), while non-genital BCC had the lowest proportion (1.2%, 95% CI 1.1–1.2). Melanoma stage IV had the highest proportion of emergency presentations [81 of 408 stage IV tumours, 19.9% (95% CI 16.3–24.0)], whereas melanoma stage I–III all had a proportion below 2%.

Women with a genital cSCC had a higher proportion of TWW referrals than men. Tumours in women were categorised as TWW in 47.8% (95% CI 44.7–51.0) of cases, compared with 35.5% (95% CI 31.8–39.5) of tumours in men.

For the same tumour type located at the same location, older patients received fewer TWW referrals than their younger counterparts. Stage I melanoma located on the head, face and scalp was referred through TWW in 65.8% ($n=123$, 95% CI 58.7–72.2) of patients aged 25–59 years, whereas patients aged $>80$ years were referred via this route in 44.2% ($n=169$, 95% CI 39.3–49.3) of cases.

Acral lentiginous melanoma had a lower proportion of TWW referrals (56.0%, 95% CI 49.47–62.33) than common melanoma (62.95%, 95% CI 62.17–63.72).

## Discussion

This study created a new, clinically relevant classification of skin tumour types and patients within NHS Digital's NDRS cancer registry. This presents the first release of routine skin cancer data in England at a level of detail which has not been achieved previously. These data are important because freely available and routinely updated information provides clinicians, researchers, commissioners, charities and the public with context about the skin cancer burden and contributes to national healthcare planning and informs research strategies.

An overall high tumour burden and increasing incidence rates were observed for most tumour types over the study period. England has a relatively high proportion of fair-skinned individuals as well as an ageing population,[20,21] which may explain increasing incidence rates. The cumulative UV exposure that fair-skinned and older individuals experience is the main risk factor for skin cancer and UV exposure is increasing across the population. This is compounded by higher rates of immunosuppression from comorbidities in addition to the effects of immune system ageing.[22]

For the first time, the national incidence of rare tumours, rare subtypes of common tumours and precancerous lesions are reported for England. Highlighting and providing statistics on these rarer groups allows for a better understanding of their epidemiology, which can in turn improve awareness, diagnosis, treatment and outcomes. Precancerous lesions and undefined entities, such as melanoma *in situ*, EMPD and atypical fibroxanthoma (AFX), represent a significant workload burden with more than 15 000 tumours recorded each year.

Genital skin cancers are rare and are often excluded from standard skin cancer reporting. Common coding systems (e.g. ICD-10) separate these genital cancers from other cutaneous sites. The most common genital skin tumour was cSCC, which supports the findings from previous studies.[23–25] One-year and five-year survival of genital skin tumours were worse than the non-genital equivalent types. This may be explained by a different underlying aetiology, including human papillomavirus infection and chronic inflammation associated with conditions such as lichen sclerosus, among other factors.[26–28]

Overall net survival varies by tumour type, with excellent survival (>100%) for BCC and melanoma *in situ* and poorer survival for tumours diagnosed at larger stages (e.g. stage IV MCC, genital cSCC, and common melanoma). Five-year net survival for cSCC (89.8%, 95% CI 88.8–90.9) was comparable with that of melanoma (89.8%, 95% CI 88.8–90.7), breast cancer (87.5%, 95% CI 87.1–87.8)[29] and prostate cancer (86.0%, 95% CI 85.5–86.6).[30] The survival estimates presented here compare survival of patients with a first cSCC with the general population, but these survival estimates are not disease-specific or age-standardised. cSCC is linked with advanced age and immunosuppression, which in turn results in a higher risk of death. Approximately 2% of patients with cSCC develop metastatic disease. It is unlikely that 10.2% of patients are dying directly as a result of cSCC; rather, advanced immunosenescence and other comorbidities are likely contributing to the lower-than-expected survival. Mortality directly attributed to melanoma (2019 deaths, $n=1922$) is twice that of NMSC ($n=754$), as reported on death certificates or coroner certificates.[31]

Groups with the poorest survival (i.e. acral lentiginous melanoma, genital cSCC and Merkel cell carcinoma) were less likely to be referred along the TWW pathway compared with more common cancer types (e.g. common melanoma). Increased awareness among clinicians and the public could lead to earlier diagnoses and better prognosis.

The high proportion of skin tumours in the 'unknown' referral route could be explained by private practice pathology, in addition to poorer coding of patients managed and treated in outpatient clinics. HES outpatient (HESOP) coding is less accurate than HES inpatient (HESAPC) coding;[19]

procedures may be coded as a 'day case' in HESAPC, while other procedures are coded as outpatient procedures and are less easily identifiable.

Comparing incidence and survival rates for skin cancer worldwide is complex; cancer registries often have incomplete NMSC registrations and registration practices differ between countries. For melanomas diagnosed in 2019, the crude incidence was 31.4, 21.7 and 27.4 per 100 000 PYs for Wales, Northern Ireland and Scotland, respectively,[7–9] which is comparable to the common melanoma incidence (26.8 per 100.000 PYs) presented here for England. Similarly, the 5-year net survival for common melanoma (90.0%, 95% CI 89.0–90.9) is comparable to the most recently published Scotland (93.9%, 95% CI 92.1–95.8), Wales (90.5%, 95% CI 88.3–92.7) and Northern Ireland (93.0%, 95% CI 90.7–95.3) net survival estimates.[7,32,33] The incidence of KCs for the UK cancer registries has previously been compared and the highest incidence rates were reported for South West England.[10,34] The findings described here do not cover all the available data. Due to the size of the dataset, not all statistics for all groups for all years can be described here. Clinicians and researchers are encouraged to access these data online for analysis and to better inform development of healthcare services and future research studies.

This study has several limitations. Cancer registrations are often initiated by a pathology report. Therefore, if no biopsy is performed and the tumour is managed conservatively or using non-surgical approaches (e.g. cryotherapy or photodynamic therapy), which do not generate a pathology report, these tumours are less likely to be registered. This is particularly true for subsequent BCC and cSCC, which are mostly identified through the presence of a pathology report and may therefore be under-reported. Unlike non-KC tumours, which are registered manually at NDRS, KC tumours are mostly registered through a validated automatic processor to reduce staff workload. Although the system has notable benefits, including the ability to identify subsequent tumours, it also may explain the data-quality issues that led to no statistics being published for those groups, such as stage or routes to diagnosis.

Tumour classification relies on the accuracy of pathology reporting and coding and NDRS processes are quality assured and audited, but misclassification is possible. Data linkage is performed at patient level using NHS number and date of birth. This means that events such as HES procedure codes and HES events used to create routes to diagnosis cannot be linked to a specific tumour. This can be seen in the data on emergency presentations where it was difficult to separate incidental accident and emergency findings from visits for other reasons.

Statistical quality criteria, such as net survival cannot increase over time and a minimum number of individuals must have died, meant that 1-year or 5-year net survival are not provided for some tumour types. To manage this limitation, overall survival using the Kaplan–Meier method was calculated for all groups.

This uniquely detailed, high-quality and openly available dataset will provide essential statistics on all registered skin tumours in England. These data will be annually updated and can be used by clinicians, the public, researchers and commissioners to improve skin cancer outcomes.

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## Conflicts of interest

B.v.B. is an employee of the British Association of Dermatologists. N.J.L. is a trustee of the British Association of Dermatologists. N.R. is a Deputy Editor at the *BJD*.

## Data availability

Raw data can be accessed through a data request with the NHS Digital's Data Access Request Service (DARS). Programming code for cohort and output creation is available on the National Disease Registration Service's (NDRS) cancerdata website.

## Ethics statement

Ethical approval was not required for this study. National Disease Registries Directions 2021, Sections 254(1) and 254(6) of the 2012 Health and Social Care Act (the 2012 Act) provides the legal basis for the collection and processing of identifiable patient information by NHS Digital and NDRS. Results presented in this paper are routine anonymised statistical outputs.

# Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's website.

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