**Ethnicity and the epidemiology of skin cancer incidence: a retrospective population-based study in England, 2013-20**

**Plain Language Summary**

Skin cancer rates are increasing worldwide, but there is a lack of information showing how this affects different ethnic groups.

We used nationally collected data from the English Cancer Registry to analyse different skin cancers including melanoma, acral lentiginous melanoma (ALM), basal cell carcinoma (BCC), cutaneous squamous cell carcinoma (cSCC), cutaneous T-cell lymphoma (CTCL) and Kaposi sarcoma (KS). We followed the UK Office for National Statistics’ classification for seven broad ethnic groups: White, Asian, Chinese, Black, Mixed, Other and Unknown.

Ethnic diversity increased between the 2011 and 2021 censuses. Availability of ethnicity data varies widely and is ‘unknown’ in 19% of BCC cases, but in only 5% of ALM. Taking age into account, melanoma rates are 33 times higher in White than in Asian, and 16 times higher in White than in Black populations. Similarly, cSCC was 13 times more common in White compared with Asian or Black populations, and BCC was 26 and 27 times more common in White compared with Asian and Black populations. By contrast, ALM is more common in Black patients and is often not referred along the urgent suspected cancer pathway. Consequently, ALM presents at a more advanced and difficult-to-treat stage with worse outcomes.  KS is more common in Other and Black ethnic groups, and in persons with reduced immunity.

This study highlights the need for improving ethnicity data collection in skin cancer. These data are essential to understand unmet healthcare needs for under-served and under-reported communities and will inform clinicians, patients and policy makers.

249 words

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**Abstract**

**Introduction**

Skin cancers primarily affect people of White ethnicity and lighter skin tones, but people of other ethnicities may face diagnostic delays and experience higher mortality, reflecting existing inequities in healthcare.  This is the first study showing incidence data from the National Disease Registration Service (NDRS) cancer registry in England for skin cancers stratified by the seven broad ethnic groups.

**Methods**

We used data from NDRS from 2013-20 to analyse melanoma, acral lentiginous melanoma (ALM), basal cell carcinoma (BCC), cutaneous squamous cell carcinoma (cSCC), cutaneous T-cell lymphoma (CTCL), and Kaposi sarcoma (KS). Tumour records were linked to datasets including census population data, Office for National Statistics (ONS) mortality data, Index of Multiple Deprivation and Hospital Episode Statistics. Ethnicity data were grouped into seven standardised broad ONS categories: White, Asian, Chinese, Black, Mixed, Other and Unknown. European age-standardized rates (EASR) were calculated using the 2013 European Standard Population and reported per 100,000 person years (PY).

**Results**

Ethnic diversity in England increased between the 2011 and 2021 censuses. 'Unknown' ethnicity cases with registry data ranged from 19.2% for BCC to 5.0% for ALM. EASR of melanoma was 33 times higher in White (27.29 CI [27.12- 27.46]) than in Asian (0.82 CI [0.67- 0.99]) and 16 times higher in White than in the Black ethnic group (1.67 CI [1.37- 2.01)]. Similarly, cSCC was 14 more common in White compared (61.75 CI [61.49- 62.0]) with Asian (4.55 CI [4.15- 4.97]) and 13 times more common with the Black ethnic group (4.73 CI [4.17- 5.34], respectively. BCC was 26 times more common in White (153.69 CI [153.28-154.09] than in Asian (5.59 CI [5.16- 6.04]) and 27 times more common in White than in Black ethnic groups (5.98 CI [5.35- 6.65], respectively. However, EASR for ALM was highest in the Black ethnic groups. ALMs were less likely to be referred along the urgent suspected cancer pathways and more likely to present at a later stage than for melanoma overall.  EASR for KS was significantly higher in Other and Black ethnic groups.
 **Conclusion**

 A lack of high-quality published ethnicity data hampers our understanding of health disparities. These findings emphasize the need for better ethnicity data collection and regular audits to better understand and address needs of underserved populations.

350 words

**‘What is already known about this topic?**’ – 70 words

Ethnicity reporting in skin cancer studies is inconsistent. Most studies that do report on skin cancer by ethnicity are from the US and typically report on melanoma, or on one skin cancer type only.

Previous reports have identified that people with skin of colour are more likely to experience delays in diagnosis and higher mortality rates. [56 words]

**‘What does this study add?** – 70 words

This is the first comprehensive report of skin cancer stratified by seven broad ethnic groups in England by the National Disease Registration Service.

Skin cancer incidence varies widely in different ethnic groups. While many skin cancers are more common in White people, acral lentiginous melanoma, Kaposi sarcoma and cutaneous T cell lymphoma are not. Failure to recognise skin cancers in people with darker skins tones may lead to healthcare disparities. [70 words]

**Introduction**

Skin cancer incidence rates are increasing worldwide.​[1]​ While skin cancers predominantly affect people of White ethnicity and lighter skin tones, people with skin of colour (SoC) are more likely to experience delays in diagnosis and higher mortality.[2, 3] A US publication identified that the largest disparity in 5-year cancer relative survival rates between Black and White ethnic groups is for melanoma (67% vs 92%, respectively).​[4]​ Highly pigmented skin has greater natural UV protection, and the risk factors and genetic drivers for skin cancers in such skin types are likely to be different. Additionally, barriers in access to care and clinician and patient knowledge may also contribute to poorer outcomes.

In a US study, melanoma was most common among people of non-Hispanic White ethnicity (21.9 per 100,000 person years [PY]), followed by all Hispanics regardless of race (4.68 PY), and least common in those of Black ethnicity (1.0 PY), but tumours presented later and with worse outcomes in the American Indians/Alaskan Natives and Asians/Pacific Islanders (API) [5]. The melanoma subtype also varied by ethnic group, with acral lentiginous melanoma (ALM) more common in people of Black ethnicity.[5] Similarly, cutaneous T cell lymphoma (CTCL) was 1.5 times more likely to occur in Black ethnicity than in White.[6]

This is the first national report on the epidemiology of skin cancer types by ethnicity in England adopting the Office for National Statistics (ONS) classifications: White, Asian, Chinese, Black, Mixed, Other and Unknown.[7,8] These data are essential for comprehensive assessment of healthcare needs and highlight the importance of collecting high-quality ethnicity data for under-served and under-reported communities to inform clinicians, patients and policy makers.

**Methods**

***Study design and cohort selection***

This retrospective cohort study used cancer registry data from the National Health Service (NHS) England’s NDRS from 2013 to 2020; the period chosen was based on availability of fully registered quality assured data at time of analyses. NDRS collect data from NHS and private pathology laboratories, multidisciplinary team meeting summaries (Clinical Outcomes and Services Dataset [COSD]), and Patient Administration System (PAS) on people with cancer to create tumour registrations. These tumour records can be linked to other datasets such as ONS mortality data, Hospital Episode Statistics (HES) and Cancer Waiting Times (CWT).

The UK NHS is unique in that persons are followed up throughout their life through data linkages with NHS dataflows.​[9]​ A protocol was written before analyses and approved by the NDRS.

Skin cancers were identified and grouped using International Classification of Diseases (ICD) version 10 and ICD for Oncology 3rd Edition morphology and behaviour codes. Staging available for melanoma using *American Joint Committee on Cancer staging system version 7 (2013-2017 diagnoses) and Union for International Cancer Control version 8 (2018–2020 diagnoses)* [10]*.*

 All cases of cutaneous melanoma (reported separately as ‘melanoma’ and ALM), basal cell carcinoma (BCC), cutaneous squamous cell carcinoma (cSCC), CTCL, and Kaposi sarcoma (KS) diagnosed between 2013 and 2020 were included. Methodology and codes used to identify melanoma, ALM, BCC, cSCC, CTCL and KS have previously been described by van Bodegraven et al. and within the NDRS Get Data Out Haematology and KS online tools.​[1, 11]​. BCC and cSCC tumours eligible for inclusion were either first-ever tumours coded to ICD-10 C44.x, or to cutaneous lip C00.x, or to external genital skin. We used cancer registry data to identify patients with immunosuppression, such as those with haematological malignancies, and through HES linked data for co-morbidities such as organ transplantation and HIV status.

Ethnicity data are recorded in secondary care from derived datasets and captured by NDRS from COSD, PAS, Radiotherapy Dataset (RTDS), Diagnostic Imaging Dataset (DID) and HES (Hospital Episode Statistics). Ethnicity data are self-reported by patients either verbally or through paper or digital forms and recorded by administrative or healthcare staff. Where two conflicting ethnicity values are found, the NDRS record is updated with the most recently recorded known ethnicity. 18 ethnicity categories +1 ‘not stated’ category are defined by ONS for the decennial census and used by NDRS. An individual is entered into the ‘unknown’ group where there is no recorded NHS ethnicity data for them.

There are seven ONS standard categories of ethnic groups: White (White British, White Irish, Traveller or any other White background), Asian (Bangladeshi, Indian, Pakistani, any other Asian background), Chinese, Black (African, Caribbean and any other Black background), mixed or multiple ethnic groups but herein referred to as ‘Mixed’, ‘Other’, and ‘Unknown’ (see Supplementary data for grouping details). Full details of covariates included can be found in the Supplementary data (Tables S1).[12]

***Statistical analyses***

Crude and age standardised incidence rates (ASR) were calculated using the European Standard Population 2013 (see Supplementary information), and 95% confidence intervals (CIs) were derived using Byar’s method with Dobson method adjustment [1, 13].

The best denominator population ethnicity data in the UK comes from the decennial census (2011, 2021) where ethnicity is a mandatory self-reporting component. For the intervening years (2012-20), there is no national dataset available. However, an “Aged-on proportion approach”, using the 2011 census distribution and applying those distributions to the following year’s mid-year population estimates (ONS created), a rough estimate can be created. This is a crude approach where the percentage of 1-year old Asians in 2011 is taken and designated as the percentage of 2-year-old Asians in 2012, and so on. ONS have previously produced estimates for 2012-18 using this approach.​[14, 15] Population counts for 2019 and 2020 were estimated by using a linear model per group (5-year age group, gender and ethnicity), anchored at the 2018 and 2021 counts for that group. 2019 and 2020 counts are extrapolated from each group’s linear model.

The ‘Unknown’ ethnicity group, as occurs in the NDRS case counts, has no comparison group in the denominator census population data. Two approaches were adopted to handle this ‘unknown’ ethnicity group: (1) a weighted redistribution of the unknown cases based upon the distribution of known cases by cancer site, gender, 5-year age band, and year; and (2) calculating incidence rates for all ethnicity groups, excluding the unknown group, which excluded a cohort of tumours from analyses [16].  Approach 1 is reported in the main results section and Table S2 while approach 2 is reported in the supplementary information (Tables S3 and S4).

The chi-squared test was used to compare proportions.  A p-value of 0.05 was considered significant.  Analyses were performed in SQL developer© (Oracle, Santa Clara, CA, USA), R, Rstudio© and Medcalc©. BvB, SV, and ZV had full access to the database to extract the study population and data linkage. No further ethical approval or informed consent was required.

RECORD reporting guidelines were adhered to.

**Results**

***Population data***

The overall population of England increased from 53,107,166 to 53,493,733 (+0.7%) between the 2011 and 2021 census (Table 1). While the self-reported ethnic diversity of the English population increased for Asian, Black and Chinese over this time, White ethnicity decreased, although the variations were subtle.

***Demographics of patients with skin cancer by ethnicity***

The proportion of ‘Unknown’ ethnicity in the cancer registry data ranged from 19.2% for BCC to 5.0% for ALM (Table 2) and ‘Unknown’ has the second highest total cases after the White ethnic group for all skin cancer types.

Median age for BCC, cSCC and melanoma was slightly older in the White ethnic group compared with the Asian, Black, Chinese or ‘Other’ ethnic groups, and with a lower or more equal male to female ratio in the latter groups compared with those of White ethnic group. ALM was the only skin cancer which was more common in women than men with an overall male:female (M:F) ratio of 0.6:1 in White, and lower still in Asian (0.4:1) and the mixed ethnic groups (0.3:1) (Table 2d). Overall, KS was more common in men than women with a M:F ratio of 9.1:1.

Variations in tumour location were identified by ethnicity. Among the Black ethnic group, genital skin was the most common site for cSCC  [121/354 (34.2%)] and this location was also relatively high among the Asian ethnic group [195/609 (32.0%)]. In comparison, genital skin involvement was proportionally less frequent among other ethnic groups, including White [10,984/225,534 (4.9%)], Unknown [394/16093 (2.5%)], Other [103/1137 (9.0%)], Mixed [35/279 (12.5%)] and Chinese [9/66 (13.6%)] ethnic groups, in whom head and neck and other sun-exposed sites were more common.

In White, Unknown and Other ethnic groups, BCC, cSCC and melanoma were more common in the least deprived quintiles, whereas in the Asian, Black, Chinese and Mixed ethnic groups skin cancer incidence is distributed equally across deprivation quintiles. More deprived quintiles were associated with BCCs and cSCCs in Asian and cSCC in Black ethnic groups (Table 2).

The proportion of people with melanoma who had stage I/II tumours at presentation was lower for Asian (53.5%, c2 p<0.0001, difference (diff) 26.3% 95% CI 18.7-34.1), Black (62.4%, c2 p<0.0001, diff 17.4% 95% CI 9.8-25.6), Mixed  (62.5%, c2 p<0.0001, diff 17.3% 95% CI 9.1-26.2), Chinese (76.2%, c2 p = 0.680, diff 3.6% 95% CI -9.6-24.9)  and Other (76.4%, c2 p=0.027, 95% diff 3.4% CI 0.4-6.7) ethnicities compared with the White ethnicities (79.8%) (Table 2c). Unknown ethnicity had a significantly higher proportion of early-stage diagnoses vs White ethnic group (c2 p<0.001, 95% CI 1.8-3.6).  The proportion of people with unknown stage may account for some of these differences.

***Referral pathways, stage at diagnosis and immunosuppression***

The proportion of people with melanoma who were referred along the Urgent Suspected Cancer (USC) pathway was lower for Asian (32.5%, c2 p = 0.001) and Black (35.5%, c2 p = 0.021) compared with White (45.1%), although higher for Chinese (47.6%, c2 p < 0.001). The proportion of people whose melanoma referral pathway was not identified (29.8%) may account for some of these differences (Table 2c).

ALMs were less likely to be referred along the USC pathway than melanoma overall (40.1% vs 44.6%, p <0.001), Table 2d. ALMs were more likely to be diagnosed at a later stage compared with melanoma overall (72% vs 80%, c2 p<0.0001 stage I/II at diagnosis) (Table 2d).

Immunosuppression was more commonly identified in people with KS, CTCL and cSCC and more common in the Black ethnic group for all skin cancers (Table 2).

***Counts, crude and age standardised incidence of skin cancers by ethnic group***

Crude and EASR for all skin cancers were highest in the White and ‘Other’ ethnicity category, followed by ’Mixed’ and Chinese and then by Asian and Black, see Figure 2, and Table S3.

EASR of melanoma was 33 times higher in White (27.29/100,000 PY) than Asian (0.82/100,000 PY) and 16 times higher in White than in Black (1.67/100,000 PY). Similarly, cSCC was 13 times more common in White (60.72/100,000 PY) compared with Asian (4.55/100,000 PY) or Black (4.73/100,000 PY) and BCC was 26 and 27 times more common in White (153.69/100,000 PY) compared with Asian (5.59/100,000 PY) and Black (5.98/100,000 PY), respectively.

The EASR for ALM which was highest in the Black ethnic group at 0.9 per 100,000 PY vs Asian (0.1 PY), Chinese (0.3 PY), Mixed (0.3 PY), Other (0.4 PY) and White (0.4 PY) ethnic groups. (Table S3) EASR for KS was highest in Other (1.6 PY) and Black (1.5 PY) ethnic groups compared with Asian (0.2 PY), Chinese (0.2 PY), Mixed (0.5 PY) and White (0.1 PY) ethnic groups.

CTCL EASR was highest in Other (1.7 PY), White (1.3 PY) and Black ethnic groups (1.3 PY) compared to Mixed (1.1 PY), Asian (1.0 PY) and Chinese (0.9 PY) ethnic groups, Figure 2.

The BCC:cSCC EASR ratio was highest in White women (3.3:1) and lowest in Asian men (1.1:1), Table S4.

Across the seven regions of England, the counts for all skin cancers in Black, Chinese, Asian, Mixed and Other ethnic groups tended to be highest in London, whereas skin cancer counts in White ethnic group was lowest in London except for KS which was more common in London than any other region across all ethnicities (London accounted for 59.7% KS cases in England) (Supplementary Table S5).

**Discussion**

This is the first population-based study of six skin cancer types by broad ethnic groups in England. We recognise that the pre-defined ONS census ethnicity classifications are not optimal. However, the need for statistically meaningful cohort sizes for analysis and patient confidentiality necessitated the use of broad groups which may miss the nuances of more granular ethnic differences. Epidemiological data on skin cancers in different ethnic groups is limited because ethnicity data are rarely of high quality in large healthcare datasets or are not sufficiently standardised. Furthermore, ethnicity does not directly correspond to skin pigmentation which is particularly relevant to UV-induced skin cancers.

Of note, ALM EASR was highest in Black ethnicities and the most common primary site for cSCCs in Black ethnicities was genital skin. Although crude and EASR rates for genital cSCC remained lower in black ethnicity (EASR: 1.57/10 000PY (95% CI: 1.26-1.93) than in white ethnicity (EASR: 3.43/10 000PY (95% CI: 3.36-3.50)). Both ALM and genital cSCC have a significantly worse 5-year net survival than their more common counterparts; ALM 5-year net survival is 80.9% versus 89.9% for melanoma overall and genital cSCC 5-year net survival is 69.7% versus 89.7% for cSCC overall.​[1]​ Aetiological factors driving these rarer cancers are likely to differ from the more common types affecting UV-exposed locations. The main risk factor for genital cSCC is HPV infection and chronic inflammation, whereas chronic inflammation, genetics and trauma, rather than UV radiation, may be more relevant to the pathogenesis of ALM.​[17–22]​ ​

Melanoma in Black and Asian ethnic groups were significantly more likely to present at a later stage than in White ethnic groups, and significantly less likely to be referred via the USC pathway.[23] Similarly, a US healthcare publication reported ALM as the most common melanoma subtype in Black-African, Hispanic and Asian populations and reported later stages at presentation and poorer melanoma-specific survival.​[24]​ This may reflect less awareness of skin cancer in these ethnic groups and less familiarity with their diagnosis amongst clinicians or this subtype might have a more aggressive behaviour due to different genetic or molecular pathways [25-27]. Public health information on skin cancer has historically been more often directed at the common presentations of skin cancers in people of White ethnicity, although this is changing with more campaigns also providing information relevant to more diverse ethnic groups and skin tones. Even though the UK NHS is free at the point-of-care, differences in skin cancer care remain and are likely to be even greater in countries with additional barriers to healthcare access.

Targeted health education initiatives aimed at raising awareness amongst healthcare professionals may also improve earlier diagnosis.[23]​  A narrative for change is developing, with recent media campaigns and publications voicing a need to improve diversity of in clinical education, medical images in clinical, dermoscopic and pathology image databanks, clinical trial recruitment, as well as research, cancer genome atlases and artificial intelligence models.​[19, 23, 28–36]​.

Immunosuppression is associated with a 65-250 times higher risk of cSCC, an elevated risk of KS and CTCL, and to a lesser extent BCC and melanoma.​[37,38]​ The lower-than-expected immunosuppression prevalence in the KS population identified in this study likely reflects incomplete HIV diagnosis recording in hospital records or perhaps increasing prevalence of other variants of KS [39]. However, the immunosuppression rates in other skin cancers align with existing literature, indicating that HIV is a less significant risk factor for these cancers.​[40, 41]​

A 2021 NHS research report highlighted that ‘data quality problems affect records for patients of ethnic groups disproportionately’ and ‘the lack of comprehensive, high quality data on health and mortality by ethnicity is a significant obstacle to understanding ethnic inequalities.’​[42]​ The lower quality of ethnicity data for BCCs, in particular, results from fewer hospital attendances and fewer multidisciplinary team meeting outcomes, both important data sources.

Ethnicity, race and nationality are often conflated, complicating self-reported ethnicity where choice can be influenced by culture or by previous nationality. In the US, the Jewish population is considered a designated group, and ancestry is the important benchmark. With the rise in multi-ethnicity, the ‘Mixed’, ‘Other’ and ‘Unknown’ are complex categories to understand.

The ‘Unknown’ ethnic group in cancer registry data (which is the second most prevalent group after White) includes individuals who do not self-report or whose ethnicity is unrecorded in healthcare data or who do not identify with any of the existing ONS groups, yet this group is not represented in census data, where ethnicity recording is compulsory.

Typically, methods like multiple imputations cannot be used to fill gaps due to the complexity of the ‘Unknown’ category not being randomly distributed. Moreover, patients may fear that providing ethnicity data could affect their care, leading administrative staff to leave this question blank. [43, 44] As the ONS divides ethnicity into only seven categories, this grouping may mask nuances between Other, Mixed and Unknown, thus reducing generalisability. Improving hospital ethnicity recording would help eliminate these issues. Census data are only collected every 10 years, but changes in migration patterns can happen rapidly due to changing immigration rules or global political tensions, further contributing to inaccurate population estimates and incidence rates.  Lower data completeness for variables such as referral pathways and stage at diagnosis means interpretation should be cautious where counts are small.

Furthermore, regarding the ‘Other’ ethnic group, many outcomes are similar to those of the ‘White’ ethnicity with a few exceptions, notably the higher incidence of KS. This ‘Other’ group includes those of Arab ethnicity, a group well established to have a higher incidence of KS than the White ethnicity​.[45]​ The issue of including Arabs within the ‘Other’ group is that it includes Middle Eastern and North African countries where Arabic is spoken but not everyone from the Middle East is of Arab ethnicity. However, given that Arab ethnicity accounts for less than half of the ‘Other’ group, more questions remain: what is the motive behind selecting the ‘Other’ ethnic group in census data? What populations are represented, and what conclusions can be made for this population?

A challenge with skin cancers in our study is that skin cancers are far less common in patients with SOC than in white ethnicities, resulting in a small sample size which can lead to potential confounders, requiring a cautious interpretation of relative incidence. For example, the lower proportion of stage I/II melanomas in Asian and Black ethnic groups may be influenced by tumour site or unknown stage/ethnicity. Due to insufficient counts, rarer skin cancers were excluded from this report.

Only self-reported ethnicity is recorded routinely in NHS data with no available details of skin phototypes, skin tones or racial ancestry.  Ideally, an objective tool such as the (not yet validated) Human Eumelanin Skin Colour Scale (HESCS) would be routinely collected to better understand the relationship between skin cancer and skin type.​[46]​  But, HESCS would not provide a wider understanding of the impact of different socio-economic, cultural or genetic backgrounds, education or country of birth, all of which may influence the risk of skin cancer and healthcare service interactions. Data collection could be improved through better use of technologies such as the NHS app [47], where healthcare records are available to patients and could be directly self-reported and through making ethnicity data collection prioritised, mandatory and regularly audited.

Standardised life tables from the ONS do not report by ethnic groups. Due to this limitation and small cohort sizes, cumulative lifetime incidence and survival analyses were not conducted.  Similarly, we are unable to provide age-standardised rates regionally but assume that the regional variations found reflect the demographics, e.g. London has a younger and more ethnically diverse population than other regions. We were limited to analysing large geographical regions due to small counts and lack of granular ethnicity census data, in future studies, more complex analysis regarding UV index, urban-rural locations and other environmental factors should be explored. We were only able to report on stage at diagnosis for melanoma and ALM due to lack of stage data completeness for BCC, cSCC and KS, highlighting a need for improvement.

**Conclusions**

The findings emphasise the need for better, targeted ethnicity data collection strategies to address incidence, outcomes and healthcare equity for not just skin cancer but all health conditions in underserved populations. While projects like the Global Burden of Disease have improved global healthcare reporting, continuous audit and improvement of collected data are essential to provide better care across people of all ethnicities.[48]

3078 words

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Data availability statement: Publicly available data can be accessed through [Cancer data interactive dashboards - NDRS](https://digital.nhs.uk/ndrs/data/data-outputs/cancer-data-hub), row-level data can be obtained through a data access request with [Data Access Request Service (DARS): process - NHS England Digital](https://digital.nhs.uk/services/data-access-request-service-dars/process).

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Conflicts of Interest: BvB and SA are employees of the British Association of Dermatologists. All other authors have no Conflict of Interest to declare.