



Public Health
England

Protecting and improving the nation's health

National Cancer Intelligence Network

Routes to Diagnosis: Investigation of melanoma unknowns

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in cancer awareness, prevention, diagnosis and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National cardiovascular intelligence network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Networks (NCMHIN) provides information and intelligence to improve decision-making for high quality, cost effective services. Their work supports policy makers, commissioners, managers, regulators and other health stakeholders working on children's, young people's and maternal health.

National Mental Health Intelligence Network

The National Mental Health Intelligence Network (NMHIN) is a single shared network in partnership with key stakeholder organisations. The Network seeks to put information and intelligence into the hands of decision makers to improve mental health and wellbeing.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

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1 Key messages

1. There is a need for improved data collection of the patient pathway to cancer diagnosis as this will increase information on the causes of treatment delay as well as enable better commissioning of cancer services.
2. It is difficult to understand the pathway of tumours treated in primary care without access to primary care data.

2 Introduction

Improving cancer survival is a key challenge identified in Improving Outcomes: A Strategy for Cancer. Cancer survival estimates in the UK currently fall below those in many European countries. The National Awareness and Early Diagnosis Initiative (NAEDI) aims to coordinate and provide support to activities and research that promote the earlier diagnosis of cancer, and thereby improve survival rates and reduce cancer mortality. Understanding the routes taken by patients to their cancer diagnoses and the impact of different routes on patient survival will inform targeted implementation of awareness and early diagnosis initiatives, and enable assessment of their success. Routes to Diagnosis uses routinely collected data sources to work backwards through patient pathways to examine the sequence of events that led to a cancer diagnosis. The Routes to Diagnosis study showed that for 8% of newly diagnosed tumours in 2006-2008 in England (20,000 cases per year), the patient pathway leading to their cancer diagnosis is not known.¹ A greater understanding of these unknowns will further support awareness and early diagnosis initiatives both locally and nationally. Ideally this will result in more appropriate referrals and earlier diagnosis of cancer as well as improving the cost effectiveness of the NHS.¹

The Route to Diagnosis study identified cancer patients using the National Cancer Registration Service and linked those data to Hospital Episode Statistics (HES) for inpatient and outpatient hospital activity in the six months prior to cancer diagnosis, Two Week Wait (TWW) data for urgent GP referrals suspected with cancer, screening data and death certificate only registrations. A tumour would be assigned to the 'unknown' route only if there was no information in any of these datasets within the set timescales in the methodology.

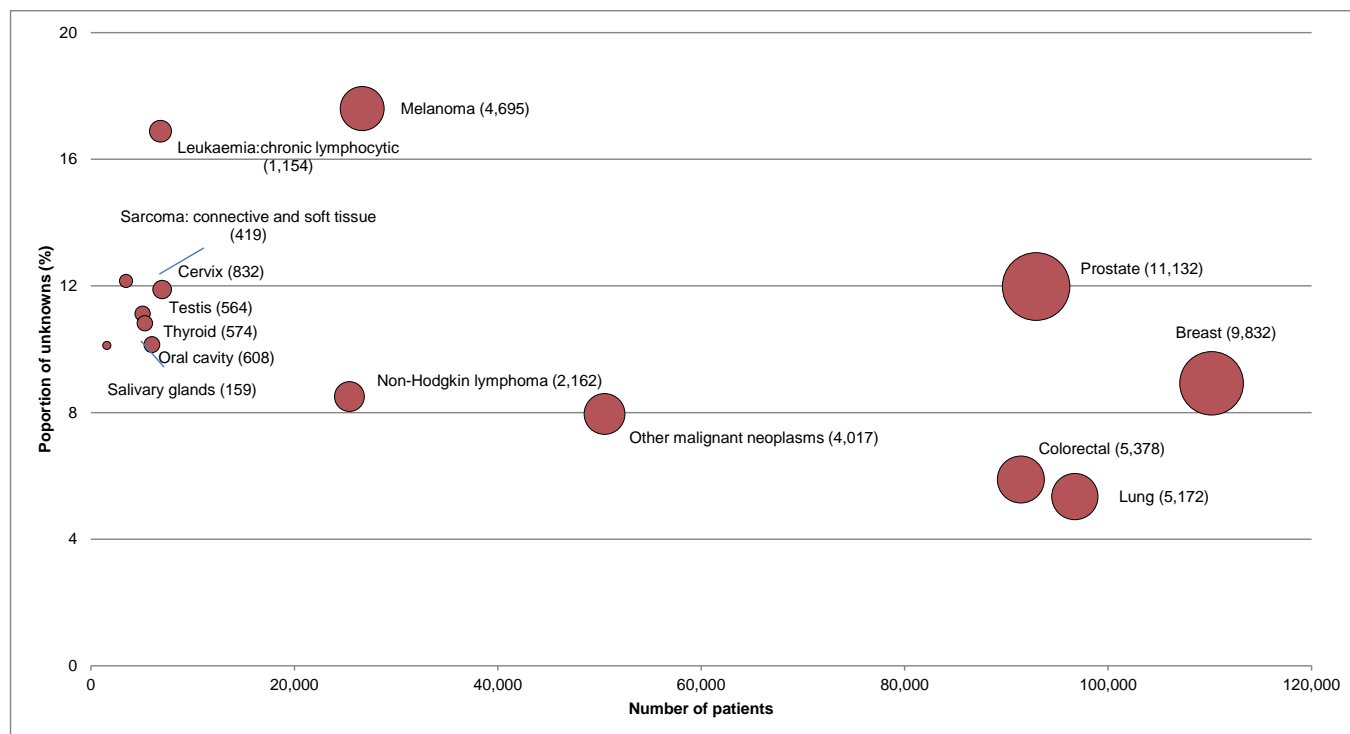
Malignant melanoma (MM) formed the highest proportion (18%, 4,695/26,660) of unknowns across all cancer types (see Figure 1). Two fifths presented to secondary care as an urgent referral suspected with cancer (TWW, 41%), while more than a quarter were referred via a standard GP referral to secondary care (27%). Only 3% of MMs presented to secondary care as an emergency, while 10% of MMs were diagnosed via other inpatient and outpatient routes.

The Public Health England Knowledge and Intelligence Team (KIT) South West is the lead KIT for skin cancer. This data briefing examines variations in the proportion of 'unknowns' across the country and then focuses on MM patients who were residents in the geographical area covered by the National Cancer Registry Service - South West (NCRS – SW). A more in-depth analysis was undertaken in the data from the South West, attempting to identify the following groups of patients that may not have been captured by the study:

- patients diagnosed in private care
- patients diagnosed in primary care
- patients that are referred through other pathways not considered

Figure 1 shows a bubble chart comparing the total number of cases for specified cancer sites with the proportion of these cases that were assigned an unknown route to diagnosis. MM had the highest proportion of unknowns across all cancer sites, while it is also a common cancer. The area of the circles represents the number of unknowns, and the number of unknowns are also reported in parentheses.

Figure 2.1: Total number of cases for specified cancer sites and the proportion of these that have an unknown route, 2006-2008, England.



Source: Public Health England.

3 Methods

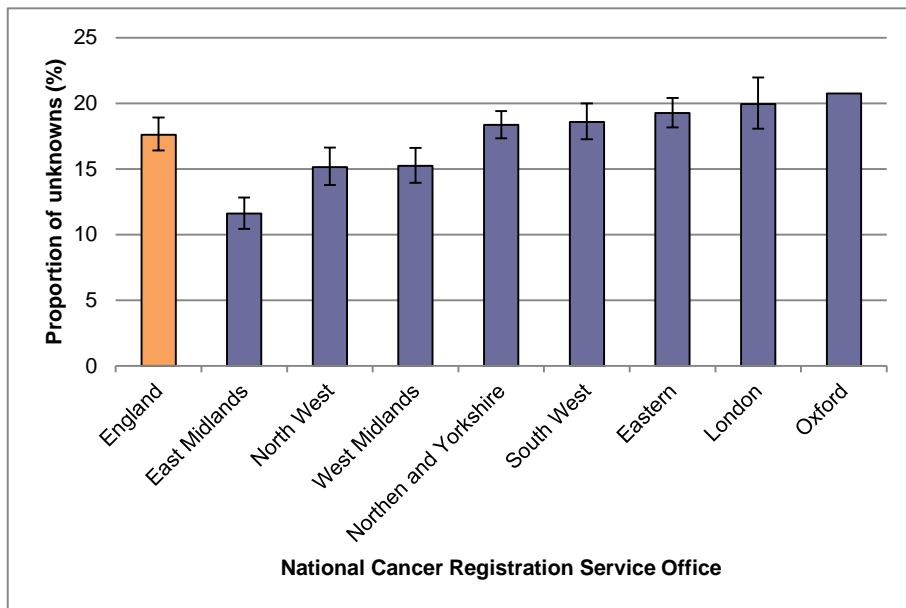
The MM (ICD-10 C43) cases assigned an 'unknown' route to diagnosis in England between 2006 and 2008 were identified.¹ The proportions of these unknowns were broken down by resident Cancer Registry and deprivation income quintiles to explore geographical and socio-economic variation. The residents of NCRS-SW were identified and formed the basis of the cohort for further investigation of these 'unknowns'.

Registrations and treatment data recorded by the Cancer Registry, hospital activity and non-TWW data were examined in order to identify these cases. Pathology reports sent to Trusts were examined using a 10% sample (stratified by Trust), for cases indicated by the registry as pathology verified. The Trust with the highest number of MM unknowns was identified and an extract of their audit system was examined.

4 Results

Variation of unknowns by Cancer Registry

Figure 4.1: Proportion of MM unknowns by National Cancer Registration Service Office, 2006-2008.

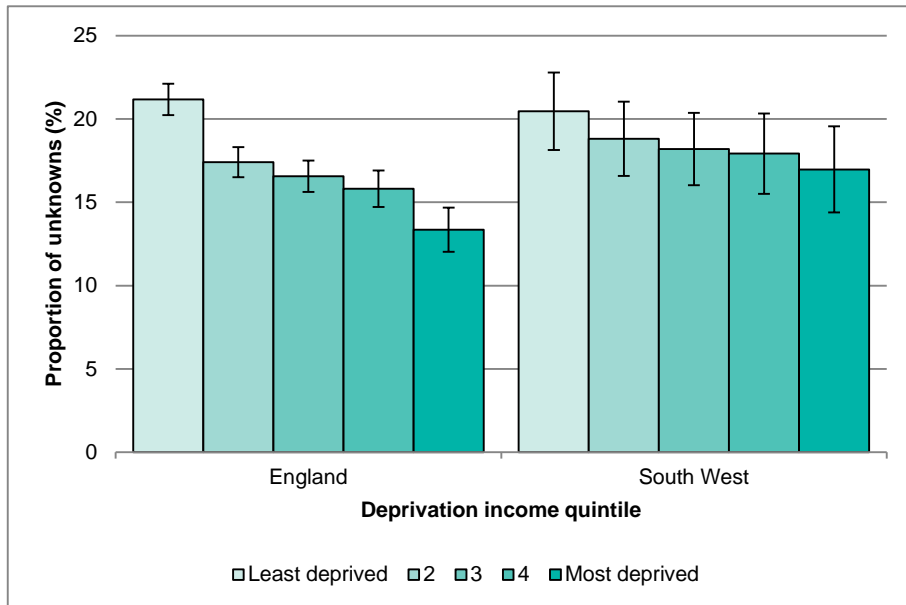


Source: Public Health England.

There was wide variation in the proportion of MM unknowns by English Cancer Registries (12% to 21%), see Figure 2. Compared to the national average (18%), the proportion is statistically significantly lower in Trent (11%, $p < 0.01$), North West (15%, $p < 0.01$) and West Midlands (15%, $p < 0.01$), while statistically significantly higher in the relatively more affluent East of England (19%, $p = 0.02$), Thames (20%, $p < 0.01$) and Oxford (21%, $p < 0.01$).

Variation of unknowns by socio-economic deprivation in the South West and England

Figure 4.2: Proportion of MM unknowns by income deprivation quintile, 2006-2008, SW and England.



Source: Public Health England.

Figure 3 shows the proportion of MM unknowns in England is statistically significantly highest in the least deprived fifth population of England (21% vs 19%, $p < 0.05$). The proportion of unknowns in the South West is statistically significantly higher in the least deprived fifth of the population compared to the most deprived fifth of the population (21% vs 17%, $p < 0.05$).

Between 2006 and 2008, the Routes to Diagnosis study identified 992 MMs resident in the National Cancer Registry Service – South West (NCRS-SW) catchment area that were recorded as having an unknown route to diagnosis. The investigation of the true route to diagnosis of these cases, using various sources of information, is detailed below.

1. NCRS-SW data: setting of treatment and diagnosis

The NCRS-SW recorded a first treatment for the majority for MM unknowns (88%, 874/992). Of those with treatment data, the majority were treated at an NHS Trust (83%, 728/874), while 13% were treated at a GP surgery (117/874) and 3% at a private practice (23/874) prior to diagnosis. There was an additional 1% (9/992) of all MM unknowns that were diagnosed at a private practice but not treated at a private practice. Overall, cancer registry data indicated that 12% of cases had their first treatment at a GP practice (117/992), while 3% of cases were either diagnosed or had their first treatment at a private practice (32/992).

2. Non-TWW referrals

Only TWW referrals with a decision to treat date within 31 days before or 62 days after date of diagnosis were considered for the Routes to Diagnosis study.¹ There were 9% (93/992) of MM unknowns that had a non-TWW referral (routine or urgent GP referral as recorded on cancer waiting times data) within this time frame, and can be considered as a standard GP referral.

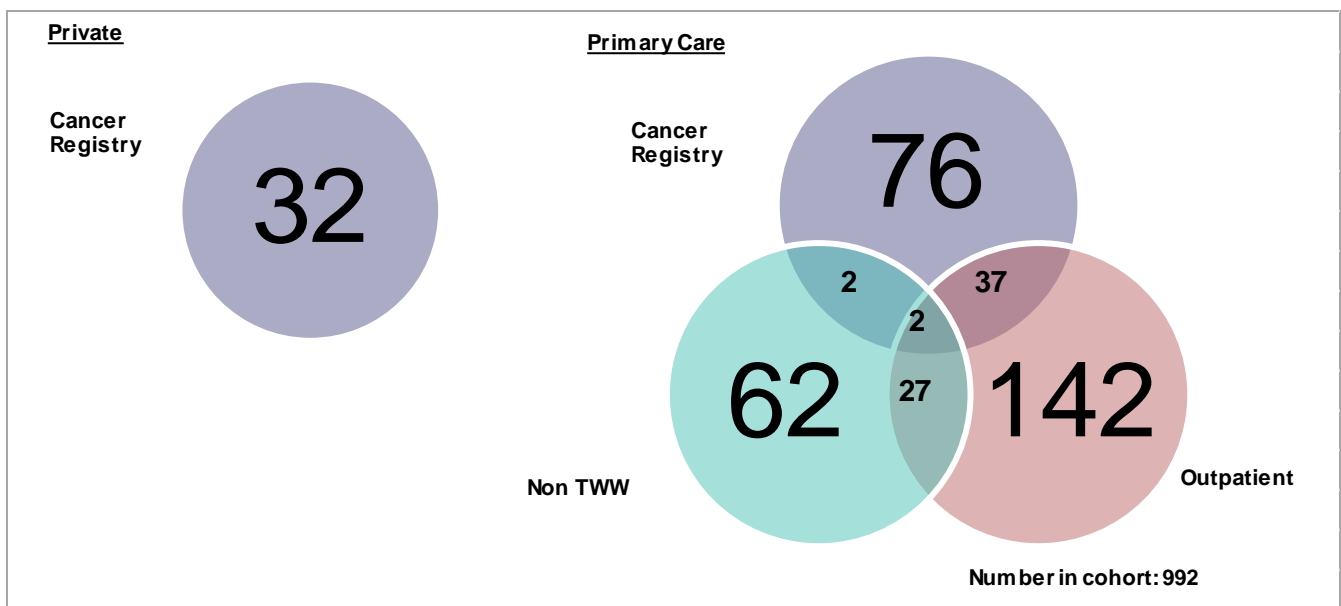
3. Post one-month HES activity

There were 10% (91/992) of MM unknowns that had an inpatient admission within one month after diagnosis, while 27% (273/992) had an outpatient attendance in this same time period and we have taken this to be the route to diagnosis. The outpatient source of referral for these cases indicated that 76% (208/273) were referred by a GP.

Combined data sources summary

Figure 4 shows both the individual and combined contribution of cancer registry data, non-TWW referral data (routine or urgent GP referral) and post one-month outpatient HES activity (with a GP source of referral) on the number of MM unknowns that may be explained by either a private or GP excision. Overall, 3% (32/992) of cases were deemed to be private patients, while 41% (406/992) were either referred to secondary care by their GP or had treatment carried out by their GP (pre- and post-diagnosis).

Figure 4.3: Venn diagram comparing the different data sources that indicate private and primary care setting for MM unknowns, 2006-2008, NCRS-SW.



4. Pathology

The NCRS–SW indicated that 92% (912/992) of MM unknowns were pathology verified. One hundred pathology records were audited and it showed that at least 20% (20/100) of cases were excised in primary care and 3% (3/100) in a private setting. However it is important to note that 42% (42/100) of pathology reports were not available electronically. The first treatment recorded on the cancer registry identified 9% (9/100) additional cases that were excised at a GP setting.

5. Trust audit data

One Trust in the South West accounted for almost 10% (97/992) of the MM unknowns cohort. The Trust audit data, which records information on patient administration, pathology and clinic letters, was used to identify where the first treatment had taken place. Of these cases, 27% (26/97) were first treated at a private practice, while 31% (30/97) were treated at a GP surgery. When this was combined with cancer registry data and post one-month outpatient HES activity, nearly half (49%, 48/97) of these cases indicated that they were either referred or had treatment carried out by their GPs.

5 Discussion

In this study, we have investigated MMs diagnosed between 2006 and 2008 for South West residents registered on the National Cancer Registration Service as having an unknown route to diagnosis derived from the Routes to Diagnosis project.

Data recorded by Trusts provides valuable information on pathology that is not recorded by Cancer Registries, but would inform how patients are diagnosed with their cancer. An audit of one of the Trusts indicated that more than a quarter of cases were first treated at a private practice, and almost a third at a GP surgery; however this will vary across Trusts. It is also clear from examination of the pathology reports alone, that the setting in which the excision took place is not always recorded. In these instances, the Registry records the Trust that sent the pathology, which may not be where the lesion was excised.

Using routine data sources alone, the NCRS-SW data indicated that 3% of MM unknowns were diagnosed or treated privately, while 12% had their first treatment in primary care prior to diagnosis. When combined with non-TWW referral data and Outpatient HES, 41% in total (406/992) were either referred to secondary care by their GP or had treatment carried out by their GP (pre- and post-diagnosis).

However, the proportion of those in a primary care setting increased to 18% when combined with non-TWW referral data (routine or urgent GP referral), and increased further still to 41% when combined with post one-month outpatient HES (with a GP source of referral).

There was no or very little HES activity prior to 6 months to diagnosis for cases with an unknown route to diagnosis, and this may be due to:

- patients diagnosed in a primary care setting, with the GP carrying out the diagnostic procedure of removing the lesion for histology, which is also usually the treatment
- patients diagnosed in a private care setting, indicated by the largest proportion of unknowns in the most affluent areas of England and South West
- data quality issues on HES

6 Recommendation

There is need for improved data collection of the patient pathway to cancer diagnosis as this will increase information on the causes of treatment delay which will enable better commissioning of cancer services. Without access to primary care data, it is difficult to understand the pathway of patients treated in primary care.

Within the mandated data collections for the new national cancer dataset, Cancer Outcomes Service Dataset (COSD), all NHS providers of cancer services should be required to report and submit the setting of the excision of tumors. This would inform how patients are diagnosed, and therefore result in more appropriate referrals and earlier diagnosis of cancer.

Treatment data recorded by the Cancer Registries and non-TWW referrals should also be examined for future iterations of Routes to Diagnosis. The General Practice Research Database (GPRD) and HES records not directly related to the cancer may also explain some of the MM unknowns for which we still do not yet have any useful information.

The Routes to Diagnosis study should also be tailored for different cancers, as in this case, because the management of skin cancer differs from that of many other cancers.

7 References

Elliss-Brookes, L, McPhail, S., Ives, A., Greenslade, M., Shelton, J, Hiom, S., and Richards, M. (2012). Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets. *British Journal of Cancer*, 107, 1220–1226