

# Guidance on clinical coding of cancer patients in primary care

## Purpose

The purpose of this guidance is to:

- Share comparative analysis of prevalence data with stakeholders – data is sourced from the National Cancer Registration & Analysis Service (NCRAS) and primary care registers (from the Quality Outcomes Framework) between 2003 and 2015
- Share an example of how practice coding registers have been ‘cleansed’ in one CCG where all GP practices use the EMIS clinical system.
- Share our learning with NHS England (regarding the national QOF review) and NHS Digital (re the implementation of SNOMED in primary care).

## Background

One in two people will get cancer sometime in their lifetime<sup>(1)</sup>. 56% of people survive their cancer longer than 10 years<sup>(2)</sup> and 70% of people affected by cancer have another long term condition<sup>(3)</sup>. It is therefore increasingly required for cancer to be managed in primary care settings as a long-term condition.

People who have had a cancer diagnosis, irrespective of their prognosis, can experience a range of consequences of the disease and the treatment they receive. These consequences can be physical, spiritual and psychosocial. They will have an impact on the person’s quality of life (and potentially their loved ones) and those consequences may become chronic. Some of the main consequences include fatigue, bladder and bowel dysfunction, heart disease, lymphoedema and osteoporosis. It is also well evidenced that people affected by cancer experience significant financial distress, particularly those who are undergoing treatment and unable to work.

Primary care teams are also taking on the role of managing long term follow up, for example the pan London primary care pathway for men with stable prostate cancer. This pathway sees men with specific criteria (as per NICE clinical guidance on prostate cancer: diagnosis and management [CG175]) receive their PSA blood tests, results and long term holistic needs identified and managed by their primary care team.

The quality and outcomes framework (QOF) has rewarded practices for the provision of 'quality care' and helps fund further improvements in the delivery of clinical care.

Framework CAN001 is defined as: *“The contractor practice establishes and maintains a register of all cancer patients defined as a ‘register of patients with a diagnosis of cancer excluding non-melanotic skin cancers diagnosed on or after 1 April 2003”*.

Performance against this measure has always been highly rated. For example, for 2017/18 in London performance was 97.4%. This is a practice held register and the data is self reported and may not be reflective of the entire prevalent cancer population.

In 2017, Transforming Cancer Services Team (TCST) and NCRAS published 21 year cancer prevalence statistics for England<sup>(4)</sup>. This resource was used to test the completeness of practice held registries against the national cancer registration service. Analysis shows that there are 110,000 more cases on the national register compared to the local QOF register. In London, there are more than 18,000 cases on the national register that do not appear on local QOF registers (Table 1).

It is important to acknowledge that clinical coding is not part of the GP curriculum, so clinicians are not taught the importance of coding accuracy. Furthermore, within and between practices, there will be differences in coding. For example, coding may be completed by GPs, practice nurses, administrative clerks, practice manager etc.

It is also important to bear in mind that with the imminent change from Read/CVTC codes to SNOMED codes in primary care, the QOF cancer code set will change. It is not possible yet to predict whether this change will have a positive, negative or no impact on cancer coding in primary care. Evaluating the impact of SNOMED will be very important to understand.

## Why accurate coding is important for people living with and beyond cancer

Macmillan Cancer Support estimate that there will be 5 million people living with and beyond cancer by 2040 in the UK. In England, General Practice provides over 300 million patient consultations each year, compared to 23 million A&E visits.

With the increasing role of primary care teams managing cancer as a long term condition, and that many consequences can appear years after the initial cancer was diagnosed, it is imperative that primary care teams have accurate practice registers. This is so that patients with a diagnosis of cancer can have their long term needs identified and met appropriately by the service that is most often the first point of contact for the public.

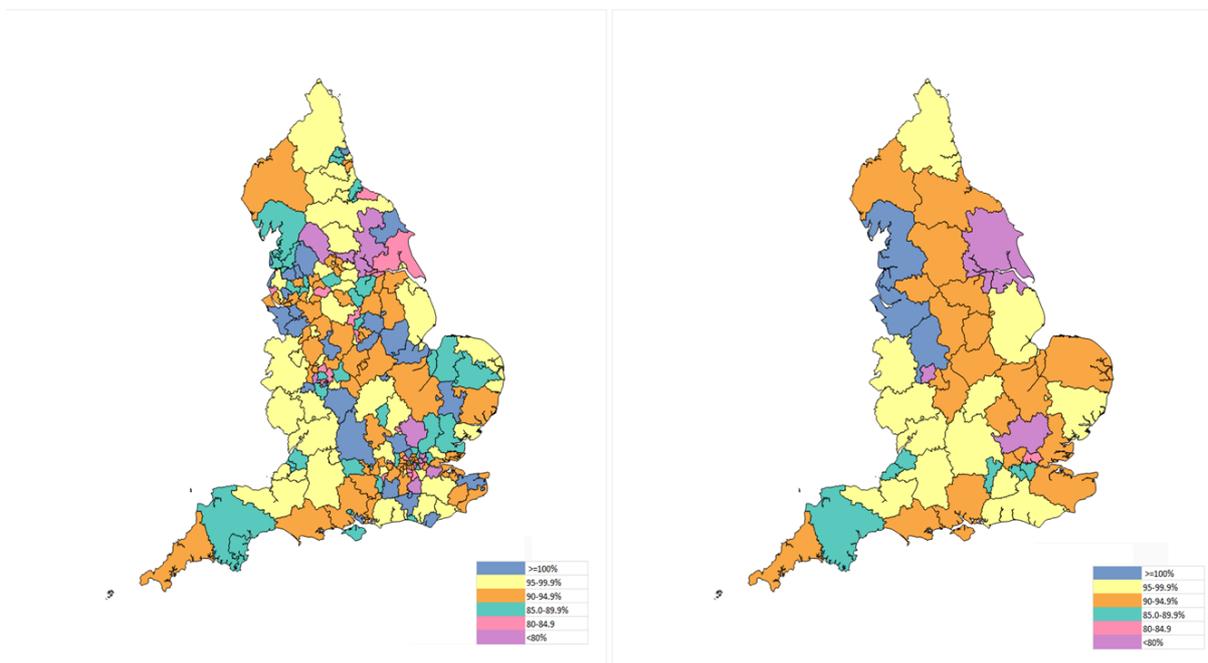
## Comparison of cancer prevalence data sources

A recut of the NCRAS cancer registry 21 year prevalence data was produced to give a prevalent population for patients diagnosed from 2003 to 2015 in England. This was to ensure comparability with QOF registers in England. Data for the 2015 QOF register cohort was then obtained, and a percentage comparison made between the two populations at CCG and STP level.

Nationally, the majority of CCGs / STPs have relatively close matches to the registry prevalent population, with an overall national match of 92.5%. However, this equates to 110,000 more cases on the national register compared to the local QOF registers.

When comparing data from these two sources it is important to consider the following:

- Case coding:
  - the long list of READ codes to define cancer can lead to variation in coding
  - not all READ codes map directly to cancer registration coding
  - the transition between ICD10 and SNOMED may prevent cases being recorded on local registers.
- Migration within the country may cause variation at a local level. However, comparison at a national level suggests that this is not the overall cause of variation.
- The QOF process is not mandatory and a minority of practices do not participate.
- Changes in CCG (formerly PCT) geographies may influence total register sizes at the CCG/STP level.



**Figure 1.** National view of QOF Register / Cancer Registration comparison (By CCG and STP of residence)

Comparison at regional levels shows the following:

Table 1. Comparison of variation between QOF and NCRAS cancer registrations (2015)

Region	Number of CCGs	Total patients recorded on QOF registers	Total patients recorded by NCRAS	Variation in case numbers (2015 Data)	% variation at regional level	Range of 'completeness' at CCG level
East of England	19	136,090	154,128	+18,038 on NCRAS register	13.3%	31.5% - 104.7%
London	32	153,384	171,752	+18,368 on NCRAS register	12.0%	71.9% - 109.9%
Midlands	43	292,904	312,461	+19,557 on NCRAS register	6.7%	9.7% - 314.2%
NE & Yorkshire	33	201,729	225,531	+23,802 on NCRAS register	11.8%	27.7% - 106%
North West	30	188,618	190,231	+1,613 on NCRAS register	0.9%	81.2% - 319.1%
South East	38	231,825	247,252	+15,427 on NCRAS register	6.7%	74.1% - 105.9%
South West	12	162,062	175,787	+13,725 on NCRAS register	8.5%	85.4% - 98.5%
England	207*	1,366,612	1,477,142	+110,530 on NCRAS register	8.1%	N/A

\*geographical boundary changes 'in year' (mergers etc.) can lead to significant % variation at CCG level.

### Tower Hamlets

In this analysis of 2015 prevalence, Tower Hamlets CCG QOF registers were 91% complete when compared to NCRAS, with **2,850** patients on QOF registers and **3,119** in the National Cancer Registry.

There are a number of hypotheses for differences between the different data sources which capture cancer prevalence, but no concrete answers:

1. *Clarification around data definitions: Hospitals report to NCRAS based on ICD-10 codes whereas primary care uses Read codes to report.*

There are many data sources in relation to cancer registers. QOF provides the business rules that define a practice register. Until recently, the rules were detailed in Read codes, which can be mapped to ICD10 codes, whereas now they are detailed in SNOMED codes.

QOF includes only includes codes in the malignant neoplasm branch (not benign, not in situ, not of uncertain behaviour), and excludes non melanotic skin cancers; it only goes back to diagnoses from 2003. This compares well to the NCRAS based prevalence counts, which are also based around malignant neoplasm excluding non melanotic skin.

The annual Joint Strategic Needs Assessment (JSNA) data provided by the Clinical Effectiveness Group (CEG), uses the QOF code-set but does not exclude diagnoses pre 2003, and so these figures are higher than those published by QOF every year. The CEG facilitator also provides ad hoc figures to TH CCG cancer clinical lead for monitoring purposes, and these figures follow the QOF method to the letter (excluding diagnoses pre 2003).

Recent data provided by the East London CEG have shown Tower Hamlets' active list size to be 334,420 and cancer prevalence to be 4,252 as of 1 April 2019<sup>(5)</sup>. This recent prevalence count reflects an up-to date QOF register that is higher and not in-line with previous trends in cancer prevalence increase in Tower Hamlets CCG. As well as the very recent time frame, the implementation of a coding improvement project (outlined below) across Tower Hamlets GP practices has contributed to this higher prevalence. Unfortunately, direct comparison of these latest Tower Hamlets figures to national cancer registrations (NCRAS) is not currently possible over the same time-frame.

- 2. Tower Hamlets has a very high population influx. People diagnosed with cancer in other countries my move into the borough and increase numbers over that expected from the registry. This could be the case in other inner London boroughs but they haven't undertaken the same intensive coding exercise*

## The Tower Hamlets story

### Why did Tower Hamlets want to improve their clinical coding of cancer patients?

Those living with and beyond cancer are not necessarily living well – they often have unmet needs and these are not always identified within primary care or supported. 70% of those with cancer have at least one other long term condition (LTC), they are often seen for reviews of other LTC yet historically cancer related needs are not necessarily being identified or met in these appointments.

One of the early drivers for improving coding in Tower Hamlets related to increasing early diagnosis – i.e. the historical Royal College of General Practitioners' tool was adapted and integrated within EMIS so that correctly coded cancer patients could be identified and their journey from presentation to diagnosis mapped and reviewed for avoidable delays. The tool is dependent on accurate coding as it pulls patients in based on their cancer coded.

A second driver for Tower Hamlets relates to the area's integrated Long Term Conditions (LTC) template – each condition has a specific page highlighting aspects that should be covered within a review appointment as well as links and resources relating to needs identified. The disease specific pages of the LTC template appear automatically, provided appropriate standardised EMIS disease codes are used. It was clear at the start of this work that a multitude of codes were being used for cancer patients and the true prevalence of cancer as a LTC in Tower Hamlets was unclear.

The aim was to:

- Standardise cancer coding, using nationally recommended READ codes where possible
- Improve overall cancer prevalence capture
- Enable the LTC template to pull in all cancer patients and thereby prompt clinicians doing holistic LTC reviews to consider cancer related issues.

### What did they already know about the coding problem?

Coding diagnoses of cancer is not as easy as one would like. Browser will bring up certain codes that look acceptable, but practices then find out that QOF searches are not picking them up and they are not appearing on the practice's cancer register.

Unless a recommended (QOF) code is used, the Tower Hamlets Long Term Conditions clinical template will not "pull in" the patient for the cancer review page. The following are examples:

- [RFC] Lung cancer (HNG0207) – NOT accepted (it is not a national code but an old EMIS LV code)
- Malignant neoplasm of bronchus or lung NOS (B22z) – Nationally accepted code
- Carcinoma in situ of prostate (B834) - NOT accepted (it is considered precancerous rather than cancerous)
- Malignant neoplasm of prostate (B46) – Nationally accepted code

## How do they standardise cancer coding in Tower Hamlets?

The East London Clinical Effectiveness Group (CEG) asks practices to:

- Use the CEG Cancer prevalence improvement searches that have been set up – to generate a list of patients with cancer codes and consider amending to the recommended national B stem codes (i.e. historical QOF cancer codes, often starting with “B”; however, be aware that not all B codes are recommended codes – carcinomas in situ and neoplasms of uncertain behaviour for example are not)
- Review these patient records and where clinically appropriate amend their cancer codes so that the LTC template will “pull in” these patients.
- Check that the national EMIS / Macmillan data Morphology alert pop-up is active (can be activated through EMIS library) this helps flag up patients with codes practices may want to review / amend opportunistically e.g. useful if a new patient registers with a non-recommended cancer code.

The cancer coding work commenced in April 2017 and has been part of an incentivised improvement project (an “enabler”) across all practices in Tower Hamlets. Practices are asked to submit the numbers of historical codes amended and monitor their own cancer prevalence registers and provide reflections on coding issues (see Appendix).

## What difference has this made to TH cancer prevalence?

Analysis of Tower Hamlets cancer data from the East London Database shows that 1.8% (80/4338) were not Tower Hamlets residents, as at 31 March 2018. Out of borough residents were spread across all ages, both genders. 61 were residents of other east London boroughs, 19 lived in boroughs outside of east London<sup>(6)</sup>.

Following the introduction of this Cancer prevalence enabler in April 2017, Tower Hamlets cancer registers identify 4252 patients. This is 1067 more patients (as at 31 March 2019) compared to the pre-enabler registers, representing a 25% rise in recorded prevalence of cancer patients in Tower Hamlets<sup>(5)</sup>. The LTC cancer page is now automatically triggered for these patients.

## What difference has this made to patients?

Tower Hamlets is mindful that improved cancer registers and automatic activation of the LTC cancer page do not in themselves necessarily equate to improved identification of patient unmet needs, quality conversations with patients and the meeting of these needs from a patient perspective. There are plans to review the impact of this work on these important aspects in the coming year.

## Next steps

1. TCST in partnership with Public Health England's National Cancer Registration and Analysis Service (NCRAS) and Dr Tania Anastasiadis, presented this paper at the pan London Personalised Care for Cancer Partnership Board in June 2019.
2. This paper to be presented at pan London Cancer Commissioning Board in summer 2019 with the following recommendations:
  - **TCST/PHE**
    - share analysis nationally with Cancer Alliance Data, Evidence and Analysis Service (CADEAS) and NHS England/Improvement national cancer programme
    - update London prevalence comparison data annually.
  - **STPs/CCGs** – to review local data comparisons via TCST/PHE prevalence pack (to be published in May 2019) and ascertain whether local improvements are required in practice register coding.
  - **Macmillan Cancer Support**
    - share TCST/PHE analysis nationally via Macmillan primary care clinical leaders
    - continue sharing learning from Tower Hamlets (and other areas as they focus on clinical coding) with the primary care community.
  - **Academic Health Science Networks** – to link improvements in primary care coding to NCRI priorities and identify local opportunities for collaboration.

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## References

1. Ahmad et al (2015). Trends in the lifetime risk of developing cancer in Great Britain: comparison of risk for those born from 1930 to 1960. BJC
2. Office of National Statistics (2016). Cancer survival in England: Patients diagnosed between 2010 and 2014 and followed up to 2015
3. Macmillan Cancer Support (2015). The burden of cancer and other long-term health conditions. Available from: <http://www.macmillan.org.uk/Documents/Press/Cancerandotherlong-termconditions.pdf>
4. NCRAS/TCST Partnership (2017). "Cancer Prevalence in England - 21 year prevalence by demographic measures and geographic measures". Available from: [http://www.ncin.org.uk/local\\_cancer\\_intelligence/tcst](http://www.ncin.org.uk/local_cancer_intelligence/tcst)
5. East London CEG data extract on 1/4/19, applying version 38 of the QOF business rules
6. Extract undertaken in February 2019 for the scoping phase of the Tower Hamlets Macmillan Local Authority Partnership Programme.
7. Macmillan-NCRAS Partnership (2015). Macmillan-NCRAS UK Cancer Prevalence Project. Available from [http://www.ncin.org.uk/about\\_ncin/segmentation](http://www.ncin.org.uk/about_ncin/segmentation)

# Appendix 1

## **Cancer Prevalence Enabler quarterly submission document 2018/2019**

NETWORK				
PRACTICE				
DATE				
Date Cancer prevalence improvement search run (CA02 search) and result				
Number of historical cancer codes corrected (where clinically applicable)				
Confirm EMIS morphology pop up activated/checked				
Practice Cancer register numbers at end of each quarter - aim is to show improvement	<u>Q1</u>	<u>Q2</u>	<u>Q3</u>	<u>Q4</u>
Comments/reflection from practices to feed into review meetings				
<b>Support contacts</b>	For clinical queries: ( <a href="#">email</a> ), CCG Cancer clinical lead For submission and payment queries: ( <a href="#">email</a> ), CCG service lead For technical queries (e.g. searches, templates, etc.): ( <a href="#">email</a> ), CEG Facilitator			

## Appendix 2

### QOF / NCRAS comparisons for London (2015)

CCG	Total patients recorded on QOF registers	Total patients recorded by NCRAS	Variation in case numbers (2015 Data)	% variation at regional level
NHS Barking and Dagenham CCG	2,423	3,330	907	72.8
NHS Barnet CCG	8,388	8,280	- 108	101.3
NHS Bexley CCG	5,941	6,349	408	93.6
NHS Brent CCG	5,052	6,015	963	84.0
NHS Bromley CCG	8,455	8,800	345	96.1
NHS Camden CCG	4,270	4,518	248	94.5
NHS Central London (Westminster) CCG	3,591	3,267	- 324	109.9
NHS City and Hackney CCG	4,002	4,439	437	90.2
NHS Croydon CCG	7,328	8,880	1,552	82.5
NHS Ealing CCG	6,269	6,731	462	93.1
NHS Enfield CCG	6,235	6,943	708	89.8
NHS Greenwich CCG	4,220	4,989	769	84.6
NHS Hammersmith and Fulham CCG	3,326	3,661	335	90.8
NHS Haringey CCG	4,571	4,935	364	92.6
NHS Harrow CCG	4,913	5,398	485	91.0
NHS Havering CCG	5,878	6,721	843	87.5
NHS Hillingdon CCG	4,999	5,826	827	85.8
NHS Hounslow CCG	4,693	4,999	306	93.9
NHS Islington CCG	3,656	3,988	332	91.7
NHS Kingston CCG	3,755	3,940	185	95.3
NHS Lambeth CCG	5,435	5,961	526	91.2
NHS Lewisham CCG	4,725	5,522	797	85.6
NHS Merton CCG	3,901	4,691	790	83.2
NHS Newham CCG	3,182	4,064	882	78.3
NHS Redbridge CCG	4,227	5,585	1,358	75.7
NHS Richmond CCG	4,727	5,111	384	92.5
NHS Southwark CCG	3,809	5,294	1,485	71.9
NHS Sutton CCG	4,058	4,921	863	82.5
NHS Tower Hamlets CCG	2,850	3,119	269	91.4
NHS Waltham Forest CCG	4,269	4,822	553	88.5
NHS Wandsworth CCG	5,871	6,238	367	94.1
NHS West London CCG	4,365	4,415	50	98.9