Comparison of cancer prevalence data sources: National Cancer Registry and Primary Care Registers

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INTRODUCTION

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

The quality and outcomes framework (QOF) rewards 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 2015 in London performance was 99.9%

In 2017, TCST and NCRAS published 21 year Cancer prevalence statistics fro England[(4)]. This resource presents an opportunity to test the completeness of practice held registries against the national cancer registration service.

METHODS

A recut of the cancer registry 21 year prevalence data was produced to give a prevalent population for patients diagnosed from 2003 to 2015. This was to ensure comparability with QOF registers.

Data for the 2015 QOF register cohort was then obtained, and a percentage comparison made between the two populations at CCG and STP level.

This data was imported into Tableau to allow for visualisation for a range of geographies.

RESULTS

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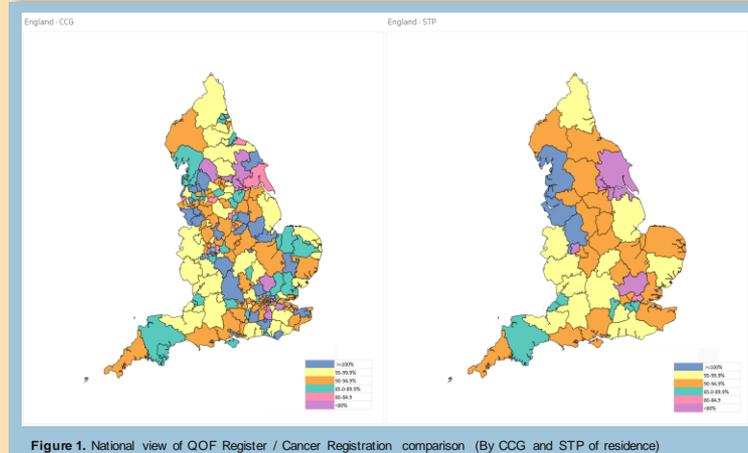
Figure 1. National view of QOF Register / Cancer Registration comparison (By CCG and STP of residence)

- For London, the pattern of variation persists, with 18,000 more cases recorded on the national registry data in the region (range 71.9%-109.9%).

Figure 2. National view of QOF Register / Cancer Registration comparison (By CCG and STP of residence)

DISCUSSION

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 will 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) geography may influence total register sizes at the CCG/STP level.

CONCLUSIONS

Primary care providers should be aware and maintain accurate lists of their patients living with a cancer diagnosis, as a fundamental basis to managing cancer as a long term condition.

We will be working with clinical leads at a small group of practices in London to apply coding cleaning methodologies and identify where coding practices may have influenced local registration.

ACKNOWLEDGEMENTS

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