A Cancer Prevalence Dashboard for London

Guidance to inform strategy and service planning

December 2019

Contents

Acknowledgement

Background

As cancer incidence increases and survival improves, the number of people living with a cancer diagnosis is increasing. Every year, approximately 34,000 Londoners get a diagnosis of cancer. We know that people living with cancer can have a range of short and longer term clinical, functional and psychosocial problems both from their cancer and from their treatment. If not addressed, these problems can have profound effects on individuals and their families, as well as placing avoidable demands on local health and social care services. While each person will have their own individual needs and resources, there are likely to be common problems and potentially appropriate services for people with similar demographic and clinical characteristics.

To understand more about the London cancer population, a Prevalence Dashboard for London was created by the Transforming Cancer Services Team (TCST) partnership with the National Cancer Registration and Analysis Service (NCRAS) at Public Health England (PHE). The dashboard shows that **231,740** people were living with a cancer diagnosis in London in 2017. Data for this work is based on patient-level information collected by the NHS. The data is collated, maintained and quality assured by PHE's National Cancer Registration and Analysis Service.

The dashboard breaks down the 2017 prevalence at CCG, STP and Cancer Alliance level showing for each geography:

- the demographic makeup of the prevalent population (age, sex, ethnicity, socio-economic)
- the number of years since diagnosis of cancer
- the number and proportion of people with cancer by cancer type
- the completeness of GP Quality and Outcomes Framework (QOF) registers compared to PHE National Cancer Registration and Analysis Service (NCRAS) data
- the proportion of patients living with a subsequent primary cancer
- forecasted growth of cancer prevalence to 2030.

The dashboard can be viewed here with a short video explaining how to use it beneath.

Notes on understanding the data

All rates in the Prevalence Dashboard are **unadjusted**, providing a descriptive picture of the population living with cancer in London. Unadjusted rates do not reflect differences in local populations that can affect overall prevalence and that should be considered when making comparisons between localities. The following should be considered when interpreting these data:

- Prevalence is a product of both incidence and survival and should be interpreted with these contextual factors in mind for each area
- Prevalence counts and rates may be lower in an area with a young population profile, where the number of people affected by cancer is likely to be lower
- Low cancer prevalence can be a consequence of a higher concentration of cancer types with poorer survival outcomes (lung, upper GI) - which in turn may be related to the demographic make-up of the local population
- Geographical breakdowns are based on area of residence at time of diagnosis. Some people will have moved since their diagnosis.

Using the cancer prevalence dashboard to inform strategy and service planning

Understanding the make-up of the prevalent cancer population will support the planning of type, location and volume of service provision required in each geography.

1. The needs of people with cancer

For all people with cancer, while individual needs vary and may change over time, they are likely to include:

➢ Physical/functional needs
➢ Psychosocial including family and carer support
➢ Financial including employment and income maximisation
➢ Housing
➢ Palliative and end of life care including bereavement support

Recommended actions based on these needs:

➢ **Map services in your geography** which can meet the range of needs of people with cancer to provide a common resource, and make this widely available, so that patients and carers can be directed to services to meet their needs (e.g. London Integrated Cancer Psychosocial Care Pathway, Cancer Rehabilitation Services in London)
➢ Ensure all cancer patients receive high quality **holistic needs assessment** and **cancer care reviews** in primary care to produce personalised care and support plans
➢ In line with care plans, ensure access to
  - **Cancer prehabilitation and rehabilitation services** which includes dietetics, physiotherapy, occupational therapy, speech & language therapy and lymphoedema services; vocational rehabilitation, which improves quality of life and function with potential for cost savings e.g. decreased length of stay, improved self- management
  - **Cancer psychosocial support** including psycho-oncology and other mental health services, which increases access and take-up of investigations, treatment adherence and engagement in rehabilitation, better clinical outcomes, improved quality of life
  - **Social care** including benefits advice and income maximisation; housing support
  - **Social prescribing**
  - **Healthy living advice** including tailored support to stop smoking, healthy eating, physical activity
  - **Family and carer support** including carers' assessment (67% of carers experience anxiety, 42% depression; of these more than 75% don't get any support)
  - **Specialist palliative care** and bereavement support
➢ Services should **regularly monitor demographic data** on users, to ensure that people with different demographic, geographic and clinical characteristics use services proportionate to their needs and the numbers affected by cancer

2. Needs and recommended actions for people with cancer of different ages

- Cancer incidence increases with age, so the age profile of the local population will affect cancer prevalence rates, and the total population size will affect numbers.
- Inner London CCG areas with younger age profiles tend to have lower overall prevalence; CCGs with larger older populations have higher prevalence.
- It's important to remember that lower prevalence doesn't equate with lower needs.

2.1 Children

The prevalence rate and number of children affected by cancer are relatively low; 0.1% of **0-19 year olds** in London in 2017 (2,556 children) with similar numbers in each STP (range 460 to 588).

Specific needs for children *in addition to those above*: educational; future fertility; palliative and end of life care for children and young people; bereavement support for parents, grandparents and siblings.

Recommended actions for children *in addition to those above*:
➢ In line with care plans, ensure access to:
- Play and education support
- Future fertility and reproductive support
- Integration of health, social care and education including the school health service

2.2 Young and working age adults

Across London, 1.7% of **working age people (20-64**) had a cancer diagnosis in 2017 (96,697 people). Counts range from 16,409 in North Central London STP to 22,021 people in North West London STP.

Specific needs for working age adults *in addition to those above*: parental, family and caring responsibilities; impact on parenting and children's wellbeing; fertility and reproduction; education, training

Recommended actions for working age adults *in addition to those above*:
➢ In line with care plans, ensure access to:
- Fertility and reproductive services
- Adult education, training and employment support

2.3 Older adults

- Prevalence rates are highest in older people. In London 11.0% of people aged 65 to 74 and 14.8% of people aged over 75 have a cancer diagnosis
- In South West London 26,736 people aged 65+ and in North West London 31,659 aged 65+ have cancer
- North East London (23,920 aged 65+) and North Central London (22,225 aged 65+) have the lowest numbers of older people with cancer

- 70% of people with cancer have at least one other comorbidity. Co- and multi-morbidity are more likely in older people

Specific needs for older adults *in addition to those above*: physical and functional including mobility, co- and multi-morbidity, frailty, falls risk; psychosocial needs including the impact of loneliness, isolation and lack of social support; caring responsibilities

Recommended actions for older adults *in addition to those above*:
➢ In line with care plans ensure access to:
  - Integrated services (physical and mental health, social care) which incorporate other long-term condition care; are close to home and include home visits where appropriate
  - Care co-ordination
➢ Ensure that community and voluntary sector provision for older people supports people with cancer, using outreach to identify and engage with them close to or at home
➢ Ensure that older cancer service users are represented/consulted in service planning and steering groups.

3. Gender

- While overall incidence rates for cancer are higher in males, prevalence is significantly higher in females in London. Across London, 2.9% of the female population and 2.4% of the male population have a cancer diagnosis
- Across London and in all STPs, the excess is driven by the high number of women of reproductive and working age (20 – 64) with a cancer diagnosis (59,830 women, 25.8% of all people with a cancer diagnosis).

Specific needs *in addition to those above*: psychosexual; reproductive; continence; upper limb including shoulder dysfunction and lymphoedema (breast cancer); needs of LGBT+ and non-binary people.

Recommended actions relating to gender *in addition to those above*:
In line with care plans ensure access to
  ➢ Cancer rehabilitation
    - for prostate cancer, to include exercise prescription, continence
    - for breast cancer to include physiotherapy, lymphoedema services
  ➢ Psychosexual services and reproductive services where appropriate
  ➢ Gender inclusive non-discriminatory services

4. Ethnicity

- Just over half (51.5%; 119,443) people with cancer in London identify as White. The proportion of non-White people in each geography affected by cancer varies relative to the ethnic make-up of local populations
- Non-White populations in London tend to have a younger age profile, which may be a factor in overall lower prevalence in areas with greater ethnic diversity

- For some cancers there are significantly different [incidence rates](#) between ethnic groups which may affect local prevalence and needs; e.g. prostate cancer incidence is significantly higher in Black men compared to White men, while it is relatively low in men of Asian ethnicity.

Specific needs *in addition to those above*: language and communication; specific cultural and religious practices; overseas travel; family and caring commitments

> **Recommended actions relating to ethnicity** *in addition to those above*:
> In line with care plans ensure access to:
> - advocacy; interpretation; translated resources;
> - culturally appropriate services,
> - inclusive and non-discriminatory services;
> - identifying individual psychosocial needs and offering different options to meet these.

5. Socio-economic status and marginalised groups

As with age, deprivation levels in the cancer population tend to reflect those of the general population in each geography. In CCGs with greater levels of affluence, the greatest proportion and number of people with cancer are in the least deprived quintiles (fifths of the population) with small numbers in the most deprived quintiles:

- In Richmond (high affluence) 3,398 people with cancer were in the least deprived quintile while less than 100 people were in the most deprived quintile
- In Barking and Dagenham (less affluent) no one with cancer was in the least deprived quintile, 39 were in the second least deprived quintile, while 2,593 people were in the most deprived quintile.

Specific needs *in addition to those above*: particularly for people in economically deprived groups - unemployment; type of employment; sick pay (and lack of); travel and other additional costs; housing including street homelessness and unstable housing e.g. temporary accommodation, houses of multiple occupancy (HMO), sofa surfing, overcrowding, poor physical access; family and caring responsibilities; smoking; low levels of physical activity and healthy eating; comorbidity such as severe and enduring mental illness, addiction issues.

> **Recommended actions relating to socio-economic status and marginalised groups** *in addition to those above*: In line with care plans ensure access to
> - Housing advice and specialist homelessness support;
> - Joined up working with addiction services and mental health services

6. Cancer site

Cancer site prevalence has been based on the first cancer diagnosis received in the 23 years to December 2017:

- Breast and prostate cancer are the most common cancer diagnosis amongst the prevalent population. Both have high incidence and relatively high survival rates.
- 1.4% of the female population in London has a diagnosis of breast cancer (60,375 women)

- 0.9% of the male population of London has a diagnosis of prostate cancer (41,478 males)
- 0.3% of the male population and 0.2% of the female population has a diagnosis of colorectal cancer (22,168 people in total)
- Lowest rates and numbers are for cancers with low survival rates (pancreas, liver, stomach, oesophagus, unknown primary); between one and two thousand patients were alive for each across London. Just over 7,000 people in London were alive with a diagnosis of lung cancer
- Service needs for patients with poor prognosis will be different from those who have cancers with better survival but potentially longer term consequences of their disease and treatment.

Specific needs *in addition to those above*: consequences of common cancers (breast, prostate and bowel) and their treatment include musculoskeletal morbidity (arm in breast cancer); deconditioning; fatigue; pain; lymphoedema; incontinence (prostate); prostheses and after care; stoma care; palliative and end of life care needs.

For people with rarer cancers additional needs may include travel to multiple and/or specialist centres without access to a CNS with specific knowledge of that cancer.

Recommended actions relating to cancer site *in addition to those above*:
In line with care plans ensure access to
➢ Care co-ordination for patients with rarer cancers
➢ For patients with rarer cancers, access to cancer psychosocial support, signposting to support services in line with their needs
➢ Specialist palliative care including inpatient and community care with 24/7 access
➢ Integrated health and social care services

7. Time since diagnosis

The health and care needs of people with cancer change over time:
- Across London, almost a fifth (19.7%) of all people with cancer were diagnosed within the previous 2 years
- Almost two thirds (64.4%) had been diagnosed at least 5 years earlier, with the greatest number and proportion in each geography diagnosed between 5 and 10 years earlier (33.2% of the prevalent cancer population)

Specific needs *in addition to those above*: During diagnosis and treatment periods, priorities are likely to relate to coping with treatment and anxiety about survival. Fifteen months after diagnosis cancer patients have 60% more A&E attendances, 97% more emergency admissions and 50% more contact with their GPs than the general population (Nuffield Trust 2014). Over time, patients may have more financial, housing or employment concerns.

With longer survival, a range of clinical and psychosocial needs related to cancer or to the consequences of cancer treatment may emerge or worsen, sometimes years after diagnosis when people may no longer be in touch with cancer services.

Recommended actions relating to time since diagnosis *in addition to those above*:
➢ Accurate coding of all cancer patients in primary care (see also section 9).
➢ Ensure referral pathways exist between cancer teams and other specialists

> - Inter-professional learning with a range of primary and community care teams (NHS, local authority, third sector as well as registered and unregistered workforce) to a) raise awareness of late effects and social needs of people affected by cancer b) improve integration between services
> - Offer long term condition reviews to people with a diagnosis of cancer, which may be part of routine personalised care and support planning for those with multi-morbidities.

8. Patients living with a subsequent primary cancer

- Across London, 5.1% of males and 3.9% of females with cancer have a subsequent cancer diagnosis
- This group are generally older; the largest groups are older men, people of White ethnicity and likely to be more deprived
- At STP level total numbers are relatively small (1,700 to 2,300 people)
- Rates and numbers are highest in areas with older population and higher overall cancer prevalence (5.5% and 4.3% for men and women respectively in South West London) and slightly lower in areas with younger populations and lower overall prevalence (4.4% and 3.6% for men and women respectively in North East London).

Specific needs *in addition to those above*: People who have had more than one cancer diagnosed may have more complex health and psychosocial care needs.

9. Completeness of Quality Outcomes Framework registers

When comparing data from GP QOF registers to the National Cancer Registration and Analysis Service register, it is important to consider the following:

Case coding in primary care
- 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

Geographic differences
- The health geography (CCG/STP) assigned in NCRAS data is defined according to postcode of residence at time of diagnosis
- 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
- Changes in CCG (formerly Primary Care Trust) geography may influence total register sizes at the CCG/STP level
- The QOF process is not mandatory and a minority of practices do not participate.

Recommended actions in relation to coding of cancer *in addition to those above:*
> - Accurate standardised coding of all cancer patients in primary care to support long term management.

10.   Forecasted growth of cancer prevalence to 2030

Caution is urged when interpreting these forecasted prevalence figures. ***These estimates are intended as an approximate guide only,*** as they are not based on explicit modelling of current cancer incidence and survival data for London. Instead, estimated rates of annual cancer prevalence increase from historic, national modelling by Maddams et al (2012) were applied to the current cancer prevalence figures. These modelled rates of prevalence increase may not be applicable to the London population at this point in time.

The dashboard shows how the prevalent cancer population will potentially increase by 52% over the next decade, with projected numbers at Cancer Alliance, STP and CCG level for 2030.

In line with an overall aging population and better cancer survival, there are likely to be greater numbers of people in older age groups living with cancer as a long-term condition with comorbidity.

11.   What the current data doesn't tell us

- The prevalence dashboard is not linked to the results of the National Cancer Patient Experience Survey. We have yet to interpret the data in the context of most recent findings of the NCPES, to understand what level of need and support patients feel that they have in areas of differing prevalence
- A number of detailed demographic indicators which further describe the cancer population cannot currently be reported at population level. For example, sexual orientation and transgender status; living alone; disability including mental health needs; housebound.

Recommended action in relation to understanding the local cancer population

- ➢ The above limitations in accessing detailed information reinforce the importance of routinely collecting and auditing services against locally collected demographic data on the cancer population
- ➢ This should include wherever possible, data about people with cancer who do - and who do not - use services, to understand needs and gaps in service

12.   Further Resources

- **Children**: https://www.macmillan.org.uk/information-and-support/childrens-cancer
- **Comorbidity** at diagnosis for people with cancer: http://www.ncin.org.uk/view?rid=3310
- **Cancer prehabilitation:** https://www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf
- **Cancer rehabilitation**: https://www.healthylondon.org/resource/guidance-for-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation/
- **Cancer rehabilitation services in London map**: https://www.healthylondon.org/resource/mapping-of-pan-london-cancer-rehabilitation-services/
- **Lymphoedema**: https://www.healthylondon.org/resource/commissioning-guidance-lymphoedema/
- **Psychosocial care**: https://www.healthylondon.org/resource/psychological-cancer-support/
- **Cancer Psychosocial services in London map:** to be published here in Autumn 2019 https://www.healthylondon.org/our-work/cancer/
- **Gender:** https://www.macmillan.org.uk/_images/supporting-lgbt-people-with-cancer_tcm9-300546.pdf
- **Inequalities**: https://www.healthylondon.org/resource/cancer-inequalities-toolkit/
- **End of life care:** Ambitions for Palliative and End of Life Care; Macmillan palliative and end of life care framework
- **Consequences of cancer** https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf
- **Coding cancer in Primary Care:** Guidance on clinical coding of cancer patients in primary care