## 1. Executive Summary

## **1.1** Introduction and Findings

- 1.1.1 London Borough of Merton appointed the Public Health Action Support Team CIC (PHAST) to undertake a cancer health needs assessment (HNA) into the current and future healthcare needs in London Borough of Merton. The study was conducted between November and December 2014.
- 1.1.2 LB Merton had good outcomes in cancer, but low levels of screening uptake. It was also known that the good outcomes were differentiated across the Borough. Overall averages showing good outcomes were masking these differences. The principle of equity required that greatest service should be provided to those in greatest need, and this informed the study that was undertaken.
- 1.1.3 The research is based on a mix of qualitative and quantitative methods, including a literature review, a review of existing data and interviews with key stakeholders, such as patients, relatives and voluntary originations.
- 1.1.4 The key issues underpinning this assessment were:
  - A good overall record of cancer detection, management and outcomes in the LB of Merton
  - Within the borough there were wide variations
  - The Public Health Department in the Council, and Clinical Commissioning Group wanted to understand this better and receive practical and implementable recommendations to improve the situation.
- 1.1.5 The demographic profile of Merton as with many other communities in London the population is ageing and over time there will be fewer working age persons to support that population. As cancer is predominantly a disease of older age, there are likely to be many more new cases and as treatment improves, there will be many more people who have experienced a range of cancers, living in the population. This is the measure of prevalence which grows both with an increase in new cases and with increasing numbers for whom cancer is a long term condition rather than a short term or terminal illness.
- 1.1.6 There are over 200 types of cancer. A GP might expect to see six or seven patients being diagnosed with one or other cancer in a year. This is not an easy task, because of the comparative rarity but also because the symptoms can be quite common, and present in a range of other diseases. Diagnosis sits on a very fine line.
- 1.1.7 The PHAST team spoke to people using and providing services. Based on a small number of respondents there are a number of opportunities identified and discussed, for providing a more equitable service. Equity requires more input where there is greater need, rather than everyone receiving the same inputs. Interviews with people who have experienced cancer, the pathway towards and beyond diagnosis, and also treatment services, give a number of indicators for improving that pathway. Because one desired outcome was earlier diagnosis in order to attain better outcomes, the report gives much focus to this "front end" of the cancer journey.
- 1.1.8 Evidence was also reviewed on primary prevention, indicators such as smoking, obesity, physical activity and alcohol, control of which can lower the incidence of many cancers. These indicators were relatively good for the borough, but again, likely to be variable in smaller areas. The Public Health Outcomes Framework shows lower cancer mortality (male and female aged under 75 years) but also confirms Breast and Cervical screening uptake rates which could be improved. Incidentally vaccination and immunisation rates are "red" in Merton, including for HPV vaccination which is protective against cervical cancer, and this indicates poor health protection in the community organised in primary care.
- 1.1.9 Cancer screening for breast, bowel and cervical cancer is effective and cost efficient, and allows for early diagnosis which can result in better outcomes. However uptake rates for



the borough as a whole do not reach national targets.

- 1.1.10 Breast screening uptake was analysed by GP practice and the lowest uptake was found in areas of greatest deprivation, but also in patients registered with two practices in more affluent areas. It is possible that women from these practices receive screening through private health arrangements and these are not recorded on the NHS databases. However we do not know.
- 1.1.11 It was noted that the fixed centres for breast screening are all outside the borough, and that some of the more deprived areas are the furthest distance from the screening centres.
- 1.1.12 Bowel Screening, a relatively new programme also has low uptake rates, but this is common in England. Merton has the third highest rate of the six boroughs in South West London. Although London as a whole has low uptake, St George's is the exception with an uptake rate of more than 50%.
- 1.1.13 Cervical Screening uptake rates nationally have been falling gradually since the 1990s. In Merton the rates are below the target and with a rising trajectory from the less affluent areas. A number of initiatives have been taken across England, seeking to understand the reasons for low uptake and to improve that situation through social marketing interventions. These are separately reported on in Appendix 6.
- 1.1.14 However these are services which have gone through yet another but far greater period of change than ever before in the NHS. Commissioning arrangements and the responsible bodies have changed. But the concern is that an even better service can be developed and this is the reason for this current project. The London Borough of Merton has comparatively good outcomes compared well with London and England but the concern is that within the borough those outcomes should be available to all.
- 1.1.15 This project has focused very much on the front end of the cancer journey where the greatest gains are to be realised in improved outcomes and reduced mortality rates.
- 1.1.16 There is much good practice in Merton and the public awareness of cancer, its symptoms and treatments will naturally support early attendance for diagnosis and clearer judgements being made by GPs.
- 1.1.17 The literature review showed an effect that might be surprising, that deprivation is not solely a personal experience but can also be exhibited by an area (spatial / locality effect) which affects all those within it even those whose own circumstances might not be socioeconomically deprived.
- 1.1.18 Poor awareness of symptoms and a whole range of reasons for avoiding a consultation with a doctor, may be a greater factor in late diagnosis than waiting times. There is evidence of people not getting a diagnosis in a timely manner, but personal delays on the part of the public play a significant part.
- 1.1.19 Ethnic minorities, and especially African women referred to being particularly uncomfortable commencing a discussion about intimate details immediately on sitting across the desk from the GP. They needed some light conversation as an introduction to enable the more important conversation to take place. Tamil speaking women would rarely question the doctor, even if they did not understand or could be turned away with a serious condition not disclosed. A strong sense of reticence prevailed. A copy of a referral letter with a note written on it about what to do if not appointment is received would help. It is likely that these barriers are also experienced by other minority ethnic groups.



## **1.2** Recommendations

Using the combined findings from literature, local data with wider comparators, and interviews with service users, the following recommendations are made:

- 1. Awareness of cancer symptoms among the general public must be increased in a way designed to work for people of the lowest socioeconomic status. The reality of personal risk must be communicated.
- 2. In a context where the church/ mosque/ ghurdwara (Sikh temple) play a part in the lives of local people, clinicians and faith leaders should work together within the context of religious beliefs to encourage clinical investigation and treatment, supporting this without compromising personal beliefs and faith.
- 3. The specific association of socioeconomic deprivation and minority ethnicity must be taken into account in planning service delivery; women of lower socioeconomic status are less likely to access breast screening, and ethnic minority women less likely to go for cervical cancer screening. These indicators for poor attendance should be addressed
- 4. The success "Be Clear on Cancer" campaigns suggests that local messages in support, and campaign timetables to coincide with national programmes would yield success.
- 5. Travel time to breast screening services and treatment centres should be investigated. Where this is found to be associated with low take-up, a mobile service should be considered.
- 6. Written information about cervical screening is provided in several languages but apparently not in Tamil. This should be investigated and rectified.
- 7. Special attention should be paid to the particular cervical screening needs of women who have never been sexually active, women with learning disabilities, lesbian and bisexual women, postmenopausal women and those who had been subject to genital mutilation.
- 8. Screening attendance may be more successful if reminders are texted to mobile phones. Numbers should be available in the GP surgery.
- 9. Screening is the responsibility of Public Health England. However GPs are well placed to offer information and reminders for opportunist encouragement to screening uptake. The opportunity to reach out to communities with appropriate public health messages may have been lost, though concerned clinicians can always do this. Any evident gaps were the effect of the transition of services (Public Health and PCTs).
- 10. Further investigation is needed to understand low levels of participation in bowel cancer screening. Some research is underway to ascertain whether a more acceptable method of carrying out the test would be effective, or whether uptake will increase as the population becomes more familiar with the screening programme.
- 11. The elevated risk factor of ethnicity for Afro-Caribbean people, of aggressive breast cancer in women and of prostate cancer in men should be considered by GPs. Equity requires that those at greatest risk should attract greatest concern.
- 12. Patients should be advised on how to "Make the most of your appointment" (see <a href="http://www.nhs.uk/choiceintheNHS/Yourchoices/GPchoice/Pages/GPappointments.aspx">http://www.nhs.uk/choiceintheNHS/Yourchoices/GPchoice/Pages/GPappointments.aspx</a>) either through reference to this website or with local information. Those with different cultural backgrounds may not understand how best to use the appointment time.
- 13. Practices should have in place a protocol to ensure that a fax for a 2WW referral has been sent, and not left by the fax machine, that it has been received and that the patient has received an appointment, or knows what to do if they do not hear within a defined number of days.
- 14. All patients should receive a copy of a letter of referral, with a note indicating when and what they should do if the referral is not received.
- 15. Those with cancer who present as emergencies or in a late stage should be the particular concern of the MDT and an audit might be informative.



- 16. Further work on the contribution of the acute services should be added to this report when it becomes available. This includes uptake of direct access to cancer diagnostics for GPs and staging results for the common cancers in Merton.
- 17. People who live alone and in disadvantaged circumstances may need greater service input to be enabled to access the choice to receive the Hospice at Home service.
- 18. Training should be provided by cancer consultants at GP training sessions to improve referrals and symptom recognition. GPs should be encouraged to consult about a particular patient or set of symptoms to assist in decision making.

