

P632 Cancer Health Needs Assessment London Borough of Merton

Final Report

Version: Final
Ref No: P632
Date: 27 November 2014
Author: Simons
Commissioner: Dr Anjan Ghosh, Consultant in Public Health LB Merton

Document Details

Date of Issue [27/11/2014] Version Final

This research has been undertaken by the Public Health Action Support Team (PHAST). The work was commissioned by London Borough of Merton.

Commissioner Lead Contact Details

Name: Dr A Ghosh

Role: Public Health Consultant

Address: LB Merton

Email:

Telephone:

Name: Margaret Simons
Role: Project Lead
Address:
Email: Margaret.simmons@clara.co.uk
Telephone: 01582 420140
Mobile: 07974 692444

Table of Contents

1.	EXECUTIVE SUMMARY	4
1.1	INTRODUCTION AND FINDINGS.....	4
1.2	RECOMMENDATIONS	6
2.	INTRODUCTION.....	8
2.1	ASSESSMENT CONTEXT.....	8
2.2	ASSESSMENT AIMS:.....	8
2.3	BACKGROUND.....	8
3.	METHODS AND APPROACH	11
4.	LITERATURE REVIEW	12
4.1	METHODS.....	12
4.2	RESULTS AND DISCUSSION.....	12
4.3	FINDINGS.....	14
4.4	RECOMMENDATIONS FROM THE LITERATURE REVIEW	16
5.	DEMOGRAPHIC PROFILE	17
6.	EPIDEMIOLOGY.....	20
7.	CURRENT SERVICE PROVISION.....	23
7.1	PREVENTION AND SCREENING.....	23
7.2	ACUTE SERVICES KINGSTON, EPSOM AND ST HELIER, ST GEORGE’S, TERTIARY ROYAL MARSDEN HOSPITAL ..	26
7.3	PALLIATIVE CARE SERVICES.....	33
8.	EVIDENCE OF HEALTH DEMAND	34
8.1	INTRODUCTION	34
8.2	METHOD.....	34
8.3	SUMMARISED FINDINGS AND RECOMMENDATIONS	34
9.	CONCLUSIONS AND RECOMMENDATIONS	37
9.1	CONCLUSIONS.....	37
9.2	RECOMMENDATIONS	37
	APPENDIX 1: REFERENCES FOR LITERATURE REVIEW	39
	APPENDIX 2: INTERVIEWS WITH SERVICE USERS AND REPRESENTATIVES	41
	APPENDIX 3: DATA COLLECTION.....	45
	APPENDIX 4: MERTON CCG MATRIX: INDICATORS BY SURGERY	48
	APPENDIX 5: A TABLE IDENTIFYING GENERAL PRACTICES BY THEIR CODES AND LOCALITY.	50
	APPENDIX 6: SOCIAL MARKETING: INCREASING UPTAKE OF CERVICAL SCREENING	51

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 organisations.
- 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/ gurdwara (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, post-menopausal 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 <http://www.nhs.uk/choiceintheNHS/Yourchoices/GPchoice/Pages/GPappointments.aspx>) 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.

2. Introduction

2.1 Assessment context

- 2.1.1 This report was commissioned to provide evidence that would improve the understanding of the current health needs of people at risk of cancer, people who have cancer, and people who have survived a cancer episode, and to inform future provision of health care in London Borough of Merton. The research has been carried out by the Public Health Action Support Team CIC (PHAST), a not-for-profit group of experienced public health professionals. This work has been commissioned by the Public Health department, London Borough of Merton and the Merton Clinical Commissioning Group.

2.2 Assessment aims:

- 2.2.1 This report provides a body of evidence, supported by appropriate quantitative and qualitative data, about the health and healthcare needs of the people of the London Borough of Merton.
- 2.2.2 The Needs Assessment fully acknowledges the comprehensive work in the chapter on Cancer in the 2013/14 Merton JSNA.
- 2.2.3 The HNA also builds on the work undertaken by North West London Commissioning Support Unit undertaken in collaboration with PHAST, "Earlier Detection of Cancer – using Practice Profiles and other development tools to improve the management of cancer in primary care", March 2014.
- 2.2.4 The particular focus of the current report is more local, responding to analysis showing lower screening uptake, and higher prevalence of cancer in certain parts of the borough.
- 2.2.5 The report was to focus on breast, bowel, prostate and lung cancers which together constitute 54% of all cancers, melanoma and cervical cancer.
- 2.2.6 This report makes recommendations based on: scientific evidence from the literature; analysis of data on current services and users; and consultation with users, providers and commissioners of healthcare services.
- 2.2.7 There are many indicators shown by charts, each relating to a single indicator comparing data across Merton. In Appendix 4: Merton CCG Matrix: indicators by surgery, they are grouped differently so all data about each practice can be viewed in one place.

2.3 Background

- 2.3.1 This report has been commissioned by Merton Clinical Commissioning Group and London Borough of Merton Public Health. These new organisations were formed in 2013 from Sutton and Merton PCT, and the move of Public Health from the NHS to become part of the London Borough of Merton. This has allowed opportunity to focus on patterns of prevention, referral and treatment of cancer in Merton.
- 2.3.2 Response to cancer is made through statutory health services, prevention through local authority public health provision and third sector including voluntary and state supported organisation in prevention, survivor support, and palliative care services. Primary prevention of cancer is particularly important and may be achieved through control of tobacco, alcohol and obesity as risk factors with diet and physical activity being protective against a number of cancers.
- 2.3.3 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.
- 2.3.4 An interesting first finding is the difference in results published in the Request for Quotation Document which gave rise to this report which quoted 'Public Health England 2014 Health

Profile for Merton' and 'Public Health England, Longer Lives'¹, and the results one year later for Merton. Based on data from GP registers Quality and Outcomes Framework (QOF) for 2013/14, the number of people in Merton who had cancer was 1.6% of the population compared with 1.4% for Merton in 2011/12 and 2.1% nationally. This may mean improved recording or a rise in cancer incidence (new cases within a specified time period) and/or improved treatment so that more people are living having experienced cancer.

- 2.3.5 For premature deaths due to cancer (in people aged under 75 years) many of which are considered preventable, in the period 2010-13 Merton had 461 premature deaths compared with 89 premature deaths in 2009-11 per 100,000 population adjusted for various factors, including the age of the population. Out of 150 local authorities this ranked Merton 10th best in all Local Authorities, still in the 'best outcomes category' for premature mortality, although its position has slipped from second in 2009-11.
- 2.3.6 Higher levels of cancer are found in the more deprived areas and in Black and Minority Ethnic (BME) groups, reflecting an inequality in the burden of the disease, with the highest rates of under 75 mortality in Cricket Green, Ravensbury and St. Helier wards. The rate in Pollards Hill has now improved and is no longer compares unfavourably with the rate for England.

Figure 2.1 London Borough of Merton: Wards



- 2.3.7 Cancer screening rates in Merton are lower than the national targets and Merton has the third lowest bowel cancer screening uptake in South West London (Wandsworth, Croydon, Merton, Kingston, Sutton and Richmond).
- 2.3.8 Cancer screening programmes are the cornerstone of primary and secondary prevention and these cover breast, cervical and bowel cancer. Nationally a little under one third of all cases of breast cancer are diagnosed following a routine screen.

In terms of the coverage for all these programmes (see Table 2.1 below), Merton is well below the national target. A snap-shot for breast cancer screening indicates that at 64.8% Merton is well below the 80% coverage target. Similarly for bowel cancer screening Merton has the third lowest coverage rate in South West London at 51%. Merton does poorly for cervical cancer screening in 25- 49 year old women while in 50-64 year old women it is closer to the national target.

¹ <http://longerlives.phe.org.uk/areadetails#are/E09000024/par/E92000001>

2.3.9

Table 2.1 Cancer screening coverage in Merton is significantly lower than for England:

Programme	Merton	England	England worst	England best V
Breast screening	66.2	75.9	57.4	83.7
Cervical Screening	69.7	74.2	59.5	79.7

Source: Public Health Outcomes Framework www.phoutcomes.info 2014

2.3.10 See figures 7.1 – 7.4 for reporting of the distribution of uptake of screening showing variation by GP practice grouped by locality for East Merton, Raynes Park and West Merton

3. Methods and approach

This report provides a description of cancers in Merton, and considers the health conditions, services and gaps, based on the analysis of all available and relevant data, and consultations with key stakeholders, including providers and service users.

A traditional approach to health needs assessment has been taken: how many cases do we expect to find and how many are there, what services are offered to meet the demand and where are the gaps, and what is the response of people using the services?

Because there is such a close correlation between high levels of deprivation (both of a general area and of individuals and families) and poor experience of cancer services and outcomes, most charts in this report include deprivation scores, so services and service uptake can be related to the area of occurrence.

4. Literature Review

The literature review was based on the question "How can we improve earlier diagnosis to reduce inequalities in cancer outcomes?"

4.1 Methods

Keywords were:

- Cancer outcomes
- Earlier diagnosis
- Reduces inequalities in outcomes

For each topic synonyms were developed:

Cancer outcome* / Cancer survival / Cancer survival rates / Cancer death / Cancer mortality / Cancer years of life

Earl* diagnosis / presentation / visit doctor / evidence best practice / referral / "best practice treatment" / "best practice management" / "best practice identification" /

Reduc* inequal* in outcomes / deprivation/ethnic* / fear / ignorance / bravado / denial /

The review searched the following databases: Medline, CINAHL and HMIC (Health Management Information Consortium). A keyword search was conducted. The search yielded 42 papers of which 6 papers were relevant. DN does this seem a small number given Cancer is such a common topic for research and publication? HMIC added no papers to the search. A Thesaurus search was then conducted using "neoplasms" exploded to a number of terms: [di=Diagnosis, ep=Epidemiology, et=Etiology, pc=Prevention & Control, sn=Statistics & Numerical Data]. This was used to search Medline and CINAHL and produced over 412,000. This was reduced by applying systematic review, literature review and "meta analysis" to the results.

In addition to the systematic review related specifically to cancer, some points are added at the end of the review on social marketing from previous research, and the value of some approaches to increase screening uptake and of avoiding delay in seeking a potential diagnosis.

4.2 Results and discussion

Thirty-three papers were identified for relevance, applicability to the question and being recent publications. Papers before 2000 were rarely included.

Some studies identified two types of deprivation affecting cancer, the structural macro-effects of an area of deprivation, in the north of England, leading to later stage diagnosis and especially in the case of colon cancer, to reduced access to treatment. (Crawford et al 2012). But this study included both socioeconomic deprivation and travel time to treatment centre in the analysis. A large cohort population study found that "different and independent socioeconomic variables are inversely associated with different cancer risks in both sexes; no one socioeconomic variable captures all aspects of socioeconomic circumstances or life course. Association of multiple socioeconomic variables is likely to reflect the complexity and multifaceted nature of deprivation as well as the various roles of these dimensions over the life course": Sharpe et al (2014) in analysing area deprivation found it remained significant after full adjustment suggesting the area deprivation cannot be fully explained by individual variables. "Regardless of cancer group, elevated risk was associated with no education and living in deprived areas."

Travel time to services referred to above has also been found to be significant (St Jacques et al 2013).

But patient barriers also operated at a personal level, those that patients applied to themselves either as emotional response to themselves, or attributing the response to their family. These also related to socioeconomic deprivation. A small study identified some

specific concerns which might cause an individual to delay presentation to a health care professional: fear of what might be found, ease of speaking to the doctor, the influence of family on decisions to attend, and the importance of a person's gender on perceptions of health-seeking behaviour. It was important to view the 'cancer journey' as including the journey leading up to a diagnosis of cancer (Leydon et al 2003).

A number of papers identified barriers using different analyses, barriers which were emotional or practical, individual or community, different barriers erected by men or by women, by the economically deprived compared to barriers put up by the more economically secure. Different barriers also produced different responses, so in a large trial of the Cancer Awareness Measure, respondents from lower socioeconomic status (SES) groups were found to endorse *emotional* barriers – worried about what the doctor might find, embarrassed and not able to speak plainly to the doctor. Respondents from higher SES groups reported more *practical* barriers, being too busy at work, or maybe a family event that had to be got through first (Robb et al 2009). The same study found that this was not carried through to access to services, where there was a difference in not wanting to "waste the doctor's time", demonstrated by 40% of white patients compared with only 24% of ethnic minorities.

Forbes et al (2014) analysed delay in presentation leading to poorer survival (delay from symptom onset to presentation by more than three months). Delay was associated with lower socioeconomic status but not age or sex, and delays also varied according to the types and location of the symptoms. A recommendation in this paper was to increase awareness of the significance of cancer symptoms among the general public, designed to work for people of the lowest socioeconomic status. In particular, awareness that rectal bleeding is a possible symptom of cancer.

A more specific recommendation was made in a study in the USA by Northington, Martin and Walker (2011), for a three-pronged integrated community education model (i.e. faith-based, community, and state agencies) particularly for African-American women. This was linked to a tendency, referred to by Mitchell et al (2002), for women with strong religious beliefs to defer consultation with a doctor preferring to seek prayer, religious intervention with or without treatment. The recommendation here was that clinicians and clergy work together within the context of religious beliefs to enhance early detection and survival from breast cancer, a recommendation that would also be valuable to Merton.

An identified belief system (fatalism), was linked to a belief that cancer was incurable. This belief was observed to delay medical consultation by more than nine months (Chojnacka-Szawlowska 2013), but it was also a factor in low screening uptake where fatalism was associated with being less positive about early detection and more fearful about seeking help for a suspicious symptom (Beeken et al 2011). Bourdeanu et al (2013) described barriers at a personal level included fatalism. It was found that low socio-economic status had been linked to fatalism regarding lung cancer which might account for differences in incidence, presentation and outcomes.

This finding is at variance with the work of Cheyne et al (2013) at a large UK teaching hospital where "if cancer fatalism is more prevalent in deprived populations, this does not appear to lead to later diagnosis nor worse disease outcome".

However a number of studies addressed delays in presentation or diagnosis of lung cancer. "This may simply reflect higher incidence of the disease, or additionally delayed presentation and worse outcomes amongst more deprived patients" (Cheyne et al 2013). However, one study described substantial delays in 28.1% of patients from presentation to when they sought therapy at hospital in the USA. The study (Bourdeanu et al 2013) found that the high prevalence of patient barriers versus physician/system barriers suggested that increased educational efforts for patients and health care professionals are needed.

One paper (Taylor-Philips et al 2013) reported an observational before and after study to assess the effect on uptake of screening following the publication of the Marmot Review and associated press coverage. No effect was found. It follows that raising public awareness is quite a fine-tuned process which needs professional management.

Uptake of screening has been the subject of a number of papers. The Populus poll of 2008 found that 32% of non-white women were unsure about their risk of developing cervical cancer, compared with just 18% of white women. This paper found that sensitive

communication and consideration of women's health beliefs was significant particularly in ethnic minority groups and advocated attention to a lack of information regarding the concept and purpose of screening, fear and embarrassment, language barriers and cultural embargos from male partners. It is still the case that screening and treatment may be provided by male doctors. Written information about cervical screening is available in several languages, Bengali, Urdu, Gujarati, Cantonese and Polish.

A large study in the UK (Moser, Patnick, Beral 2009) found that 91% of women aged 40-74 years reported ever having had a cervical smear, and 93% of those aged 53-74 years reported ever having had a mammogram; but 3% of women aged 53-74 years had never had either breast or cervical screening. There were clear indicators of correlation with take up: women were significantly more likely to have had a mammogram if they lived in households with car(s) and in owner occupied housing compared with rented housing; for cervical screening, ethnicity was the most important predictor; white British women were significantly more likely to have had a cervical smear than were women of other ethnicity.

But there were also groups for whom a specific approach was needed: previous sexual abuse, women who have never been sexually active, women with learning disabilities, lesbian and bisexual women, post-menopausal women and those who had been subject to genital mutilation.

A number of recommendations for improving uptake of breast cancer and which showed success were given in a study in Tower Hamlets (Eilbert 2009). These included text messaging (with the proviso that GP surgeries hold mobile numbers), community outreach workers and a "Bosom Buddy" scheme (being piloted).

One study countered the suggestion that South Asians GPs were more likely to have negative attitudes towards bowel screening using FOBt. The authors conducted a survey of 3,191 GPs and with a 30.7% response found that practices in deprived locations and GPs being of Asian or Asian British ethnicity were more likely to have positive attitudes to FOBt and its recommendation to patients (Damery, Clifford, Wilson 2010).

Some cancers do have different clinical profiles in different groups of people. Black ethnic groups have a higher breast cancer mortality than White groups. American studies have identified variations in tumour biology and unequal health-care access as causative factors. This is also borne out in the work of Copson et al (2014) relating to tumour pathology, treatment and outcomes in three ethnic groups in young breast cancer patients treated in the United Kingdom. Despite equal access to health care, young Black women in the United Kingdom have a significantly poorer outcome than White patients.

Unequal access has also been identified in hospice at home services. Campbell et al (2010) explored differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester. Referral rates were lower and cancer mortality higher in the most deprived areas (Salford). Referral rates were significantly associated with deprivation, particularly multiple deprivation, but not significantly associated with cancer mortality (service model and resources available were held constant). At the population level, the socio-economic characteristics of those referred to hospice at home rather than service provision strongly predicted referral rates. Inequalities of referral were strongly related to both global deprivation (shown by the Index of Multiple Deprivation) and discrete deprivation indicators at the population level.

4.3 Findings

- 4.3.1 A number of papers drew attention to the close correlation between deprivation, in an area or in personal circumstances with poor attendance at screening and higher prevalence of cancer with poorer outcomes.
- 4.3.2 Other factors were identified as causing delay in a patient attending the GP with a problem. These included fear of the diagnosis, or conversely concern not to "waste the doctor's time". The question of family loyalty and the contribution of the patient to family support may lead to unwillingness to admit to illness. The individual may perceive a potential loss of love and acceptance towards themselves if they admit to serious illness. Avoidance tactics were also

classified; some were more likely to be used by women, others by men, some arguments (possibly not expressed) were emotional, others practical. Emotional arguments were more likely to be expressed in lower socioeconomic groups: "worried about what the doctor might find, embarrassed and not able to speak plainly to the doctor" whereas wealthier people might avoid going to the doctor as they were "too busy" and had important engagements they wanted to fulfil before going to the doctor.

4.3.3 These barriers had to be recognised and overcome. It was seen that this could be done to an extent but keeping cancer in the public chatroom, so it was socially acceptable and symptoms were more difficult to deny. A strong message was that a cancer diagnosis is no longer a death sentence, but facing it early and seeking help reduced the seriousness further.

4.3.4 Social marketing takes concepts known to be effective in everyday marketing and applies them to social situations in order to obtain the return which is sought as might also be found in everyday marketing. The techniques have been applied to the world of health and health promotion, for example, what people will forego to obtain the product, where the product can be found or how it gets to the customer, and minimum inconvenience for continued customer engagement. Commercial marketing is often focused at selling something to increase comfort, satisfaction, and conspicuous wealth. Instead, social marketing may be trying to "sell" less attractive commodities:

- give up an addictive behaviour (stop smoking)
- change a comfortable lifestyle (reduce thermostats)
- establish new habits (exercise five days a week)
- give up leisure time (volunteer)

A key feature of marketing in its relevance for screening is the principle of exchange. You accept the inconvenience and possible discomfort of screening for the benefit of protecting your future health. This message needs to be announced clearly. For people from cultures where screening is not known (Sri Lanka) or the word is not capable of being translated (Polish), or the processes are anathema to the ethics and lifestyle (the Muslim world where there is a strong sense of fatalism, and where women are expected to remain private and covered), a strong message of the return on the exchange needs to be made, and not just to those receiving screening but to their families as well. Understanding the potential benefit minimises the "cost" to the customer.

There is a higher cost to potential participants:

- who have never previously been scanned
- who perceive lack of evidence (unconvinced or uninformed)
- in transportation costs
- in loss of earnings (a morning off work to attend)
- who forget to attend and need to rebook (GP letters are needed to encourage attendance)

Trusted local community workers, health trainers and Health Champions are well placed to market the opportunity for screening if they understand the exchange that is being asked. The message could be specific to the market segment (age, sex, ethnicity) and "fronted" by someone of consequence to the individuals concerned (much as TV advertisements include famous faces to add desire and attractiveness to the product being marketed).

The same arguments could be made for patients in terms of early attendance at the GP surgery where there are symptoms suspicious of cancer. Here the "exchange" could be a better outcome; that delay is not a good option – the opportunity might have gone – that you will serve your family better if you keep yourself fit and strong. This is a topic slightly beyond the remit of this report, and a more comprehensive set of ideas and arguments are available and might be considered for increasing screening uptake and early diagnosis.

Please see Appendix 1 for references.

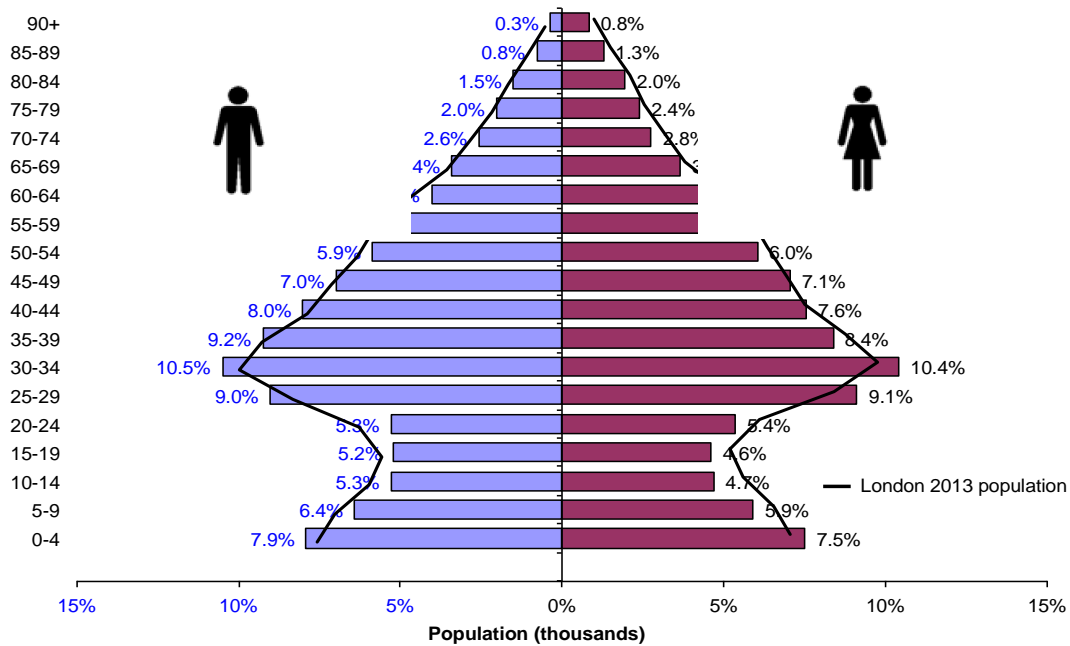
4.4 Recommendations from the Literature Review

- Increase awareness of the significance of cancer symptoms among the general public, designed to target people of lower socioeconomic status (Regardless of cancer group, elevated risk was associated with no education and living in deprived areas). Local efforts should be aligned with the national Be Clear on Cancer initiatives. It was suggested that increased educational efforts for patients and health care professionals are needed.
- Make available written information about cervical screening and other screening programmes in local minority languages.
- Travel time to services has also been found to be significant and should be investigated in Merton and specifically related to uptake of breast screening services, and also treatment centres.
- Particular attention should be paid to groups at risk of exclusion from screening: those with previous sexual abuse, women who have never been sexually active, women with learning disabilities, lesbian and bisexual women, post-menopausal women and those who had been subject to genital mutilation. Practical interventions found to be successful in Tower Hamlets should be introduced – text reminders and “bosom buddies”.
- Principles of social marketing should be considered in encouraging uptake of screening. Little has as yet been published on increasing uptake of bowel screening though an interim report on a social marketing trial in NE London is available at http://www.resonantmedia.co.uk/portfolio-bowel_cancer.php, results requested.
- Unequal access has also been identified in hospice at home services. This may not be a problem in Merton where Palliative care services are energetically promoted, but the potential not to provide the additional support needed for people who live alone and wish to remain at home through terminal illness should be noted from the literature.

5. Demographic profile

This section provides a profile of the target population.

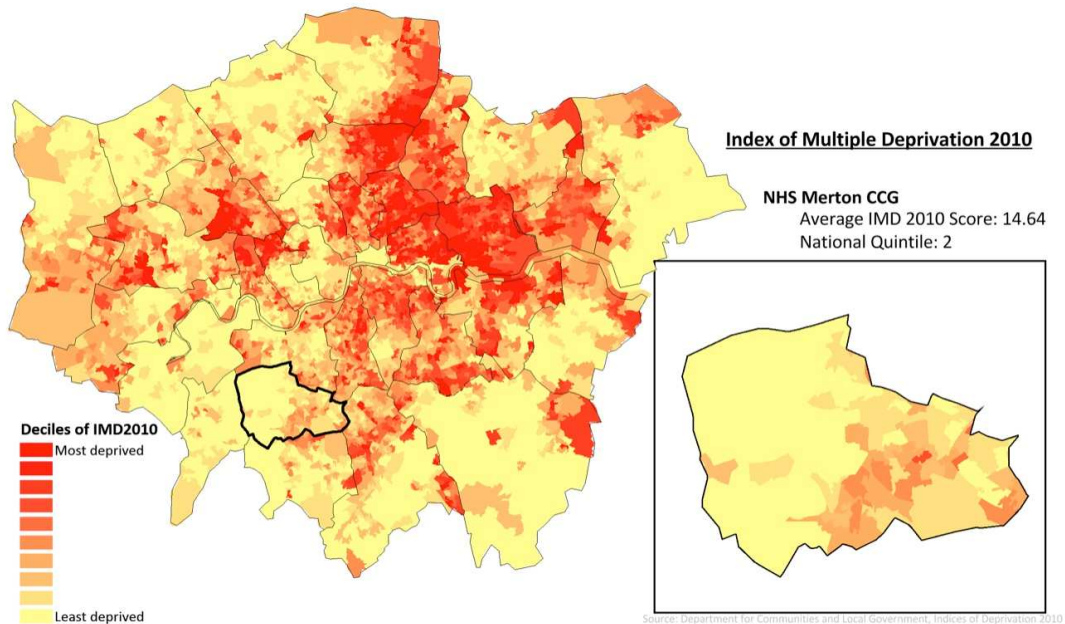
Figure 5.1: Age distribution in Merton mid-2013 Population



Source: Office for National Statistics

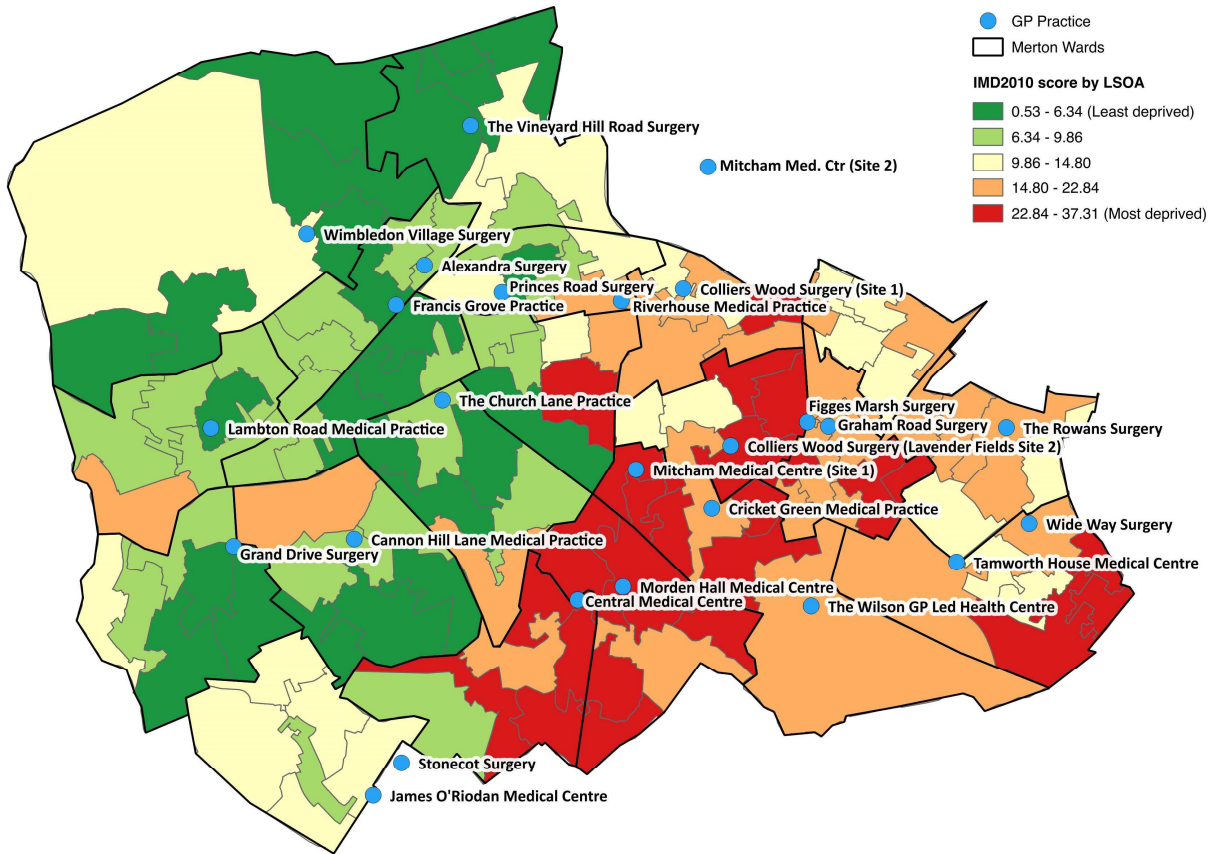
This chart shows the significance of a new age group recorded, age 90+, rather than those in this age group simply being included with 85+.

Figure 5.2: Index of Multiple Deprivation of Merton (IMD), 2010



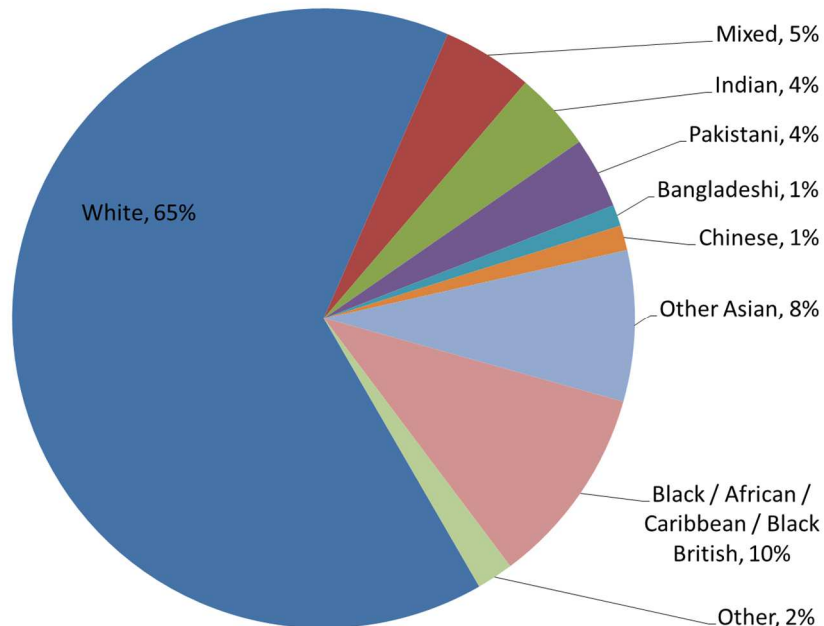
Source: Department of Communities and Local Government, 2010

Deprivation is calculated once every 4 years so the latest data available are for 2010.



Source: Department of Communities and Local Government, 2010

Figure 5.4: Black and Ethnic Minority Population, 2011

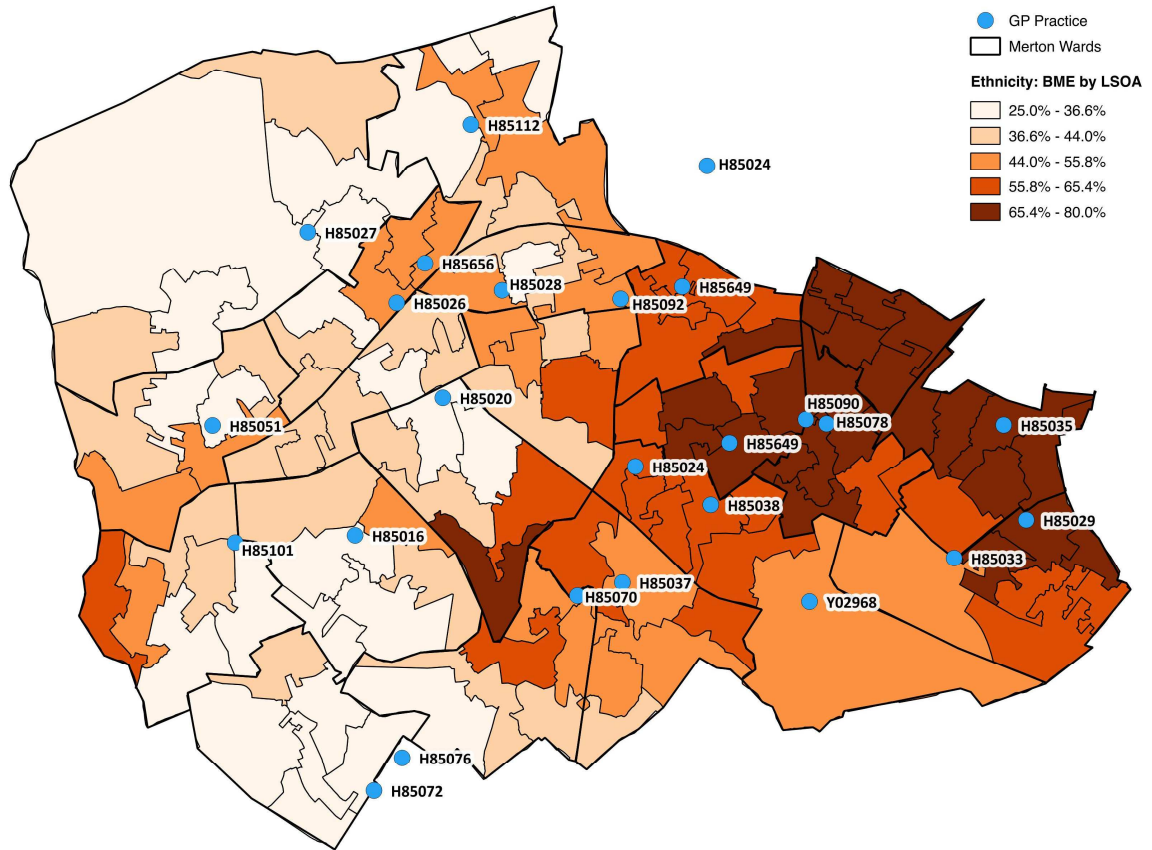


Source: Office for National Statistics

These data are calculated from the UK decennial population census so will not be updated until after 2021.

However the Census 2011 data, using the 'country of birth' tables indicates a Chinese population in Merton of 0.4% (n=749), Sri Lankan population of 3.2% (n=6,327), and a Polish population of 3.5% (n=6,895). Although Polish would be included in "White" and the Sri Lankan population in "Other Asian" these are significant communities.

Figure 5.5: BME ethnic breakdown in relation to GP surgeries, LB Merton



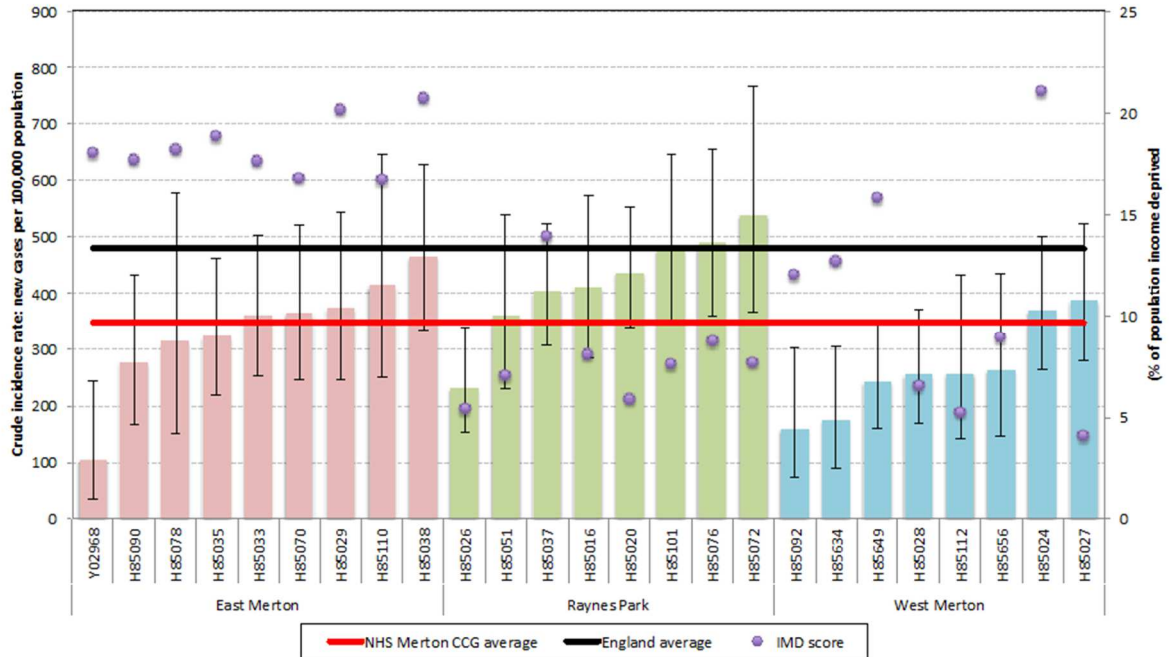
Source: Office for National Statistics

A Table identifying General Practices by their codes may be found in Appendix 5.

6. Epidemiology

Epidemiology reviews what is known about the incidence (how many new cases in a given time in a given population) and prevalence (how many total cases are there in a given population in a given time period, usually one year). Incidence and prevalence measure both the efficiency of case finding and of treatment to prolong the life of people who have had the disease. Actual incidence and prevalence are here compared with the rate per 100,000 population for the Borough of Merton, and that for London. Data on mortality are also included, but the very important measures of staging and survival (especially one year) are not yet available.

Figure 6.1: New Cancer Cases by GP Practice, per 100,000 population, LB Merton 2011

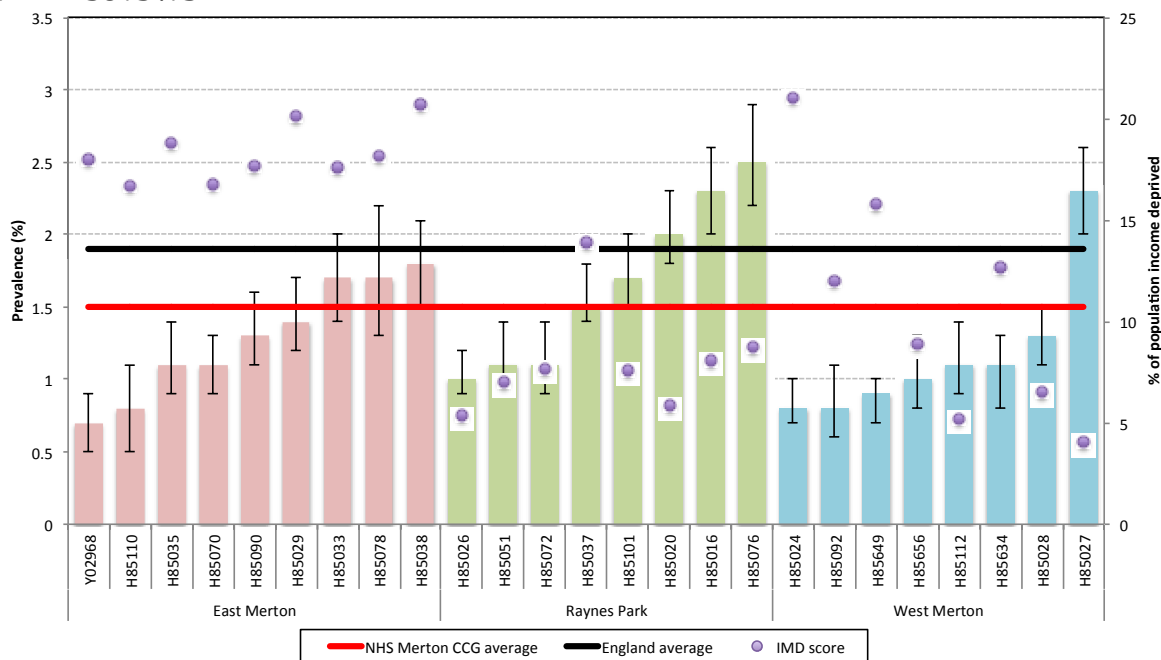


Source: National GP Practice Profiles (Association of Public Health Observatories)

A Table identifying General Practices by their codes may be found in Appendix 5.

This suggests greater incidence of cancer in practices with less deprivation, or greater case finding. However few of the differences seen are statistically significant. The incidence of cancer in four practices are statistically lower than the rate for Merton as a whole. Two practices with relatively lower deprivation show statistically higher incidence of cancer diagnosis.

Figure 6.2: Prevalent cancer cases (% of practice population on practice cancer register) LB

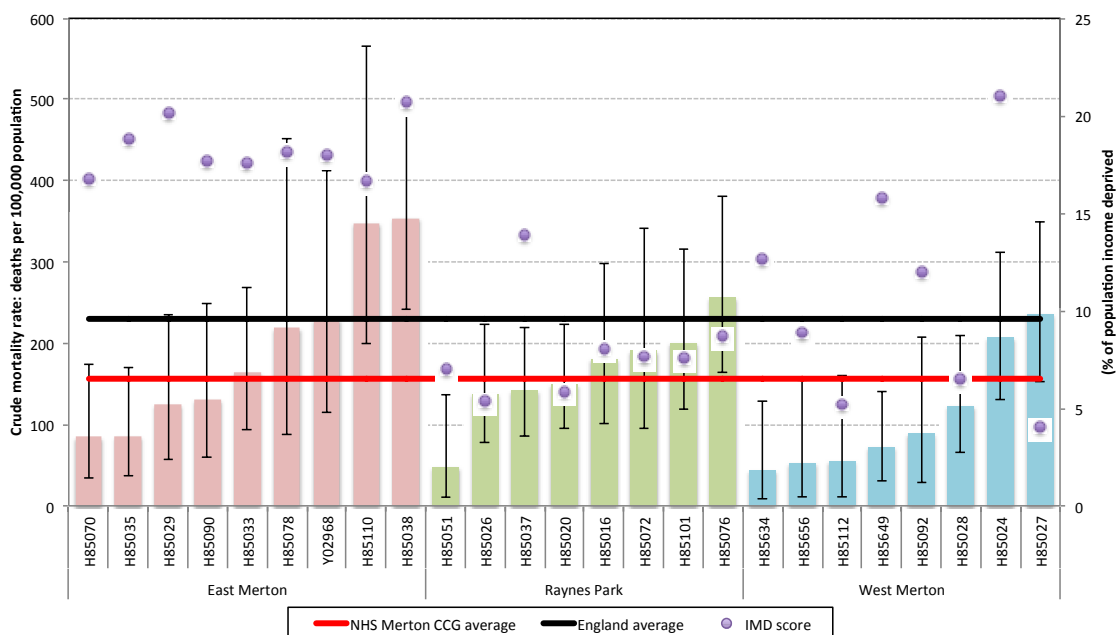


Source: National GP Practice Profiles (Association of Public Health Observatories)

A Table identifying General Practices by their codes may be found in Appendix 5.

Prevalence is an indicator of both efficiency in treatment to prolong life (thus increasing the number of 'survivors' in a population) and also in this case, of record keeping as the percentage is drawn from registers maintained by practices. Here six practices with relatively high deprivation show statistically lower prevalence compared with Merton. Five practices with lower deprivation have higher prevalent levels of cancer compared with Merton. Audit would indicate whether this was due to better recording, better treatment or initial case finding.

Figure 6.3 Crude Cancer Mortality Rate by GP Practice, LB Merton 2013 with deprivation score.



Source: National GP Practice Profiles (Association of Public Health Observatories)

A Table identifying General Practices by their codes may be found in Appendix 5.

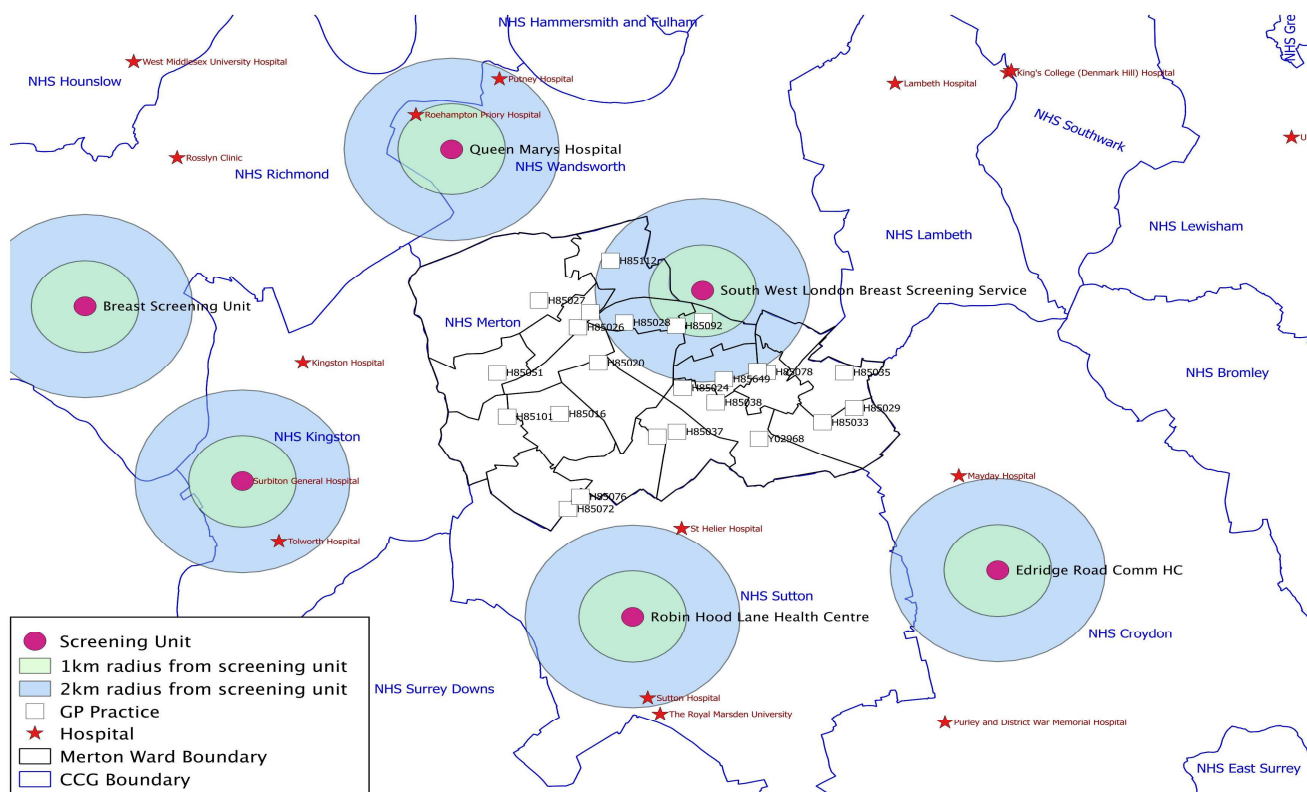
- 6.1.1 These data show that one practice has a significantly higher mortality rate when compared with England. Twelve practices have a rate which is approximate to the rate for England, and twelve have rates significantly lower than that for England.
- 6.1.2 Although rates appear higher in east Merton, there are two practices whose rate is significantly lower than those for England.

7. Current service provision

7.1 Prevention and screening

- 7.1.1 Breast, lung, prostate and colorectal cancer make up approximately 54% of all cancers, and these have a number modifiable risk factors attached. Please see Appendix 3 for detail.
- 7.1.2 Prevention services are offered by LiveWell Sutton and Merton. The service offers traditional stop smoking services, healthy eating advice, opportunities for increasing physical activity and reducing alcohol intake. Services are open to any who wish to receive them. People can be referred to other services, for example if there is a matter which concerns the borough council, the police or a probation officer. There is a Macmillan researcher at Epsom and St Helier Hospital, working with the Cancer Information Centre.
- 7.1.3 LiveWell develops links with the community at every level, through community events, taking GP and self-referrals.
- 7.1.4 Health Trainers work at four GP surgeries in the areas of highest deprivation, Central Medical Centre, Ravensbury Park, The Rowans Surgery and Riverhouse Medical Practice.
- 7.1.5 LiveWell has a Health Improvement Co-ordinator. The organisation employs Health Trainers, professionals who work with individuals to achieve the health goals the clients have set themselves. These are developed as a result of a one-to-one meeting with the Health Trainer who is expert in Motivational Interviewing. GPs provide approximately 20% of all referrals to Health Trainers often because of obesity or other long term conditions. Health Trainers are able to speak some languages used by ethnic minority groups in the area including Tamil and Polish. There is a newly appointed Health Trainer who is able to speak Ghanaian, able to reach out to a particular local group.
- 7.1.6 Health Champions are community volunteers required to obtain the Royal Society of Public Health qualification at Level 2. They will work through community organisations bringing health messages. Links are made wherever possible, for example with the Bowel Screening Co-ordinator who uses the opportunity to encourage take up of bowel screening.
- 7.1.7 Livewell is commissioned by Public Health Merton but Public Health England (PHE) is responsible for running cancer screening programmes. Local Livewell staff are keen to promote screening but it is not a specifically commissioned activity as this lies with PHE. early cancers.
- 7.1.8 Breast screening services are offered at six static centres which serve South West London and none of which is in the Borough of Merton although some are near the borders, and there is no local mobile service. A national target for coverage for breast screening is 75%.

Fig 7.1 Breast Screening centres in South West London, and distance from LB Merton

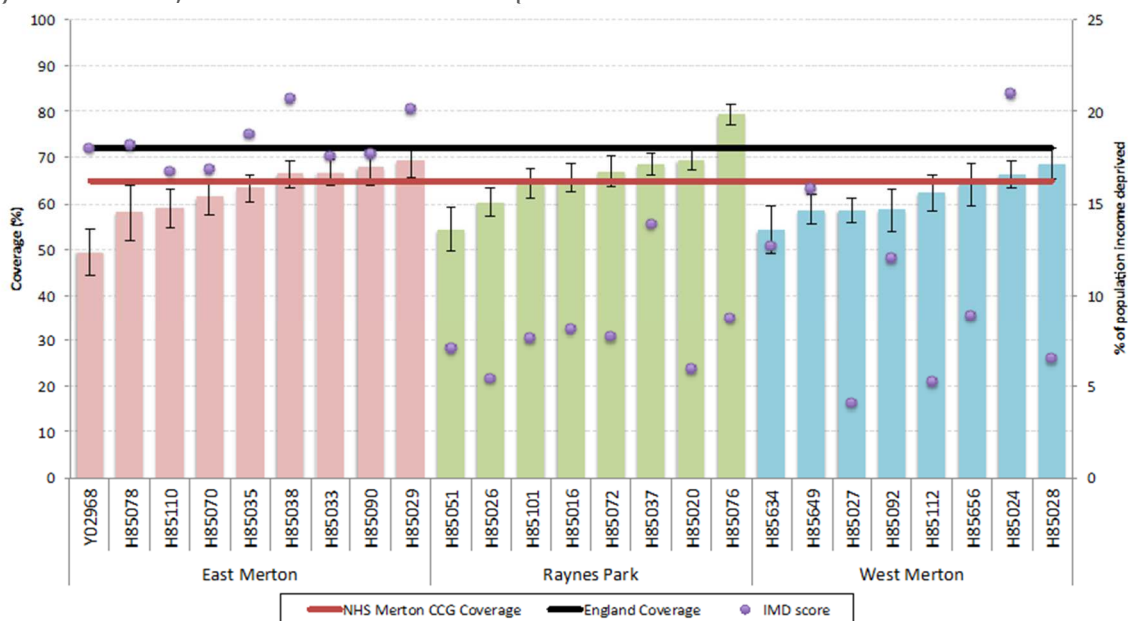


Source: <http://www.swlbreastscreening.co.uk/>

A Table identifying General Practices by their codes may be found in Appendix 5.

Most of the practices whose patients are least likely to respond to national call/recall system for breast screening uptake come from the east of the borough (except Lambton Road and Wimbledon Village and special study would be needed to determine whether women from these practices access screening privately, a possible cause of low uptake recorded on NHS systems). Central Medical, The Wilson surgery, Colliers Wood and Graham Road are all situated in areas of increased deprivation and greatest distance from St George’s Breast Screening Centre. There is a body of literature showing that distance from treatment centres can be correlated with poor uptake of service.

Figure 7.2 Females, 50-70, screened for breast cancer in last 36 months (3 year coverage, %) by GP Practice, LB Merton 2013 with deprivation score.



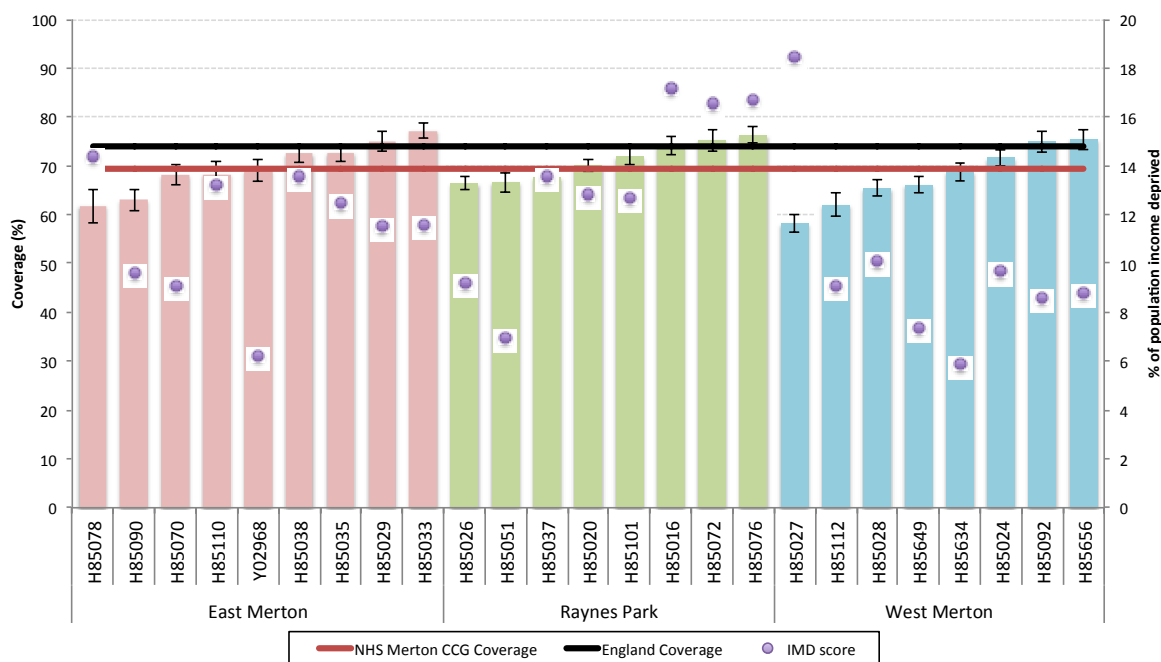
Source: National GP Practice Profiles (Association of Public Health Observatories)
 A Table identifying General Practices by their codes may be found in Appendix 5.

It is surprising that where there is less deprivation, screening levels remain low which is unexpected. It is possible, though there is no evidence that some women from more affluent backgrounds may get breast screening through a private organisation, the results not kept on the public record.

Across the borough breast screening levels are significantly lower than coverage for England and only one practice is above the 75% target at 79.4% coverage.

Cervical screening is more evenly accessed and closer to the target than breast screening. Cervical screening is offered at every GP surgery and also two Family Planning Clinics. The call/recall system is centrally managed and letters would include an explanatory leaflet. This would also be offered in local languages, but nationally is not available in Tamil. Leaflets could be made available in GP surgeries in predominant local languages as available, whether that is English or not. Target uptake is 80%.

Figure 7.3 Females, aged 25-64, attending cervical screening (3.5 year coverage, %)



Source: National GP Practice Profiles (Association of Public Health Observatories)
A Table identifying General Practices by their codes may be found in Appendix 5.

There is low uptake in bowel screening as well, against a target of 60%. However, Merton has the third highest take up compared with the six boroughs of SW London.

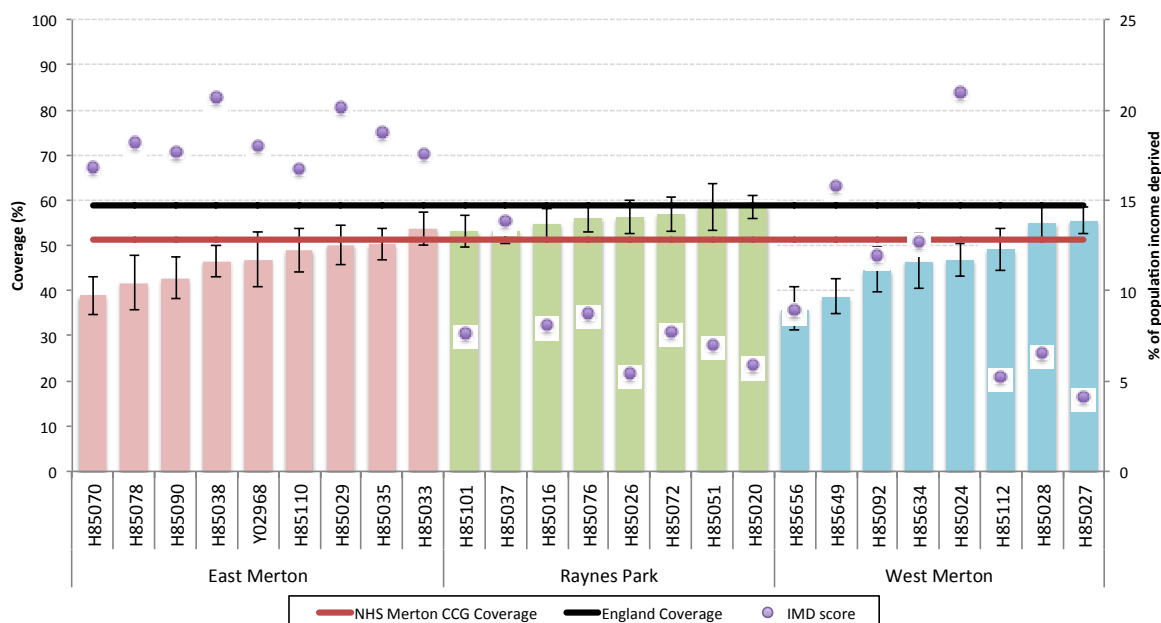
Table 7.1 Q1 Bowel Screening uptake data to June 2014, Merton and SW London

Wandsworth	47.1
Croydon	49.2
Merton	50.3
Kingston	54.2
Sutton	55.1
Richmond	56.7

Source: HSCIC

There is also variation within the borough:

Figure 7.4 Persons aged 60-69, screened for bowel cancer in last 30 months (2½ year coverage %) at April 2013 (period 2010/11 to Q3 2012/13)



Source: National GP Practice Profiles (Association of Public Health Observatories)

A Table identifying General Practices by their codes may be found in Appendix 5.

Take up of bowel cancer screening in London generally is lower than in other parts of England. The following table shows results for some of the bowel screening centres in England in which the lowest uptake figures are in London apart from Sandwell and West Birmingham, the only other centre with a percentage uptake lower than 50%. In London the exception is St George’s which achieved an uptake of 51.71%. Highest results were obtained in Cumbria and Morecambe, Hampshire and Somerset.

Table 7.2 %Comparison of Take up of Bowel Cancer Screening by Screening Centre 2012/13

Bowel Screening Centre	% Uptake
Sandwell and West Birmingham	47.77
West London	42.48
South East London	49.89
NE London	45.39
St Marks, London	48.93
University College London	49.13
St George's, London	51.71
Cumbria and Morecombe	64.34
Hampshire	64.36
Somerset	64.91

Source: <https://www.beatingbowelcancer.org/news/apr2014/%E2%80%9Cunacceptable%E2%80%9D-variations-uptake-bowel-cancer-screening-revealed> (last accessed 1/1/15)

The data for Merton do not compare badly with SW London, and the results across London suggest that SW London is performing well compared with the rest of the capital. However efforts to improve uptake and coverage of the screening programme should be strenuously continued in order that the 60% target can be achieved.

7.2 Acute services Kingston, Epsom and St Helier, St George’s, tertiary Royal Marsden Hospital

One of the key processes in seeking early diagnosis is the two week wait (2WW) scheme. However, a significant proportion of patients with cancer are diagnosed by other routes

(detection rate), only a small proportion of 2WW referrals have cancer (conversion rate) and there is considerable between-practice variation. An important paper analysing the relationship between detection and conversion following 2WW referral (Meechan et al 2012²) found a consistent relationship between conversion and detection rates. This consistent relationship can be interpreted as representing quality in clinical practice, and recommends the 2WW referral rate should not be used as a measure of clinical care. Practices are encouraged to review the relationship between the practice conversion and detection rates.

A suggested conversion rate of about 8% -14% has been said to indicate efficient use of the referral route. However this range cannot be referenced and the better comparison of conversion and detection rates discussed above, with the use of cancer-specific audit and significant event analysis may help practices with low conversion and detection rates to identify where they may have scope for improvement.

The conversion rates in Raynes Park locally are within the 8% - 14% range except for the practice with a 2.6% conversion rate. Practices in other localities are mostly lower which may suggest that more cases than expected are referred by 2WW. Most other practices in Figures 7.6 and 7.7, have wide 95% confidence intervals indicating no statistically significant difference between them.

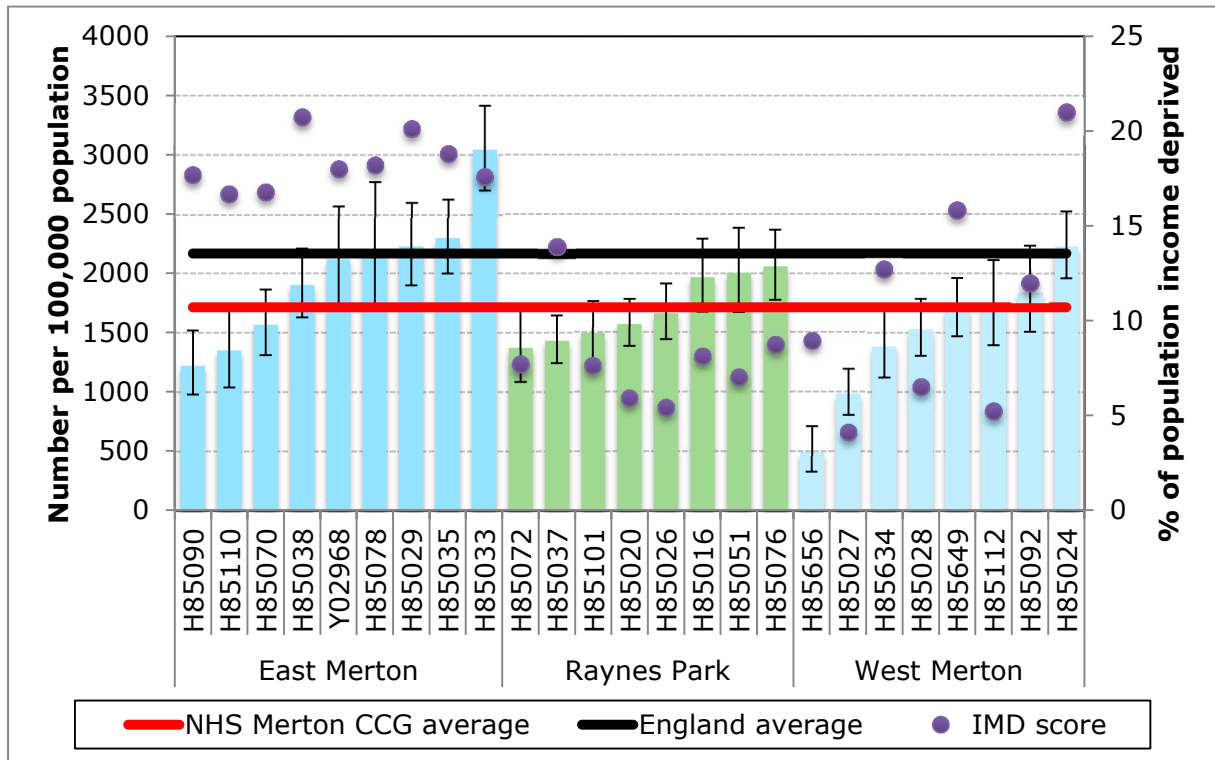
A practical observation was made about the systems in place within general practices, to enable 2WW referrals to be made efficiently, with a failsafe to ensure that the fax has been sent, not left by a machine, that it has been received and that the patient has received an appointment, or knows what to do if they do not hear within a defined number of days. This observation was also made by some of the minority ethnic groups whose communication style is not forceful and who could be missed if they do not receive the expected appointment.

The corresponding question to be asked here to which data cannot be provided is the usage made by GPs of direct access to cancer diagnostics. Local provider units can quantify the number of tests per practice, but not where there was a suspicion of cancer. GPs do have direct access to cancer diagnostics, with no cap or ceiling, but the suspicion is that they are not widely used. However without robust information, this cannot be verified.

Data are available on: In-patient or day-case colonoscopy, sigmoidoscopy and procedures by GP practice Merton 2012/13, but it is not known which were performed for possible diagnosis of cancer and so are not relevant to this assessment. Although the Cancer General Practice Profiles include a section entitled, 'Presentation and Diagnostics', which list the number of day-case or in-patient procedures was summed for persons registered at each practice (as recorded in the HES dataset). These procedures were not filtered by the diagnostic field in the HES data so contain both patients subsequently diagnosed with cancer, those not subsequently diagnosed with cancer, and patients where there was no suspicion of cancer (NCIN website).

² <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3426597/>

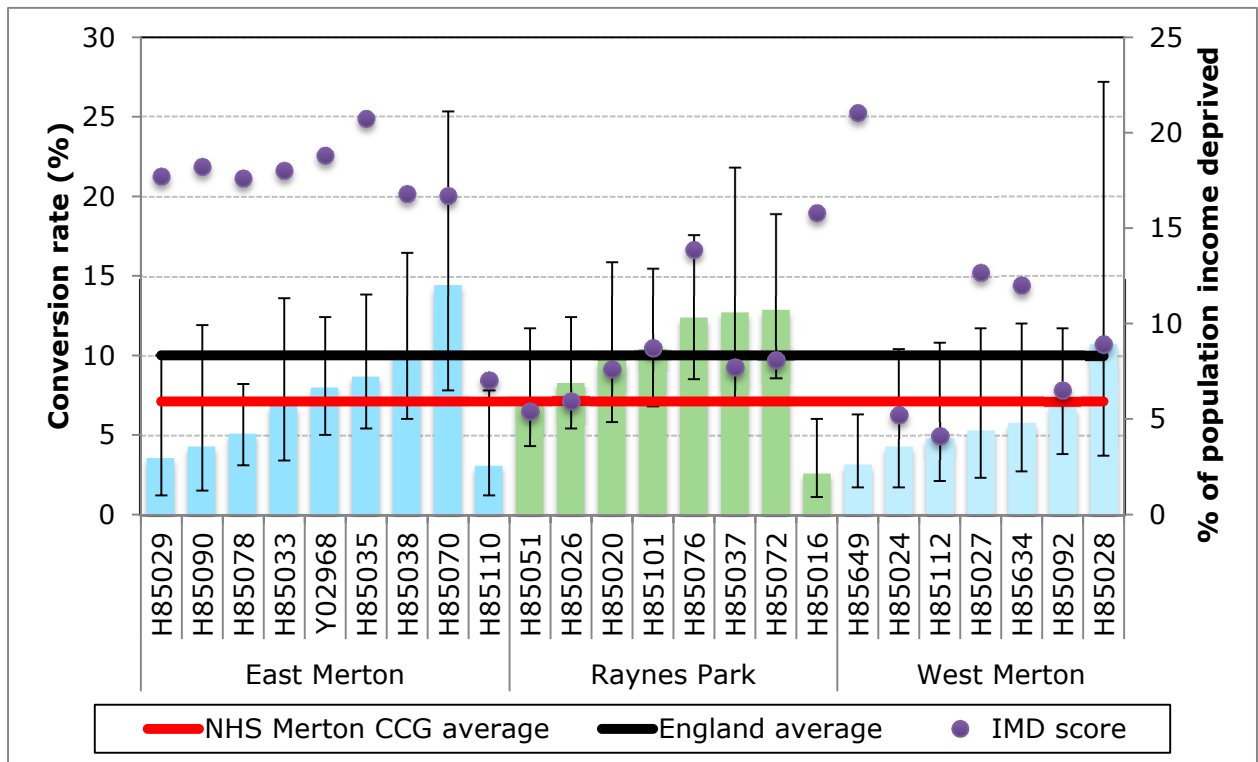
Figure 7.5 Two-week wait referrals – population rates - by GP practice LB Merton 2012/13



Source: PHE, National General Practice Profiles

A Table identifying General Practices by their codes may be found in Appendix 5.

Figure 7.6 Two-week referrals with cancer (conversion rates) by GP practice 2012/13

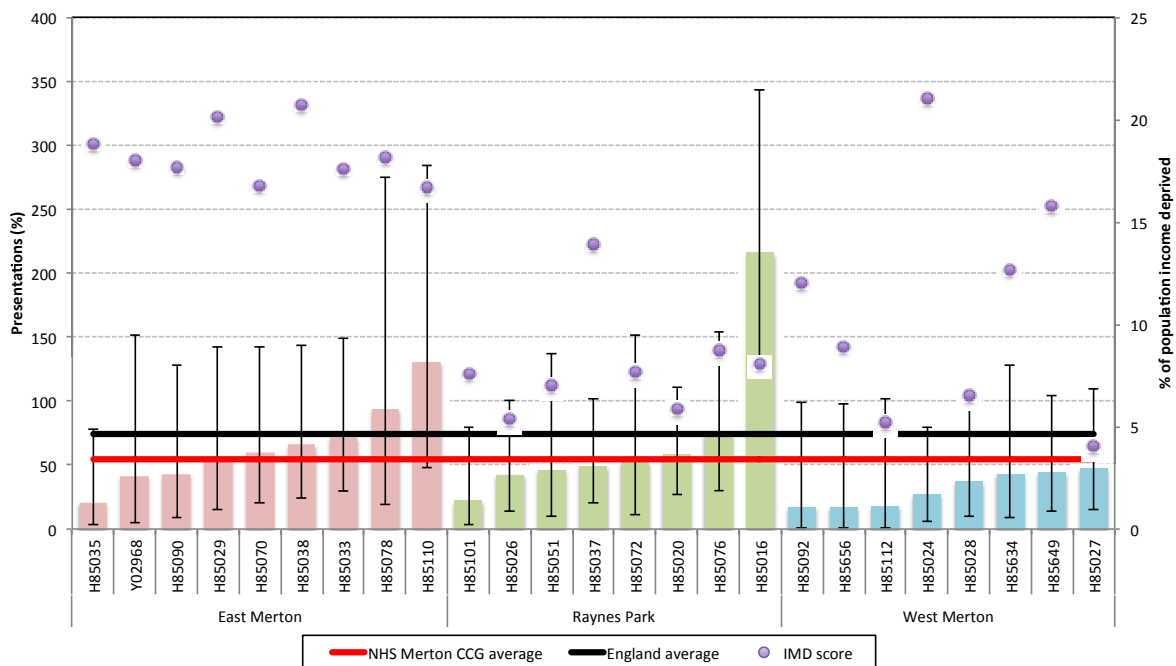


Source: PHE, National General Practice Profiles

A Table identifying General Practices by their codes may be found in Appendix 5.

Emergency admission for first diagnosis of cancer is another predictor for poorer outcomes. Planned admissions which are likely to have been seen earlier in the development of the cancer before a crisis, lead to better outcomes.

Figure 7.7 Emergency presentations with cancer

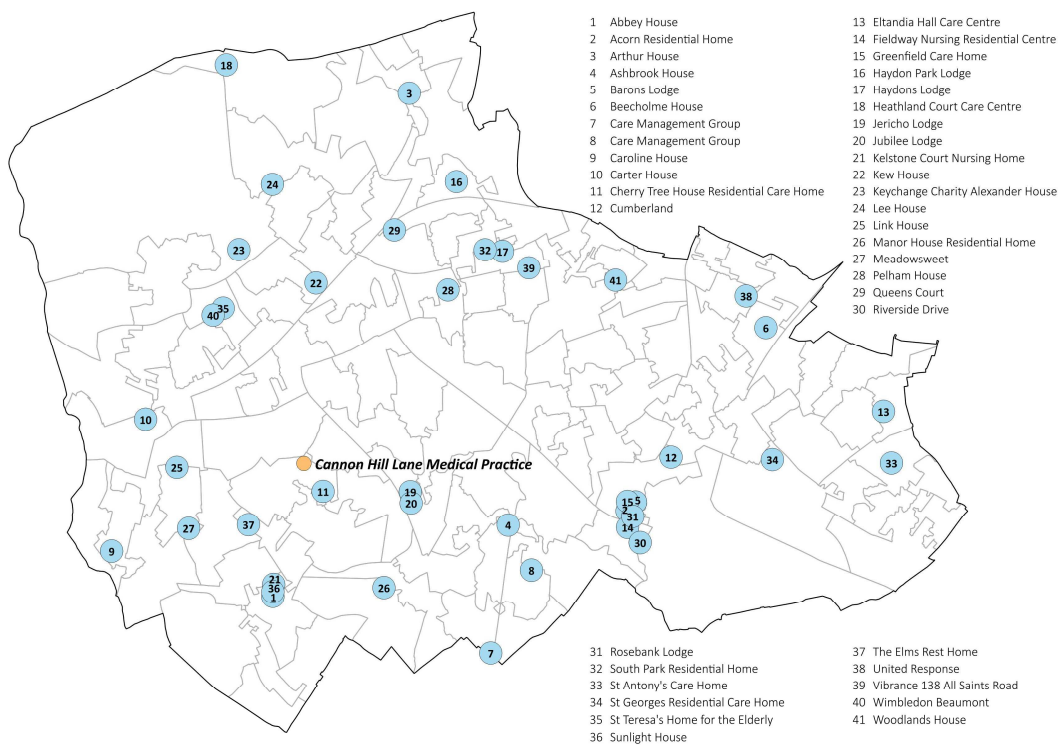


Source: PHE, National General Practice Profiles

A Table identifying General Practices by their codes may be found in Appendix 5.

These data do need to be considered together, for example in Fig 7.6 Practice H85016 has a low conversion rate but in Figure 7.7 this practice has a statistically significantly higher rate of emergency admissions. A hypothesis was suggested that this practice has a number of care homes among its patients, but the following map seems to suggest otherwise. Discussion with the practice would determine the source of their care home patients.

Figure 7.8 Geographical distribution of care homes in LB Merton, with GP Practice



Source: LB Merton Commissioning Team

Having received the diagnosis patients should then commence treatment within the target timeframes, most of which are met in Merton, but there are some areas which fall short:

Table 7.3: Merton CCG Scorecard April 14 –present

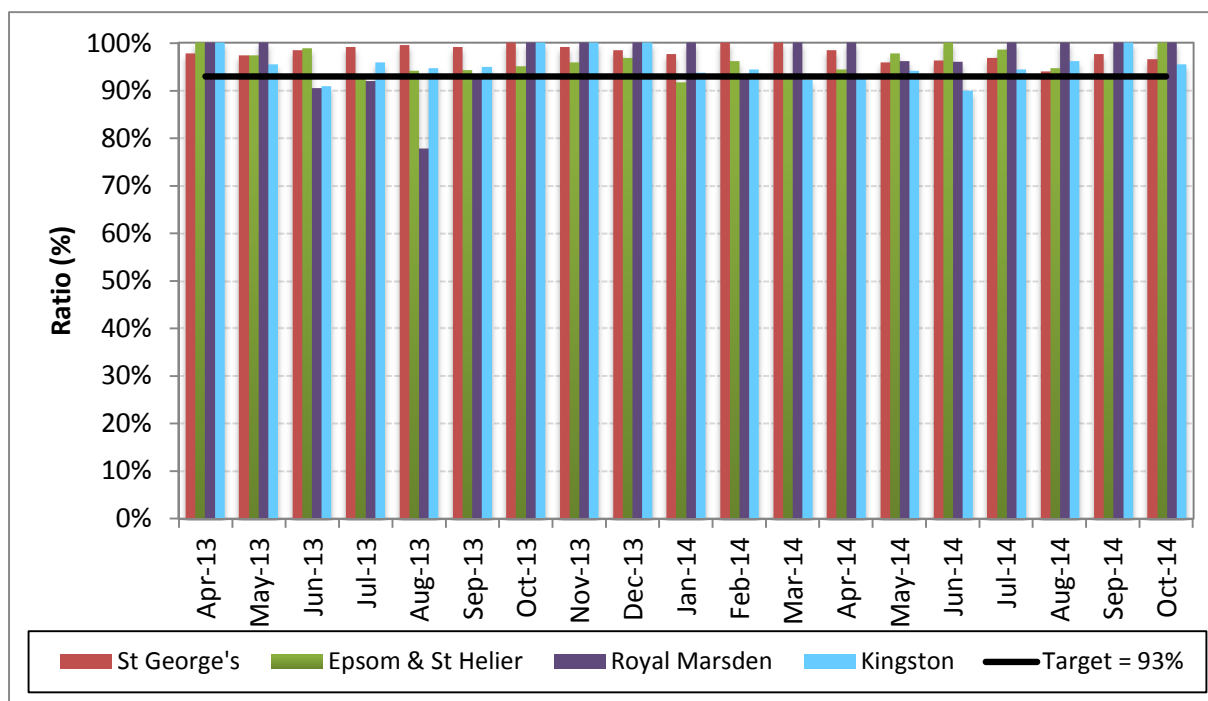
	Target	Apr	May	Jun	Jul	Aug	Sep	Oct
OUTCOMES FRAMEWORK								
Cancer two weeks	93.0 %	96.7%	96.4%	96.7%	96.8%	94.5%	97.0%	97.4%
Breast symptoms two weeks	93.0 %	96.8%	90.1%	91.0%	98.8%	98.6%	98.6%	97.1%
Cancer first definitive treatment 31 days	96.0 %	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	96.8%
Cancer subsequent treatment 31 days surgery	94.0 %	100.0%	100.0%	90.0%	100.0%	100.0%	100.0%	100.0%
Cancer subsequent treatment 31 days, drug	98.0 %	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Cancer subsequent treatment 31 days radiotherapy	94.0 %	100.0%	92.0%	94.3%	100.0%	94.1%	100.0%	100.0%
Cancer first treatment 62 days, GP Referral	85.0 %	80.8%	76.5%	87.5%	90.0%	84.0%	87.0%	85.7%
Cancer first treatment 62 days, Screening	90.0 %	100.0%	100.0%	100.0%	100.0%	83.3%	100.0%	100.0%

Source: Transforming Cancer Services Team, South East CSU

These timescale failures are particularly important when patients commence first treatment for purposes of clinical outcomes but also for patient satisfaction at a time of great anxiety. Reporting from the main Merton provider units do show some variation in compliance with target periods.

The following charts show the response by Merton provider Trusts to referral targets. There is no discernible trend.

Figure 7.9: All cancer two week waits, Merton providers, % achieving target, April 2013 to date.

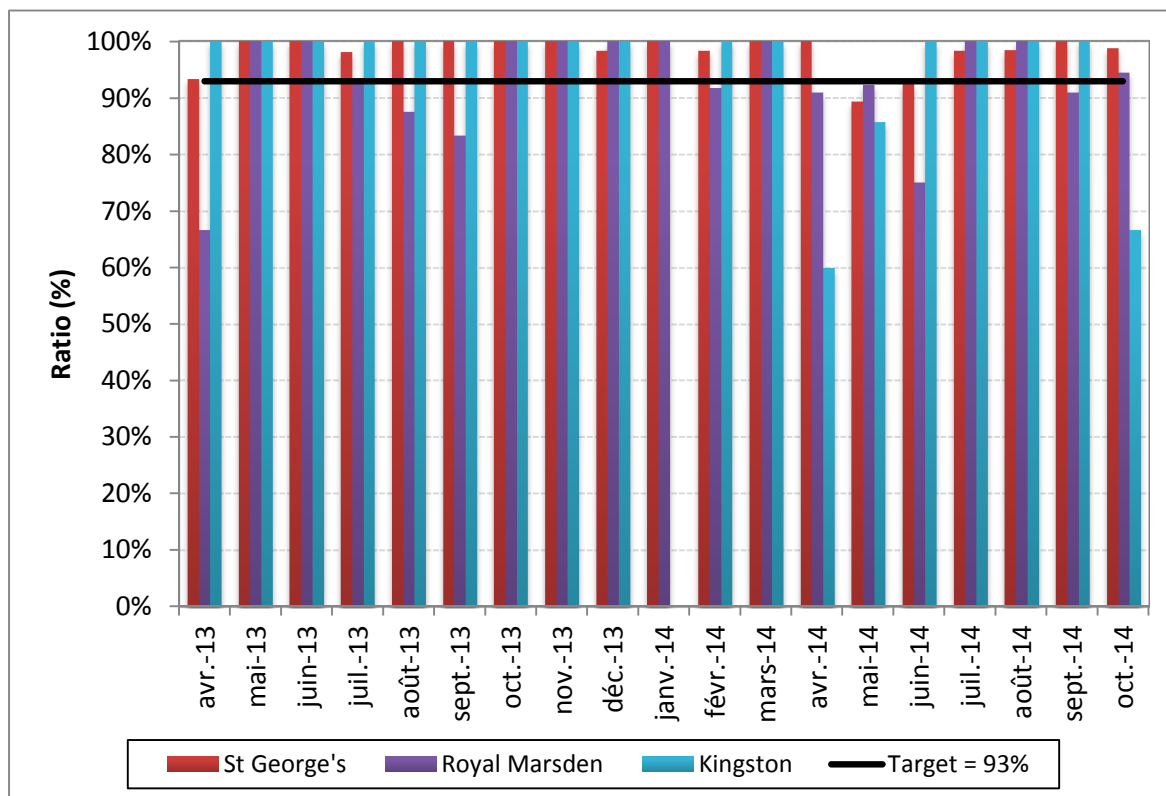


Source: Merton Cancer Waiting Analysis Pack

A Table identifying General Practices by their codes may be found in Appendix 5.

St George's is the only unit consistently above the target. However there are no confidence intervals to support the data. Patients should commence their first definitive treatment within 31 days and the chart indicates that St George's, Epsom and St Helier, and Kingston were all recorded with amber – near misses – from the target, and Royal Marsden showing one 'red' in August 2013.

Figure 7.10 Breast symptoms two week waits, Merton providers, % achieving target, April 2013 – October 2014.

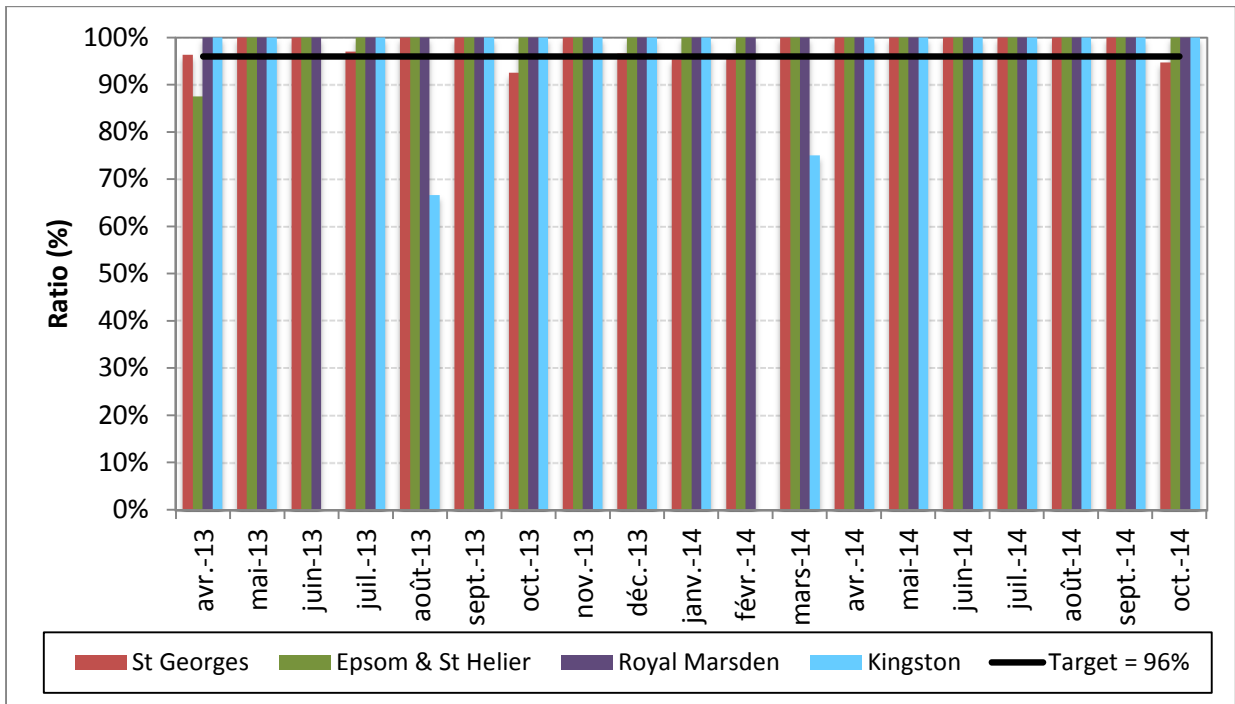


Source: Merton Cancer Waiting Analysis Pack

A Table identifying General Practices by their codes may be found in Appendix 5.

Here Royal Marsden have four red recordings and Kingston Hospital has three. In five months, Royal Marsden records amber returns (all over 90% but not achieving the target of 93%). St George's achieves the target for all months bar two where there is an amber record.

Figure 7.11 First definitive treatment within 31 days, Merton providers, % achieving target, April 2013 – October 2014.

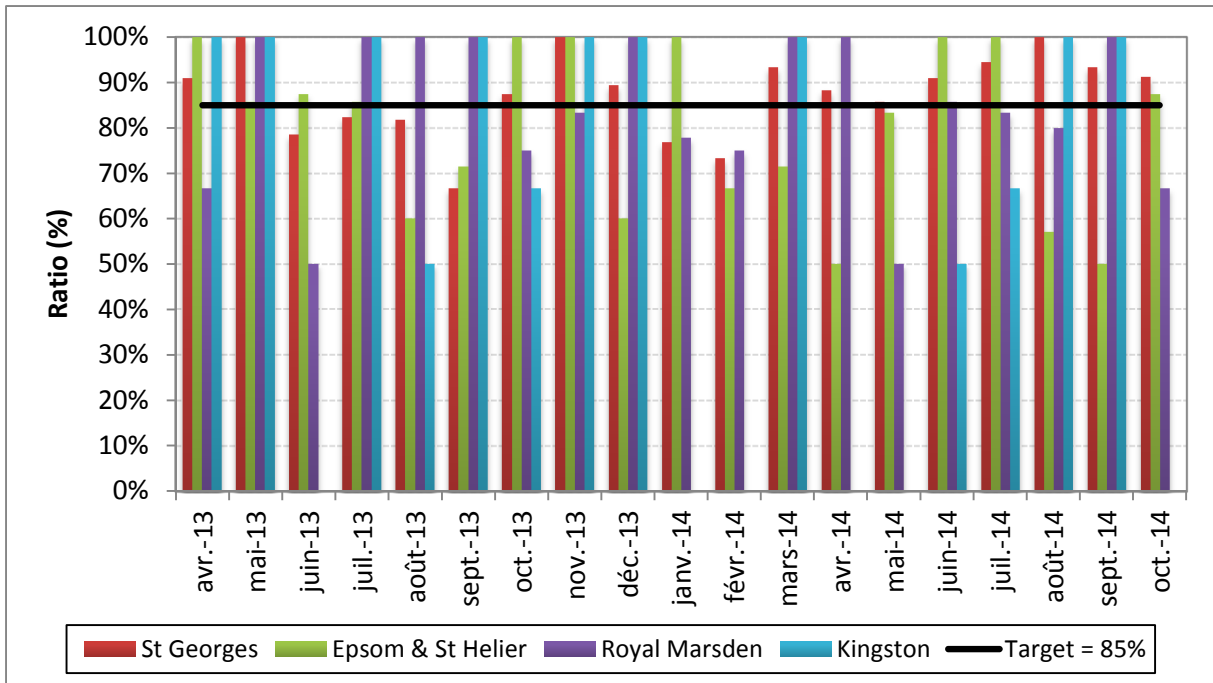


Source: Merton Cancer Waiting Analysis Pack

A Table identifying General Practices by their codes may be found in Appendix 5.

Here there is more variation, some months where the target was missed by each of the Trusts except Royal Marsden, but two months in which Kingston scored a red rating and two months in which no data were submitted for that Trust.

Figure 7.12 First treatment within 62 days following GP referral, Merton providers, % achieving target, April 2013 – October 2014.



Source: Merton Cancer Waiting Analysis Pack

A Table identifying General Practices by their codes may be found in Appendix 5.

First cancer treatment following referral by a GP outside the 2WW route is much less consistent in achieving the target.

7.3 Palliative Care Services

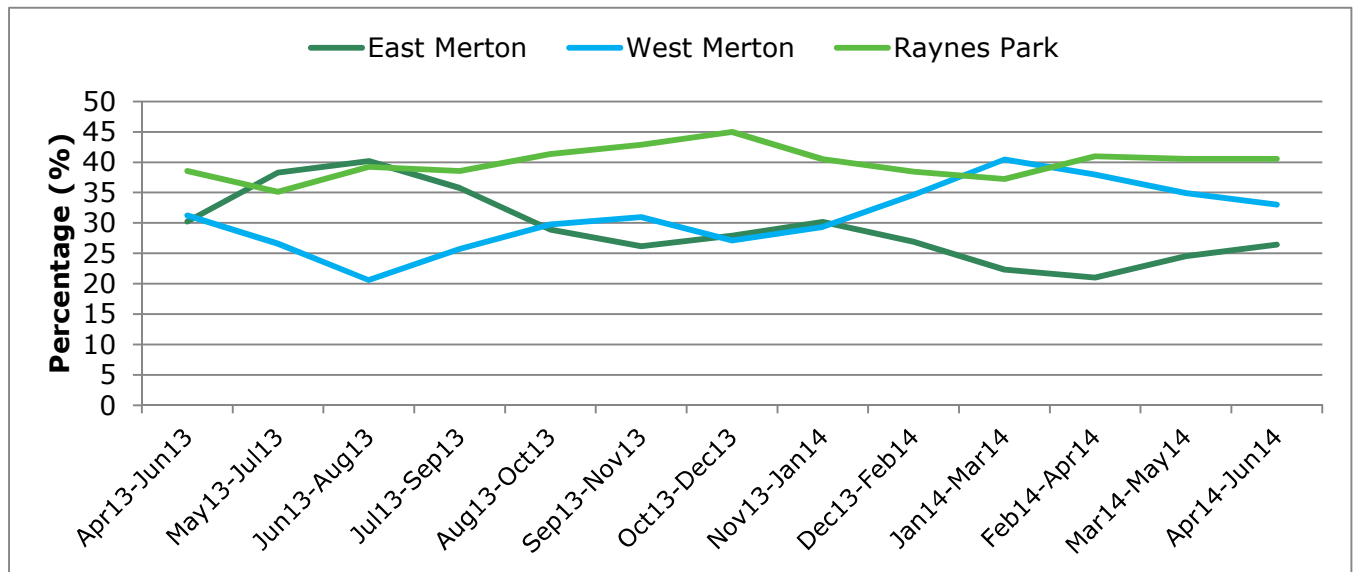
A comprehensive palliative care service is being built in Merton encompassing the “Coordinate My Care” programme, hosted by The Royal Marsden Hospital. This is based on the “surprise question” asked by healthcare professionals: “Would I be surprised if this patient died within the next year?” The answer has been found to have remarkable accuracy and allows planning for good care to death. Initially the care plan will be for the current situation but as the patient is ready to consider the fact that they are nearing the end of life, decisions about management at that time can be added.

The objective is to understand from the patient with a chronic healthcare condition or life limiting illness how they would like their path to go, where they would like to be when they die, who should be their main supporters. A personalised secure record of this information is developed, accessible only to the out of hours GP service, the “111” service, London Ambulance Service and the GP. It means that whenever there is an event, especially in an emergency, the record can be accessed by specific trained healthcare staff and the plan acted on.

Work is underway to extend access to the record by nursing homes and liaison social workers.

As most people request to die at home, ‘deaths at home’ is a quality service measure. Recording of deaths at home currently includes death in the person’s own home or in the care home where they live.

Figure 7.13 Percentage of deaths that occur at home



Source: HSCIC PCMD

This chart is reproduced as it was provided without the source data. It may be useful to review the actual numbers involved as some may be small, and the annual percentage totalled by area.

The question of opportunity to remain at home until death in relation to deprivation data is explored in the literature review, Section 3.2.

More conventional provision of general and specialist palliative care is also in place in Merton. St Raphael’s Hospice provides symptom control and end of life care, inpatient beds, day care, respite care, and hospice at home, to the London Boroughs of Merton and Sutton. The hospice at home service enables in particular people living alone to stay at home, providing night sits and additional visits.

Trinity Hospice, Clapham Common North Side also provides a service to Merton. However, all hospices in London work on a collaborative basis to facilitate care in the area where it is needed.

Every nursing home in Merton has a named end of life care nurse who visits on a monthly basis.

Coordinate my Care (CMC) allows more than 70% of people to die in their preferred location where they have expressed a preference, and of those 42% are people with cancer.

8. Evidence of health demand

8.1 Introduction

- 8.1.1 As there is a great deal of literature on the views of cancer service users and the needs and requirements of those who are affected by cancer, and the short time allocated to this review, it was decided not to interview individuals initially but to seek out services and support networks through whom local information could be obtained. In the event the researcher spoke to a number of individuals, mainly from minority ethnic groups and mainly in the east of the borough. This was purposive as the west of the borough is more affluent, better served with a very active cancer friendship group, and not demonstrating the same need as is seen in the east. Finding contacts in the east of the borough was more difficult, pragmatic and the results not systematic. An article in the HealthWatch leaflet, emailed out to a range of people did produce six direct and indirect responses.
- 8.1.2 Please see Appendix 2 for additional detail on interviews. The main inputs and outcomes are recorded here. Important views were expressed which offer guidance to improving services.

8.2 Method

Mindful of limitations of time and need for confidentiality, a pragmatic approach has been taken to gathering user and stakeholder data. Some "easy" contacts were offered in Wimbledon and the west of the borough, but focus on the east was maintained although more difficult to find contacts.

Fourteen organisations were contacted by telephone and follow up email.

- Some were very forthcoming with help
- Some referred on to other organisations.
- Some felt unable to allow access to information or support groups because of confidentiality constraints.

The most responsive organisations were from the voluntary sector. However this meant that the data were not solely from Merton residents but may include those from neighbouring boroughs. Three of the organisations offered the opportunity to meet with 13 users and have email and/or phone contact with a further three.

User information was gathered through:

- Attendance at two support groups
- Email responses from a newsletter article kindly sent out by Merton Voluntary Services Council (MVSC)
- Telephone interviews with cancer patients
- Information from healthcare and voluntary sector workers was obtained by
- telephone interviews
- Email responses to questions
- Face to face meetings

8.3 Summarised Findings and Recommendations

In all, thirteen individuals provided information and ten who represented organisations.

There were seven areas which concerned the interviewees:

1. Not presenting to the doctor in time.

- Acknowledge that translation does not overcome fear. It might not be the language per se but the system they do not understand, a broader question of health literacy.
- Offer for people to be accompanied by a same sex health assistant or a friend as well/ instead of a translator.
- Attendees could be advised to bring a friend.

2. Missing the signs

- Offer chance for patients to talk through concerns with practice nurse so they can build confidence in talking to doctor
- Translators only translate they do not build confidence.
- Even a same sex healthcare assistant could act in an advocacy role alongside a translator.
- CCG to create a leaflet called 'A list of questions to ask your doctor' or 'How to prepare for a meeting with your doctor' to help patients who don't like to challenge authority to feel confident it is okay to ask. We found <http://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/gp-referrals.aspx> but it would be needed in local languages.
- Are different effects in different ethnic groups included when GPs are offered training in symptom recognition for cancers?

3. Lack of progress chasing

- GPs to give a copy of the referral letter to the patient.
- GPs to give clear instructions to patients of what to do if nothing has happened within 2 weeks for example to contact a named person at the surgery to help follow up.

4. Take up of screening.

- There were differences in culture where screening is not seen as important: the Polish representative suggested using language like 'Just in Case' to develop a campaign for screening.
- The Tamil community as represented by the Tamil Health Advocacy Project Officer and Early Years Community Engagement Officer would welcome more speakers to come to the Centre and encourage people to go to the doctor.
- Also they need reassurance they can see a same gender GP and will not be asked to remove unnecessary items of clothing.
- The Afro Caribbean community would like to discuss a similar campaign to the one previously used to convince church leaders to support HIV awareness.

5. Stakeholders not knowing each other

- While there appear to be a number of interested stakeholders of cancer matters in Merton very few seem to know each other
- There is limited communication between the voluntary sector and the GPs it may be the case that some GPs do not even know the cancer support centres exist
- St George's appear to be creating ambassador roles but these are still in early stages of linking with voluntary sector who have been looking to link with primary care for some time
- GPs to be informed about and display information about cancer support centre. Also proactively encourage patients to go.

6. Community engagement

- It seems that the links with the communities largely consist of meeting with PPI leads about generic issues but this do not currently translate in to specific campaigns
- Ideas for improvement are being undertaken in isolation of other interested parties so initiatives such as awareness campaigns are not joined up with targeted screening.

And finally

A Merton cancer stakeholder convention could be held to bring together interested parties, present the findings of this project and agree a way forward.

9. Conclusions and recommendations

9.1 Conclusions

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.

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.

The literature review showed an effect that might be surprising, that deprivation is not solely a personal circumstance but can also be exhibited by an area and this affects all those within it even those whose own circumstances might not be socioeconomically deprived. Middle class people have higher expectations of education and health services and their impact on providers can improve local services quality for lower SES patients/pupils but if they are not a significant enough proportion of the population, the impact is less and poorer quality service pertains.

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 much evidence of people not getting a diagnosis in a timely manner, but personal delays on the part of the public play a significant part.

Some ethnic minority people, particularly African women, expressed being uncomfortable commencing a discussion about intimate details immediately on sitting across the desk from the GP. They needed some introduction to enable the more important conversation to take place. It may be possible for a practice nurse to facilitate discussion on delicate matters.

Cultural understanding was also needed for example about the acquiescence of Tamil speaking women who would not question a professional, even if they did not understand or had not disclosed a serious condition. Patients should receive a copy of a referral letter with a note written on it about what to do if notification of an appointment does not arrive.

9.2 Recommendations

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, post-menopausal 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 <http://www.nhs.uk/choiceintheNHS/Yourchoices/GPchoice/Pages/GPappointments.aspx>) 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.

Appendix 1: References for Literature Review

- Beeken R, Simon A, von Wagner C, Whitaker K and Wardle J (2011). Cancer fatalism: deterring early presentation and increasing social inequalities? *Cancer Epidemiology Biomarkers and Prevention* 20: 2127-2131
- Bourdeanu L, Luu T, Baker N et al. (2013). Barriers to treatment in patients with locally advanced breast cancer. *Journal of the National Comprehensive Cancer Network*. 11 (10), 1193 - 8.
- Cadman L, et al. *J Fam Plann Reprod Health Care* 2014;0:1-10. doi:10.1136/jfprhc-2013-100705
- Campbell M, Grande G, Wilson C, Caress AL, Roberts D. (2010). Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK. *Palliative Medicine*. 24 (4), 403 - 9.
- Cheyne L, Taylor A, Milton R, Fear J, Callister ME. (2013). Social deprivation does not affect lung cancer stage at presentation or disease outcome. *Lung Cancer*. 81 (2), 247-51.
- Chojnacka-Szawlowska G et al. (2013). Delays in seeking cancer diagnosis in relation to beliefs about the curability of cancer in patients with different disease locations. *Psychology & Health*. 28 (2), 154-170.
- Cooper, M. (2011). Reasons for non-attendance at cervical screening. *Nursing Standard*. 25 (26), 41-46.
- Cope, Diane G. (2013). Breast Cancer: Reviewing the Past to Give Direction for the Future. *Oncology Nursing Forum*. 40 (5), 425-428
- Cope, Diane G.. (2013). Breast Cancer: Reviewing the Past to Give Direction for the Future. *Oncology Nursing Forum*. 40 (5), 425-428
- Copson E, Maishman T, Gerty S et al. (2014). Ethnicity and outcome of young breast cancer patients in the United Kingdom: the POSH study. *British Journal of Cancer*. 110 (1), 230-41.
- Crawford SM, Sauerzapf V, Haynes R, Forman D, Jones AP. (2012). Social and geographical factors affecting access to treatment of colorectal cancer: a cancer registry study. *BMJ*. 2 (2), e000410. doi:10.1136/bmjopen-2011-000410
- Damery S, Clifford S, Wilson S. (2010). Colorectal cancer screening using the faecal occult blood test (FOBT): a survey of GP attitudes and practices in the UK. *BMC Family Practice*. 11 (20), doi: 10.1186/1471-2296-11-20.
- Downing A, Prakash K, Gilthorpe M, Mikeljevic J and Forman D (2007). Socioeconomic background in relation to stage at diagnosis, treatment and survival in women with breast cancer. *Br J Cancer*. 96:836-840
- Eilbert KW, Carroll K, Peach J, Khatoon S, Basnett I, and McCulloch N. (2009). Approaches to improving breast screening uptake: evidence and experience from Tower Hamlets. *British Journal of Cancer*. 101, S64 - S67.
- Forbes LJ, Warburton F, Richards MA, Ramirez AJ. (2014). Risk factors for delay in symptomatic presentation: a survey of cancer patients. *British Journal of Cancer*. July (3), 581 - 8.
- Grande GE, Addington-Hall JM, Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998; 47: 565-579.
- Grande GE, McKerral A, Todd CJ. Which cancer patients are referred to Hospital at Home for palliative care? *Palliat Med* 2002; 16: 115-123.
- Lammi UK, Kosunen E, Kellokumpu-Lehtinen P. Palliative cancer care in two health centres and one hospice in Finland. *Support Care Cancer* 2001; 9: 25-31.
- Leydon GM, Bynoe-Sutherland J & Coleman MP (2003). The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers *European Journal of Cancer Care* 12, 317-326.
- Mitchell J, Lannin DR, Mathews HF, and Swanson MS. *Journal of Women's Health*. December 2002, 11(10): 907-915. doi:10.1089/154099902762203740. *J Womens Health (Larchmt)*. 2002
- Moser K, Patnick J, Beral V (2009). Inequalities in reported use of breast and cervical screening in Great Britain: analysis of cross sectional survey data. *British Medical Journal*. 338, b2025.
- National Council for Hospice and Specialist Palliative Care Services. *Palliative Care Survey 1999*. London: NCHSPCS.

Northington L, Martin T, Walker JT. (2011). Integrated community education model: breast

health awareness to impact late-stage breast cancer. *Clinical Journal of Oncology Nursing*. 14 (4), 387-92.

NS717 Bennett A, White J (2013) Improving care and quality of life for patients with lung cancer. *Nursing Standard*. 28, 9, 50-58.

Palmer SJ. (2013). The impact of national policy on the early diagnosis of cancer. *British Journal of Nursing*. 22 (0), S18 - S23.

patient delay. *British J Cancer*104: 1249-1255

Pederson A, Oleson F, Hansen R, Zacheriae R and Vedsted P (2011). Social support, gender and

Richards M (2009). The National Awareness and Early Detection Initiative in England: assembling the evidence. *Br J Cancer*. 101: S1-S4

Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Waller J, Hiom S, Wardle J. (2009). Public awareness of cancer in Britain: a population-based survey of adults.. *British Journal of Cancer*. 101 (Suppl 2), S1-S18. IMPORTANT

Sant M, Allemani C, Capocaccia R et al., (2003). Stage at diagnosis is a key explanation of differences in breast cancer survival across Europe. *Int J Cancer*106: 416-422

Sharpe KH, McMahon AD, Raab GM, Brewster DH, Conway DI (2014) Association between Socioeconomic Factors and Cancer Risk: A Population Cohort Study in Scotland (1991-2006). *PLoS ONE* 9(2): e89513. doi:10.1371/journal.pone.0089513

St-Jacques S, Philibert MD, Langlois A, Daigle JM, Pelletier E, Major D, Brisson . (2013). Geographic access to mammography screening centre and participation of women in the Quebec Breast Cancer Screening Programme. *Journal of Epidemiology & Community Health*. 67 (10), 861 - 7.

Taylor-Phillips S, O'Sullivan E, Kearins O, Parsons H, Clarke A. (2013). The effects of a UK review of Breast Cancer Screening on Uptake: an observational before/after study. *Journal of Medical Screening*. 20 (2), 86 - 90.

Appendix 2: Interviews with Service users and representatives

Informants

	Role/ organisations	Notes
Claire Lowrie- Kanake	PPI lead Merton CCG	Provided some contacts
Dr Shweta Singh	GP MacMillan lead Merton CCG	Provided some contacts
Mary Volunteer	Wimbledon Friendship Group	Enabled Meeting with users
Adele Williams	Healthwatch/ MVSC	Sent email newsletter to all members
Subitiri and Sue	Ethnic Minority organisation	Provided some contacts Mentioned health ambassadors
Hannah Neale (Revd.)	Founder and Director of The African Educational Cultural Health Organisation (AECHO)	Gave telephone interview with examples and suggestions.
Sue Batley /Mary Goodwin	Carers group	Referred to Karen Gray at St George's
Slaweck Szcwpanski	Polish Co-ordinator at Association for Polish Family	Face to Face meeting
Saratha Tarada	Tamil Health Advocacy Project Officer and Early Years Community Engagement Officer	Face to Face meeting
Bev Van der Molen	Paul's Centre and St Georges	Organised Meeting with users
Tarlika Patel	St Helier's support group	Offered to support me to meet patients if agreed by Hilary Hollis.
Hilary Hollis	St Helier's Hilary Hollis, Head of Nursing /Macmillan Lead Cancer Nurse	Referred me to patient experience lead Lynn Godfrey James
Lynn Godfrey James	Patient experience lead St Helier	Referred me to patient experience questionnaire
St Raphael's	Hospice	No response to phone call and emails
Fulham	Breast Cancer Haven	Not contacted
Royal Marsden	Maggie Centre	Not yet open

Themes from conversations with interviewees.

From the patient stories certain themes started to emerge

For patients who presented with clear symptoms such as a lump, referral to hospital was prompt.

Two women in particular praised their GPs for being prompt and proactive

Symptoms that were not explicit such as feeling unwell, tired or weird particularly from middle-aged women, two from ethnic minorities and one white were put down by their GPs to menopause. It seemed that the insistence that their feelings were 'not normal' was not followed through with vigour and only the persistence of the women themselves sometimes over month or years resulted in the cause being found. Two of the women lived alone and one was a carer of her elderly mother. All felt their doctors did not listen to them.

The young man with the brain tumour was assumed to have an ear infection even though he was complaining of severe symptoms. It was his mother who insisted he went to A and E.

Two of the male patients (both white and in their 60/70s) found their prostate cancer as a result of a routine test. One because the GP was proactive in looking when the man was in for something else, the other was on a data base invited from screening. They felt their doctors were very proactive and supportive.

Another theme that emerged was the feeling that once the medical treatment was over the doctors had no interest in how they were coping, Macmillan nurse support stopped and they only found out about support groups by chance. A number talked about a sense of abandonment and loss of confidence.

The experience of the diagnostic process itself was variable and had changed over the last few years. Stories from a few years ago include the initial referral to hospital taking longer but the tests once arranged all being done on the same day with results on the same day.

There is a perception that the creation of the 2 week wait has meant the initial meeting taking place sooner but multiple visits are now required and about a week delay before diagnosis. The only exception to this was a woman who had to go away on a school trip so proactively contacted the hospital to endure all tests and results were done on the same day.

After treatment has stopped patients described a feeling of abandonment and depression starting to set in.

They found it puzzling that the doctors do not know about/ refer them to the support centres. For example the Wimbledon Cancer Friendship Group and Paul's centre which has a wider ethnic mix.

Users from both centres described the value they get from the facilitated support and social groups as well as the wide range of therapies to increase general well-being and combat depression. Some who had been going a long time missed the counselling service group service that used to be on offer at the Paul's Centre.

Themes from conversations with professionals and volunteers.

These discussions were informal and took place at short notice sometimes over the phone. People were asked to give their impression/gut feeling about stories they had been told. These are top of the mind stories/ examples not a systematic study.

What, in your experience of talking to patients, stops them presenting to a doctor in good time?

- Issues such as long hours at work or second jobs to support the family in the UK and in country of origin can prevent early presentation for diagnosis and early treatment.
- Fear of the effect a diagnosis will have on the ability to care for the family and relationships with spouse and other family members.
- English language limitation: explaining the problem and of not understanding what is going

on (Polish, Tamil, Afro Caribbean).

- Symptoms assumed to be something less serious, tiredness, family upsets etc.
- Some members of certain faiths believe in spiritual healing and will confer with their pastors, faith healers before seeing a doctor.
- Embarrassment – they don't like talking about their vagina, breast, and penis especially to someone of the opposite sex.
- They could not get time off from work or looking after the children.
- Their culture does not see screening important (Polish, Tamil, Afro Caribbean).
- Fear – they don't want to know what is going on – all groups.
- They do not want their family to know there is something wrong.
- In the Polish community there are a number of private doctors and it was mentioned that some prefer to go to them because they speak the language. However it is not known how many this would affect.

Once at the doctor what did they say about their experience?

- Most of the stories related to women. In the Tamil community if the doctor told them it was nothing to worry about or just age they accepted it even if they were in a lot of pain.
- Polish families if they did not get helped would go to the private Polish doctor and sometimes go back to Poland for treatment because they did not want to wait.
- Afro Caribbean women would try to hide pain and symptoms from the family and some might go to their priest for help.
- An Afro Caribbean young man was told he could not have cancer because he was too young.
- Communication came across as a huge issue much broader than simple translation. People do not understand NHS language and get very confused by the system
- In Poland it is not uncommon to go to the hospital if you cannot see a GP. So it is confusing if they cannot get an appointment with their GP so go to A and E and are told to see their GP.
- An example was given of a Tamil woman who was told by her doctor that she had been referred to hospital but he did not tell her which hospital or what she has been referred for. When she went back to say she had not heard anything he just said he had done his bit and she would have to wait. This story is in direct contrast to stories told by more assertive women who persistently go back and progress chase their referrals.
- Examples were given from the Afro Caribbean community of tests being done one at a time with long gaps in between. This led to long delays in diagnosis that then required more radical treatment.
- Sometime several other diagnosis are made and treatment is given for those before cancer was diagnosed.
- The Afro Caribbean respondents spoke about the length of time it takes to feel confident talking to a doctor. The patient may need time to 'warm up', pass some pleasantries before going straight into a delicate conversation. The time in the surgery does not allow for this and they lose their nerve.
- Tamil women said it is against their culture to show their body to anyone but their husband so they must be absolutely sure there is something wrong before they break that code.

Compliance with treatment / completion of treatment

- In the Afro Caribbean community some cancer treatments were rejected either because of impact on family or because the patient believed in faith healing.
- One example was of an Afro Caribbean women who agreed to take tablets but no other intervention because she do not want her family to know. It was only when her pain became so great that she agreed to more aggressive interventions.
- One man stopped his prostate medication; it was not clear if this was because of the side effects or because he felt better. The effect of stopping medication was that the disease has now spread.

Attitude to screening

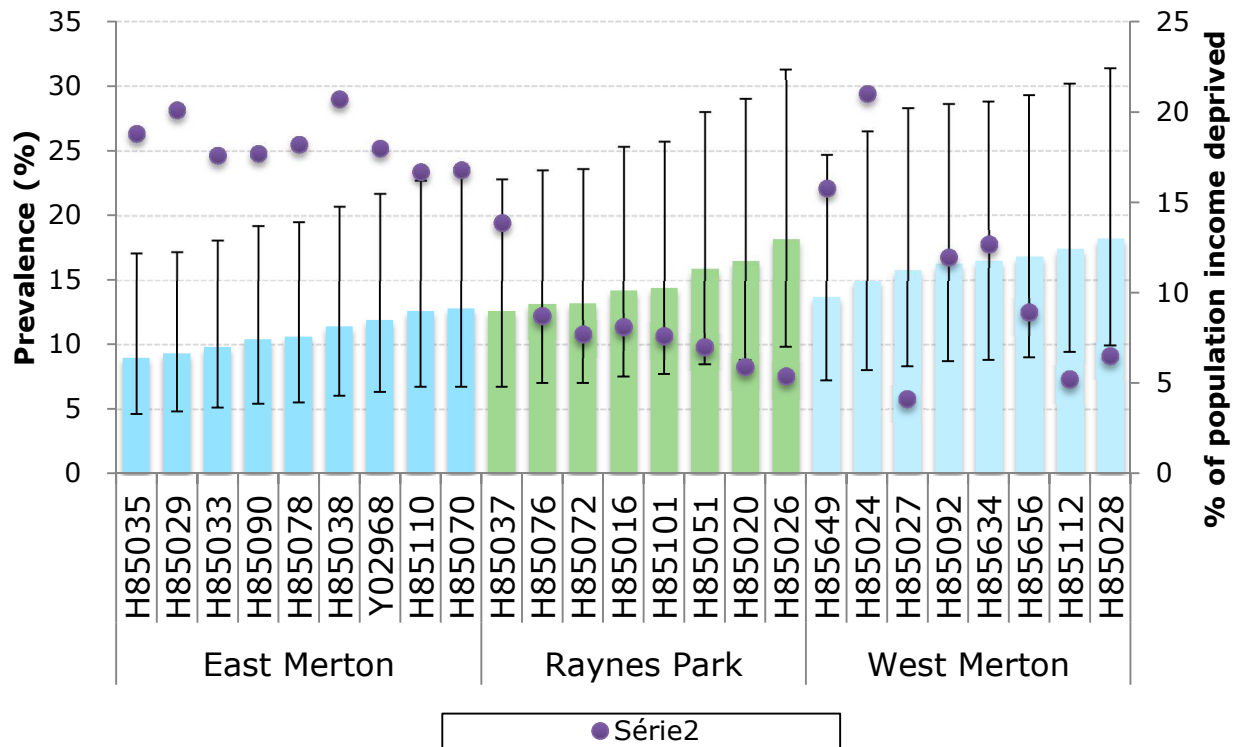
- The reasons for this differed between groups
- All stated taking time off work / child care to be an issue
- Some Afro Caribbean women were perceived to be more fatalistic and it was suggested they would not go for screening if there were no symptoms.
- Afro Caribbean men were perceived as proud of their manhood and not comfortable to disclose any information about the sexual parts of their body.
- Tamil women did not understand the invitation letter for screening. Such activity is not in their culture. They not discuss such things with their husband.
- When asked about the men they said the men would not be proactive in going unless some education had been done with them first

Polish women were described as the full time child carers and would not take time off to go for screening. It was also suggested that because of the perceived language barrier and lack of understanding of system they would not go in case they did not know what was going to happen to them. A discussion then took place regarding the use of language and the difference between literal translation and understanding of culture. In the Polish community depression is an issue but it is not useful to use that word to encourage people to come forward. Words like 'stress management' are more acceptable. This idea was then applied to the concept of screening and what might be more acceptable language. The idea of a "Just in Case" campaign emerged from the conversation.

Appendix 3: Data Collection

These data were collected and whilst useful in themselves, do not contribute to the argument in the paper. All data will be available on a CD Rom.

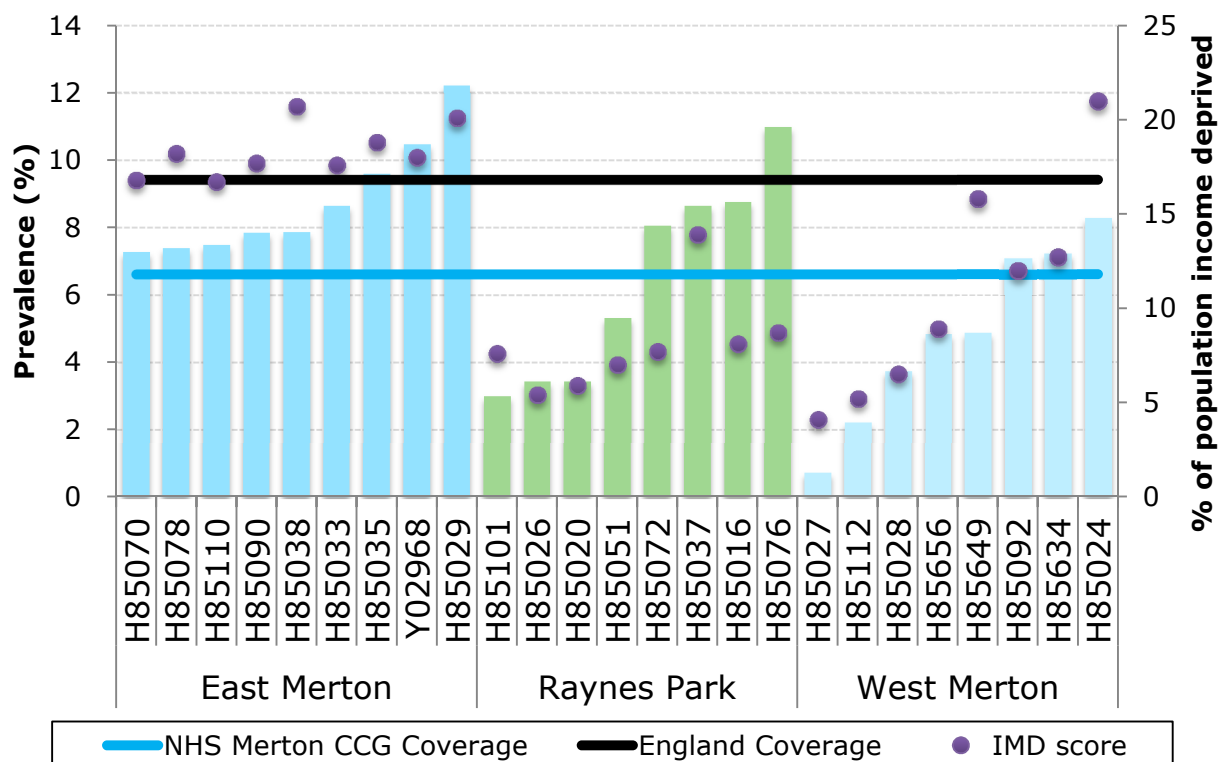
Binge drinking adults by GP practice, 2007-08



Source: Public Health Outcomes Framework 2012 – 14

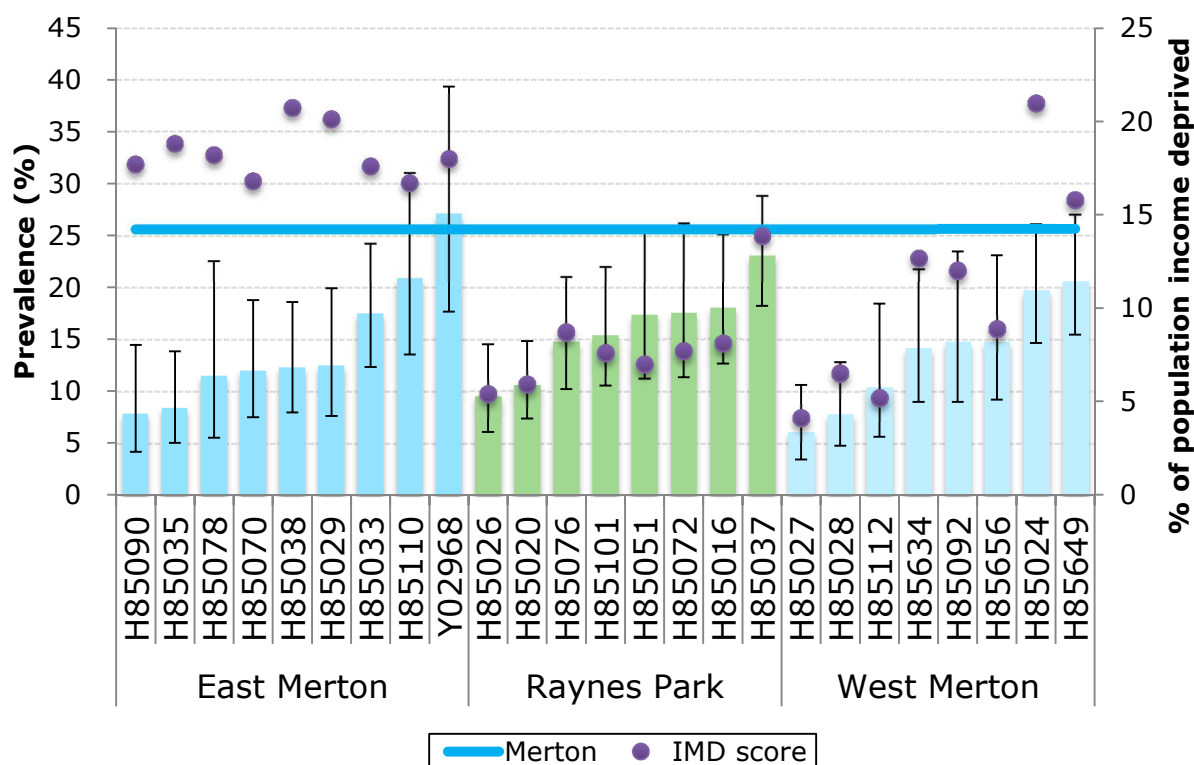
A Table identifying General Practices by their codes may be found in Appendix 5.

Obesity prevalence by GP practice, 2013/14



Source: Public Health Outcomes Framework 2012 – 14

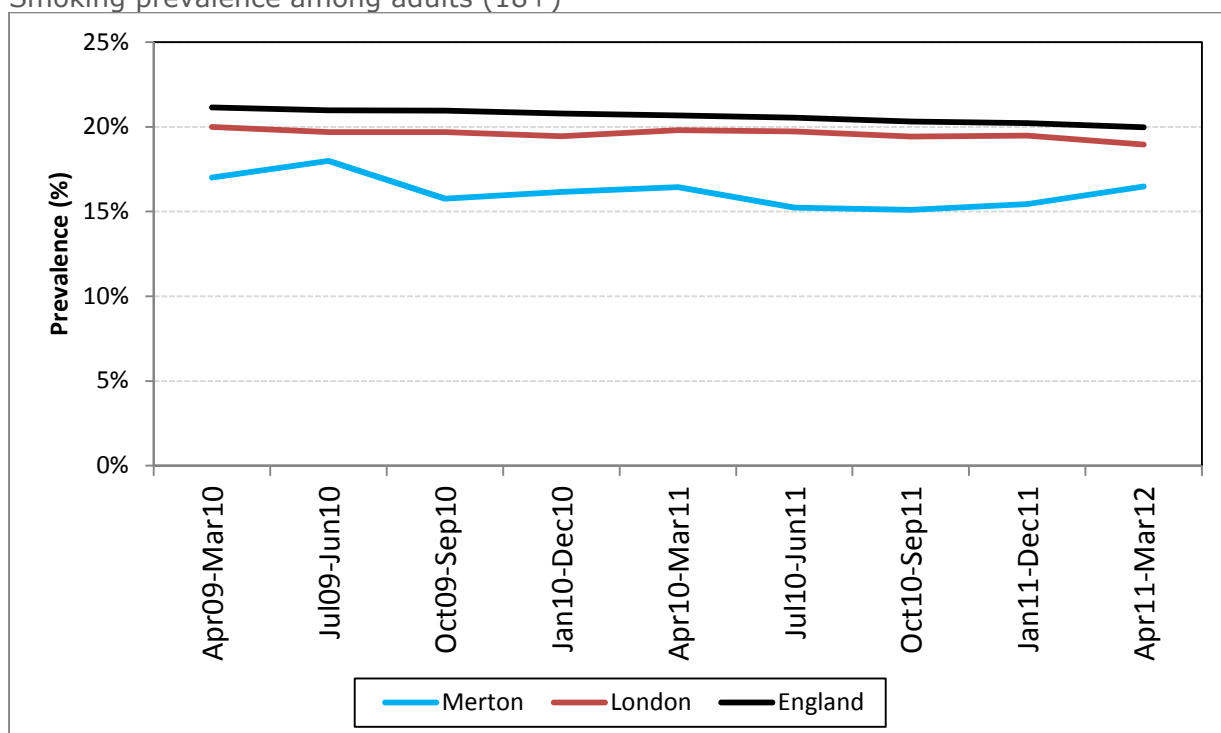
Smoking prevalence by GP practice, 2012/13



Source: Public Health Outcomes Framework 2012 - 14

A Table identifying General Practices by their codes may be found in Appendix 5.

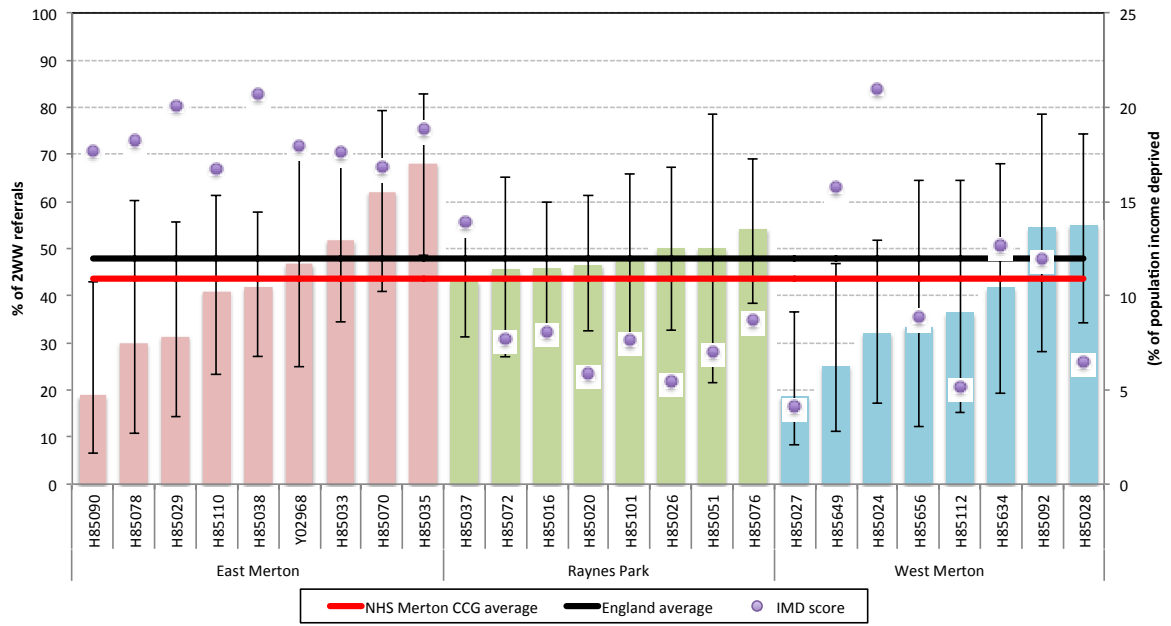
Smoking prevalence among adults (18+)



Source: Integrated Household Survey, ONS (experimental statistics - in the testing phase and not yet fully developed.)

A Table identifying General Practices by their codes may be found in Appendix 5.

Number of new cancer cases treated (% of which are TWW referrals) by GP Practice LB Merton



Source: National GP Practice Profiles (Association of Public Health Observatories)

A Table identifying General Practices by their codes may be found in Appendix 5.

Appendix 4: Merton CCG Matrix: indicators by surgery

Practice Code	Locality	QOF Smoking Prevalence (2013/14, %)	Practice Population	Practice Population aged 65+ (%)	IMD2010 Quintile (Quintile 1 = Most Affluent)	IMD2010 Score	% of population income deprived	Number of New cancer cases - 2011 (incidence)	Crude incidence rate (new cases per 100,000 population)	Number of Cancer deaths 2011/12	Crude mortality rate (deaths per 100,000 population)	Prevalent cancer cases (count)- 2012/13	Prevalent cancer cases (%) - 2012/13	Females, 50-70, screened for breast cancer in last 36 months (3 year coverage, number) - 2012/13	Females, 50-70, screened for breast cancer in last 36 months (3 year coverage, %)	Females, 25-64, attending cervical screening within target period (3.5 or 5.5 year coverage, number) - 2007/08 - Q3 2012/13	Females, 25-64, attending cervical screening within target period (3.5 or 5.5 year coverage, %)	Persons, 60-69, screened for bowel cancer in last 30 months (2.5 year coverage, number) - 2010/11 - Q3 2012/13	Persons, 60-69, screened for bowel cancer in last 30 months (2.5 year coverage, %)	Two-week referrals with cancer (Conversion rate: number of all TWW referrals with cancer) 2012/13	Two-week referrals with cancer (Conversion rate: % of all TWW referrals with cancer)	Number of emergency presentations (number of presentations)- 2012/13	Number of emergency presentations (% of presentations) - 2012/13
H85016	Raynes Park	24.6	1427	17.2	Q1	9.48	8.1	34	410	15	181	190	2.3	605	65.5	1584	74.1	430	54.8	21	12.9	18	216
H85020	Raynes Park	20.7	1955	12.8	Q1	7.85	5.9	67	436	23	150	315	2	1149	69.4	3252	70.1	809	58.7	20	8.3	9	58
H85026	Raynes Park	17.0	1041	9.2	Q1	8.22	5.4	27	231	16	137	120	1	553	60.3	2564	66.5	378	56.3	14	7.2	5	42
H85027	West Merton	19.7	1841	18.5	Q1	6.95	4.1	41	387	25	236	240	2.3	717	58.6	1589	58.3	640	55.5	5	4.8	5	47
H85028	West Merton	16.5	1034	10.1	Q1	9.63	6.5	27	255	13	123	136	1.3	545	68.7	2095	65.5	381	54.9	11	6.8	4	37
H85034	Raynes Park	*	1160	15.3	Q1	7.51	5.6	27	345	11	140	181	2.3	511	62.5	1461	66	393	53.5	3	3.6	3	38
H85051	Raynes Park	17.8	427	7	Q1	9.17	7	23	360	3	47	72	1.1	231	54.4	1335	66.7	195	58.6	4	3.1	3	46
H85072	Raynes Park	25.3	960	16.6	Q1	10.3	7.7	31	539	11	191	64	1.1	525	67	1129	75.3	380	56.9	10	12.7	3	52
H85101	Raynes Park	22.5	1148	12.7	Q1	8.31	7.6	43	478	18	200	156	1.7	550	64.3	1948	71.9	389	53.2	13	9.7	2	22
H85112	West Merton	15.5	480	9.1	Q1	7.67	5.2	14	257	3	55	60	1.1	348	62.5	988	62	214	49.1	4	4.3	1	18
H85076	Raynes Park	32.7	1556	16.7	Q2	12.61	8.7	46	490	24	256	238	2.5	953	79.4	1789	76.4	544	56.1	20	10.4	7	74
H85656	West Merton	19.9	492	8.8	Q2	12	8.9	15	263	3	53	57	1	271	64.1	1204	75.4	137	35.8	3	10.7	1	17
H85037	Raynes Park	22.9	1873	13.6	Q3	16.94	13.9	57	404	20	142	218	1.5	957	68.6	2447	67.7	608	53.3	25	12.4	7	49
H85092	West Merton	20.0	482	8.6	Q3	14.98	12	9	159	5	89	47	0.8	247	58.7	1213	75	167	44.5	6	5.8	1	17
H85634	West Merton	14.9	396	5.9	Q3	16.74	12.7	12	175	3	44	73	1.1	185	54.3	1619	68.8	117	46.4	5	5.3	3	43
H85024	West Merton	23.4	1050	9.7	Q4	25.7	21	41	369	23	207	93	0.8	642	66.3	2037	71.7	347	46.8	8	3.2	3	27

Practice Code	Locality	QOF Smoking Prevalence (2013/14, %)	Practice Population	Practice Population aged 65+ (%)	IMD2010 Quintile (Quintile 1 = Most Affluent)	IMD2010 Score	% of population income deprived	Number of New cancer cases - 2011 (incidence)	Crude incidence rate (new cases per 100,000 population)	Number of Cancer deaths 2011/12	Crude mortality rate (deaths per 100,000 population)	Prevalent cancer cases (count)- 2012/13	Prevalent cancer cases (%) - 2012/13	Females, 50-70, screened for breast cancer in last 36 months (3 year coverage, number) - 2012/13	Females, 50-70, screened for breast cancer in last 36 months (3 year coverage, %)	Females, 25-64, attending cervical screening within target period (3.5 or 5.5 year coverage, number) - 2007/08 - Q3 2012/13	Females, 25-64, attending cervical screening within target period (3.5 or 5.5 year coverage, %)	Persons, 60-69, screened for bowel cancer in last 30 months (2.5 year coverage, number) - 2010/11 - Q3 2012/13	Persons, 60-69, screened for bowel cancer in last 30 months (2.5 year coverage, %)	Two-week referrals with cancer (Conversion rate: number of all TWW referrals with cancer) 2012/13	Two-week referrals with cancer (Conversion rate: % of all TWW referrals with cancer)	Number of emergency presentations (number of presentations)- 2012/13	Number of emergency presentations (% of presentations) - 2012/13
H85029	East Merton	28.9	828	11.5	Q4	21.6	20.1	27	374	9	125	101	1.4	486	69.2	1379	75	244	50.2	5	3.1	4	55
H85033	East Merton	26.6	1109	11.6	Q4	20.49	17.6	35	362	16	165	163	1.7	714	66.7	1959	77.2	399	53.7	15	5.1	7	72
H85035	East Merton	27.2	1141	12.5	Q4	21.73	18.8	30	323	8	86	104	1.1	628	63.4	1772	72.7	385	50.3	17	8	2	21
H85038	East Merton	28.5	1236	13.6	Q4	24.52	20.7	42	464	32	354	163	1.8	657	66.5	1794	72.5	357	46.4	15	8.7	6	66
H85070	East Merton	27.9	750	9.1	Q4	20.93	16.8	30	365	7	85	88	1.1	377	61.4	1361	68.1	197	38.9	13	10.1	5	60
H85078	East Merton	27.3	442	14.4	Q4	21.23	18.2	10	313	7	219	54	1.7	150	58.1	441	61.9	106	41.7	3	4.3	3	94
H85090	East Merton	23.9	656	9.6	Q4	20.98	17.7	19	277	9	131	92	1.3	387	67.8	1165	63	181	42.7	3	3.6	3	43
H85110	East Merton	25.9	612	13.2	Q4	21.25	16.7	19	414	16	348	35	0.8	313	59.1	845	68.3	201	48.9	9	14.5	6	130
H85649	West Merton	20.3	816	7.4	Q4	19.85	15.8	27	242	8	72	96	0.9	509	58.6	2114	66.1	234	38.6	5	2.6	5	44
Y02968	East Merton	20.4	309	6.2	Q4	22.18	18	5	105	11	230	32	0.7	185	49.5	1023	69.1	125	46.8	7	6.9	2	41
NHS Merton CCG			25221			14.56			348		156		1.5		64.8		69.4		51.3		7.1		54

Appendix 5: A Table identifying General Practices by their codes and locality.

Practice Code	Practice Name	Locality
H85016	S J Woropay	Raynes Park
H85020	Church Lane Practice	Raynes Park
H85026	Francis Grove Surgery	Raynes Park
H85027	Dr Allen + Partners	West Merton
H85028	V Sharma	West Merton
H85034	I C R Hartley	Raynes Park
H85051	Lambton Road Medical Practice	Raynes Park
H85072	J J Jephcott	Raynes Park
H85101	The Grand Drive Surgery	Raynes Park
H85112	J R Jones	West Merton
H85076	Stonecot Surgery	Raynes Park
H85656	Sornalingham	West Merton
H85037	Dr Gibbs + Partners	Raynes Park
H85092	M N Baig	West Merton
H85634	Merton Medical Practice	West Merton
H85024	Dr B Naha	West Merton
H85029	M N Patel	East Merton
H85033	G P Hollier	East Merton
H85035	K Worthington	East Merton
H85038	Cricket Green Medical Practice	East Merton
H85070	Central Medical Centre	East Merton
H85078	R Lall	East Merton
H85090	Figges Marsh Surgery	East Merton
H85110	T Keyamo	East Merton
H85649	Dr Ayub + Partners	West Merton
Y02968	GP Led Health Centre	East Merton

Appendix 6: Social marketing: increasing uptake of cervical screening

This is a brief review of some social marketing interventions which have been trialled to increase the uptake of cervical screening.

“What’s Pants, but could save your life?” campaign³.2008

Background

This campaign in the West Midlands was the first initiative in the UK linking cervical screening to a social marketing approach. It was fully integrated, directly linking data trends, audience segmentation and social behaviour research with the construction of an awareness campaign. The programme targeted 25 – 29 year old women and aimed at achieving the target 80% uptake of screening in that age group. At the end of quarter 1 (2008/09) they had achieved an increase of 16% but not the target.

A number of drivers had led to the campaign, a rise in lower screening age from 20 to 25 in 2004, and declining attendance for screening since 2001. A greater proportion of women in deprived areas were diagnosed with invasive cervical cancer having previously not been screened. So in 2008 a three year social marketing intervention was planned to take place across the whole of the West Midlands.

Intervention

The campaign was based on two stages of research. The first found the following reasons women did not attend cervical screening:

- Embarrassment
- The test is uncomfortable
- Anxiety
- A lack of knowledge about cervical cancer
- Do not understand the benefits of cervical screening
- Screening not a priority for young women, because of the perception that young people do not get cancer
- Cultural reasons
- Inconvenient appointment times
- Difficulty making an appointment
- Difficulty getting to the clinic
- The possibility of a male smear-taker.

The research also suggested that 33% of women aged 25 – 29 were not attending screening when they were first invited, and that those who did not respond to the first screen, were not likely to attend future invitations. Many different research methods identified the “What’s pants” theme as highly memorable and identifiable; a few young women in focus groups had referred to cervical screening as “pants”. This was found to be not offensive to either the young women from deprived areas nor to the young Asian women.

Advertising was widely spread, on buses, trains, radio, a website, GP surgeries and credit card sized cut-outs in the shape of pants and displaying key messages in lingerie stores and supermarkets.

They also discovered that location and opening hours of screening centres were crucial to the success of a programme, with out-of-hours screening playing a particularly important role and due to their success some of these clinics have become permanent, such as a walk-in facility in Stoke-on-Trent.

Outcome

However despite the carefully constructed research and intervention, and an initial surge of a 16% increase, these outcomes were not sustained:

Cervical screening coverage for 25 – 29 year olds:
2007/08: 66% (prior to campaign)
2008/09: 66.6%
2009/10: 65.6%

Further analysis of results was confounded by the death of Jade Goody in 2009 which caused a significant but temporary increase in screening uptake.

Conclusion

Although ongoing outcomes did not meet expectations, a number of useful and generalisable insights had been gained.

³ <http://www.thensmc.com/node/668/pv>

Using a social marketing approach to increase uptake of cervical screening in women aged 25 – 34 years old. Kirklees Council⁴ 2013

Background

The behavioural goals of the social marketing project were to: •

- positively shift attitudes and behaviours amongst local women •
- shift attitudes of wider influencers (mum, family member, friend, partner) •
- encourage women to go for their smear test

The groups on which the campaign was focused were Acorn Group N, “Struggling Families”, and a secondary target audience was Acorn Group K, young Asian women.

Intervention

This was mainly a literature based campaign, running in a two month period early in 2013, working on language, ideas and clarity about the process.

The Primary message is “Smear tests. Have yours before it’s too late”. Key messages that were included in the campaign literature were:

- It’s private and you won’t be rushed
- It only takes a few minutes
- You can ask for a female doctor or nurse
- You can take a friend with you to your appointment
- You will be treated with dignity and respect.

Research had shown that women understood – and would respond to “smear test” better than “cervical screening”. Another finding was that there needed to be a strong emotional connection for women and that what is motivating is the dramatization of what might happen *to them* if they don’t take the test.

Outcome

Of the GP practices included in local analysis (54 in total), there was a 37% increase in the number of smear tests carried out in the 25-30 year age group, during the campaign period (January – April 2013), compared with the same time period in 2012.

In addition, the Contraception & Sexual Health clinic in Kirklees reported a 61% uplift in number of cervical screening appointments in the campaign period, compared with the same period in 2012.

Although the team hope to see that this effect sustained over a longer period of time, evidence was not yet available. Some years would have to elapse owing to the three year cycle of call/recall.

Learning Points

- Segmentation of the target audience allowed the campaign materials and activity to be focussed around the area with high proportion of Group N women. This segmentation also informed from whom insight should be sought.
- The approach was structured in response to an understanding of the target women’s experiences of screening.
- The project showed that assumptions cannot be made on what are the most appropriate messages. In this case initial research showed that it was a strong message which was needed in order to motivate the women to change their behaviour.
- Community engagement was also a crucial element of the campaign. Face-to-face engagement helped to normalise cervical screening in day to day conversation.
- Extensive stakeholder engagement was the key behind the successful delivery of this campaign. This was both labour intensive and time-consuming, however the report indicates that without the number of stakeholders engaged, and the range of frontline teams, the extent and success of the campaign would have been limited.

⁴ <http://www2.kirklees.gov.uk/involve/entry.aspx?id=528>

IT ONLY TAKES A MINUTE, GIRL **Insights into women's perceptions of cervical screening in Blackpool⁵ 2009**

Background

This was the first stage of a larger project to increase uptake of cervical screening in the area covered by NHS Blackpool where 22% of women aged 25 – 29 years (994 women) and 10% of women aged 30 – 34 years (389 women) had never had a cervical smear. This first stage researched what the young women valued and wanted.

Intervention

An extensive literature review explored health beliefs and behaviour change and also successful social marketing campaigns. This was accompanied by four focus groups with groups from different segments of the community.

Outcome

Findings ranged from a checklist of inputs to successful campaigns:

- Information regarding the need for change
- Motivation to change behaviour
- Skills to initiate and sustain new behaviour
- Technical skills
- Social skills
- Feeling that change is possible
- Supportive changes in community norms
- Policy structure changes to support educational efforts and behaviour changes

Overall findings suggested that lack of knowledge and fear about the screening process were the main factors that affected participation in screening:

- Lack of knowledge about cervical cancer and risk factors
- Fear of embarrassment and/or pain
- Lack of understanding of the screening procedure
- Low level awareness of the benefits of screening

From the young women in Blackpool focus groups, four key insights were obtained:

1. family life comes first: women were prepared to sacrifice a great deal of time and effort for the goal of happy family life
2. freedom for "me-time" is needed
3. friends and Facebook matter. Traditional means of social networking – meeting up with friends at home or by telephone, or going out for a drink together was being supplanted by social media networking.
4. Feeling safe and secure is important

Women in the focus groups agreed with the need to keep themselves fit and healthy for the sake of the family, but tended to have a fatalistic attitude and did not feel it was something they could have a great deal of control over.

Living a long and healthy life was not something that the women in the focus groups aspired to, suggesting that promoting or "selling" health in itself would be ineffective.

NHS Haringey: increase in uptake of cervical cancer screening⁶

Access to this report is restricted but may be available to NHS Merton CCG or LB Merton Public Health Department.

⁵ <http://www.cph.org.uk/wp-content/uploads/2012/08/it-only-takes-a-minute-girl---womens-perceptions-of-cervical-screening-in-blackpool---full-report.pdf>.

⁶ <http://www.lho.org.uk/viewResource.aspx?id=16394>

An Evaluation of a Social Marketing campaign to reduce the number of London women who have never been screened for cervical cancer. ⁷ 2002

Background

This letter to the Journal of Medical Screening took as its departure a systematic review⁸ which showed that the best predictor of attendance for a smear test is previous attendance. If a woman attends once, she will attend again. A new software development identified women aged 40 – 64 years who had never previously had a cervical smear test. The letter described a social marketing intervention to target these women for cervical screening.

Intervention

The intervention consisted of personalised contact with the women by the health authority or PCT, and also public advertising via broadcast and print media, billboards and posters in health facilities. The individual contact gave more detailed information, and the public advertising was fronted by a TV personality, a month long poster campaign on London buses, and posters and credit card sized reminders offering simple messages.

Outcome

Women within the target group were three times more likely to have a high- grade abnormality when compared with all English women who participated in the programme in 2002 – 03. Whilst the aim and quality standard for cervical screening is 80% coverage, the findings indicate additional health gains to be achieved by targeting groups of women not previously screened.

Yorkshire and Humber Health Intelligence (YHHI)⁹

An interesting and potentially very useful project is described here. The website “aims to give cervical screening leads in Yorkshire and the Humber a quick and easy roadmap to the wealth of learning, insights and recommendations that have resulted from the research into:

- which groups of women are contributing most to the decline in screening attendance
- what perceived or actual barriers are discouraging these women from attending their screening appointments
- what messages and service innovations will work best, according to local women and local health professionals, in halting and reversing the decline in uptake.”

However YHHI is now part of Public Health England, which continues to maintain the website, but the website advertised has expired. Contact with PHE has been made to find the report of this project, as yet without success. However this project underlines a key feature of social marketing, that the intervention has to be defined in relation to research undertaken with the local community, with whom the intervention is to be carried out.

Cervical Screening: The Facts¹⁰

A number of projects referred to use of “Cervical Screening: The Facts”. This is a useful leaflet available in a number of languages, but not in Tamil, a point which LB Merton Public Health Department might want to pursue.

⁷ Millett C, Zelenyanszki C, Furlong C, Binysh K. (2005). An Evaluation of a Social Marketing campaign to reduce the number of London women who have never been screened for cervical cancer. *Journal of Medical Screening*. 12 (4), 2004 - 2005.

⁸ Jepson R, Clegg A, Forbes C. The determinants of screening uptake and interventions for increasing uptake: a systematic review. *Health Technol Assess* 2000;**4**:14

⁹ <http://www.yhpho.org.uk/resource/item.aspx?RID=127465>

¹⁰ <http://www.cancerscreening.nhs.uk/cervical/publications/the-facts-other-languages.html>

Conclusions

It is important to remember that these were keys that have been discovered in each of these projects were for the particular group of women who were the subjects of the study. Social marketing requires analysis of the local people who are the focus of social marketing. This "segmentation analysis" was the first step in each report cited.

Concentration on what has been found to be the single most important predictor of attendance for cervical screening was previous attendance. Therefore targeting women who had no history of attendance is likely to be most cost- and clinically- effective, also delivering future increases in uptake and achieving the highest pick up rate of pre-cancerous changes not previously identified.

However there are common themes through the studies that have been reviewed. These relate both to emotional responses, and to practical ones.

Key elements of responses which were seen in more than one study include:

Response from women	Proposals by programmes
Embarrassment	It's private and you won't be rushed
The test is uncomfortable	It only takes a few minutes
Anxiety	You can ask for a female doctor or nurse
A lack of knowledge about cervical cancer	You can take a friend with you to your appointment
Do not understand the benefits of cervical screening	You will be treated with dignity and respect.
The possibility of a male smear-taker	Motivation to change behaviour
The letter was impersonal and they did not readily understand what was proposed.	A need to bring cervical screening out more as a topic of general conversation

Research had shown that

- women understood – and would respond to "smear test" better than "cervical screening".
- there needed to be a strong emotional connection for women and that what is motivating is the dramatization of what might happen to them if they don't take the test.
- Relating the value of cervical screening to a component of care of self and of the family. Women would put family before themselves. Cervical screening benefits the family.
- Most programmes found the need for either personal contact with non-attenders and/or literature that was easy to assimilate, made clear messages in local jargon, had a humorous aspect, and made compliance seem easy.