



MIND THE GAP

Cancer Inequalities in London

WE ARE
MACMILLAN.
CANCER SUPPORT

CONTENTS

Welcome	4
Executive summary	7
Cancer patient experience in London	8
Exploring inequalities for socioeconomically deprived cancer patients	10
Exploring inequalities for minority ethnic cancer patients	14
Inequalities in cancer outcomes	18
What's next?	20
Glossary of key terms	21
Appendix	22
Endnotes	26

WELCOME

At Macmillan Cancer support, we believe that everyone should receive excellent cancer care, irrespective of income, ethnicity, gender, age or postcode.



If you live in London, you are likely to receive world-class treatment and medical care. You might even be helping ground-breaking research and treatments. It is however, equally important that your experience of cancer care is similarly world-class – such as receiving clear information and being treated with compassion and respect. This makes a huge difference to patients and their loved ones at the most difficult times of their lives. In fact, 'Achieving world-class cancer outcomes: a strategy for England 2015-2020' established that patient experience is on a par with clinical effectiveness and safety¹.

We know that this is the case for many Londoners, but we also know that not everyone experiences the highest quality of care. The Mayor of London has highlighted this in his recently launched Draft Health Inequalities strategy², which we hope will shed more light on these important issues.

In this report, we explore inequalities in cancer care that exist in London. Analysis that Macmillan commissioned recently, shows that people living with cancer in London report worse experiences of cancer care than those elsewhere in England³. **This is worse still for minority ethnic groups who account for around two in five – that's 42.5%⁴ – of all people living in London.** We also found that patient experience is worse for those who live in the most socioeconomically deprived areas. It may be counterintuitive

but, in fact, **our capital city has a higher proportion of people in poverty (after housing costs) than the rest of England (27% compared to 21%)⁵.**

These differences matter. In terms of clinical outcomes, we know that there are differences at a national level for those from minority ethnic groups and those living in deprived areas⁶. London has the most ethnically diverse population in the country and significant pockets of socioeconomic deprivation.

Macmillan Cancer Support believes this situation is unacceptable. This report sets out the current position, and aims to help commissioners, policy makers, politicians, and the NHS to better understand the issues of inequalities in cancer care, in London. By shining a spotlight on these issues, we hope to work with all our partners to address them, and ensure that the current inequalities in cancer care become a thing of the past.

Ed Tallis

Head of Services in London
Macmillan Cancer Support

'Cancer touches the lives of millions of Londoners. Chances are we all have a friend, a neighbour or a family member whose life has been turned upside down. That's why as Mayor I'm doing everything that I can and in collaboration with Macmillan Cancer Support I'm proud to be launching the London Cancer Community. This initiative will place people living with cancer at the heart of services, ensuring their views are represented and their voices are heard. By working together, we can help raise awareness and help tackle the inequalities in care that we still see across our city.'

Sadiq Khan, Mayor of London




CANCER STATS

 = 1000 people


Almost
14,000
people die from cancer
in London every year.⁷



On average, almost
33,000
people are diagnosed with
cancer in London every year.⁸



In 2010, there were
more than
178,000
people living with or
beyond cancer in London.⁹



By 2030, it is estimated that
the cancer population will
double with
347,000
people living with or beyond
cancer in London.⁹



Methodology: The patient experience data in this report comes from a London-specific analysis of the National Cancer Patient Experience Survey 2016, commissioned by Macmillan Cancer Support. We have used tests of statistical significance to determine with confidence which differences are reliable and not random. In this report, we include only these questions.¹⁰

EXECUTIVE SUMMARY

In this report, we will explore cancer inequalities in London in terms of patient experience, and focus specifically on deprivation and ethnicity.

We also look at inequalities in cancer outcomes based on national data in relation to these two issues (as London specific analysis is unfortunately not available).

It is vital that we understand what types of inequalities exist – at both a national and London level – so that we can address them.

London is the most ethnically diverse area of the UK, and has some of the country's most deprived boroughs. Often, these two factors of inequality combine in a single individual to provide significant challenges.

Our analysis has led us to the following key findings:

- 1. Overall, London cancer experience is good, although worse than in the rest of England.**
- 2. Patients from the most deprived areas report worse experiences than those from the least deprived areas in practically all aspects of care.**
- 3. Minority ethnic cancer patients have poorer experiences of cancer services than those who identify as white, on nearly all dimensions of care.**

- 4. Analysis at a national level shows that in England, people living in areas of higher deprivation are more likely to get some types of cancer and have worse survival rates for many types of cancer¹¹. We also know that there is geographic variation in one-year survival across different areas in London¹².**

We need to raise awareness of the continued inequalities so that we can work together to eradicate them. Listening to and engaging with the experiences and needs of Londoners with cancer is key to achieving this aim.

To this end, Macmillan is very proud to be launching the London Cancer Community, a network of Londoners affected by cancer, who represent the city's diverse population and reflect the variety of cancer experiences across the capital. Only by working closely with people from all walks of life in London will we find ways to start addressing cancer inequalities.

**LONDON
CANCER
COMMUNITY.**

CANCER PATIENT EXPERIENCE IN LONDON

Although in general, the experience of people with cancer in London is good, with respondents giving an average rating of 8.6 out of 10 and improving over time, Londoners¹³ living with cancer report worse patient experience than people with cancer in the rest of England¹⁴ (Appendix).

London has world-class facilities, world-leading research, and cutting-edge teaching hospitals. General cancer care is very good and so is patient experience. In fact, there are three areas in which London outshines the rest of England:

- More Londoners than in other parts of the country said that they were given the name of a Clinical Nurse Specialist (CNS) – although they didn't find it as easy to contact their CNS or get understandable answers as people with cancer in the rest of the country.
- Londoners felt that there were enough nurses on duty.
- More Londoners were asked if they wanted to take part in cancer research.

But we can do much more. In response to our 52 questions on their cancer care, Londoners told us their experience was poorer than the rest of England in 43 instances. In this report, we focus on only these 43 questions.

The reasons behind poorer cancer experience in London are varied and complex, and while some can be explained by the challenges of providing healthcare and living in the UK's capital city, **the need to continue working towards improving Londoners' experience of their cancer care is apparent.**

For instance:

- 12.3% fewer Londoners said that staff asked them what name they preferred to be called by (London 56.6% versus non-London 68.9%).
- 9.8% fewer Londoners felt that they were given enough support from health or social services during treatment (London 44.3% versus non-London 54.1%).
- 9.4% fewer Londoners said that the length of time they had to wait when attending clinics and appointments was right (London 59% versus non-London 68.4%).
- 7.4% fewer Londoners said that hospital and community staff always worked well together (London 54.7% versus non-London 62.1%).
- 4.9% fewer Londoners felt that they could discuss worries and fears with staff during hospital visit (London 66.2% versus non-London 71.1%).

The Bromley by Bow Centre in East London partnered with Macmillan Cancer Support to create an innovative Social Prescribing service. The service supports people by helping them access a wide range of non medical services including work and welfare advice, walking groups and gardening sessions.¹⁵

Althea, Macmillan Social Prescribing service user



Exploring

INEQUALITIES FOR SOCIOECONOMICALLY DEPRIVED CANCER PATIENTS

There are significant areas of deprivation across London. In fact, 22.5% of London's deprived areas are within the most deprived 20% of England.¹⁶

Analysis from the Greater London Authority (GLA) in 2015 shows the areas with some of the highest socioeconomic deprivation¹⁷ that stretch from Enfield south through Haringey to Islington, Camden and Hackney and east – through Tower Hamlets and Newham into Barking and Dagenham. There is a similar, although weaker pattern, reflected

from Croydon north across Lambeth, Southwark, Lewisham and Greenwich. Another significant, albeit smaller, cluster of areas of higher deprivation is apparent from the centre of Brent through the northern parts of Hammersmith & Fulham and Kensington & Chelsea into Westminster.



Our analysis of the Cancer Patient Experience Survey data revealed that the Londoners from the most deprived areas¹⁸ report worse cancer patient experience than those living in the least deprived areas.

Key findings:

Our analysis revealed that there are 19 questions with statistically significant differences in patient experience broken down by level of socioeconomic deprivation in London¹⁹. The most negative experience is reported by those in the most deprived areas on 17 out of 19 questions or dimensions of care, which means that the **people from the most deprived areas report worse experience on almost 90% of the questions**. That's true on all but two questions, which are about (1) being given information about radiotherapy and (2) being given a care plan.

For instance:

- 11.8% fewer people from the most deprived areas in London said that they got enough care and support from health or social services during treatment (patients from most deprived areas 40% and least deprived 51.8%).

- 8.3% fewer people from the most deprived areas in London said they were given answers they could understand from their Clinical Nurse Specialist (patients from most deprived areas 81% and least deprived 89.3%).
- 8.1% fewer people from the most deprived areas in London said that they thought the GPs and nurses did everything they could to support them during treatment (patients from most deprived areas 53.1% and least deprived 61.2%).
- 7.7% fewer people from the most deprived areas in London said there were enough nurses on duty (patients from most deprived areas 64.8% and least deprived 72.5%).

Felt they got enough care and support from health or social services during treatment:



Felt they were given answers they could understand from their Clinical Nurse Specialist:



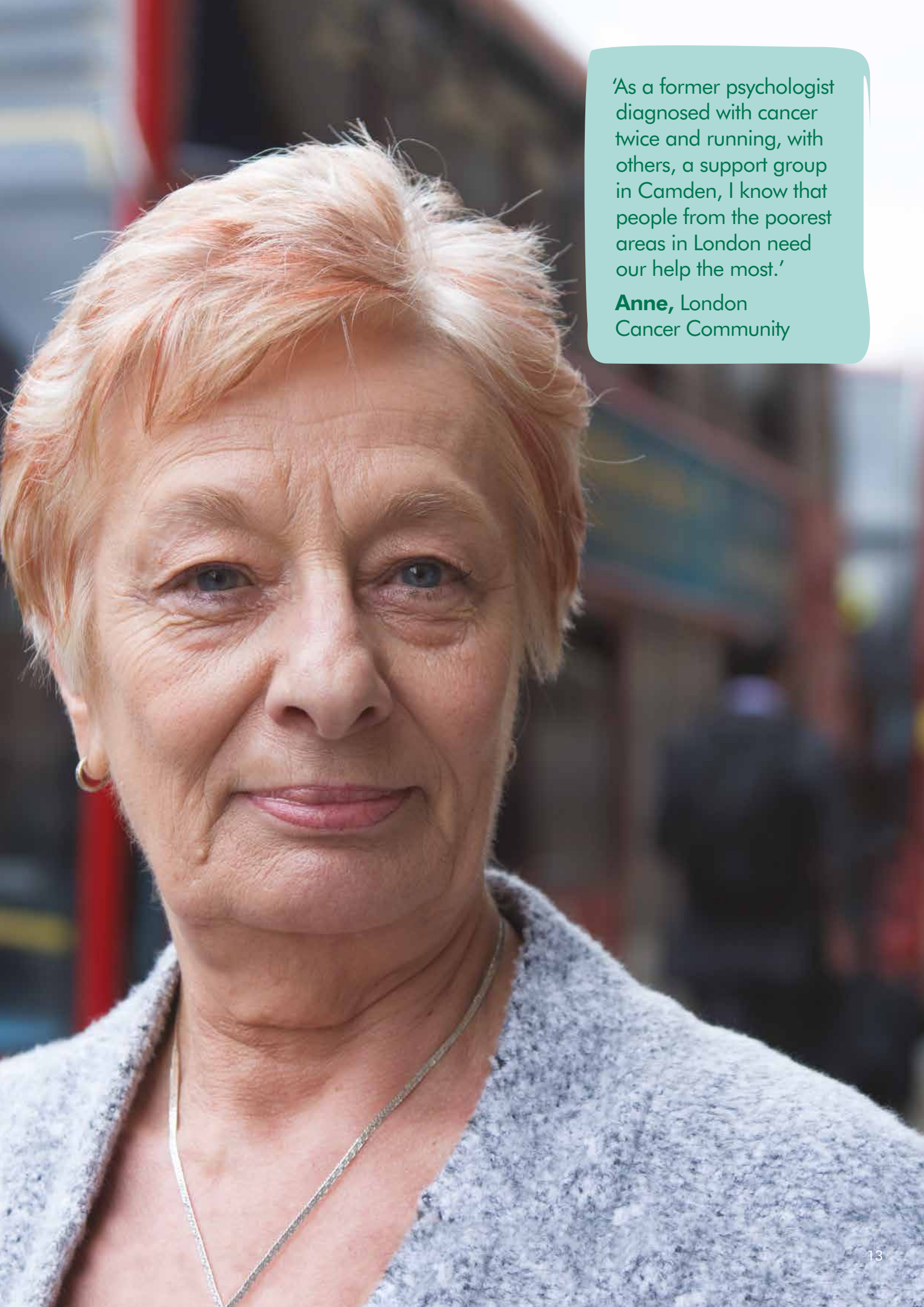
Felt the GPs and nurses did everything they could to support them during treatment:



Exploring inequalities for socioeconomically deprived cancer patients *(continued)*

The following table compares the responses of people from the most deprived areas with those from the least deprived areas. The most negative experience (red) is reported by those in the most deprived areas and the most positive experience (green) is reported by the people with cancer living in the least deprived areas.

	Most deprived	Least deprived	Difference
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	68.4%	78.5%	-10.0%
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	76.1%	82.5%	-6.4%
Overall, how did you feel about the length of time you had to wait for your test to be done?	84.3%	89.5%	-5.2%
Were you involved as much as you wanted to be in decisions about your care and treatment?	73.7%	78.7%	-5.1%
When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	81.0%	89.3%	-8.3%
Did groups of doctors and nurses talk in front of you as if you weren't there? <i>(these percentages reflect the 'no' answers)</i>	71.9%	81.5%	-9.6%
In your opinion, were there enough nurses on duty to care for you in hospital?	64.8%	72.5%	-7.7%
Do you think the hospital staff did everything they could to help control your pain?	80.3%	85.9%	-5.6%
Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	61.5%	51.1%	10.4%
During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	40.0%	51.8%	-11.8%
Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	33.7%	42.6%	-8.9%
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	90.4%	96.2%	-5.7%
Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	53.1%	61.2%	-8.1%
Have you been given a care plan?	38.1%	27.2%	10.9%
Overall, how would you rate your care?	8.47	8.73	



'As a former psychologist diagnosed with cancer twice and running, with others, a support group in Camden, I know that people from the poorest areas in London need our help the most.'

Anne, London
Cancer Community

INEQUALITIES FOR MINORITY ETHNIC CANCER PATIENTS

Our analysis found that minority ethnic groups were more likely to report a poorer experience than those who identify as white.

Key findings:

Looking at breakdowns by ethnicity, there are 32 questions in London that have statistically significant differences. Of those 32 questions, White respondents report the most positive experience on 19, (almost 60% of the questions). Black respondents report the most positive experience on just one question. Respondents who recorded their ethnicity as "Other" report the most positive experience on five questions.

For instance:

- 23.2% more patients of Mixed ethnic background were more likely to say that groups of doctors and nurses talked in front of them as if they weren't there (Mixed ethnic background 42.4% and White patients 19.2%)*
- 15.8% fewer Black patients felt they were seen as soon as necessary by their GP before going to the hospital (Black patients 61.2% and White patients 77%)
- 13.9% fewer patients of Mixed ethnic background said that test results were explained to them in a way they understood (Mixed ethnic background 64.1% and White patients 78%).
- 13.3% fewer Black patients said that that they understood the explanation of what was wrong with them (Black patients 58.9% and White patients 72.2%).
- 12.6% fewer Asian patients felt positive about the length of time they had to wait for their test (Asian patients 75.8% and White patients 88.4%).
- 11.4% fewer Asian patients said that they could find someone in the hospital to discuss their worries and fears (Asian patients 56.9% and White patients 68.3%).

Patients felt groups of doctors and nurses talked in front of them as if they weren't there:



Patients felt they were seen as soon as necessary by their GP before going to the hospital:



Patients felt positive about the length of time they had to wait for their test:



* These percentages reflect the aggregated 'yes, sometimes' and 'yes, often' answers.

'I want to be listened to. Being part of the London Cancer Community, which is a very diverse group of people, makes me feel empowered and enriched. Macmillan Cancer Support gave me the courage to represent other people with cancer in London and enabled me to talk to a lot of people from different ethnicities.'

Patrick, London
Cancer Community



Exploring inequalities for minority ethnic cancer patients (continued)

The following table compares the responses of people from different ethnic backgrounds who reported the most negative (red) and the most positive (green) cancer patient experience (green).

	People living with cancer identified themselves as:				
	Asian*	Black*	Mixed*	Other*	White
Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	65.1%	61.2%	63.4%	66.3%	77.0%
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	70.6%	78.1%	70.0%	68.3%	81.5%
Beforehand, did you have all the information you needed about your test?	89.7%	89.7%	89.5%	85.3%	94.4%
Overall, how did you feel about the length of time you had to wait for your test to be done?	75.8%	86.7%	80.9%	78.2%	88.4%
Were the results of the test explained in a way you could understand?	65.7%	67.3%	64.1%	64.7%	78.0%
Did you understand the explanation of what was wrong with you?	67.4%	58.9%	64.5%	70.4%	72.2%
When you were told you had cancer, were you given written information about the type of cancer you had?	66.8%	64.8%	65.0%	67.4%	70.9%
Before your cancer treatment started, were your treatment options explained to you?	75.6%	74.9%	73.7%	83.5%	80.7%
Were the possible side effects of treatment(s) explained in a way you could understand?	69.7%	66.2%	61.2%	74.8%	70.7%
Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	59.9%	63.9%	54.3%	66.4%	64.0%
Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	53.2%	49.6%	46.5%	64.4%	52.5%
Were you involved as much as you wanted to be in decisions about your care and treatment?	70.2%	67.9%	64.8%	69.3%	75.8%
How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	80.5%	78.2%	83.8%	79.0%	84.2%
When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	80.0%	77.9%	82.6%	77.6%	86.7%
After the operation, did a member of staff explain how it had gone in a way you could understand?	71.2%	69.4%	68.1%	77.8%	77.7%
Did groups of doctors and nurses talk in front of you as if you weren't there? (these percentages reflect the 'no' answers)	65.5%	71.1%	57.6%	73.0%	80.8%
Did you have confidence and trust in the ward nurses treating you?	68.3%	65.7%	64.0%	62.9%	71.5%

	People living with cancer identified themselves as:				
	Asian*	Black*	Mixed*	Other*	White
In your opinion, were there enough nurses on duty to care for you in hospital?	63.3%	63.2%	58.6%	63.3%	69.6%
While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	52.2%	47.7%	45.5%	53.9%	58.9%
Do you think the hospital staff did everything they could to help control your pain?	76.6%	79.1%	75.8%	74.2%	82.6%
Overall, did you feel you were treated with respect and dignity while you were in the hospital?	83.9%	81.3%	77.5%	87.8%	87.3%
While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	56.9%	62.8%	61.9%	58.9%	68.3%
During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	42.8%	36.4%	33.6%	41.7%	46.7%
Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	36.9%	28.3%	32.5%	39.7%	39.5%
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	85.8%	93.0%	87.1%	92.6%	95.2%
Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	50.3%	51.9%	53.7%	52.5%	58.7%
Did the different people treating and caring for you (such as GPs, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	47.0%	48.8%	50.6%	48.9%	56.6%
Have you been given a care plan?	43.4%	43.9%	37.6%	35.6%	30.1%
Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	55.4%	56.0%	60.6%	54.6%	59.5%
Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	40.6%	43.5%	47.4%	46.6%	38.3%
Overall, how would you rate your care?	8.09	8.23	8.26	8.33	8.72

* Minority Ethnic Groups

INEQUALITIES IN CANCER OUTCOMES

As mentioned previously, in “Achieving world-class cancer outcomes: a strategy for England 2015-2020”, it is clearly stated that measuring both cancer outcomes and experience is equally important.²⁰

Although we don't have London analysis for outcomes, in terms of deprivation and ethnicity, London has some of the most deprived areas and the most ethnically diverse population in the country. So for context, it is worth mentioning some of the national insights in cancer outcomes.

People living in areas of higher deprivation are more likely to get some types of cancer and have worse survival rates for many types of cancer.²¹

Analysis published by the National Cancer Intelligence network shows that that incidence and mortality for most cancers were higher in the more deprived groups in the period 2006-2010. If rates for the more deprived groups had been the same as the least deprived, there could have been about 15,300 fewer cancer diagnoses per year.

Even more worryingly, since incidence and mortality rates were not the same for the more and the least deprived, we have a yearly excess of around 19,200 more deaths from cancer in the period 2007-2011.²²

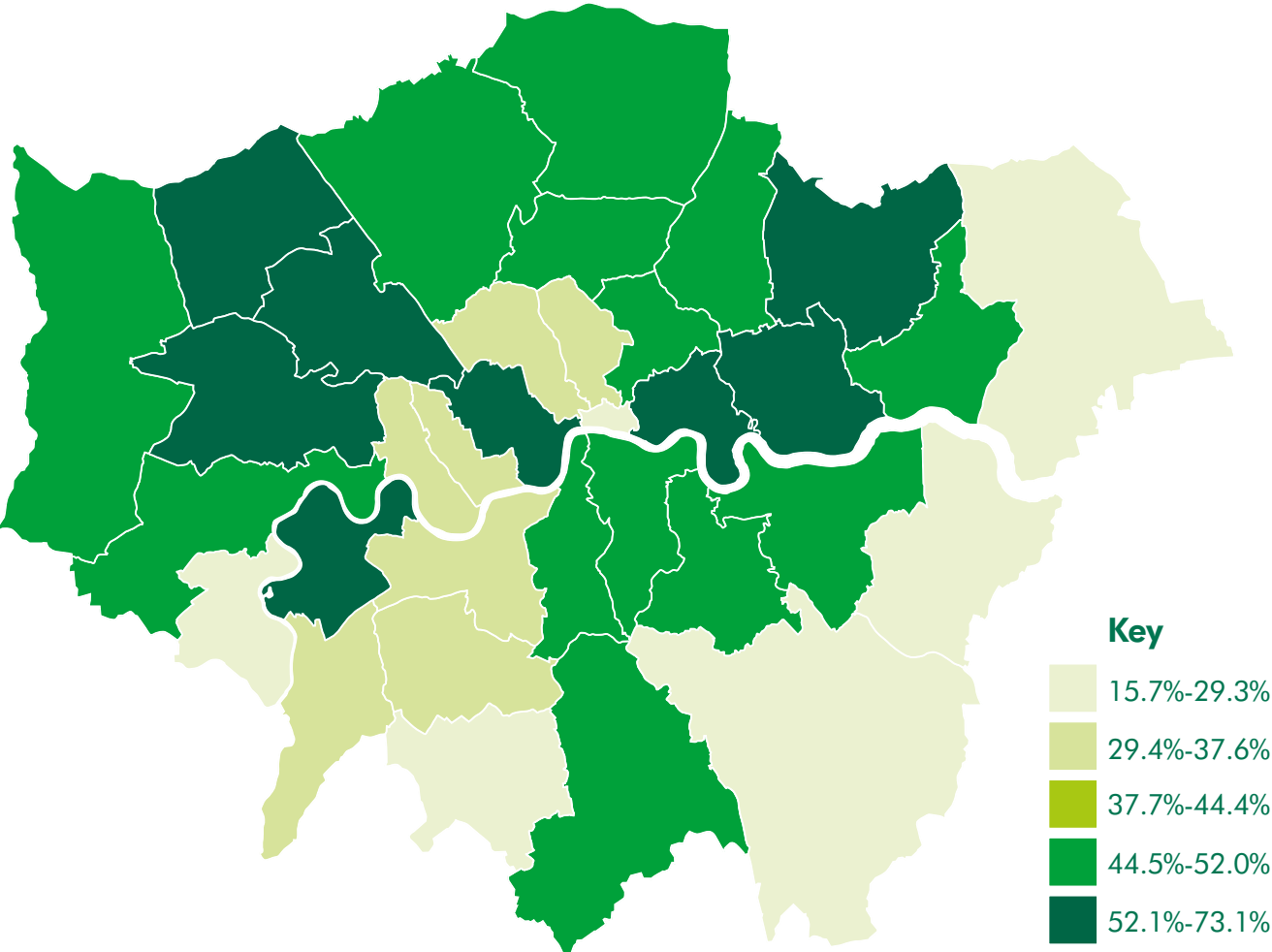
It is important to note that deprivation alone cannot be seen as the only root cause of worse cancer outcomes.

There are further, complex and interrelated factors which could contribute to cancer inequalities, such as:

- Age and deprivation – some of the highest rates of income deprivation exist among older people in London.²³
- People living in deprived groups may be more likely to struggle with the high cost of cancer since we know that cancer costs four in five patients on average £570 a month.²⁴
- Higher costs of living in London (higher than national average with higher rents, food bills and in some instances, transport costs²⁵) and sometimes lower wages (12% of full time employees and 45% of part time employees in London earning less than London living wage in 2014)²⁶.

The national picture tells us that overall, people from minority ethnic groups are less likely to get most types of cancer but this varies by ethnic group and type of cancer.²⁷

Recent analysis has shown variation in stage at diagnosis by ethnic group for breast, lung, colorectal and prostate cancer patients.²⁸



Map of London showing concentration of minority ethnic groups (2011 Census data)²⁹

WHAT'S NEXT...



Today there are over 178,000 living with or beyond cancer in the capital. By 2030, this will almost double to 347,000. Whilst it must be recognised that the overall experience of cancer patients in London is positive, it is clear that cancer patients in London report a worse experience than those living outside London. Put simply, this isn't good enough.

As this report highlights, people living with cancer in London's most deprived areas have poorer cancer experience across many areas of care. Minority ethnic groups also report worse cancer care experience. Identifying the root causes of these inequalities can be difficult but we, as a society, must work to address these issues.

This is ever more pressing as being diagnosed with cancer is now one of the most common life changing events no matter who you are or where you are from.³⁰

It is this desire that is driving much of Macmillan Cancer Support's work in London. For example, our Local Authority Partnership Programme aims to work with health and social care teams in Tower Hamlets, to improve the experiences of all people living with cancer in that borough.

We recognise the value of partnerships in ensuring that people are able to access the support they need, how and when they want it, right from the point of diagnosis.

Macmillan also understands that life with cancer is still life. For a person's experience to be excellent, we must offer the earliest possible support and consider the whole person.

- This report recommends therefore, that we work to connect everyone with a cancer diagnosis to the Recovery Package³¹, which includes a holistic needs assessment³², and which aims to address all the concerns that people with cancer may have – not just the clinical issues.
- We are leading and investing in a range of primary and community care projects across London, such as Social Prescribing³³, and resourcing GPs to ensure people can access the right support in the right place.
- Initiatives such as the Centre for Cancer Outcomes Unit, led by the UCLH Cancer Collaborative, are key in helping us to understand cancer outcomes at a local level. We therefore continue to call for better local outcomes data, to enable us to better understand the inequalities highlighted in this report.
- Finally, this report calls on all of us to spend more time listening to people affected by cancer. That's why Macmillan in London is launching a new initiative called the London Cancer Community; a network of Londoners affected by cancer, who reflect the diversity of the London population and the variety of cancer experiences.

Only by listening to those directly affected by cancer can we work together to bridge the gaps, and ensure everyone gets the excellent care and treatment they deserve.

Chris Parker

Engagement & Volunteering Manager
in London, Macmillan Cancer Support

GLOSSARY OF KEY TERMS

Cancer inequalities

are the differences between individuals' cancer experience or outcomes which may link to their socioeconomic status, race, age, gender, disability, religion or belief, sexual orientation, cancer type, or geographical location.³⁴

Patient experience

looks at the individual experience of the care and treatment a person has received since diagnosis. This could be positive things such as having clear information on treatment or feeling involved in decisions. It could also be more negative experiences such as feeling unable to navigate the health system.³⁵

Patient outcomes

look at the overall success of the care and treatment that an individual has received. These can be either short term such as being able to return to work after treatment or longer-term outcomes including quality of life and managing consequences of treatment.³⁶

In this report, we look at clinical outcomes such as survival and mortality (or incidence that is sometimes considered as an outcome especially in the space of prevention).

Ethnicity

guidance on Measuring Equality from the Office of National Statistics discusses ethnicity as a multifaceted and changing phenomenon, noting that; 'various possible ways of measuring ethnic groups are available have been used over time. These include country of birth, nationality, language spoken at home, skin colour (an aspect for consideration for some and not for others), national/geographical origin and religion. What seems to be generally

accepted however, is that ethnicity includes all these aspects, and others, in combination'³⁷. Just as it is with the notion of ethnicity itself, the definition of minority ethnic groups is open to interpretation. In the UK context, more widely it is most often described as people of non-White ethnic descent, although there are differences in cancer patient journeys and mortality within this group³⁸.

In this report, where patient experience is referred to, ethnicity is categorised into five groups which correspond to the categories used in the National Cancer Patient Experience Survey analysis: White, Asian, Black, Mixed and Other³⁹. 'Not given' is excluded.

Deprivation groups

sometimes refer to population-based quintiles based on a person's postcode at the time of diagnosis⁴⁰. Different indicators or measures of deprivation are used in different types of analysis. The English 'Index of Multiple Deprivation' 2015 (IMD 2015) is the official measure of relative deprivation for small areas or neighbourhoods in England. It combines information from seven domain indices to produce an overall relative measure of deprivation. For cancer analyses in England, deprivation is usually based on the income domain only, however in some cases – such as analyses of the national Cancer Patient Experience Survey (CPES) – overall IMD 2015 is used. In this report, we distinguish between the two by referring to 'deprivation', where this is based on IMD 2015 (or earlier versions where relevant), and 'income deprivation' where this relates to analyses using only the income domain.

APPENDIX

Charts for CCG-level data in 2016, comparing London with non-London scores

SEEING YOUR GP

Saw GP once / twice before being told had to go to hospital:



Patient thought they were seen as soon as necessary:



DIAGNOSTIC TESTS

Received all the information needed about the test:



Given complete explanation of test results in understandable way:



FINDING OUT WHAT WAS WRONG WITH YOU

Patient told they could bring a family member or friend when first told they had cancer:



Patient felt they were told sensitively that they had cancer:



Patient completely understood the explanation of what was wrong:



Patient given easy to understand written information about the type of cancer they had:



DECIDING THE BEST TREATMENT FOR YOU

Patient felt that treatment options were completely explained:



Possible side effects explained in an understandable way:



Patient given practical advice and support in dealing with side effects of treatment:



Patient definitely told about side effects that could affect them in the future:



Patient definitely involved in decisions about care and treatment:



CLINICAL NURSE SPECIALIST

Patient given the name of the CNS who would support them through their treatment:



Patient found it easy to contact their CNS:



Get understandable answers to important questions all or most of the time:



SUPPORT FOR PEOPLE WITH CANCER

Hospital staff gave information about support groups:



Hospital staff gave information about impact cancer could have on day to day activities:



Hospital staff gave information on getting financial help:



Hospital staff told patient they could get free prescriptions:



OPERATIONS

Beforehand had all the information needed about the operation:



Staff explained how operation had gone in understandable way:



HOSPITAL CARE AS AN INPATIENT

Groups of doctors or nurses did not talk in front of patient as if they were not there:



Patient had confidence and trust in all doctors treating them:



Patient had confidence and trust in all ward nurses:



Always / nearly always enough nurses on duty:



All staff asked patient what name they preferred to be called by:



Always given enough privacy when discussing condition or treatment:



Patient was able to discuss worries or fears with staff during visit:



Hospital staff definitely did everything to help control pain:



Always treated with respect and dignity by staff:



Given clear written information about what should / should not do post discharge:



Staff told patient who to contact if worried post discharge:



HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

Patient was able to discuss worries or fears with staff during visit:



Doctor had the right notes and other documentation with them:



Beforehand patient had all information needed about chemotherapy treatment:



HOME CARE AND SUPPORT

Hospital staff gave family or someone close all the information needed to help with care at home:



Patient definitely given enough support from health or social services during treatment:



Patient definitely given enough support from health or social services after treatment:



CARE FROM YOUR GENERAL PRACTICE

GP given enough information about patient`s condition and treatment:



Practice staff definitely did everything they could to support patient:



YOUR OVERALL NHS CARE

Hospital and community staff always worked well together:



Patient given a care plan:



Overall the administration of the care was very good / good:



Length of time for attending clinics and appointments was right:



Taking part in cancer research discussed with patient:



Patient`s average rating of care scored from very poor to very good:



ENDNOTES

- 1) Independent Cancer Taskforce (2015) Achieving World Class Cancer Outcomes: a strategy for England 2015 - 2020. Available at: https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf [Accessed October 2017]
 - 2) Greater London Authority (2017). Better Health for all Londoners: Consultation on the London Health Inequalities Strategy. Available at: <https://www.london.gov.uk/talk-london/healthstrategy> and <https://www.london.gov.uk/what-we-do/health/have-your-say-better-health-all-londoners> [Accessed October 2017]
 - 3) Macmillan -Quality Health (2017) Statistical analysis of National Cancer Patient Experience Survey results in London for CPES 2015 and CPES 2016 (unpublished). The National Cancer Patient Experience Survey (CPES) in England has been run by Quality Health for the Department of Health and NHS England since 2010. From the overall CPES response data set Quality Health separated out individual patient response data that relates to London patients. Data was extracted for all patients resident within the 32 Clinical Commissioning Groups or CCGs within London (including those whose GPs have referred them for treatment outside London). For the purposes of this report therefore, where we refer to 'Londoners' or 'London cancer patients' this refers to survey respondents who are resident in one of the 32 CCGs. In 2016, 7,865 patients from London CCGs responded. The analysis explored differences over time (between 2015 and 2016) and between patient groups using five demographic factors (gender, age, ethnicity, deprivation and tumour groups). The definitions of individual patient groups, demographics, and the statistical tests, are exactly the same as those developed and defined for the 2015 and 2016 National Cancer Patient Experience Survey Official Statistics publications (published in July 2016 and July 2017, respectively, and available at www.ncpes.co.uk). All supporting documentation (technical documentation, sampling guidance for Trusts, questionnaires, etc.), are available at Quality Health dedicated website, www.ncpes.co.uk. For most questions, scores are presented as the percentage of responses which were positive. Ethnic groups have been categorised as 'White, Asian, Black, Mixed, Other, and Not given'. For the variable of deprivation, English Index of Multiple Deprivation (IMD) 2015 quintiles have been used in the analysis of results. These were generated by mapping the postcode of referral for each patient, against the most recently available published English IMD 2015 data.
 - 4) Source: Greater London Authority Datastore (2015). Based on 2013 population projections. Available at: <https://data.london.gov.uk/> [Accessed 10/10/2017]
 - 5) Tinson A, Ayrton C, Barker K et al (2017) London's Poverty Profile. Trust for London and New Policy Institute. Available at: <https://www.trustforlondon.org.uk/publications/londons-poverty-profile-2017/> Source: Households Below Average Income dataset, Department for Work and Pensions. The data uses three-year averages to the year shown. [Accessed October 2017]
 - 6) Analysis of cancer incidence and survival by ethnic group published by the National Cancer Intelligence Network. Source: NCIN (2009) Cancer Incidence and Survival by Major ethnic group. England, 2002 – 2006. Available at: <http://www.ncin.org.uk/view.aspx?rid=75> Notes: Data are for England only. There are several limitations to the analysis presented here. The methodology in the source report makes use of a number of relatively crude procedures to assign these patients to specific ethnic groups for incidence data. However, despite these limitations, the report has been able to provide a first look at the overall pattern of cancer incidence by ethnicity in England.
- Variation, in England, of incidence and mortality for all cancers combined (excluding non-melanoma skin cancer, by socio-economic deprivation, as recorded by the income domain of the Indices of Multiple Deprivation (IMD) [CLG 2011]. Source: National Cancer Intelligence Network: Cancer by deprivation in England, Incidence 1996-2010, Mortality, 1997 – 2011. Available at: http://www.ncin.org.uk/about_ncin/cancer_by_deprivation_in_england Notes: This report is part of an existing literature on deprivation and cancer incidence and/or mortality. Data were analysed for 37 cancer sites, grouped using codes from the 10th revision of the International Classification of Diseases (ICD-10), as well as for all cancers combined (excluding non-melanoma skin cancer)
- 7) Mortality of all cancers (ICD10 codes C00-C97). Directly age-standardised registration rates (DSR) per 100,000 European Standard population and average number per year, all ages, for 2012-2014 period. **Source:** NHS Digital © Crown Copyright. Compendium of Population Health Indicators. Source of data: Office for National Statistics.
 - 8) Incidence of all cancers (ICD10 codes C00-C97 exc C44); Incidence of female breast cancer (ICD10 C50); Incidence of prostate cancer (ICD10 C61); Incidence of lung cancer (ICD10 C33-C34); Incidence of colorectal cancer (C18-C20); Incidence of malignant melanoma [skin cancer] (ICD10 C43). Directly age-standardised registration rates (DSR) per 100,000 European Standard population and average number per year, all ages, for 2012-2014 period. **Source:** National Cancer Registration and Analytical Service (NCRAS) and Public Health England Source of data: Cancer Stats
 - 9) 20-year prevalence in 2010 is the number of people who were diagnosed with cancer between 1991 and 2010 and still alive on 31st December 2010. Prevalence in 2030 is an indicative future estimate. These figures serve as indicators and are likely to change as more data becomes available. Growth rates in prevalence in each local authority are based on a single UK wide growth rate. **Source:** Prevalence in 2010: Macmillan Cancer Support and National Cancer Registration and Analysis Service (NCRAS). 2014. Macmillan-NCRAS work plan. Segmenting the cancer population: All malignant neoplasms combined (excluding non-melanoma skin cancer) by Local Authority, 20-year cancer prevalence based on diagnosis 1991-2010. Available at: http://www.ncin.org.uk/about_ncin/segmentation Projections to 2030 derived from: Maddams J, Utley M, Moller H. 2012. Projections of cancer prevalence in the United Kingdom (Scenario 1), 2010-2040. *Br J Cancer* 2012; 107: 1195-1202.
 - 10) In this report, when discussing differences in percentages or scores from the London specific analysis of CPES data commissioned by Macmillan we use the word "significant" to mean statistically significant differences at the 95% confidence level, unless otherwise specified.
 - 11) Variation, in England, of incidence and mortality for all cancers combined excluding non-melanoma skin cancer, by socio-economic deprivation, as recorded by the income domain of the Indices of Multiple Deprivation (IMD) [CLG 2011]. This report is part of an existing literature on deprivation and cancer incidence and/or mortality [Quinn et al 2001; Rowan 2007; Shafique et al 2012; WCISU 2009; and WMCIU 2010]. Data were analysed for 37 cancer sites, grouped using codes from the 10th revision of the International Classification of Diseases (ICD-10), as well as for all cancers combined (excluding non-melanoma skin cancer). **Source:** National Cancer Intelligence Network: Cancer by deprivation in England, Incidence 1996-2010, Mortality, 1997 – 2011. Available at: http://www.ncin.org.uk/about_ncin/cancer_by_deprivation_in_england

- org.uk/about_ncin/cancer_by_deprivation_in_england Accessed 10/10/2017
- 12) Analysis of one year survival rates for London CCGs by Transforming Cancer Services Team in collaboration with PHAST (Public Health Action Team). Available at: <https://www.healthylondon.org/cancer/survival-rates> Notes: In depth analysis of current positions and trends in one-year cancer survival for each of the 33 London and West Essex CCGs. Bespoke reports were produced and shared with CCGs, strategic planning groups (SPGs) and sustainability and transformation planning (STP) leads, along with red/amber/green (RAG) rated analysis - grouped by SPG - of 33 key indicators relating to cancer survival.
 - 13) Data was extracted for all patients resident within the 32 Clinical Commissioning Groups or CCGs within London (including those whose GPs have referred them for treatment outside London). For the purposes of this report therefore, where we refer to 'Londoners' or 'London cancer patients' this refers to survey respondents who are resident in one of the 32 CCGs.
 - 14) Macmillan - Quality Health (2017) Statistical analysis of National Cancer Patient Experience Survey results in London for CPES 2015 and CPES 2016 (unpublished).
 - 15) Source: <http://www.bbbc.org.uk/macmillan-social-prescribing>
 - 16) Source: Greater London Authority Intelligence Briefing (2016) on Indices of Multiple Deprivation 2015. Available at: <https://files.datapress.com/london/dataset/indices-of-deprivation-2015/2016-05-24T18:16:14/indices-deprivation-2015.pdf>
 - 17) Source: Greater London Authority Intelligence Briefing (2016) on Indices of Multiple Deprivation 2015. Available at: <https://files.datapress.com/london/dataset/indices-of-deprivation-2015/2016-05-24T18:16:14/indices-deprivation-2015.pdf>
 - 18) The CPES data was analysed using the Index of Multiple Deprivation (IMD) 2015 – further guidance and information available here: can be found here <https://www.gov.uk/government/collections/english-indices-of-deprivation>. The index is a measure of relative deprivation for small areas. In CPES analysis, deprivation quintiles are used, where IMD 1 is the most deprived and IMD 5 is the least deprived.
 - 19) Significance tests were carried out in the analysis of the Cancer Patient Experience Survey that Macmillan Cancer Support commissioned to establish where there are statistically significant differences within London between cancer patients from different ethnic groups and cancer patients living in areas with differing levels of deprivation among other variables.
 - 20) Independent Cancer Taskforce (2015) Achieving World-class Cancer Outcomes: a strategy for England 2015 - 2020. Available at: https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf
 - 21) Sources: <http://www.ncin.org.uk/view?rid=2991> <https://www.macmillan.org.uk/about-us/what-we-do/evidence/research-funding/our-partnerships/information-services-division-scotland.html>
 - 22) Excluding non-melanoma skin cancer. Source: Source: National Cancer Intelligence Network: Cancer by deprivation in England, Incidence 1996-2010, Mortality, 1997 – 2011. Available at: http://www.ncin.org.uk/about_ncin/cancer_by_deprivation_in_england
 - 23) Source: Greater London Authority Intelligence Briefing (2016) on Indices of Multiple Deprivation 2015. Available at: <https://files.datapress.com/london/dataset/indices-of-deprivation-2015/2016-05-24T18:16:14/indices-deprivation-2015.pdf>
 - 24) Source: https://www.macmillan.org.uk/about-us/news/latest_news/cancercosts-fourinfivepatientsonaverage570amonth.aspx
 - 25) Source: London Health Commission (2014), Better Health for London. Available at: https://www.london.gov.uk/sites/default/files/better_health_for_london.pdf
 - 26) Office for National Statistics Report 2015 "Estimates of employee jobs paid less than the living wage in London and other parts of the UK" http://webarchive.nationalarchives.gov.uk/20160106031621/http://www.ons.gov.uk/ons/dcp171766_419154.pdf
 - 27) Source: NCIN (2009) Cancer Incidence and Survival by Major ethnic group. England, 2002 – 2006. Available at: <http://www.ncin.org.uk/view.aspx?rid=75> Notes: Data are for England only. There are several limitations to the analysis presented here. The methodology in the source report makes use of a number of relatively crude procedures to assign these patients to specific ethnic groups for incidence data. However, despite these limitations, the report has been able to provide a first look at the overall pattern of cancer incidence by ethnicity in England.
 - 28) "National cancer registration and analysis service data briefing: Ethnicity and stage at diagnosis" 2016 Data briefing Ethnicity and Stage at diagnosis. Available at: <http://www.ncin.org.uk/view?rid=3286>
 - 29) It should be noted that this relies on 2011 Census data and there may be changes in residential patterns since then, and this data should be considered along with other contextual information if it is to be used to generate hypotheses around potential need.
 - 30) Macmillan 'The C word' report <https://www.macmillan.org.uk/assets/1426915-the-c-word-macmillan-cancer-support-2017.pdf>
 - 31) Source: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package>
 - 32) Source: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package#297633>
 - 33) Source: <http://www.bbbc.org.uk/news/373/new-macmillan-wellbeing-service>
 - 34) Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer (2009). Available at: <http://www.macmillan.org.uk/documents/getinvolved/campaigns/appg/britainagainstcancer2009/cancerinequalitiesreport.pdf> [Accessed October 2017]
 - 35) Source: <https://www.macmillan.org.uk/about-us/what-we-do/evidence/cancer-story-is-changing/cancer-patient-experience.html#265419>
 - 36) Source: <https://www.macmillan.org.uk/about-us/what-we-do/evidence/cancer-story-is-changing/cancer-patient-experience.html#265419>
 - 37) Office for National Statistics: Measuring equality: A guide for the collection and classification of ethnic group, national identity and religion data in the UK. Available at: <https://www.ons.gov.uk/methodology/classificationsandstandards/measuringequality/ethnicgroupnationalidentityandreligion> [Accessed October 2017] Source: Macmillan Rich Picture: People with cancer from BME groups (2014).
 - 38) Source: Macmillan Rich Picture https://www.macmillan.org.uk/_images/BME-groups_tcm9-282778.pdf [Accessed October 2017]
 - 39) See national analysis and guidance material for National Cancer Patient Experience Survey: <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>
 - 40) Source: https://www.macmillan.org.uk/_images/exploring-patterns-of-deprivation-for-people-living-with-cancer_tcm9-297571.pdf

**We believe life with cancer is still life
and so we'll help you live it in London.**

If you believe the same, and have a cancer experience, then why not join our London Cancer Community? It is a community of people passionate about shaping cancer care and improving patient experience in the capital. To find out more, email Londoncancercommunity@macmillan.org.uk

Alternatively, if you have questions about the Macmillan services in London please contact **Nikki Cannon**, Strategic Partnership Manager at ncannon@macmillan.org.uk

**WE ARE
MACMILLAN.
CANCER SUPPORT**