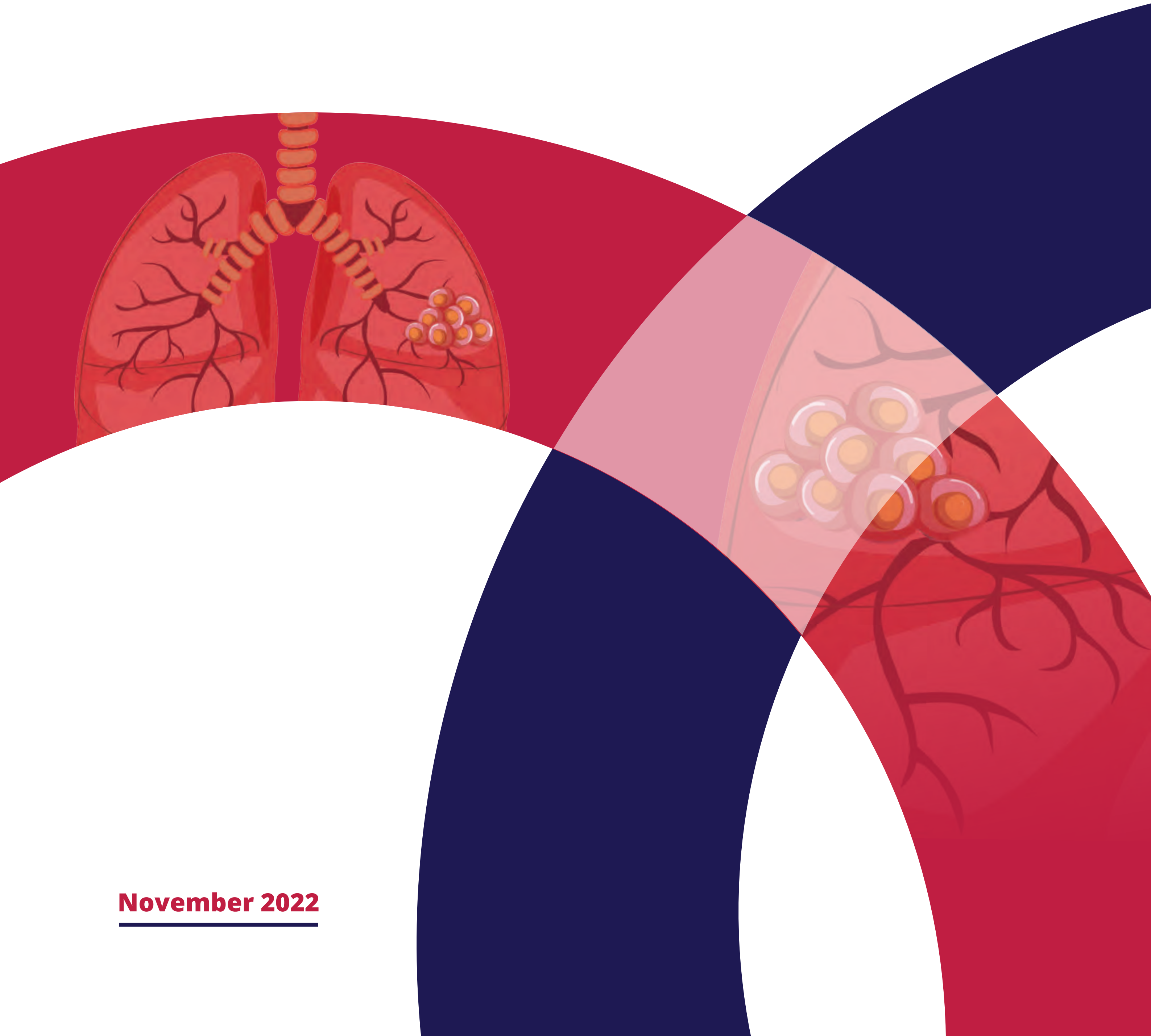
UNITED KINGDOM
LUNG CANCER COALITION

BRIDGING THE GAP

The challenge of mitigating health inequalities in lung cancer



November 2022

Clinical Advisory Group Membership

The UKLCC's Clinical Advisory Group is a panel of senior clinicians, each representing specialities involved in the care of lung cancer patients, from the time of first suspicion to diagnosis, and through to palliative care.

The members of the group are:

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About the UKLCC

The United Kingdom Lung Cancer Coalition (UKLCC) – the country's largest multi-interest group in lung cancer – is a coalition of the UK's leading lung cancer experts, senior NHS professionals, charities, and healthcare companies.

Through our campaigning activity we aim to:

- Raise political awareness of lung cancer
- Raise the general public's awareness of lung cancer – and especially encourage earlier presentation and symptom recognition
- Improve lung cancer services
- Empower patients to take an active part in their care

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Contact Details

The UKLCC is keen to work with all interested organisations and bodies to improve the quality and outcomes of lung cancer treatment and care. For more information about our work and a list of our partners, please visit our website at: **www.uklcc.org.uk** or contact our Secretariat: info@uklcc.org.uk

Foreword

Professor Robert Rintoul, Clinical Lead

Martin Grange, Chair

> **“The case for tackling health inequalities is clear and overwhelming, and yet attempts to do so over the past decades have had variable success.”**

The case for tackling health inequalities is clear and overwhelming, and yet attempts to do so over the past decades have had variable success.

The Covid-19 pandemic, together with the current cost of living crisis, have shone a light on the huge health disparities and deep inequalities running through our society - not least in UK lung cancer.

While we welcome initiatives such as the establishment of the Office for Health Improvement and Disparities, Core20PLUS5 and the NHS Race Health Observatory - the Government’s priority must be to act now to tackle inequalities in lung cancer.

The reason is simple. Lung cancer is the biggest cause of UK cancer deaths – and has by far the biggest deprivation gap compared to any other cancer. Yet almost 80% of lung cancer cases are preventable. Addressing health inequalities successfully in lung cancer will have a huge impact on overall UK cancer outcomes.

Health inequalities are complex and far reaching. Removing them is hard and takes time. However, they will be mitigated more rapidly if we work together as a lung cancer community and ensure more systematic and robust data collection across all communities. Doing so will provide a framework for tackling health inequalities on multiple levels – local, regional, and national.

This report, based on the opinions of the UKLCC's Clinical Advisory Group, interviews with experts and desk-top research, aims to provide a set of recommendations which will ensure that all people with lung cancer, regardless of their social or economic status, age, gender, ethnicity, religion, beliefs, language, or disability etc. have equitable access to diagnosis, treatment and care.

We hope that this report will serve as a blueprint for tackling health inequalities - not only in lung cancer but also in other cancers and other diseases.

Professor Robert Rintoul, Clinical Lead

Martin Grange, Chair

Methodology

This report sets out the expert opinions of the Clinical Advisory Group (CAG) of the UK Lung Cancer Coalition, from a meeting in June 2022. It is supplemented by views and information gathered from 15 one-to-one interviews comprising CAG members and other leading lung cancer and health inequalities experts during July and August 2022, and by desk research and literature reviews carried out over the same period.

Summary of recommendations

01

The remit of the National Lung Cancer Audit (NLCA) should be extended to include more data on health inequalities including more complete data on ethnicity, LGBTQ+ and other health inequality factors.

02

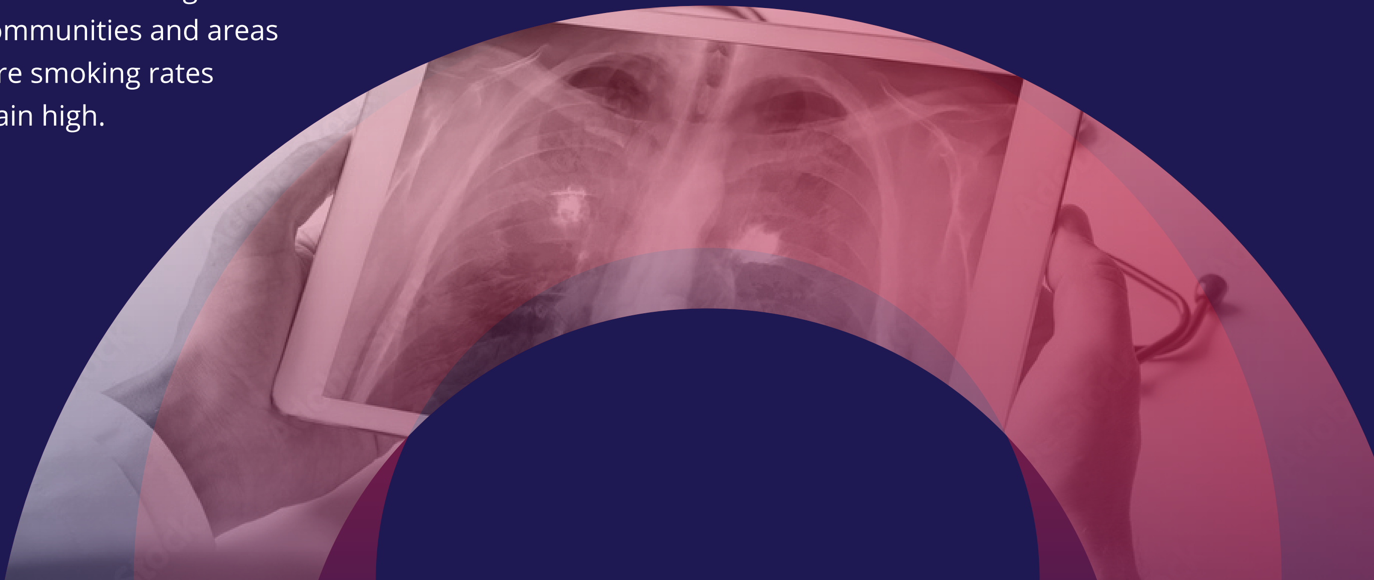
To improve fair access to lung cancer services, the Holistic Needs Assessment should be commenced at the time of referral to diagnostic services and the information held with the personalised care plan on file and in a Personal Care and Access Card carried by each patient.

03

A Single Coordinated Data Strategy is required to combine information on equality from the National Lung Cancer Audit (NLCA), and aggregate data from Holistic Needs Assessments and other local/ regional sources together with information on NHS resources and capacity.

04

National (UK-wide) smoking cessation campaigns and services should be integrated with National Lung Cancer Screening programmes, as recommended by the UK National Screening Committee and targeted at communities and areas where smoking rates remain high.



05

The Governments of all UK nations should implement the recommendations of the UK National Screening Committee and urgently establish National Lung Cancer Screening programmes.

06

Disease awareness campaigns across the four UK nations should be targeted to address local needs and take into consideration the fact that lung cancer can occur in people who have never smoked.

07

A dedicated lung cancer helpline, should be set up at regional level providing direct access (triaged) to specialist diagnostic services as well as support and information tailored to local communities.

08

Barriers that create health inequality, such as the cost of transport and child care, should be removed by Trusts and Health Boards through establishing sustainable budgets targeted at communities affected by health inequality.

09

All NHS Trusts and Health Boards should monitor access to the full range of treatments for lung cancer to ensure health inequalities are adequately mitigated for both curative and palliative approaches.

10

Throughout the UK, NHS services should have regular local reviews based on information from the Single Coordinated Data Strategy to ensure adequate capacity and workforce to meet local needs particularly in areas with high levels of inequality.

1.0 Introduction

Professor Michael Peake OBE. Clinical Director, Centre for Cancer Outcomes, North Central and East London Cancer Alliance; Emeritus Consultant and Honorary Professor of Respiratory Medicine, University of Leicester

> **"If you successfully improve access to lung cancer diagnosis and treatment, you will be able to adapt and apply that to other tumour sites and other diseases."**

The challenge and scale of health inequalities in lung cancer

This report focuses on the identification, assessment and mitigation of health inequalities that affect people who have, or who are at high risk of, lung cancer. It does not attempt to address and reduce gaps caused by inequality (e.g. the deprivation gap). Instead this document focuses on ways in which the gaps could be bridged with additional help and support for those people who need it to ensure they are able to access diagnosis, treatment and care services for lung cancer on an equitable basis compared with other lung cancer patients.

The UKLCC, along with health care professionals and officials, is looking to the Government White Paper on Health Disparities, when or if it is published, to begin such a process that should eventually go beyond the boundaries of health policy.

Lung cancer – an exemplar

Our report focuses on mitigating health inequality, which will benefit patients quickly. We concentrate on lung cancer. Our reason for doing so is that lung cancer has by far the largest number of excess deaths because of socio-economic variation (9,900 persons per year or **52%** of all excess cancer deaths)[1]. Socio-economic variation is a major health inequality factor about which we have reliable data. Therefore, lung cancer is a well-defined disease area in which to pilot a full range of mitigating activities and then assess their benefits on patients. Since nearly **80%** of lung cancer cases are preventable, the benefits of this approach are likely to be reflected in outcomes.

It is crucial that we identify all factors causing health inequality and that we have a thorough understanding of the extent, nature and impact on lung cancer outcomes for each. We must also identify all people and communities who are impacted by health inequalities.

Due in large part to its association with smoking, there tends to be more data about lung cancer and inequality - particularly social and economic inequality. There are a few lung cancer health inequalities about which we have some data in certain communities, and we will focus on these later in this report when we look at mitigating actions. By using lung cancer as a pilot for developing the approach to mitigating health inequalities we will produce data that can be used to shape similar approaches in other cancer types and other disease areas. Undertaking this work in lung cancer will also provide a proof of concept.

Devolved nations

All four devolved nations are affected by the same health inequality factors. Some factors are more prominent in some nations, e.g. the contrast between rural and urban communities is more pronounced in Wales and Scotland. In general, comments made in this report apply to all nations of the UK. Some data may be specific to individual nations: this is highlighted where quoted.

More data urgently needed – the crucial role of the National Lung Cancer Audit

Whie a few health inequalities have adequate evidence in relation to lung cancer, there is an urgent and overarching requirement for more data on a wider range of health inequalities and their impact communities across all disease areas. This pressing need applies to all types of cancer and other diseases. It includes the most basic information; for example we do not have any informed estimates as to how many people overall experience a health inequality in any cancer or other disease area.

The National Lung Cancer Audit (NLCA) has demonstrated its crucial role in measuring variations in outcomes throughout England and Wales. It has demonstrated unwarranted variations in practice and has acted as a driver in reducing them.

The outcomes data from the NLCA, should be combined with data on health inequalities and access to diagnosis, treatment and care. This would be a powerful way of measuring success of mitigating actions in lung cancer. It would also improve our understanding of what, and how, health inequalities affect groups not studied before. This could be achieved by mandating trusts and boards to complete information on inequalities and encouraging the cancer registry in each nation to collect data on inequalities.

The need for comprehensive data collection and analysis relating to health inequalities is one of the most important requirements in mitigating their impact on patients. Our recommendation for the National Lung Cancer Audit is one of the most important we have made in this report and we should explore this with NLCA as a matter of priority.

The outcomes data from the NLCA, if combined with data on health inequalities and access to diagnosis, treatment and care would be a powerful way of measuring success of mitigating actions in lung cancer

Professor Bernard Rachet, Professor of Cancer Epidemiology, The London School of Hygiene and Tropical Medicine

> **“The amount of data we have on health inequalities in lung cancer is pitifully poor. There are some individual health inequalities where we have good evidence, but in many others we know very little. This situation needs urgent coordinated improvement.”**

01

Recommendation

The remit of the National Lung Cancer Audit (NLCA) should be extended to include more data on health inequalities including more complete data on ethnicity, LGBTQ+ and other health inequality factors.

Collecting data at both community and individual patient level is essential for developing actions and measures that will mitigate health inequalities. However, applying these for greatest benefit must be done at individual patient level as most people are likely to be affected by more than one factor causing health inequality and the combinations are likely to vary from one individual to another. Therefore gathering data can be complex and challenging - yet essential if we want to provide a framework for tackling health inequalities on multiple levels – local, regional, and national.

The application of mitigating factors will require information on individual patients. This complements the shift towards individual care plans and the information needed on the individual can be collected by relatively small changes to the Holistic Needs Assessments (HNAs) carried out already. Where appropriate, the needs resulting from health inequalities could be recorded with the patient's personal care plan in a combined document (see Focus point: Personal care and access cards).

In summary the small changes to the NLCA could provide the data needed to define appropriate mitigating measures and the adaptation of the Holistic Needs Assessment would guide health care professionals in how best to apply them on an individual basis.

02

Recommendation

Recommendation 2: To improve fair access to lung cancer services, the Holistic Needs Assessment should be commenced at the time of referral to diagnostic services and the information held with the personalised care plan on file and in a Personal Care and Access Card carried by each patient.

FOCUS POINT:

Personal care and access cards

Patients who have a Holistic Needs Assessment should have a means of retaining the information that they can carry with them to NHS appointments. This would be particularly useful where diagnosis and treatment are carried out in different centres. Personal care plans contain vital information on diagnosis, treatment and care. These should be integrated with information collected as part of the Holistic Needs Assessment. This would create a single document containing all information relevant to each patient's lung cancer pathway. A copy of this would be retained by the patient as well as being kept on their NHS file so that it was immediately accessible to health care professionals as well as the patient. It would ensure each patient received appropriate access to the diagnostic, treatment and care services they needed.

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The National Cancer Patient Experience Survey

Alongside the NLCA, the National Cancer Patient Experience Survey (NCPES) is a valuable source of information on existing patients. The 2021 NCPES involved 134 NHS Trusts. The number of people invited to take part was 107,412, of which 55% (59,352) responded. The survey is detailed, having around 60 questions. The questions relate to what care, diagnosis and treatment patients received and patients' ratings of their quality.

Increasing the sample size and additional analysis would provide insight into the impact of health inequality factors. The NCPES measures variations in the answers to all questions by a number of factors relating to health inequalities including age, ethnicity and Indices of Multiple Deprivation (IMD) quintile. This offers the opportunity to compare and contrast the negative impact health inequalities have on patient satisfaction with the impact of surgical, medical, support and care services provided for them, if the number of patients taking part is increased. This approach could be piloted in lung cancer patients. Since the results are corrected for age, ethnicity and IMD quintile, comparing these with unadjusted scores could provide a simple way of assessing the overall impact of health inequalities.

Additional data should not be limited to understanding patients and their needs. Of equal importance is the routine collection of data on NHS care capacity and resources along the lung cancer patient pathway. This should include workforce capacity and diagnostic equipment with the purpose of forming a reliable baseline from which services can be adapted to meet varying needs in different populations around the country.

Modifying data collection within existing systems will keep the need for new databases to a minimum but an audit of existing data sources will be needed to clarify data already available.

Intuitively we know that health inequalities impact on certain groups, but it is important that actions to mitigate these are based on data. The evidence base is increasing for some groups and this should be encouraged and coordinated. For example a recent study of 126,627 people who reported features of seven cancers, including lung cancer, looked at the length of the period between initial primary care presentation and diagnosis in people with different ethnic backgrounds. It found minority groups experienced a longer time to diagnosis compared with the White group. The differences were small but likely to contribute to differences in outcomes and should be addressed.[2]

We must therefore ensure data collection in lung cancer covers all aspects of health inequality and that it includes the following groups: socio-economic deprived groups, all ethnic groups, rural communities, people who are HIV+, refugees, homeless people, traveller communities, religious groups, LGBTQ+ groups, mental health conditions, physical disabilities inc. deaf and blindness, illicit drug users, prisoners.

This can only be achieved by establishing an overarching Single Coordinated Data Strategy to ensure the appropriate data are collected, that they are comparable and that there is no duplication of effort.

03

Recommendation

A Single Coordinated Data Strategy is required to combine information on equality from the National Lung Cancer Audit (NLCA), and aggregate data from Holistic Needs Assessments and other local/regional sources together with information on NHS resources and capacity

FOCUS POINT:

Health Determinants Research Collaborations

The announcement in October 2022 of a £50 million investment in research into health inequalities that will be made available to 13 Local Authorities is a welcome step towards a better understanding of the needs of people who are experiencing health inequalities. The UKLCC is keen to learn more from the National Institute for Health and Care Research (NIHR) as to how this initiative will work. We would welcome the opportunity to take part in the new Health Determinants Research Collaborations (HDRCs) that will address knowledge gaps in local areas.

2.0

> “Who delivers the message is as important as the message itself.”
>
> *Professor Francis Chinegwundoh MBE. Chairman of Cancer Black Care. Urology lead at Newham University Hospital. Honorary visiting Professor in the School of HealthSciences, City University, London.*

Health inequalities and their impact

It is important to distinguish between factors that cause health inequalities and the communities on which they impact. A particular community may have specific health inequality factors impacting it. However, each person in a particular community may be affected by different types of health inequality to a variable extent in a unique combination. Some may not be affected at all. The impact of health inequality is likely to vary within any given community, which is why it is important to measure the inequality factor, not the community and to reflect this person-based approach in mitigating health inequality.

In lung cancer, the factors that are or may be relevant include:

Factors where there are data*	Factors with little or no data
Biological sex	Gender identity
Socio-economic deprivation	Religion
Ethnicity	Social values (attitudes to health and modern medicine not linked to religious beliefs etc.)
Age	Ability to speak English
Digital literacy	No fixed contact point (address, telephone etc.)
Health literacy	Social exclusion
Geographical position (distance to services)	Disability (Physical and learning)
	Mental health problems
	Literacy level

**Even where there are data they are often inadequate for use as a basis for helping people access NHS services (lung cancer services) and mitigating health inequality at a community or an individual level.*

Communities vulnerable to health inequalities include:

Communities where there are data	Communities with little or no data
Socio-economically deprived	Religious groups
Various ethnic groups (not necessarily all)	Immigrants
Rural communities	Travellers
	Homeless people
	People in prison
	People who are HIV+
	LGBTQ+ people
	People with mental health problems
	Illicit drug users

Socio-economic deprivation:

10.5 million people (16% of the population) are in relative low income before housing costs (BHC) and 13.4 million after housing costs (AHC) (20%).[3]

People with the highest socio-economic deprivation are the most likely to develop lung cancer and the least likely to survive.[4] In England based on 2013-2017 data adjusted for age, the incidence rate of lung cancer is **174%** higher in women and **168%** higher in men in the most deprived quintile compared with the least.[5]

If the incidence rates in every quintile were the same as in the least deprived quintile, there would be 6,600 fewer cases of lung cancer per year in women and 7,800 fewer in men, a total reduction of 14,400 cases per year.

For lung cancer in Scotland the differences are even greater: the incidence rate is **312%** higher (men and women combined) and the mortality rate is **320%** higher in the most deprived quintile compared with the least.[6]

Age:

Data on outcomes by age in lung cancer[7] show poorer results with increasing age.

Digital literacy:

We know that this is closely linked to other factors such as deprivation and age. In March 2020, 99% of households in the income bracket of £40,000+ pa had home access to the Internet.

However, in the £6,000pa to £10,000pa income bracket this figure fell to only **51%**.[8] The Digital Skills Report 2021 estimates that there are 10.0 million people who do not have the skills to access the Internet by themselves. That includes being able to use a device, connect to a Wi-Fi network and create and update passwords. It also estimates that approximately 2.8 million people are completely digitally excluded and unable to use digital devices and media at all.[9]

A study of 15,244 adults with cancer has shown that lower levels of digital literacy are related to lower overall survival in cancer patients.[10]

In a recent report endorsed by the UKLCC, **7%** of lung cancer patients interviewed regarding virtual consultations during the pandemic said that they did not know how to video call.[11]

Health literacy:

More fundamental than digital literacy in accessing and understanding information about lung cancer is health literacy. The National Institute for Health and Care Research estimates that around half of the population finds it difficult to understand the information that is provided to them to help them look after their own health.

More specifically, over **40%** of adults have difficulty in understanding health information that is designed for the public. This is not just about the individual's knowledge of health; in the UK 7.1 million adults read at or below the level of an average nine year old.[12]

Patients with lower health literacy may have more difficulty understanding and recalling the information they have been given, demonstrate lower knowledge and have higher unmet information needs.[13]

Clearly there are some very broad issues behind the variation in health literacy that go far beyond the remit of this document e.g. access to broadband in rural areas of Scotland and Wales.

Digital literacy and health literacy are therefore important but as indicated in the National Institute for Health and Care Research estimates above, general literacy is also a crucial factor.

People with the highest socio-economic deprivation are the most likely to develop lung cancer and the least likely to survive.

Geographical location:

This includes the distance people must travel to reach NHS services as well as the type of location (how urban or rural it is, availability and affordability of public transport).

Mid-year 2020 population estimates show that 9.7 million people (17% of the population) live in rural areas in England.[14] Roughly the same proportion live in rural environments in Scotland (930,000 or **17%** of the population). However, **6%** of these live in remote rural environments. Access to NHS services is an important challenge in the Highlands and islands in Scotland and in mid-Wales.

People living in rural areas generally have poorer access to NHS services. Studies have shown geographical variation in the use of surgical treatment for non-small-cell lung cancer and in mortality.[15] The higher risk of early death from lung cancer associated with the level of 'rurality' of the area where the patient lives has been calculated as 1.22 (multivariate Odds Ratio).[16]

However, considering people who are deprived, even a relatively short distance of travel to NHS services within an urban environment can be a major barrier if they are unable to afford to pay for public transport.

A recent study at the Francis Crick Institute and University College London, has found that exposure to air pollution promotes the growth of cells carrying cancer-causing mutations in the lungs.[17] This can cause lung cancer in people who have never smoked and is likely to disproportionately affect people in more urban, polluted areas.

Ethnicity:

There are limited data currently available. Within ethnicity are several factors including religion and social values. Whilst there are some data comparing outcomes across different ethnic groups, these have not been broken down to find the root cause. Some issues are obvious such as overcoming language barriers.

Ensuring people can choose to access information in their first language (whether part of an awareness campaign or provided during and in support of consultations) is important. In Wales, the Welsh language is protected by legislation and a set of Welsh Language Standards apply to NHS primary care. This means that written material must be provided in Welsh as well as English and consultations with health care professionals must be conducted in Welsh if the patient requires it. However, this is not the case for other languages in other devolved nations. In engaging with different ethnic communities, being able to communicate with people in their own language is crucial to ensure that they understand the information they are given. Furthermore, it is important to hold conversations about health and health risks in the community (at least initially) rather than expecting people to go to a hospital to do so. It is equally important that people in these communities are able to talk to health care professionals with the same ethnic background.

A study of data from 1998 – 2003 by the National Cancer Intelligence Network showed that Bangladeshi men had a similar rate of lung cancer to White men, while rates for Indian and Pakistani men were much lower. Black Caribbean and Black African men had incidence rates around half that of White men, and Chinese men had a rate ratio of 0.75. Compared with White women, women from the other ethnic groups studied have much lower lung cancer incidence rates. The rate ratios ranged from around 0.20 to 0.40.[18] A more recent study published by Cancer Research UK in 2022 looked at cancer incidence by broad ethnic group in England, between 2013–2017. It showed that lung cancer was one of the four most common cancers in all broad ethnic groups, and as with most other cancers, incidence rates for lung cancer were lower in non-White minority ethnic groups compared with the corresponding White group.[19] The UK Million Women Study showed a significantly increased incidence of lung cancer in never smokers who were non-white compared with white.[20]

Across all cancers there are variations between different ethnic groups in the time it takes to receive a diagnosis. A recent study of seven cancers including lung has shown the median time between a white person first presenting symptoms to a GP and getting diagnosed is 55 days. For Asian people, it is 60 days (9% longer). For black people, it is 61 days (11% longer).[2] UK ethnic minority groups are also less likely to report a positive experience of care.[21]

FOCUS POINT:

Have we created a new health inequality?

The massive workload pressures on GPs caused by the COVID pandemic, of necessity changed the way in which we accessed primary care. We saw increased use of telephone consultations and longer waiting times for appointments. As we have emerged from the pandemic, the recovery of primary care services has varied. In some practices access has returned to near-pre-pandemic levels, but in many others it remains difficult to speak to a GP at short notice unless the situation is clearly urgent. Pressures on primary care staff, COVID-related illness and an ageing primary care health professional group are likely to exacerbate this going forward. Despite the rapid progression of lung cancer, securing an appointment to discuss possible symptoms – even if in response to the Government's 'Help Us to Help You' campaign – often results in a significant wait in many cases. So, this variable access to a GP is potentially creating a new, albeit reversible, health inequality in lung cancer. All avoidable delays are crucially important as we know that lung cancer is an aggressive cancer and tumours grow, stage increases, and survival falls relatively rapidly.[22]

Other communities:

Looking at an even wider group of communities is vital in understanding health inequalities that impact people with lung cancer.
We know that some groups are at higher risk of lung cancer or cancer in general, but we have little or no information on how health inequalities impact on them. This is a serious gap in our knowledge that should be addressed urgently.

It is known that people in the LGBTQ+ community have a higher consumption of tobacco-containing products (25-37%).[23] Therefore, there is a concern that this group may have a higher incidence of lung cancer. Further data are required.

A recent paper studying the impact of COVID 19 on LGBTQ+ health inequalities found higher rates of smoking and alcohol consumption made LGBTQ+ people more likely to be affected by certain cancers, and respiratory illness.[24]

In 2014 the United Nations High Commissioner for Refugees said cancer was a major issue amongst refugees that host countries often struggled to deal with.[25] This was based on data from refugees in Jordan and Syria, but how much do we know about refugees who have settled in the UK?

A 2021 study of Gypsies, Roma and Travellers concluded that risky health behaviours (e.g. smoking) were often justified by socio-economic factors, amplified further by traditional attitudes. These same factors also reduce the probability of individuals taking part in screening.[26]

Macmillan Cancer Support have provided an information booth distributing cancer awareness messages at the Appleby Horse Fair, a major annual event attended by large numbers of Gypsies, Roma and Travellers. Between 2016 and 2019 (the start of the COVID pandemic), in collaboration with Macmillan, the Roy Castle Lung Cancer Foundation also attended distributing specific fliers on symptom awareness and risk reduction designed to overcome literacy barrier using infographics.

Other conditions can sometimes be linked to lung cancer. For example in HIV-infected patients, the risk of lung cancer has been estimated to be 2-7 times that in the general population.[27]

Ongoing campaigns such as the "Spot the Difference" campaign run by the Roy Castle Lung Cancer Foundation are already improving awareness of lung cancer symptoms and knowledge of the disease and its treatment across many different communities. This and other campaigns need to be supported by better data and understanding of the needs of different communities and groups of people.

3.0

Mitigating health inequalities in lung cancer

3.1 Smoking cessation and inequalities – the need to localise for maximum impact

Smoking rates increase with social deprivation. This is shown in a 2012 paper in which secondary analysis of the Health Survey for England general population samples was undertaken. Over 88,000 adults, age 16 or over, living in England were included and the percentage who smoked was recorded by indicator of low socio-economic status *(Fig. 1)*.[28]

Number of indicators of low SES	N	% smoking
0	28956	**15.3** (14.8 to 15.8)
1	23513	**21.5** (20.8 to 22.1)
2	14594	**26.3** (25.4 to 27.1)
3	9555	**30.3** (29.2 to 31.4)
4	6307	**36.1** (34.7 to 37.4)
5	3630	**46.1** (44.2 to 48.0)
6/7	2567	**60.7** (58.2 to 63.3)
Total	88337	**24.0** (23.6 to 24.4)

Figure 1. Smoking rates by number of socio-economic indicators
Hiscock R, Bauld L, Amos A et al. Smoking and socioeconomic status in England: the rise of the never smoker and the disadvantaged smoker. J Public Health (Oxf). 2012 Aug;34(3):390-6.

However, within deprived groups, the rates of smoking vary considerably according to a range of factors, for example between different ethnic groups *(Fig.2)*[29] and also by age group.[30] This limits the impact of smoking cessation campaigns unless they can be tailored to individual groups and the different types of tobacco consumption within each group. For example, smokeless tobacco that may be chewed, inhaled (sniffed) or placed in the mouth. There are many types which must be addressed by name rather than using the generic term 'smoking'. In 2019, **7%** of South Asian people and **5%** of Black/African/ Caribbean people, **5%** of Indian people and **12%** Bangladeshi people regularly used smokeless tobacco of one kind or another. In addition, the use of shisha pipes, traditionally used in the Middle East to smoke tobacco, has increased in the UK. In 2019, these were used once per year or more by **11%** of South Asian people, 6% of Black/African/ Caribbean people and **2 %** of white people.[31]

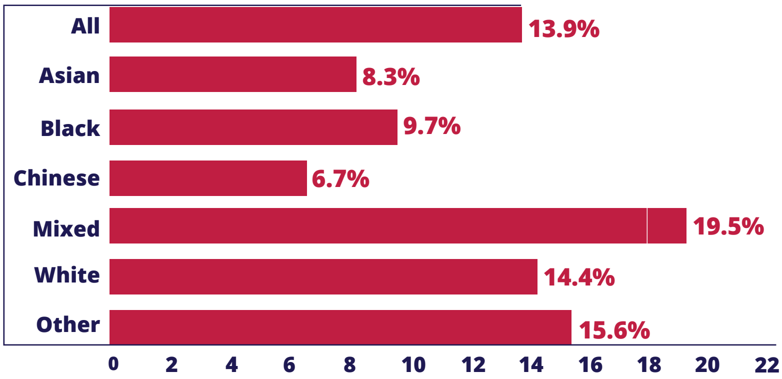


Figure 2. Percentage of adults who smoked cigarettes by ethnicity
Gov.co. Ethnicity Facts and Figures: Cigarette Smoking Among Adults – England 2019. Sourced from The Annual Population Survey.

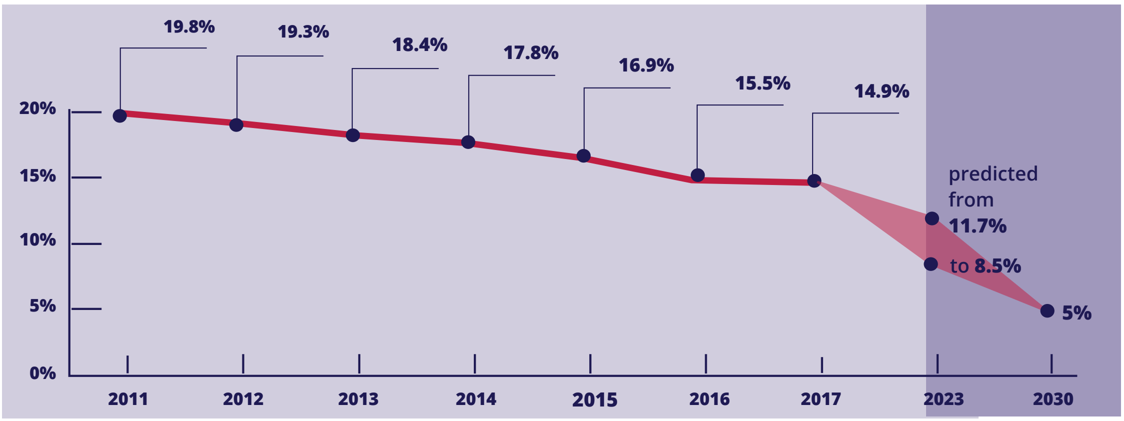


Figure 3.
Smoking prevalence in England 2011 to 2017
Health Matters: Stopping smoking – what works? Public Health England 2019

The Marmot report highlighted smoking cessation as one of the most cost effective ill-health preventions. Marmot also advocated localised initiatives based on psychosocial reasons for smoking, particularly in deprived groups.

National level smoking cessation campaigns and services continue. The 'Stoptober' campaign has resulted in 2.3 million attempts to quit smoking since it was launched in 2012.[32] We believe such campaigns should continue at national level. Smoking prevalence is falling *(Fig. 3)* and we believe a great deal more activity is needed locally to make the messages impactful with all local communities. This should be coordinated and where possible, materials produced centrally to achieve better cost effectiveness.

To maximise their impact, local campaigns should be delivered by people within the target communities, taking into consideration their social and religious conventions and should be coordinated with national campaigns.

The different messaging in smoking cessation campaigns and disease awareness campaigns for lung cancer must be kept separate to avoid confusion amongst their target audiences, which will reduce their overall impact. The introduction of lung cancer screening will make this even more important as, unlike smoking cessation, awareness of screening must be communicated more broadly i.e., to ex-smokers.

FOCUS POINT:

In Wales a Tobacco Control Delivery Plan was launched in 2021, covering the period 2022 to 2024.[33] One of its five priorities is to target priority groups, which are defined quite broadly, but in which are included people from socio-economically deprived backgrounds. It advocates a cohesive, community-led approach.

04

Recommendation

National (UK-wide) smoking cessation campaigns and services should be integrated with National Lung Cancer Screening programmes, as recommended by the UK National Screening Committee and targeted at communities and areas where smoking rates remain high.

> “Following the very welcome recommendation from the UK National Screening Committee that screening should be offered to people aged 55 to 75 who are at higher risk of developing lung cancer it is important that this is approved by Government without delay so that the benefits already shown in England can be more widely seen in all UK countries.”

Professor David Baldwin.
Honorary Professor of Respiratory Medicine;
Consultant Respiratory Physician,
University of Nottimgham

3.2 National screening programme

The UK National Screening Committee has recommended recently that the four UK nations implement targeted national lung cancer screening programmes, integrated with smoking cessation services, for people at high risk.[34]

The UKLCC welcomes this recommendation, which when fully implemented, will fulfil the requirement for a UK-wide lung cancer screening programme, which the UKLCC has been recommending for some time.[35] The UKLCC is calling for this recommendation to be implemented throughout the UK as an urgent priority.

The number of sites offering NHSE Targeted Lung Health Checks (TLHCs) in England has been slowly increasing. A recent written answer in Parliament confirmed that the number of sites offering Targeted Lung Health Checks in England will increase from 23 to 43 in 2022/23, funded by around £70 million from the NHS Cancer Programme.[36] The UK National Screening Committee has now acknowledged that the TLHC Programme provides a basis for the implementation of a National Screening Programme in England.

The introduction of a national lung screening programme is a major opportunity to address some of the impact of health inequalities on lung cancer. Work being carried out in the pilot centres in Liverpool, Manchester, Leeds and University College London is demonstrating that the way in which screening is introduced will be a major factor in its uptake.

05

Recommendation

The Governments of all UK nations should implement the recommendations of the UK National Screening Committee and urgently establish National Lung Cancer Screening programmes.

In England in 2018, 32% of people first access specialist care as emergency cases

FOCUS POINT:

National screening to reduce emergency admissions

Many lung cancer patients present as an emergency admission into hospital. In England in 2018, **32%** of people first access specialist care as emergency cases.[37] However, patients entering care via this route are over five times more likely to die within one year of diagnosis than those who are referred via a GP.[38] This is because patients admitted as an emergency are generally seeking help later than those who have gone via their GP. The consequential late diagnosis with more advanced stage often means that their outcomes are much worse.

Screening programmes that call forward ever-smokers are a major opportunity to access people who are less likely to come forward early, who are likely to include people with high deprivation scores and older people who may be more likely to be afraid of what the findings will show. When fully implemented, a national screening programme should invite all ever-smokers for screening to encourage them to engage earlier with NHS services and reduce emergency admissions.

Screening and diagnostic services in the community

Screening programmes will need to be specifically targeted at communities that have high smoking rates. The four pilot centres listed above are showing that it is essential to target people in sectors of the community who are particularly affected by health inequalities.

Making the pathway to initial diagnostic investigations as short as possible is essential and here the 1st Touch[39] approach to communications with individuals will be important. If messages are customised for different groups impacted by health inequalities, this is an opportunity to galvanise more people to seek help.

Results from the Yorkshire Lung Cancer Screening Trial *(Fig. 4)*[40] show that socio-economically deprived individuals are less likely to respond to a telephone call inviting them for a face-to-face lung health check. More direct contact with local communities is needed, led by designated individuals who lead on health promotion.[41]

The experience of other screening programmes supports this. [42, 43, 44]

Community or mobile clinics concentrated on areas where factors causing health inequality are common, e.g., mobile screening clinics in supermarket car parks in deprived areas, which are being trialled in some lung cancer screening pilots. This is more than just convenience; it reduces the need for people to travel to attend hospital appointments.[45]

In planning screening programmes, the Independent Review of Adult Screening Programmes in England recommends engagement with faith leaders and community groups and relevant voluntary, community and social enterprise organisations that work with the NHS at national, regional and local levels. It is also worth noting that it recommends improvements in the understanding amongst screening health professionals of trans- and gender diverse issues.[46]

IMD Quintile	Univariate Odds ratio (± 95% Confidence intervals)	P value	Multivariate Odds ratio (± 95% Confidence intervals)	P value
1 (most deprived)	0.46 (0.43, 0.49)	<0.001	0.58 (0.54-0.62)	<0.001
2	0.63 (0.59, 0.68)	<0.001	0.71 (0.66-0.76)	<0.001
3	0.78 (0.73, 0.83)	<0.001	0.84 (0.78-0.89)	<0.001
4	0.95 (0.89, 1.01)	0.09	0.98 (0.92-1.05)	0.54
5 (least deprived)	1.00		1.00	

Figure 4. Odds ratio of responding in response to the telephone triage line by deprivation index
Crosbie P, et al. Eur Resp J, 2022, in pre-publication

06

Recommendation

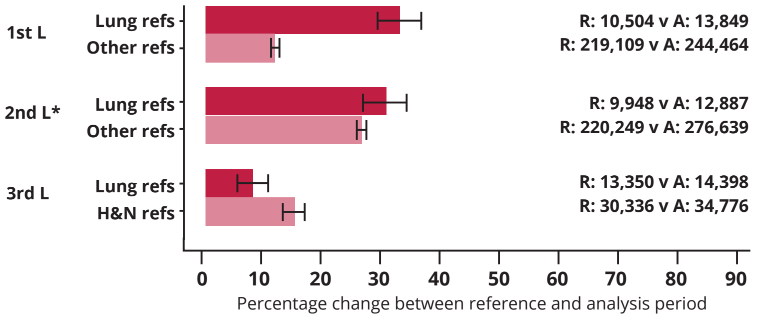
Disease awareness campaigns across the four UK nations should be targeted to address local needs and communities impacted by health inequality, taking into consideration the fact that lung cancer can occur in people who have never smoked.

3.3 Localising disease awareness initiatives & patient risk assessment by GPs

Disease awareness campaigns not only increase awareness, they also increase help seeking activities from individuals.

The Be Clear on Cancer campaigns are good examples of this. A study of 11 ‘Be Clear on Cancer’ campaigns for bowel, lung, bladder and kidney, breast and oesophagogastric cancers[47] shows increases in:

- attendances for symptoms highlighted in the campaigns
- relevant urgent referrals
- diagnostic tests carried out
- diagnoses (including diagnosis at early stages)



R XX v A XX = Number of referrals reference vs analysis periods
Asterisk* = two year comparison

H&N = Head and Neck (the unrelated cancer comparator chosen by the investigators).

Figure 5. Percentage change between reference and analysis period, in the number of urgent referrals for suspected cancer, England
Lai J, Mak V, Bright CJ, et al. Reviewing the impact of 11 national Be Clear on Cancer public awareness campaigns, England, 2012 to 2016: A synthesis of published evaluation results. Int J Cancer. 2021 Mar 1;148(5):1172-1182.

Figure 5 shows percentage increases in urgent (2-week) referrals for suspected lung cancer in three ‘Be Clear on Cancer’ campaigns (L1 – L3). The upper column in each case shows the percentage increase in urgent (2-week) referrals for suspected lung cancer during the awareness campaign period. As there are long-term increasing trends in the number of urgent referrals for suspected cancer, the increases for campaign-related referrals were compared to increases for other referrals, which should not have been affected by the respective campaigns (In this case, head and neck cancer).

In the first two campaigns the increase in lung cancer urgent referrals was greater than the increase in that of other referrals, which shows the positive impact awareness campaigns have on lung cancer urgent referrals. The increase in urgent referrals for suspected lung cancer for the third national campaign **(8%)** was smaller than the increase for other referrals **(15%)**.

In contrast, the impact of disease awareness programmes on health inequalities has not been widely studied. However, they should be delivered nationally and locally, customised to individual communities especially those affected by health inequalities.

Delivery of the local campaigns should:

- be in the community (and not the hospital) setting
- be carried out by people who represent the community being targeted
- be actively supported by leaders of the community
- identify and address local barriers to seeking help
- make use of existing social groups in each community (social clubs etc.) where people already come together and community health services e.g. community pharmacies, where people may also be buying regular cough medicines

Telephone helpline and self-referral for screening

We have already seen socio-economically deprived individuals are less likely to respond to a telephone call inviting them for a face-to-face lung health check.

However, experience with lung cancer screening pilots is showing that helplines which people can choose to call if or when they wish are valuable. These findings need further investigation, but it may be the ability of the person to choose their own time and moment that makes the difference.

Helplines that patients can choose to contact could be key to shortening the pathway into diagnosis if they also included direct access to initial screening services, including diagnostic imaging, if the caller wished to take up these options having had a discussion about their concerns.

Normally, people would be encouraged to contact their GP, indeed the latest *NHS Help Us Help You* campaign, which is targeted at raising awareness of lung cancer, advises patients to go to their GP to be checked.[48] However, the excessive workloads on GPs in the COVID 19 aftermath and the difficulties this causes for people to speak to a GP is a major barrier to help-seeking actions from people responding to lung cancer awareness campaign.

FOCUS POINT:

In west Wales, an awareness campaign incorporating self-referral for chest x-ray that is booked through a nurse, thus bypassing GPs is being piloted. If the chest x-ray shows the signs of lung cancer (NICE defined), the patient goes forward for CT.

Providing a helpline

- Callers should be able to speak to a person with the same ethnic background. This should include access to interpreters but also the facility to talk to a person who understands the cultural and religious influences on the individual.
- Information about lung cancer should be provided in a way that is easily understood, including access to professionals trained in educating people with learning difficulties.
- Access to initial diagnostic testing should be available from the helpline
- Advice given out should include support available to help individuals access the diagnostic services (transport etc.)

A telephone line dedicated to lung cancer offering direct access to lung health checks for people who wanted them, would reduce the barrier of GP access, provided GPs were kept informed. This would also improve the consistency of chest x-ray requests, which is currently highly variable in primary care.

07

Recommendation

A dedicated lung cancer helpline, should be set up at regional level providing direct access (triaged) to specialist diagnostic services as well as support and information tailored to local communities.

GP risk assessments

Disease awareness programmes should be supported by proactive identification of patients at high risk of developing lung cancer. GPs should be supported in using patient record search engines to identify such patients on their list who should be contacted and offered a risk assessment. Patients who are confirmed as high risk should then be offered screening. The principles of '1st Touch' should be followed. This way of identifying at risk patients will be particularly helpful in groups of patients affected by one or more factors leading to health inequalities.

3.4 Equitable access to rapid specialist diagnosis, treatment and care

In England, 32% of patients are diagnosed following an emergency admission to hospital.[37] More work should be carried out to identify the reasons for emergency lung cancer admissions which occur throughout all levels of deprivation.

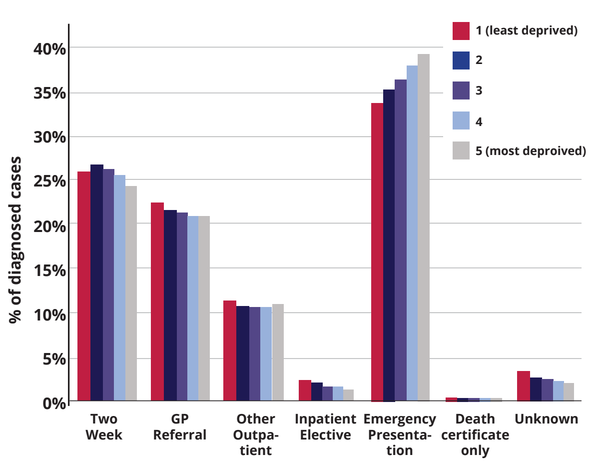


Figure 6. Lung cancer: routes to diagnosis by deprivation index
National Cancer Registration and Analysis Service: http://www.ncin.org.uk/search/routes+to+diagnosis

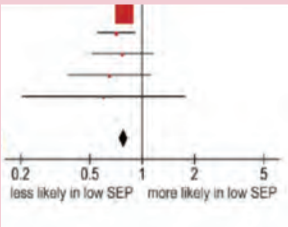
However, the rate increases with the level of deprivation *(Fig. 6)* and it is likely that the rate of emergency admissions is made worse by health inequality factors such as income (and inability to take time off work), and health and digital literacy. It is likely that emergency admissions could be reduced if the impact of socio-economic deprivation are mitigated and people are able to seek help on an equitable basis, including lung cancer screening.

The impact of health inequalities on lung cancer patients continues beyond early presentation and diagnosis. Mitigation must continue into treatment and throughout the pathway.

The holistic needs assessments of all patients should therefore be reviewed regularly to ensure their needs continue to be met. Entering treatment may present additional challenges e.g. patients should be supported in making informed choices from the full range of treatment options appropriate for them on the basis of clinical need, and this should not be compromised by health inequalities such as concerns about income or commitments to family. Studies indicate that this is an area that requires significant improvement. Based on a systematic review and meta-analysis of 23 papers, including studies of patients in the UK *(Fig. 7)*, lung cancer patients are less likely to receive any kind of treatment, surgery or systemic anti-cancer treatment (SACT) if they live in socioeconomically deprived circumstances. This difference is not due to late presentation with symptoms as described previously.[49]

For people in the most deprived group, the odds ratio of receiving any treatment was 0.78 compared with people in the least deprived group. People who are more socioeconomically deprived are less likely to receive surgery OR=0.68 or SACT OR=0.82

In addition to variations due to health inequalities, variations in the use of different lung cancer treatments not associated with differences in patient or tumour attributes have been observed

Study or Subgroup	log [Odds Ratio]	SE	Weight	Odds Ratio IV, Random, 95% CI	Odds Ratio IV, Random, 95% CI
Crawford et al 2009 (36)	-0.236	0.032	90.7%	0.79 [0.74, 0.84]	
Erridge et al 2009 (18) C	-0.342	0.128	5.7%	0.71 [0.55, 0.91]	
Gregor et al 2001 (38)	-0.261	0.21	2.1%	0.77 [0.51, 1.16]	
Jack et al 2006 (40)	-0.431	0.282	1.2%	0.65 [0.37, 1.13]	
Stevens et al 2008 (47)	-0.511	0.55	0.3%	0.60 [0.20, 1.76]	
Total (95% CI)			100%	0.78 [0.74, 0.83]	

Heterogeneity: Tau² = 0.00; Chi² = 1.33, df = 4 (P = 0.86); I² = 0%
Test for overall effect: Z = 8.06 (P < 0.00001)

Figure 7. Meta-analysis of odds of receipt of any active treatment (lung cancer) in low versus high Socio-economic groups
Forrest et al, 2013; PLoS Med 10(2)

in different parts of England. These unwarranted variations may be due to differences in treatment approach from one area to another. In particular, this applies to three treatment types associated with patient survival: the use of surgical resection, radical radiotherapy and chemotherapy. Measurement of the impact on survival that this has suggests that each year over 800 lung cancer patients could have a clinically relevant extension of their lives if treatment levels were increased throughout England to match those of the highest treating areas.[50]

Trusts should ensure all clinically relevant treatment options are explained and offered to each patient. Non-clinical barriers affecting access to these options due to health inequalities e.g. the cost of transport, should be identified and addressed. This allows treatments to be considered in terms of their effectiveness and potential side effects whilst minimising the influence of health inequalities on the treatment decision.

The National Optimal Lung Cancer Pathway (NOLCP) is central to reducing variations and improving the quality of treatment in England.[51] The Lung Pathway in Northern Ireland[52] and the National Optimal Pathway for Lung Cancer in Wales[53] fulfil equally important roles in their respective nations. National pathways indicate the optimum treatment(s) for lung cancer at every stage and should be used as the basis of when and what treatments are offered, irrespective of the part of the country in which the patient lives *(Fig. 8)* and the health inequalities they may face. This should be done before considering what health inequality factors are affecting the patient and how they will need to be mitigated for the given treatment chosen.

In Scotland, lung cancer has a set of quality performance indicators on which Cancer Regions and Health Boards are measured.[54] A national guideline was published by the Scottish Intercollegiate Guidelines Network in 2014 and updated in 2015[55] but not since. However, an Optimal Lung Cancer Pathway for Scotland is needed and is being considered in a recent initiative that is under review.

A factor that can significantly affect the choice of treatment is the distance between the patient's home and their treatment centre. This can be a major cause of health inequality. In urban settings, people who live in deprived areas often have concerns about costs involved in reaching a treatment centre - even if it is in the same city. This has been extensively studied and Crawford et al not only showed that the probability of definitive management for lung cancer falls with the deprivation level in which the patient lives but also that this is amplified by the travel time to reach services. *(Fig. 9)*

Quartiles – Deprivation distance	**1**	**2**	**3**	**4 most deprived**
1	**1**	**0.79**	**0.69**	**0.74**
2	**0.84**	**0.81**	**0.80**	**0.75**
3	**0.90**	**0.87**	**0.87**	**0.78**
4 furthest	**0.83**	**0.78**	**0.78**	**0.61**

Figure 8. Lung cancer: Odds ratio of having a histological diagnosis by distance and deprivation
Crawford SM, et al. Br J Cancer 2009;15;101(6):897-901

In rural areas, e.g. the Highlands in Scotland, also Mid-Wales, and the Scottish islands, distance to treatment affects more than the cost of reaching the treatment centre. Long journeys are often involved (in terms of distance and time). If the patient does not have access to a private car, public transport can be difficult to navigate and schedule times may mean a patient has to stay near the treatment centre overnight because there is no transport for their return until next day.

FOCUS POINT:

A study looking at differences in accessing treatment and specialist care in rural and urban areas is being conducted by Cancer Research UK working with services in NE London centred at St Bartholomew's Hospital and in Lincolnshire. This is currently at an early stage of development.

This can be exacerbated by the number of separate visits required. Lung cancer can require a sequence of tests to reach a clear diagnosis and staging. Treatment can also involve multiple visits to a centre of excellence, which is usually located in a city. The age of the patient and in any case, the patient’s general health (comorbidities) can all present barriers that need to be mitigated.

FOCUS POINT:

To overcome some of the difficulties in accessing multiple diagnostic tests, which may require several long journeys from remote areas, the concept of diagnostic hubs is being considered in Scotland. This would involve bringing people from remote locations to hubs where they would stay for a week, during which time all diagnostic tests would be completed.

England already has 92 community diagnostic centres and announced a further 7 in September 2022, but although they will be able to carry out CT scans and blood tests, they will not be equipped to carry out most of the specialised tests required in diagnosing lung cancer, such as Positron Emission Tomography-CT or Endobronchial Ultrasound/Endoscopic Ultrasound.

08

Recommendation

Barriers that create health inequality, such as the cost of transport and child care, should be removed by Trusts and Health Boards through establishing sustainable budgets targeted at communities affected by health inequality.

> **“A more evolved version of the navigator role could help overcome health inequalities if it provided a more holistic assessment, acknowledging and addressing the real logistical, practical and financial barriers, not just simple scheduling of tests.”**

Professor Kevin Blyth. Professor of Respiratory Medicine, University of Glasgow; Honorary Consultant Respiratory Physician, Queen Elizabeth University Hospital, Glasgow

A Holistic Needs Assessment (HNA) should have been carried out before the patient is referred for specialist diagnosis. This should be reviewed and updated as part of the decision on treatment so that health equalities barriers in lung cancer can be dealt with. The HNA should be kept with the patient’s personalised treatment plan – in fact it should become part of it.

NHS lung cancer pathway navigators

Since 2019, the UK Lung Cancer Coalition has recommended the introduction of NHS pathway navigators to help patients manage their diagnosis and treatment appointments, travel etc.[56] These are being piloted in some centres, but should be used more widely and at an earlier stage in relation to lung cancer. Their role would not only provide practical help to patients, but would also act as a source of encouragement, reducing the number of missed appointments. In addition, people from different ethnic backgrounds and/or religions, should be able to access an NHS pathway navigator who has the same ethnic background and religious beliefs, if they wish.

Quartiles – → Deprivation ↓ distance	**1**	**2**	**3**	**4 most deprived**
1	**1**	**0.85**	**0.76**	**0.74**
2	**0.91**	**0.85**	**0.76**	**0.74**
3	**0.89**	**0.84**	**0.80**	**0.78**
4 furthest	**0.93**	**0.83**	**0.71**	**0.55**

Figure 9. Lung cancer: Odds ratio of any active treatment by distance and deprivation

Crawford SM, et al. Br J Cancer 2009;15;101(6):897-901

Community lung cancer navigators

The navigator role should be extended into the community to provide support and encouragement, facilitating people to seek help. They should come from within the community and be separate from NHS navigators. However, community and NHS navigators should liaise closely so that patients have a seamless transition from community to NHS support.

Integrated Care Systems

Integrated Care Systems and the 42 newly-formed Integrated Care Boards should develop delivery plans that cross over health, social care, transport and other local services with the specific objective of providing efficient but effective measures to mitigate factors causing health inequality, particularly in areas of high need. The community lung cancer navigators (above) would work within these plans, tailoring the delivery to the needs of individual patients.

3.5 Follow up, palliative and end of life care

Survival is the main metric by which the quality and effectiveness of cancer services are judged in the public eye: quality of life is an important consideration, but less so.

Understandably, this has influenced policy e.g. the emphasis on early diagnosis in the Long Term Plan. Lung cancer accounts for around a fifth of all cancer deaths[57] so it is particularly affected by this perception.

The emphasis on survival is of benefit to patients as it drives research and development as well as clinical practice to seek more effective treatments, but it tends to portray palliative care as less important, despite the number of patients relying on it.

Since around three-quarters of patients present with lung cancer at an advanced stage that cannot be cured, only a relatively small proportion are offered surgery, radiotherapy or chemotherapy with curative intent. The vast majority of lung cancer patients receive treatment with palliative intent.

Palliative care is embedded in the national lung cancer pathways, and quality of life metrics have been developed and are being used, including in the Quality Performance Indicators in Scotland and the National Cancer Patient Experience Survey (NCPES) in England.

Palliative care, by definition, has a significant impact on the patient's holistic needs. It is therefore impacted by health inequalities – often more so than curative treatment. In cancers with high mortality rates and major health inequalities as in lung cancer, policymakers and planners should ensure that palliative care is resourced and accessible to all patients who need it and in accordance with national pathways.

Particular attention must be paid to the benefits of palliative care in lung cancer when communicating with patients, particularly with people in communities affected by health inequalities. This should be encompassed within the application of 1st Touch.

09

Recommendation

All NHS Trusts and Health Boards should monitor access to the full range of treatments for lung cancer to ensure health inequalities are adequately mitigated for both curative and palliative approaches.

4.0 Addressing health inequalities (Evidence : Impact : Action)

Actions must be based on evidence

The breadth and complexity of health inequalities and the many communities on which they impact present a daunting challenge to initiatives to mitigate their impact. There have been numerous reports drawing attention to the problem and offering potential ways of tackling (not mitigating) the inequalities themselves. Health policy across the UK has reflected some of the recommendations in these reports but they have had only a modest impact on health inequalities. Health inequality targets were scrapped in 2011.

As with the collection of data on health inequalities, mitigating them requires a coordinated approach. Actions taken to mitigate health inequalities should be based on data and evidence of their nature and impact and of the communities they affect. The impact of mitigation should also be measured.

Early Holistic Needs Assessments

As mentioned earlier, in deciding what mitigating actions need to be applied at an individual patient level, the existing Holistic Needs Assessment (HNA) could play a crucial role.

At present if an HNA is carried out, it is done when patients enter treatment. This already captures much of the information needed to assess an individual's health inequalities profile. The HNA should be carried out in all patients as early as possible, preferably by primary care practitioners on day one at the point of referral for diagnostic testing. This should identify needs that could affect the patient's ability to attend multiple diagnostic test appointments, and future treatment and care, which should be addressed as part of the personalised care plan.

Once created, the HNA should be retained with the patient notes and a copy given to the patient to carry between appointments and to present if they are seen in another hospital, similar to the current obstetric record that is given to expectant women. Giving a copy to the patient would be important because it would prevent the collection of duplicate and redundant information if a patient moved between different hospitals during diagnosis and treatment. In addition it would overcome problems in IT systems transferring data between different trusts.

The HNA should be reviewed and updated regularly; at least when the patient transfers from diagnosis to treatment (especially if treatment is provided at a different trust), and when treatments are changed).

Templates for HNAs should be reviewed to ensure they prompt the collection of sufficient and appropriate information from which to assess the impact of health inequalities on the individual and to improve the linkage to the National Lung Cancer Audit. The necessary measures identified should then become part of the patient's personalised care plan and should be regarded with equal importance to agreed diagnosis tests, treatment and care.

Workforce and resources have to match the local need

Taking action to mitigate health inequalities on which we do have good evidence, needs to be properly and sustainably resourced. In the current environment, it is naïve to rely on the availability of additional funding. In such circumstances, resources will have to be found by working more efficiently and by redistributing existing resources if necessary.

This is not only in terms of budgets from which to pay for transport and other essential needs, but also to ensure that NHS resources and workforce are deployed appropriately and take into consideration additional support required in areas where there are large communities affected by health inequalities. This is likely to mean increasing existing resources and workforce in deprived areas, for example.

10

Recommendation

Throughout the UK, NHS services should have regular local reviews based on information from the Single Coordinated Data Strategy to ensure adequate capacity and workforce to meet local needs particularly in areas with high levels of inequality.

Such changes can only be carried out effectively if they are based on accurate, reliable data. Currently, such information is not easily accessible, and some might not be collected. Addressing this need is an important priority (see recommendation 3). The data must be collected routinely so that services can be regularly reviewed and efficiently adapted to local needs.

Lung cancer clinical nurse specialists

Lung cancer clinical nurse specialists (LCNSs) are a vital part of the workforce in lung cancer and are crucial in identifying individuals who are affected by health inequalities and helping in their mitigation. Existing LCNSs should be given adequate administrative support and should not be required to divide their hours between their specialist role and general nursing. This would increase their capacity significantly, though future plans for workforce capacity must include more LCNSs and must ensure that LCNSs are trained in diagnostic processes as well as treatment of lung cancer. Appropriate training and access to clinical supervision is essential in retaining staff.

Dr Craig Dyer. Clinical Lead Cardiff and Vale University Health Board

> **“In Wales our lung cancer nurse specialists often live locally, which means they have unique knowledge of the geographical area but also the local issues that can impact on patients. It is this knowledge, plus good relationships with primary care, that mean we are able to deliver more care, closer to home for patients.”**

Measuring the impact that actions taken to mitigate health inequalities are having will be important in sustaining the actions in lung cancer. However, they will also provide valuable evidence for other cancers and other disease areas to follow suit. This should be done as part of routine clinical reporting. This will encourage NHS staff to regard mitigating health inequalities as an integral part of diagnosis and treatment of lung cancer.

> **“It is key that appropriately trained lung cancer nurse specialists are involved in the diagnostic pathway.”**

Dr Wendy Anderson. Consultant Respiratory Physician, Antrim; Previous Chair of the Lung Cancer Clinical Reference Group for Northern Ireland (NiCAN)

Materials must be written in simple language without technical jargon and should be available in languages spoken locally. For people who may be undecided as to whether or not to seek help, materials must have clear messages that tackle the reasons for their hesitancy, which may or may not be related to health care. Some people may benefit from one-to-one discussion.

Retain essential non-digital communications

Whilst digital media are an excellent way to communicate with many people, they cannot be the sole form of communication in the equitable delivery of an awareness campaign, whether on screening, disease awareness or smoking cessation. The design of lung cancer programmes must include careful consideration of non-digital ways to reach people who have limited or no access to any digital media.

Materials must be written in simple language without technical jargon and should be available in languages spoken locally. For people who may be undecided as to whether or not to seek help, materials must have clear messages that tackle the reasons for their hesitancy, which may or may not be related to health care. Some people may benefit from one-to-one discussion.

Better communication needed with people who have no fixed point of contact

Crisis estimated that approximately 227,000 people were rough sleeping, sleeping in vans and sheds, and stuck in B&Bs – across England, Scotland and Wales in 2021.[58] There is an obvious additional challenge in communicating with people who have no fixed point of contact. Recent work on the No Fixed Address Programme by Shelter and other local charities with HSBC UK to provide bank accounts for homeless people may eventually provide a valuable route of communication in the future.[59]

Travellers' lifestyle means they seldom stay within a single trust area for long. This means we have to find a way to provide diagnosis and treatment services that are sufficiently flexible to meet their needs.

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> **"In Northern Ireland improving health literacy in the poorest quintile of people could be a cost effective way of reducing mortality."**

Measuring the impact that actions taken to mitigate health inequalities are having will be important in sustaining the actions in lung cancer.

5.0

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