cancer52
the common voice
for rare & less common cancers

Taking Action on Inequalities in Rare and Less Common Cancers:

Understanding the Issues

cancer52

Taking Action on Inequalities in Rare and Less Common Cancers: **Understanding the Issues**

Contents

October 2022

Executive Summary

All people with cancer must receive the best possible diagnosis, treatment and care, no matter who they are or where they live. This includes people with rare and less common cancers, who are currently more likely to die than people with the four more common cancers[1].

People with rare and less common cancers can face inequalities in care and outcomes across their cancer journey. They can experience inequalities, due to their sex, ethnicity, age, sexual orientation, socioeconomic group or where they live or the type of cancer that they have.

- **Awareness:** Inequalities may first be experienced at diagnosis. Some groups of people have less awareness of cancer and its symptoms and may find it harder to spot that something is wrong, for example, younger people. In others it can be a taboo subject that is not openly discussed[2]. This can lead to later stage diagnosis which is associated with poorer survival outcomes.
- **Diagnosis:** Some groups of people may find it harder to obtain a diagnosis than others. Research by Cancer52 shows that people with rare and less common cancers often visit their GP several times before they are referred[3]. Differences in access to diagnostics and varying wait times exist across the country, for example, people from Asian and Black groups with oesophageal cancer face longer waits than people from White backgrounds, and the same is true for Black people with myeloma[4]. Black and Asian communities face longer diagnosis times for myeloma than people from White communities with the same cancers[5]. Not speaking English as a first language can create a barrier when communicating vague symptoms to a GP[6].
- **Treatment:** Some types of rare and less common cancers have no or very few treatment options available. Older people (for example, with ovarian cancer) and people from the most deprived groups are less likely to receive treatments. Not all young people are given access to fertility preserving procedures before they undertake treatment for their cancer[7].
- **Experience of care:** People can receive different experiences of care, with some experiencing more positive care while others have a more negative experience. Negative experiences can centre around poor communication or lack of support. Data from the 2021 Cancer Patient Experience Survey suggests people with rare and less common cancers have a poorer experience of care than those with common cancers[8].

  White people with cancer report a more positive experience of care than people from Black, Asian or Minority Ethnic groups[9]. People with another long-term condition as well as cancer report a more negative experience of care[10] as do people from the most deprived socio-economic groups[11].
- **Living with and beyond cancer:** People can be left with ongoing needs, including psychosocial needs, as a result of their cancer. There are varying levels of support available across the country and for different cancer types[12]. Support may not be age or culturally appropriate.
- **Research:** Investment in research for cancer varies across different cancer types, with some cancers receiving far more investment than others[13]. Certain groups of people, such as younger people, have poorer access to clinical trials[14]. This ultimately has had an impact on the treatment and support available to different groups.

People with rare and less common cancers can face inequalities in care and outcomes.

Recommendations

There is a lack of focus as well as a lack of data and evidence on inequalities in cancer and in rare and less common cancers especially. This hinders understanding and therefore productive action to address and remove such inequalities. More research is required into the inequalities that exist for rare and less common cancers, alongside the improvement of data collection and greater transparency on work by bodies to tackle these problems. In particular:

- **A National Cancer Inequalities Oversight Group:**

  The focus, dedicated team and oversight provided by the National Cancer Equalities Initiative led to valuable work and a greater understanding of inequalities. Tackling inequalities in cancer should be a clear priority for the Government and the NHS. A new National Cancer Inequalities Oversight Group should be established, to work with stakeholders from across the cancer community and have ownership and responsibility for improving cancer inequalities.

- **The Health and Social Care Select Committee recommendations relating to inequalities should be implemented:**

  - *"Cancer Alliances must reflect on new data provided to them by NHS England and the Department of Health and Social Care about cancer outcomes by ethnicity in their areas. In particular they should review the care provided to people from Black, Asian and Minority Ethnic backgrounds to ensure that no one is receiving worse care on account of their race.*
  - *The new Office for Health Improvement and Disparities should review the drivers of disparities in cancer outcomes and develop a joint strategy with NHS England to address these disparities."*

Data collected on inequalities, particularly ethnicity and sexuality, needs to be improved.

A new National Cancer Inequalities Oversight Group should be established, to work with stakeholders from across the cancer community and have ownership and responsibility for improving cancer inequalities.

- **Targeted action:**

  Tackling inequalities is a complex problem and requires a multi-faceted approach. This report highlights inequalities in a multitude of areas, from people from Black and Asian communities experiencing worse overall care to not receiving treatment because of age, as just a few examples.

  The NHS and the rare and less common cancer community need to work together to identify gaps for individual cancers due to inequalities and what action is needed to close these gaps. This will require targeted, specific projects in order to make progress and we look forward to working jointly with NHS teams on developing these projects.

- **National measures that include everyone:**

  Data collected on inequalities, particularly ethnicity and sexuality, needs to be improved. The Office for National Statistics (ONS) should report mortality, survival and incidence data for age, ethnicity, sexual orientation and region. Efforts should be made to ensure registration of cancers and staging data is complete for all rare and less common cancers to inform the production of the cancer official statistics by ONS.

  Key national metrics that measure progress against ambitions must measure all cancer types, otherwise there is a risk of progress stalling for cancers that are not included in the metrics. For example, the earlier diagnosis ambition relies on staging data. However, not all types of cancer (for example, blood and brain) can be staged. In such cases, proxy measures must be created.

- **Disaggregation and analysis of data:**

  Charities are well placed to help tackle the inequalities people face. However, understanding what data and evidence tells us about the problems and issues people face is key. There needs to be greater disaggregation and accompanying analysis of nationally collected data to understand how different groups of people are affected. Not only should this cancer data be disaggregated by cancer type but also by age, sex, ethnicity, sexuality, geographical location and other factors that will help to improve understanding.

  This data must then be analysed. Analysis of what the data shows must be undertaken to allow all stakeholders to use the data. Many smaller charities do not have the skills or resources to analyse data but could be helping to tackle inequalities with the knowledge this data would provide.

- **Ensuring data captures the experiences of all groups:**

  Data collected on inequalities, particularly ethnicity and sexuality, needs to be improved. Cancer52 welcomes the ongoing work by the Cancer Patient Experience Survey team to engage under-represented groups. We look forward to seeing the results and learnings from this work and support any efforts to increase the number of responses from people with rare and less common cancers. We would like to see this work carried out elsewhere in the NHS.

  It is challenging to collect data on very small groups of people (for example, those with very rare cancers) using the most common routes (for example surveys). Often this is due to concerns that data may be identifying. However, there are different methods beyond surveys (for example, case studies and focus groups) that can and should be used to understand experiences of diagnosis, treatment and care so that improvements can be made.

People with rare and less common cancers can experience inequalities due to their sex, ethnicity, age, sexual orientation, socioeconomic group or where they live or the type of cancer that they have.

Foreword

Cancer does not discriminate. It affects all of us. One in two of us will be diagnosed with cancer in our lifetime.

Figures show there are 375,000 new cancer cases annually in the UK[15]. Of these, 47% were rare and less common cancers and 53% were breast, prostate, lung and bowel cancers[16]. Yet rare and less common cancers account for 55% of cancer mortality[17]. That's nearly 75,000 deaths in England every year.

Having a rare or less common cancer is therefore an inequality in itself. Yet people with rare and less common cancers can experience further inequalities. This report 'Understanding the issues' is based on evidence supplied by our charity members and starts to outline the additional inequalities that affect people with a rare or less common cancer.

From people being diagnosed late because of their ethnicity to older people being less likely to receive treatment, factors such as deprivation, ethnic group, age and disability have an impact on a person's quality of care and ultimately their outcomes. This is simply unacceptable.

This report shows that we need to understand more about what inequalities exist and how they affect people.

This means listening more closely to those affected and ensuring everyone has a voice in decisions about health and social care, whether at a national and regional level, or on an individual basis.

It means collecting comprehensive data so it's possible to understand where inequalities exist in much better detail. It means working together more to take action to reduce inequalities where they exist.

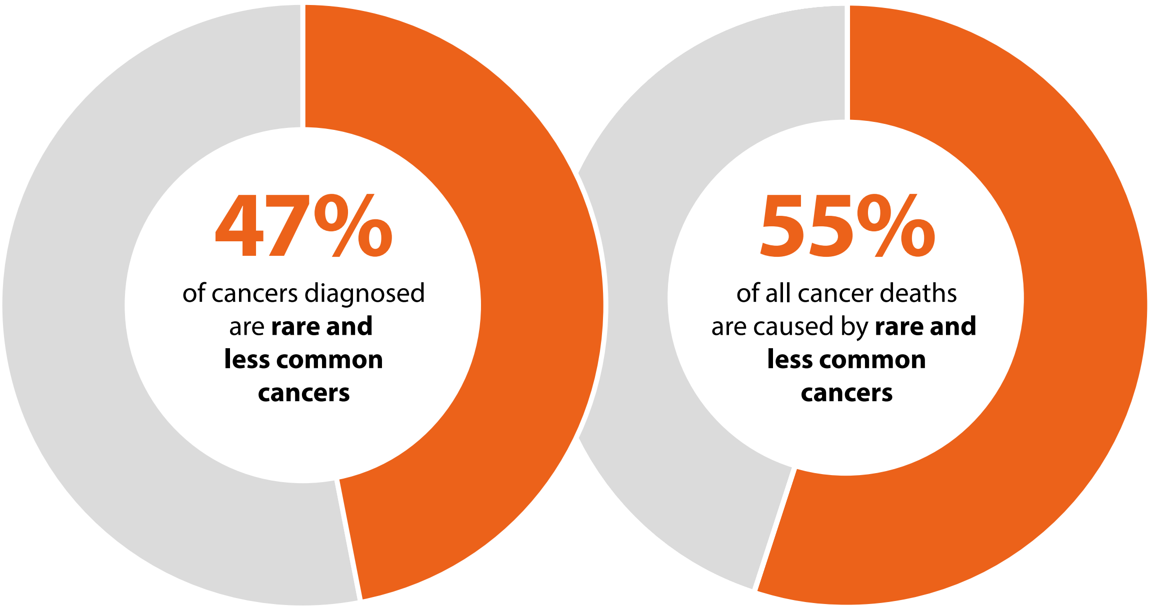
Across the health, care and charity sectors, we can all do better to ensure everyone receives the best possible care and treatment for their cancer. Nobody should lose out because of who they are, the type of cancer they have or where they live.

Cancer52 and its members are looking closely at what we can do to improve representation and outcomes. Taking action will require us all to play a role, working collaboratively to identify and work on the next steps in tackling the issues this report starts to identify.

Our thanks to all those who contributed to this report.

Best wishes

Jane Lyons
CEO
Cancer52



The inequalities gap

Having a rare or less common cancer is an inequality in itself. People with a rare or less common cancer are more likely to die than people with the four more common cancers (breast, prostate, lung and bowel)[18].

Yet people with rare and less common cancers can also face further inequalities, due to their sex, ethnicity, age, sexuality, socioeconomic group or where they live. These inequalities can impact diagnosis, treatment, care and outcomes. Whether a person has other health conditions or disabilities, or speaks English as a first language, can also impact their cancer journey.

This report sets out what is currently known about the inequalities that exist for people with rare and less common cancers and the effects they have. It outlines information and data about inequalities and makes recommendations to close the gap.

Cancer52 worked with its charity members to develop this report. The 110 Cancer52 charity members work to support people with a rare or less common cancer, usually through patient support and information and research funding. Members were surveyed during winter 2022 and asked to highlight any known data on inequalities for their cancer type. This report summarises the data provided and was supported by additional desk research. A working group inputted into, and oversaw the development of, this report.

It is unlikely that this report has captured all known evidence on the topic of inequalities in rare and less common cancers. There is a lack of data on inequalities across all cancers but particularly in rare and less common cancers. Where data does exist on inequalities it is often reported at an all-cancer level or focuses on the four most common cancers (breast, prostate, lung and bowel). However, we hope it will act as a starting point to demonstrate where gaps lie, where evidence does exist and what can be done to address these problems.

This report sets out what is currently known about the inequalities that exist for people with rare and less common cancers and the effects they have.

It outlines information and data about inequalities and makes recommendations to close the gap.

We hope it will act as a starting point to demonstrate where gaps lie, where evidence does exist and what can be done to address these problems.

What inequalities exist?

Being diagnosed with a rare or less common cancer presents an inequality in itself. Fewer people are diagnosed with a rare or less common cancer[19] than the four more common cancers each year and yet more people die from a rare or less common cancer. This highlights a key inequality in outcomes between the most common and rare and less common cancers.

Research by Cancer52 has shown that people with rare and less common cancers face particular issues that can disadvantage them[20]. These include:

- Not recognising their symptoms could be cancer
- Delays in obtaining a diagnosis - people with rare and less common cancers are more likely to be diagnosed via emergency presentation compared with the four most common cancers[21]
- Difficulties receiving the most suitable treatment
- Challenges accessing appropriate levels of support.

People with rare and less common cancers can face inequalities in care and outcomes across their cancer journey.

- **Awareness:** Inequalities may first be experienced at diagnosis. Some groups of people have less awareness of cancer and its symptoms and may find it harder to spot that something is wrong, for example, younger people. In others it can be a taboo subject that is not openly discussed[22]. This can lead to later stage diagnosis which is associated with poorer survival outcomes.
- **Diagnosis:** Some groups of people may find it harder to obtain a diagnosis than others. Research by Cancer52 showed that people with rare and less common cancers often visit their GP several times before they are referred[23].

  Differences in access to diagnostics and varying wait times exist across the country, for example, people from Asian and Black groups with oesophageal cancer face longer waits than people from White backgrounds, and the same is true for Black people with myeloma[24]. Black and Asian communities face longer diagnosis times for myeloma than people from White communities with the same cancers[25]. Not speaking English as a first language can create a barrier when communicating vague symptoms to a GP.
- **Treatment:** Some types of rare and less common cancers have no or very few treatment options available. Older people (for example, with ovarian cancer) and people from the most deprived groups are less likely to receive treatments. Not all young people are given access to fertility preserving procedures before they undertake treatment for their cancer[26].
- **Experience of care:** People can receive different experiences of care, with some experiencing more positive care while others have a more negative experience. Negative experiences can centre around poor communication or lack of support. Data from the 2021 Cancer Patient Experience Survey (CPES) suggests people with rare and less common cancers have a poorer experience of care than those with common cancers[27].

  White people with cancer report a more positive experience of care than people from Black, Asian or Minority Ethnic groups[28]. People with another long term condition as well as cancer report a more negative experience of care[29] as do people from the most deprived socio-economic groups[30].
- **Living with and beyond cancer:** People can be left with ongoing needs as a result of their cancer including psychosocial needs. There are varying levels of support available across the country and for different cancer types[31]. Support may not be age or culturally appropriate.
- **Research:** Investment in research for cancer varies across different cancer types, with some cancers receiving far more investment than others[32]. Certain groups of people, such as younger people, have poorer access to clinical trials[33]. This ultimately impacts the treatment and support available to different groups.

Evidence for Inequalities for Rare and Less Common Cancers

Sex

There are no overarching trends across rare and less common cancers when outcomes are broken down by sex. For some cancers one particular sex may face disadvantages, while this may be different for another cancer. Men and women may face different challenges and issues when it comes to diagnosis, treatment and care.

Diagnosis

- Men are more likely to be diagnosed via emergency presentations for melanoma, non-Hodgkin lymphoma and thyroid cancer[34].
- Women are more likely to be diagnosed via emergency presentation for chronic lymphocytic leukaemia, oesophageal, stomach, bladder, and brain cancer[35].
- Women with neuroendocrine cancer (NC) are more likely to face diagnosis delays than men[36].

Mortality

- According to a National Cancer Intelligence Network (NCIN) 2015 report, the age standardised mortality rate in males is around 70% higher than females for all cancers combined (excluding non-melanoma skin cancer (NMSC), breast, lung and sex specific cancers)[37].
- The same report found that for bladder and oesophageal cancers, age standardised cancer mortality rates were more than two and a half times higher for males compared with females.
- Survival is higher for females than males with malignant melanoma, while male colorectal cancer patients have a better survival than their female counterparts[38]. There was little difference between the sexes in one-year relative survival for patients with non-Hodgkin lymphoma[39].
- A study from the USA found women diagnosed with bladder cancer had worse overall survival than men diagnosed with bladder cancer[40].

Care

- A review of gender differences in mesothelioma (a rare form of lung or peritoneal cancer caused by exposure to asbestos), supported by Mesothelioma UK, found no statistically significant differences between men and women in treatment and care[41]. There were differences in obtaining diagnoses and how people communicated during their care, and research suggests a gender inequality in pursuing compensation for exposure to asbestos, with women less willing to pursue a civil compensation[42].

Cancer52 member case study

Lymphoma Action

Reducing health inequalities is and continues to be a priority at Lymphoma Action.

In May 2021, they undertook a health inequalities research project to understand how to improve their services to eliminate health inequalities for people affected by lymphoma. Following the recommendations made in the report, they have been working on several initiatives to provide better information and support. They are working to produce easier to understand information, including exploring the use of animations (with potential translations) to make complex information more accessible to all.

They are also working to provide more differentiated support through their services. Their vision is to have a suite of support and information services which can be tailored to the individual's needs, accessed easily at a time that is right for them and in a format that is right for them. This will include a new range of online support meetings addressing different types of lymphoma, user demographics, and treatment pathways.

www.lymphoma-action.org.uk

Deprivation

Across all health outcomes, the most deprived in society face the worst outcomes. Between the most and least deprived areas of England, the level of inequality, or gap, in life expectancy is 9.3 years for males and 7.3 years for females[43]. The gap in healthy life expectancy (years lived in good health) between the most and least deprived areas of England is around 19 years for both males and females[44].

This inequality also exists for cancer; socioeconomic status is the key determinant of poor outcomes[45]. People in the most deprived areas are more than twice as likely to die prematurely from cancer[46].

A report by Cancer Research UK in 2020 found that more than 30,000 cases a year are attributable to socio-economic variation[47].

Survival is worse for the most deprived groups[48]. People from more deprived socio-economic groups rated their overall care more poorly than those in less deprived groups in the latest CPES (2021)[49].

This trend applies to rare and less common cancers as well. A recent analysis in 2021 by Neuroendocrine Cancer UK of NCRAS data found that the main influencer on inequalities across all fields (late presentation, referral, treatments, outcomes) was deprivation status[50].

In 2015 the NCIN published a report into equality in cancer which showed differences in mortality rates between the least and most deprived groups for a range of rare and less common cancers[51]. This is summarised in the table below.

Figure 1: Table showing mortality differences between least and most deprived areas for men and women in rare and less common cancers[51].

	Men	Women
Mortality rates at least double for most deprived groups compared to least deprived	• Oropharynx • Oral Cavity • Larynx • Stomach • Anus • Lung • Penis	• Oropharynx • Cervix • Lung
Mortality rates higher in most deprived compared to least deprived	• Salivary gland • Oesophagus • Liver • Pancreas • Colorectal • Kidney • Bladder • Cancer of unknown primary	• Stomach • Anus • Oral cavity • Oesophagus • Liver • Pancreas • Colorectal • Breast • Vulva • Vagina • Uterus • Kidney • Bladder • Cancer of unknown primary

It is not entirely clear what is driving the differences between socio-economic status. NHS England has a focus on improving early-stage diagnosis as part of its CORE20PLUS5 initiative but other factors may also be at play. People from the most deprived backgrounds are less likely to receive treatments or receive different treatments.

A study in England showed that for lung, oesophageal, stomach and pancreatic cancers, the most deprived patients received different treatments for late-stage disease compared to the least deprived, even after accounting for patient characteristics such as age, sex, ethnicity and comorbidities[52].

More deprived patients were around 20% less likely to receive chemotherapy, or chemotherapy and radiotherapy combined, compared with the least deprived. Differences were more evident for oesophageal cancer than the other cancer types studied.

Age

Age is the biggest risk factor for cancer. While older people are more likely to develop cancer than younger people, inequalities are experienced by both younger and older age groups. The inequalities faced by different age groups can differ in nature. While children and younger people may face more challenges receiving a diagnosis, older people may be less likely to receive treatment for their disease.

Older people (over 70 years old):

Older people can struggle to be diagnosed promptly.

- Older women are significantly less likely to be referred by their GP for diagnostic tests such as ultrasounds when presenting with symptoms in the year preceding a diagnosis of ovarian cancer. The median time for women aged 75-79 to be referred for further investigation following the reporting of any relevant symptom was 20 weeks, compared to the average time for all ages of 10 weeks[53].
- 28% of women diagnosed with ovarian cancer in their 70s are diagnosed through emergency presentation[54]. The likelihood of being diagnosed through emergency presentation increases with age[55].

Older people can be less likely to receive treatments.

- A report by Ovarian Cancer Action found that older women are less likely to receive treatment for ovarian cancer, with 37% of women above the age of 70 not receiving any treatment, rising to over 60% for those aged 80 and over[56]. Almost half (48%) of ovarian cancer patients aged 70-79 don't have surgery to treat their ovarian cancer, despite it being the treatment which offers the best long-term prognosis for women with the disease[56].
- Surgery information contained within Hospital Episode Statistics was linked to cancer registration information to assess whether patients underwent major resections as part of their cancer treatment for 13 different types of cancer (including less common cancers uterus, ovary, kidney, cervix, stomach, liver, bladder, pancreas and oesophagus). For all of these cancer types, older patients were less likely to have had surgery, and this decline often started from the youngest age group[57].

Older people can have worse mortality rates.

- Mortality rates for all cancers combined in the UK are highest in people aged 90+ (2016-2018)[58]. Each year more than half (54%) of all cancer deaths in the UK are in people aged 75 and over (2016-2018)[59].
- 43% of women diagnosed aged 70-79, and 70% of women diagnosed over the age of 80, died in the first year after their ovarian cancer diagnosis[60]. This is significantly higher than the average one-year mortality rate for all ovarian cancer patients which is 28%[61]. Five-year survival for ovarian cancer is highest in younger women and drops with increasing age[62].
- The mortality rate for pancreatic cancer has been shown to increase with age (for example the rate is 0.3 for those aged 30 to 34 compared to 74.2 for those aged 75 to 79)[63].
- A study in the USA found that older adults with muscle-invasive bladder cancer had higher mortality than younger patients[64].

Younger people (up to 40 years old):

Awareness of cancer can be lower in young people and the health professionals who care for them.

- Young people often don't seek medical advice about symptoms as they can lack knowledge and awareness of cancer. A recent UK study suggested that young people only recognise on average four of 11 cancer risk factors[65]. It typically takes young people more appointments to get a referral to see a cancer specialist than it does for most other age groups[66]. Recent research found that nearly half (47%) of young people with cancer (12-24 years old) waited longer than two months from first noticing a symptom to their first oncology appointment[67]. Almost half of parents (49%) reported visiting their GP at least three times before their child's cancer was diagnosed[68].

Costs incurred can be higher for younger people.

- Children and younger people are more likely to be treated at specialist centres, increasing the need to travel and to stay overnight. Young cancer patients and their families are travelling twice as far and spending twice as much on travel costs as adults with cancer[69]. Parents spend an average of £600 in additional expenses a month as a result of their child's active cancer treatment and one of the top extra expenses is travel[70].

Younger people are more likely to report a negative experience of care.

- Teenagers and young people are more likely to feel that results and procedures were not explained to them as fully as they desired[71]. They are more likely to allocate a negative response for questions around trust in the doctors treating them and to feel as if they were not involved enough in treatment decisions compared to older patients[72]. They are also more likely than the older age group to raise issues such as medical staff talking about them as if they were not there and be concerned that they had deliberately had information withheld from them[73].
- Younger people with cancer rated their overall care lower than older people in the latest Cancer Experience Survey (2021)[74].

Teenagers and young adults are significantly under-represented in cancer research.

- In the UK recruitment rates for trials are between 14-30% in 15-24year olds, compared to 50-70% of children[75].

Ethnicity

Historically there has been limited data available on ethnicity for rare and less common cancers. A recent publication from Cancer Research UK analysed the incidence rate of cancer among Black, Asian and Minority Ethnic populations and showed substantial improvements in ethnicity data collection since 2012[76]. However, the analysis also highlighted ongoing gaps in data and the need to improve data collection on ethnicity.

A 2018 report by the Race Equality Foundation[77] found that:

- There is a higher incidence of certain cancers in Black and Minority Ethnic communities and the general incidence of cancer in these communities is rising.
- Understanding the prevalence and experiences of cancer in Black and Minority Ethnic groups is hindered by a lack of data.
- People who are members of Black and Minority Ethnic groups report more negative experiences of cancer care than White ethnic groups.
- Health care providers have a poor understanding of the needs of Black and Minority ethnic communities. There is a lack of health education regarding cancer and awareness of the availability of support services is limited among Black and Minority Ethnic communities. As well as this, there is a lack of cultural competence education for health providers, especially in cancer awareness.
- There is clear evidence of a lack of focus, priority and urgency of the cancer needs of Black and Minority Ethnic populations in NHS policy documents and in NHS cancer data collection exercises.

People from Black, Asian and Minority Ethnic communities with rare and less common cancers face a range of inequalities related to incidence, diagnosis, treatment, experience, and outcomes.

- For most cancer sites, White people have higher incidence rates. However, Black people have higher rates of myeloma compared to their White counterparts. Black and Asian people have higher rates of several gastrointestinal cancers, Hodgkin lymphoma and thyroid cancers[78].

- Differences in access to diagnostics and varying wait times exist across the country, for example, people from Asian and Black groups with oesophageal cancer face longer waits than people from White backgrounds, and the same is true for Black people with myeloma[79]. Black and Asian communities face longer diagnosis times for myeloma than people from White communities with the same cancers.
- White people typically rate their cancer patient experience more positively than people from Black, Asian, Mixed and other ethnic groups[80, 81], and their cancer may be diagnosed at a later stage, compared with people in the White ethnic group[82, 83].
- People from some minority ethnicity groups may be less likely to be recruited into clinical trials[84]. Poor monitoring of ethnicity remains a problem.
- Regarding stem cell donation, 72% of people from White Northern European backgrounds find the best possible match from an unrelated donor, compared to 37% of people from Minority ethnic backgrounds[85].

A little more is known about the experiences of people from Black, Asian and Minority Ethnic communities across all types of cancer. The most recent CPES (2021)[86] found that:

- People from Black, Asian, mixed and other ethnic groups rated their overall care more poorly than people from White ethnic groups.

There is a higher incidence of certain cancers in Black and Minority Ethnic communities and the general incidence of cancer in these communities is rising.

White people typically rate their cancer patient experience more positively than people from Black, Asian, Mixed and other ethnic groups.

- People in the White ethnic group were more likely to say that their referral for diagnosis was explained in a way they could completely understand (64.8%). Respondents in the Asian ethnic group were the least likely to say they understood the referral for diagnosis (54.8%).
- People from White ethnic backgrounds were the most likely to say it was ‘very’ or ‘quite easy’ to contact their main contact person. People from Asian ethnic backgrounds were the least likely to say it was ‘very’ or ‘quite easy’ to contact their main contact person.
- People from White ethnic backgrounds were the most likely to say they were involved as much as they wanted to be in decisions about their treatment (79.7%). Respondents from Black ethnic backgrounds were the least likely to say this was the case (70.9%)
- People from a mixed ethnic background were the least likely to say they were always treated with respect and dignity while they were in the hospital.
- People from White ethnic backgrounds were the most likely to say that they got the right amount of support from staff at their GP practice while they were having cancer treatment. People from the other ethnic group were the least likely to say this was the case.

Sexual Orientation, Gender and Variations in Sex Characteristics

Lesbian, Gay, Bisexual, Transgender, Queer and Intersex (LGBTQI+) people can face inequalities due to a tendency for healthcare services to take heteronormative and cisnormative approaches to care, or because healthcare professionals may make assumptions about a person based on their sexuality.

Research has shown that LGBTQI+ people experience differing cancer risk factors compared with non-LGBTQI+ patients and persistent inequalities in cancer care[87]. LGB people are more likely to be current smokers, drink at harmful levels and have a limiting longstanding illness[88]. Transgender people may experience a change to their cancer risk as result of medical transition, for example the increase in breast cancer risk for trans women taking oestrogen[89].

There is a paucity of data on sexual orientation and trans status at national level. Although the way in which data is collected and recorded on sexual orientation has been standardised, it is not mandated. Nationally collected data on cancer outcomes are not routinely published by the ONS on LGBTQI+ status.

LGBTQI+ status is published and reported collected as part of the CPES. In the latest CPES (2021), people with a different sex than that registered at birth, or those who preferred not to give this information, were less likely to say they were given enough privacy when receiving diagnostic test results[90].

In the same survey non-binary people, people who preferred to self-identify their gender, or those who preferred not to give their gender, were less likely to say that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns.

They were also less likely to say that they definitely got the right level of support for their overall health and wellbeing from hospital staff. People who are transgender need personalised information and support and treatment that takes into account any hormones that they may be taking[91].

Many young people fear their LGBTQI+ status could lead to healthcare professionals treating them differently, and 44% of adolescent and young adult LGBTQI+ cancer patients experienced discrimination during treatment, with 72% of transgender and non-binary patients reporting discrimination[92].

One study, based on a survey of cancer health care professionals (predominantly oncologists), found that they would like more education on the unique healthcare needs of LGBTQ+ patients with cancer[93]. In the same survey gay and lesbian respondents had significantly poorer scores for 15% of the questions when compared to the national average, whereas for bisexual respondents this rose to 59%. They reported that they were less likely to be treated with dignity and respect and bisexual respondents gave an overall poorer rating of care.

In addition to the overarching inequalities LGBTQI+ people face, there are some specific inequalities or issues related to particular rare or less common cancers. For example, people who are LGBTQI+ are less likely to be aware of risk factors relating to cervical cancer[94]. A study of trans men and non-binary people found they were less likely to attend cervical screening and would prefer trans specific clinics[95].

Cancer52 member case study

Trekstock

In 2018, Saima Thompson, one of the charity's Young Adult Ambassadors and founder of BAME Cancer Support, challenged the charity on its lack of diverse representation.

Saima also raised the question of cancer being a cultural taboo in some communities and the different views on cancer. This resulted in a series of 'Lifting the Lid' events on experiences within the young people's cancer community.

In 2021 the charity brought experts together to talk about institutional inequalities when it came to data collection, analysis and how cancer care is built around a white, cisgender, able-bodied centric narrative, and is not accessible or catering to all. Trekstock is now working to create a shared non-judgemental space where charities can explore different inequality themes and what role charities can play in addressing these and learn from each other.

www.trekstock.com

Regional differences

National cancer data has been broken down regionally for some time to allow for quality monitoring. This can reveal inequalities in access to care and outcomes related to where a person lives in the country. Research suggests that outcomes are better for people that receive treatment in specialist centres[96, 97]. However, not everyone is referred to specialist centres.

A report by Pancreatic Cancer UK demonstrated the differences in survival across regions of England, with one-year survival for pancreatic cancer ranging from 21.3% to 29.1% and five-year survival ranging from 4.8% to 10.6% across Cancer Alliances[98]. The proportion of people with pancreatic cancer receiving surgery in England is 9.7%, ranging from 7% to 13.5% across Cancer Alliances (2013 to 2015)[99].

The first report of the Ovarian Cancer Audit Feasibility Pilot ('Disease Profile in England', published in January 2020) revealed the proportions of patients diagnosed at early and late stages vary considerably around the country.

For ovarian cancer, 33% of patients were diagnosed at stage 1 or 2 in England, but the proportion of patients diagnosed early in England's Cancer Alliances ranged from 26% to 44%[100]. The report also highlighted significant regional variation in five-year survival, which ranged from 29% to 50%[101]. The Audit's second report concluded regional differences in access to treatment, particularly surgery[102]. Research in 2016 showed that overall survival for ovarian cancer was 45% better in major regional centre-treated patients than the median overall reported in UK trials[103].

Cancer52 member case study

Oracle Cancer Trust

Oracle Cancer Trust is launching a UK wide research programme in collaboration with North West Cancer Research in late 2022.

It aims to gain a better understanding of the inequalities that exist in Head and Neck Cancers. The ambition is to understand inequalities in outcomes (for example, quality of life and survivorship) but also within each stage of the patient care pathway (diagnosis, treatment and post treatment support).

www.oraclecancertrust.org

Other health conditions or disabilities

Many people with cancer are living with other conditions such as a long-term condition, mental health condition or learning disability. In people who responded to the CPES (2021), 60.8% had another long-term condition, 4.4% had a mental health condition and 0.6% had a learning disability[104]. Having one or more additional health conditions or disabilities can impact upon a person's cancer diagnosis, treatment, care and outcomes. More data is required to understand the inequalities that people with cancer who also have an additional health condition face.

There is some evidence about people with mental health conditions:

- A review of Neuroendocrine Cancer charity's counselling service showed that those most at risk of delays in their diagnosis included anyone with a pre-existing mental health issue, and those with a history of past trauma or 'attachment difficulties'[105].
- Overall survival and disease-specific survival was inferior in bladder cancer patients with a pre-existing mental disorder[106].
- In the latest CPES (2021), people with a mental health condition were least likely to say they had been given the option of having a family member, carer or friend with them when they found out they had cancer, and were also least likely to say their family or someone else close to them were given all the information they needed from the team looking after them to help care for them at home[107].

There is also some limited data regarding people with learning disabilities and cervical cancer:

- Women with learning disabilities are less likely to receive a cervical screening test and more likely to be ceased from screening (not receive invitations for screening) than other women[108]. Data from the General Practice Extraction Service (GPES) for 2017/18 indicated that 31.2% of women aged 25 to 64 with learning disabilities had a cervical smear in the prior 5 years compared to 73.2% of women without learning disabilities[109].

What needs to change

A greater focus on cancer inequalities at national level

There has been a patchy focus on inequalities in cancer at national level. The National Cancer Equality Initiative, formed in 2008, oversaw research, initiatives, reports and policies into equalities in cancer.

Nothing on this topic has been taken forward at a national level since 2016 until recently with the launch of Core20PLUS5. This is a national NHS England and NHS Improvement approach to support the reduction of health inequalities at both national and system level. The approach defines a target population cohort – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement. The earlier diagnosis of cancer at stage 1 and stage 2 has been included as one of the Core20PLUS5 clinical areas requiring improvement[110].

However, this earlier diagnosis ambition only applies to cancers that can be staged, which means that cancers that are not stageable are not included. Blood cancers and brain tumours are examples of cancers that are not staged. A metric to measure progress against diagnosing cancers that can not be staged needs to be developed urgently.

The focus, dedicated team and oversight provided by the National Cancer Equalities Initiative led to valuable work and a greater understanding of inequalities. Tackling inequalities in cancer should be a clear priority for the government and the NHS. While many parts of the government and NHS are undertaking work to understand inequalities and looking at how these can be tackled, there does not appear to be one team or overarching group with clear responsibility[111].

This makes it difficult for outside stakeholders to gain a rich picture of the problems or to understand what activity is happening. A central focus is required.

The Health and Social Care Select Committee ran an inquiry into cancer services in summer 2021. It published its report in April 2022, alongside a report from its Expert Panel.

> The National Cancer Equalities Initiative led to valuable work and a greater understanding of inequalities.

In terms of inequalities, the Health and Social Care Select Committee focused on variation and found that there was variation in care by ethnicity and region. It recommended that:

'Cancer Alliances must reflect on new data provided to them by NHS England and the Department of Health and Social Care about cancer outcomes by ethnicity in their areas. In particular they should review the care provided to people from Black, Asian and Minority Ethnic backgrounds to ensure that no one is receiving worse care on account of their race.

The new Office for Health Improvement and Disparities should review the drivers of disparities in cancer outcomes and develop a joint strategy with NHS England to address these disparities.'

The Expert Panel evaluation of the Government's commitments in cancer services in England[112], published in March 2022, included a chapter on inequalities and reaffirmed that:

'There is inequality in the treatment received, and care experienced, by people diagnosed with less common and rare cancers, and patients diagnosed with cancers which are less survivable such as thyroid cancer, acute lymphoblastic leukaemia and oral cancer.'

At the time of writing this report, The Department of Health and Social Care has stated frequently that the ten year cancer plan will address inequalities caused by factors such as deprivation and ethnicity. NHS England is in the process of carrying out a review of evidence and data available on inequalities in cancer and the Office for Health Improvement and Disparities is due to publish a white paper on health disparities.

Recommendations

- **A National Cancer Inequalities Oversight Group:**

  The focus, dedicated team and oversight provided by the National Cancer Equalities Initiative led to valuable work and a greater understanding of inequalities. Tackling inequalities in cancer should be a clear priority for the government and the NHS. A new National Cancer Inequalities Oversight Group should be established, to work with stakeholders from across the cancer community and have ownership and responsibility for improving cancer inequalities.

- The Health and Social Care Select Committee recommendations relating to inequalities should be implemented:

  - *"Cancer Alliances must reflect on new data provided to them by NHS England and the Department of Health and Social Care about cancer outcomes by ethnicity in their areas. In particular they should review the care provided to people from Black, Asian and Minority Ethnic backgrounds to ensure that no one is receiving worse care on account of their race.*
  - *The new Office for Health Improvement and Disparities should review the drivers of disparities in cancer outcomes and develop a joint strategy with NHS England to address these disparities."*

- **Targeted action:**

  Tackling inequalities is a complex problem and requires a multi-faceted approach. This report highlights inequalities in a multitude of areas, from people from Black and Asian communities experiencing worse overall care to not receiving treatment because of age, as just a few examples.

  The NHS and the rare and less common cancer community need to work together to identify gaps for individual cancers due to inequalities and what action is needed to close these gaps. This will require targeted, specific projects in order to make progress and we look forward to working jointly with NHS teams on developing these projects.

The NHS and the rare and less common cancer community need to work together to identify gaps for individual cancers due to inequalities and what action is needed to close these gaps.

More comprehensive collection of data

A lack of data and hence evidence on cancer inequalities exists in England. The data that is collected is incomplete on certain characteristics such as ethnicity which makes understanding the existence and impact of inequalities challenging.

Registration of all cancer cases must be encouraged; all tumour types report missing stage data in the final statistics and sometimes this is a significant percentage of all cancer cases, particularly for rare and less common cancers[113]. For example, 17% of bladder cancer cases in 2018 and 28% of all cervical cancers in 2018 were not registered, compared to only 8% of breast cancer cases[114].

Data is only routinely collected and reported based on age and sex. Incidence data provided by the Office for National Statistics (ONS) includes age, sex and region but data on ethnicity or sexuality is not available[115]. Mortality data is recorded for age and sex.

Survival data (one year and five year) is reported for age and sex but not for sexuality, ethnicity or socio-economic deprivation[116].

Analysis of inequalities is dependent upon individual charities conducting studies and any analyses commissioned by researchers and organisations such as NHS England and the Office for Health Disparities. NCRAS (the National Cancer Registration Service) does facilitate site specific tumour groups[117]. These tumour groups have published analyses of variations in care, particularly across regions, sex and age, but since the demise of the NCIN, fewer of these reports have been produced. Historically, inequalities have been considered as part of geographical variation, where outcomes differ between regions[118]. Differences between sexes have also been considered[119] but there is no regular analysis of data.

Figure 2: Table showing what data is routinely published by Office for National Statistics

	Incidence	Survival (one and five year)	Mortality
Collected	✓ Age ✓ Sex ✓ Region	✓ Age ✓ Sex	✓ Age ✓ Sex
Not collected	✗ Ethnicity ✗ Sexuality	✗ Ethnicity ✗ Sexuality ✗ Socio-economic deprivation	✗ Ethnicity ✗ Sexuality ✗ Socio-economic deprivation

Recommendations

However, understanding inequalities is so important that the collection, analysis and reporting of cancer incidence, survival, quality of life and mortality data for ethnicity, sexuality, age and socio-economic status should be routine.

- **National measures that include everyone:**

  Data collected on inequalities, particularly ethnicity and sexuality, needs to be improved. The ONS should report mortality, survival and incidence data for age, ethnicity, sexual orientation and region. Efforts should be made to ensure registration of cancers and staging data is complete for all rare and less common cancers to inform the production of the cancer official statistics by ONS.

  Key national metrics that measure progress against ambitions must measure all cancer types, otherwise there is a risk of progress stalling for cancers that are not included in the metrics. For example, the earlier diagnosis ambition relies on staging data. However, not all types of cancer (for example, blood and brain) can be staged. In such cases, proxy measures must be created.

- **Disaggregation and analysis of data:**

  Charities are well placed to help tackle the inequalities people face. However, understanding what data and evidence tells us about the problems and issues people face is key. There needs to be greater disaggregation and accompanying analysis of nationally collected data to understand how different groups of people are affected. Not only should this cancer data be disaggregated by cancer type but also by age, sex, ethnicity, sexuality, geographical location and other factors that will help to improve understanding.

  This data must then be analysed. Analysis of what the data tells shows must be undertaken to allow all stakeholders to use the data. Many smaller charities do not have the skills or resources to analyse data but could be helping to tackle inequalities with the knowledge data provides.

Data collected on inequalities, particularly ethnicity and sexuality, needs to be improved.

Key national metrics must measure all cancer types.

Cancer52 member case study

Fight Bladder Cancer

Informed by quantitative and qualitative studies, Fight Bladder Cancer has designed solutions to address some of the current inequalities facing bladder cancer patients.

The charity has designed a suite of full-colour booklets that they post for free anywhere in the UK to help digitally excluded people who are unable to access online materials. Their website uses simple language, with clear diagrams, and plenty of photos to help people who may have lower literacy and/or lower health literacy. To help people living in regional areas who are unable to attend face-to-face support groups, they host monthly online Zoom support groups.

To tackle low awareness of bladder cancer in people in high-risk professions, they have partnered with a workers' union to send information to occupational health and safety officers.

www.fightbladdercancer.co.uk

Understanding patient experience and quality of life

As well as ensuring that inequalities data is collated and collected by cancer registries and the ONS, it is crucial that people from all backgrounds are encouraged to complete other surveys that help to gain an understanding of patient experience and quality of life, including the Cancer Patient Experience Survey and Quality of Life Metric.

Surveys like these are a valuable way of understanding how people from different backgrounds experience care, treatment, and of understanding their needs.

The CPES (2021) found significant differences on a range of measures between different groups, including rare and less common cancers and all cancers, but the Quality of Life Metric has not yet been rolled out to rare and less common cancers. When it is, it must collect and report data for age, sex, sexual orientation, ethnicity and other disabilities.

These surveys need to be representative of communities who are disabled, LGBTQI+, have specific language, cultural and religious needs, are a range of ages, come from different socioeconomic backgrounds, ethnic groups and people with a long term condition. The latest CPES figures are broken down for different inequality groups but the Quality of Life Metric has not reported data on sexuality, for example.

Cancer52 wholeheartedly welcomes the comprehensive data collection and analysis by the CPES team, as well as efforts to reduce suppression numbers so that more rare cancers can be included in reporting and analysis. Other surveys should endeavour to follow their example.

> Charities and the NHS should work together to improve participation in groups that are currently underrepresented.

NHS England has also established a group to encourage more representation from across population groups which are less likely to respond to the survey. Based on the response rates from CPES 2019, focused efforts have been on those aged 16-54 (with particular focus on ages 16-35), people from more deprived areas and ethnic minority groups across different ethnicities, age groups and deprivation. Figures showing 2021 representation are shown in Figure 3.

Charities and the NHS should work together to improve participation in groups that are currently underrepresented.

They also need to be designed so that they capture the experiences of people with cancers with poor outcomes such as less survivable cancers and secondary cancers, or alternative methods found to evaluate the experiences of these groups of people.

People with less survivable cancers often do not survive long enough to be included in the CPES or the Quality of Life metric, which is conducted four to five months after discharge as an inpatient or day case, or eighteen months for the Quality of Life metric.

Disease areas with small numbers of people can mean inequalities data is not published or scrutinised. Small populations should not prevent work to understand the experiences and outcomes of different groups with rare cancers. Different methods beyond surveys can be used to understand and engage with groups with these cancers.

Figure 3: Table showing participation in the 2021 Cancer Patient Experience Survey by population group

Ethnicity

Year	Ethnicity	Responders	Total	Percentage	Difference
2021	Asian Bangladeshi	54	242	22.3%	-32.9%
2021	Asian Pakistani	224	737	30.4%	-24.9%
2021	Mixed White and Black African	28	90	31.1%.	-24.1%
2021	Black African	300	880	34.1%	-21.2%
2021	Black Carribean	331	919	36.0%	-19.2%
2021	Black other	166	455	36.5%	-18.8%
2021	Asian Indian	483	1,291	37.4%	-17.8%
2021	Mixed other	104	270	38.5%	-16.7%
2021	Mixed White and Black Caribbean	64	160	40.0%	-15.3%
2021	Asian other	378	932	40.6%	-14.7%
2021	Mixed White and Asian	59	141	41.8%	-13.4%
2021	Any other ethnic group	821	1,824	45.0%	-10.2%
2021	White other	1,972	4,278	46.1%	-9.1%
2021	Chinese	146	301	48.5%	-6.8%
2021	White Irish	419	801	52.3%	-2.9%
2021	Not stated	7.385	13,309	55.3%	0.1%
2021	White British	44.396	77,248	57.5%	2.2%

Age

Year	Age group	Responders	Total	Percentage	Difference
2021	16-24	200	733	27.3%	-28.0%
2021	25-34	566	1,998	28.3%	-26.9%
2021	35-44	1,800	5,403	33.3%	-21.9%
2021	45-54	5,457	12,806	42.6%	-12.6%
2021	55-64	12,927	24,667	52.4%	-2.9%
2021	65+	2,737	5,164	53.0%	-2.3%
2021	65-74	20,612	32,772	62.9%	7.6%
2021	75-84	15,053	23,869	63.1%	7.8%

Deprivation

Year	IMS quintile	Responders	Total	Percentage	Difference
2021	1 (most deprived)	7192	16,080	44.7%	-10.5%
2021	2	10,194	200,27	50.9%	-4.4%
2021	3	12,785	22,880	55.9%	0.6%
2021	4	14,025	23,787	58.7%	3.5%
2021	5 (least deprived)	14,791	23,955	61.7%	6.5%

Recommendations

- **Ensuring data captures the experiences of all groups:**

Data collected on inequalities, particularly ethnicity and sexuality, needs to be improved. Cancer52 welcomes the ongoing work by the CPES team to engage under-represented groups. Cancer52 looks forward to seeing the results and learnings from this work and supports any efforts to increase the number of responses from people with rare and less common cancers. Cancer52 would like to see this work carried out elsewhere in the NHS.

It is challenging to collect data on very small groups of people (for example, those with very rare cancers) using the most common routes (for example surveys). Often this is due to concerns that data may be identifying. However, there are different methods beyond surveys (for example, case studies and focus groups) that can and should be used to understand experiences of diagnosis, treatment and care so that improvements can be made.

> Cancer52 welcomes ongoing work to engage under-represented groups.

Conclusion

All people with cancer must receive the best possible diagnosis, treatment and care, no matter who they are or where they live.

This includes people with rare and less common cancers. Stakeholders across government, healthcare and social care should be working to remove the gaps that exist in outcomes for different people with cancer.

There is a lack of focus as well as a lack of data and evidence on inequalities in cancer and in rare and less common cancers in particular. This hinders understanding and therefore productive action to address and remove such inequalities.

More research is required into the inequalities that exist for rare and less common cancers, alongside the improvement of data collection and greater transparency on work by bodies to tackle these problems.

All people with cancer must receive the best possible diagnosis, treatment and care, no matter who they are or where they live.

References

1. Cancer52 (2020), Getting a Better Deal for Rare and Less Common Cancers. Available at: www.cancer52.org.uk/ single-post/2019/07/10/-getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-fro . Accessed: May 2021
2. www.huffingtonpost.co.uk/entry/very-much-a-taboo-subject-asian-cancer-survivors-on-dealing-with-stigma-after-diagnosis_uk_5dde58ede4b0d50f3299eaec, https://civilservice.blog.gov.uk/2020/10/19/breaking-down-the-taboos-lifting-the-lid-off-cancer-in-bame-communities/
3. Cancer52, Getting a Better Deal for Rare and Less Common Cancers, 2020, www.cancer52.org.uk/ single-post/2019/07/10/-getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-fro. Accessed: May 2022
4. Martins T, Abel G, Ukoumunne OC, Price S, Lyratzopoulos G, Chinegwundoh F, Hamilton W. Assessing Ethnic Inequalities in Diagnostic Interval of Common Cancers: A Population-Based UK Cohort Study. Cancers. 2022; 14(13):3085. https://doi.org/10.3390/cancers14133085
5. Ibid.
6. www.theurbankitchen.co.uk/blogs/the-urban-kitchen-blog/inequalities-in-cancer-care-in-the-uk-the-poorest-record-in-europe
7. Anderson RA, Weddell A, Spoudeas HA, Douglas C, Shalet SM, Levitt G, Wallace WH. Do doctors discuss fertility issues before they treat young patients with cancer? Hum Reprod. 2008 Oct;23(10):2246-51. doi: 10.1093/humrep/den252. Epub 2008 Jul 9. PMID: 18614615.
8. National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/
9. Ibid.
10. Ibid.
11. Ibid.
12. Health and Social Care Select Committee, Expert Panel: evaluation of the Government's commitments in the area of cancer services in England, 2022
13. A 2014 Cancer52 and NCRI report found that research spend in Treatment for less common cancers was significantly higher in percentage and cash terms when compared with more common cancers. By contrast research into Prevention, Early Detection, Diagnosis and Prognosis and Cancer Control, Survivorship and Outcomes Research was higher, in percentage and cash terms, for the more common cancers. There were similar amounts of relative spend on Biology, Aetiology and Scientific Model Systems. Cancer52 and NCRI, Research into less common cancers An analysis of research spend by Cancer52 members and National Cancer Research Institute (NCRI) Partners in 2012, 2012
14. HSJ, Dec 2019, Ending cancer inequality for young people, www.hsj.co.uk/comment/ending-cancer-inequality-for-young-people/7026479.article
15. Cancer Statistics for the UK – Cancer Incidence. Cancer Research UK. Cancer Statistics for the UK (cancerresearchuk.org). Accessed 22/08/22.
16. www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2017
17. www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2017
18. Cancer52 (2020). Getting a Better Deal for Rare and Less Common Cancers. Available at: www.cancer52.org.uk/single-post/2019/07/10/-getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-fro. Accessed: May 2022
19. Cancer52 (2020). Getting a Better Deal for Rare and Less Common Cancers. Available at: www.cancer52.org.uk/single-post/2019/07/10/-getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-fro. Accessed: May 2022
20. Ibid.
21. NCRAS, Routes to diagnosis 2006-2016, 2021. Available at: www.ncin.org.uk/publications/routes_to_diagnosis. Accessed: May 2022.
22. www.huffingtonpost.co.uk/entry/very-much-a-taboo-subject-asian-cancer-survivors-on-dealing-with-stigma-after-diagnosis_uk_5dde58ede4b0d50f3299eaec, https://civilservice.blog.gov.uk/2020/10/19/breaking-down-the-taboos-lifting-the-lid-off-cancer-in-bame-communities/
23. Cancer52, Getting a Better Deal for Rare and Less Common Cancers, 2020. Available at: www.cancer52.org.uk/ single-post/2019/07/10/-getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-fro. Accessed: May 2022
24. Martins T, Abel G, Ukoumunne OC, Price S, Lyratzopoulos G, Chinegwundoh F, Hamilton W. Assessing Ethnic Inequalities in Diagnostic Interval of Common Cancers: A Population-Based UK Cohort Study. Cancers. 2022; 14(13):3085. https://doi.org/10.3390/cancers14133085
25. Ibid.
26. Anderson RA, Weddell A, Spoudeas HA, Douglas C, Shalet SM, Levitt G, Wallace WH. Do doctors discuss fertility issues before they treat young patients with cancer? Hum Reprod. 2008 Oct;23(10):2246-51. doi: 10.1093/humrep/den252. Epub 2008 Jul 9. PMID: 18614615.
27. National Cancer Patient Experience Survey 2021, https://www.ncpes.co.uk/2021-national-results/
28. Ibid.
29. Ibid.
30. Ibid.

31 Health and Social Care Select Committee, Expert Panel: Evaluation of the Government's commitments in the area of cancer services in England, 2022

32 A 2014 Cancer52 and NCRI report found that research spend in Treatment for less common cancers was significantly higher in percentage and cash terms when compared with more common cancers. By contrast research into Prevention, Early Detection, Diagnosis and Prognosis and Cancer Control, Survivorship and Outcomes Research was higher, in percentage and cash terms, for the more common cancers. There were similar amounts of relative spend on Biology, Aetiology and Scientific Model Systems. Cancer52 and NCRI, Research into less common cancers An analysis of research spend by Cancer52 members and National Cancer Research Institute (NCRI) Partners in 2012, 2012

33 HSJ, Dec 2019, Ending cancer inequality for young people, www.hsj.co.uk/comment/ending-cancer-inequality-for-young-people/7026479.article

34 National Cancer Intelligence Network Cancer and equality groups: key metrics 2015 report www.ncin.org.uk/view?rid=2991

35 National Cancer Intelligence Network Cancer and equality groups: key metrics 2015 report www.ncin.org.uk/view?rid=2991

36 Basuroy R, Bouvier C, Ramage JK, et al.: Delays and routes to diagnosis of neuroendocrine tumours. BMC Canc 2018, 18: 1122, https://doi.org/10.1186/s12885-018-5057-3

37 National Cancer Intelligence Network, Cancer and equality groups: key metrics 2015 report www.ncin.org.uk/view?rid=2991

38 Ibid.

39 Ibid.

40 Jeannie Hoffman-Censits, Ravindran Kanesvaran, Rick Bangs, Lola Fashoyin-Aje, and Chana Weinstock, Breaking Barriers: Addressing Issues of Inequality in Trial Enrollment and Clinical Outcomes for Patients With Kidney and Bladder CancerAmerican Society of Clinical Oncology Educational Book 2021 :41, e174-e181

41 Mesothelioma UK, 2020, The Gendered Experience of Mesothelioma Study, , https://mesothelioma.uk.com/wp-content/uploads/dlm_uploads/2021/02/GEMS_Report_FINAL.pdf

42 Ibid.

43 Public Health England, Health profile for England: 2018, 2018, www.gov.uk/government/publications/health-profile-for-england-2018/chapter-5-inequalities-in-health

44 Ibid.

45 Cancer Research UK, Cancer in the UK 2020: Socio-economic deprivation, 2020 www.cancerresearchuk.org/sites/default/files/cancer_inequalities_in_the_uk.pdf

46 Public Health England, Health profile for England: 2018, 2018, www.gov.uk/government/publications/health-profile-for-england-2018/chapter-5-inequalities-in-health

47 Cancer Research UK, Cancer in the UK 2020: Socio-economic deprivation, 2020, www.cancerresearchuk.org/sites/default/files/cancer_inequalities_in_the_uk.pdf

48 Ibid.

49 National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/

50 White et al (2021), Incidence, prevalence of survival of neuroendocrine neoplasia in England 1995–2018. Endocrine Abstracts 80 OC1 | DOI: 10.1530/endoabs.80.OC1

51 National Cancer Intelligence Network, Cancer and equality groups: key metrics, 2015 www.ncin.org.uk/view?rid=2991

52 Henson, K.E., Fry, A., Lyratzopoulos, G. et al, Sociodemographic variation in the use of chemotherapy and radiotherapy in patients with stage IV lung, oesophageal, stomach and pancreatic cancer: evidence from population-based data in England during 2013–2014. Br J Cancer 118, 1382–1390 (2018). https://doi.org/10.1038/s41416-018-0028-7

53 Ovarian Cancer Action, Equality spotlight report: Age, https://cdn.ovarian.org.uk/media/documents/Ovarian_Cancer_Action_Equality_Spotlight_Report_Age.pdf

54 Ibid.

55 Ibid.

56 Ibid.

57 National Cancer Intelligence Network, Cancer and equality groups: key metrics, 2015 www.ncin.org.uk/view?rid=2991

58 Ibid.

59 Cancer Research UK, www.cancerresearchuk.org/health-professional/cancer-statistics/mortality#heading-Two, Accessed June 2022

60 Ovarian Cancer Action , Equality spotlight report: Age, https://cdn.ovarian.org.uk/media/documents/Ovarian_Cancer_Action_Equality_Spotlight_Report_Age.pdf

61 Ibid.

62 Ibid.

63 www.cancerdata.nhs.uk/incidence_and_mortality

64 Noon AP, Albertsen PC, Thomas F, Rosario DJ, Catto JW. Competing mortality in patients diagnosed with bladder cancer: evidence of undertreatment in the elderly and female patients. Br J Cancer. 2013 Apr 16;108(7):1534-40. doi: 10.1038/bjc.2013.106. Epub 2013 Mar 12. PMID: 23481180; PMCID: PMC3629420.

65 Health Service Journal, Dec 2019, Ending cancer inequality for young people, www.hsj.co.uk/comment/ending-cancer-inequality-for-young-people/7026479.article

66 Ibid.

67 Forster, A.S., Herbert, A., Koo, M.M. et al., Associations between diagnostic time intervals and health-related quality of life, clinical anxiety and depression in adolescents and young adults with cancer: cross-sectional analysis of the BRIGHTLIGHT cohort. Br J Cancer (2022). https://doi.org/10.1038/s41416-022-01698-6

68 Young Lives vs Cancer, The best chance from the start, 2016

69 Young Lives vs Cancer, Cancer Costs Follow-up: Finances, 2019 www.younglivesvscancer.org.uk/wp-content/uploads/2019/08/Cancer-costs-follow-up_Finances-1.pdf

70 Ibid.

71 Cancer Patient Experience in the Teenage Young Adult Population— Key Issues and Trends Over Time: An Analysis of the United Kingdom National Cancer Patient Experience Surveys 2010–2014. Journal of Adolescent and Young Adult Oncology, 6 (3). pp. 450-458. https://eprints.whiterose.ac.uk/112956/3/CPES%20revised%2018.12.pdf

72 Ibid.

73 Ibid.

74 National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/

75 Ending cancer inequality for young people, HSJ, Dec 2019, www.hsj.co.uk/comment/ending-cancer-inequality-for-young-people/7026479.article

76 Delon, C., Brown, K.F., Payne, N.W.S. et al. Differences in cancer incidence by broad ethnic group in England, 2013–2017. Br J Cancer 126, 1765–1773 (2022). https://doi.org/10.1038/s41416-022-01718-5 https://www.nature.com/articles/s41416-022-01718-5

77 Race Equality Foundation, Cancer and Black and Minority ethnic communities, 2018.

78 Delon, C., Brown, K.F., Payne, N.W.S. et al. Differences in cancer incidence by broad ethnic group in England, 2013–2017. Br J Cancer 126, 1765–1773 (2022). https://doi.org/10.1038/s41416-022-01718-5

79 Martins T, Abel G, Ukoumunne OC, Price S, Lyratzopoulos G, Chinegwundoh F, Hamilton W., Assessing Ethnic Inequalities in Diagnostic Interval of Common Cancers: A Population-Based UK Cohort Study. Cancers. 2022; 14(13):3085. https://doi.org/10.3390/cancers14133085

80 Pinder RJ, Ferguson J, Møller H., Minority ethnicity patient satisfaction and experience: results of the National Cancer Patient Experience Survey in England. BMJ Open. 2016;6:e011938.

81 National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/

82 National Cancer Intelligence Network (NCIN), Routes to Diagnosis 2006-2016 workbook v2.1a. 2017. www.ncin.org.uk/view?rid=3814.

83 Martins T, Hamilton W, Ukoumunne OC., Ethnic inequalities in time to diagnosis of cancer: a systematic review. BMC Fam Pract. 2013;14:197.

84 Godden S, Ambler G, Pollock AM., Recruitment of minority ethnic groups into clinical cancer research trials to assess adherence to the principles of the Department of Health Research Governance Framework: national sources of data and general issues arising from a study in one hospital trust in England. J Med Ethics. 2010;36:358–62.

85 Anthony Nolan unpublished data

86 National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/

87 Berner, Alison & Hughes, Daniel & Tharmalingam, Hannah & Baker, Tom & Heyworth, Benjamin & Banerjee, Susana & Saunders, Daniel. (2020). An evaluation of self-perceived knowledge, attitudes and behaviours of UK oncologists about LGBTQ+ patients with cancer. ESMO Open. 5. 906. 10.1136/esmoopen-2020-000906.

88 Health Survey England Additional Analyses - Health and health-related behaviours of Lesbian, Gay and Bisexual adults (2021) https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-england-additional-analyses/lesbian-gay-and-bisexual-adults

89 Jackson SS, Nambiar KZ, O'Callaghan S, Berner AM. Understanding the role of sex hormones in cancer for the transgender community. Trends Cancer. 2022 Apr;8(4):273-275. doi: 10.1016/j.trecan.2022.01.005. Epub 2022 Jan 31. PMID: 35101413; PMCID: PMC8930500.

90 National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/

91 Berner, Alison, Daniel Hughes, Hannah Tharmalingam, Tom Baker, Benjamin Heyworth, Susana Banerjee, and others, An Evaluation of Self-Perceived Knowledge, Attitudes and Behaviours of UK Oncologists about LGBTQ+ Patients with Cancer, ESMO Open, 5 (2020), 906 <https://doi.org/10.1136/esmoopen-2020-000906>

92 Study finds health professionals 'less confident' with LGBTQI+ patients, Nursing Times, Dec 2021, www.nursingtimes.net/news/research-and-innovation/study-finds-healthcare-professionals-less-confident-with-lgbtqi-patients-03-12-2021/

93 Berner, Alison, Daniel Hughes, Hannah Tharmalingam, Tom Baker, Benjamin Heyworth, Susana Banerjee, and others, An Evaluation of Self-Perceived Knowledge, Attitudes and Behaviours of UK Oncologists about LGBTQ+ Patients with Cancer, ESMO Open, 5 (2020), 906 <https://doi.org/10.1136/esmoopen-2020-000906>

94 Ibid.

95 Berner, Alison M., Dean J. Connolly, Imogen Pinnell, Aedan Wolton, Adriana MacNaughton, Chloe Challen, and others, Attitudes of Transgender Men and Non-Binary People to Cervical Screening: A Cross-Sectional Mixed-Methods Study in the UK, British Journal of General Practice, 71.709 (2021), e614–25 https://bjgp.org/content/71/709/e614

96 Pancreatic Cancer UK, Optimising the pathway for pancreatic cancer, www.pancreaticcancer.org.uk/wp-content/uploads/2020/09/scoping-the-optimal-pathway-for-pancreatic-cancer.pdf

97 Jayson et al, Improved survival from ovarian cancer in patients treated in phase III trial active cancer centres in the UK, Clinical Oncology, 2016

98 www.gov.uk/government/publications/geographic-patterns-of-cancer-survival-in-england-adults-diagnosed-2013-to-2017-and-followed-up-to-2018/geographical-patterns-of-cancer-survival-in-england-adults-diagnosed-2013-to-2017-and-followed-up-to-2018

99 www.ncin.org.uk/view?rid=3682

100 NCRAS, Ovarian Cancer Audit Feasibility Pilot Disease Profile in England: Incidence, mortality, stage and survival for ovary, fallopian tube and primary peritoneal carcinomas, 2020 www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/ovarian_cancer_audit_feasibility_pilot_outputs

101 Ibid.

102 Ibid.

103 Jayson et al., Improved Survival from Ovarian Cancer in Patients Treated in Phase III Trial Active Cancer Centres in the UK, Clinical Oncology Volume 28, Issue 12, P760-765, 2016, https://doi.org/10.1016/j.clon.2016.06.011

104 National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/

105 Winter et al, Open Conversations: Neuroendocrine Cancer & Mental Health Report - awaiting publication

106 N Sathianathen et al, Disparities in Bladder Cancer Treatment and Survival Amongst Elderly Patients with a Pre-existing Mental Illness, European Urology Focus, Volume 6,

Issue 6, P1180-1187, November 15, 2020 www.eu-focus.europeanurology.com/article/S2405-4569(19)30027-6/fulltext

107 National Cancer Patient Experience Survey 2021, www.ncpes.co.uk/2021-national-results/

108 https://fingertips.phe.org.uk/documents/Health_inequalities_cervical_cancer.pdf

109 NHS Digital, Health and Care of People with Learning Disabilities: Experimental Statistics: 2017 to 2018, 2019

110 NHS England, www.england.nhs.uk/about/equality/equality-hub/core20plus5/

111 For example, the 2021-22 Cancer Experience of Care Improvement Collaborative focused on improving the understanding of test results for people from ethnically diverse communities.

112 Health and Social Care Committee, Expert Panel: evaluation of the Government's commitments in the area of cancer services in England, 2022, https://publications.parliament.uk/pa/cm5802/cmselect/cmhealth/1025/report.html#heading-2

113 www.cancerdata.nhs.uk/stage_at_diagnosis

114 Ibid.

115 Office for National Statistics, Cancer registration statistics, England: 2017, 2019, www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2017#main-points

116 Office for National Statistics, Cancer survival in England - adults diagnosed, 2019, www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancersurvivalratescancersurvivalinenglandadultsdiagnosed

117 For rare and less common cancers, the following tumour groups exist: Children, teenage and young adult; CNS cancers; Sarcoma; Gynaecological; Haematological;Head and neck cancers; Skin cancers; Urological cancers www.ncin.org.uk/cancer_type_and_topic_specific_work/

118 For example, Working Paper on variation in delivery of radiotherapy for patients with Lymphoma www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/haematological_cancers/

119 For example, NCIN, Excess cancer burden in men, 2013 www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/equality,

Acknowledgements

Cancer52 would like to thank the Cancer52 Inequalities working group for their support and input into this report.

Rincy George, Blood Cancer UK
Marc Auckland, CLL Support Association
Julie Harrington, Guts UK
Vince Wolverson, It’s on the ball
Emma Fleming, Jo’s Trust
Rebecca Shoosmith, Jo’s Trust
Tamara Kahn, Oracle Cancer Trust
Victoria Clare, Ovacome
Georgia Papacleovoulou, Pancreatic Cancer UK
Julie Worrall, Penny Brohn UK
Emma Kinloch, Salivary Gland Cancer UK
Alan Miller, Team Margot
Yaser Martini, Team Margot
Helen Ross, Teenage Cancer Trust
Jemima Reynolds, Trekstock
Sonia Malik, Young Lives vs Cancer
Gemma McKnight, Oracle Cancer Trust

Also thanks to **Stewart O’Callaghan**, Live Through This, and the CPES Insight and Feedback Teams who provided valuable advice and comments.

Finally, thanks to all the Cancer52 member charities who provided case studies for the report and contributed to the data collection survey.

cancer52

cancer52

the common voice
for rare & less common cancers

www.cancer52.org.uk
info@cancer52.org.uk

🐦 Cancer52

Tel. 0203 355 1989

c/o 54 Dulwich Village
London SE21 7AJ

Charity number: 1174569