



**EQUALITY IMPACT ASSESSMENT**

**ACHIEVING WORLD-CLASS CANCER OUTCOMES**

**A STRATEGY FOR ENGLAND 2015-2020**

**July 2015**

## 1. Inequalities and the NHS Cancer Strategy: 2015-2020

### Statement of duties

1. The independent Cancer Taskforce recognises that this Equality Impact Assessment is an essential part of identifying and assessing relevant evidence on the proposed new initiatives to improve cancer services, helping the NHS meet its duties in relation to equality legislation and regulations.
2. The Equality Act 2010 provides a framework of protection against direct and indirect discrimination, harassment and victimisation, in the workplace and in wider society. It covers everyone in Great Britain and includes: disability; gender; gender reassignment; marriage/civil partnership; pregnancy and maternity; race; religion or belief; sexual orientation and age.
3. The Public Sector Equality Duty came into force on 5 April 2011 and includes:  
**A general duty** - to eliminate discrimination, harassment and victimisation; advance equality of opportunity; and foster good relations  
**Specific duties** – these require public bodies to publish relevant, proportionate information showing compliance with the equality duty, and to set equality objectives
4. The Health and Social Care Act 2012 introduced the first specific legal duties on health inequalities, including duties on the Secretary of State. All staff undertaking NHS and public health functions on behalf of the Secretary of State are responsible for ensuring compliance with these duties. A breach of these requirements could result in a judicial review.
5. One of the key aims the report proposes for the new NHS Cancer Strategy is to reduce inequalities in cancer services and outcomes. The purpose of assessing the policies in the Independent Cancer Taskforce report for the differing impact they have on different groups is that where any differences are found these can be mitigated and in rare cases justified on the grounds of the greater good. In addition by conducting an equality impact assessment potential policies are improved in relation to inequalities before they become Government policy.
6. This equality impact assessment has been developed concurrently with the NHS Cancer Strategy. Hundreds of different stakeholders from a wide range of backgrounds, specialities and organisations have been involved in contributing to the development of the NHS Cancer Strategy. A number of workshops were held with particular audiences. These included: primary care; charities; clinicians; industry; patients; researchers; early career clinicians and nurses.

7. A series of dedicated meetings were held on the following topics: prevention; diagnostic pathway; screening; commissioners/service delivery; data; incentives/levers/inspection; living with and beyond cancer; older people; and children and young people. In addition, there were 226 submissions to a call for written evidence.
8. Across all of this stakeholder engagement, reducing inequalities and promoting equality were seen as a key over-arching theme, along with variation between services, workforce and data.
9. This equality impact assessment builds on the comprehensive assessments of both the Cancer Reform Strategy (2007) and Improving Outcomes: A Strategy for Cancer (2011), It attempts to provide a baseline for the evidence and assess how the specific initiatives in the report affect the promotion of equality and the elimination of discrimination in each of the equality groups.

## **2. Cancer inequalities baseline assessment**

- 2.1 Each summer NCIN publishes the report *Cancer and Equality groups: Key metrics*, which sets out a collection of cancer equality metrics covering: incidence; mortality; survival; ethnicity coding; screening; routes to diagnosis; patient experience; treatment; stage; and Patient Reported Outcome Measures (PROMs).
- 2.2 The metrics, developed by the National Cancer Equality Initiative, are available for as many equality groups as the data currently allow. Every piece of national analysis on cancer that is undertaken within PHE through the NCIN and its site specific clinical reference groups considers all equality groups when assessing which breakdowns of results can be produced.
- 2.3 Age, sex and deprivation are the most commonly reported equality metrics as they are routinely collected as part of the cancer registration process. Completeness of ethnicity information has been improving over recent years, and ethnic groups are now included more widely in analyses. Information on sexuality and long term conditions are only able to be examined as part of the cancer patient experience survey, and NCIN has said that the description of cancer metrics for these groups will need to be considered in future.
- 2.4 Data included in the NCIN key metrics reports are taken from a variety of different sources, including analysis produced within the NCIN, PHE Knowledge and Intelligence Teams, Cancer Research UK, Macmillan Cancer Support, and the Office for National Statistics, with data from the Health and Social Care Information Centre, NHS Cancer Screening Programme, and the Cancer Patient Experience Survey. NCIN has said that the value of bringing these data together presents an overall view of data on cancer and equalities. Some of the data highlight where there are differences between equality groups, whilst others show that differences do not exist.

2.5 NCIN's 2015 key metrics report <sup>1</sup> was published in June 2015, and to avoid duplication will be used as the baseline on which to assess the initiatives outlined in the new NHS Cancer Strategy. The 2015 report is the first to include cancer prevalence, chemotherapy, radiotherapy and information from the colorectal, cervical, womb and ovarian cancer-specific patient reported outcome measures. NCIN has commented that these are significant steps in understanding the full picture for cancer patients by different equality groups. The report is summarised below.

### **Incidence**

2.6 For the majority of common cancer types, males have higher incidence rates than females. With certain causes of cancer being higher in males, such as smoking and exposure to asbestos, it is to be expected that lung, bladder and other smoking related cancers are higher in males. However, higher rates for males are also seen for many other cancer types.

2.7 A joint NCIN/Cancer Research UK (CRUK) report from 2014<sup>2</sup> showed that inequalities in relation to socioeconomic deprivation are of major concern. Some risk factors, such as smoking, are strongly influenced by socioeconomic determinants. The report showed that incidence rates of some cancers (oral cavity in males, larynx, liver in males and lung cancer) in the most deprived group were at least double those of the least deprived group.

2.8 Black people have higher rates of myeloma and stomach cancer, and black males have higher rates of prostate cancer. Incidence rates of liver cancer are highest amongst Asian people compared with white people. Rates of mouth cancer are higher in females and rates of cervical cancer are higher in the over 65s.

### **Mortality**

2.9 For the majority of common cancer types, males have higher cancer mortality rates than females. Mortality rates for bladder and oesophageal cancers were more than two and a half times higher for males than females.

2.10 The joint NCIN/CRUK report showed that mortality rates for many cancers (eg oral cancer, stomach, anus, lung, cervix and penis) were at least double in the most deprived group compared to the least deprived group. Only malignant melanoma showed higher mortality rates for the least deprived compared to the most deprived group.

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<sup>1</sup> *National Cancer Intelligence Network: Cancer and equality groups: key metrics – 2015 report*, Public Health England

<sup>2</sup> *National Cancer Intelligence Network: Cancer by deprivation in England, Incidence, 1996 – 2010; Mortality, 1997 – 2011*, Public Health England

- 2.11 Currently national data on cancer mortality by ethnic group are not available. Given the improved completeness of ethnicity coding for cancer, NCIN will look at the feasibility of including cancer mortality by ethnic group in the future.

### **One-year survival**

- 2.12 Survival is higher for females than males with lung cancer and malignant melanoma, while male colorectal cancer patients have better survival than females.
- 2.13 Patients resident in more deprived areas have worse survival for colorectal, lung and ovarian cancer, with small differences between the deprivation groups for breast and prostate cancer.
- 2.14 As we do not have complete ethnicity coding for cancer registrations, it is difficult to draw any conclusions from survival estimates by ethnic group.

### **Prevalence**

- 2.15 At the end of 2010 there were over 1.8 million people alive who had been diagnosed with cancer in the previous 20 years. Over a million of these were females. There were just under 600,000 people aged 75 or over, and around 240,000 aged under 50 who had a diagnosis of cancer in the previous 20 years.
- 2.16 As many cancers are more commonly diagnosed in more deprived areas, the lower numbers of one-year survivors in the more deprived groups partially reflect the worse survival for these patients.
- 2.17 As ethnicity has historically been poorly recorded for cancer registrations, it is not possible to assign an ethnic group to all patients, particularly those diagnosed in an earlier period.

### **Ethnicity coding compliance**

- 2.18 Ethnicity recording has been improving. For newly diagnosed cancers in 2002 to 2006, 76% had an ethnicity derived from Hospital Episode Statistics (HES). The proportion of registrations in 2008 to 2010 with an assigned ethnicity is now 95%.

### **Cancer screening**

- 2.19 In cervical screening, coverage is lowest in the youngest age group (25-29) and highest in the 50-54 age group.
- 2.20 In breast screening, coverage generally increases with age until women aged 60 to 70, and is lower in 70-74 year olds. Much of this will be due to the changing age range of women routinely invited for screening appointments.

- 2.21 In bowel screening, for men and women aged 60-69 uptake is slightly higher amongst women than men. There is little difference in uptake between men and women aged 70-74.
- 2.22 As deprivation is measured based on post code of residence, it is not routinely reported. Calculating uptake by ethnicity is more difficult as knowing the ethnicity of people invited for screening who do not attend relies on ethnicity information recoded by GPs which is not routinely linked to screening data.

### **Routes to diagnosis**

- 2.23 Very low proportions of breast and prostate cancer are diagnosed through an emergency route in patients aged under 80 years, with the proportion increasing with age, being highest in the 85 and older group. Lung cancer patients have the highest proportions of emergency presentations (38% overall), increasing with age with 57% of patients aged 85 or older diagnosed through this route.
- 2.24 Males have a higher proportion of emergency presentations for melanoma, non-Hodgkin lymphoma and thyroid cancer. Females had a higher proportion for chronic lymphocytic leukaemia, oesophagus, stomach, bladder and brain cancer.
- 2.25 For many cancer types, differences were observed by deprivation with a higher proportion of emergency presentations in the most deprived group. A clear gradient is observed for female breast, colorectal, lung and prostate cancer.
- 2.26 Further work is required to fully understand the differences in presentation routes by ethnicity.

### **Patient experience**

- 2.27 In the Cancer Patient Experience Survey (CPES), the youngest age groups are generally the least positive about their patient experience. For example, in the 2014 survey 51% of the youngest age group said they completely understood the explanation as to what was wrong with them compared to 75% of the oldest age group.
- 2.28 Differences in the views of patients related to their gender tend to be of a smaller scale than for some of the other demographic factors.
- 2.29 Of the 37 questions in the 2014 survey with a statistically significant difference in responses between the least and most deprived groups, patients living in less deprived areas reported a better experience in 25 questions. This included reporting health getting worse whilst waiting to see a hospital doctor and receiving written information about tests.
- 2.30 In 2014, there were 21 questions where different ethnic groups had significantly different responses. White patients were least likely to agree that they had been asked to take part in research and been given a written assessment and care plan. A lower proportion

of patients from Asian groups reported that they did not feel like they were treated as a 'set of symptoms'.

- 2.31 There were 24 questions where there was a difference in the response by sexual orientation. For all of those, the heterosexual group reported a more positive experience. LGBT groups were less likely to report being given enough privacy when discussing their condition or treatment, not feeling treated like set of symptoms and being able to discuss their worries or fears with staff.

### **Treatment**

- 2.32 For all cancer types assessed, older patients were less likely to have had surgery, and this decline often started from the youngest age group.
- 2.33 The number of patients undergoing chemotherapy for bowel cancer increases with age until a peak in the 65-69 age group. While cases then decline slightly, the number of patients receiving chemotherapy rapidly drops to much lower numbers in the 85 years and older age group.
- 2.34 There is an early peak in the proportion of patients having radiotherapy in the five to nine age group, reflecting childhood cancer treatment. After decreasing in teenagers and young adults, the proportion increases again, reaching a peak in patients aged 50 to 69 and decreases for older patients.

### **Patient reported outcome measures (PROMs)**

- 2.35 Patients aged 65 to 74 had the highest proportion in 'perfect health' (40%) with the lowest proportion in patients aged 85 and over (21%). The proportion of patients in 'perfect health' decreased with increasing deprivation, from 39% in the least deprived group to 28% in the most deprived group. Males (37%) were more likely to report being in 'perfect health' than females (32%).

## **3. Assessment of the NHS Cancer Strategy: 2015-2020 impact on equality**

- 3.1 The Independent Cancer Taskforce report contains a significant number of proposed actions to promote equality and reduce inequalities.
- 3.2 It would not be practicable to undertake an equality impact assessment on all the many actions outlined in the new strategy. For the purposes of this document, we have concentrated on what the Taskforce has said are its highest priorities over the next five years. These are listed below, with an equality impact assessment (EqIA) against each where appropriate:

***Spearhead a radical upgrade in prevention and public health: The NHS should work with Government to drive improvements in public health, including a new tobacco control strategy within***

*the next 12 months, and a national action plan on obesity. We should aim to reduce adult smoking prevalence to less than 13% by 2020 and less than 5% by 2035*

EqlA:

- One in five adults (20 per cent) in Great Britain aged 16 and over reported smoking in 2012, compared to just over one in four (26 per cent) a decade earlier in 2002<sup>3</sup>. Unemployed people (39 per cent) (not working but seeking work) were around twice as likely to smoke as those either in employment (21 per cent) or economically inactive (17 per cent) (for example, students or retired people)
- Amongst 11 to 15 year olds in 2013, less than a quarter of pupils reported that they had tried smoking at least once. At 22 per cent, this is the lowest level recorded since the data were first collected in 1982, and continues the decline since 2003, when 42 per cent of pupils had tried smoking
- In 2013, 17 per cent (79,700) of all deaths of adults aged 35 and over were estimated to be caused by smoking. This proportion is unchanged from 2005
- Any new tobacco control strategy will have its own EqlA, but it will be important for the report to attempt to reduce smoking rates in more disadvantaged groups

***Drive a national ambition to achieve earlier diagnosis:*** *This will require a shift towards faster and less restrictive investigative testing, quickly responding to patients who present with symptoms, by ruling out cancer or other serious disease. We recommend setting an ambition that by 2020, 95% of patients referred for testing by a GP are definitively diagnosed with cancer, or cancer is excluded, and the result communicated to the patient, within four weeks. Delivering this will require a significant increase in diagnostic capacity, giving GPs direct access to key investigative tests, and the testing of new models which could reduce the burden and expectation on GPs*

EqlA:

- NICE published its final referral guidance on suspected cancer on 23<sup>rd</sup> June 2015<sup>4</sup>. The guidance updates and replaces guidance originally published by NICE in 2005. The guideline will help GPs make decisions about when to refer people to specialists when they present with symptoms that could be caused by cancer. But of course there has always been a challenge in GP access for some disadvantaged groups
- That is why the new strategy recommends that the *Be Clear on Cancer* campaigns should continue, aiming to raise awareness of the symptoms of cancer and to encourage people with relevant symptoms to visit their GP. The target audience of the campaigns is largely more disadvantaged (C2DE) and older age groups (over 50). Since they began in 2010, a number of papers have been published in the literature on the impact of the campaigns on equality and health inequalities:
  - A study by Moffat et al on the impact of the campaigns for bowel and lung cancer symptoms on sociodemographic inequalities in symptom awareness and GP attendance found that the campaigns reached their target audience, but also

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<sup>3</sup> Statistics on Smoking, HSCIC, England 2014

<http://www.hscic.gov.uk/catalogue/PUB14988/smok-eng-2014-rep.pdf>

<sup>4</sup> Referral guidelines for suspected cancer, NICE, June 2015

<https://www.nice.org.uk/guidance/cg27>

- influenced younger and more affluent groups. There would seem to be no undue concern regarding widening inequalities<sup>5</sup>
- A study by Power et al on the change in public awareness of symptoms and barriers to seeing a doctor found that, although awareness increased, barriers to visiting a GP were not reduced<sup>6</sup>
  - A paper by Whitaker et al on applying symptom appraisal models to understand sociodemographic differences in responses to possible cancer symptoms concluded that a better understanding of the processes through which people interpret their symptoms, and the way these processes differ by sociodemographic factors, could help guide the development of interventions with the aim of reducing inequalities in cancer outcomes<sup>7</sup>
  - A study by Rutherford et al on estimating the potential survival gains by eliminating socioeconomic and sex inequalities in stage at diagnosis of melanoma found that reducing socioeconomic and sex inequalities in stage at diagnosis would result in substantial reductions in deaths within five years of a melanoma diagnosis<sup>8</sup>
- In addition, the campaigns use everyday language to help people feel more comfortable when discussing symptoms with their GP, but we know there are various barriers preventing people within some of the protected characteristics from presenting early to their GPs. With each campaign, a range of activity takes place to promote early diagnosis by encouraging people with symptoms to present to their GP without delay. PHE works with a range of partners including disability support groups; and a specialist multicultural marketing consultancy to develop activity aimed at BME groups including public relations activity and targeted TV, radio and press advertising in key national and regional black and South Asian media.
  - For most national campaigns, easy read versions of leaflets have been developed, along with versions in Braille, audio, and large print for the visually impaired
  - As part of the BME public relations activity healthcare professionals and, where possible, cancer survivors from ethnic minorities, are recruited to participate in media interviews to address the cultural, religious and language barriers preventing early presentation to GPs. These discussions take place in ethnic languages where appropriate
  - As cancer is most common in older people, the campaigns have very clear target audiences - primarily aimed at those over 50 and positive results have been seen in older populations for lung, “blood in pee” (bladder and kidney cancers) and the oesophago-gastric (oesophageal and stomach cancers) campaigns

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<sup>5</sup> Moffat et al, *The impact of national cancer awareness campaigns for bowel and lung cancer symptoms on sociodemographic inequalities in immediate key symptom awareness and GP attendances*, Br J Cancer. 2015 Mar 31;112 Suppl 1:S14-21

<http://www.ncbi.nlm.nih.gov/pubmed/25734383>

<sup>6</sup> Power et al, *Change in public awareness of symptoms and perceived barriers to seeing a doctor following Be Clear on Cancer campaigns in England*, Br J Cancer. 2015 Mar 31;112 Suppl 1:S22-6

<http://www.ncbi.nlm.nih.gov/pubmed/25734386>

<sup>7</sup> Whitaker et al, *Applying symptom appraisal models to understand sociodemographic differences in responses to possible cancer symptoms: a research agenda*, Br J Cancer. 2015 Mar 31; 112 Suppl 1: S27-S34

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4385973/>

<sup>8</sup> Rutherford et al, *Estimating the potential survival gains by eliminating socioeconomic and sex inequalities in stage at diagnosis of melanoma*, Br J Cancer. 2015 Mar 31;112 Suppl 1:S116-23

<http://www.ncbi.nlm.nih.gov/pubmed/25734390>

- A national breast cancer campaign in February to March 2014 targeted women over 70 because the disease is often diagnosed at a later stage in this age group. Research shows that older women have low knowledge of non-lump breast cancer symptoms, are unaware that they are more likely to develop breast cancer or dismissive of symptoms as a sign of ageing and are more likely to delay presenting to their GP with breast cancer. A national reminder campaign will run this year from 13 July to 6 September.
- A prostate cancer pilot campaign in October-November 2014 in six London boroughs targeted black men over 45, as research showed that majority (90%) of black men were not aware of their increased risk. 1 in 4 black men in the UK will be diagnosed with prostate cancer at some point in their lives compared to 1 in 8 white men. Qualitative evaluation showed that there was good recall of the different elements of the campaign outreach and community engagement work. Further evaluation is awaited

***Establish patient experience as being on a par with clinical effectiveness and safety:*** We have the opportunity to revolutionise the way we communicate with and the information we provide to cancer patients, using digital technologies. We recommend giving all consenting patients online access to all test results and other communications involving secondary or tertiary care providers by 2020. We should also systematise patients having access to a Clinical Nurse Specialist (CNS) or other key worker to help coordinate their care. We should continue to drive improvement through meaningful patient experience metrics, including the annual Cancer Patient Experience Survey;

EqIA:

- Whilst this recommendation will benefit most groups in society, as it is developed the NHS needs to take account of those people and communities for which English is not the first language, along with people with learning difficulties who may need a carer to interpret the information. Much of this information may be very scientific and medical, so it will be important to use as plain language as possible
- It also needs to be noted that not all groups in society are yet on the internet

***Transform our approach to support people living with and beyond cancer:*** We recommend accelerating the roll-out of stratified follow up pathways and the “Recovery Package”. The aim should be that by 2020 every person with cancer will have access to elements of the Recovery Package, and stratified pathways of follow-up care will be in place for the common cancers. A national quality of life measure should be developed by 2017 to ensure that we monitor and learn lessons to support people better in living well after treatment has ended. We also recommend that CCGs should commission appropriate End of Life care, in accordance with the NICE quality standard, and taking into account the independent Choice Review and forthcoming Ambitions

EqIA:

- As NICE says, local authorities are uniquely placed to tackle health inequalities, as many of the social and economic determinants of health, and the services or activities which can make a difference, fall within their remit. The challenge is to reduce the difference in mortality and morbidity rates between rich and poor and to increase the quality of life and sense of wellbeing of the whole local community

- This should benefit all groups in society and reduce geographical variation. As part of the consultation and engagement surrounding the development of the Choice Review, specific engagement work was undertaken with BME groups – NHS England commissioned interviews with 20 black or minority ethnic families and with organisations not directly related to End of Life Care, asking for comments on the care principles and what the impact might be on different groups. The Deputy Director for Equalities at NHS England was involved with this work. The responses were summarised, setting out how this work had regard to people from population groups sharing the protected characteristics defined in the Equalities Act and others affected by health equalities
- Developers of the review sought advice from expert advisory groups (Clinical advisory group and Guidance education and training advisory group) in developing the proposals and their deliberations have included regard to equality issues.
- Developers of the review sought and received input from Alliance members and the organisations they represent on matters relating to equality. This has included advice on equality issues, such as respecting cultural and religious needs
- As a result of this work, the five priorities for care which are the central plank of the Alliance’s approach to care in the last few hours and days of life have been formulated and worded with specific regard to equality issues. One example of this regard is the wording “the dying person and those identified as important to them”, which is carried through to all the documents to be published and has been selected as the most inclusive phrase – specifically it does not exclude non family members, such as carers or friends that the dying person has said should be involved.

***Make the necessary investments required to deliver a modern high-quality service, including:***

- *Implementing a rolling plan to replace linear accelerators (linacs) as they reach 10-year life and to upgrade existing linacs when they reach 5-6 years;*
- *Working to define and implement a sustainable solution for access to new cancer treatments, building from the Cancer Drugs Fund;*
- *Rolling out a molecular diagnostics service which is nationally-commissioned and regionally delivered, enabling more personalised prevention, screening and treatment;*
- *Implementing plans to address critical workforce deficits and undertaking a strategic review of future workforce needs and skills mix for cancer. The priority deficit areas to address should be radiology, radiography and endoscopy for diagnosis; and clinical oncology, medical oncology and clinical nurse specialists for treatment and care;*
- *Supporting a broad portfolio of cancer research.*

**EqIA:**

- Replacing old radiotherapy equipment will benefit all groups in society. It will need to be monitored to ensure machines are replaced in all parts of the country. The NHS also needs to be aware of the concerns over the under-treatment of older people as equipment is replaced
- The NHS also needs to be aware of the concerns over the under-treatment of older people as a replacement for the CDF is developed.

- The development of molecular diagnostics will benefit all groups in society. However, the NHS needs to be aware of the concerns over the under-treatment of older people as this important work develops.

***Overhaul processes for commissioning, accountability and provision.*** We recommend setting clearer expectations, by the end of 2015, for how cancer services should be commissioned. For example, most treatment would be commissioned at population sizes above CCG level. By 2016, we should establish Cancer Alliances across the country, bringing together key partners at a sub-regional level, including commissioners, providers and patients. These Alliances should drive and support improvement and integrate care pathways, using a dashboard of key metrics to understand variation and support service redesign. We should also pilot new models of care and commissioning. For example, the entire cancer pathway in at least one area should have a full devolved budget over multiple years, based on achieving a pre-specified set of outcomes.

EqIA:

- This is largely managerial, but is likely to reduce geographical variation and hopefully benefit all groups in society.
- Increases in appropriate workforce groups will benefit all groups in society. Deployment of the newly trained staff will need to be monitored so hospitals in all parts of the country benefit.

#### **4. Conclusion**

4.1 This Equality Impact Assessment has shown that the independent Cancer Taskforce has embedded equality and inequalities throughout the new strategy document. Few of the new initiatives have the potential to increase equalities between different groups, and where they do, such as the reliance on GPs on earlier diagnosis, we have tried to set out how best the seven ALBs can work to resolve such potential inequalities.

4.2 The Cancer Taskforce states that if we are successful in implementing the initiatives set out in this strategy, their expectation is that we will: improve survival rates for all groups; close the gap in survival rates between England and the best countries in Europe and elsewhere; better integrate health and social care such that all aspects of patients' care are addressed, particularly at key transition points; and reduce the variability of access to optimal diagnosis and treatment and the resulting inequalities in outcomes.

4.3 Ultimately it will be for the seven ALBs to ensure that, as we strive to improve survival rates for cancer, we do so for all groups in society by advancing equality and striving to tackle inequalities where they exist.