

# Getting a better deal for people with rare and less common cancers: the next ten years

# Foreword

**Cancer52 was established just over ten years ago when 52% of deaths from cancer were from rare and less common cancers; in other words all those that lay outside the four 'common' cancers of breast, bowel, lung and prostate. The then National Cancer Director, Professor Sir Mike Richards, recognised that there were specific challenges for patients with these cancers and asked a group of charities to work together to ensure that the voice of these patients was heard.**

Ten years on and the purpose remains constant, though the numbers have shifted - deaths from rare and less common cancers account for nearer 55% of all cancer deaths, and, from a handful of founding charities, Cancer52 has grown to a membership of nearly 100 charities.<sup>1</sup> The broad scenario for people with rare and less common cancers has not improved.

Now we are presented with a once in a lifetime opportunity to change that. We are being asked what will improve outcomes for the 140,000 people diagnosed with a rare and less common cancer in England each year?<sup>2</sup>

To ensure our voice was as informed as possible in answering that question, we consulted over the summer of 2018 with a very wide spectrum of charities, patients and stakeholders engaged in the field of rare and less common cancers. 55 charities, 671 patients and 14 key stakeholders responded to our requests for workshops, survey completion, and one-on-one interviews.

We now know that much of what is needed for rare and less common cancers is the same as for all cancers: identify what is working or has potential and invest further in those programmes, particularly where it leads to speedier diagnosis, better patient care and easier and earlier access to treatment.

Where the demand for rare and less common cancers is different is in how we must shift the focus and priorities for these cancers.

Long the poor relation, these cancers must now be prioritised at a national and local level through ring fenced funding, dedicated leadership and investment in coordination. Can we start with the rare and less common cancers, rather than leaving them till afterwards? And the targets which exist or are developed for all cancers must mean just that - 'all' cancers. Data must be as available for rare and less common cancers as it is for other cancers; otherwise there's no benchmark and no means of measuring improvement.

We've included in this briefing our submission to NHS England, feedback on our engagement and further details of our priorities.

***We want to see these priorities in the new cancer plan.***

Finally my thanks to the fantastic rare and less common cancer community who got behind us in feeding into our response, and who participate so freely and fully in our day to day work. It's that ongoing commitment to a shared cause that enables Cancer52 to deliver the voice of rare and less common cancers.

**Jane Lyons**

CEO

Cancer52

October 2018



# Contents

1. Introduction .....	4
2. What we learned during our consultation .....	5
3. What needs to be done .....	8
4. Why do rare and less common cancers deserve particular attention? .....	10
5. Maintaining focus until 2023 .....	12
6. Longer-term action to 2028 .....	16
7. What next? .....	17
Appendices .....	18
Acknowledgements .....	19
References .....	19

# 1. Introduction

**Cancer52 provides one voice for rare and less common cancers, and represents nearly 100 predominantly small patient support group cancer charities united by their vision of seeing a better future for everyone affected by these cancers. Cancer52 was originally founded by Professor Sir Mike Richards CBE in 2006 to provide a collaborative voice for rare and less common cancers and inform the development of the Cancer Reform Strategy published in 2007. The organisation was so named because at the time, 52% of cancer deaths were from rare and less common cancers.**

This briefing explains the wide-ranging consultation we undertook during the spring and summer of 2018. This was the first time Cancer52, supported by its members, had undertaken an engagement on this scale. We used the findings to inform our recommendations for the NHS Long Term Plan.

## How we developed this briefing

Cancer52 undertook a wide-ranging consultation during the spring and summer of 2018 to develop our recommendations for the NHS Long Term Plan.

***The consultation consisted of the following activities:***

### Patient survey

Over 670 patients with a rare or less common cancer, or a friend or family member on their behalf, responded to an online survey created by Cancer52. Patients were asked three open questions, with no word limit, about the positive aspects of their cancer experience, the negative aspects and their suggestions for improvements. Patients were recruited to this survey via Cancer52 member charities.

### Member Survey

Cancer52 also surveyed its member charities via an online questionnaire. The survey asked for their views on progress of the 2015 Cancer Strategy, *Achieving world class outcomes for cancer: A strategy for England 2015–2020*, their priorities for each stage of the cancer pathway, suggestions for issues that should be addressed, and potential solutions. Some 33 charities responded to the survey.

### Workshops

Cancer52 ran two consultative workshops with its members to garner views on priorities for any future cancer strategies and consider solutions. A further 25 member charities took part in these sessions.

### Stakeholder interviews

In depth face-to-face or telephone interviews were held with 14 key senior stakeholders from across the cancer community. A list of interviewees is given in the appendices. Stakeholders were questioned about the issues that people with rare and less common cancers face and potential solutions.

## 2. What we learned during our consultation

Rare and less common cancers made up 47% of cancers diagnosed in England in 2016.<sup>3</sup> They are defined as all cancers outside the four most common (breast, lung, prostate and bowel). Rare cancers have an incidence of less than 6 per 100,000 population and include cancers such as bone, liver, gallbladder and eye. Less common cancers have an incidence greater than 6 per 100,000 but do not include the four most common. Less common cancers include uterus, melanoma, pancreatic, ovarian and Non-Hodgkin lymphoma. There are hundreds of rare and less common cancers.

Although 47% of cancer diagnoses in England were for rare or less common cancers in 2016, 55% of the deaths from cancer in 2016 were from rare or less common cancers (a percentage increase of 3% since 2006).<sup>4, 5</sup>

Given this gap between incidence and mortality, it is unsurprising that people with a rare or less common cancer face difficulties in diagnosis, treatment and care. This in part can be attributed to the smaller numbers of people with these cancers, which means there is less awareness in the health system and among the wider public, there are fewer health professionals with knowledge and expertise, and fewer other patients who can provide mutual support or information. Third sector organisations, which may provide support and information to people with rare and less common cancers, are often smaller charities with fewer funds and resources. The nature of treatment and care itself can be more complex with the need to travel further for treatment or be treated over several sites. This all combines to create a perfect storm and means when the health system works less efficiently these patients feel the consequences more acutely.

*Some of the difficulties people with rare and less common cancers face include:*

### Getting a speedy and early diagnosis

Lack of awareness of the rare and less common cancers, coupled sometimes with vague symptoms, means patients do not recognise they have cancer and present late. It can also mean that GPs or other health professionals fail to recognise the symptoms may be cancer and do not refer to secondary care. For those patients with cancer where symptoms are less well-known, or they relate to organs which cannot be easily palpated or inspected, they report visiting their GP three or more times before hospital referral.<sup>6</sup> Our survey of patients confirmed this, with patients relating tales of frequent visits to the GP and long delays before they were diagnosed.<sup>7</sup> One patient had been told by their GP that their symptoms were 'in their head'. Another had been accused by their GP of wanting time off work. One patient had seen their GP 52 times in the 11 months before their diagnosis.

## Accessing clinical trials and sufficient research to inform treatment options

For some rare and less common cancers there are few, poor or no treatment options and as a consequence, poor outcomes and survival rates. For example, surgery is the only potential curative treatment for cholangiocarcinoma, a rare cancer of the bile duct, and often the cancer is too advanced for surgery.<sup>8</sup> Pharmaceutical companies may be disincentivised from developing medicines for rare or less common cancers because small population sizes mean a lower return on investment. Recruiting patients for clinical trials for rare and less common cancers is harder because of smaller population sizes so trials require multi-centre site or international trials which are more expensive and complicated. Our members said that this means people with rare and less common cancers find it hard to access clinical trials because there are fewer available.

## Accessing specialist treatment

It is now widely accepted that treatment is more successful and outcomes improved if treatment is overseen by a specialist with the expertise and experience for that condition. However, patients reported that their care was not always overseen by a specialist and some had had to 'fight' for a referral.<sup>9</sup>

Some patients told us that because their cancer was rare, certain health professionals did not have the knowledge or experience needed to treat or care for them. For some this had led to poor decision making about their care and treatment, and for a few there had been errors.

Patients did not have trust in these professionals, one describing the team at their local hospital as being 'out of their depth'.<sup>10</sup> Some of the key stakeholders we interviewed also expressed concern that not everyone's treatment is currently overseen by a specialist or specialist centre.

## Getting support for living with and beyond cancer

The Cancer Patient Experience Survey (CPES) shows that people with rare or less common cancers can find it difficult to access support and information; for example, they are less likely to be given easy to understand written information about the type of cancer they have and less likely to be given enough support from health and social services.<sup>11</sup> This is supported by our own patient survey and by what patient groups told us. The knock-on effect of lower awareness and smaller populations of patients is that support services such as accurate information, support groups and psychosocial services are not widespread and therefore difficult to access. This is because there is less funding available, particularly from the third sector which is often made up of small patient groups for these cancers, and fewer healthcare professionals within these specialties. One patient responding to the patient survey described the range of holistic support available to them as a bowel cancer patient but said that this was not available to them when they were later diagnosed with a less common cancer.<sup>12</sup>

## Access to a Clinical Nurse Specialist (CNS)

Patients also reported that they either had no access to a CNS or found it difficult to get access to one. Members reported that pressures in the health system and workforce capacity issues mean there are gaps in access to a CNS for people with rare and less common cancers.<sup>13</sup> Yet, this support can be particularly vital for these patients whose pathway through the health system can often be more complex and where other health professionals have little or no understanding of their condition. Without a CNS to navigate and advocate, they can experience care which is poorly joined up and find it difficult to access other services such as benefits because the nature of their cancer and its impact is poorly understood.

## Access to data

Small patient numbers mean data on outcomes and experience are not published for some rare and less common cancers due to concerns about anonymity. This means it is difficult for patient groups and charities to understand how much progress is being made and to hold the NHS to account. It can also mean that issues experienced by people with rare and less common cancers are not seen by system leaders and therefore service improvements are not implemented.



## 3. What needs to be done

If outcomes for cancer in England are to be among the best in Europe or the world, progress in rare and less common cancers must accelerate. Cancer52 believes that progress can only be made with a concerted focus and leadership on these cancers. Cancer52 therefore has identified three key priorities.

### Priority 1: Establish a Rare and Less Common Cancer Task and Finish Group

To deliver earlier and speedier diagnosis and improve survival rates across all cancers, the NHS Long Term Plan must have a clear focus on rare and less common cancers.

Cancer52 therefore recommends that NHS England establishes a Rare and Less Common Cancer Task and Finish Group to lead and drive through service improvements in the NHS to benefit people with rare and less common cancers.

The Group should focus on issues specific to rare and less common cancers, particularly the priority areas of early diagnosis, access to specialist expertise, treatments and support, using real world data to test new drugs and new workforce models so that everyone with a rare and less common cancer has access to a CNS.

### Priority 2: Create a high level system target that incentivises the reduction of deaths from rare and less common cancers

Cancer52 recommends the development of a high-level target to incentivise the reduction of deaths from rare and less common cancers.

Targets can drive improvements, attention and mindsets in the NHS, and permit transparency and accountability. Currently, there is no target specifically for rare and less common cancers. For example, the Cancer Waiting Times targets are for 'all cancers' (though there is a waiting time target for acute leukaemia, testicular and paediatric referrals to be treated within 31 days) and data on the Cancer Dashboard is only available for 'all tumours' or the four most common cancers. Not having data or targets specifically for rare and less common cancers causes blind spots in the system, removing the possibility of benchmarking and creating difficulties in understanding what progress is being made for rare and less common cancers and where issues may lie. There is also the risk that it means services and leadership are focused elsewhere.



Within the 'all cancer' group, there is a range of experiences and outcomes, and data grouped at the 'all cancer' level can mask these differences. Outcomes for some types of cancer, particularly those with a poor prognosis, have not made as many improvements over the last 10–20 years as other cancers. A high-level target specifically for rare and less common cancers is imperative to allow NHS England, Public Health England (PHE), Cancer Alliances, Providers and patients to identify whether sufficient progress is being made.

**Priority 3: Drive access to specialist expertise, treatment and support that improves outcomes for people with rare and less common cancers by providing Cancer Alliances with a ring-fenced fund and ensuring Cancer Alliances drive change**

**Cancer Alliances will be unable to drive improvements unless they are adequately resourced to do so and we therefore strongly recommend that a proportion of Cancer Alliance funding is ring-fenced for rare and less common cancers.**

Pressures on the NHS can mean that general funding is redirected to other areas of care. We wish to see ring-fenced funding so real progress can be made in improving treatment and care for people with rare and less common cancers.

**To drive the provision of high quality treatment and support services, Cancer52 recommends one individual in each Cancer Alliance should be responsible for overseeing diagnosis, treatment and care of people with rare and less common cancer in their alliance.**

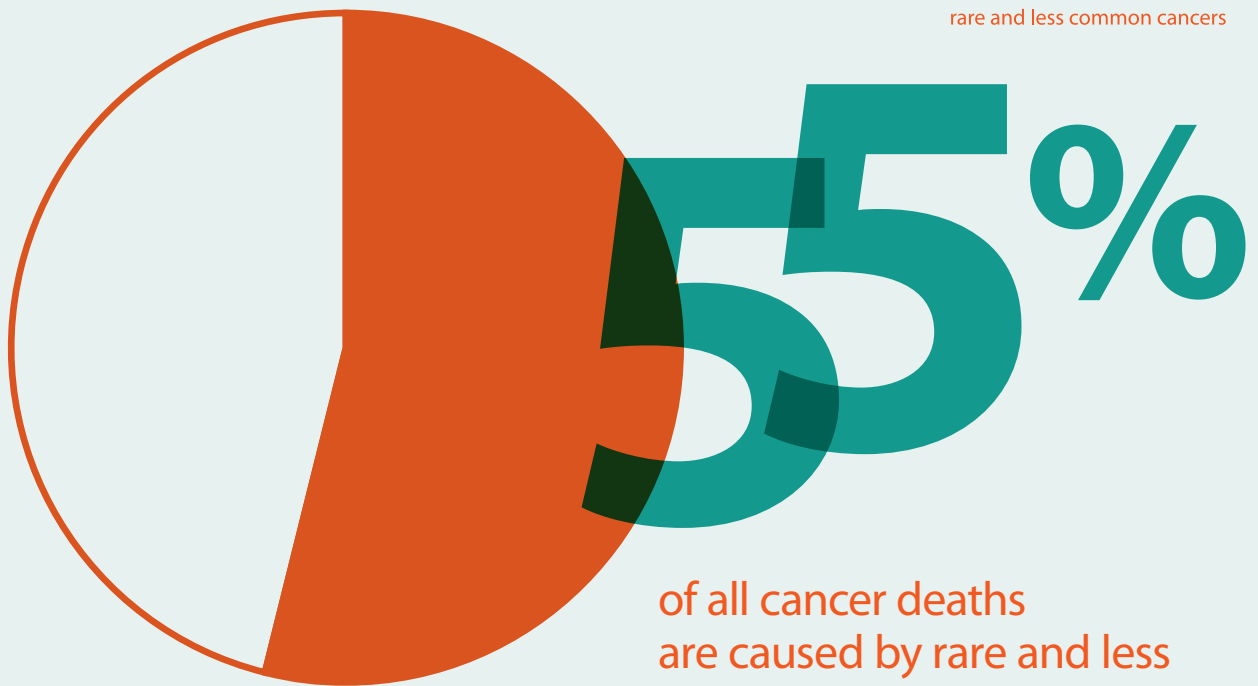
The lead Cancer Alliance individuals should form a national group, meeting frequently to share and spread best practice and drive improvements across the country, and regularly link with the national Rare and Less Common Cancer Task and Finish Group.

## 4. Why do rare and less common cancers deserve particular attention?

While previous cancer strategies and plans have taken an 'all cancer' approach, in reality, individual action and initiatives has sometimes meant that progress has been limited to individual cancers or for individual patient groups; for example, screening programmes in bowel, breast and cervix have been established and the National Cancer Equality Initiative was established to better understand inequalities in cancer for certain groups of patients. At a national and alliance level (for example, the Cancer Dashboard) progress is reported in the four most common cancers, as well as for all cancers, but not for rare and less common cancers. In addition, new innovations are often piloted in a common cancer first (for example, development of national pathways in lung and bowel cancer), meaning those with rare and less common cancers wait longer for improved treatment and care.

This approach of focusing on specific areas or cancers within an 'all cancer' strategy or plan has driven attention, action and progress in those areas and cancers. Establishing a focus on the rare and less common cancers supports established protocol and allows improvement in survival and experience in rare and less common cancers to ensure the all cancers targets are reached.

This approach would also allow the NHS to prepare for advances in the understanding of cancer. Research is leading to a greater understanding of the molecular structures and pathways that constitute different cancers, and this is leading to new developments in medicines and treatments. Many stakeholders observed that we are moving towards a world where the four common cancers will become a series of rare and less common cancers and may therefore require a new approach to treatment and care. Improving diagnosis, treatment and care for people with rare and less common cancers now will lead to improvements for all cancer patients in the future.



of all cancer deaths  
are caused by rare and less  
common cancers.

Despite this, these cancers  
remain severely under-  
represented and underfunded  
across all areas, including  
policy, services and research.

Cancer52 is an alliance of  
nearly 100 organisations  
working to address this  
inequality and improve  
outcomes for patients with  
these highly challenging  
diseases.

## 5. Maintaining focus until 2023

Cancer52 supports the general direction of travel of cancer policy, which is focused on implementing and, where there is evidence of success, accelerating the recommendations of the 2015 Cancer Taskforce report. Efforts to raise awareness, improve prevention and early diagnosis, establish Cancer Alliances, reform the Cancer Drugs Fund, review Multi Disciplinary Teams and invest in the Recovery Package as well as Health Education England taking a strategic approach to workforce, will undoubtedly benefit everyone with cancer, including those with a rare and less common cancer. The NHS Long Term Plan will set out a detailed financial plan for the NHS up until 2023. Specific areas, where more can be done for rare and less common cancers over the next five years, are outlined below.

### Prevention

There is clear evidence that risk factors for cancer include smoking, being overweight or obese, lack of exercise, alcohol intake and sun exposure. Cancer52 supports efforts by Government, PHE and NHS England to raise awareness of cancer risk factors and encourage people to make changes to their behaviour. Cancer52 recommends that there is further research into the risk factors for rare and less common cancers, including exploring genetic risk factors.

### Early diagnosis

Cancer52 welcomes the NHS drive to encourage earlier diagnosis. The 'Be Clear on Cancer' awareness programme, the cervical screening programmes and the development of Rapid Diagnostic Centres are key to improving outcomes for people with rare and less common cancers.

***To improve earlier stage and speedier diagnosis even further, Cancer52 recommends:***

- Building on PHE's 'Be clear on cancer' awareness campaigns by moving towards and investing in campaigns that focus on 'knowing your body' and 'vague symptoms', with concomitant awareness raising aimed at primary healthcare professionals.
- The development of an all cancer target focused on diagnosing more cancers at stage one or stage two.
- Continuing to pilot Rapid Diagnostic Centres, where people who may have cancer are assessed within a day and cancer is ruled in or out, and establishing them nationally if pilots prove them to be successful by 2023.
- Piloting a vague symptoms pathway, as recommended by the Cancer Taskforce report 2015, and establishing these pathways in all Cancer Alliances by 2023. Rare and less common cancers can present with vague symptoms. A clear pathway for vague symptoms, from GP to secondary care (that includes safety netting to ensure all patients have cancer ruled out, diagnosed or another condition diagnosed) is essential to stop people from repeatedly visiting GPs or being 'ping-ponged' from primary care to secondary care. The development of a vague symptoms pathway also has the potential to improve productivity and efficiency of the NHS.
- Investigating giving GPs and patients direct access to tests.
- Investing in research to improve diagnostic techniques, including liquid biopsies and genetic services, and ensuring that new diagnostic techniques are swiftly rolled out into practice.
- Piloting case finding for rare or less common cancers.
- Investigating how apps and Artificial Intelligence aimed at both the public and health professionals could be used to encourage earlier diagnosis.

## Treatment

### Care overseen by specialists

People with rare and less common cancers feel reassured when their treatment and care is overseen by a specialist and evidence shows that outcomes are better when cancer care is led by specialist teams.<sup>14, 15</sup> Cancer52 believes there is a consensus that everyone with a rare and less common cancer should have their treatment and care overseen by a specialist; with specialists overseeing the parts of diagnosis, treatment and care that require specialist input or knowledge and more local services delivering the treatment and care which do not require this (sometimes called the 'chain model'). Health Education England, NHS England and Cancer Alliances need to work together to ensure this model is implemented swiftly across the country and that the right specialists are in place. Every person with cancer should have the right to be seen by a consultant with expertise in their type of cancer.

**We recommend that an individual lead within each Cancer Alliance is assigned to ensure that this happens.**

### Access to treatments

People should also have speedy and equal access to specialist treatment that will improve their outcomes. While we commend improvements to the NICE system and the Cancer Drugs Fund, more could be done to ensure medicines for rare and less common cancers are available to patients on the NHS. This requires improving the end of life criteria used so as not to disadvantage cancers with poor survival rates, and recognising the difficulties of developing medicines for rarer conditions in the NICE evaluation process. It also requires consideration of how to approve the use of off-label drugs.

**One of our key recommendations is the establishment of a Rare and Less Common Cancers Task and Finish Group to consider these issues, as well as the development of a specific target for rare and less common cancers to monitor progress.**

## Support

### Support services available for everyone with rare and less common cancers

Cancer52 supports the development of the Recovery Package and the broadening of the concept from support after treatment ends to providing personalised care and support from diagnosis onwards.

Our member survey showed that access to support services was a priority for Cancer52 members, with over a third of respondents citing this as a priority, and over three-quarters saying that access to post-treatment support services, such as help with finding a counsellor or getting back to work, needs to be prioritised.<sup>16</sup> It can be more difficult for people with rare and less common cancers to access support services, because they need to find either generic cancer or long-term condition services, which might not be tailored to their needs, or services specific to their cancer, which may not exist or be some distance away.

Cancer52 wants people with rare or less common cancers to be able to access the support services they need, both during and after treatment, and for them to have the support of a CNS as they go through treatment.

**Cancer Alliances should be supported via ring fenced funding to develop support pathways for people with rare and less common cancers and these pathways should form part of the Recovery Package.**

### Access to a Clinical Nurse Specialist

Research shows that access to a Clinical Nurse Specialist impacts positively on a patient's experience of care. This is confirmed by our own survey of people with rare and less common cancers, where the support of a CNS was frequently given as an example of a positive aspect of care.<sup>17</sup> Cancer52 believes everyone with a rare or less common cancer should have access to a CNS. CNSs are invaluable in coordinating patient's treatment and care, in helping patients to educate their other health professionals and in helping them to find support.

**We recommend that NHS England investigate and pilot different models so that this can be achieved and that these pilots are overseen by the Rare and Less Common Cancers Task and Finish Group that we recommend is established.**

## Research

### Use of real world/time data to test drugs

We believe that there is merit in considering the use of more real world and real time data. Many of the clinicians and experts Cancer52 has spoken to believe that it is time to be pragmatic in relation to medicines testing and data collection. Technological advances mean that the use of real world data and innovative new trial design are now possible and can be used to speed up the adoption of new treatments and discount those that do not work.

For example, real world data could be used to measure the effects of, say, a new drug on pancreatic cancer patients across England, should one be developed. Pancreatic cancer (and many other rare or less common cancers) has a poor prognosis and waiting for a full clinical trial before all patients can try new treatments could mean patients die before being able to access the drug.

Without the use of real world data, clinical trials are required, which are less attractive and more difficult to run in smaller cohorts of patients. With the public nature of the NHS, and the expertise of the National Institute for Health Research (NIHR) and PHE, there is an opportunity to use England as a test bed for the use of real world data and new drugs.

**We recommend that PHE and NIHR work together to pilot at least one drug trial for a rare or less common cancer using real world/time data by 2023.**

The establishment of Health Data Research UK also offers another opportunity to explore innovative trial design and real world data.

For some very rare cancers, clinical trials need to take place across several countries. The UK leaving the EU should not be allowed to impede opportunities for people with these very rare cancers taking part in those trials.

## Data

Cancer52 commends the work of PHE to 'get more data out' for rare and less common cancers. Data can drive action within the NHS and the invisibility of some cancers due to lack of data leads to a poor awareness of issues and subsequently initiatives to address them.

We recommend this work by PHE continue and for more data on rare and less common cancers to be available at national, alliance and trust level. Likewise, we recommend that more reporting of progress on cancer is broken down to rare and less common cancers as well as the four common cancers and all cancers. Without this data, it will continue to be difficult to understand where variation and inequality between cancers lies.

**To ensure improvement and focus, we recommend the establishment of a national target for rare and less common cancers.**

## Using patient stories

Cancer52 supports the Cancer Patient Experience Survey (CPES) as a vital tool in driving up standards in patient care. We recommend that data from the CPES be routinely broken down at a national, alliance and trust level for rare and less common cancers so that areas for improvement and discrepancies in standards can be identified. Small patient populations should not be an excuse for lack of action in improving patient care. To ensure that improvements can be made Alliances and trusts can use patients sharing stories of their care or service improvement techniques that involve patients in co-producing services to understand the experiences of those with rare and less common cancers.



## 6. Longer-term action to 2028

### New diagnostics

The stakeholders we spoke to were heartened by the advent of potential new diagnostic techniques including liquid biopsies and genetic services. They felt these new techniques had the ability to be game changers for the early diagnosis of cancers.

It is therefore imperative that NHS England begins to consider now the impact of these new techniques to ensure that new diagnostic techniques are swiftly rolled out into practice and that the workforce is in place to deliver them.

### New medicines

We are aware of new advances in medicines that have the potential to challenge the current medicines evaluation system. This includes medicines used in combination, medicines which have several indications and one-off treatments which may be very expensive.

Again, it is important that NICE and NHS England begin to explore now how these types of treatments can be evaluated and prices negotiated fairly so that the system keeps pace with the science.

### Use of technology

Cancer52 welcomes the Health Secretary's announcements regarding the trial of an NHS App and the transformation of a group of NHS Trusts into centres for technological and digital innovations. Patients reported the problems of administrative errors in their care and the inability of different centres to 'talk to each other', in some cases leading to scans or tests being repeated because results could not be shared.<sup>18</sup>

Stakeholders suggested that there was potential to use technology to help support earlier diagnosis, for example, by developing an app based on NICE Guideline 12, *Suspected Cancer: Recognition and Referral*, and provide people with support once they have a cancer diagnosis. Our patient survey demonstrated the importance of the internet as it has already provided a huge improvement to the quality of life experienced by people with rare or less common cancers by connecting them to charities, information and other patients with their disease.<sup>19</sup>

Cancer52 believes technology advances provide further opportunities to improve quality of life for people with rare or common cancers, for example, by providing remote monitoring and allowing people to manage their own condition. There is also the opportunity to use technology to better understand the effects of treatment on a patient's quality of life both in the short and long term. In ten years, demographic changes will mean that the use of technology such as smartphones will be even more commonplace than now.

We would urge NHS England to take a strategic and innovative approach to using digital technologies and recommend the development of a **Rare and Less Common Cancers Task and Finish Group** to consider how digital technology such as apps could be used to provide support to people with rare or less common cancers.

## 7. What next?

Cancer52 would like to see the recommendations set out above included in the NHS Long Term Plan. We will closely analyse the plan when published in order to continue to hold the Government and NHS to account in improving outcomes for those with rare and less common cancers.

Cancer52 will publish a fuller and more in-depth report of our consultation findings in early 2019, having reviewed the NHS Long Term Plan and considered its implications for people with rare and less common cancers.

We will continue to engage with our partners and colleagues in Government and the NHS to push for change where it is needed and to offer our support and expertise where appropriate. We very much hope that the Independent National Cancer Advisory Group will continue to provide constructive support to NHS England and the Alliances and we will continue to be an active member in this group. We also recommend that the Cancer Taskforce's 2015 report is updated in light of the activity and insight that has been undertaken to inform the development of the NHS Long Term Plan.

Cancer52 has worked with specific partners on initiatives that drive benefit for people with rare and less common cancers and this has included PHE on its drive to 'get more data out'. We would very much welcome the opportunity to continue to work in such partnerships and openly offer our expertise and experience.

# Appendices

## Note on Cancer52 Patient Survey 2018

The patient survey ran online from 26th July to 22nd August 2018. 671 people with a rare or less common cancer, or their carer on their behalf, completed the survey. Respondents were asked three open ended questions about the positive and negative aspects of their diagnosis, treatment and care and what improvement they would make. There was no word limit. All responses were read in full and themes identified.

## Note on Cancer52 Member Survey 2018

The member survey ran online from June to July 2018. 33 members responded. Respondents were asked to rank their priorities for different aspects of the cancer pathway and asked about progress of the Cancer Taskforce's 2015 report.

## Cancer52 Member Workshops

Cancer52 held two workshops with member charities to inform our submission. In June, Cancer52's Policy and Public Affairs Steering Group considered the progress of the 2015 Cancer Taskforce Report and priorities for the next cancer strategy. Nine members attended. In July, Cancer52 held an all member meeting where participants considered the results of the member survey and considered solutions to the priorities identified by the member survey. 16 members attended, along with two representatives from NHS England.

## Note on stakeholder interviews

14 stakeholders were interviewed, from June to August 2018. Interviewees are listed below:

- Paul Catchpole, ABPI, Values and Access Director
- Prof Peter Clark, NHS England, Chair Chemotherapy Reference Group; National Clinical Lead, Cancer Drugs Fund
- Moira Fraser, Macmillan Cancer Support, Director of Policy and Campaigns
- Emma Greenwood, Cancer Research UK, Director of Policy
- Sam Hackett, Sarcoma UK, Specialist Sarcoma Nurse
- Prof Chris Harrison, NHS England, National Clinical Director for Cancer; Medical Director, The Christie NHS Foundation Trust
- Ian Lewis, National Cancer Research Institute, Head of Strategy and Initiatives
- Baroness Delyth Morgan, Breast Cancer Now, CEO; Cancer52, Honorary President
- Cally Palmer, NHS England, National Cancer Director; CEO, The Royal Marsden NHS Foundation Trust
- Jem Rashbass, Public Health England, National Director for Disease Registration and Cancer Analysis
- Prof Sir Mike Richards, Independent National Cancer Advisory Group, Interim Chair; Cancer Research UK, Trustee
- Stakeholder, The King's Fund
- Stakeholder, Technology Appraisals, NICE
- Stakeholder, Cancer Alliance

# Acknowledgements

Our thanks go to the many patients, member charities and all the people we interviewed who helped make this project happen by sharing their expertise, stories and insight. We are also very grateful to the companies whose funding supported the project. Our thanks also go to Jennifer Mitchell and Laura Thomas, of Brighter Together Consulting, who project managed the engagement we undertook and to Ingrid Copperman, who provided invaluable project support.

We would like to gratefully acknowledge the support of the following companies in enabling us to publish this briefing.



**Bristol-Myers Squibb**  
Together we can prevail.®



**Celgene/Janssen/Merck:** While Cancer52 has received funding from these companies, they were not involved in developing the content of this material.

**Bristol-Myers Squibb:** Bristol-Myers Squibb has supported the general aims and mission of Cancer 52 through a charitable donation. It has had no editorial input into this specific briefing.

**Shire:** Cancer52 has received funding from Shire Pharmaceuticals. Shire was not involved in developing the content of this educational material.

## References

- <sup>1</sup> Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality>. Accessed May 2018
- <sup>2</sup> Office for National Statistics, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/final2016>. Accessed September 2018.
- <sup>3</sup> <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2016>
- <sup>4</sup> <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality>
- <sup>5</sup> <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality>
- <sup>6</sup> NHS England, Cancer Patient Experience Survey. 2014, Quality Health.
- <sup>7</sup> Cancer52 Patient Survey 2018
- <sup>8</sup> <http://ammf.org.uk/treatment-options-2/>
- <sup>9</sup> Cancer52 Patient Survey 2018
- <sup>10</sup> Cancer52 Patient Survey 2018
- <sup>11</sup> NHS England Cancer Patient Experience Survey, 2016, Quality Health
- <sup>12</sup> Cancer52 Patient Survey 2018
- <sup>13</sup> Cancer52 Policy and Public Affairs Steering Group meeting June 2018
- <sup>14</sup> Cancer52 Patient Survey 2018
- <sup>15</sup> Brown, H., et al., An evaluation of cancer surgery services in the UK. 2014, Health Services Management Centre, University of Birmingham, and ICF-GHK consulting.
- <sup>16</sup> Cancer52 Member Survey 2018
- <sup>17</sup> Cancer52 Patient Survey 2018
- <sup>18</sup> Cancer52 Patient Survey 2018
- <sup>19</sup> Cancer52 Patient Survey 2018

For further information on this briefing please contact: [info@cancer52.org.uk](mailto:info@cancer52.org.uk)  
[www.cancer52.org](http://www.cancer52.org)

Cancer52 – a company limited by guarantee and registered in England and Wales with company number 7994413  
Registered Charity Number 1174569  
Registered office at c/o Teenage Cancer Trust, Third Floor, 93 Newman Street, London W1T 3EZ