

# Getting a Better Deal for Rare and Less Common Cancers

One Year on from the NHS Long Term Plan



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## Foreword

The NHS Long Term Plan, published in early 2019, set out ambitions to ensure patients would receive more choice, better support, and joined-up care at the right time in the right care setting. It also aimed to improve outcomes, reduce inequalities and enhance prevention. One year on from the publication of the NHS Long Term Plan, there has been sustained efforts from all stakeholders to make progress on the pledges and commitments made. Much has been achieved, there remains more to do.

To ensure momentum and focus continues, we have prepared this report to highlight where we believe commitments are progressing well and where more progress needs to be made. Our report has been informed by our near 100 charity members, all of whom represent people with rare or less common cancers (all those cancers that are not one of the four most common - breast, lung, bowel and prostate). More information about Cancer52 and our work can be found at our website <https://www.cancer52.org.uk/>

Cancer remains a key priority for the NHS and received particular attention in the NHS Long Term Plan. Rightly so. One in two of us will develop cancer in our lifetimes<sup>1</sup> and 136,967 people died from the disease in England in 2017<sup>2</sup>. While 47% of cancers diagnosed in England are rare or less common, 55% of people die from these cancers and this has risen from 52% in 2006<sup>3</sup>.

People with rare and less common cancers can face many issues - over 600 people with rare and less common cancers told us about their experience of diagnosis, treatment and care for our 'Getting a better deal for people with rare and less common cancers: what we can learn from patients' report (available on our website<sup>4</sup>). Delayed diagnosis, difficulty accessing support from a Clinical Nurse Specialist and limited treatment choices are all problems for many people with rare and less common cancers.

We were pleased to see the continued commitment from the NHS to focus on improving outcomes for people with cancer in the Long Term Plan. The new earlier diagnosis target stating that 75% of all cancers will be diagnosed at stage 1 or 2 by 2028, which Cancer52 called for in our

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<sup>1</sup> <https://www.nature.com/articles/bjc2014606>

<sup>2</sup> Cancer Research UK, <https://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/all-cancers-combined>, Accessed February 2020

<sup>3</sup> <https://www.ndrs.nhs.uk/wp-content/uploads/2019/05/FINAL-SHARE-SLIDE-DECK-Development-in-data-for-rare-and-less-common-cancers-220519.pdf>

<sup>4</sup> <https://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-from-patients-1>

submission to NHS England, and initiatives such as the roll out of Rapid Diagnostics Centres that focus on vague and nonspecific symptoms will, we hope, drive earlier diagnosis of rare and less common cancers meaning more people can receive potentially life-saving treatment. Across all cancers, the Long Term Plan hopes to save 55,000 lives. Ensuring such initiatives work for rare and less common cancers and are given the focus they warrant is vital.

But there are big challenges to overcome. Increasing numbers of people referred with cancer and ongoing workforce shortages have placed strain on services and some waiting time targets have been consistently missed. Cancer52's extensive consultation with member charities and patients shows that these challenges can be amplified for rare and less common cancers because of the smaller numbers involved, adding an extra layer of complexity.

Cancer52 and its members are pleased to be working with the NHS to overcome these challenges and deliver on the pledges and commitments made in the Long Term Plan, both through the new governance structures and by ensuring that the knowledge and expertise of our diverse membership of cancer charities is integrated into planning and policy at every opportunity. We look forward over the coming years to continuing to work to help improve and save the lives of those with rare and less common cancers.

**Jane Lyons**

**Cancer52 CEO**

## Postscript April 2020

The work to inform, and the drafting of, this report was undertaken before the outbreak of the Coronavirus pandemic in 2020 and the serious implications this has led to for the National Health Service and the wider country.

Cancer52 has decided to publish this report knowing that plans and activity will need to be halted while this national emergency is dealt with. The report will stand as a record of where developments and progress for people with rare and less common cancers had been made against the NHS Long Term Plan by early Spring 2020.

Cancer52 remains here to support its members, people with rare and less common cancers, and our colleagues in the NHS and Government.

## Executive summary

Cancer52 welcomed the publication of the NHS Long Term Plan in 2019 and the commitments made to improve outcomes for cancer. One year on, this report examines the progress made against the cancer pledges and milestones outlined in the Long Term Plan, where cancer is a key priority, and what more needs to be done for people with rare and less common cancers.

So far, several of the key cancer commitments that will benefit people with rare or less common cancers have made positive progress. Appendix One shows milestones and pledges identified within the NHS Long Term Plan applicable to rare and less common cancers, and progress made against them to date. A new governance structure has been implemented to oversee the successful delivery of the NHS Cancer Programme and the NHS Long Term Plan, and rare and less common cancers are well represented within this, with Cancer52 included on several of the key groups including the National Cancer Board.

The NHS Long Term Plan aims to accelerate a shift towards earlier diagnosis of cancer. Cancer52 welcomes the new early diagnosis target (by 2028, 75% of cancers will be diagnosed at stage one or two) and that it includes all cancers. – indeed, this target cannot be reached without improving early diagnosis rates for rare and less common cancers. This target should drive progress in early diagnosis.

However, proxy measures must be found to allow those cancers which cannot be staged to be included, and data collection must be improved so that cancers are not excluded on the grounds of having minimal staging data. Cancer52 would also like to see continued and sustained investment in the Be Clear on Cancer Campaign so that people are aware of the symptoms of cancer and consequently present to their GP. This would also help improve earlier diagnosis. Cancer52 also welcomes the introduction of the Faster Diagnosis Standard from April 2020 as a driver to speed up diagnosis. Cancer52 hopes the threshold for this target will be set at the upper limit as delayed diagnosis remains a key issue for people with rare and less common cancers.

Cancer52 is pleased that Rapid Diagnosis Centres, aimed particularly at people with non-specific symptoms, are being rolled out. People with rare and less common cancers often have non-specific symptoms and can struggle to get a diagnosis. Cancer52 welcomes continuing evaluation of RDCs to determine if they are successfully providing a diagnostic pathway for people with non-specific symptoms.

Personalisation for all patients was another key theme of the NHS Long Term Plan with the milestone that people with cancer will have personalised care by 2021. To date the roll out of care plans and changes to follow up have focused on the most common cancers and Cancer52 would like to see these beneficial changes extended to rare and less common cancers as quickly as possible.

Cancer52 was disappointed to see some areas missing from the NHS Long Term Plan and other areas where progress has not been as rapid. Workforce remains a key area of concern for all cancer charities. There are already capacity issues across the cancer workforce, particularly in diagnostics and specialist nursing that, if they continue, will impact on delivery of the NHS Long Term Plan. Cancer52 wants a comprehensive plan that tackles these capacity issues as well as addressing the unique difficulties that can exist in the rare and less common cancer workforce.

It was disappointing that some key recommendations from the 2015 Cancer Strategy do not appear to have been taken forward in the NHS Long Term Plan, including extending direct access to diagnostic tests for GPs, the inclusion of metrics for rare and less common cancers in the Cancer Dashboard and ensuring more people with cancer can take part in clinical trials. Cancer52 would like to see these recommendations taken forward.

Research shows that outcomes are improved when people with cancer have their treatment overseen by a specialist. Therefore, Cancer52 would like to see the creation of more specialist treatment pathways and service specifications to ensure that this happens. More also needs to be done to encourage research into rare and less common cancers and to allow people to take part in clinical trials. Cancer52 hopes that the NICE Methods and Process review will improve participation of the patient voice in the technology appraisal process and allow more flexibility when clinical numbers are smaller and data therefore potentially less robust.

Cancer52 commends work by Public Health England to allow more access to data for rare and less common cancers. This allows for greater accountability and understanding. Cancer52 continues to encourage greater data collection in all cancers.

Genomic medicine presents an opportunity to ensure more people with cancer receive the most appropriate treatment for themselves. NHS England must ensure that the NHS is sufficiently prepared for the roll out, and future implications, of this new area of medicine, and that people with rare and less common cancers have access to reliable information so that they can make informed choices about their options.

## Introduction

### What are rare and less common cancers?

Rare and less common cancers are all those that are not included in the group of the four most common cancers - bowel, lung, prostate and breast.

Every year, about 144,600 people in England are diagnosed with a rare or less common cancer - cancers such as testicular, leukaemia, sarcoma and pancreatic.<sup>5</sup> Although fewer people are diagnosed with these cancers than the four most common cancers, more people die from these cancers: 74,500 people every year.<sup>6</sup> In fact, 47% of the cancers diagnosed in 2017 in England were rare or less common cancers but 55% of the deaths from cancers were from these conditions<sup>7</sup>.

Rare and less common cancers affect people of all ages, gender, ethnicity and across the whole of the country. They include cancers such as appendix where only one in a million cases are seen each year and cancers such as ovarian where 6,323 women were diagnosed in England in 2016.<sup>8</sup>

### About Cancer52

Rare and less common cancers remain severely under-represented and under-funded across all areas, including policy, services and research. Cancer52 is an alliance of nearly 100 predominantly patient support group charities working to address this inequality and improve outcomes for people with rare and less common cancers.

Cancer52 was instigated by Professor Sir Mike Richards CBE in 2006 to provide one collaborative voice for rare and less common cancers. The organisation was so named because at the time 52% of cancer deaths were from rare and less common cancers. That percentage has since risen to 55%.

### This report

In the Summer of 2018, Cancer52 conducted a patient survey, interviews with key stakeholders and a survey of members, to inform its submission to the NHS Long Term Plan (*Getting a better*

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<sup>5</sup> 144,642 were diagnosed with a rare or less common cancer in 2017 PHE/NCRAS May 2019

<sup>6</sup> 74,416 died from a rare or less common cancer in England in 2017 PHE/NCRAS May 2019

<sup>7</sup> <https://www.ndrs.nhs.uk/wp-content/uploads/2019/05/FINAL-SHARE-SLIDE-DECK-Development-in-data-for-rare-and-less-common-cancers-220519.pdf>

<sup>8</sup> Cancer Research UK, <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/incidence#heading-Zero>, Accessed January 2019

*deal for people with rare and less common cancers: The next ten years*)<sup>9</sup>. Cancer52 welcomed the publication of the NHS Long Term Plan in January 2019 and commends the progress made towards its implementation since then. The health and social care system needs both solid financial commitment as well as the opportunity to take a longer term view on priorities if it is to meet the challenges of the future. Cancer52 welcomes the new Government's commitment to continued NHS funding and intentions to enshrine this in law.

Following the NHS Long Term Plan's publication, a survey of Cancer52 charity members in spring 2019 found that two-thirds of respondents thought the NHS Long Term Plan would have a positive impact, but members were concerned that issues such as workforce, data and access to treatments were missing from the Plan. They were also keen that the priorities set out in the 2015 Cancer Strategy, *World Class Outcomes: A strategy for England 2015-2020*, were clearly identifiable within the ongoing plan, and were not lost<sup>10</sup>.

Since the NHS Long Term Plan was published, Cancer52 has worked to support the Long Term Plan's successful implementation and to identify what more can be done for people with rare and less common cancers.

This report sets out Cancer52's findings and recommendations. Within this report, case studies are also featured which showcase the innovative ways in which Cancer52 members are supporting the NHS to improve outcomes for people with rare and less common cancers.

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<sup>9</sup> [https://docs.wixstatic.com/ugd/e22361\\_9f08a0fe505243dca319f72fae51795f.pdf](https://docs.wixstatic.com/ugd/e22361_9f08a0fe505243dca319f72fae51795f.pdf)

<sup>10</sup> [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

# Cancer52's views on the NHS Long Term Plan

## What Cancer52 welcomes

### Cancer remains a priority

The NHS Long Term Plan is a plan for the whole of the NHS in England and for many conditions. There was a risk that the plan would result in a lack of focus for cancer, especially as a new cancer strategy to update the 2015 Cancer Taskforce report was not planned. Therefore, Cancer52 is pleased that cancer features prominently in the NHS Long Term Plan.

It is crucial that the NHS remains focused on improving outcomes for all people with cancer. One in two people will develop cancer in their lifetime<sup>11</sup> and almost half of those diagnoses will be rare or less common cancers<sup>12</sup>. It remains a major cause of death in England, with many people also living with cancer and its consequences long term. It is very welcome that cancer remains a key priority for the NHS and there are important commitments for cancer services in the NHS Long Term Plan.

### Commitments for rare and less common cancers

Ahead of publication of the NHS Long Term Plan, NHS England conducted a consultation with stakeholders. Cancer52 submitted a response to this consultation, following extensive consultation with its stakeholders, including nearly 100 member charities and over 600 patients.

Cancer52 knows that for people with a rare or less common cancer, diagnosis and treatment can be a struggle. A higher percentage of cancer deaths are from rare and less common cancers.

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<sup>11</sup> <https://www.nature.com/articles/bjc2014606>

<sup>12</sup> <https://www.ndrs.nhs.uk/wp-content/uploads/2019/05/FINAL-SHARE-SLIDE-DECK-Development-in-data-for-rare-and-less-common-cancers-220519.pdf>

Surveys of Cancer52 members and patients show that patients with rare and less common cancers have

- fewer specialist clinicians
- less opportunity to join clinical trials
- further to travel to find a specialist clinician
- fewer support groups
- far less understanding from the general public of their particular disease<sup>13</sup>.

Based on this extensive consultation, Cancer52 set out key asks of the NHS Long Term Plan, and was pleased that some of these asks were met and hopes that others may be in the future.

Cancer52 Ask	NHS Long Term Plan commitment
<p>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.</p>	<p>Within the new and emerging NHS England governance structure, people with rare and less common cancers are represented by Cancer52 with a presence on:</p> <ul style="list-style-type: none"> <li>● The National Cancer Board</li> <li>● Task &amp; Finish group on Rapid Diagnostic Centres</li> <li>● Task &amp; Finish group on Cancer Workforce</li> <li>● Advisory Group for Cancer Patient Experience Survey</li> <li>● Be Clear on Cancer Oversight Group</li> </ul>

<sup>13</sup> Cancer52, *Getting a Better deal for People with Rare and Less Common Cancers: What we can learn from patients*, 2019 <https://www.cancer52.org.uk/single-post/2019/07/10/%E2%80%98Getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-from-patients%E2%80%99-1>, Cancer52, *Getting a Better Deal for People with Rare and Less Common Cancers: The next ten years*, 2018 <https://www.cancer52.org.uk/single-post/2018/10/17/Getting-a-better-deal-for-people-with-rare-and-less-common-cancers-the-next-ten-years>

<p>The development of a high-level target to incentivise the reduction of deaths from rare and less common cancers.</p>	<p>A new early diagnosis target has been introduced at the highest system level – 75% of <i>all</i> cancers to be diagnosed at stage 1 or 2 by 2028. This target can't be achieved without improvements in the diagnosis of rare and less common cancers.</p>
<p>A proportion of Cancer Alliance funding is ring-fenced for rare and less common cancers. 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.</p>	<p>Cancer52 was invited as the first external presenter at the Cancer Alliance Leadership Forum and will continue to work with and support Cancer Alliances.</p>

## All cancer early diagnosis target

The NHS Long Term Plan included a new cancer target: by 2028, the NHS will diagnose 75% of cancers at stage 1 or 2. Cancer52 was especially pleased that this target will apply for *all* cancers. This target cannot be met by focusing purely on the more common cancers alone, and attention will need to be driven towards the diagnosis of rare and less common cancers. While work is needed to shift diagnosis for some cancers earlier and a method for determining progress found for cancers that cannot be staged, this target will help to drive much needed progress in the right direction.

To ensure that those rare and less common cancers that cannot be staged (such as certain blood cancers) do not miss out on this drive towards earlier diagnosis, Cancer52 strongly suggests that proxy measures are used to determine progress for these cancers. This could include measures such as:

- the number of diagnoses via emergency routes,
- the number of GP appointments prior to referral.

Both of these measures would give an indication of the level of delayed diagnosis and could act as a benchmark by which to measure future progress. The Cancer Patient Experience Survey 2018

found that there were significant differences between the number of times people with rare and less common cancers attended their GP compared to people with more common cancers before diagnosis. If proxy measures for cancers that are not staged are identified it would mean that they could be included in the indicator and would ensure a fairer playing field for unstageable cancers. In addition, data collection must be improved across all cancers so that progress can be tracked accurately (see *access to data* below).

In order to drive earlier diagnosis, there must also be a focus on ensuring people present to their GP in good time. Campaigns that aim to raise awareness across the board for all cancers are needed to ensure people and some healthcare professionals are aware of the symptoms, or combination of symptoms, that may indicate the possibility of cancer. The 2015 Cancer Strategy, *Achieving World Class Outcomes: A Strategy for England, 2015-2020* recommended that 'Be Clear on Cancer', a programme to raise awareness of signs and symptoms of cancer, be continued.

The NHS Long Term Plan did not state whether the 'Be Clear on Cancer' campaign would continue. Cancer52 strongly believes there is a need to raise awareness of the symptoms of cancer. While much important work is being undertaken to diagnose cancer earlier, the first step towards a diagnosis is most often when the patient presents to their GP with an issue. If individuals are unaware of the symptoms that could be cancer, delays in diagnosis will be inevitable. Investment in 'Be Clear on Cancer' must, therefore, continue.

Cancer52 welcomes changes to the cervical screening programme which from December 2019 has seen primary screening for high risk strains of the Human papillomavirus (HPV). However, myths and misinformation remain around this virus which can lead to distress for those women diagnosed with HPV. Women must be properly supported and accurate information about the virus, the way it is spread and how common it is. Cancer52 also commends efforts to increase screening uptake and hopes that this will continue, as well as knowledge and experience about successful strategies and tactics shared and replicated across the NHS.

## Rapid Diagnostic Centres

Rapid Diagnostic Centres (RDCs) have been welcomed by the rare and less common cancer community as a vehicle by which diagnosis for people with rare and less common cancers may be improved, by ensuring that one RDC per Cancer Alliance will focus on serious but non-specific symptoms. The concept of RDCs evolved from Multidisciplinary Diagnostic Centres developed as part of the Accelerate Coordinate Evaluate (ACE), a joint initiative programme supported by Cancer Research UK, Macmillan Cancer Support and NHS England to improve outcomes for

people with non-specific symptoms. Over half of cancers diagnosed by MDCs as part of the programme's evaluation were rare or less common.<sup>14</sup>

It is hoped RDCs will speed up diagnosis as well as improve the patient's experience of diagnosis. At the moment, people with rare and less common cancers can make multiple trips to their GPs and can be bounced between different diagnostic or medical departments, before they receive a definitive diagnosis. This can impact negatively on their experience of care.

The NHS Long Term Plan committed to the roll out of RDCs in 2019. In the latest update from the NHS Cancer Programme<sup>15</sup>, it was stated that in 2019/20 all Cancer Alliances were expected to set up two RDCs in their areas and there is £200m in capital funding available for diagnostics. A specification has also been written and initial focus is on those patients with non-specific symptoms, which Cancer52 welcomes, as these people are more likely to have rare or less common cancers.<sup>16</sup> For example, RDCs have shown promising results for pancreatic cancer, the second most common type of cancer to be diagnosed in RDCs; this will help to increase earlier diagnosis and reduce emergency presentation for the disease.

However, if RDCs are to prove successful in aiding the shift towards earlier diagnosis and improved patient experience, it is essential that the workforce and infrastructure needed to offer all the necessary diagnostics for people with rare or less common cancers are in place.

Cancer52 welcomes the fact that the roll out of RDCs is to be evaluated to determine whether these factors are in place and whether RDCs are indeed ensuring that people:

- receive a diagnosis more quickly
- benefit from a high-quality experience of care and
- are diagnosed at an earlier stage.

It is imperative that now clear referral routes for people with vague or non-specific symptoms are being developed that they continue, as these routes appear to be particularly beneficial for diagnosing people with rare and less common cancers.

Working with NHS England, Cancer52 brought together member charities to inform NHS thinking and development of policy on RDCs at an NHS England/Improvement workshop and would welcome future opportunities to inform NHS work in this area.

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<sup>14</sup> Cancer Research UK, *Accelerate, Coordinate, Evaluate: Working collaboratively to support innovation in cancer services*, 2019. [https://www.cancerresearchuk.org/sites/default/files/ace\\_mdc\\_report\\_may\\_2019\\_1.1.pdf](https://www.cancerresearchuk.org/sites/default/files/ace_mdc_report_may_2019_1.1.pdf)

<sup>15</sup> <https://www.england.nhs.uk/wp-content/uploads/2019/12/200124-Quarterly-Report-Q3-Final-22.pdf>

<sup>16</sup> <https://www.england.nhs.uk/wp-content/uploads/2019/07/rdc-vision-and-1920-implementation-specification.pdf>

## Faster Diagnosis Standard

Cancer52 welcomes the introduction of the Faster Diagnosis Standard<sup>17</sup>. The new Faster Diagnosis Standard will ensure that 75% of all patients who are referred urgently for the investigation of suspected cancer by their GP or a screening programme find out, within 28 days, if they do or do not have a cancer diagnosis. This standard is being introduced in April 2020. Cancer52 believes this new standard can help to ensure that those with rare and less common cancers receive a diagnosis more quickly. Many people with rare and less common cancers face lengthy delays in diagnosis, potentially impacting their chances of successful treatment.

In addition, Cancer52 has asked NHS England for clarity regarding whether the Faster Diagnosis Standard will include referral by GPs for primary care tests undertaken to rule out cancer that occur before further referral onto secondary care, such as blood tests for ovarian and blood cancers. For some rare and less common cancers failing to include such primary care tests would mean that the new standard has little impact on speeding up diagnosis as this is where delays in the system can occur. The recommendation to establish this new standard made in the 2015 Cancer Taskforce report<sup>18</sup> appeared to intend such testing to be included, as it stated that ‘Patients referred for testing by a GP, because of symptoms or clinical judgement, should either be definitively diagnosed with cancer or cancer excluded and this result should be communicated to the patient within four weeks’.

## Focus on personalisation

People with rare and less common cancers have told Cancer52 that they can struggle to access support and care appropriate to their needs. The sometimes complicated nature of their cancer journey can impact their experience of care. The milestone within the NHS Long Term Plan to ensure people with cancer have personalised care by 2021 is therefore welcomed. Ensuring people with rare and less common cancers are given a needs assessment will help to identify their specific and individual needs. If this is then supported by a care plan and health and wellbeing information and support, people are more likely to obtain the help they need.

To date the focus has been on developing care plans for people with breast, prostate and bowel cancer with all breast, prostate and bowel cancer patients will be offered personalised support

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<sup>17</sup> <https://www.england.nhs.uk/cancer/early-diagnosis/>

<sup>18</sup> [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

by March 2021, rolling out to all cancer patients by 2022.<sup>19</sup> Though a commitment to providing individual care plans for all cancer patients is welcome, this will be delivered a year later than pledged in the NHS Long Term Plan. This illustrates how people with rare and less common cancers often wait to benefit from new initiatives or innovation, which is disappointing and this commitment must not slip further. Cancer52 and its members are willing to work with NHS England and Cancer Alliances to help deliver this commitment. Cancer52 welcomes the planned publication of a new handbook from the NHS Cancer Programme that will outline the latest evidence and best practice on helping to improve support and care after cancer treatment, and will track how prominently rare and less common cancers are featured in this.

Needs are not just medical. Cancer can impact a person's emotional and psychological wellbeing as well as impacting on their finances and ability to work or undertake every day practical tasks. Care must be holistic, helping people to manage all these needs.

It is important that personalised care planning takes into account the needs of people with rare and less common cancers. One size will not fit all. For example, some people with blood cancer require continual treatment and medication, whereas others with blood cancer will not start treatment for some years. Children, teenagers and young adults have very specific needs and require care from a specialist workforce that understands the challenges they face and can provide age-appropriate and tailored support. Therefore, Cancer52 welcomes the development of a new patient experience survey for children and young people under 16 years old which will allow stakeholders to determine if the needs of children and young people are being met.

NHS services, supported by their Cancer Alliances, will need to look carefully at the information and support available to people with rare and less common cancers and determine how best to fill any unmet needs. Cancer52's member charities have a wealth of expertise on rare and less common cancers, many providing information and signposting to people with cancer and could aid such work. Many of our members charities are already supporting people with rare or less common cancers with personalised care, or working with the NHS to deliver this. Some are funding healthcare professionals and others have identified the type of high-quality care and standards that should be offered. Others provide specialist patient information.

Work has also started on redesigning follow up for people with breast cancer to ensure they receive the ongoing care they need and can manage their own condition. The December update from the Cancer Programme highlighted that trusts and Cancer Alliances are working together to

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<sup>19</sup> <https://www.england.nhs.uk/wp-content/uploads/2019/12/NHS-Cancer-Programme-quarterly-report-Q12.pdf><https://www.england.nhs.uk/wp-content/uploads/2019/12/cancer-programme-update-report-april-sept-2019.pdf>

redesign follow-up pathways so that they are in place for prostate and colorectal cancer patients by March 2021.<sup>20</sup> Cancer52 wants to see appropriate redesign extended to other cancers beyond the most common but to date there is no mention of plans to redesign follow up for rare and less common cancers.

## Myeloma UK

Myeloma UK is working to improve patient experience and outcomes through the Clinical Service Excellence Programme (CSEP) – a best practice initiative supporting hospitals to deliver optimum, patient-focused myeloma treatment and care. It aims to recognise and share excellence in myeloma care and identify any areas for improvement that better meet the needs of people with myeloma. Participation brings about positive change by helping frontline staff define, drive and share service improvements.

One of the ways potential changes are identified is through patient surveys. Patient experience surveys are collected from a minimum of 20 patients per centre. This data is shared with the clinical team to allow them to make any changes or improvements in the service using the patient perspective.

The Myeloma UK CSEP Accreditation is based on a set of Best Practice Standards. These standards cover all aspects of clinical service and were conceived and designed jointly by healthcare professionals, patients and their families.

Since 2016, Myeloma UK have accredited more than 25 hospitals in the UK with the CSEP award. The Myeloma service at Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT) is one of the hospitals which has been awarded the accreditation, having received ‘excellent’ ratings across all eight standards, including patient experience, follow up and support.

Suzanne Renwick, Healthcare Professional Projects Manager, Myeloma UK, said “Being presented with the Myeloma UK CSEP Accreditation is a considerable achievement and shows that the hospital is dedicated to providing excellent treatment and care. The Myeloma UK CSEP accreditation demonstrates the gold standard of myeloma care”.

As the number and duration of treatments increases, people with rare and less common cancers may come into contact with an increasing range of secondary care professionals. For example, with increasing use of maintenance treatments, such as PARP inhibitors, treatments are taken at

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<sup>20</sup> *ibid.*

home and monitoring (through regular blood tests) can be delivered by a range of professionals, which can include a Clinical Nurse Specialist but may also sit elsewhere in secondary care. Many people with cancer will see a CNS and oncologist through their initial treatment, but, once they begin chemotherapy treatment, support is most likely to be provided by a chemotherapy nurse. It is therefore important that all professionals understand the holistic nature of cancer and can signpost to support.

## Governance and engagement

Any large programme needs to be well governed and to engage with its stakeholders. Cancer52 welcomes the clear governance arrangements that have been put in place and are pleased that people with rare and less common cancers are represented on the National Cancer Board as well as the following working groups:

- Workforce
- RDCs in full
- Cancer Patient Experience Survey
- Be Clear on Cancer Oversight Group

Cancer52 also welcomes the continued engagement provided by the regular Cancer Charity Forums, which allow the cancer charity community to come together with NHS England/Improvement colleagues and others to share information and help develop the Cancer Programme. It also ensures that people with cancer are represented by charities and patient groups and their concerns can be raised. There has also been increased levels of collaboration between cancer charities as a result of encouragement from NHS England, for example, charities have come together under a One Cancer Voice banner to lead the debate on workforce and the cancer charity CEOs meet regularly.

## What more could be done

While Cancer52 welcomes the commitments made in the NHS Long Term Plan and the progress since then, there are some areas where work still needs to be done. It remains disappointing that new initiatives and innovations are most often trialed in the most common cancers, meaning that people with rare and less common cancers have to wait to benefit from them.

## Workforce capacity

Improvements in cancer treatment, care and experience for people with rare and less common cancers cannot be achieved without the right workforce in place. Workforce capacity issues will impact the successful delivery of the NHS Long Term Plan and are already hindering NHS performance. The 62 day wait Cancer Target across England has only been met once in the last five and half years both because of the increasing number of referrals as well as workforce pressures<sup>21</sup>. Capacity issues exist across the workforce but are particularly problematic in the diagnostic and specialist nursing workforce. Short and long term action must be taken.

Cancer52 members were surveyed about workforce issues and they identified problems with recruitment and retention of staff, as well as ensuring staff have access to continuing professional development<sup>22</sup>. For example, despite the clear benefits to patients, healthcare professionals are finding it challenging to implement the fast tracking of surgery for pancreatic cancer partly because of lack of workforce capacity.

There is a lack of Clinical Nurse Specialists (CNS) for people with rare and less common cancers. The 2018 National Cancer Patient Experience Survey (CPES) showed that there was a significant difference in patient experience between people with more common cancers who had contact with a CNS compared to people with rare and less common cancers. People with a rare and less common cancer were significantly more likely to find it difficult to get in touch with a CNS compared to people with one of the four more common cancers. They were also less likely to be given a named CNS.

Recruiting CNSs for rare and less common cancers can be difficult because the workforce is less exposed to people with these cancers. Therefore, professionals may not be aware it is an option, or may be unsure about the route to become a rare and less common cancer specialist. Continuing Professional Development (CPD) is not always funded and staff sometimes use annual leave to attend courses.

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<sup>21</sup> <https://www.nuffieldtrust.org.uk/news-item/combined-performance-summary-november-december-2019>

<sup>22</sup> Available from Cancer52 upon request

## Mesothelioma UK

Since 2012 Mesothelioma UK has helped to fund and recruit Mesothelioma specific clinical nurse specialists. The charity aims to enable the NHS to deliver its vision for cancer to all patients including those with rarer tumours. Each Mesothelioma UK CNS is expert in all aspects related to the disease and each works in the NHS helping local and regional teams to provide the expert support, treatment and care all cancer patients should receive. The organisation also 'adopts' existing Mesothelioma CNS to support their development while enhancing specialist mesothelioma expertise and knowledge.

There are currently 24 Mesothelioma CNS across the UK with plans to increase this to 30 by 2021. Each CNS is employed within a NHS Trust which agrees to a service level agreement with Mesothelioma UK. This outlines local, regional and national responsibilities for each postholder focused on equitable access to the best treatment, care and support for all patients.

The nurses also come together to share knowledge and are in regular contact to support one another. One CNS explains that one of the best things about the roles is 'being part of a driven, passionate, supportive and highly knowledgeable community that makes a real difference to patients locally and nationally'.

## The 2015 Cancer Strategy

Cancer52 was part of the Independent Taskforce that produced the 2015 Cancer Strategy)<sup>23</sup>. Cancer52 supported the recommendations made and has been pleased to see progress made against many of them, including: the roll out of RDCs, the development of the Faster Diagnosis Standard and the continuation of the Cancer Patient Experience Survey. For the duration of the Cancer Taskforce's report, Cancer52 tracked progress against the 22 recommendations that related to rare and less common cancers - some of these related to specific individual rare or less common cancers, while others benefited all rare and less common cancers. The tracker document can be viewed on the Cancer52 website. Cancer52 is pleased to see that the following key recommendations that should benefit all rare and less common cancers are being taken forward in the Long Term Plan:

<sup>23</sup> [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

Recommendation	Progress
<p>Recommendation 21: NHS England should pilot, in up to 5 vanguard sites and in conjunction with Wave 2 of the ACE programme, multi-disciplinary diagnostic centres for vague or unclear symptoms. These should have the capability to carry out several tests on the same day.</p>	<p>Long Term Plan update: This has evolved into the roll out of Rapid Diagnostics Centres</p>
<p>Recommendation 24: By the end of 2015, NHS England should develop the rules for a new metric for earlier diagnosis measurable at CCG level. Patients referred for testing by a GP, because of symptoms or clinical judgement, should either be definitively diagnosed with cancer or cancer excluded and this result should be communicated to the patient within four weeks. The ambition should be that CCGs achieve this target for 95% of patients by 2020, with 50% definitively diagnosed or cancer excluded within 2 weeks. Once this new metric is embedded, CCGs and providers should be permitted to phase out the urgent referral (2-week) pathway.</p>	<p>Long Term Plan update: This has been taken forward and is being implemented as the Faster Diagnosis Standard from April 2020</p>
<p>Recommendation 54: NHS England should continue to commission CPES annually. It should also take steps to increase BME representation in CPES for a minimum of 1 to 2 years to understand drivers of poorer experience within these groups better. It should consider how CPES data can be linked with other datasets to understand experience across the pathway. It should also develop a methodology to collect data on patient experience for under 16s.</p>	<p>Long Term Plan update: CPES is continuing with recent efforts to increase black and minority ethnic participation and the introduction of a survey for those under 16</p>

However, some of the key recommendations that Cancer52 identified as bringing benefit to people with rare and less common cancers have not appeared to be taken forward in the NHS Long Term Plan. Cancer52 would like to see the following recommendations picked up and taken forward by NHS England and Cancer Alliances:

**Recommendation 1:** NHS England, working with the other Arms Length Bodies, should develop a cancer dashboard of metrics at the CCG and provider level, to be reported and reviewed regularly by Cancer Alliances.

**Recommendation 15:** Public Health England should continue to invest in “Be Clear on Cancer” campaigns to raise awareness of possible symptoms of cancer and encourage earlier presentation to health services. Campaigns should include lung, breast over 70s, and other cancer types where plots prove effective. PHE should also explore the use of this brand to improve uptake of screening programmes, particularly among disadvantaged groups.

**Recommendation 17:** NHS England [to] mandate that GPs have direct access to key investigative tests for suspected cancer – blood tests, chest x-ray, ultrasound, MRI, CT and endoscopy by the end of 2015.

**Recommendation 26:** CRGs should regularly evaluate emerging evidence to determine whether service configuration for surgery merits further centralisation and advise NHS England accordingly. Any reconfiguration should be undertaken with regard to broader commissioning and patient experience factors.

**Recommendation 50:** NHS England should ensure commissioners and providers are incentivised to maintain the UK’s world-leading position in cancer studies and applied health research. This should ensure that as many patients as possible have the opportunity to be part of a study, including in smaller stratified trials.

## Treatment pathways

While ensuring people with rare and less common cancers are diagnosed quickly is an important priority, people must have access to the best possible treatment once they are diagnosed. This means ensuring people with rare and less common cancers are seen by specialists with the knowledge and experience to treat them. Research has shown that outcomes for people with cancer are improved when their treatment and care is overseen by a specialist - for example, clinics dedicated to people with inoperable pancreatic cancer have better disease outcomes than clinics where oncologists are not pancreatic cancer specialists<sup>24</sup>.

National cancer pathways have so far focused on lung, bowel, prostate and breast. A service specification has recently been developed for sarcoma and a service specification for Teenage and Young People has recently finished a consultation. Some of our member charities have already undertaken work to determine what such pathways could look like for example for

<sup>24</sup> <https://www.pancreaticcancer.org.uk/media/1845106/scoping-the-optimal-pathway-for-pancreatic-cancer.pdf>

pancreatic cancer (Pancreatic Cancer UK)<sup>25</sup>, and for teenagers and young people (Teenage Cancer Trust)<sup>26</sup>.

Cancer52 would like to see the creation of more specialist treatment pathways and service specifications to ensure that the treatment and care provided to people with rare or less common cancers is overseen by a specialist.

## Pancreatic Cancer UK

Pancreatic Cancer UK, in partnership with University Hospitals Birmingham charities, funded a project at the University Hospitals Birmingham NHS Trust to speed up access to surgery for people with pancreatic cancer. Surgery offers people with pancreatic surgery the only realistic option of curative treatment and long term survival. Of those diagnosed with pancreatic cancer, only 15–20% are considered candidates for surgery yet less than 10% currently undergo this.

International and UK studies have shown that the longer someone waits to receive surgery from the time of diagnosis, the smaller the chances of actually having surgery due to the fast progression of the disease<sup>27,28</sup>. Survival rates for pancreatic cancer are very low so ensuring people are operated on quickly before their tumour becomes too large or difficult to remove is vital. Also people with pancreatic cancer go on to develop jaundice which requires stenting, associated with complications and poorer patient experience. Early surgery can avoid this need for stenting.

The team led by Mr Keith Roberts, Consultant Pancreatic, Hepatobiliary and Liver Transplant Surgeon, and the team in University Hospitals Birmingham (UHB) NHS Trust implemented a fast-track surgery pathway that reduced the time between an initial CT scan and potentially curative surgery to 16 days. One of the ways this was managed was by no longer stenting patients with jaundice as this not only created delays before surgery but was associated with serious morbidities. The NICE guidelines on pancreatic cancer recommend that individuals with jaundice who can have potentially curative surgery should be offered surgery rather than having treatment for jaundice first<sup>29</sup>.

<sup>25</sup> <https://www.pancreaticcancer.org.uk/media/1845106/scoping-the-optimal-pathway-for-pancreatic-cancer.pdf>

<sup>26</sup> [https://www.teenagecancertrust.org/sites/default/files/BlueprintOfCare\\_2ndEdition.pdf](https://www.teenagecancertrust.org/sites/default/files/BlueprintOfCare_2ndEdition.pdf)

<sup>27</sup> Roberts, K. J. et al. *A reduced time to surgery within a 'fast track' pathway for periampullary malignancy is associated with an increased rate of pancreatoduodenectomy*. HPB (Oxford), doi:10.1016/j.hpb.2017.04.011 (2017).

<sup>28</sup> Sanjeevi, S. et al. *Impact of delay between imaging and treatment in patients with potentially curable pancreatic cancer*. British Journal of Surgery 103, 267-275, doi:10.1002/bjs.10046 (2016)

<sup>29</sup> <https://www.nice.org.uk/guidance/ng85>

The team found that it was critical to have a dedicated Clinical Nurse Specialist (CNS) to act as a pancreatic cancer pathway patient navigator, to provide psychological, emotional and practical support to the patient, and to act as a contact and liaison point between referral hospitals and specialised teams.

In the model of fast-track surgery implemented at University Hospitals Birmingham NHS Trust, the time from diagnosis to surgery was reduced from 65 to 16 days. An additional 20% of people underwent potentially curative surgery in the fast-track group. Moreover, the implementing pathway had a cost benefit of £3,200 per individual having fast-track surgery. The UHB team are working to increase the number of people with pancreatic cancer who could benefit from the model by raising awareness among NHS Staff, clinicians, GPs and commissioners.

Pancreatic Cancer UK would like to see the pathway implemented across the country. This model is the cornerstone of the award-winning Demand Faster Treatment campaign and has also been awarded the NICE Shared Learning Award 2019.<sup>30,31</sup>

## Access to treatments

For some cancers, little progress has been made on survival rates in decades, with few new treatments made available. It is welcome that the Cancer Drugs Fund has ensured that more treatments are available to patients through the NHS. However, the approval of medicine for use by the NHS or the recommendation of their use in NICE guidelines, does not always mean patients receive these treatments. For example, NICE guidelines recommend the use of Gemcitabine/Capecitabine combination chemotherapy after surgery for pancreatic cancer but only 50% of patients who have surgery undergo adjuvant chemotherapy and there is variation among Cancer Alliances in provision of this treatment<sup>32</sup>.

In addition, more still needs to be done to encourage research into the area of rare and less common cancers to ensure that future patients have treatment options available to them. Most rare and less common cancers receive less research attention and funding than the more common cancers<sup>33</sup>. There are fewer commercial incentives to conduct research into these cancers, as well as potentially less awareness, or perceivably fewer opportunities available for

<sup>30</sup> <https://www.pancreaticcancer.org.uk/policy-and-campaigning/policy/the-case-for-faster-treatment/>

<sup>31</sup> <https://www.nice.org.uk/news/article/shared-learning-awards-2019-winning-example-announced>

<sup>32</sup> [http://www.ncin.org.uk/cancer\\_type\\_and\\_topic\\_specific\\_work/topic\\_specific\\_work/main\\_cancer\\_treatments](http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatments)

<sup>33</sup> National Cancer Research Institute, *Cancer Research Spend in the UK 2002-2011: An overview of the research funded by NCRI Partners*, 2011

professionals working in this kind of research. When numbers are lower, clinical trials can be more difficult to set up requiring multi-sites, sometimes over many different countries.

More patients must also be given the opportunity to take part in clinical trials. Participation in a clinical trial can mean earlier access to new, potentially improved treatments. However, because of the smaller numbers involved, there are not always live clinical trials for people with rare and less common cancer to join or awareness of trials that do exist may be low. Teenagers and young people have a particularly low participation rate in clinical trials - this is in part because arbitrary age restrictions can prevent them from taking part. The NHS Long Term Plan included a commitment for 50% of children and young people to be included in clinical trials by 2025 but it is not yet clear if this is happening. More trials must be open to all age ranges and healthcare professionals should make patients aware of clinical trials of relevance to them. Cancer52 welcomes the establishment of the Radiotherapy Learning Healthcare System with the hope it will aid access to clinical trials.

Separate to the NHS Long Term Plan, but of importance if outcomes are to be improved, is the NICE Methods Review which is looking to replace four existing programmes, one of which is the Technology Appraisal Programme, with a single Manual for the evaluation of new products. Cancer52 welcomes the undertaking of this review. Actions that will lead to the increase of the patient voice within the appraisals of new treatments is both needed and positive. Cancer52 would also welcome any changes that allow more flexibility in the review of treatments where patients numbers are smaller and the data source may not be considered as robust.

## Data

PHE are developing a measure to track whether the target for 75% of all cancers to be diagnosed at stage 1 or 2 is being met. It will rely on accurate data on stage being collected by registries. Currently there is incomplete staging data, particularly for some rare cancers, including myeloma at 35% and Uvea (eye) at 20%<sup>34</sup>. NHS England and PHE are working together to improve staging data collection. It would be unacceptable if progress for certain cancers could not be tracked as a result of insufficient data collection, or for cancers with low staging data to be excluded from the target.

The Getting Data Out programme has been successful at sharing data and insight more widely with the cancer community. There have been useful interrogations of data for cancers, including

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<sup>34</sup> <https://www.ndrs.nhs.uk/wp-content/uploads/2019/05/FINAL-SHARE-SLIDE-DECK-Development-in-data-for-rare-and-less-common-cancers-220519.pdf>

sarcoma, ovarian, pancreatic and mesothelioma.<sup>35</sup> New data about stomach, oesophageal, bladder and kidney cancers, and sarcomas, will be released at the end of March 2020. Some of these insights were shared at a joint Cancer52/PHE conference in May 2019. These data analyses can show differences in treatment and/or cohort of subtypes of cancer and could lead to better treatment and care. Cancer52 strongly supports the continuation of this successful programme as a key improvement vehicle for rare and less common cancers.

Cancer52 has welcomed the Getting Data Out programme as a true commitment to working with the rare and less common cancer community. In the spirit of this programme, some of these insights were shared at a joint Cancer52/PHE conference in May 2019, Developments in Data for Rare and Less Common Cancers. Cancer52 thanks PHE and NCRAS for their work in this area and for hosting the conference in collaboration with Cancer52 - their first partnership one day event. A film about the conference can be found on the Cancer52 website ([www.cancer52.org.uk](http://www.cancer52.org.uk)).

## Genomics

The rapid developments in genomic medicine is leading to more personalised and precise treatments for people with cancer. It presents the opportunity for people to receive the most appropriate treatments for their cancer with the possibility of ensuring the best outcomes and preventing unnecessary treatment. For advanced cancers where there may only be time to try one treatment, getting it right first time is imperative.

Cancer52 welcomes the establishment of the NHS National Genomic Medicine Service. When fully operational, this service has the potential to be of huge benefit to both people with rare and less common cancers and the research community. To ensure patients are afforded the full benefits promised by genomic medicine, the forthcoming service must be fit for purpose: testing must be equitable, the NHS workforce must be genomically literate, and the supporting Genomic Laboratory Hubs must be configured in an optimal manner. In addition, people with rare and less common cancers must have access to appropriate and accurate information about genomic testing and medicines, so that they can make informed choices about their treatment and care.

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<sup>35</sup> <https://www.ndrs.nhs.uk/wp-content/uploads/2019/05/FINAL-SHARE-SLIDE-DECK-Development-in-data-for-rare-and-less-common-cancers-220519.pdf>

## Recommendations

**Cancer52 welcomes the progress made since the publication of the NHS Long Term Plan. To ensure that the plan is successfully delivered and outcomes for people with rare and less common cancers improved, Cancer52 recommends the following:**

- A method must be found that satisfactorily allows progress for all cancers to be tracked against the earlier diagnosis target. It will not be sufficient to combine data for cancers or to miss some out altogether because of poor collection rates or staging difficulties, as this could mask poor performance for some cancers.
- The specific workforce issues that exist for rare and less common cancers must be properly taken into account, considered and addressed within the NHS People Plan.
- In order to improve earlier diagnosis of rare and less common cancers, awareness of rare and less common cancers needs to be raised among the public and some healthcare professionals. We strongly recommend further investment in the *Be Clear on Cancer* campaign
- The NHS must be prepared and ready for the changes in diagnosis, treatment and care that genomics medicine will bring.
- The NICE Methods and Process reviews must lead to the increase of the patient voice within the appraisals of new treatments, and changes should be made to allow more flexibility in the review of treatments where patients numbers are smaller and the data source may not be considered as robust.
- Cancer52 supported the recommendations made in the 2015 Cancer Taskforce report. Some have been delivered. However, some recommendations that would bring benefits to people with rare and less common cancers are yet to be taken forward. Within this report, we have highlighted the recommendations that should be taken forward by NHS England and Cancer Alliances including ensuring that rare and less common cancers are included in the Cancer Dashboard metrics, that people with rare and less common cancers can take part in clinical trials, and allowing GPs greater direct access to diagnostic tests.
- While the NHS Long Term Plan sets out an achievable high level plan for cancer over the next 10 years, we would like to see the publication of the detailed delivery plan that sits beneath this. This will allow organisations such as ours to monitor progress and ensure accountability and transparency.

## Appendix One: Topline analysis of progress against the NHS Long Term Plan. Cancer Milestones and Pledges

### Milestones and Pledges related to Cancer

The following table shows milestones and pledges identified within the NHS Long Term Plan applicable to rare and less common cancers, and progress made against them to date.

Milestone	Progress
From 2019 we will start to roll out new Rapid Diagnostic Centres across the country.	Rolling out
By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including a needs assessment, a care plan and health and wellbeing information and support.	Breast, prostate and colorectal by 2021; others by 2022
By 2023, stratified, follow-up pathways for people who are worried their cancer may have recurred. These will be in place for all clinically appropriate cancers.	Currently rolling out for breast, and colorectal and prostate by March 2021
By 2028, the NHS will diagnose 75% of cancers at stage 1 or 2.	Implementing - awaiting results
In 2020 a new faster diagnosis standard for cancer will begin to be introduced so that patients receive a definitive diagnosis or ruling out of cancer within 28 days.	Implementing from April 2020
By 2020 HPV primary screening for cervical cancer will be in place across England.	Implemented from Dec 2019

Pledge	Progress
<p>We want to ensure that all GPs are using the latest evidence-based guidance from NICE to identify children, young people and adults at risk of cancer.</p>	<p>Rolling out</p>
<p>Primary care networks will be required to help improve early diagnosis of patients in their own neighbourhoods by 2023/24.</p>	<p>Rolling out</p>
<p>We will speed up the path from innovation to business-as-usual, spreading proven new techniques and technologies and reducing variation.</p>	<p>Progress unclear</p>
<p>We will extend the use of molecular diagnostics and, over the next ten years, the NHS will routinely offer genomic testing to all people with cancer for whom it would be of clinical benefit, and expand participation in research.</p>	<p>Progress unclear</p>
<p>Safer and more precise treatments including advanced radiotherapy techniques and immunotherapies will continue to support improvements in survival rates.</p>	<p>Rolling out</p>

## Appendix Two: How we informed this report

Cancer52 has continued to collect evidence since the publication of the NHS Long Term Plan to understand how best to support its implementation and to continue to improve outcomes for people with rare and less common cancers.

### Stakeholder roundtable

In April 2019, Cancer52 hosted a roundtable with stakeholders from across the cancer community. This included representatives from NHS England, Cancer Alliances, Public Health England, National Cancer Research Institute, National Institute for Health and Care Excellence, Cancer52 members and other cancer charities. Attendees discussed the risks and opportunities represented by the NHS Long Term Plan for people with rare and less common cancers; how structural changes in the NHS will impact on diagnosis, treatment and care; and how the early diagnosis target can be met.

### Members' Survey

In the Summer of 2019, Cancer52 surveyed its members to better understand their hopes for the NHS Long Term Plan and any concerns they had. 24 members responded.

- 67% of respondents felt the NHS Long Term Plan would have a positive impact,
- 25% did not know
- 0% thought it would have a negative impact.

Members were concerned that some key issues needed to be addressed in order for the NHS Long Term Plan to be successfully implemented. These included

- more funding for the NHS and social care (67%),
- addressing workforce shortages (87%),
- ensuring access to medicines on the NHS (58%) and
- increasing research into rare and less common cancers (79%).

Topics that members felt were missing from the NHS Long Term Plan included Data, Workforce, Symptom awareness, Improving and increasing research, and Mental health awareness.

## Engagement with Cancer Alliances

Since publication of the NHS Long Term Plan, Cancer52 has been increasing its engagement with Cancer Alliances to understand what they are doing to improve outcomes for people with rare and less common cancers, and how Cancer52 and its members can help this activity. Representatives from the South East London Cancer Alliance contributed to the Cancer52 Stakeholder Roundtable. Cancer52 also presented and helped to facilitate a discussion about rare and less common cancers at the first NHS England Leadership forum with key personnel from all Cancer Alliances. Notes from this meeting were captured and circulated. Cancer52 has also facilitated the centralisation of access to its members' patient materials as a resource for alliances.

## Data conference

In May 2019 Cancer52 and PHE held a full day joint conference on data and rare and less common cancers. Speakers presented on a range of topics, including the development of an indicator to measure cancers diagnosed at stage 1 and 2, how data has helped to identify trends in individual cancers, and the various data tools and datasets available to researchers.

## Workforce Survey

In November 2019, Cancer52 surveyed its members to understand their concerns about the cancer workforce and where they felt attention should be focused. 26 members responded to this survey and a briefing of the findings was shared with NHS England.

## National Cancer Patient Experience Survey

Cancer52 requested that analysis of the 2019 National Cancer Patient Experience Survey be carried out to determine if there were any differences in experience between people with common cancers and people with rare and less common cancers. The resulting analysis showed statistically significant differences under many of the areas of experiences and that people with rare and less common cancers tended to have more negative experiences in these cases. For example, people with rare and less common cancers were less likely to understand the explanation of what was wrong with them and less likely to have a care plan.

## Thank you

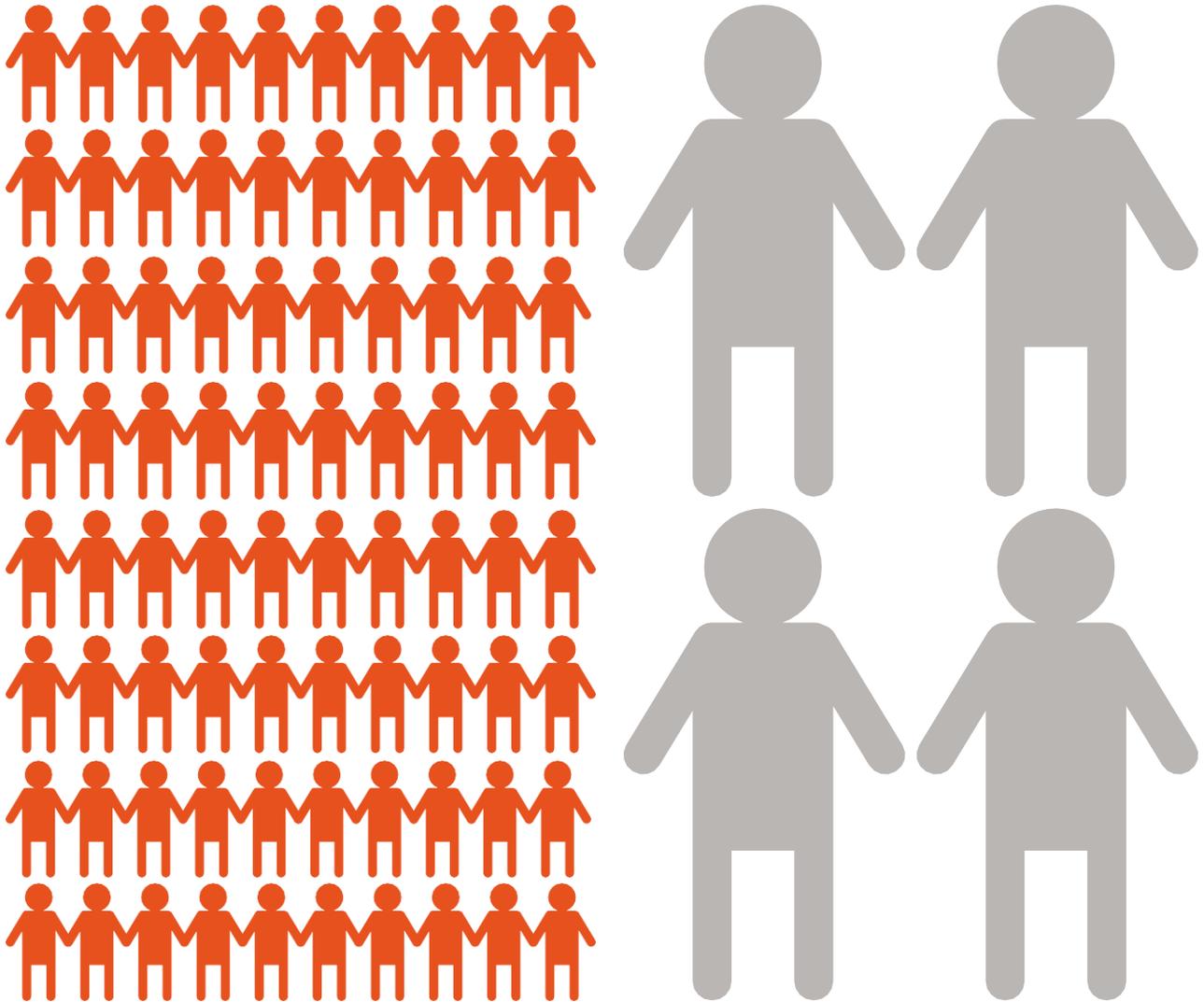
Cancer52 would like to thank all those member organisations who helped gather intelligence and contributed to this report:

Action Against Heartburn	Lymphoma Action
Action on Womb Cancer	MDS UK Patient Support Group
Barrett's Patients Support Group at UCLH	Mesothelioma UK
Bloodwise	MPN Voice
Brain Tumour Research	Mummy's Star
Brainstrust	Myeloma UK
Chronic Lymphocytic Leukaemia Supp. Ass.	Orchid Cancer Appeal
CLIC Sargent	Pancreatic Cancer Action
CLL Support	Pancreatic Cancer UK
CUP Foundation - Jo's friends	Pseudomyxoma Survivor
GIST Support	Sarcoma UK
Heartburn Cancer UK	Target Ovarian Cancer
Kidney Cancer Research	Team Margot Foundation
Kidney Cancer Support Network	Teenage Cancer Trust
Leeds Teaching Hospital Trust	Trekstock
Leukaemia Care	

Cancer52 is particularly grateful to members of the Cancer52 Policy and Public Affairs Steering Group for their input, and to Pancreatic Cancer UK, Mesothelioma UK and Myeloma UK for sharing examples of their work for this report.

Cancer52 also wishes to thank the NHS England Cancer Policy Team for their help in supplying detail and information to inform the accuracy of this report.

If we **work together** we can make  
as much noise as the big four



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