

## 10-Year Cancer Plan: Call for Evidence Cancer52 Response, March 2022

### About Cancer52

Cancer52 is a charity which represents over 100 charities working to support the 150,000 people diagnosed with rare and less common cancers every year. Cancer52 members represent over £220 million of charitable spend and range in size from tiny, volunteer run charities with incomes of only thousands, to large million-pound organisations, which invest heavily in research and support services.

Rare and less common cancers are all cancers except the four most common cancers (breast, prostate, bowel and lung). 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.

In 2017, there were 366,457 new cancer cases in the UK. Of these 53% were breast, prostate, lung and bowel cancers, and 47% were rare and less common cancers, as defined by Cancer52. **Deaths from rare or less common cancers in England are more common than the four most common cancers combined.<sup>1</sup> The percentage of deaths from rare or less common cancers has risen from 53% in 2001 to 55% in 2017.<sup>2</sup>** The total number of people living with a rare or less common cancer in England was estimated to grow to around 1.25 million people in 2020, 1.63 million in 2030, and 2.06 million in 2040.<sup>3</sup>

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## About this submission

This submission is based on Cancer52's experience and insight from working with over 100 rare and less common cancer charities, the expertise of Cancer52's Policy and Public Affairs Steering Group (comprising of representatives of 15 charities), a members' survey and a patient survey and Cancer52's medical advisers and trustees.

Cancer52 also led the work to develop the One Cancer Voice Consensus Statement and we support that submission.

Below we outline our key recommendation for the 10-year Cancer Plan and then we answer the questions as set out in the Call for Evidence.

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## Priorities for the Cancer Plan: A focus on rare and less common cancers

We welcome the development of a new 10-year Cancer Plan. We recommend that the Cancer Plan includes a strong focus on rare and less common cancers. England can only match outcomes in other countries if more attention is paid to rare and less common cancers.

Too often, rare and less common cancers are considered under the 'all cancer' umbrella and new pilots and initiatives are piloted in the four most common cancers first, with the result that people with rare and less common cancers are consistently left behind. For example, stratified pathways of follow-up have been rolled out first in breast, prostate and colorectal cancer with cancer alliances.<sup>4</sup> Although the latest NHS planning guidance for 2021 states that cancer alliances should agree three new additional cancer types for stratified follow-up and implement one by 2022, this illustrates how rare and less common cancers usually follow behind the more common cancers. Similarly, the new Quality of Life Metric is also being rolled out to patients with breast, prostate or colorectal cancers first. Although all cancers were due to be included by autumn 2021 this has not yet happened.<sup>5</sup>

We recognise that the Government is seeking solutions to incorporate into the Cancer Plan. However, solutions to improve cancer care evolve over time; solutions in 2022 might not suit 2032. A group that brings together the NHS, charities, people affected by rare and less common cancer and other stakeholders such as the Royal Colleges to enable continual improvement is essential.

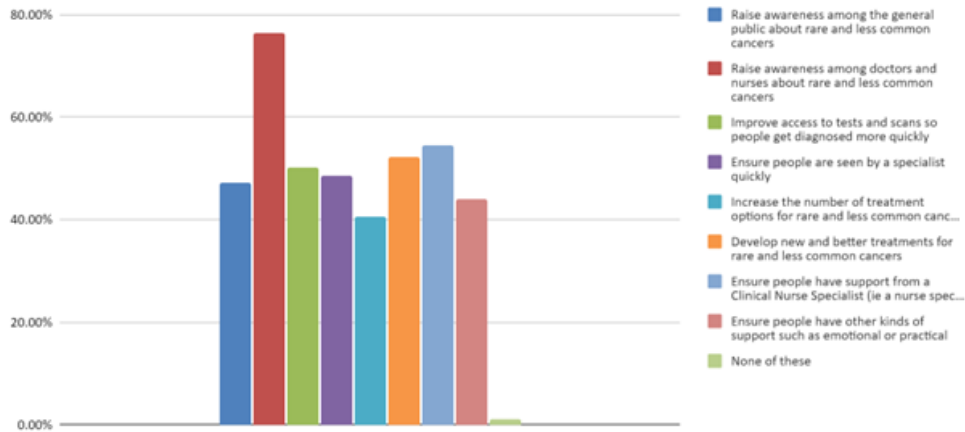
Therefore we recommend that the Cancer Plan establishes a Rare and Less Common Cancer Taskforce to provide an ongoing focus and reporting structure on progress in improvements in rare and less common cancer care.

### The views of people living with rare and less common cancer

In Spring 2022, Cancer52 ran a short survey of people with rare and less common cancers to understand their priorities for the new Cancer Plan. 259 people responded.<sup>6</sup> We asked them for their views on where the NHS should focus efforts to improve services, care and outcomes for people with rare and less common cancers.

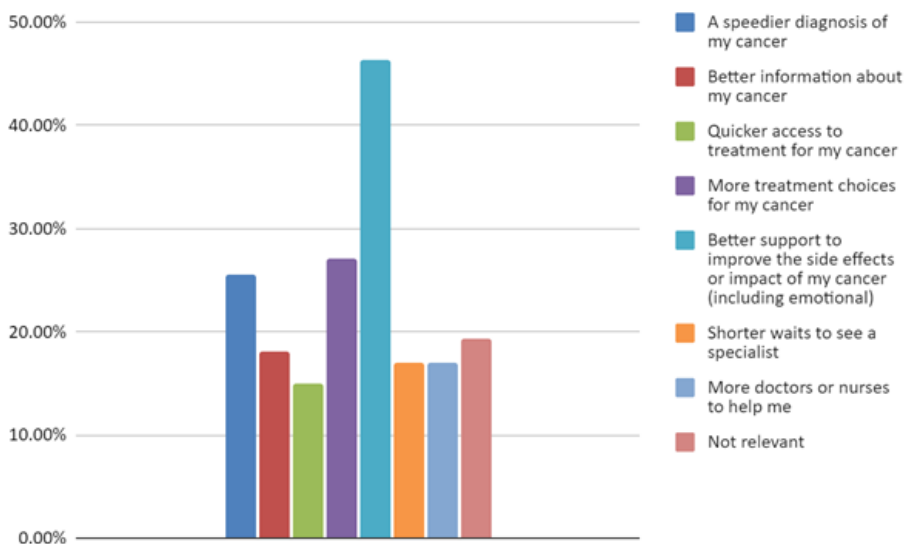
The chart below shows their responses; the majority of people with rare and less common cancers wanted doctors and nurses to understand more about rare and less common cancers. About half of respondents wanted better treatments for rare and less common cancers and quicker access to scans and tests.

**Figure 1: Chart showing where people with rare and less common cancers think the NHS should focus efforts to improve services, care and outcomes for people with rare and less common cancers**



They were also asked where improvement could have been made to their treatment and care over the last year; nearly 50% wanted better support to improve the side effects of their cancer or treatment. See Question 7 for further discussion.

**Figure 2: Chart showing where improvements in care could have been made, over the last year**



## The views of Cancer52 Member charities

At the beginning of 2022, Cancer52 surveyed its member organisations to understand their views on progress made against the cancer commitments in the NHS Long Term Plan.<sup>7</sup> 18 charity members responded.

Ten charities felt progress had been made in some areas but not all, whereas five felt progress was disappointing. Members felt better progress had been made in rolling out RDCs and the Faster Diagnosis Standard, with poorer progress against the early diagnosis ambition and rolling out personalised care.

We asked how the pandemic had impacted the people with cancer they support. Most often our members highlighted the increased mental health issues faced by people with rare and less common cancers (88%) and less access to CNS for people with rare and less common cancers (69%). Our members also highlighted delays in diagnosis (44%) and treatment (56%) as well as people with rare and less common cancers being given new (50%) or different (56%) treatments, which could affect outcomes. We also asked our members what the areas of focus should be for the future. The top three areas of focus were:

- Addressing workforce shortages
- Restructures in the health and social care system
- Cancer alliances working collaboratively with the charities

It's clear from both surveys that improvements can be made across the whole of the cancer pathway. We welcome the development of a new 10-year Cancer Plan, though we recommend that the recommendations of the Long Term Plan (LTP) are not lost but built upon and accelerated in the new plan. The new Cancer Plan should be clear on which recommendations from the LTP have been carried over, amended or removed and why.

## Key recommendations

- **NHS England establishes a Rare and Less Common Cancer Taskforce to continue to provide a focus for Rare and Less Common Cancers throughout the lifetime of the Cancer Plan. This is needed to make progress on rare and less common cancers and then go beyond to meet the NHS Long Term Plan target of 75% of cancers diagnosed at an early stage by 2028, to save more lives and to support patient experience.**
- **The progress against cancer commitments in the NHS Long Term Plan is built upon and accelerated.**
- **By 2032, there is a reduction in incidence of rare and less common cancer.**
  - Investing in research to understand the causes of rare and less common cancer where this is not currently well understood.
  - Raising awareness of the full range of risks and causes of rare and less common cancer.
- **The public are aware of the risk factors, signs and symptoms of rare and less common cancers and act on them, leading to improvements in presentation, supporting the early diagnosis ambition.**
  - Public behaviour and engagement campaigns are run each year by the NHS. At least half of the budget invested in awareness campaigns should refer to signs and symptoms of rare and less common cancers.
  - Awareness campaigns are developed in partnership with cancer charities.
  - There is a regular tracker of awareness among the public and propensity to act.
- **By 2032, 78% of people with cancer are diagnosed at stage one or stage two.**
  - Development of proxy measures for cancers that are not staged.
  - Roll out of Community Diagnostic Centres (CDCs) to include people with non-specific symptoms.
- € **By 2032, every person with rare and less common cancer can access the treatment they need.**
  - People with rare and less common cancers are treated by specialists and in the right centres.
  - Development of specialist pathways and service specifications for all rare and less common cancers.
- **Everyone with rare and less common cancer is able to access mental health support.**
  - Implementation of recommendations of NHS Psychosocial Task and Finish Group.

- The NHS signposts people with rare and less common cancers to charities that can support them.
- Data collection is timely, accessible, standardised and comprehensive and it is analysed and published swiftly to support the delivery and monitoring of all aspects of cancer across the pathway and cancer research. Progress against this recommendation is made well in advance of 2032.
  - Investment in data analysts and informatics both locally (at point of collection) and nationally.
  - Target for registration data.
  - Data disaggregated for all cancer types and ages.
  - Investment in routes to diagnosis data.
- By 2032, cases of rare and less common cancer attributable to inequalities have decreased.
  - Data is collected on protected characteristics including age, gender, ethnicity, and sexuality as well as other aspects of inequality, such as socio-economic group, and published in an accessible and timely manner.
  - Key cancer surveys collect and report on data relating to inequalities.

## Response to Call for Evidence questions

### Question 1

Where do you think the NHS should focus efforts to improve services, care and outcomes for people with rare and less common cancers?

- *Raise awareness among the general public about rare and less common cancers*
- *Raise awareness among doctors and nurses about rare and less common cancers*
- *Improve access to tests and scans so people get diagnosed more quickly*
- *Ensure people are seen by a specialist quickly*
- *Increase the number of treatment options for rare and less common cancers*
- *Develop new and better treatments for rare and less common cancers*
- *Ensure people have support from a Clinical Nurse Specialist (ie a nurse specialising in the type of cancer you have)*
- *Ensure people have other kinds of support such as emotional or practical*
- *None of these*

All of these are essential for rare and less common cancers.

Question 2 - In your opinion, which of these areas would you like to see prioritised over the next decade? (You can select more than one option)

- *Raising awareness of the causes of cancer and how it can be prevented*
- *Raising awareness of the signs and symptoms of cancer*
- *Getting more people diagnosed quicker*
- *Improving access to and experiences of cancer treatment*
- *Improving after-care and support services for cancer patients and their families*

All of these areas are important. Please see the commentary below.

Question 3 - Do you have any suggestions for how to raise awareness of the causes of cancer and how it can be prevented?

### Prevention

**By 2032, there is a reduction in incidence of rare and less common cancer.**

- **Investing in research to understand the causes of rare and less common cancers where this is not currently well understood.**
- **Raising awareness of the full range of risks and causes of rare and less common cancers.**

4 in 10 cancers could be prevented.<sup>8</sup> More must be done to tackle the factors that can cause cancer. We support the recommendations in the One Cancer Voice Consensus Statement.

For some rare and less common cancers it is well understood what causes them. For example, asbestos causes mesothelioma and therefore efforts to raise awareness of the dangers of asbestos and how it should be removed need to continue. The HPV virus can cause cervical cancer and head and neck cancers.

However, for many rare and less common cancers, it is not clear what causes them. For example, the causes of brain cancer are not well understood. There needs to be investment in research to understand more about the causes of some cancers.

Awareness should be raised of the whole range of causes of cancer. For example, the importance of family history which is important for BRCA1/2 in ovarian cancer and increasingly linked to others. This might need to go beyond awareness raising for example, by removing barriers to attend screening and raise the uptake of HPV vaccinations.



## Question 4 - Do you have any suggestions for how to raise awareness of the signs and symptoms of cancer?

### Awareness of rare and less common cancers

**The public are aware of the risk factors, signs and symptoms of rare and less common cancers and act on them, leading to improvements in presentation, supporting the early diagnosis ambition.**

- **Public behaviour and engagement campaigns are run each year by the NHS. At least half of the investment is spent on rare and less common cancers.**
- **There is a regular tracker of awareness among the public and propensity to act.**

It is imperative that people have good awareness of the signs and symptoms of rare and less common cancers and are aware of the importance of presenting to their GP if they notice anything untoward. This would help to ensure that people are diagnosed with cancer at an earlier stage, with better hope of successful treatment.

That people in England present later than those in other countries in Europe has regularly been cited as a reason for England and the UK lagging behind other countries in survival and mortality outcomes. A study in 2012 found that UK attitudes of not wishing to bother their doctor was another factor in people not presenting.<sup>9</sup> Such attitudes likely increased during the pandemic when there was clear messaging to stay at home. It is unclear how this will have impacted attitudes longer term and therefore people's willingness to come forward with symptoms.

Fewer people have come forward for diagnosis and treatment since the pandemic began. NHS England has responded to this by regularly running campaigns under the banner 'Help Us Help You'. We were pleased with the recent renewed investment in a new abdominal/urological campaign. These campaigns follow on from the 'Be Clear on Cancer' campaigns that were run prior to the pandemic. However, the NHS Long Term Plan did not state whether the 'Be Clear on Cancer' campaign would continue, so there was some uncertainty about their future prior to the pandemic. There has been no public evaluation of whether the 'Help Us Help You' campaigns have achieved their aims.

Recognition of the signs and symptoms of cancer is relatively high in some studies. Figures from Cancer Research UK's most recent tracker showed 95% of people recognised any cancer symptom, 95% recognised red flag symptoms and 92% recognised vague symptoms. However, Cancer52's survey of people with rare and less common cancer found that 70% of people were not aware of the signs and symptoms of their cancer before diagnosis.<sup>10</sup>

Cancer Research UK's study also showed that people are not likely to visit the doctor because they think their symptoms are cancer; instead they attribute them to other conditions.<sup>11</sup> Only 7% of people attributed symptoms to cancer, with people attributing them to existing physical conditions instead. The study also found that only 49% of people contacted their GP within six months if they

had vague symptoms, compared to 59% with red flag symptoms.<sup>12</sup> However, only about one in two people who visit their GP with symptoms is too low; people need to be encouraged to visit their GP more promptly and everyone needs to do so.

It is vital that a regular awareness tracker of the public's knowledge of signs and symptoms of cancer is conducted. It is also vital that the NHS continues to run regular HelpUsHelpYou campaigns (at least three a year) to ensure that people are reminded of possible signs and symptoms of cancer and encouraged to come forward. Both the awareness tracker and campaigns like HelpUsHelpYou need to be fully funded until 2032. Cancer52 recommends that a commitment to long-term and multi-year investment is provided in the Cancer Plan so that these campaigns continue to be run regularly. Cancer charities should be involved with their development, as they understand the needs of their populations.

Efforts should also be put into trying out new methods to encourage people to come forward, such as self-referral. The signs and symptoms hotlines that some cancer alliances are piloting should be rolled out if successful. Cancer52 also runs its own campaign, DoYouCUs?, which uses the stories of people living with rare and less common cancer to raise awareness of rare and less common cancers.<sup>13</sup> Cancer52 and its member charities are willing to work with the NHS in any way possible to support awareness raising campaigns and is currently working closely with the engagement and communications teams to help build on the current awareness campaigns.

## Question 5 - Do you have any suggestions for how to get more people diagnosed quicker?

### Diagnosing at an early stage

**By 2032, 78% of people are diagnosed at stage one or stage two and the 95% Faster Diagnosis Standard is met.**

- **Development of proxy measures for cancers that are not staged.**
- **Roll out of Community Diagnostic Centres (CDCs) to include people with non-specific symptoms.**

People with rare and less common cancers need to be diagnosed at an early stage of their cancer and receive that diagnosis in a timely fashion. A range of elements support timely diagnosis: awareness, presenting early, and swift and accurate diagnostic pathways.

Diagnosis of rare and less common cancers can be complicated because some symptoms of rare and less common cancers can be vague and awareness of these symptoms is low. People with rare or

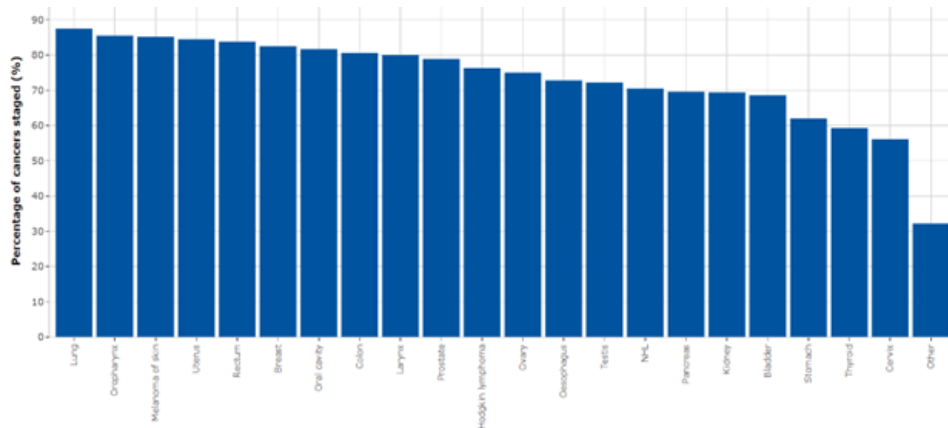
less common cancers can have a more complicated route to diagnosis and are more likely to be diagnosed through emergency routes.<sup>14</sup> It can also mean that GPs or other health professionals fail to recognise symptoms that may be cancer and do not refer to secondary care. For those patients with 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>15</sup> Cancer52's 2018 survey of patients confirmed this, with patients relating tales of frequent visits to the GP and long delays before they were diagnosed.<sup>16</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.

The NHS Long Term Plan contained a commitment for 75% of all cancers to be diagnosed at stage 1 or stage 2 by 2028. This commitment can only be achieved by efforts to improve early diagnosis across all types of cancer, including rare and less common cancers. Though some rare and less common cancers are more likely to be diagnosed at stage 1 and stage 2, some rare and less common cancers are not. These include cancers such as pancreas and ovarian.<sup>17</sup> This ambition should be retained, with a further target for 2032 of 78% of cancers.

However, proxy measures must be found to allow those cancers which cannot be staged, such as blood and brain cancers, to be included in the stage 1 and stage 2 target. These proxy measures could include reductions in numbers of diagnoses made via emergency presentation and numbers of GP visits before referral to secondary care.

There is variation in how many cancers are staged (see Figure 4), with many rare and less common cancers performing poorly on this measure. There should be minimum targets for recording registrations of cancer and investment to meet those targets. Data collection must be improved so that cancers are not excluded on the grounds of having minimal staging data.

**Figure 3: Graph showing percentage of cancers staged by cancer site in England, 2019.**<sup>18</sup>

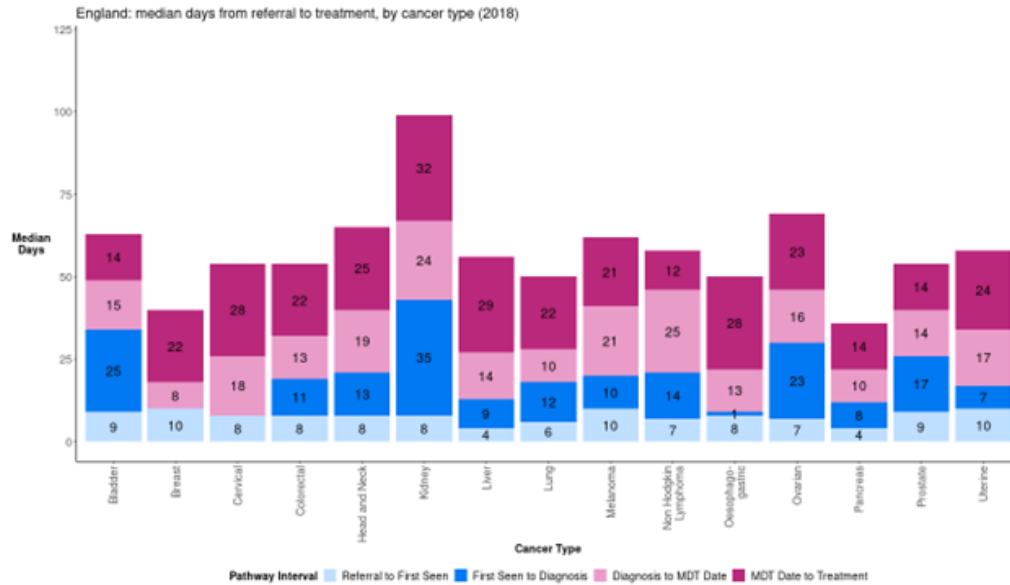


We welcome NHS England’s focus on innovations to reach the 75% ambition, such as the pilot liver health checks. Moving the dial on the early diagnosis ambition will require a focus on individual cancers in order to find interventions that make a difference.

There is variation in time from referral to treatment, particularly for people with rare and less common cancers (see Figure 4). We welcomed the development of rapid diagnostic centres (RDC) - soon to be referred to as Non-Specific Symptom pathways - to provide a pathway for people with vague symptoms to have a diagnosis of cancer ruled in or out. Evaluation of the Cancer Research UK Accelerate, Coordinate, Evaluate (ACE) programme on Multidisciplinary Diagnostic Centres (MDCs) has shown promising results for people presenting with non-specific symptoms.<sup>19</sup> There must now be clarity on how RDCs will interact with the roll out of Community Diagnostic Hubs (CDCs), as recommended by the 2020 Richards Review and the Delivery Plan for Tackling the Elective Backlog.

As part of rolling out CDCs, cancer diagnostic pathways must be integrated within them and there must be further clarity on what proportion of funding will be spent on cancer. **People with non-specific symptoms of all ages must be able to access CDCs**, as has proven successful for the Rapid Diagnostic Centre programme. This is particularly important for people with rare and less common cancers. The ability to self-refer should be piloted and evaluated and evaluations of how RDCs and CDCs are performing for people with suspected cancer. It should also be clear what specific tests are included at each point in the pathway in each area, as we understand there is variation in provision of these tests. For example, in some places a full blood count is not included. GPs and primary care professionals must be better supported to recognise the non-specific signs and symptoms of cancers, through training and the development of clinical decision support systems.<sup>20</sup>

Figure 4: Chart showing time from referral to treatment, by tumour type<sup>21</sup>



It is important that RDC and CDC data outputs are transparent and accessible to all in the cancer community, including cancer charities. Data must be scrutinised to ensure RDCs and CDCs are meeting the needs of patients with rare and less common cancers, and action taken if this is not the case. Any RDC or CDC review should look at enabling patients to self-refer for diagnostic tests at RDCs or CDCs and how this could be implemented.

RDCs and CDCs must have sufficient understanding and attentiveness to rare and less common cancers, which must be supported at the GP level by ensuring they have RDC and CDC referrals at the front of their mind. Frequent feedback mechanisms to primary care on RDC and CDC performance will be required. Cancer charities are experts in signs and symptoms of their respective cancers and are willing to support RDCs and CDCs in any way they can.

Diagnostics capacity remains a critical issue in this country, hampering progress in earlier diagnosis of cancers. Diagnostics were also hit during the pandemic and it is known that endoscopy services reduced their activity substantially during the earlier wave. This certainly contributed to the delays in diagnosis and treatment.

It is crucial that diagnostic capacity receives the investment required both in kit (estimated to require £1.3 bn over the next three years) and workforce, and that diagnostic activity is protected in any future healthcare crisis.<sup>22</sup> Earlier diagnosis ambitions cannot be met without this.

## Question 6 - Do you have any suggestions for how to improve access to and experiences of cancer treatment?

### Access to medicines and treatment

**By 2032, every person with cancer can access the treatment they need.**

- **People with rare and less common cancers are treated by specialists and in the right centres.**
- **Development of specialist pathways and service specifications for all rare and less common cancers.**
- **Awareness of NICE shared-decision making guidance to improve patient involvement in their own care and treatment. Collation of cancer-specific shared decision aids on the NICE website.**

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.

People with rare and less common cancers must be 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>23</sup> Treatment also needs to happen in the right centre - there is a 45% increase in survival in ovarian cancer for those treated in research active settings.<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 pancreatic cancer (Pancreatic Cancer UK), and for teenagers and young people (Teenage Cancer Trust).<sup>25 26</sup> Cancer52 would like to see the development of specialist treatment pathways for all cancers and service specifications to ensure that the treatment and care provided to people with rare or less common cancers is overseen by a specialist and in the right centre.

People with rare and less common cancers should also be involved in decisions about their care and treatment. NICE decision aids can help people understand what questions to ask. People with rare and less common cancers should be signposted to NICE decision aids and charities that can support them with decision making. More decision aids need to be produced, so that everyone with rare and less common cancer can be involved fully in their own care.

Cancer52 is also concerned that the implementation of the new severity modifier in the NICE Methods manual will disadvantage patients in the end-of-life setting. A transition process with both modifiers used in parallel is required while further evidence of the impact is gathered.

## Workforce and personalised care

**By 2032, everyone with a rare or less common cancer has swift access to a CNS and specialist workforce to support their treatment and care.**

- **Workforce planning to deliver timely care.**
- **Annual publication of workforce projections.**

Improvements in cancer treatment, care and experience for people with rare and less common cancers cannot be achieved without the right workforce in place. The 62 day wait Cancer Target across England has not been met since 2013 in the last five and half years, because of the increasing number of referrals as well as workforce pressures and the pandemic.<sup>27</sup>

Prior to the pandemic, capacity issues already existed across the workforce and have only been exacerbated. Issues are particularly problematic in the diagnostic and specialist nursing workforce. Short- and long-term action must be taken. Like others in the cancer community, we welcome recent commitments to invest in the workforce made in the 2021 Comprehensive Spending Review. As part of the cancer plan, there needs to be workforce planning to deliver timely care and annual publication of workforce projections.

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. Our members reported that the pandemic had affected access to CNSs.

Cancer52 members were surveyed in 2018 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>28</sup> For example, despite the clear benefits to patients, healthcare professionals find it challenging to implement the fast tracking of surgery for pancreatic cancer, partly because of lack of workforce capacity.

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. The new cancer plan should include measures to ensure everyone with rare and less common cancer has access to a CNS and the specialist workforce that they require.

Cancer52 is aware that while referrals for cancer have increased in recent months, diagnostic and treatment activity has not increased to match. We suspect this is due to capacity issues in diagnostics where shortages of staff have been an ongoing issue. People with rare and less common cancers are known to bounce around the system; often requiring several different tests before a diagnosis is reached.<sup>29</sup> Any delays in access to diagnostics caused by workforce shortages is likely to impact upon the speed of diagnosis for people with rare and less common cancers.

## Question 7 - Do you have any suggestions for how to improve after-care and support services for cancer patients and their families?

### Support services for people with rare and less common cancers

**Everyone with rare and less common cancer is able to access mental health support.**

- **Implementation of recommendations of NHS Psychosocial Task and Finish Group**
- **The NHS signposts people with rare and less common cancer to charities that can provide support**

People with rare and less common cancers have a range of needs but can struggle to access support services. The Cancer Patient Experience Survey (CPES) shows that people with rare or less common cancers can find it more 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>30</sup>

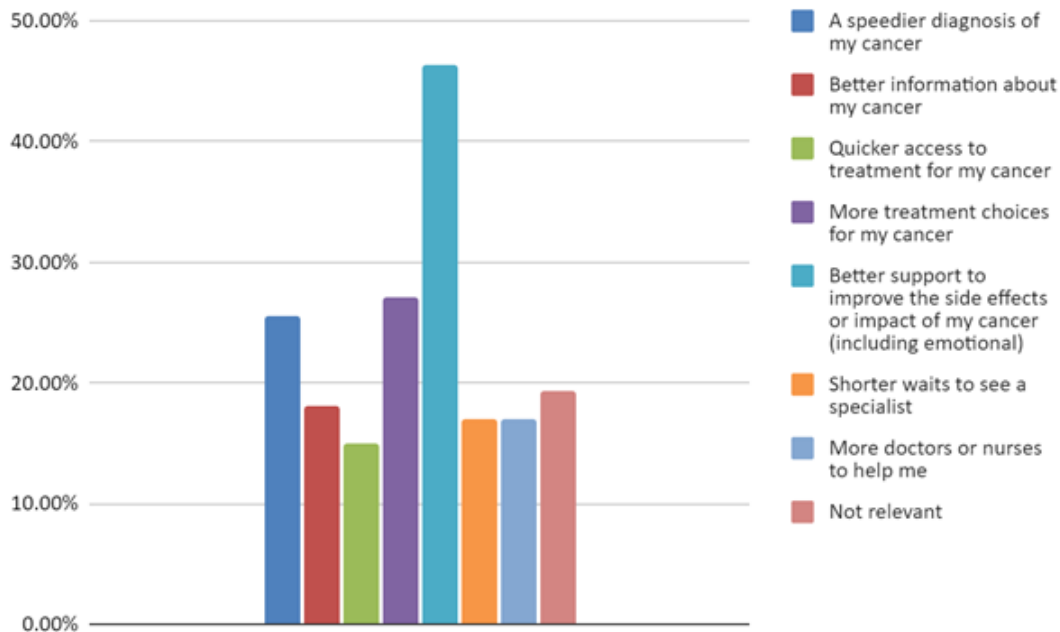
This is supported by Cancer52's patient surveys and by what patient groups have told us. The knock-on effect of lower awareness and smaller populations of patients is that support services such as the availability of accurate information, support groups and psychosocial services are not widespread and therefore more 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. Cancer52 members also tell us that health professionals are often less aware of the patient support offered by the rare and less common cancer voluntary sector. One patient responding to the 2018 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>31</sup>



The support needs of people with rare and less common cancers heightened during the pandemic. Respondents to our survey about the impact of the pandemic on people with rare and less common cancer told us that their cancer had caused additional burdens to them during the pandemic. A quarter said their finances had been impacted. Three in five said their mental health had been impacted.<sup>32</sup> In our 2022 survey of people living with rare and less common cancer, 50% of respondents said they thought there could have been improvements to the treatment and care they received over the last year to manage side effects. This was the most popular choice.

Cancer charities have a key role to play in providing information and support, as many offer comprehensive information and helplines. The NHS needs to work in partnership with charities so that people with rare and less common cancer are signposted to relevant charities that can provide them with information and support.

**Figure 5: Chart showing percentage of people who think improvements could have been made to their treatment and care in the last year**



In our charity member survey, charities recommended that mental health support should be prioritised. Cancer52 was pleased to be involved in the NHS Cancer Psychosocial Task and Finish Group. The recommendations of the Group should be incorporated into the cancer plan, implemented in full and progress on their implementation reported on annually.

**Question 8 - Do you have any suggestions for how we can maximise the impact of research and data regarding cancer and cancer services in England, including how we can translate research and data into practice sooner?**

## Data

Data collection is timely, accessible, standardised and comprehensive and it is analysed and published swiftly to support the delivery and monitoring of all aspects of cancer across the pathway and cancer research. Progress against this recommendation is made well in advance of 2032.

- Investment in data analysts and informatics both locally (at point of collection) and nationally.
- Target for registration data.
- Data disaggregated for all cancer types and ages.
- Investment in routes to diagnosis data.

Good data is imperative to understand outcomes for people with rare and less common cancers. We are grateful for the PHE Get Data Out Programme, which provided detailed analyses of data for a variety of cancer types, including many rare and less common cancers.<sup>33</sup> However, too often cancer data is not fully disaggregated for all cancers. For example, the Cancer Dashboard, where CCGs can access their statistics and compare them to national data, shows data for breast, lung, bowel and prostate and all cancers, but not any more individual tumour sites than the four most common cancers.<sup>34</sup>

The cancer community consists of the NHS as well as a myriad of cancer charities, which provide vital patient support and invest in research. Yet for rare and less common cancers these charities are stymied because data is usually not disaggregated by cancer type. This has been particularly true of data shared during the pandemic. For example, cancer data sets often include 'Upper GI' or 'gynaecological', yet the former comprises a range of cancers including stomach, oesophageal and pancreatic as does the latter which includes ovarian, cervical and vulval. Although these cancers occur in similar locations in the body, the diagnostic and treatment pathways are quite different. Blood cancers may be reported individually or as a group, making it difficult to conduct analyses to identify differences in experiences. Cancers such as sarcoma and neuroendocrine can be found across the body, so it is important that these cancers are reported individually as well.

Cancer52 recommends that a principle of always disaggregating datasets by all tumour types be undertaken to allow the NHS and charities to better plan services and support their community of patients. Data should also be disaggregated for age.

There also needs to be investment in analysts so that data is produced more quickly. Staging data for 2019 was not published until December 2021, two years after the event. It is important that staging data for 2020 and 2021 is released much more quickly, so that the impact of the pandemic can be identified and mitigation steps put in place as soon as possible. Registration of all cancer sites must also be encouraged; all cancers report missing stage data in the final statistics and sometimes this is a significant percentage of all cancer cases.<sup>35</sup> For example, 17% of bladder cancer cases in 2018 and 28% of all cervical cancers in 2018 were not registered, compared to only 8% of breast cancer cases.

In addition, we recommend that there is further investment in routes to diagnosis data, to understand the impact on different ways people with rare and less common cancers receive a diagnosis and whether that has changed since the pandemic.

## Health inequalities

**By 2032, cases of cancer attributable to inequalities have decreased.**

- **Data is collected on protected characteristics including age, gender, ethnicity, and sexuality as well as other aspects of inequality, such as socio-economic group, and published in an accessible and timely manner.**
- **Survey collect and report on data relating to inequalities.**

Although 47% of cancer diagnoses in England are rare or less common cancers, 55% of deaths from cancer are from rare or less common cancers. People with rare or less common cancers already face difficulties in diagnosis, treatment and care contributing to the gap between incidence and mortality. This in part can be attributed to the smaller numbers of people with these cancers, which means there is lower 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. Inequalities across age, sex, gender, ethnicity and disability will only exacerbate this issue.

We welcome the continuation of the Cancer Patient Experience Survey and the development of the Quality of Life survey; these must both collect and report on data relating to inequalities. These surveys need to be designed so that they include people with cancers with poor outcomes such as less survivable cancers and secondary cancers or alternative approaches found. They should be representative of communities who are disabled, LGBTQ+, have specific language, cultural and religious needs, a range of ages and from different socioeconomic backgrounds.

Cancer52 members are working to reduce health inequalities and we are also pleased that NCRAS and CADEAS have developed statistics delving into inequalities in more detail. We are also pleased that NHSE is focusing on early diagnosis of cancer as part of its Core20 Plus 5 programme. Data is key to improving health inequalities and there needs to be more investment in ensuring that data on protected characteristics as well as socio-economic data is collected, so gaps in outcomes between different groups can be identified and steps put in place to diminish them.

## Conclusion

We welcome the opportunity to contribute to the 10-year Cancer Plan. We are grateful to the people with rare and less common cancer who responded to our surveys and to Cancer52's member charities, who also contributed by completing surveys and commenting on this submission. We believe that people with rare and less common cancers must be at the centre of the next Cancer Plan so that real improvements in outcomes can be delivered.

For further information on this submission, please contact Jane Lyons CEO, Cancer52, [info@cancer52.org.uk](mailto:info@cancer52.org.uk)

**Cancer52, March 2022.**

## Appendix One: Patient Survey Questions

1. How confident are you that the NHS is providing the best treatment and care it can for you right now?
  - Very confident
  - Confident
  - Neither confident nor unconfident
  - Unconfident
  
2. Were you aware of the signs and symptoms of your cancer before you were diagnosed?
  - Yes, all of them
  - Yes, some of them
  - No
  - Don't know
  
3. Thinking about your treatment and care over the last year, where do you think improvements to your treatment and care could have been made?
  - A speedier diagnosis of my cancer
  - Better information about my cancer
  - More treatment choices for my cancer
  - Better support to improve the side effects or impact of my cancer (including emotional)
  - Shorter waits to see a specialist
  - More doctors or nurses to help me
  - Not relevant
  
4. Where do you think the NHS should focus efforts to improve services, care and outcomes for people with rare and less common cancers?
  - Raise awareness among the general public about rare and less common cancers
  - Raise awareness among doctors and nurses about rare and less common cancers
  - Improve access to tests and scans so people get diagnosed more quickly
  - Ensure people are seen by a specialist quickly
  - Increase the number of treatment options for rare and less common cancers
  - Develop new and better treatments for rare and less common cancers
  - Ensure people have support from a Clinical Nurse Specialist (i.e. a nurse specialising in the type of cancer you have)
  - Ensure people have other kinds of support such as emotional or practical
  - None of these

We also asked a range of demographic questions.

## Appendix Two: Member Survey Questions

1. What is your name?
2. What organisation do you represent?
3. What type of cancer or group of people does your organisation represent?
4. What is the annual income of your organisation?
  - Below £100,000 or no income indicated
  - £100,000 to £499,999
  - £500,000 to £999,999
  - £1m to £2m
  - £2m to £5m
  - £5m +
5. In your view, overall progress against the cancer commitments in the NHS Long Term Plan has been:
  - Better than expected
  - On track
  - Made in some areas but not all
  - Disappointing
  - Don't know
6. Regarding your answer to the last question, what progress do you think has been made against the following specific commitments that were included in the NHS Long Term Plan?
  - Diagnosing 75% cancers at stage 1 or stage 2 (early diagnosis ambition)
  - Saving 55 000 lives
  - Roll out of personalised care
  - Roll out of Rapid Diagnostic centres
  - Stratified follow up pathways
  - Patients receive a diagnosis within 28 days (faster diagnosis standard)
  - Other
7. How has the pandemic affected cancer care for the people your charity supports?
  - No impact
  - Diagnosis delays
  - Treatment delays
  - New treatments being used
  - People swapped on to different treatments

- Less access to CNSs
  - Increased mental health issues
  - Other (please state)
8. What are the most important things to tackle now to help support the people your charity represents? (Please choose up to three)
- Reducing the backlog in diagnosis
  - Asking people to come forward for diagnosis
  - Improving access to GPs
  - Reducing the treatment backlog
  - Better communications for people with cancer regarding the implications of COVID-19 for example, on vaccines and risk
  - More funding for the NHS and social care
  - Addressing workforce shortages
  - Updating equipment
  - Ensuring access to medicines on the NHS
  - Increasing research into rare and less common cancers
  - Restructures in the health and social care system
  - NHS Cancer programme working collaboratively with cancer charities
  - Cancer alliances working collaboratively with cancer charities
  - Timely data
  - Other (please state)
9. Is there anything that needs to be added to the NHS Long Term Plan following the pandemic?
- Free text response