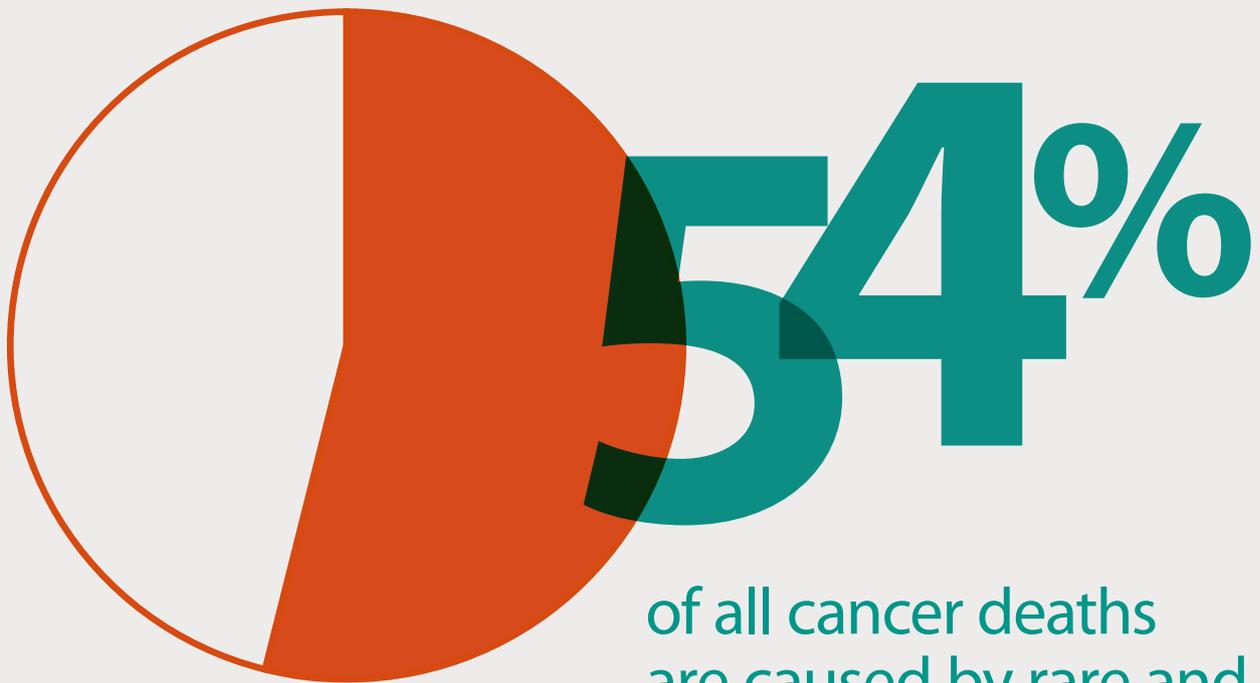


# Living with a **rare or less common cancer**

Patient experiences of treatment and care



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

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# Foreword

**Cancer52 exists to provide a voice for those organisations that represent people with rare and less common cancers. As such, we have a duty to speak up when we see clear evidence of the inequalities in treatment and care that exist in the field of cancer - inequalities that have a significant impact on both the quality of life and the prognosis of people with rare and less common cancer.**

That is why we commissioned an analysis of the results from the national cancer patient experience survey, focused solely on the experiences of people with rare and less common cancer. We wanted to understand more about where care and cancer services differ between those with the big four cancers and everyone else, as well as understanding more about the impact that has on people with cancer and their families and friends.

We knew that there were likely to be disparities between the experiences of people with different types of cancer. But what surprised and shocked us was just how widespread and how big those differences are.

People with a rare or less common cancer have a poorer experience in almost every aspect of their treatment and care. Some of the differences between tumour groups are large - as much as 30-40% in some areas, with those who have one of the big four cancers having a significantly better experience. Some of the differences in care are also hard to explain - why should you be more than twice as likely to receive information if you have one type of cancer compared to another? Why is it that people with a rare or less common cancer are less likely to see a clinical nurse specialist or be given a choice of treatment? These are big questions to which we need some urgent answers.

People with a rare or less common cancer are disadvantaged at every step of their journey with cancer. From the speed of diagnosis through to treatment and research, people with rare and less common cancers often get a second class service and a poor deal. It is time to level the playing field - by ensuring that people are treated equally, that they get the specialist treatment they need and that they are properly supported to live their lives as fully as possible. It is time for policy makers, health professionals and commissioners to acknowledge the differences in patient experience and to take positive and meaningful steps to address them.

**Jonathan Pearce**  
Chair of Cancer52



# Executive summary

**Across all types of cancer, on the whole, people's experience of treatment and care is improving year on year. However, the experience of people with rare and less common cancers is less positive across almost every aspect of treatment and care, compared to those people with one of the big four cancers (lung, prostate, breast and bowel). In many cases, there appears to be no obvious reason why this should be the case.**

- There are some groups of people with cancer, such as those from ethnic minority groups or areas of economic deprivation, who have a poorer experience of care than others.
- The clinical nurse specialist (CNS) plays an important role in improving patient experience. People who have access to a clinical nurse specialist have a more positive experience, across almost all areas of treatment and care. However, 15% of people with rare and less common cancer do not have access to a CNS.
- There is inequity in the provision of Clinical Nurse Specialists. Not every individual has access to a CNS, and in some areas there are no CNSs in post to support people with certain types of tumour.
- People who have access to high quality and relevant information about their cancer and its treatment report a more positive experience of care. Access to good information is linked to positive health outcomes.<sup>1</sup>
- Information provision, both written and verbal, is the area where people with a rare or less common cancer report the biggest differences in care, compared to people with one of the big four cancers. They report less positive experiences around information, sometimes by as much as 10%. This includes information about treatments, side-effects, long-term health, emotional support and practical matters such as finances.
- The quality of information, and its availability, varies nationally. People with a rare or less common cancer need information at the right time and in the right format for them. That information needs to be well communicated and easy to understand.
- Treatment at a specialist centre makes a difference. Everyone with a rare or less common cancer should be referred to an appropriate specialist centre.
- People with a rare or less common cancer have a less positive experience when moving between services. Communication between non-specialist and specialist services and between primary and secondary care is sometimes poor. This is one area where the patient experience is getting worse over time, rather than better.
- Early diagnosis of rare and less common cancers is a significant issue. When symptoms are vague, as they can be for people with rare or less common cancers, diagnosis can be more challenging. In general, it takes longer for people to be tested and for the results to be reported on. Diagnosis may improve with better access to diagnostic tests for GPs, and/or quicker referral to a specialist.
- When asked to take part, people with a rare or less common cancer are more likely to participate in research. This was the only aspect of experience where people with a rare and less common cancer scored more positively than those with one of the big four cancers

# Calls to action

**People with a rare or less common cancer deserve equality of treatment and care, which puts them on an equal footing with people who have one of the big four cancers. Cancer services need to be evaluated, reconfigured and improved to ensure that people with a rare or less common cancer no longer receive a second class service.**

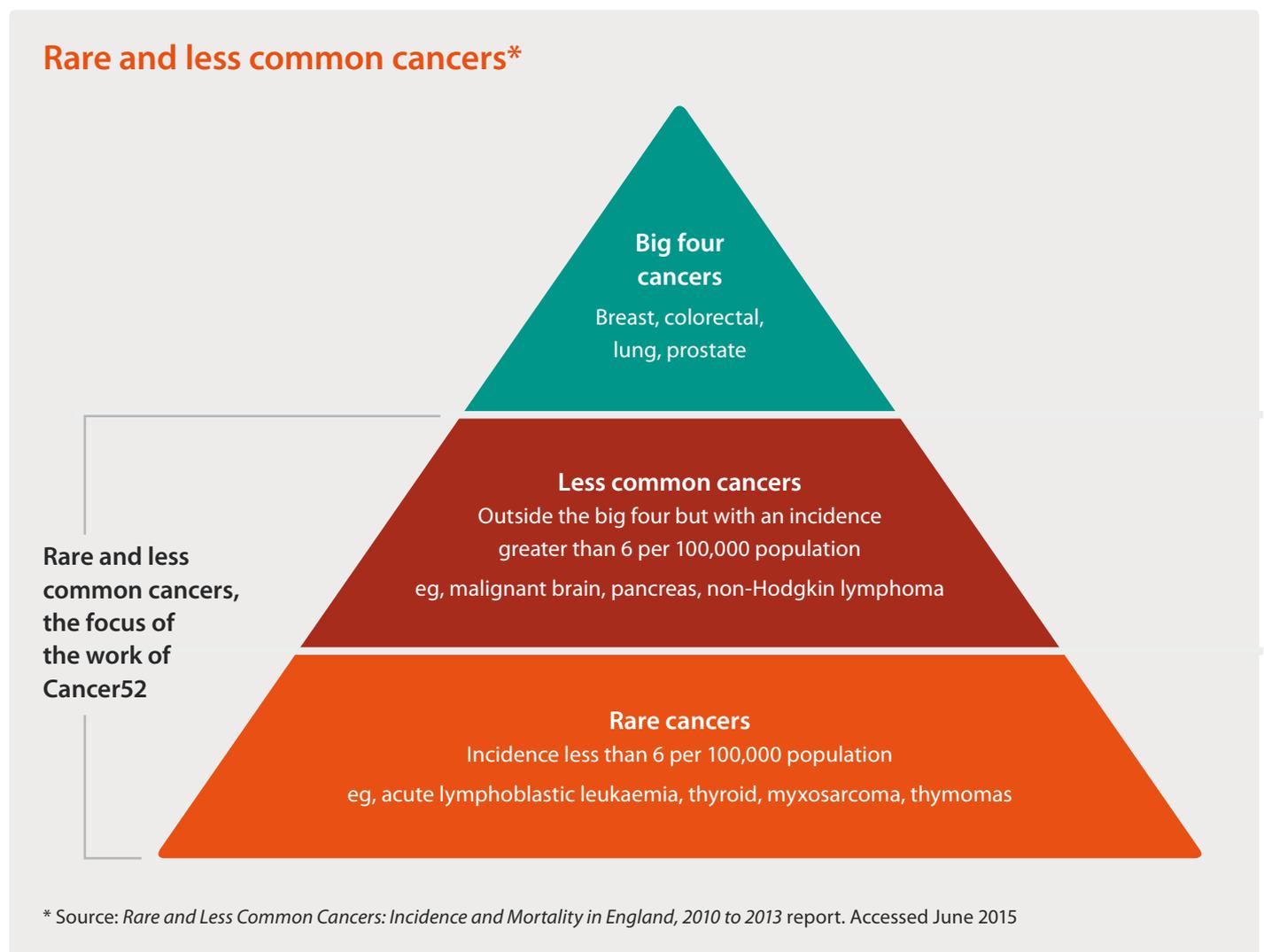
- People with a suspected rare or less common cancer should have access to a multidisciplinary diagnostic centre to ensure that their cancer is identified and treated as quickly as possible.
- Every individual with a rare or less common cancer should be routinely assessed and treated by a specialist in their particular cancer, or be treated at a specialist centre.
- Every individual with a rare or less common cancer must have access to a named Clinical Nurse Specialist, who can provide expertise and support around their particular cancer and provide a point of contact across services.
- Clinical Nurse Specialists must have access to appropriate training and resources and be part of a multidisciplinary team that straddles both primary and secondary care.
- Every individual with a rare or less common cancer must have access to high-quality, relevant information about their cancer, its treatment and living day to day with cancer, regardless of where they live or what type of cancer they have.
- People with a rare or less common cancer must be properly supported and followed up after their treatment has ended, to help them come to terms with, and manage, the emotional and social impact of their condition.
- GPs must be part of the local multidisciplinary team that cares for people with rare or less common cancers, to help ensure good communication and seamless care across services. To support them in this role, GPs need appropriate training and support.
- National or regional multidisciplinary teams must be established for rare cancers where treatment options are low volume and/or high risk. This will help to ensure more effective information sharing and decision-making, and a better experience for patients.

# About rare and less common cancers

There are more than 200 different types of cancer. However, there are four types of cancer which together cause almost half (46%) of cancer deaths in the UK - lung, breast, prostate and colorectal cancer.<sup>2</sup> These types of cancer grouped together are sometimes called 'the big four'.

**Less common cancers** affect more than six in every 100,000 people and include cancers such as uterus, ovary, melanoma, kidney and cervix, as well as those listed below.<sup>3</sup>

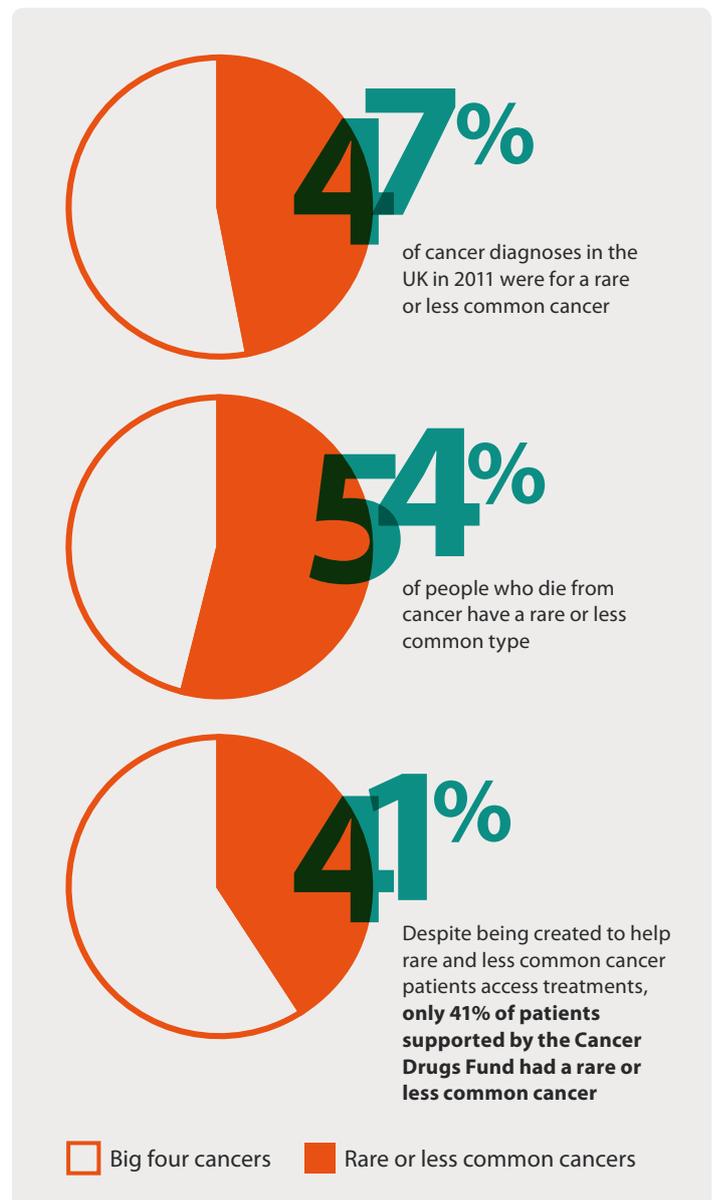
**Rare cancers** are those that affect fewer than six in every 100,000 people and includes thyroid, myxosarcoma, thymomas, liver, ALL (acute lymphoblastic leukaemia) and bone cancers.<sup>4</sup>



## The outlook for people with a rare or less common cancer

**Just under half (47%) of people diagnosed with cancer in the UK in 2011 had a rare or less common cancer.<sup>5</sup> However, more than half (54%) of people who die from cancer have a rare or less common type.<sup>6</sup>**

- People who have a rare or less common cancer also have a less positive health outlook than those with a big four cancer (there are however variations for specific cancers that are either above or below the generalised statistics and averages for all rare and less common cancers):
  - Although the number of people diagnosed with rare or less common cancer remains in line with the general increase in all cancer diagnoses, the number of people who die from this type of cancer has increased year on year. In 2013 there were around 2,700 more deaths than in 2010, outside of breast, colorectal, prostate and lung cancers.<sup>7</sup>
  - People with a rare or less common cancer are less likely to survive for 5 years after their diagnosis; 47% of people survive for 5 years compared to 65% of people who have one of the big four cancers.<sup>8</sup>
- For people with a rare or less common cancer, every stage of the cancer pathway from diagnosis to access to treatments is more difficult. The patterns vary from cancer to cancer, but overall less is invested in research. Diagnosis is more complex because the numbers of people with the cancer are smaller and symptoms less well known (and thus the individual cancers themselves and their treatments are less understood). Once diagnosed, the patient experience is worse and the number of drugs and research programmes developed are fewer, with less innovation in the field.
- One of the main objectives of the Cancer Drugs Fund was to help people with rare and less common cancers access new and innovative treatments. Yet, 59% of the patients supported by the Fund were being treated for colorectal, prostate and breast cancer (three of the four most common types of cancer), which account for only 41% of overall cancer prevalence.<sup>9</sup>



## Cancer strategy in England

'Cancer survival in England has improved significantly over the last 15 years. More than half of people receiving a cancer diagnosis will now live ten years or more. But our mortality rates are higher than they could be. In addition, unacceptable variability exists in access to and experience of care across different areas, sub-groups of the population and cancer types. There is much we could do to improve patient experience and long-term quality of life, and to make our care more patient-centred.'

**Achieving world-class cancer outcomes a strategy for England 2015-2020, Executive Summary**

In July 2015 the Independent Cancer Taskforce published a new five-year national Cancer Strategy for England.<sup>10</sup> Cancer52 was involved in the development of the cancer strategy from its inception, with former Chair Clara MacKay representing the coalition alongside other key representatives from the cancer community.

The plan, which aims to make significant improvements in cancer care in England, comes at a time when cancer cases are increasing. 280,000 people were diagnosed with cancer in England in 2013/14 and this is expected rise to more than 360,000 in the next 15 years. Half of the population of the UK will develop cancer at some point in their lives. If recent trends continue, the majority of these will have a rare or less common type of cancer.

Overall, people are now more likely to survive cancer, though survival rates vary widely across cancer types with some cancers with one year survival rates as low as one in five.<sup>11</sup> However, many more people are living long-term with the condition. The cancer strategy sets out six priorities, including proposals for how patient experience can be transformed both during and after treatment.

### The six priorities are:

- 1. Improved cancer prevention and public health**, including a focus on public awareness of lifestyle risk factors such as smoking and obesity.
- 2. Earlier diagnosis.** The ambition is that, by 2020, 95% of people with suspected cancer will be referred for testing by a GP, and receive a clear diagnosis (of cancer or not) within four weeks.
- 3. Putting patient experience on a par with clinical effectiveness and safety.** The strategy recommends giving people electronic access to their test results and other communications by 2020. There is also an ambition that all patients should have access to a clinical nurse specialist or other key worker to help coordinate their care.
- 4. Better support for people living with, and beyond, cancer.** One of the main aims of the strategy is that every person with cancer should benefit from elements of a 'Recovery Package' - a comprehensive plan that outlines treatment as well as post-treatment support and care.
- 5. Investment to deliver a modern high-quality service**, including better diagnostics and a permanent cancer drugs fund.
- 6. Improved processes for commissioning, accountability and provision.**

### The cancer strategy also sets out some specific recommendations about the treatment and care of people with rare and less common cancers:

- **National or regional multi-disciplinary teams** should be established for rarer cancers.
- **Multi-disciplinary diagnostic centres** for vague or unclear symptoms should be developed and tested.
- **Clinical research** should be maintained at its current level, to ensure that as many patients as possible have the opportunity to be part of a study. Steps should also be taken to reduce the time it takes to get studies set up, which should open up the prospect of additional clinical trials, particularly in rarer cancers.
- **A directory of local services** should be provided for people with cancer, their carers and families. This includes services for people with rare and less common cancers who often report difficulties in accessing this kind of information.
- **Follow-up pathways of care** for some rarer cancer types should be piloted.
- **National commissioning of treatment services** should take place for rare cancers (fewer than 500 cases a year) across England.
- **Clinical Reference Groups** should take responsibility for developing minimum service specifications where patient volumes are too low to be covered by a NICE clinical guideline, for example for rarer cancers.

# The Cancer52 patient engagement meeting

In the spring of 2015, Cancer52 held a meeting to explore the care that people with rare and less common cancers receive, and how that might be improved. The aim was to bring together key stakeholders from the rare and less common cancer community, including patients, patient group representatives, clinicians, cancer policy representatives and researchers, to consider the key challenges and issues facing this patient population.

The purpose of the event was twofold: first, to identify the action needed to ensure the interests of this patient population are adequately served by the NHS; and, secondly, to inform Cancer52's priorities and work programme for 2016.

Representatives from more than 20 different patient organisations attended, some with direct experience of living with a rare or less common cancer. The organisations represented at the meeting are listed on page 26.

The programme was shaped around the current NHS cancer policy framework and key themes, including early diagnosis, access, patient experience and research.

Attendees heard from three key speakers:

- **Daniel Ratchford**, Chief Executive at Quality Health, who talked about the results of the National Cancer Patient Experience Survey and the experiences of people with rare and less common cancers.
- **Dawn Green**, a Pseudomyxoma Survivor, who gave a candid account of living with pseudomyxoma peritonei, a very rare type of cancer.
- **Sean Duffy**, National Clinical Director for Cancer for NHS England, who talked about the future for cancer services and for rare and less common cancers.

Attendees took part in two question and answer sessions and a wide ranging discussion about the experiences of people with rare and less common cancers. The common themes and issues, plus the main discussion points from the day, form part of this report.

# Results of the National Cancer Patient Experience Survey

## Key points

1. People with a rare or less common cancer report a significantly worse experience of care.
2. The Clinical Nurse Specialist (CNS) is especially important for people with rare and less common cancers. Where people have access to a CNS, they have a better experience of care.
3. A positive experience around written and verbal information is linked to positive health outcomes.
4. When moving between services in secondary and primary care, people with cancer are seeing a worsening of care.

## The survey

The National Cancer Patient Experience Survey (NCPES)<sup>12</sup> has been running since 2010 and is the largest survey of its kind in the world. The survey is sent out to every patient in England treated for cancer within a specified three month period. The 2014 National Cancer Patient Experience Survey was sent out to over 109,000 NHS patients being treated at 153 different NHS Trusts.

The survey has a high response return rate, nearly 65%, and therefore the results are a very accurate representation of people's perceptions of their care. The number of years that the survey has been running also enables comparisons to be made year on year, and any improvements in experience to be clearly seen.

Cancer52 commissioned an analysis from the independent research agency Quality Health (the company currently commissioned by NHS England to run the NCPES), exploring the responses of people with a rare and less common cancer, compared to those people with one of the big four cancers. It is the first analysis of its kind.

'In the survey world, this is about as good as it gets in terms of gathering sensible and accurate information.'

**Daniel Ratchford, Quality Health**

## The results

### General findings for all types of cancer

- In England, cancer patients are doing better and are having a better experience on most aspects of their care than in most other countries where the same, or similar, survey data is being collected, for example Australia, Wales and Northern Ireland.
- Overall the experience of people with cancer is positive, with 80% or more being scored on more than half of the questions asked.
- Cancer patients are more positive about their care than non-cancer patients.<sup>13</sup>
- In most (but not all) areas covered by the survey questions, experience is improving over time. The areas that have shown an improvement in experience include the provision of written information, choice of treatment, being given an explanation of tests and treatments, and confidence and trust in ward nurses. Such improvements demonstrate the value of gaining regular, consistent and reliable data which commissioners can use to improve outcomes.
- Some people with cancer have a poorer experience of care compared to others with cancer. People with a long-term condition other than cancer, or multiple long-term conditions, were less likely to be positive about their care - as were some ethnic minority patients; younger patients aged 16-35; patients attending London hospitals; lesbian, gay, bisexual and people classifying themselves as 'other'; and women.
- Most individual NHS Trusts have seen improved results since 2010 when the survey first ran. The greatest improvements have been seen in those Trusts that have taken deliberate steps to improve the experience of their patients.
- The number of patients being given the name of a clinical nurse specialist (CNS) has increased.
- Analysis shows that the single most important factor is having access to a Clinical Nurse Specialist; it drives positive responses in all other questions in the survey. If people have access to a clinical nurse specialist their overall experience is better.<sup>14</sup>
- When asked whether hospital and community staff always work well together, people reported a worsening experience from the previous year, rather than an improving one.
- People who were diagnosed with cancer more than five years ago tend to be less positive than those diagnosed more recently.
- People who are diagnosed as a result of a visit to the emergency department are much less likely to be positive about their experiences than those who are diagnosed through any other route.
- People who have a recurrence of cancer, and those whose treatment is ineffective, have a less positive experience of care.

'...we've done some really interesting statistical analysis that shows that this one question (about being given the name of a clinical nurse specialist) drives positive satisfaction with virtually every other question in the survey. So, if you get this one right, everything else absolutely follows from it.'

**Daniel Ratchford, Quality Health**

## Survey findings for rare and less common cancers

Around half of survey respondents in 2014 had a rare or less common cancer.

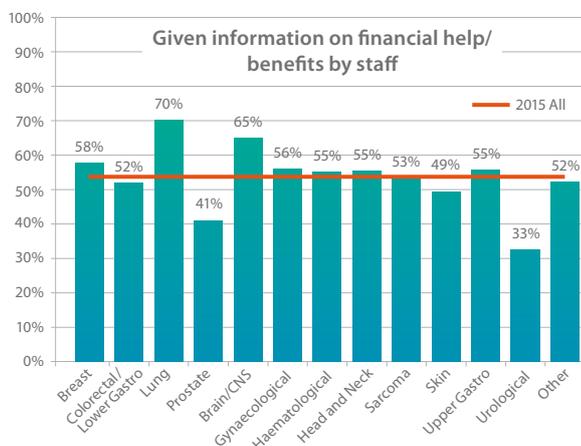
Comparisons between the experiences of those with one of the big four cancers and those with a rare or less common cancer show that, in almost every area, the experience of treatment and care is less positive. In some areas the difference in results between the two groups as a whole was as much as ten percent.

*'Anyone with a cancer outside the top four tends to be significantly less positive on pretty much every question.'*

**Daniel Ratchford, Quality Health**

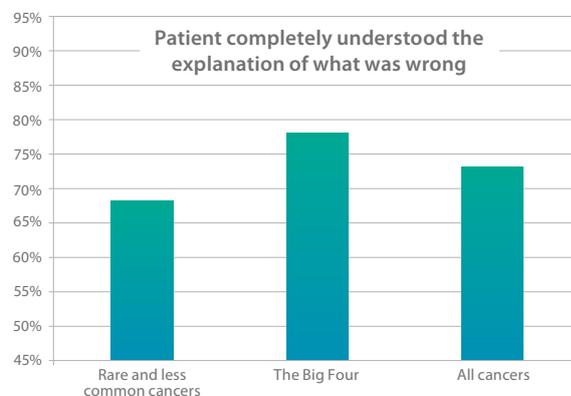
### Information and communication needs

- In some areas there are significant differences in information provision depending on the type of tumour someone has. For example, 80% of people with prostate cancer were given written information about their type of cancer compared to 58% of people with sarcoma; and 70% of people with lung cancer were given information on financial help, compared to 33% of people with urological cancer.

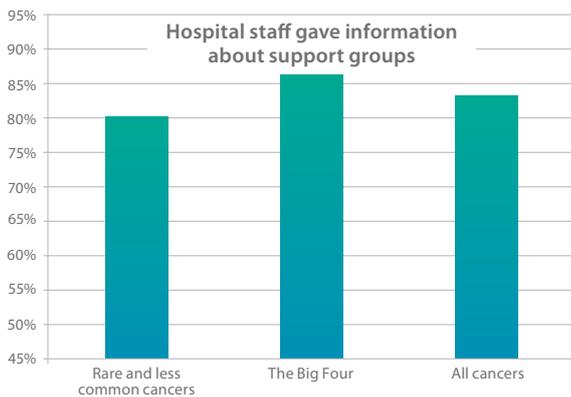


Quality Health, (2014) National Cancer Patient Experience Survey 2014. Leeds. NHS England. P58

- People with the one of the big four cancers were more likely to be given a complete explanation of their test results than someone with a rare or less common type of cancer. 80% of people with one of the big four cancers were given a full explanation, compared to 76% of people with a rare or less common cancer.
- There were differences in the provision of written information about side effects - 86% of people with one of the big four cancers received information, whereas 79% of people with a rare or less common cancer received it. People with a rare or less common cancer were also less likely to have side-effects explained in a way they could understand (73% compared to 77%).
- When asked whether they completely understood the explanation of what was wrong, 68% of people with a rare or less common cancer said yes, whereas 78% of people with one of the big four cancers said yes.



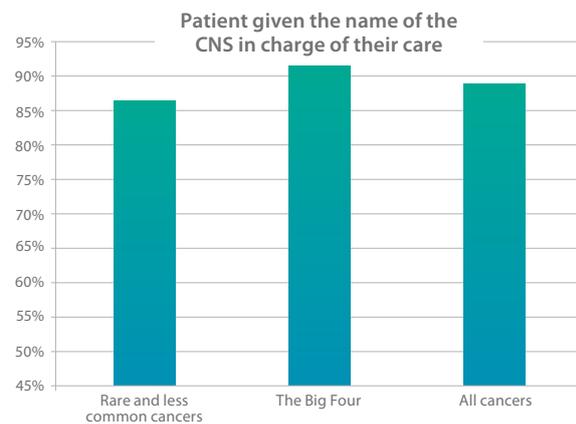
- There were also differences in the experiences of people with rare and less common cancer when it came to support information. 80% of people with a rare or less common cancer were given information about local support groups, compared to 86% of people with one of the big four cancers.



- Fewer people with a rare or less common cancer were given clear written information about their operation (70% compared to 80%) or about what they should, or should not, do once they had left hospital (83% compared to 87%).
- When it came to information about the future, again there were marked differences between the two groups. 59% of people with one of the big four cancers were told about the side-effects that could affect them in the future, whereas for people with a rare or less common cancer that figure was 52%.

### The Clinical Nurse Specialist (CNS)

- 86% of people with a rare or less common cancer were given the name of the CNS in charge of their care. However, 92% of people with one of the big four cancers were given the name of a CNS.



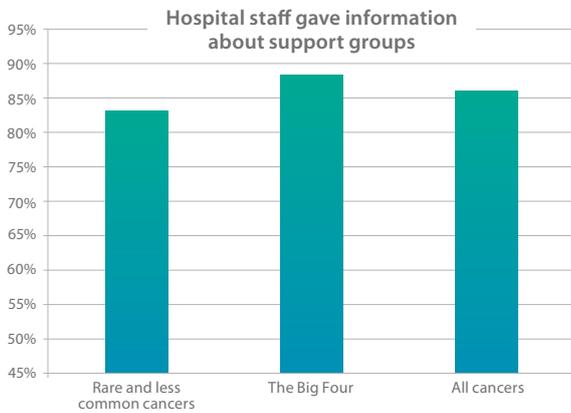
- If people with a rare or less common cancer have access to a clinical nurse specialist, it is the main factor driving their experience (as is the case for all forms of cancer (see earlier)); if people have access to a CNS it improves their experience in every other area.

'Just over 85% of people were told the name of their CNS. Not bad, but it ought to be 100% and this is the question that we know drives all others; so if there is one thing that needs to be got right for people with rare and less common cancers, it ought to be this one and this will then automatically drive more positive responses in all other areas. So, if you've got a named CNS and if you're communicating effectively with that CNS, you will be getting more information and you will understand more about your treatment.'

**Daniel Ratchford, Quality Health**

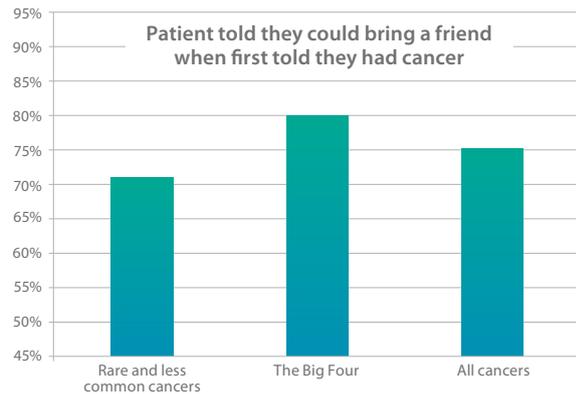
## Treatment and care

- 83% of people with a rare or less common cancer were given treatment choices, compared to 88% of people with one of the big four cancers.



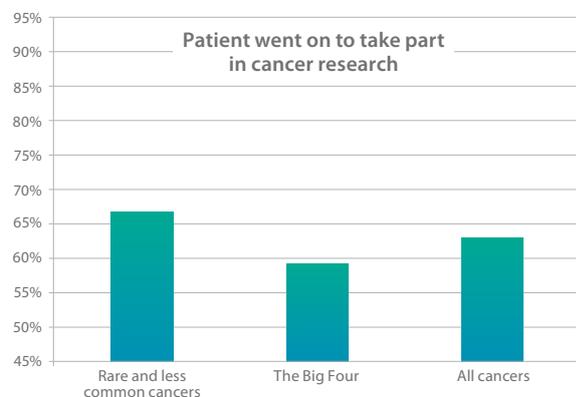
- When asked if they had 'definitely been given enough care from health or social services', there was a difference between the types of cancers; 56% of people with a rare or less common cancer said yes, compared to 61% of people with one of the big four cancers.
- People with a rare or less common cancer were also less likely than people with one of the big four cancers to think that they were seen as soon as necessary (81% compared to 86%), and less likely to find that their health got better or remained about the same while waiting (74% compared to 86%).

- There were differences in approach to the support needed at diagnosis too. 71% of people with a rare or less common cancer were told they could bring a friend with them when first being told that they had cancer, compared to 80% of people with one of the big four cancers.



## Research

- People with a rare or less common cancer were less likely to see information about cancer research in the hospital; and less likely to be asked whether they would like to take part. But when they were asked to take part, 67% of people with a rare or less common cancer said that they did, compared to 59% of people with one of the big four cancers. This was the only question in the survey where people with a rare or less common cancer scored more highly than those with one of the big four cancers.



# Improving care for people with rare and less common cancers

This part of the report sets out four main challenges facing people with a rare or less common cancer, and presents some possible solutions. These challenges reflect the main issues highlighted during the Cancer52 event held in London on 3 March 2015, and are also common themes evident in other work that the organisation has undertaken. They are the views of patients, and the organisations that represent and support them, alongside policy makers and health professionals.

## Access to a Clinical Nurse Specialist (CNS)

Clinical nurse specialists provide expert advice about conditions and treatments. They focus on improving patient care and, as part of their role, they provide specialist advice and assess, plan, implement and evaluate evidence-based care.<sup>15</sup>

Clinical nurse specialists in oncology (cancer) support and care for people with cancer and their families and carers. For people with rare and less common types of cancer they provide an invaluable source of expertise and information, as well as a consistent point of contact across services and between hospital and primary care.

The National Cancer Patient Experience Survey shows clearly the importance of the CNS role for people with cancer, in that it is linked strongly to people's perceptions of their care. Those who have access to a clinical nurse specialist have a better experience of care.

However, not everyone has access to a CNS, and those people with a rare or less common cancer are least likely to.

The role of the CNS, and the part it plays in the care of people with rare and less common cancer, was discussed at length at the Cancer52 event.

### These are the main points raised:

- The clinical nurse specialist role is important and needs to be prioritised.
- The CNS has an important impact on the overall quality of life of people with cancer, and can help to reduce the anxiety and stress levels of their patients.
- Some patients and their families do not understand what a CNS is, or what he or she does.
- People with a rare or less common cancer may find that their CNS has little experience or expertise in their particular type of cancer.

'For rare and less common cancers, you may have access to a nurse specialist but, in our experience for rarer cancers, he or she may not be a specialist with expert, insider knowledge.'

**Clara Mackay, Interim Chair, Cancer52**

- There is inequity in the provision of clinical nurse specialists across England. Not every patient will have access to a CNS and in some areas there are no CNSs in post to support people with certain types of tumour.
- The CNS role is under pressure. Nurses often have little time or funding available for training, education or peer support. Patients may also get less time than they need with their nurse, due to workload pressures.
- The CNS role in oncology should be evaluated, to ensure that it continues to meet patient needs.
- The CNS usually takes a holistic approach to care, including managing non-clinical aspects. Patient groups and charities also have a role in providing this type of non-clinical support to patients and their families.

'I think generally there's very little support for Clinical Nurse Specialists, in terms of time, in terms of opportunities for them to get together, in terms of sponsorship to conferences where they could get together.'

**Sophie Wintrich,**  
**MDS Patient Support Group**

### ➤ Recommendations

1. Every clinical nurse specialist should explain their role clearly to their patients.
2. If a patient does not have access to a CNS, they should be given an alternative named health professional contact.
3. More research should be undertaken to demonstrate the value and impact of the Clinical Nurse Specialist on people with cancer and their families, on the NHS and on the wider economy.

## UK Oncology Nursing Society President Catherine Oakley comments on the vital role of the Clinical Nurse Specialist



Cancer52's analysis of the data from the National Cancer Patient Experience Survey shows that access to a Clinical Nurse Specialist (CNS) improves patient experience of cancer care. Why? I believe that is because CNSs

are highly experienced, well qualified and uniquely placed to support patients with rare and less common cancers; by offering holistic, expert care which crosses care boundaries and which supports people emotionally and practically as well as physically.

Being diagnosed with cancer is deeply upsetting and confusing for patients and their families and friends. It can be difficult to make sense of everything, to have to make big decisions about treatment and to navigate through an increasingly complex health service to find the right care. This is an even greater challenge if you have a rare or less common cancer.

Cancer CNSs support patients through diagnosis and treatment by providing psychological support, they help with decision making and they also help people to stay well and out of hospital. They provide invaluable information too, which helps people to understand what is happening to them and empowers them to manage their own care. Communication with and between services is another important aspect of their role, joining

up hospital, community, hospice and other care, thereby helping patients to have seamless and continuous care. In essence, being a CNS is about being in a position of trust and respect, and being someone that patients and their families can rely on in a time of acute distress.

There are more than 3000 oncology (cancer) nurse specialists in the UK,<sup>16</sup> many of whom care for patients with specific tumour types. More than half all of CNSs care for people with a rare or less common cancer, including some specific tumour groups such as sarcoma, gynaecological cancers and mesothelioma.<sup>17</sup> However, there is some variation across geographical areas, which means that not everyone with a rare or less common cancer will have access to a CNS. Though the number of CNSs is increasing steadily year on year,<sup>18</sup> so is the number of people with cancer. Therefore, there are still some patients who miss out on the opportunity to make use of such an invaluable resource. Sadly, it is those people with a rare or less common cancer who are most affected.

There is no doubt that the NHS is under severe pressure at the moment. However, the evidence shows clearly how valuable CNSs are, not just for patients and their families, but for health services too - they are cost effective, efficient and lead to better health outcomes for people with cancer.<sup>19</sup> They are a vital part of high quality care for people with rare and less common cancer and my hope is that in the future everyone will have access to their skills, compassion and expertise.

**Catherine Oakley**, chemotherapy nurse consultant, Guys and St Thomas' Foundation Trust, and president, UK Oncology Nursing Society

## Information and support for people with rare and less common cancers, and their families and carers

Evidence clearly shows that providing high quality health information to people is beneficial. It has a positive impact on their experience of healthcare and on their health behaviours.<sup>20</sup>

Providing good information helps people to improve their knowledge and understanding, to participate in shared decision making, to form realistic expectations about their treatment and to have a better quality of life. By providing information, health professionals can empower their patients to engage more fully in their care, reduce their fear and anxiety levels and increase their feelings of being in control.<sup>21</sup>

Many of the National Cancer Patient Experience Survey questions where there were the largest differences between the experiences of people with different types of cancer were those relating to information and communication. This was also one of the major discussion themes at the Cancer52 event.

‘What we know from the data is that there’s more written information given to patients with one of the big four cancers than patients with a rare or less common cancer. We also know from the data that there’s massive variation in practice around the country, so in some NHS trusts, far more patients are getting written information than in other trusts.’

**Daniel Ratchford, Quality Health**

### The main issues highlighted were that:

- More written information is given to people with one of the big four cancers than to people with a rare or less common cancer.
- People with a rare or less common cancer can wait a long time to receive information about their condition. There can also be a long period between an initial diagnosis and the next appointment when people are without appropriate information and support.
- More detailed information about treatment options is needed.
- The onus is sometimes on the individual to find their own information and start the discussion about treatment options with their health professional.

‘This information thing is so frustrating, it’s so easy to fix, there is good information, we’re all in this business, we can help. It wouldn’t cost the NHS anything and yet we see this constant failure.’

**Clara MacKay, Interim Chair, Cancer52**

- People with a rare or less common cancer need information at the right time and in the right format for them. That information needs to be well communicated and easy to understand. People also need support to assess and choose quality information sources.
- The quality and availability of information provision varies across England. Whether someone receives written information may be related to how information is managed within an NHS Trust, rather than whether it exists.
- Some organisations are finding the Information Standard<sup>22</sup> certification scheme for health information onerous.
- There is a belief among some patient groups that NHS organisations will not provide information to their patients unless the producing organisation has the Information Standard. Other patient groups say that in Trusts where there is a clinical nurse specialist, information is often provided to patients whether the producing organisation has the Information Standard or not.
- Sometimes health professionals make decisions about the information they think their patients need, and choose for them.

'I'm a great supporter of nurses and healthcare specialists but there is something about their understanding what a good service looks like from a patient experience point of view, rather than what a good service looks like from a clinical perspective. Because I think that's when we hear things... about selective provision of information, not wanting to frighten people, not wanting to put patients in touch with other patients because that's too grim, and these are all the things that patients say would have made a difference to them.'

**Clara MacKay, Interim Chair, Cancer52**

### ➤ Recommendations

1. People with rare or less common cancer must have access to readable, accurate and relevant information, given at the right time and in the right format for them.
2. Patients and their families should be supported to assess and choose appropriate, high-quality information sources.
3. More information is needed about treatment choices.
4. NHS organisations should be resourced and supported to routinely provide information about rare and less common cancers to their patients.
5. More explicit information about research and clinical trials should be made available to people with cancer.
6. Cancer52 should act as a resource, providing details of organisations that produce information about rare and less common cancer.

## One woman's experience of chordoma



It started back in 2007 with what I thought was a slipped disc. I have always been incredibly fit and had an active and busy life, so when my back went I really went through it, the pain was incredible. I'm

an advocate of alternative treatments so I went along to a chiropractor who told me it was a slipped disc. For a few weeks I had chiropractic treatment and acupuncture but it was getting worse. So, I went to my GP who took one look at me and said you're having an MRI scan straightaway.

It took six weeks to diagnose a Chordoma. I searched for information on Google, and there was nothing; it didn't even recognise the word. There was nothing in books either and the doctors knew very little about it. There was no one to turn to at all, and that's incredibly

**Susan Fitz-Gibbon, founder, Chordoma UK**  
[www.chordoma-uk.org](http://www.chordoma-uk.org)

isolating. No-one was able to give me any real information about how my life was going to be from now on. I felt I had lost control, not a feeling I'm particularly comfortable with and I confess to being scared. Eventually I did find some information, but even now, with a long term pain control infusion, I still find that there is no one to talk to about that; I'm very much left to my own devices.

In 2012 I became ill again and felt I needed to do something about the lack of awareness, information and research into Chordoma. My husband and I set up Chordoma UK – to raise money for direct research about the condition and to raise awareness among the public and the health professions. Getting information to people with the condition is still a challenge and we work hard to get it out there – with a website, Twitter, flyers, a Facebook page and by word of mouth. We are known now in the cancer community, but attitudes to rare and less common cancers need to change. We need to be heard, to shout about things and to have a voice.

## Moving between services (transition)

People with cancer need joined up services which focus on person-centred care from diagnosis through to end of life care. When care is joined up, people feel better supported and more confident that all of the health professionals involved in their care are working together to understand their needs. When people with cancer move between their hospital and GP surgery or to tertiary or hospice care, it is vital that the information about them follows and that care continues seamlessly.

However, no single body or person at local, national or regional level has overall accountability for the patient pathway for people with cancer, whatever type they have.<sup>23</sup> This can lead to people with cancer and their families being unable to access the services and support that they need. People with cancer can also 'fall through the cracks' because their referrals are not being picked up, or because the information about them is not being properly shared.

### **These were the main issues raised about moving between services:**

- For people with rare or less common cancer, problems are most likely to arise when moving from treatment in hospital to care given in general practice, and vice versa.
- Communication between local hospitals and specialist centres is sometimes poor or inadequate.
- Better communication within GP practices would ensure better continuity of care.
- GP training about rare and less common cancers needs to improve.
- Shared electronic records would improve communication and understanding for both people with cancer and for health professionals.

'Transition failures, handovers from hospital to local area, whatever, are just disastrous and because they're disastrous, because they're inefficient, inaccurate, and filled with errors, it's costing the NHS a fortune and causing patients unnecessary problems.'

**Chris Arthur, PRDA**

'...access to tests would have made a difference to GPs in about 6% of cases. But when you go back to the key cancers where it isn't that easy to make a diagnosis - brain, pancreas, kidney, stomach, testicular and ovarian cancers - in one in five cases, 20%, tests would have made a difference.'

**Sean Duffy, NHS England**

### **➤ Recommendations**

1. Primary care doctors, and local hospital consultants where appropriate, should be involved in the multidisciplinary teams looking after people in specialist centres. This would help to ensure greater continuity, regardless of where the patient's main care is focused.
2. Clinical nurse specialists should maintain contact with their patients when they are discharged to primary care, or to a hospice.
3. In larger practices there should be a GP or healthcare professional who has oncology skills and experience.

## Getting the right treatment from the right people

In 2009, Cancer52 contributed to a consultation led by National Cancer Survivorship Initiative<sup>24</sup> which explored the treatment and care of people with rare and less common cancers. In a summary of their findings they reported that there are fewer specialist resources available for the treatment and care of people affected by the less common cancers, compared with those available to people affected by the big four cancers.

The consultation also found that there are fewer centres of excellence, and this impacts on many aspects of people's cancer journey. It has implications for the quality of care and treatment, including in the longer-term, but it also has important practical and financial implications due to the distance that people need to travel for treatment.

### **Access to specialist treatment continues to be an important issue for people in 2015:**

- Referral to a specialist centre can make an enormous difference to people with rare and less common types of cancer. However, some people are concerned about asking their consultant for a referral, or experience reluctance from their consultant to refer them on.
- Patient organisations believe that everyone with a rare or less common cancer should be referred to a specialist multidisciplinary centre.
- When symptoms are vague, as they can be for people with rare or less common cancers, diagnosis can be more challenging.
- The main differences between England and those countries that have the best survival rates for cancer are, for GPs to have access to appropriate diagnostic tests, having a willingness to test someone if cancer is suspected, and having access to a specialist opinion.
- Early diagnosis of rare and less common cancers remains a significant issue. In general, it takes longer for people to be tested and for the results to be reported on when the patient is seen in primary care, compared to in a hospital.
- Some rarer cancers may not fit the standard cancer pathway, because people with these cancers are sometimes seen by non-oncology specialists.
- Some people may not know that they are being treated at a specialist centre; they may think that because they are being treated by an oncologist, the hospital is a specialist centre.

### ➤ **Recommendations**

1. Everyone diagnosed with a rare or less common cancer should automatically be referred to an appropriate specialist multidisciplinary centre.
2. A vague symptoms pathway and resources should be developed to help doctors to identify rare and less common cancers more quickly.
3. GPs must have better access to diagnostic tests and/or quicker referral to specialists.
4. All rare and less common cancers should have clear referral guidelines.

## 15 months to diagnosis



It took 15 months to get diagnosed. I had pain when I ate and a swollen abdomen. I was losing weight too - in the end I lost seven stone. But I wasn't taken seriously and I was fobbed off again and again. Eventually

I asked to see a different consultant, and he did a CT scan which showed what they thought was ovarian cancer. I was told it was inoperable and that I had three months to live.

I wasn't given a name for my cancer, I was just told that it may have started in my appendix and basically told to go home and prepare my funeral. I was a single mum with two girls, 10 and 11 at the time, so I had a little panic, wondered what to do and started to research on the internet. I just typed in a Google search for appendix cancer and all of this information came up; treatment choices and the details of specialist centres in the UK.

I asked for a referral to one of the specialist centres and ended up having several lots of major

surgery. My experience there could not have been more different from my local hospital. I didn't feel so alone and they understood me and my symptoms. When I said I had a symptom, I got a nod, a smile and an explanation rather than a disgruntled look. They understood what was happening to me and for the first time I had some choices.

I'm angry and disappointed that it took so long to get the right diagnosis and treatment. My local hospital is a big teaching hospital and they should have known their stuff. I was shocked that they got it so wrong. It was horrendous to be in that situation. There seemed to be a lack of willingness to be open minded and if I hadn't been persistent and fought, it would have cost me my life.

People in my situation must, must, ask for and get specialist help. If a consultant isn't a specialist in their type of cancer, their knowledge won't stretch far enough. Even if they get the diagnosis right, the treatment may be wrong. Non-specialists also need to understand rarer cancers better, and need to know where to send their patients for the best possible treatment.

**Dawn Green**, founder, Pseudomyxoma Survivor  
[www.pseudomyxomasurvivor.org](http://www.pseudomyxomasurvivor.org)

# The future

Cancer services are constantly developing and the cancer strategy for England published in 2015 aims to tackle some of the important issues affecting survival rates and care. Among the priorities set out in the strategy are some which have particular relevance to, and resonance with, people living with rare and less common cancers, such as early diagnosis and better diagnostics.

The discussions at the Cancer52 meeting were wide ranging and touched on many areas, aside from those discussed at length in this report. It is encouraging to see that many of the issues raised by attendees are being explored and addressed by the NHS, government, patient groups and other organisations.

## Here are a few examples:

1. The questions on the national cancer experience survey could be improved and be made clearer.

The questions that form the National Cancer Patient Experience Survey (NCPES) are currently under review. The discussions from the Cancer52 meeting have been taken into account in the review and the revised questions will be used in the next survey.

2. Combining cancer data sets can be challenging and the restrictions on the use of data around cancer and cancer services may be preventing progress.

An NCIN initiative is exploring the wealth of data that exists on cancer, to ensure that it is used effectively and to its fullest extent, so that it can provide insight which will help to improve services and survival rates.

3. Rare and less common cancers often have vague symptoms, which can make diagnosis challenging and mean that people may first visit their doctor when the cancer is advanced.

Work has begun on new public awareness campaigns to highlight some of the vaguer signs and symptoms of cancer, which can arise together. Cancer52 is part of the Department of Health's expert group exploring this area.

4. Communities and cancer patients must be empowered and involved in the discussions about improving the quality of care, and hold providers to account.

The 2015 cancer strategy for England recommends that Cancer Alliances be developed to improve local services and accountability in cancer. These Cancer Alliances will bring together CCGs (Clinical Commissioning Groups) and providers to oversee key metrics, address variation and ensure the quality and effective integration of treatment and care pathways. Cancer Alliances will include local people and carers, nurses and Allied Health Professionals.

# Organisations represented at the Cancer52 meeting

## Organisations representing people with rare and less common cancers

### **AMMF - the Cholangiocarcinoma Charity**

[www.ammf.org.uk](http://www.ammf.org.uk)

### **Butterfly Thyroid Foundation**

[www.butterfly.org.uk](http://www.butterfly.org.uk)

### **Cancer52**

[www.cancer52.org.uk](http://www.cancer52.org.uk)

### **Chordoma UK**

[www.chordoma-uk.org](http://www.chordoma-uk.org)

### **CLIC Sargent**

[www.clicsargent.org.uk](http://www.clicsargent.org.uk)

### **CML Support Group**

[www.cmlsupport.org.uk](http://www.cmlsupport.org.uk)

### **Debbie Fund**

[www.debbiefund.org](http://www.debbiefund.org)

### **Independent Cancer Patients' Voice (ICPV)**

[www.independentcancerpatientsvoice.org.uk](http://www.independentcancerpatientsvoice.org.uk)

### **James Whale Fund for Kidney Cancer**

[www.jameswhalefund.org](http://www.jameswhalefund.org)

### **Jo's Trust Cervical Cancer**

[www.jostrust.org.uk](http://www.jostrust.org.uk)

### **Leukaemia CARE**

[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

### **Living Beyond Diagnosis**

[www.facebook.com/LivingBeyondDiagnosis](http://www.facebook.com/LivingBeyondDiagnosis)

### **Lymphoma Association**

[www.lymphomas.org.uk](http://www.lymphomas.org.uk)

### **MDS UK Patient Support Group**

[www.mdspatientsupport.org.uk](http://www.mdspatientsupport.org.uk)

### **Myeloma UK**

[www.myeloma.org.uk](http://www.myeloma.org.uk)

### **NET Patient Foundation**

[www.netpatientfoundation.org](http://www.netpatientfoundation.org)

### **Pancreatic Cancer UK**

[www.pancreaticcancer.org.uk](http://www.pancreaticcancer.org.uk)

### **Pelvic Radiation Disease Association (PRDA)**

[www.prda.org.uk](http://www.prda.org.uk)

### **Pseudomyxoma Survivor**

[www.pseudomyxomasurvivor.org](http://www.pseudomyxomasurvivor.org)

### **Psychosocial Oncology and Survivorship Clinical Studies Group**

[csg.ncri.org.uk/groups/clinical-studies-groups/psychosocial-oncology](http://csg.ncri.org.uk/groups/clinical-studies-groups/psychosocial-oncology)

### **Target Ovarian Cancer**

[www.targetovariancancer.org.uk](http://www.targetovariancancer.org.uk)

### **Tom Bowdidge Foundation**

[www.tombowdidgefoundation.org](http://www.tombowdidgefoundation.org)

### **Urostomy Association**

[www.urostomyassociation.org.uk](http://www.urostomyassociation.org.uk)

## Other organisations

### **NHS England**

[www.england.nhs.uk](http://www.england.nhs.uk)

### **Public Health England**

[www.gov.uk/government/organisations/public-health-england](http://www.gov.uk/government/organisations/public-health-england)

### **Quality Health**

[www.quality-health.co.uk](http://www.quality-health.co.uk)

# About Cancer52

Cancer52 represents more than 80 predominantly small patient support cancer charities united by their vision of seeing a better future for everyone affected by the rare and less common cancers, which account for more than half of all cancer deaths in the UK.

Our aim is to promote improved diagnosis, treatment and support for those affected by rare and less common cancers, leading to improved quality of life and increased survival.

We work on matters that impact on the rare and less common cancer community - defined as all cancers outside the 'big four' of breast, prostate, lung and bowel.

## Supporting Cancer 52

If you would like to support the work of Cancer52 please get in touch at [info@cancer52.org.uk](mailto:info@cancer52.org.uk)

# Credits

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**Susan Fitz-Gibbon** of Chordoma UK who first shared her story for Cancer52 with parliamentarians and has allowed us to share it within this report too. Susan's dignity in the face of years of the most challenging of times has been inspirational to us all.

**Catherine Oakley**, Chemotherapy Nurse Consultant, and leader of the UK Oncology Nurses Society. The role of the CNS is so key to the patient experience of people with rare and less common cancers that Cancer52 is now aiming to champion that role in all routes open to it.

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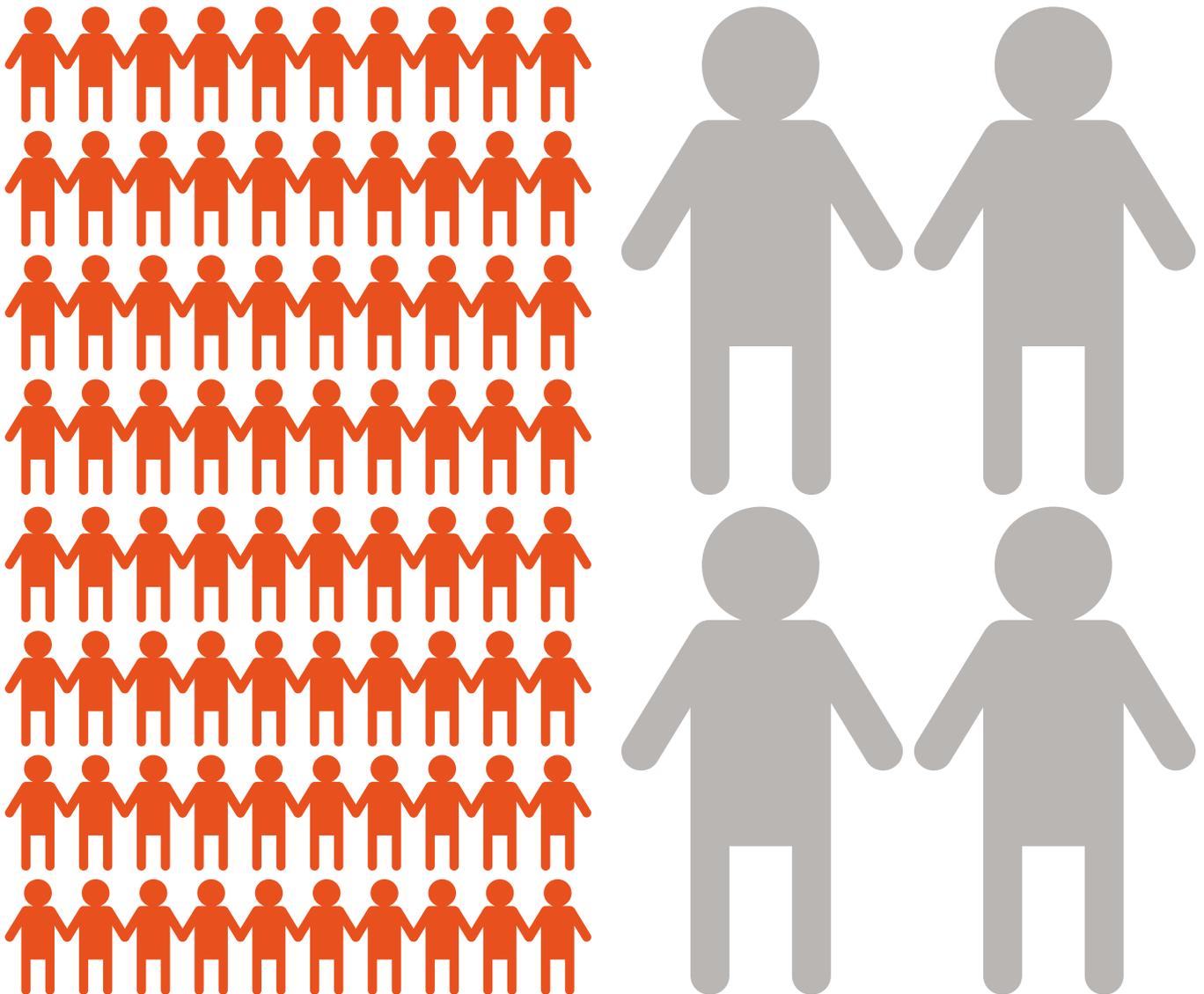
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If we **work together** we can make  
as much noise as the big four



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