

# Getting a better deal for people with rare and less common cancers

## What we can learn from patients



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# Foreword

**One in two of us will develop cancer in our lifetime.**

**With nearly half of new diagnoses, and over half of cancer deaths being from rare or less common cancers, improving care and support for people with rare and less common cancers cannot be ignored.**

In 2018 over 670 people with a rare or less common cancer shared their experiences with us in the hope that changes can be made in the future.

They told us about the issues they face. The difficulties and delays experienced when obtaining a diagnosis, the challenges to access treatment from specialist centres and the need for suitable support and care. But they've also shown us what can make a positive difference. Accurate and tailored information, access to support from peers and care from health professionals determined to help.

The NHS has committed to ensuring progress for all cancers. The earlier diagnosis target of 75% of all cancers diagnosed at stage 1 or 2 set out in the January 2019 NHS Long Term Plan can only be met with improvements across all cancers including rare and less common cancers. But improvements must be made along the whole cancer pathway. This is why we want a focus on rare and less common cancers at NHS England and Cancer Alliance level, with money and people identified to help achieve this.

We hope sharing this insight from people with rare and less common cancers will help us and all who work with us to improve diagnosis, treatment and care for all those with rare and less common cancers.

**Jane Lyons**

CEO

Cancer52



*We want a focus on rare and less common cancers at NHS England and Cancer Alliance level, with money and people identified to achieve this.*

# Background

## What are rare and less common cancers?

Every year, about 144,600 people in England are diagnosed with a rare or less common cancer<sup>1</sup> - cancers such as testicular, leukaemia, sarcoma and pancreatic. Although fewer people are diagnosed with these cancers than the four most common cancers (bowel, lung, prostate and breast) - more people die from these cancers; 74,500 people every year<sup>2</sup>.

Rare and less common cancers affect all people of all ages, gender, ethnicity and across the whole of the country. They can include cancers such as appendix where only one in a million cases are seen each year and cancers such as ovarian where 6,102 women were diagnosed in England in 2015<sup>3</sup>.

Some of these rare and less common cancers have benefitted from new advances in science and technology and have seen survival rates rise dramatically - for example in the 1970s, around seven in ten men diagnosed with testicular cancer survived their disease beyond ten years, now it's almost all men<sup>4</sup>. Others have seen little improvement in outcomes over the last decades - only 1% of people diagnosed with pancreatic cancer survive for 10 or more years and this figure has not changed since the 1970s.

*Every year, about 144,600 people in England are diagnosed with a rare or less common cancer.*

## About Cancer52

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

In the Summer of 2018, Cancer52, with the help of its members, undertook work to better understand the issues faced by those with rare and less common cancers. As well as working with the patient groups who represent people with rare and less common cancers, Cancer52 ran an online survey. Over 670 patients with a rare or less common cancer, or a friend or family member on their behalf, responded. This report explores what people with rare and less common cancers told us. All quotes highlighted within this report are from people who responded to our survey.

Cancer52 used the insight and information provided by people with rare and less common cancers to inform its priorities and work. This included shaping the ask of the NHS cancer plans within the NHS Long Term Plan published in January 2019. You can read the Cancer52 briefing on what should be done to improve outcomes for people with rare and less common cancers by visiting our website<sup>5</sup>.

- 1 144,642 were diagnosed with a rare or less common cancer in 2017 PHE/NCRAS May 2019
- 2 74,416 died from a rare or less common cancer in England in 2017 PHE/NCRAS May 2019
- 3 Cancer Research UK [www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/incidence#heading-Zero](http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/ovarian-cancer/incidence#heading-Zero). Accessed March 2019
- 4 Cancer Research UK [www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/testicular-cancer#heading-Two](http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/testicular-cancer#heading-Two) Accessed March 2019
- 5 Cancer52 briefing [www.cancer52.org.uk/single-post/2018/10/17/Getting-a-better-deal-for-people-with-rare-and-less-common-cancers-the-next-ten-years](http://www.cancer52.org.uk/single-post/2018/10/17/Getting-a-better-deal-for-people-with-rare-and-less-common-cancers-the-next-ten-years)

# About the Cancer52 survey

Cancer52 ran an online survey for six weeks during the summer of 2018. People were recruited to take part in the survey via Cancer52 members' communications and networks. Over 670 people responded to the survey.

People were asked three open questions, with no word limit, about the positive aspects of their cancer experience, the negative aspects and their suggestions for improvements. Information on age, gender, type of cancer and date of diagnosis were also captured but are not reported in this report in order to maintain the anonymity of the people who responded to this survey.

While a wide range of different people with rare or less common cancers or their carers took part, this survey does not claim to be representative of the cancer population. However, we received responses from both women and men of all ages across many different types of cancer, some diagnosed recently and some diagnosed many years ago.

The answers captured paint a vivid and useful picture of the issues people with rare and less common cancers face and is vital reading by those wishing to improve outcomes for people with rare and less common cancers.

We are very grateful to all those who took the time to respond to the survey and to those who have shared their stories in greater depth within this report.

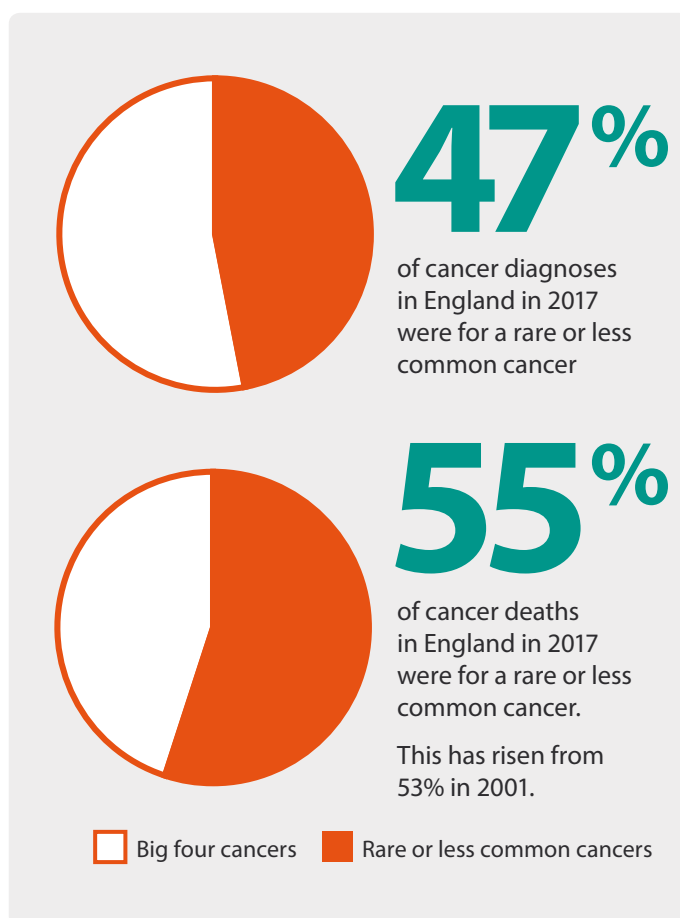
*The answers paint a vivid and useful picture of the issues people with rare and less common cancers face.*

670 people responded to our survey

# Rare and less common cancers: The key facts

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

- **47%** of all cancer diagnoses in England are for rare and less common cancers.
- **55%** of all cancer deaths in England are from rare or less common cancers.
- The percentage of deaths from rare and less common cancers has risen from 53% in 2001 to **55%** today.
- In 2017 about **144,600** people in England were diagnosed with a rare or less common cancer.
- Around **74,500** people in England died from a rare or less common cancer in 2017.



In England there were **144,600** diagnoses and **74,500** deaths relating to a rare or less common cancer.



# The issues faced by people with rare and less common cancers

Rare and less common cancers include a huge range of different types of cancer with different outcomes and which affect people and those around them in different ways.

Despite this huge variation, there is commonality in the issues that people face because they have been diagnosed with a rare or less common cancer. We explore each of these issues in detail within this report.

## Diagnosis

### Getting a diagnosis

Generally speaking, the earlier cancer is detected, the easier it can be to treat and the more successful treatment is likely to be. Yet many people with rare and less common cancers struggle to be diagnosed. Some face a very long or difficult journey.

*"The diagnosis was actually fairly quick for such a rare cancer."*


While some cancers are picked up through national screening programmes such as the cervical screening programme that uses tests to check if someone has cancer or pre-cancerous cells, other cases are spotted because the person noticed unusual symptoms or something felt wrong. In these cases, they will most often see their GP and if the GP suspects cancer, they are referred on for tests or to see a specialist.

*"The only positive was finally getting a diagnosis."*

*"The consultant explained things well and spent time with me to make sure I understood."*

However, rare or less common cancers are less familiar to the general population and health professionals alike which means symptoms may not be linked to a potential cancer. Other rare and less common cancers have vague symptoms which makes them harder to spot. Some people with rare and less common cancers told us that they felt that nobody had taken their concerns or symptoms seriously and that they were not believed by health professionals. Some had visited GPs or clinics several times before receiving a diagnosis. Others had been given an incorrect diagnosis or their cancer had not been spotted. These patients had endured often months, sometimes years, of pain or other uncomfortable symptoms before an explanation was found. For some people this meant that the opportunity to treat their cancer earlier, before it had worsened or spread, had been missed.

*"Once the diagnosis had come through, my GP came to my house to break the news and I was seen by the consultant the following day."*

A middle-aged man with thinning grey hair and blue eyes is shown from the waist up. He is wearing a light pink polo shirt with a small dog logo on the left chest and a dark belt. His arms are crossed over his chest. He is standing in a room with a doorway and a coat rack visible in the background.

*Roy has found an online community that is supportive and informative.*

*He often finds that he knows more about the condition than his GP.*



*"The time the consultant gave me when telling me the bad news. No pressure to leave given all the time I needed and phone number to ring if we thought of some questions after the consultation."*

For those people who had received a quick diagnosis, this made a positive contribution to their experience. It meant they weren't left to worry for too long and treatment could be started quickly. Other people said they were pleased to finally receive a definitive diagnosis and to understand what was wrong.

*"Getting a definitive diagnosis was helpful."*

### The manner of diagnosis

The manner in which a diagnosis of rare or less common of cancer is delivered to a person can impact on their experience of care. For all, it is a difficult and life changing event. However, for some people it can become more traumatic if the diagnosis is given with little support, time or information. Many people with a rare and less common cancer felt the news of their diagnosis had been delivered insensitively or with not enough time to properly talk about it.

*"On day of diagnosis I saw a specialist that day, had a bone marrow biopsy that day and started treatment a week later."*

*"Took far too long waiting for treatment after being diagnosed. Nothing could be done for my son."*

*"Diagnosed and referred to a consultant within 2 hours, seen within a week and explanation and prognosis given at first consultation. Wonderful speed. No time to worry. During that intermediate time gleaned knowledge and reassurance from the myeloproliferative neoplasm voice website. Incredibly helpful to have a reliable monitored online resource."*

Some had been given the news when alone with nobody else there for support. Others had found out accidentally by overhearing conversations, reading a scan result or collecting their medication. Some had been given the news over the phone or in a letter. One described the experience as 'brutal', another as 'blunt'. One person had been told their cancer 'would get them'.

The manner of giving a diagnosis need not be negative. Those who had been given clear explanations and information were more positive. One person's GP had visited them at home to give them the diagnosis face to face.

*"A multi disciplinary team had to meet before a confirmed diagnosis. As this was over the summer, it took 7 weeks before the information was given. That was disappointing and worrying."*

## Case study - Roy



Roy was 60 and training for the Edinburgh half marathon, when he began to experience constipation and stomach and back pain. He visited the GP several times but was told his symptoms were down to IBS - something he'd never suffered from before. After several months and further visits to his local surgery, Roy saw a different GP and was sent for a blood test, colonoscopy and CT scan via the fast track bowel cancer referral pathway.

Before seeing the consultant to discuss his results, he received the blood test findings in the post and on googling what they meant, realised it was bad news. He hadn't been told to bring anyone with him to his appointment, but fearing his results indicated he might have cancer, his wife accompanied him. To their shock, Roy and his wife were told that Roy had pancreatic cancer - and that he was being referred to a specialist centre at the Royal Free Hospital.

The consultant, a bowel specialist, was unable to provide any further information or reassurance.

Roy's father had died of pancreatic cancer but before Roy was diagnosed nobody had asked about his family history or made the connection to the symptoms Roy was suffering.

At this point Roy and his family decided that they didn't want to waste any further time and paid for Roy to have surgery privately. Roy had a 10 hour operation to remove part of his pancreas, spending time in intensive care afterwards and a total of eight days in hospital. He then had follow up chemotherapy at his local NHS hospital.

Roy has found the online community of other pancreatic cancer patients supportive and informative. He often finds that he knows more about the condition and the latest treatments than his GP and other health professionals.

However, he continues to live with the long term effects of his cancer. He has been left diabetic as a result of the operation and has to take enzymes to help him digest his food. Although he returned to work, he has since taken early retirement and has not returned to his hobby of running. He sees his consultant every six months for a blood test and CT scan, but he's hopeful that almost five years since his treatment, his cancer may be gone for good.

# Treatment

## Choices

Treatment for rare and less common cancers includes surgery, chemotherapy, radiotherapy and in some cases the option to wait and see if the cancer progresses before taking action. People with rare and less common cancers felt having treatment options available was positive. Treatment presents an opportunity to prolong life or to manage symptoms such as pain. People like the opportunity to be able to make choices about their treatment or benefit from the latest advances.

Sadly for some people with rare and less common cancers, there is no treatment available or their cancer has advanced to such a stage that it is not treatable. In some cases there are treatments available but they are not funded by the NHS. For some rare and less common cancers, there has simply not been enough research conducted to find new cures.

*"Some excellent NHS staff got the right (expensive) drug."*

*"No funding for her treatment as she had such a rare cancer, as a family had to raise \$150k minimum for immunotherapy and as it took so long to raise the funds, she was too ill and weak to try the drug."*

## Side effects

In addition, the side effects and impact of treatment can be unpleasant for people with rare and less common cancers. People highlighted pain, discomfort and sickness. For some this had been worse than they expected or were led to believe.

Some people with rare and less common cancers will experience ongoing long term effects of cancer or treatment that may affect them for the rest of their lives. For example those who have undergone radiotherapy for ovarian cancer may experience bowel problems due to damage to these organs and those treated for different types of eye cancer may live with poorer vision.







*"I've had to challenge doctors, ask difficult questions and tell them 'no I don't like what you're saying and I'm going to go to someone else'"*



*"It's hard living with the symptoms, the fatigue, the knowledge that I'll always be a patient. It's difficult to have a disease that is often unknown and therefore not understood by even the medical profession.  
It's hard to explain how this impacts on daily living and quality of life, especially when to others I look well."*

*"Being treated at a Sarcoma centre was key for me. I felt I was in the best possible place."*

*"The long term side effects of surgery and radiotherapy were not explained."*

*"When eventually diagnosed I started treatment within two days."*



## Specialist treatment

It is generally accepted that care is safer and outcomes better when people are seen and treated by specialists with the relevant experience and expertise. This has seen new ways of organising care for people with cancer where diagnosis, treatment and care is split up into the parts which require specialist input and the parts which can be undertaken by more generalist professionals. This means specialists oversee the parts that require their specialist input or knowledge, while services based more locally to the patient can deliver the treatment and care which do not require this.

People with rare and less common cancers feel reassured when their treatment and care is overseen by a specialist. However, they report that their care is not always overseen by a specialist and some had had to insist on a referral.

*"Taking so long for a diagnosis then not having a lot of treatment options."*

## Case study - Steve



"If you have a rare disease, you have to become the expert." explains Steve who has been living with Gastrointestinal stromal tumours (GIST cancer) for over 20 years. "I've had to challenge doctors, ask difficult questions and tell them 'no I don't like what you're saying and I'm going to go to someone else'."

Steve is a recently retired independent politician. He is just one of four people in the UK with his type of variant to GIST cancer. He is Exon 8.

It was back in 1998, that Steve was rushed to hospital with suspected appendicitis. When he woke from the operation, he knew straight away that this hadn't been a routine procedure.

"They found a tumour the size of a fist in my appendix. It had burst and this is what had caused the pain. Before that I'd had no forewarning - it came completely out of the blue."

At the time little was known about GIST and Steve's tumour had to be sent to America for analysis. He was followed up for five years and then told he had the all clear.

However, some years later, Steve bent down and couldn't get up again. Doctors told him it was probably a hernia. Steve fought for a scan which showed a new tumour.

"After five months of dillying and dallying, I was referred for an MRI and then booked in for surgery to remove a large tumour, two thirds of my liver and my gall bladder. If any more time had been wasted, the tumour would've been inoperable."

Steve and his wife then took matters into their own hands, did their own research and Steve referred himself to a centre of excellence with the knowledge and expertise to treat his type of cancer. However, it is nearly four hours away which means he has often ended up in local hospitals.

"Five years later the pain in my side returned and the local hospital kept missing the tumour on my scans. They then told me there was nothing that could be done when a tumour was found but the specialist at the centre of excellence removed it."

Steve's cancer has continued to return and is no longer operable but his clinician placed him on a treatment path which has shrunk and stabilised his four tumours. The clinicians at the specialist centre have also used the latest scientific technology to re-test Steve's tumour allowing them to understand exactly what type of cancer Steve has and how best to treat it. Steve, as far as can be seen, is the only Exon 8 GIST patient being treated by targeted chemotherapy in the country.

"I am dealing with the side effects of my cancer and the treatment. I've just come out of hospital having been there a week with pain and tummy trouble. There are lots of things I can't take and I worry whenever I go in that the person seeing me won't understand my condition."

# Support

*"I can't think of anything positive. I was left alone to get on with it."*

People with rare and less common cancers can require emotional, practical and financial help throughout their experience of cancer and beyond. However, the smaller numbers involved means they can struggle to find support that is designed for them. They may need help to understand their diagnosis and to make decisions about their treatment and care. They might need assistance to navigate the complex health and social care system or to apply for benefits. The impact of their cancer and its treatment and side effects may mean they need help to cook meals, shop for food or make the journey to and from hospital. People with rare and less common cancers can struggle to access this support; particularly once they have left hospital or when treatment has ended.

*"At the time of diagnosis, my Clinical Nurse Specialist was incredibly helpful and reassuring at such a stressful and difficult time."*

## Emotional support

People with rare and less common cancers told us about the emotional impact of their cancer. Some had found help and information through support groups; often they had found these online. Others had found this kind of help from third sector organisations.

*"I go to a leukemia group every month, my husband attends with me and occasionally my daughter. It's nice to meet up with others. I have ... a very rare blood cancer, another person attending the meetings has same too. First time I met them was lovely, I can ask them questions as they've had it a few years more than myself."*

However, because these types of cancer are rare or less common, there are fewer support services available to meet the specific needs of these types of cancer and so people do not benefit from some of the support available to those with more common cancers.

## Clinical Nurse Specialists

Clinical Nurse Specialists (CNS) can be a huge source of support to people with cancer and have been shown to make a person's experience of care more positive. They can provide emotional support and information, often providing reassurance via a phone call or in clinics. They also ensure a person's care is 'joined up' and people don't get lost in the system, for example, by ensuring a person's GP understands what has happened to them or directing a patient to the right clinic or source of support.

*"The information and support pack I was given by the consultant at my first visit in clinic (sponsored by Macmillan), gave me the understanding of my disease and prognosis."*





*"The registrar we saw was dismissive but I am a nurse and paramedic by background and argued he needed to be seen."*



*"I gather that some people with my condition have nurse specialists they can contact between appointments. I don't and it would be useful. I don't think I'm being given up to date information on my condition and how I should be managing it. I have learnt much more from patient forums and disease specific conferences than from medics."*

Despite this, some people with rare and less common cancers do not have access to a CNS, find it hard to get hold of their CNS when they need them or face delays in being assigned one. This is supported by the findings of the National Cancer Patient Experience Survey.

## Information

Understandably, the general public is less familiar with less common and rare cancers. Some people have never heard of their type of cancer before diagnosis. Once diagnosed, people are keen to understand their cancer and their treatment options but also want to understand how it will impact on the different aspects of their life and how they can help themselves. However, there is often less information available on these types of cancer or it can be harder to find. Respondents to the Cancer52 survey said that the internet has made this easier for people with rare or less common cancers, but often they would have liked more information or clearer explanations from their health professional.

*"Initially the patient support group was the best support and source of information and advice."*

*"Thank goodness for Google and the internet!"*

*"No local groups of my condition to talk too."*

*"My specialist nurse - she is amazing, always available to speak to, email etc for information and advice."*

Some had been given incorrect or conflicting information - for example one patient had sold her business as nobody had properly explained to her the prognosis of her cancer.

## Patient empowerment

Some people with rare and less common cancers felt their experience had been more positive because they had been kept well informed about their cancer and treatment and professionals had been honest. For some, being able to make choices about their care, to be involved in decisions and to have their views respected was important. A few had taken the opportunity to have a second opinion.

*"A complete lack of information about the disease and prognosis, particularly no information about any support organisations."*

## Case study - Sam and Rita



Over the Christmas holidays in 2016, Rita's son Sam complained of a blocked nose and not being able to smell.

"He was a fit and well fifteen year old but over the next few weeks suffered a bad headache and had to miss school." Rita explains. "When he then developed a swollen neck and dizziness, I tried to get a GP appointment but failed so we took him to the urgent care centre instead. They got him seen by a GP who diagnosed an infection and started him on antibiotics."

However, Sam remained unwell and Rita wanted to get him seen by the GP again:

"The registrar we saw was dismissive but I am a nurse and paramedic by background and argued he needed to be seen. I'll never forget what the Partner of the surgery said to me: if you insist, we will send him to the Children's Hospital."

A CT scan revealed a mass in Sam's nose and he was transferred by ambulance to the cancer centre. There, Sam was diagnosed with olfactory neuroblastoma and told the tumour was inoperable.

This type of cancer is rare, particularly for someone of Sam's age. The clinician took his case to a national meeting for experts to discuss what treatment would be best. At the beginning of February, Sam started treatment, consisting of a cycle of chemotherapy every 10 days. After four rounds his tumour had shrunk massively and his case was taken back to the national group for further discussion where they decided the tumour could be removed.

Rita continues. "After his surgery, he was going to have radiotherapy but I knew Proton Beam treatment could be an option which has lesser long-term side effects. I asked for this option to be explored."

Sam was sent by the NHS for proton beam treatment in the USA. Rita found this treatment the hardest.

"The side effects were horrible. But we knew there was light at the end of the tunnel and we just had to get through it!"

Rita's work were supportive; helping her to find ways to take the time off she needed to be with Sam while ensuring she could still receive pay. However, while friends and family rallied around to support Rita and her husband, they weren't offered any emotional support by the NHS.

"We haven't been offered any psychological support or family therapy. It's been offered to Sam but not to us and not from the GP."

Since returning home, Sam has gone from strength to strength. He sat his GCSEs while undergoing treatment and is about to sit his A-levels. He hopes to join the army and would like to go to Sandhurst.

# Pressures in the system

In recent years both financial and workforce pressures have impacted on the health and social care system. Key targets for cancer have been missed (the two week GP referral to consultant appointment target and the 62 day wait GP referral to treatment target). This has adversely affected the treatment and care of some people with rare and less common cancers.

*"Administration, I have spent a lot of time on the phone to hospitals and nurses chasing up appointments. There were occasions when these hadn't been booked in. Also sometimes professionals have assumed that we've understood the processes but we haven't as we have not had experience of this before."*

Some have encountered delays in the system: delays receiving a diagnosis, delays to see a consultant, delays in getting test results back or delays in starting treatment. In some cases this meant waiting time targets had been missed and their cancer had worsened. Others have experienced frequently overrunning clinics with long waits for a consultation or for chemotherapy to be given. A few patients had their treatment impacted by a lack of beds on wards or chairs in chemotherapy units, while others had surgery, treatment or consultations cancelled. Lack of staff on wards had affected the quality of care a few had received while staying in hospital. One patient had spent three months on 24 hour stand by for surgery.

*"The first few weeks, post diagnosis, were really tough both physically and emotionally. I found the emotional impact more challenging than the physical impact."*

The care and treatment of people with rare and less common cancers can often be complex, requiring people to be seen by different healthcare professionals in different centres. However, the NHS often fails to make this easy for people because care is not joined up.

Some people with rare and less common cancers described being 'ping ponged' around the system - one commenting that they felt like 'no one's patient'. They also highlighted poor communication between different parts of the system and the inability to share notes or information. A couple of patients had to have scans repeated as it was not possible for one centre to access the results from another centre.

*"The gaps between the nursing/medical teams at the hospital. Things can take longer than necessary, from small things like getting your medication from the pharmacy to allow you to be discharged to more major things like getting a feeding bag made up and fitted (this took five days from being prescribed by the consultant!)."*

*"Not enough staff on wards to attend to requests quickly enough."*

Sometimes it is the seemingly simple things that can go wrong in a patient's care leading to frustration and a lack of trust with the NHS or, at worse, a person not receiving the treatment they need. For example, people with rare and less common cancers have encountered administrative errors such as being incorrectly discharged from clinics, notes not being available when they arrived at clinics, consultations failing to be scheduled or referral letters not being sent or being lost. One patient had received another patient's details in a letter.

*"Very little information available about my type of cancer in someone my age - even the big charities have very little - with a rare cancer, it is hard for anyone to determine appropriate treatment when comparatively little is known."*



*"It transpired that I had been discharged from the consultant's care without her knowledge or mine. I have not been told how or why that happened. I am back under her care now."*

*"I felt there was no-one who took my treatment as their responsibility and followed through. I had to do a great deal of research on my own and no-one seemed to have a complete overview of treatments and outcomes."*



# Healthcare professionals

Often it is the people delivering care or providing treatment that overwhelmingly impact on whether a person with rare or less common cancer has a positive or negative experience.

People with rare or less common cancers can speak warmly about their healthcare professionals. They appreciate the compassion and care shown by staff as well as their knowledge and skills. Often patients can pick out key individual members of staff who had given them time or had worked hard to get them seen or treated.

*"The positivity of the surgeon and nurses - particularly the nurses in the chemo department. The support of our GP was above and beyond the call of duty."*

They often mentioned their CNS or nurse, consultant or GP. They noted the attitude and friendliness of staff and being made to feel like a person not a number. One person commented on the 'upbeat and positive attitude' of their doctor; another that the support from their GP had been 'above and beyond the call of duty'. For some, continuity of care from the same professional, such as their GP or CNS was important to them.


*"The nurses administering my husband's chemo were all lovely, he enjoyed a laugh and a joke with them."*

*"I was told I was going to die before I was 60. Nobody seemed to know anything about my illness, what was normal or expected. A lonely, scary time."*

Unfortunately, many people with rare and less common cancers had experienced negative encounters with different members of the health profession during their care. This included GPs, consultants and nurses. Often it was the attitude of the healthcare professional which people found dismissive or uncaring. One respondent had been left with a phobia of needles after a negative experience.

*"Following my diagnosis the follow up appointments were handled really well, my consultant in particular was very personable and took the time to ask me about personal aspects of my life and he actually remembered them!!"*

*"My main consultant was willing to listen to the research I had done."*

A woman with blonde hair and bangs is sitting at a table covered with a light blue patterned tablecloth. She is wearing a blue and yellow checkered shirt. Her hands are clasped on the table. In front of her are several books, including one titled 'Color Test' and another with 'Pi' on the cover. A vase of red and pink flowers is also on the table. The background shows a white wall and a wooden door.

*"When you're first diagnosed with cancer, you have no idea what it means. For two months I didn't know what was going to happen."*



*"I had a lot of doctors not believing my pain was real and just brushing it off. And not knowing what to do with me or how to treat me."*

Sometimes health professionals had not given them enough time, had failed to listen to or had dismissed their concerns, or had been rude or thoughtless. One person described their surgeon as having a 'God-like complex' and refusing to answer questions. Another described a consultant shouting at his wife. A couple described staff talking about them and not to them.

In addition, people with rare and less common cancers can find that, because their cancer is not common, certain health professionals do not have the knowledge or experience needed to treat or care for them. Sometimes this led to poor decision making about their care and treatment or led to errors. People with rare and less common cancers do not always have trust in these professionals - one describing the team at their local hospital as being 'out of their depth'. Some felt the nature of their cancer meant professionals had given up on them, thought they weren't worth treating or treated them as a source of fascination - one commented that they were 'treated like a specimen'.

*"Other health professionals have very little awareness of the disease."*



## Case study - Liz



Liz's daughter, training to be an occupational therapist, insisted her mum got the small lump on her thigh seen by a medical professional.

Liz says: "The lump had been growing very slowly over several years. At first I thought it was from bumping my leg on furniture. Then I thought it was just a fatty lump or a blind boil so I saw the practice nurse and asked if she could lance it. She sent me to see a GP the next day who referred me to another doctor in the practice to have it removed as he conducts minor surgery at the local cottage hospital. They sent the tissue off for analysis and when I was contacted six weeks later and asked to make an appointment for the following week to discuss the results, I knew something was wrong. I asked to speak to the GP who had removed the 'cyst' there and then on the phone."

He told Liz she had sarcoma but not to worry as it wasn't skin cancer. Further tests were needed to confirm the type of cancer: soft tissue sarcoma - a cancer that grows in the connective tissues of the body.

"When you're first diagnosed with cancer, you have no idea what it means. For two months I didn't know what was going to happen."

"It took a long time for the lab results to come through to confirm exactly what I had. I felt alone and didn't trust the medics around me - they incorrectly referred me twice! I didn't tell anyone at first because I wanted to tell my two daughters face to face. But I've suffered from post-traumatic stress disorder in the past and the diagnosis triggered it again and I fell apart. Eventually I told a close friend and took myself off to see a counsellor at another local hospital who helped me immensely."

Liz also did her own research and realised her type of rare sarcoma was very rare and needed to be seen at a specialist centre.

"My tumour was like a jelly fish shape. The original surgeon had removed the tip of the head but not the tentacles and so I had further wide margin surgery at the specialist centre because my kind of cancer doesn't respond to chemo, radiotherapy or other treatment."

At first, Liz's thigh felt very numb and heavy but after 6-8 weeks she was back walking her dog and after three months back driving. However, she is still living with the side effects.

"I had to have lymph nodes removed and this means I get a painful build-up of fluid around my knee. My surgeon mentioned something about needing to massage my thigh at the time of the surgery but I didn't really understand what he meant. It took me 18 months to work out what to do with the help of my daughter. I was never referred to see a specialist physiotherapist."

Liz is now keen to raise awareness of her kind of cancer and has given her GP surgery information to help educate them about sarcoma. She has also completed the 'Couch to 5k' nine week running course and runs three times a week in training so she can tackle sponsored challenges for a cancer charity with which she also sings in a choir for people affected by cancer.



# What do people with rare and less common cancers want?

We asked people with rare and less common cancers what could be done to improve treatment and care for people like them.

## Greater awareness

More needs to be done to raise awareness of rare and less common cancer among the general public and within the health service. Health professionals need to be better educated about these types of cancer so they have a better understanding of how to spot and treat them, as well as an understanding of how to support patients during and after treatment.



## Better information

People with rare and less common need access to better information. Information needs to be accurate, up-to date and relevant or tailored to the patient's needs.



## More support

People with rare and less common cancers need access to all types of support including emotional, practical and financial. This is particularly important after treatment ends. Healthcare professionals should signpost to these types of support including support groups so that people have someone they can talk to.



## More treatment options

People with rare and common cancers need more treatment options. More research needs to be done into these types of cancers to find potential future treatments and these must be made available on the NHS.



# What next?

**Cancer52 wants to see a world where more people with a rare or less common cancer are surviving for longer and their quality of life is improving. This means more people with rare and less common cancers will be diagnosed early, will receive treatment, and will have a positive experience of care.**

Cancer52 has been encouraged by the increasing attention rare and less common cancers are receiving by decision makers within the NHS. There is an increasing understanding that improvements in outcomes for people with cancer cannot be made unless progress is seen across all types of cancers.

Cancer52 is heartened by the pledges set out in the NHS Long Term Plan as well as recent work by NHS England, Cancer Alliances and NHS services. The new early diagnosis target, which applies to all cancers, as well as the continuing roll out of Rapid Diagnostics Centres should see more rare and less common cancers diagnosed earlier leading to more lives saved. The reorganisation of services with more specialist centres will mean more patients with rare and less common cancers receive the best possible treatment and care. The focus on personalised care should help more people to receive the support that is right for them and their condition.

In publishing this report, Cancer52, and its members, hope to continue to shed light on the issues that people with rare and less common cancers face. Cancer52 will continue working with the Government, the NHS and other partners to find solutions to address these issues and to ensure the voice of those with rare and less common cancers is heard.

Back in Autumn 2018 we set out our asks for the NHS Long Term Plan: high level focus on rare and less common cancers, a target to act as a catalyst for progress for rare and less common cancers and funding and resource for Cancer Alliances to drive improvements.

Cancer52 has been working with NHS England and Public Health England to ensure this new early diagnosis target will accelerate progress for rare and less common cancers.

We are also working to ensure the new high level cancer governance structures provide focus on rare and less common cancers and are beginning to reach out to Cancer Alliances to determine how we can best support their work. In addition we are working to draw the attention of members of parliament to our cause and to raise the profile of rare and less common cancers with the National Cancer Research Institute (NCRI) and the National Institute of Health and Clinical Excellence (NICE).

We are grateful to all those that work with us to help achieve better outcomes for people with rare and less common cancers.

You can find out more about our most recent work, or get in touch, by visiting our website at [www.cancer52.org.uk](http://www.cancer52.org.uk).

# Thank you

**Cancer52 would like to thank all those people with rare and less common cancers, their relatives, friends and carers who took the time to complete our survey and to share their experiences with us.**

We are also grateful to all our member organisations who helped to spread the word about our survey and promoted it through their communications.

Finally, we are most grateful to Roy, Liz, Steve, Rita and Sam for sharing their stories in depth with us and for their time and patience.

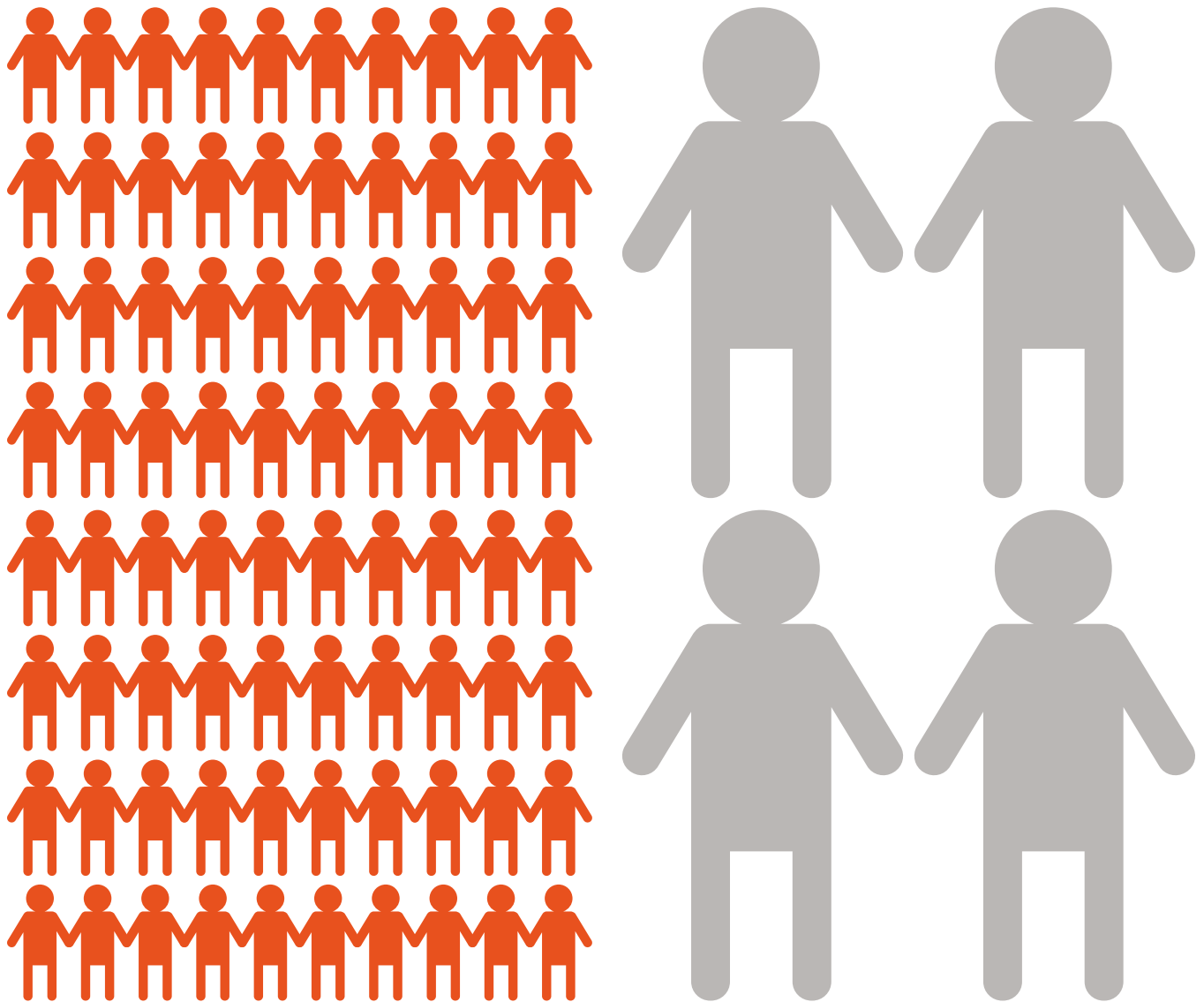
We hope that shining a light on everyone's experiences, good and bad, will lead to further improvements for people with rare and less common cancers in the future.



We dedicate this report in memory of our dear colleague and friend Ingrid Copperman, who died of ovarian cancer in February 2019.

**Ingrid Copperman**  
1968 - 2019

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



**Cancer52**

**E:** [info@cancer52.org.uk](mailto:info@cancer52.org.uk)

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

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