

'Do You C Us?' is a campaign led by a partnership of Cancer52 and Pfizer UK, funded by Pfizer UK, aiming to improve outcomes for people living with rare and less common cancers. It seeks to raise awareness of the unique challenges faced by those living with these cancers and amplify their voice in policy-making decisions.

Do you C us?

Raising awareness of the challenges facing people living with rare and less common cancers and highlighting the need for change.

Understanding the issue

Rare and less common cancers account for **nearly half of new cancer diagnoses** and **over half of cancer-related deaths**.¹

Rare and less common cancer is defined as all cancers outside the four most common cancers (breast, prostate, lung and bowel). Examples of rare and less common cancers include appendix, brain, leukaemia, ovarian, pancreatic and testicular.

Rare and less common cancers affect people of all ages, genders and ethnicities. People often face a range of similar issues such as:

- Not recognising their symptoms could be cancer
- Delays in obtaining a diagnosis
- Difficulties receiving the most suitable treatment
- Challenges accessing appropriate levels of support

As a result of COVID-19, fewer people have come forward with symptoms and then been diagnosed with cancer, and there have been delays to treatment for people already diagnosed.²

Prevalence



47% of all cancer diagnoses in England are for rare or less common cancers¹

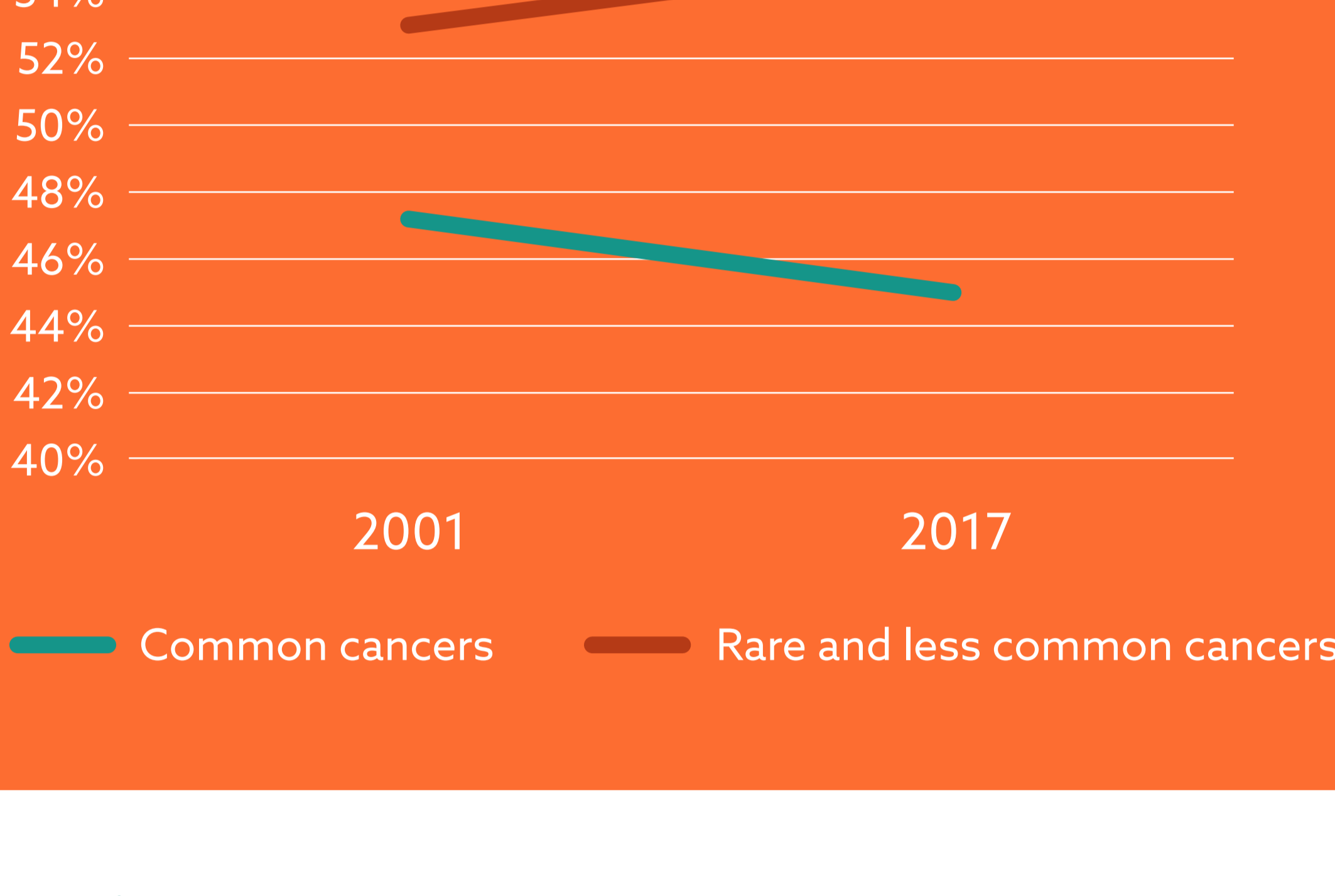
Approximately **144,600 people** in England are diagnosed with a rare or less common cancer every year¹



The total number of people living with a rare or less common cancer in the UK has been estimated to grow from around **1.25 million people in 2020**, to **1.63 million in 2030**, and to **2.06 million in 2040**³

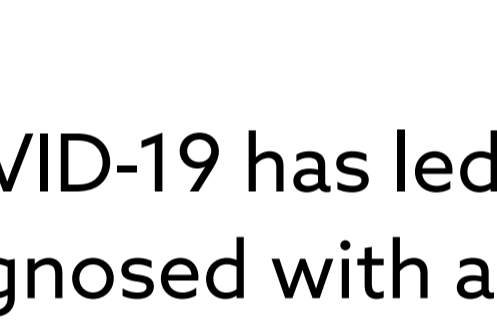
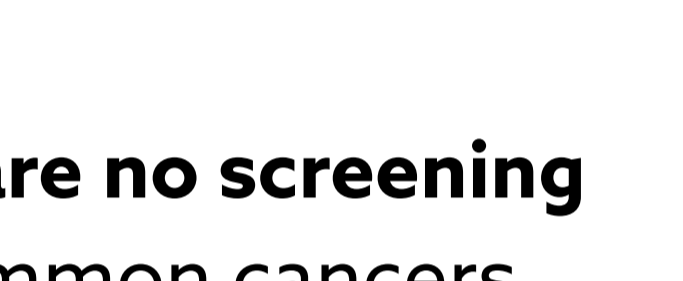
Deaths from rare or less common cancers in England are **more common than the four most common cancers combined**¹

The **percentage of deaths from rare or less common cancers has risen** from 53% in 2001 to 55% in 2017¹



Diagnosis

People with rare and less common cancers are **more likely to be diagnosed via emergency presentation**, compared with the four most common cancers⁴



Except for cervical cancer, **there are no screening programmes** for rare and less common cancers

COVID-19 has led to a fall in the number of people diagnosed with all kinds of cancer.² Some people with rare and less common cancers also faced delays or changes to their treatment and had difficulty accessing support⁵



What needs to change

- 1 In the NHS Long Term Plan, the NHS committed to diagnosing 75% of all cancers at stage 1 or 2 by 2028.⁶ In order to meet this target, improvements are required across all cancers – including rare and less common cancers.
- 2 Work should be undertaken to identify people 'missing' from the system, including people with rare and less common cancers. People must be reassured that it is safe to come forward for treatment.
- 3 Cancer must remain a Government priority. Cancer services and the cancer workforce, including those for people with rare and less common cancers, should receive sufficient investment and funding for the future. This must be set out in the next Comprehensive Spending Review.

Do you C us?

I support the 'Do You C Us?' campaign and its mission to raise awareness of the challenges facing people living with rare and less common cancers whilst highlighting the need to do more.

Read more about the campaign at:

www.DoYouCUs.org.uk



Support for the campaign

“Our united vision is to see a better future for everyone affected by rare and less common cancers. We need to work together to promote improved diagnosis, treatment and support. The 'Do You C Us?' campaign is an important way of bringing people together to improve awareness and understanding of the challenges faced.”

Jane Lyons, CEO, Cancer 52

“It doesn't matter the type of cancer; everyone should have the treatment and support they need. The problem is people often haven't heard about rare or less common cancers and because they are not common, doctors don't always consider them when determining a diagnosis. It can be difficult finding information and other people who have been through similar experiences. I hope raising awareness of the issues people like me have faced will result in more help in the future.”

Bob Moon, person living with a rare or less common cancer

“Rare and less common cancers can present themselves in a variety of ways, so any new or unusual changes to your body should prompt a discussion with your doctor. More often than not, symptoms won't be anything sinister, but if it is something serious, the chances of effective treatment are always better when they are detected early. We all need to work to ensure we are more aware and empowered to diagnose cancers as early as possible.”

Dr Ellie Cannon, GP

“The challenges faced by those living with rare and less common cancers were already far reaching – the pandemic has further exacerbated these. Despite rare and less common cancers accounting for around half of all cancers, patients may face delayed diagnosis as symptoms are harder to 'see', have a poor patient experience, and can struggle to access support. If the NHS is to meet its early diagnosis target, it is vital that cancer remains a Government priority – and that rare and less common cancers feature heavily in this renewed focus.”

Paul Bristow, MP

“As patients and doctors continue to navigate care post-COVID-19, it is of critical importance that we work together to raise awareness of the challenges faced by those living with rare and less common cancers and do more to support timely diagnosis, provision of suitable treatment and ultimately improved levels of support and care.”

Dr Olivia Ashman, Oncology Medical Director, Pfizer UK

References

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