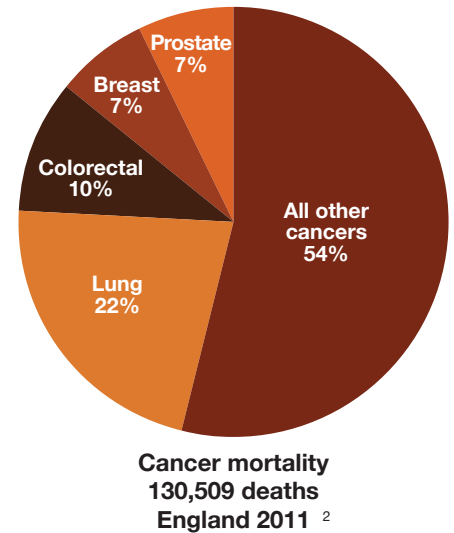
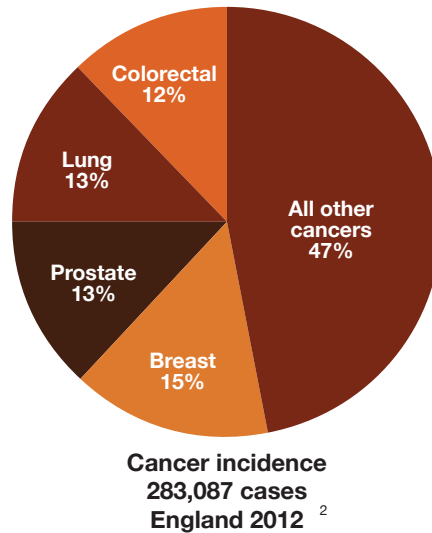


The hidden majority: Improving outcomes for people with rare and less common cancers in your constituency

Briefing for Parliamentary event on 10 December 2014 hosted by John Baron MP, Chairman of the All Party Parliamentary Group on Cancer, and organised by Cancer52 and Novartis Oncology

Rare and less common cancers make up over half of all cancer deaths

Rare and less common cancers (defined as all cancers outside the 'big four' common cancers of breast, prostate, lung and bowel) accounted for 47 per cent of all cancer cases diagnosed in 2012.¹ More shockingly they represented 54 per cent of all cancer deaths with over 130,000¹ people dying from a rare or less common cancer in 2011. This figure has increased from 52 per cent of all cancer deaths in England in 2006.¹



Why is there a disparity between incidence and mortality rate of rare and less common cancers?

Cancer52 believes that at every stage of the cancer pathway, from diagnosis to access to treatments, patients with rare and less common cancer encounter additional hurdles. Specific challenges may vary from cancer to cancer, but are often linked to:

- Delayed diagnosis because the number of people with these cancers is smaller and symptoms less well known;
- Poorer NHS experience than patients with more common cancers - as highlighted in the NHS National Cancer Patient Experience Survey (NCPES 2012-13)³;
- Lower levels of investment in research resulting in fewer advances in treatment.

Policymakers should ensure a parity of focus between common cancers and rare and less common cancers

The Government and the NHS have focused on improving survival rates for common cancers, but this strategy has led to patients with rare and less common cancers being left behind. Parliamentarians, policy makers and the NHS must ensure that there is parity of policy focus and outcomes between rare and less common cancers and the four common cancers. Without this parity outcomes for patients with rare and less common cancers will continue to lag behind. While the Government's objective of saving 5,000 to 10,000 lives each year may be achieved by focusing on the common cancers, the increasing number of patients with rare or less common cancers makes the human cost of this disparity less and less acceptable.

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What would improve outcomes for people with rare and less common cancers in the future?

In September 2014 Cancer52 published its Manifesto⁴ with a call for the following three key policy changes to improve outcomes for people with rare and less common cancers.

1. Refreshed cancer strategies across the UK

We recognise all four nations have made progress in tackling cancer through their adoption of cancer strategies. We want all political parties to commit to refreshing their strategies and include extensive policies and programmes whose objectives are tailored to addressing the problems confronting the less common cancers patient population.

2. More research into rare and less common cancers

Thanks to ongoing research efforts, in which the UK plays a leading role and which some of our members fund, we know more about cancer. But research into less common cancers lags behind that for the big four cancers. That is echoed in the flagship 100,000 Genomes Project. This is not aligned with commitments made elsewhere that recognise the era of stratified medicines where small patient groups, often sub groups, are the focus. We want all political parties to ensure a place is found for all patient populations in the Genomes Project.

3. Early access to modern treatments and services

Early diagnosis and onward referral of cancer patients has been the key focus for tackling rising mortalities for the less common cancers. This is not enough if waiting times for treatments are growing and patients struggle to access effective treatments. In England, the uncertainties relating to Value Based Assessment and expiry of the Cancer Drugs Fund exacerbate this situation. Similar uncertainties prevail in the other nations. We want all parties to commit to decision-making where patients' experiences and perspectives form a core part of the process.

Since September 2014 NICE has published draft guidelines and Cancer52 has submitted its response to the Cancer Drug Fund consultation.

We welcome the recently updated draft guidelines from NICE on suspected cancer, published in November 2014, that hope to improve symptom identification at the primary care level, and bring in safety netting.⁵ But even though this is important, it is not enough on its own when waiting times for treatments are growing and patients struggle to access effective treatments. In England, the uncertainties relating to funding models for cancer drugs, including reform of the Cancer Drugs Fund (CDF), exacerbate this situation.

Accordingly, we call on all parties to commit to develop a sustainable mechanism for the funding of cancer drugs that includes genuine and meaningful patient involvement in the decision-making process.

1. Page 1, New report from Cancer52; Percentage of cancer deaths outside the big four rises to 54%, <http://www.cancer52.org.uk/wp-content/uploads/2013/03/Cancer52-NCIN-Report-press-release-10-June-2014.pdf>
2. Source Data Report from Cancer52 on National Cancer Intelligence Network data on rare and less common cancers published June 2014
3. Page 12, NCPES 2013 survey <http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file>
4. Cancer52 Manifesto, <http://www.cancer52.org.uk/wp-content/uploads/2014/09/Cancer52-Manifesto-for-2015-General-Election.pdf>
5. <https://www.nice.org.uk/news/press-and-media/nice-updating-guidance-for-faster-cancer-diagnoses>