



Public Health
England



Press release

Issue date for immediate release

Deaths from rare and less common cancers in England continues to rise

Data on nearly 280 cancers is published by Cancer52 and Public Health England's National Cancer Intelligence Network for the first time.

Deaths from rare and less common cancers continue to rise in England, confirms a new report published today (Monday 8th June 2015) jointly by Cancer52ⁱ and Public Health England'sⁱⁱ National Cancer Intelligence Network (NCIN)ⁱⁱⁱ. The report, "*Rare and Less Common Cancers: Incidence and Mortality in England, 2010 to 2013*" shows that there were 2,700 more deaths annually in 2013 from rare and less common cancers^{iv} in England than in 2010^v.

This reflects the ongoing trend of a higher percentage of deaths coming from this group of cancers (defined as those outside the big four, namely lung, bowel, breast and prostate cancers). Rare and less common cancers made up just under half (47%) of all newly diagnosed cancers in England in 2013 yet accounted for 54% of all cancer deaths, a percentage that has increased from 52% in 2007.

This report marks a milestone in the recognition of the number of people affected by the rare and less common cancers as it has brought together incidence and mortality figures for nearly 280 cancers for the first time. The report highlights a number of cancer sites as having comparatively high mortality rates considering their incidence rates, while others show both high incidence and mortality rates.

Jonathan Pearce, Chair of Cancer52 said: "The enormous initial task of preparing this data has been carried out by the NCIN team and robust incidence and mortality figures identified. The figures illustrate that although people are less likely to get a rare or less common cancer, if they do develop one they are more likely to die from it. Cancer52 calls on policy makers to more strongly address the inequalities and inequities that allow this scenario not only to continue, but to worsen."

Dr Mick Peake, lead clinician at the National Cancer Intelligence Network said: "We are delighted to be part of this analysis which supports the smaller groups within the cancer community, many of which are so often overlooked. These numbers, available for the first time across England, will make an enormous difference to the development of high quality care for the patients who suffer from

these cancers. We will be working with Cancer52 to ensure that their members can utilise the data to its best effect."

The report, which was produced with the advice and guidance of a project board^{vi} from within NCIN and Cancer52, is being launched at the NCIN conference in Belfast. Cancer52 is extremely grateful to the NCIN for all its work and support on this project.

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ⁱ Cancer52 is an alliance of more than 80 organisations working to address the inequalities faced and improve outcomes for people with rare and less common cancers. Named in 2007 to reflect the 52 per cent of cancer deaths from these cancers recent statistics show an increase to 54%. Despite this, rare and less common cancers remain severely under represented and under-funded across all areas, including policy, services and research.

ⁱⁱ Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health. Website: www.gov.uk/phe, Twitter: @PHE_uk, Facebook: www.facebook.com/PublicHealthEngland

ⁱⁱⁱ The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

^{iv} Rare and less common cancers together are those outside the 'big four' of breast, colorectal, lung, and prostate. Rare cancers have an incidence of less than 6 per 100,000 of population; whilst less common cancers have an incidence great than 6 per 100,000 but are outside the big four.

^v "[Rare and Less Common Cancers: Incidence and Mortality in England, 2010 to 2013](#)" report

^{vi} The project board comprised from within the NCIN and in alphabetical order Nicky Coombes, Lucy Elliss-Brookes, Sam Johnson, Claudia Oehler and Mick Peake; and from within Cancer52 Jane Lyons, Clara Mackay of Pancreatic Cancer UK, Helen Morement of AMMF, The Cholangiocarcinoma Charity