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Issue date 24th February 2014

Cancer52 publishes position statement on the UK Strategy for Rare Diseases

Making sure that rare cancers aren't written out of the script

[Cancer52](#), an alliance of more than 70 predominantly patient support charities working in the field of rare and less common cancers, is today (24th February 2014) publishing its position statement on the [UK Strategy for Rare Diseases](#).

Detailed national implementation plans from all four nations in response to the Strategy are due for publication on Rare Disease Day (28th February 2014).

More than 84,300 people died of a rare or less common cancer in the UK 2011, accounting for 54% all of cancer deaths¹. 46% of cancers diagnosed are rare and less common cancers².

More than 80 per cent of Cancer52's 74 member organisations³ work with rare cancers, ie one that affects five people or fewer in 10,000⁴.

Says Cancer52 Head of Policy David Ryner of Cancer52's position statement, "Despite accounting for thousands of deaths every year rare cancers, and the increasingly disproportionate and widening gap between diagnosis and mortality rates for rare and less common cancers⁵, they have to date warranted only a single reference across the 35 pages of the Strategy, and then only in reference to the NHS England 100,000 Genomes Project.⁶"

Says Cancer52 Chair Allyson Kaye, MBE, "For the future we want to ensure that rare cancers are not written out of the script and are asking the government for specific actions to ensure that this happens - specifically by inviting Cancer52 to join the Department of Health Rare Diseases Stakeholder Forum Group."

In summary Cancer52 is asking that

- **Cancer52 be represented** on the Department of Health Rare Diseases Stakeholder Forum Group
- Progress reports **be published every year** and the Health Select Committee (and respective Committees across the UK) run **annual inquiries** to hold each country to account

¹ source <http://www.cancerresearchuk.org/cancer-info/cancerstats/mortality/> accessed 14th February 2014

² source <http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/> accessed 14th February 2014 -

³ Source Cancer52 member survey February 2014

⁴ A rare disease is a life-threatening or chronically debilitating disease that affects 5 people or fewer in 10,000 and requires special, combined efforts to enable patients to be treated effectively.

⁵ Cancer52 was established at the end of 2007 at the behest of the then Cancer 'Tsar' Professor Sir Mike Richards. The alliance was so named because at the time rare and less common cancers accounted for 52% of all cancer deaths, a percentage that has now increased to 54% - an increase of 3% in seven years

⁶ <http://www.genomicsengland.co.uk/100k-genome-project/>

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- the focus on Rare Diseases **be maintained** despite all the pressures that the NHS is under
- **Rare cancers are clearly identified in all work relating to the Strategy.** No mention was made of rare cancers, or indeed cancer, in the consultation on the UK Strategy. Now there is a single reference to cancer
- **Sight is not lost of the importance of access to treatments.** This was one of the key elements of the European Commission's requirements and yet little more than half a page in the Strategy covers these issues.
- The government **work with patient and carer organisations** to help implement, evaluate and improve; research, shared data collection, diagnosis, access to services and treatments for those with rare diseases.
- Each department of health across the four nations set up **stakeholder groups and publish their Terms of References** and, as part of annual progress reports, publish the views of stakeholders. In England, we want NHS England to host the stakeholder group.

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