

Cancer52

Fifth Annual All Stakeholder Briefing

Cancer 52's response to the Cancer Strategy

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Cancer Strategy

Achieving world class outcomes 2015-20

Some key points for rare/less common cancers

- Overall cancer incidence to rise to over 300,000 new diagnoses per year by 2020 (and 360,000 per year by 2030).
- About half these diagnoses will be of rare and less common cancers.
- Although overall patient experience is improving year on year, for some groups (including those with rare and less common cancers) experience and service satisfaction is worse.
- National or regional MDTs for rare/less common cancers should be established where treatment options are low volume and/or high risk (Recommendation 40).

Cancer Strategy

Achieving world class outcomes 2015-20

Some key points for rare/less common cancers

- Government and Medicines and Healthcare products Regulatory Agency should lead on ensuring EU Clinical Trial Regulations are finalised and implemented as soon as possible – will help reduce the time it takes to set up clinical studies, which should help trials re rarer cancers and in younger people.
- NHS providers' directories of local information and support services should cover all cancers, including rare and less common cancers.
- NHS England should pilot stratified pathways for some rarer cancers (Recommendation 67).
- All treatment services for rare cancers (fewer than 500 cases per annum across England, including all paediatric, teenage and young adult services) should be commissioned nationally.

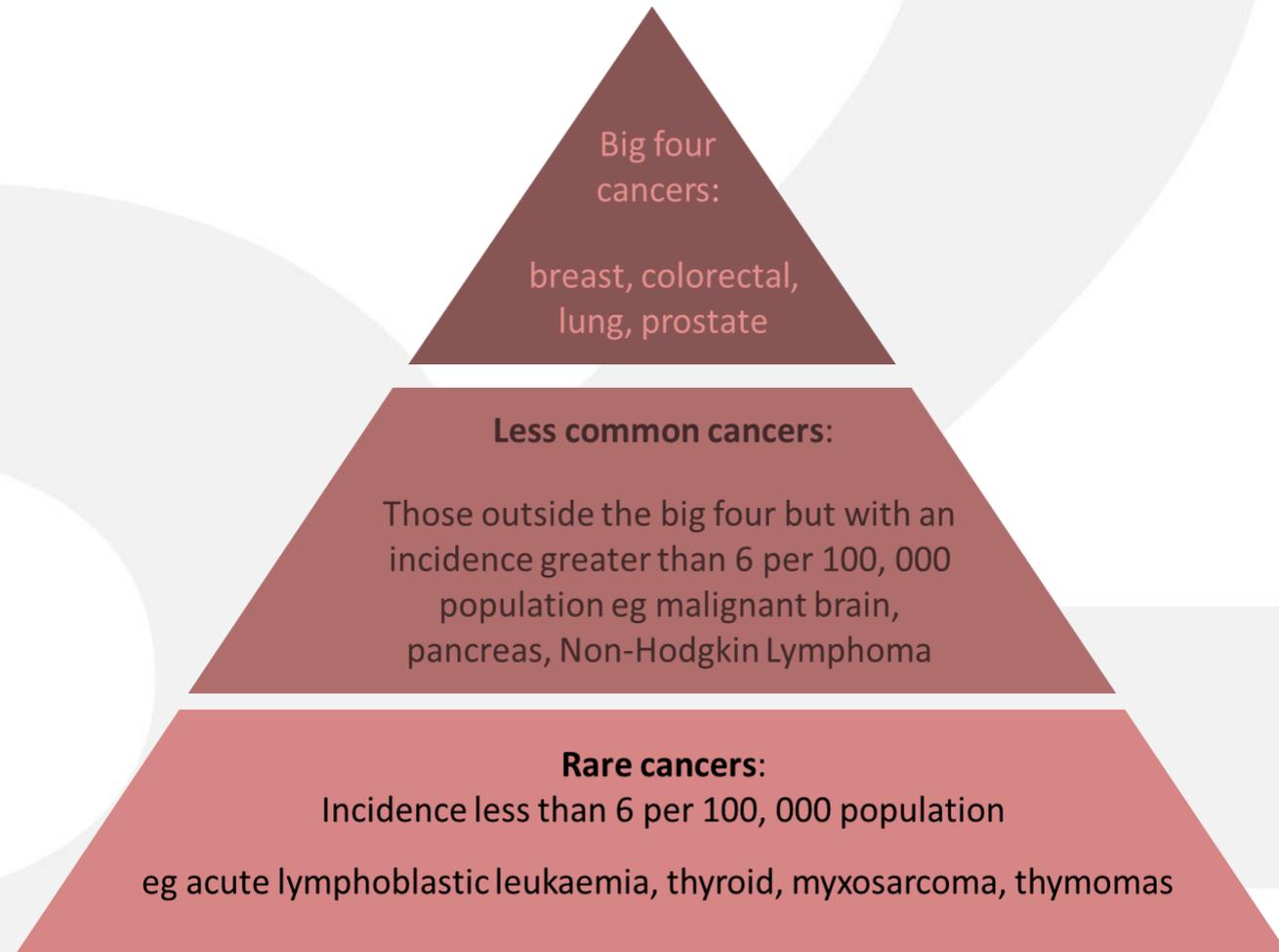
Cancer Strategy

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Some key points for rare/less common cancers

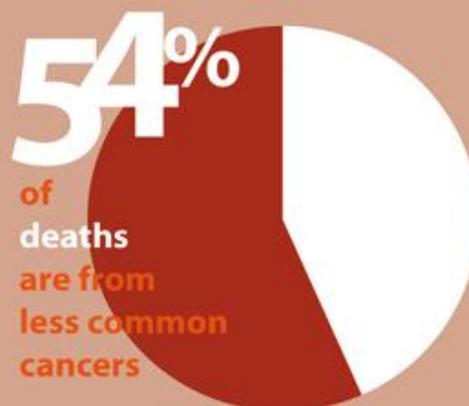
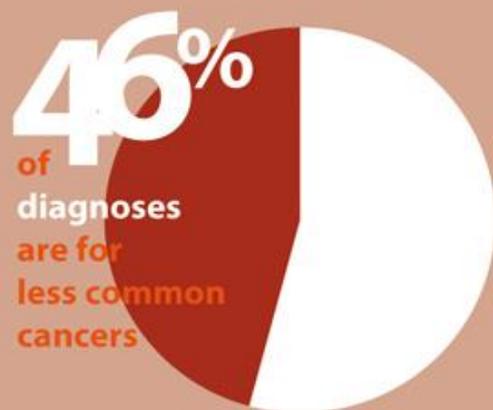
- Clinical reference groups should take responsibility for developing minimum service specifications where patient volumes are too low to be covered by a NICE clinical guideline, for example for rarer cancers (Recommendation 79).
- There is an urgent need for investment in cancer specialist nursing roles, particularly in rarer cancers and certain geographies.

Rare and less common cancers¹



¹ Source: "[Rare and Less Common Cancers: Incidence and Mortality in England, 2010 to 2013](#)" report accessed June 2015

Incidence and mortality



Key areas for Cancer52 member organisations

- **Diagnosis** – pretty much across the board.
- **Research and clinical trials** – variable across different cancer types, but for many rare/less common cancer types there is a disproportionate research spend (eg, brain tumours).
- **Access to, and choice of, treatments** – reduced opportunities for rare/less common cancers (CDF and NICE unable to deal equitably and appropriately with such treatments).
- **Patient experience and support** – worse for those with rare/less common cancers.

Key areas for Cancer52 member organisations

Priority areas

- Children, teenagers and young adults.
- Cancers specifically affecting women (outside of breast cancer).
- Cancers specifically affecting men (outside of prostate cancer).
- Cancers with very low or historically poor outcomes (eg, pancreatic, oesophageal, brain).
- Chronic cancers (as opposed to those treated with curative intent).
- Haematological or systemic cancers (different paradigm to solid tumour cancers).
- Older people – equitable access to diagnosis, treatment and care.

Cancer52 calls for

1. Cross-party political support for the implementation of the strategy in NHS England.
2. Confirmation from the Government that it is committed to driving up standards in cancer care through the implementation of the strategy.
3. Explicit inclusion of the strategy, and the financial resources to implement it, in the NHS settlement within the Chancellor's Autumn Budget Statement
4. Confirmation that NHS England are committed to implementing the recommendations; and a blueprint or action plan to be produced to take this forward.
5. The Strategy Taskforce to become an Implementation Taskforce, with rare and less common cancers representation.

Implementation

Priority areas

- Diagnosis of rare/less common cancers – in addition to the pilots and strategies identified within primary care, there need to be further specific initiatives (including digital decision support tools) developed and implemented by NHS England and Public Health England.
- Piloting as a priority the creation of multi-disciplinary diagnostic centres to investigate vague or unclear symptoms (see Recommendation 21).
- Ensuring that the recommendation on the audit of A&E cancer diagnoses is not only implemented, but strengthened, by the requirement that discussion between primary and secondary care services takes place and leads to recorded actions to improve practice (see Recommendation 25).

Implementation

Priority areas

- Creating a sustainable solution for rapid access to new and innovative cancer drugs (see Recommendation 31).
- Development a clear strategy and action plan to transform access to molecular diagnostics as a way of ensuring personalised medicine on the NHS is realised (see Recommendation 37).
- National or regional MDTs for rare cancers (see Recommendation 40).
- Prioritising the importance of clinical research for rare and less common cancers (see Recommendations 50, 51 and 52).
- Access to Clinical Nurse Specialists (see Recommendation 61).

Implementation

Priority areas

- Specific catering for the information needs of people affected by rare or less common cancers.
- Recognition of the post-treatment needs of rare and less common cancer patients, especially given the lower levels of knowledge and awareness of such cancers.
- Confirmation from NHS England that treatments services for rare cancers will continue to be commissioned nationally.