

# **Cancer52 Policy Briefing**

**Achieving World-Class Cancer  
Outcomes**

**A strategy for England 2015-2020**





## Introduction

This is a Cancer52 Policy Briefing on the implementation of *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020*.

Cancer52 has been involved in the development of the Cancer Strategy since its inception. Former Chair Clara MacKay represented the coalition on the Cancer Taskforce alongside other key representatives from the cancer community. Below we outline the Cancer52 position on the implementation of the Strategy and the key elements we would like to see taken forward for rare and less common cancers.



## **About Cancer52**

Cancer52 is a coalition of more than 80 cancer charities representing rare and less common cancers, which account for more than half of all cancer deaths in the UK. We campaign and work on issues and policies that impact on the rare and less common cancer community, including improving diagnosis, treatment and support.

Current data shows that 46% of cancers diagnosed are rare and less common cancers, yet they account for 54% of cancer deaths.



## **Implementation**

In January 2015, NHS England announced the establishment of an independent taskforce to develop a “Five-year action plan for cancer services that will improve survival rates and save thousands of lives”. This was designed to support the NHS England Five Year Forward Review and was given a short timeframe of around six months to consult with the cancer community, and to develop a series of recommendations for NHS England to take forward.

Given the haste at which the Taskforce was established and conducted, and the amount of time and resource that has been allocated from a range of stakeholders, it is surprising that there has been minimal reaction from the Government or NHS England to its publication. It is also notable that there has been little mention of a strategy for implementation in the NHS or whether any additional capacity or financial resources will be made available in the coming financial year(s).

Whilst the Strategy outlines some potential areas of increased spending, efficiency savings will be realised in the long-term when benefits are made to the health service through improved cancer patient outcomes and experience.

## **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 implementation of the Strategy.
3. An express mention of the Strategy and financial resources made available for its implementation to be included in the NHS settlement provided within the Chancellor's Autumn Budget Statement. This will ensure that NHS England has political confidence, capacity and resources to ensure that the plan is taken forward.
4. Confirmation that NHS England is committed to implementing recommendations contained within the Strategy and a blueprint outline for how this is going to be prioritised and executed.
5. A seat for Cancer52 on any Implementation Taskforce established to ensure that the Strategy is delivered.

## Rare and less common cancers

The Strategy specifically includes reference to key issues and recommendations for patients with rare and less common cancers which span across all the Strategy key areas:

- **Incidence** (page 7): Current incidence for all cancers is around 280,000 individuals with cancer in a year, which is expected to rise to over 300,000 in 2020 and more than 360,000 in 2030. Half of these will be of rare and less common cancer types.
- **Patient experience** (page 13): Whilst patient experience, as measured by the Cancer Patient Experience Survey, shows continuous improvement and less variation, patients with rare and less common cancers report less satisfactory experience.
- **Research** (page 46): The EU Clinical Trials Regulation offers a real opportunity to reduce the time it takes to get studies set up. This will open up the prospect of additional clinical trials, particularly in rare cancers and in younger people, if implemented appropriately.
- **Information** (page 53): Providers should maintain a directory of local services for people with cancer, their carers and families, and signpost to appropriate services. This should cover all types of cancer; people with rare and less common cancers in particular often report difficulties in accessing this kind of information.
- **Nursing** (page 71): The specialist adult cancer nursing workforce in general is not expanding sufficiently to keep pace with the growing number of people with cancer. There is an urgent need for investment in cancer specialist nursing roles, particularly in rare cancers and certain geographies.
- **MDTs - Recommendation 40:** The Trust Development Authority, Monitor and NHS England should strongly encourage the establishment of national or regional MDTs for rarer cancers where treatment options are low volume and/or high risk. Clinical Reference Groups will need to play a key role in supporting these.
- **Follow up pathways - Recommendation 67:** NHS England should pilot stratified follow-up pathways of care for other tumour types, ideally including prostate and colorectal and some rarer cancer types, with an aim to roll out nationally for at least two other cancer types by 2020.
- **National commissioning - Recommendation 76:** 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.
- **Minimum service specifications - Recommendation 79:** CRGs 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.

## What would Cancer52 like to see implemented from the Strategy as a priority?

1. Rare and less common cancers are often the most difficult cancers to diagnose in primary care. This is due to the small numbers of patients that General Practitioners (GPs) see and also due to the symptoms often being confused with more common conditions. Whilst we welcome the inclusion of pilots and strategies for improving cancer diagnosis in primary care, we would like to see further specific initiatives developed and implemented by NHS England and Public Health England to try and tackle the challenges of diagnosis in rare and less common cancers. We would also welcome a comprehensive roll out of digital decision support tools to assist diagnosis of rare and less common cancers in primary care.
2. **Recommendation 21** which outlines the creation of multi-disciplinary diagnostic centres to investigate vague or unclear symptoms should be piloted as a priority. If successful, this could ensure that patients with rare and less common cancers do not present at the GP repeatedly prior to being diagnosed and could improve patient treatment outcomes in the long-term.
3. **Recommendation 25** which outlines that significant event audit should become routine if patients are diagnosed in Accident and Emergency (A&E). Rare and less common cancers are more likely to present in the emergency setting, so information to demonstrate why this happens is crucial. However, audit alone will not ensure that these events do not reoccur. In local areas where patients present at A&E, discussion should take place at a local level between primary and secondary care to ensure that lessons are learnt.
4. **Recommendation 31** states a “sustainable solution for access to cancer drugs” should be created. Cancer52 agrees that this should be a key priority, as cancer commissioning through the Cancer Drugs Fund has been an anomaly and we need sustainable systems in place to ensure that patients are able to receive the treatments they need on the NHS.
5. NHS England chemotherapy algorithms are likely to restrict flexibility in prescribing in patients as trusts are held to account in their implementation. Moving forward, we would like to see innovative uses of the algorithms to ensure that cancer patient outcomes are improved. It is hoped that **Recommendation 76** - to ensure that NICE guidance is implemented as a minimum - is built upon to ensure that innovation takes place in the treatment of rare and less common cancers. We would also like to see more consideration given to the challenges presented by high-cost-low volume drugs.
6. **Recommendation 37** outlines that access to molecular diagnostics on the NHS should be transformed. We would welcome a commitment from the Government and NHS England to ensure that a clear blueprint is developed moving forward to ensure that personalised medicine on the NHS is realised. However, it should also be recognised that there are a range of challenges across the NHS, particularly within commissioning, that may hinder the progress towards personalised medicine – as a cancer and wider disease community we need to be having discussions now on how we prepare the NHS for personalised and genomic medicine to ensure that it is realised. As a start, we welcome the NHS England Board Paper on Personalised Medicine Strategy and hope the emerging vision for this will be realised.

7. We agree with the provisions within **Recommendation 76**, that treatment services for rare cancers will be commissioned nationally. This is a model that has been successful and we would welcome confirmation from NHS England that this will be continued.
8. **Recommendation 40** recommends that national or regional multi-disciplinary teams (MDTs) should be established for rare cancers where treatment options are low volume and/or high risk. MDTs are important for all cancers but are particularly important for cancers which have a low occurrence and benefit from information sharing and decision-making across a wider geographical area.
9. **Recommendation 61** outlines that providers should ensure that all cancer patients should have access to a Clinical Nurse Specialist (CNS). Cancer52 endorses this, as the NHS England Cancer Patient Experience Survey and feedback from our members highlights that patient experience improves if they have access to a CNS. CNS help cancer patients access information about their cancer and can cater to the patient's holistic needs throughout their treatment pathway.
10. **Recommendations 50, 51 and 52** all outline the importance of conducting clinical research in the NHS. Cancer52 fully supports the need for a clear excess treatment costs policy, as this has been lacking within NHS England, and will ensure that high quality clinical research continues in England. We also support increasing the numbers of trials, but NHS England should ensure that we conduct studies that ask useful questions to advance treatment and care and make the best use of rare and less common cancer populations. There also needs to be international collaboration, particularly with rare and ultra-rare cancers given the small nature of the populations involved.
11. The information needs and preferences for people with a rare or less common cancer may differ to patients with more common cancers. This is because there is often less information and support available and also less understanding and access to expertise. Whilst we welcome the provisions made within the Strategy for increased information provision, shared decision-making and on communication skills of healthcare professionals, we would like to see the specific information needs of patients with rare or less common cancers catered for within NHS England. The role that cancer charities and patient organisations play in the provision of information and improving patient experience should also be stressed.
12. We welcome the recommendations within the Strategy that aim to ensure patients are supported and followed up after completing treatment. Patients with rare and less common cancers often feel cast adrift after this time, and often experience emotional and social problems as a result of this. The medical contact patients receive following a discharge from secondary care is with a GP, who is unlikely to have come across the rare/less common cancer before.



## **Credits and thanks**

Cancer52 would like to thank the members of its Policy and Public Affairs Steering Group, particularly Kate Morgan of Myeloma UK, for their work in producing this briefing.

Members of the Group are:

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- Jonathan Pearce, CEO Lymphoma Association and Chair of Cancer52
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## **Further information**

For further information about the work of Cancer52 please visit [www.cancer52.org.uk](http://www.cancer52.org.uk) or email [info@cancer52.org.uk](mailto:info@cancer52.org.uk)





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