

**Rare and Less Common Cancer
Recommendations
Cancer Strategy Review April 2017**

Introduction

When the Cancer Strategy 'Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020' was published in July 2015 Cancer52 published a Policy Briefing which identified those of the 96 Recommendations contained within the Strategy that were the most important or relevant to rare and less common cancers in the implementation of the Strategy.

Our then chair Clara Mackay represented Cancer52 on the development of the Strategy and our CEO Jane Lyons now represents Cancer52 on the National Cancer Advisory Group that reviews progress of the implementation.

As part of its tracking work on progress of recommendations Cancer52 reviewed those recommendations originally identified by the Policy Briefing, and reviewed progress as at April 2017.

Findings are contained within this Review.

Priority areas	Cancer Strategy - relevant recommendations	Cancer Implementation Plan – May 2016	Cancer Strategy annual report – October 2016	Comments
Prevention and public health	None specific.	No change	No change	Although no formal recommendation this is an important area of work for rare and less common cancers and we ask that where possible work is identified that is relevant for rare and less common cancers.
Earlier and faster diagnosis	Recommendation 21: NHS England should pilot, in up to 5 vanguard sites and in conjunction with Wave 2 of the ACE programme, multi-disciplinary diagnostic centres for vague or unclear symptoms. These should have the capability to carry out several tests on the same day.	Six pilots of MDDCs to run over the next 2 years	Patients with vague or non-specific symptoms can often experience long delays in being diagnosed, even when their GPs are concerned their symptoms may be serious. This year we have started to trial new MDDCs to speed up the time to diagnosis for those patients. The pilots are taking place in London, Greater Manchester, Leeds, Bristol, Oxfordshire and Airedale, Wharfedale and Craven (Yorkshire)	Making progress towards the MDDCs is a priority for Cancer52 and we are involved with have input work to this and will continue to monitor and champion this work.
	Recommendation 25: All GPs should be required to undertake a Significant Event Analysis for any patient diagnosed with cancer as a result of an emergency admission.	Not mentioned	Not mentioned	The accountability for this work is unclear. Information about accountability and progress on this would be useful.

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Patient experience	Recommendation 61: NHS England and the Trust Development Authority should encourage providers to ensure that all patients have access to a CNS or other key worker from diagnosis onwards, to guide them through treatment options and ensure they receive appropriate information and support. In parallel, NHS England and Health Education England should encourage providers to work with Macmillan Cancer Support and other charities to develop and evaluate the role of support workers in enabling more patient centred care to be provided.	Over the next year, work will be done on the best way to improve access to Cancer Nurse Specialists or key workers.	New innovative approaches for commissioning and providing CNS care will be identified. New and innovative approaches for commissioning and providing CNS care will be identified to enhance care for patients, particularly focussing on those groups who report a poorer experience of care or where fewer patients report having access to a CNS. We propose to test, and implement these approaches in coming years.	The work on improvements to patient experience is important for Cancer52, we continue to be involved - good progress so far.
Living with and beyond cancer	Recommendation 67: The Trust Development Authority and NHS England should ensure all providers are incentivised to start implementing stratified follow-up pathways of care for patients treated for breast cancer. 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.	The spread of risk stratified follow-up pathways for breast cancer will be underway by March 2017. This approach will be applied to other cancer types in subsequent years.	Not mentioned	An update on meeting the March 2017 deadline for breast cancer risk-stratified follow-up pathways would be good as well as more information about the programme moving on to cover rare and less common cancer pathways.

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<p>High quality modern services</p>	<p>Recommendation 31: NHS England should work with NICE, the Government, the pharmaceutical industry and cancer charities to define a sustainable solution for access to new cancer drugs. This updated process should enable NHS England to confirm clinical utility, whilst managing within a defined budget, and should be aligned with NICE appraisal processes. The new process should be published for consultation in summer 2015, with a view to implementation from April 2016. The solution should set out reforms to NICE processes to make them more flexible for cancer drugs.</p>	<p>Not mentioned</p>	<p>In July, NHS England launched a new approach to the appraisal and funding of cancer drugs in England, which will mean faster access to the most promising new treatments for patients. https://www.england.nhs.uk/cancer/cdf/</p>	<p>Access to medicines and treatments remains a high priority for Cancer52. We will be producing a position paper on our response to the NICE/NHS England reforms which will set out our concerns for how these reforms will have a negative impact for rare and less common cancer patients. We will share this paper with NCAG.</p>
	<p>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.</p>	<p>Not mentioned</p>	<p>Not mentioned</p>	<p>Cancer52 has input to the development of the work on a regional MDT for rare cancers. It is a priority for us to monitor how this work develops, including reviewing alternative options to an MDT if this approach is not progressed.</p>

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	<p>Recommendation 50: NHS England should ensure commissioners and providers are incentivised to maintain the UK’s world-leading position in cancer studies and applied health research. This should ensure that as many patients as possible have the opportunity to be part of a study, including in smaller stratified trials.</p>	<p>A programme of better cancer research will be developed by 2017 with the National Institute for Health Research and the National Cancer Research Institute; within the year, priorities for research on outcomes for older people with cancer will be set out.</p>	<p>Over the last year we have worked with the NCRI to help them incorporate the priorities identified in the Taskforce report into their work programme, and support the cancer research community to get behind the key Taskforce ambitions. Cancer Alliances will be crucial in supporting and speeding up the roll out of research and its results.</p>	<p>The agenda around improved research is important, and an update on the role of the Cancer Alliances would be useful.</p>
	<p>Recommendation 51: By the end of 2015, NHS England should publish clear guidance that commissioners must meet excess treatment costs for clinical trials accepted on to the NIHR portfolio as part of routine business. ETCs for radiotherapy trials should be distributed through a national fund held by NHS England to ensure high quality clinical trials are developed and delivered optimally.</p>	<p>Not mentioned</p>	<p>Not mentioned</p>	<p>The agenda around improved research is important, and an update on the role of the Cancer Alliances would be useful.</p>

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	Recommendation 52: NHS England strongly encourage NIHR, research charities and other funders to ensure that relevant and effective patient and public involvement in research becomes the norm for research funders, funded applications and for grant applicants, in line with the overall drive to see a more patient-centred NHS.	A programme of better cancer research will be developed by 2017 with the National Institute for Health Research and the National Cancer Research Institute; within the year, priorities for research on outcomes for older people with cancer will be set out.	Not mentioned	An update on the programme of better cancer research, due in 2017, would be useful.
Commissioning, provision and accountability	Recommendation 76: By the end of 2015 NHS England should set out clear expectations for commissioning of cancer services. All commissioners should commission to NICE guidelines and CRG-approved service specifications as a minimum. The following principles should form the basis of the new cancer commissioning landscape, to be clearly defined in national guidance from NHS England (see Figure 23): <ul style="list-style-type: none"> • 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 	Not mentioned	In the coming months we would like to see a clearer focus and central expectations for the commissioning of cancer services. It would be useful to see more detail on how the recommendation regarding the split in commissioning responsibilities is addressed, including the split within elements of common cancer pathways as well as commissioning for rare cancers.	The commissioning environment for cancer remains critical to improvements in delivery. An update on the expectations and structures would be useful, including the relationship with Cancer Alliances.

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	<p>Recommendation 79: Clinical Reference Groups within NHS England should work with NICE and its other stakeholders to decide when clinical guidelines need updating. NICE should ensure that its surveillance and updating processes take into account emerging evidence, changing clinical practice and the ambitions set out in this report. CRGs should take responsibility, with support from NICE, to develop clinical guidelines into more detailed service specifications where necessary by the end of 2016. 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.</p>	Not mentioned	Not mentioned	Similarly to above, the specialised commissioning environment remains critical, an update about the role of the CRGs and Programme of Care would be useful.