

Summary of Cancer52 Policy Roundtable Discussion

Held 4th April 2019

Cancer52 held a roundtable on 4th April 2019 to explore the implications of the NHS Long Term Plan and what it means for rare and less common cancers. Following opening remarks from Jane Lyons, Chair, and David Fitzgerald, NHS England, attendees discussed three questions, covering risks and opportunities, integrated care and earlier diagnosis. The discussion is summarised in this document.

Roundtable Attendees

ORGANISATION	NAME	JOB TITLE
AMMF – The Cholangiocarcinoma Charity / Cancer52 Trustee	Helen Morement	Founder and CEO
Association of the British Pharmaceutical Industry	Mike Ringe	NHS Engagement Partner (London) and Specialised Commissioning Lead
Bloodwise/Cancer52 Trustee	Chris Walden	Head of Policy And Campaigns
Cancer Research UK	Emlyn Samuel	Head of Policy Development
Cancer52	Jane Lyons	CEO
Cancer52	Laura Thomas/ Jennifer Mitchell	Policy Adviser
King's Health Partners Accountable Cancer Network	Dr Kate Haire	Clinical Director
Macmillan	Moira Fraser-Pearce	Director of Policy, Campaigns and Influence
National Cancer Research Institute	Andrea McConnell	Clinical Research Group
National Institute for Health and Care Excellence	Helen Knight	Associate Director
NHS England	David Fitzgerald	National Cancer Programme Director
Public Health England	Dr Luke Hounsome	NCRAS Analytical Programme Manager
South East London Cancer Alliance	Dr Anthony Cunliffe	Clinical Lead
Target Ovarian Cancer / Cancer52 Trustee	Rebecca Rennison	Director of Public Affairs and Services

Summary of Discussion

Opening remarks by David Fitzgerald, NHS England

David Fitzgerald is pleased with the Long-Term Plan (LTP) with respect to cancer. Cancer remains a key priority and there are over 30 commitments related to cancer included with the plan.

Rather than a lot of new ideas, the LTP delivers continuity, which had been a plea from the cancer community. There was a real sense of engagement across the cancer sector to help create the LTP and that has continued following its publication.

However, there has been a change in direction towards the front end of the pathway and early diagnosis. It is also unashamedly ambitious from a cancer point of view.

There is a huge opportunity for rare and less common cancers, in that the target of diagnosing 75% of cancers at stage 1 or stage 2 applies to all cancers. At the moment, due to methodology, the national measure only includes 10 cancers. However, the target will not be reached without improving stage shift in most or all cancers.

The LTP also includes commitments on:

- Prevention and smoking cessation
- Risk based screening
- Improving diagnosis early via primary care networks
- Rapid Diagnostic Centres (RDCs)
- The faster diagnosis standards
- Genomics
- Investment in radiotherapy
- Personalisation agenda including the holistic needs assessment.

Immediate next steps include planning for implementation, particularly for lung health and personalisation, and for RDCs (though these are admittedly at an earlier stage). Another focus is ensuring the governance structures for cancer are correct. Cancer Alliances will be the primary delivery vehicle and have recently been informed of their funding allocations, which are now based on population size and measures of deprivation and health inequalities, rather than rewarding those alliances that meet targets. Most Cancer Alliances (16 out of 19) will receive an increase in funding.

Question one: What are the risks and opportunities presented by the NHS Long Term plan for people with rare and less common cancers?

Attendees discussed the difficulties people with rare and less common cancers face, in getting a timely diagnosis, and accessing specialist care. In some cancers, few treatments exist. Some cancers, for example some blood cancers, are chronic conditions for which people must take a pill every day for the rest of their life. Pathways have not been mapped for all types of cancer. However, it is welcome that the LTP mentions rare and less common cancers.

The amount of data available has increased over recent years but there can still be issues with data collection. For example, the number of women with ovarian cancer diagnosed each year varies by 1500 from year to year; sometimes fallopian and peritoneal cancers are included in the coding figure. Cholangiocarcinoma, the second most common primary liver cancer, is not well known by GPs, yet in 2013 more people died from it than from cervical cancer.

RDCs are a helpful development but GPs will need to refer to them and RDCs will need to understand rare and less common cancers. People with rare and less common cancers can also struggle to get onto trials, because there are few trials and people do not always find out about them. They also struggle to find the support of a CNS, and CNSs don't always have much knowledge of rare and less common cancers.

Solutions discussed included developing pathways for all rare and less common cancers, and making a rare and less common cancer module compulsory at medical school. The development of personalised medicine means that the system needs to consider how it deals with uncertainty, where phase 3 trials may not be suitable, and NICE needs to adapt to that. There are opportunities with the development of the life sciences industrial strategy and the development of digital innovation hubs, which will bring data together.

NICE's Office for Market Access exists to make sure that industry can start the conversation early and get the right people around the table. NICE aims to deliver its standard technology appraisals as fast as possible, within 90 days.

The point was raised that NICE needs to start seeing the value of progression free survival, because for cancers where prognosis is poor, a few months extra of life can be of real value.

Genomics is a great opportunity for data and research to come together. It will be important to manage patient expectations, because if genomic testing identifies a molecular marker that can be treated, then the patient will need access to the drug. Academics tend to drive research into rare and less common cancers and there is a sense that bigger trials are crowding out these smaller academic driven trials.

Another risk around delivering the LTP is workforce shortages which have an impact on diagnostics and across the whole of the pathway. The importance of workforce was acknowledged but not explored further to retain the focus of the discussion on rare and less common cancers.

Question two: How will the new structural changes such as Integrated Care Systems impact on the diagnosis, treatment and care of those with rare and less common cancers?

Attendees discussed the impending advent of Integrated Care Systems and what it means for rare and less common cancers. The LTP was felt to be quite acute sector focussed, whereas stage shift will not be delivered unless there is a focus on prevention and awareness in primary care. The narrative needs to be right - GPs concentrate on diagnosing conditions based on symptoms, not diagnosing cancer per se, and do not wish people to be diagnosed with cancer late.

GPs need earlier and better access to diagnostic tests, such as liver function or CT scans. ICSs and the collaboration they should bring plus the Early Diagnostic Quality Initiative that will be introduced in next year's GP contract, should aid earlier diagnosis in primary care. RDCs will also help if people can get there quickly. However, there needs to be a focus on GPs safety netting - they must not dismiss patients but nor should they refer everyone.

There is also the need to focus on those who have had radical treatment and need care and treatment in the community afterwards.

It is hoped that Alliances will give people the head space to build the necessary relationships and work out how to make changes/improvements.

Alliances can help build the infrastructure to allow access to clinical trials across sites. They are also looking at innovative ways to recruit to posts including sharing workforce across sites.

Disadvantaged patients may not be receiving the best care but ICS should help to address this. The ICS will be responsible for tackling wider determinants of ill health. The integrations created by ICSs should also help to address screening, which needs better working between services, and end of life care, for which nobody or sector currently owns responsibility.

The challenges include financial constraints within the NHS especially among Trusts. Also alliances have been focused on cancer access targets and therefore the four most common cancers. However, there is now a shift from faster to earlier access.

Question three: How can the target of 75% of all cancers diagnosed at stage 1 and 2 be realised?

Dr Luke Hounsome from PHE presented data on cancers and staging. The data shows that some types of cancers have a high percentage of stage recorded, while others do not. Those cancers with clinical audits tend to have a higher percentage of cancers staged. Some cancers (approx. 1.5%) cannot be staged such as the blood cancers.

The 75% diagnosis ambition cannot be met unless progress is made on all cancers. At present, the early diagnosis data published for CCGs is across the ten most common cancers; this will increase to 22 cancers which will account for about 75-80% of all cancers. The data published for the national ambition will be for all cancers. CCG data will be aggregated to create alliance level data. This follows a move to publish more data at an alliance level first (although CCG level data will still remain important).

Charities and patient groups should encourage clinical communities to ensure they are collecting and recording data. They should also challenge when data is not complete. All trusts should be looking at this as it is one of their five priority measures. The problem is usually with the way data is captured and the issues of resource to undertake this as most cancers are staged.

NCRI hold responsibility for designing trials on early diagnosis. They are interested to get more patient group input into this, particularly for rare and less common cancers.

Closing comments/ points

- Macmillan raised the point that it is helpful to know when broad policy positions do not work for the rare and less common cancers. Cancer52 responded that the issues are most often the same for the rare and less common cancers but are just more challenging because of the smaller numbers involved.
- ABPI highlighted that the solutions do not always have to be in-house (eg within the NHS) and that industry can help.
- There was a plea not to miss the boring, less glamorous issues which can be the things that make the real difference.

Next steps

Cancer52 will use the information and insight gained from this discussion to help update Cancer52's policy thinking in light of the publication of the NHS Long Term Plan. This will be used alongside input from Cancer52 members and information gathered in 2018 to inform a fuller policy report. Cancer52 will publish this in autumn 2019.

Cancer52 will also investigate the issues of importance to Cancer Alliances that can help or hinder progress on improving outcomes for people with rare and less common cancers.