

## **Cancer52 position statement on the England Cancer Strategy Implementation Plan**

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.

Cancer52 has been involved in the development of the England Cancer Strategy since its inception. Former Chair, Clara MacKay, represented the coalition on the Cancer Taskforce alongside other key representatives from the cancer community. At the time of the publication of the Strategy we published a [position paper](#) highlighting the key elements we would like to see taken forward for rare and less common cancers. Subsequently Cancer52 has been invited to sit on the National Cancer Advisory Group to represent the voice of rare and less common cancers in the formal review of the implementation of the Strategy.

Cancer52's focus for the Implementation of the Strategy is to see the key elements we've outlined for rare and less common cancers prioritised and delivered. The recent publication of the Implementation Plan includes some of these key areas of work which we support in this first year of implementation as long as they include rare and less common cancers. There are also other recommendations and areas of work not prioritised in the Implementation Plan which Cancer52 will continue to champion to ensure progress is made for rare and less common cancer patients.

Whilst Cancer52 supports the Implementation Plan we are mindful that it focuses solely on the 96 formal recommendations from the Strategy. This excludes much of the context and substance and other informal recommendations relevant to rare and less common cancers. It is important that the wider context of the Strategy, and its commentary on issues important to specific patient groups, is not lost in transition to a narrower focus for the Implementation Plan.

### **Calls to action:**

- It is critical that rare and less common cancers are explicitly included in the delivery of the Implementation Plan
- Key elements of the Strategy that are not in this Implementation Plan should be included in the next version
- The National Cancer Transformation Board and National Cancer Advisory Group must not lose sight of the wider context provided in the Strategy beyond the 96 formal recommendations

## **Summary of key elements of the Implementation Plan for rare and less common cancers**

### **Prevention and public health**

There are no specific relevance to rare or less common cancers in this section. This is an area where more innovative thinking and work needs to be considered.

### **Earlier and faster diagnosis**

The work on piloting 6 multi-disciplinary diagnostic centres (MDDCs) must include rare and less common cancers. The next Implementation Plan must include work on the routine introduction of significant event audit (SEA) for patient diagnosed in A&E (Strategy recommendation 25).

### **Patient experience**

The work on linking cancer patient experience data with cancer registration data, the review of the digital needs of people with cancer and work on improving access to Clinical Nurse Specialists (CNSs) must include at least a 50% proportion of rare and less common cancers.

### **Living with and beyond cancer**

The work on the Quality of Life measure and piloting the Holistic Needs Assessment must include work with rare and less common cancer patients and be relevant to their needs.

### **High quality modern services**

The work on a programme of better cancer research and the workforce vision and competencies must include rare and less common cancers. The next Implementation Plan must prioritise work the establishment of national and regional multi-disciplinary teams (MDTs) for rare cancers (Strategy recommendation 40), as well as continue to work alongside developments in access to treatments and drugs (Strategy recommendation 31).

### **Commissioning, provision and accountability**

Rare and less common cancers must be included in the key developments across this workstream including the cancer dashboard, cancer alliances, cancer vanguards and Care Quality Commission inspections. The next Implementation Plan must include work on ensuring innovation takes place in the treatment of rare and less common cancers (Strategy recommendation 76) and clinical reference groups (CRGs) take responsibility for developing minimum service specifications where patient volumes are too low to be covered by a NICE clinical guideline, for example rare cancers (Strategy recommendation 79).

22nd June 2016

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