

# Review of the Cancer Reform Strategy: Macmillan's response

## Executive Summary

People living with and beyond cancer continue to have serious physical, emotional, social, practical and financial problems that need addressing. We want the new CRS to focus on the following outcomes for people living with and beyond cancer:

- Every patient to have access to the best treatment and care for their cancer
- Everyone to understand information about their cancer and treatment, so they are able to make good decisions
- Everyone who has finished treatment to be supported with their ongoing needs
- Every patient to receive care in high-quality cancer environments
- Every person nearing the end of their life able to die at home if they wish
- Every person to have fair access to treatments and services, regardless of gender, age, race, disability, sexual orientation, socio-economic status or type of cancer.

To deliver these outcomes the revised strategy needs to address the following challenges:

### Access to treatment: implementing the Cancer Drugs Fund

England continues to lag behind Europe in giving cancer patients access to most effective treatments. Therefore we welcome the Government's commitment to develop a Cancer Drugs Fund.

#### **We want:**

A Cancer Drugs Fund that:

- Includes drugs for rarer cancers
- Is implemented to ensure that those with rarer cancers benefit
- Is efficient and transparent in order to reduce stress for patients
- Is measured by an audit of all applications that records the demographic and equality dimensions of those receiving the drugs, where they live and the reasons for their application.

### Provision of information: rolling out Information Prescriptions (IPs)

The principle of 'no decision about me without me', a key strand of the Health White Paper, can only be adhered to if patients have access to high-quality, relevant information about their condition and the various treatment and support options available to them.

#### **We want:**

- Clear commitment to the roll out of IPs over the next two years

- Information and support provision, including delivery of IPs, to be included in the NICE Quality Standards for cancer
- The delivery of IPs to be included in the commissioning guidance provided to GP commissioning consortia.

## Ongoing support: survivorship

Macmillan supports the National Cancer Survivorship Initiative (NCSI) vision. We want everyone reaching the end of treatment to work with their health care professional to develop a written, personalised care plan and to be able to access services to meet their needs.

### We want:

- The Government to give its public support to the NCSI as it continues to pilot and disseminate new models of care
- NICE to incorporate standards for post-treatment care in all NICE Quality Standards for cancer, including provision of an assessment and care plan
- The development of a payment by results tariff which rewards provision of assessments and care plans, treatment summary records from consultant to GP, patient education events, supported self-management programmes and physical activity packages
- The new NHS Commissioning Board to include provision of an assessment and care plan as part of the commissioning framework for GP commissioners
- The development of a robust reporting procedure to ensure that providers of care collect information on the incidence of the consequences of treatments. This data should be collated on a national level in order to inform the development of cancer services
- The national cancer survivorship survey to be repeated every two years.

## Work and cancer

Back to work support for people with cancer is inadequate. Most people with cancer of working age want to remain in, or return to work, during or after their treatment. However, more than four in ten people who are working when diagnosed have to make changes to their working lives after cancer, with almost half of those changing jobs or leaving work altogether.<sup>1</sup>

### We want:

- Information and advice on working through treatment for cancer, or returning to work afterwards, to be routinely provided by the NHS
- Vocational Rehabilitation (VR), to support people with health conditions to remain in, or return to work, offered to every cancer patient that needs it.

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<sup>1</sup> YouGov online survey of 1,740 UK adults living with cancer. Fieldwork took place between 26 July-9 August 2010. Survey results are unweighted.

## High quality environments

We believe that cancer patients deserve to be treated and supported in high quality cancer environments, which are designed around their needs and help to improve their outcomes, no matter where they are in the cancer journey.

### We want:

- A renewed commitment in the CRS to the continued improvement of cancer environments
- All cancer facilities to aim and be encouraged to achieve the Macmillan Quality Environment Measure (QEM)
- The inclusion of a patient experience indicator for cancer environments within domain four of the NHS outcomes framework
- NICE to establish a single cross-cutting quality standard for cancer environments that recognises the QEM as best practice in the delivery of excellent cancer environments
- The QEM to be recognised as best practice in guidance for commissioners.

## Choice about place of death

We believe that people should be able to die at home if they wish.

### We want:

- The NICE Quality Standard on end of life care to include non-clinical as well as clinical needs
- The end of life tariff, to be developed as part of the end of life funding review, should accurately reflect the cost of providing care in different settings and actively incentivise good practice
- An indicator on end of life care, which measures the quality of end of life care and whether people are able to die in their place of choice, included in the NHS Outcomes Framework.

## Equalities in cancer care

We believe that every single person who is diagnosed with cancer should have access to high-quality treatments and services that are appropriate and responsive to their needs at every stage of their cancer journey, no matter who they are, what part of the country they live in, or what type of cancer they have.

### We want:

- Ongoing DH commitment to implement the National Cancer Equality Initiative (NCEI) vision and projects
- The NHS Outcomes Framework to measure the progress being made to tackle inequalities in care and treatment<sup>2</sup>
- NICE and the NHS Commissioning Board to use learning from NCEI projects in the development of cancer Quality Standards and commissioning guidance respectively.

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<sup>2</sup> *Transparency in Outcomes – a Framework for the NHS*, Department of Health 2010

## Delivery that meets the needs of people living with and beyond cancer

We believe that effective service delivery for people affected by cancer requires that:

- GP consortia ensure they commission services to meet the clinical and non-clinical needs of cancer patients along the whole of the cancer pathway, except where those services are specialised
- GP commissioners are likely to require access to specialist advice when commissioning cancer services. We think mechanisms need to be put in place, whether on the current network model or a new form, to provide coordination and cancer commissioning expertise
- Indicators in the NHS Outcomes Framework must reflect the needs of people living with and beyond cancer and include:
  - Disaggregation by disease, including cancer, and equality dimension
  - Indicators that measure people's health status at key points (domain two)
  - Cancer included in the indicator for emergency admissions (domain three)
  - Indicators relating to information and support, the provision of equitable care, whether people are able to die where they wish and whether people are satisfied with the clinical environment (domain four)
- NICE Quality Standards for cancer must cover the whole patient journey, include non-clinical as well as clinical needs and must be mandatory
- There needs to be a strategic approach to workforce development and investment in the workforce, including additional Clinical Nurse Specialist and Allied Health Professionals, and the development of new roles to deliver post-treatment services.

Macmillan Cancer Support  
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contact us for further information:  
[campaigns@macmillan.org.uk](mailto:campaigns@macmillan.org.uk)  
020 7840 7840