



Macmillan Cancer Support response to the draft Programme for Government (December 2016)

1. Introduction

1.1 Macmillan Cancer Support is working to ensure that everyone living with cancer in Northern Ireland will receive high quality clinical treatment and person-centred care throughout their cancer journey – wherever they live, whatever type of cancer they have and whatever hospital they attend for treatment.

1.2 We provide a wide range of services to support people with cancer to live well during and after treatment, including:

Macmillan Professionals: As of October 2016, there are over 170 Macmillan professionals working on an array of cancer programmes in hospitals and community settings across the five Health and Social Care Trust areas. We work in partnership with HSC and other provider organisations and our professionals are fully integrated in clinical teams. For many people affected by cancer, Macmillan professionals are a valued and trusted source of expert information, advice and support. The types of professionals we fund and develop include nurses, pharmacists, physiotherapists, dieticians, occupational therapists and welfare benefits advisers as well as GPs, consultants and service leads.

Information and Support Services: These provide people with face-to-face assistance in cancer units across Trusts, and a Macmillan Information Centre is due to open in early 2017 on the new Health and Wellbeing Campus at Altnagelvin. Our comprehensive cancer information is also available in all public libraries and elsewhere in communities.

Financial support: In 2015, our welfare rights services and patient grants helped 6,000 people affected by cancer receive over £14 million to help cope with the financial impact of the disease.

1.3 Macmillan welcomes the opportunity to participate in this second phase of consultation on the Programme for Government 2016-21. We have a long and successful record of working in partnership with the NI Executive in the development and implementation of policies and services to improve the lives of people affected by cancer. Highlights from during the lifetime of the Programme for Government 2011-15 include the Transforming Cancer Follow-Up programme and the Clinical Nurse Specialist Workforce Plan. We are therefore pleased to note the commitment made in the consultation introduction, to involving stakeholders in every stage of development and delivery.

1.4 We have studied the outcomes and indicators included in the Programme for Government Framework and the commitments presented in the draft delivery plans. These include numerous initiatives and interventions with the potential to impact positively on cancer incidence, the quality of care and the effects of a cancer diagnosis on quality of life for individuals, families, and carers. We are particularly delighted that the delivery plan for indicators 17, 32 and 33 commits to building on our past and current work by developing a holistic and integrated service model for people living with cancer.

1.5 We believe the Programme for Government should also contain a clear commitment to developing a new cancer strategy for Northern Ireland. This should be led by the Department for Health in partnership with the Department for Communities, Department for the Economy,

Department of Finance, Health and Social Care organisations and key stakeholders including the voluntary and community sector. The expertise of healthcare professionals and the voice of patients should also be used to guide this work. The development and delivery of a cancer strategy is something which Macmillan would welcome the opportunity to be involved in as fully as possible.

2. The case for committing to a new cancer strategy in the Programme for Government

2.1 There is a strong case for committing to a new cancer strategy as part of the Programme for Government, which the introduction describes as “designed to help deliver improved wellbeing for all of our citizens” (pg. 4) The fourth outcome in the Framework (“We live long, healthy, active lives”) is perhaps the most important and closest in meaning to this overall aim. A cancer strategy that is properly developed, resourced and implemented can make a major contribution towards turning the curve on indicators 2, 3, 4 and 6, which are all integral to accomplishing the fourth outcome. There are several additional indicators which a cancer strategy would also have a desirable influence on, including numbers 5, 9, 17, 19, 28, 32 and 42. We would welcome opportunities to engage further with the Senior Responsible Officers for each of these indicators to share knowledge, evidence and suggestions as the delivery plans evolve.

2.2 Macmillan has long been committed to understanding the evidence and trends relating to cancer in Northern Ireland. In 2016, we launched the online Local Cancer Intelligence NI tool (<http://lcini.macmillan.org.uk>) in partnership with the NI Cancer Registry. We have also conducted and funded a wide range of research which has provided us with a greater understand of the numbers, needs and experiences of people affected by cancer than ever before. We believe the available evidence demonstrates the urgent need to improve how services are provided if they are to meet the needs of a growing number of people being diagnosed and living with the disease.

2.3 The annual number of people diagnosed with cancer increased by almost 25% in the ten years to 2014,ⁱ a trend which is due to a range of factors including an ageing population, genetics, lifestyles, and environment. This has pushed the number of new cancer cases each year above 9,000 for the first time. Current projections indicate that almost 1 in 2 (47%) of people living in the United Kingdom in 2020 will receive a cancer diagnosis in their lifetime.ⁱⁱ

2.4 It is cause for celebration that more people are also surviving following a cancer diagnosis, due to improvements in how cancer is detected and treated. However, this has caused a significant increase in cancer prevalence and the need for care and support within the population. Our research has shown that around 63,000 people are now living with cancer in Northern Ireland and this will rise to over 74,000 during the lifetime of the Programme for Government 2016-21.ⁱⁱⁱ

2.5 Sadly the survival rates for different cancer types vary widely and there is no uniformity in quality of life during and after treatment. Macmillan’s analysis of UK-wide cancer data describes three cancer groups into which most cancer types can be stratified^{iv}:

- The longer-term survival group includes cancers where 90% or more people live one year or more after a cancer diagnosis. More than 80% go on to live five years or more and many go on to live at least a decade. An estimated 39% of people newly diagnosed in 2013 were in this group.
- The shorter-term survival group includes cancers where fewer than 50% of people survive a year. An estimated 27% of people newly diagnosed in 2013 were in this group.
- The intermediate group experience moderate survival (one-year survival is over 50% but less than 90%). An estimated 21% of people newly diagnosed in 2013 were in this group.

The differences between these groups are not just about length of life, but also differences in needs. Early diagnosis and good treatment or palliative care is essential in supporting people with shorter-

term survival cancer types. The long-term consequences of cancer and its treatment include both physical and mental effects, such as chronic fatigue, sexual difficulties, urinary and gastrointestinal problems and lymphoedema. Approximately one in four (25%) of those who have been diagnosed with cancer face poor health or disability after treatment for cancer. Around one in eight are living with mental health problems, which can include moderate to severe anxiety or depression, and post-traumatic stress disorder.^v Macmillan has long been involved in the development and implementation of initiatives to improve the lives of those affected by the consequences of cancer and its treatment. These include the Recovery Package (which has underpinned the successful Transforming Cancer Follow Up programme), improved patient information and access to physical activity programmes.

2.6 There is also a high level of multi-morbidity within the cancer population. As many as 70% of people living with cancer will also have been diagnosed with at least one other potentially serious long-term illness.^{vi} These include diabetes, arthritis, chronic kidney disease and hypertension. Cancer specialists are also treating an increasing number of people with dementia which, like cancer, affects people aged over 65 more than any other age group. The first Macmillan Dementia Nurse Consultant was recruited in England in 2014,^{vii} creating an innovative role that helps to address gaps in care provision for people with both physical and mental health problems. It is vital that we continue to transform how cancer services are delivered, ensuring that we have a system that can care for the whole person in addition to treating their cancer.

2.7 We strongly welcome the importance placed on collaboration and co-production in this Programme for Government, as well as in the Health Minister's vision for transforming services. A cancer strategy could also help to identify good practices in engagement with people affected by cancer and to embed these in services across the region. It could also be used to realise the potential of volunteering in contributing solutions for planning and delivering services. Volunteers are at the heart of several Macmillan services, providing much needed support in hospitals and the community.

2.8 Health and Social Care in Northern Ireland is facing a period of significant change through the ongoing transformation process and restructuring. The strengthening and redesign of cancer services must continue if the challenges described above are to be met. We consider it essential that the Northern Ireland Cancer Network is supported in continuing to deliver its multi-dimensional functions effectively. Its role in future commissioning arrangements should also be maximised. In England, the NHS reforms in 2013 resulted in the loss of cancer networks which many commissioners described as a major setback for cancer commissioning because of the fragmentation of specialist knowledge and expertise. The success of recent developments (such as Transforming Cancer Follow Up, Acute Oncology and Cancer Patient Experience Survey) would have been much more difficult to achieve in the absence of a clinical network and the regional leadership it brings.

2.9 The broad challenge to government, Health and Social Care and partners is to respond with the best possible use of resources, making sure that the growing demand can be managed in a sustainable way. This will be best achieved through a comprehensive strategy to drive the redesign of cancer services and enhance working across Departments and sectors to deliver interventions.

3. Summary of Macmillan's priorities for a cancer strategy

3.1 We believe that a cancer strategy can ensure high quality clinical treatment and person-centred care throughout the cancer journey. Key steps to achieving this include:

- Committing to the full implementation of the revised Cancer Service Framework.
- Improving the care and support people with cancer receive from primary care services.

- Addressing the social determinants of cancer and associated variation in outcomes by improving the provision of information and support and making sure everyone diagnosed with cancer receives a Holistic Needs Assessment and written care plan.
- Strengthening the integration and coordination of services across Health and Social Care, and the voluntary sector, so that people living with cancer receive seamless care and are signposted to the non-clinical support they need at each stage of their cancer journey.
- Continuing improvements in the quality and availability of holistic and person-centred palliative and end of life care.
- Enhancing the involvement of people affected by cancer in the development, redesign and delivery of services.
- Supporting the NI Cancer Network to continue its essential role in facilitating a regional approach to service development and improving patient experience and outcomes.
- Long term cancer workforce planning, with integration across Health and Social Care and Higher Education to ensure a more knowledgeable and skilled workforce with effective recruitment and succession across disciplines and settings.
- Routinely using data collection tools, such as Cancer Patient Experience Surveys, to identify any gaps or inequities in cancer care and pinpoint areas for improvement locally.

Contact

Michael Moore
 Policy Officer NI
mmoore@macmillan.org.uk

ⁱ <http://lcini.macmillan.org.uk/All-Northern-Ireland/Incidence>

ⁱⁱ Cancer mortality trends: 1992-2020, Macmillan Cancer Support (2013)

ⁱⁱⁱ Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Projections scenario 1). Macmillan analysis based on extrapolation of 2010 and 2020 projections.

^{iv} 'Three Cancer Groups: Explaining the different complexity, intensity and longevity of broad clinical needs.' Macmillan Cancer Support (2015)

^v 'Cured – but at what cost? Long-term consequences of cancer and its treatment.' Macmillan Cancer Support (2013)

^{vi} 'The burden of cancer and other long-term health conditions.' Macmillan Cancer Support (2015)

^{vii} 'Dementia and Cancer.' Mac Voice, the magazine for Macmillan professionals: Spring 2016

<http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/newsandupdates/macvoice/spring2016/dementiaandcancer.aspx>