Key points:

- Northern Ireland is the only part of the UK without a current strategy for cancer services. There is an increasingly urgent need for government and healthcare leaders to set out a clear and ambitious plan to improve care and support for people affected by cancer. Macmillan is extremely concerned about the impact that the absence of an NI Executive, and the growing policy gaps, is having on cancer services at a time of unprecedented demand which continues to increase.

- More people are being diagnosed with cancer and living for longer due to advances in diagnosis and treatment. The number of people living with cancer is expected to continue rising rapidly, regardless of whether rates of diagnosis and survival continue to increase or remain as they are today. Our evidence shows that services are already struggling to cope and too many people are facing cancer without the right care and support.

- The previous cancer strategy is now ten years old and the cancer care landscape has undergone vast changes in the intervening period. No formal performance review was undertaken, making it difficult to assess the extent and effectiveness of implementation. Much of the available evidence demonstrates the urgent need for a new government-led plan for cancer services in the region. Cancer waiting times in NI, for example, are now significantly worse than five years ago and much worse than elsewhere in the UK.

- Cross-party support for a new cancer strategy emerged during the last NI Assembly mandate. There is also evidence of widespread public support for government to take strategic action to improve cancer care. However, the collapse of the NI Executive in January 2017 has created a situation in which there is no way for much-needed policy initiatives like this to proceed.

1. Introduction

1.1 Macmillan welcomes the opportunity to response to the Northern Ireland Affairs Committee’s inquiry on Devolution and democracy in Northern Ireland: dealing with the deficit.

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

1.3 Macmillan has been campaigning for a new cancer strategy for Northern Ireland, to cover the whole cancer pathway. In the weeks preceding the breakdown of the NI Executive, 435 of our supporters, living in every constituency, wrote to the Health Minister to call for a strategy. The evidence we have amassed demonstrates alarming gaps in cancer policy in the region and the impact these are having on the provision of care and support.

1.4 Our response to the Inquiry lays out key evidence demonstrating the urgent need for a new cancer strategy to meet the needs of a growing number of people being diagnosed and living with the disease.
2 More people are living with cancer than ever before

2.1 The number of people being diagnosed with cancer in NI increased by almost 25% in the ten years to 2014. This is due to a range of factors including an ageing population, lifestyles, and environment, and has pushed new cancer cases above 9,000 per year for the first time. Current projections suggest that around 1 in 2 (47%) people living in the UK in 2020 will receive a cancer diagnosis in their lifetime.

2.2 Macmillan’s 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 current Parliament. It is cause for celebration that more people are surviving for longer after a cancer diagnosis, due to improvements in detection and treatment. However, this has caused a significant increase in cancer prevalence and the need for care and support within the population.

3 Evidence of unmet needs of people living with cancer

3.1 Survival rates for different cancer types vary widely and there is no uniformity in quality of life during and after treatment. The most recent five-year survival rate for Northern Ireland is 54% for all people diagnosed with cancer between 2002 and 2009. However, this ranges from more than 80% for melanoma, prostate and breast cancers, to below 10% for pancreatic and liver cancers. Early diagnosis and good treatment or palliative care is essential in supporting people with cancer types for which survival rates are lowest. There are clear indications that more needs to be done to fulfil these requirements across Northern Ireland.

3.2 Waiting times for cancer diagnosis and treatment in Northern Ireland are significantly worse now than five years ago, and are also the worst in the UK. In 2016-17, just 68% of people with cancer started treatment within 62 days of urgent GP referral. This is much lower than the target of 95% and performance across the UK (Scotland 88%, Wales 87%, England 82%). It also represents a significant decline compared to 2011-12, when the figure was 82%. Furthermore, April-June 2017 saw the worst Q1 performance (68%) since the target was introduced almost ten years ago. Timely diagnosis and treatment should be something every person can rely when told they might have cancer. Any delay can cause unnecessary stress and risks the worsening of symptoms.

3.3 Compared to the NI average, cancer is 14% more common in the most deprived groups. But cancer deaths among people aged under 75 is 43% higher. This gap is far bigger in Belfast (54%) than in the other four Trust areas (25-36%). Achieving better survival rates and overall cancer outcomes will require careful planning to make the best possible use of resources.

3.4 Evidence also shows that the differences between these groups are not just about length of life, but also differences in needs. 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 1 in 4 people with cancer face poor health or disability after treatment. Around 1 in 8 face mental health problems, such as anxiety, depression, and post-traumatic stress disorder. Planning is needed to ensure that everyone living with cancer can access the right care and support – whether this is information, financial assistance, vocational rehabilitation, or emotional support.

3.5 Person-centred care during and after cancer treatment can greatly improve outcomes by helping to ensure that non-clinical needs are met. Macmillan has been leading the redesign of services in recent years through the Transforming Cancer Follow Up (TCFU) programme across Northern Ireland. Key objectives included providing tailored information, guidance on lifestyle changes for health and wellbeing and helping patients to manage their condition. These steps are all part of a Recovery Package, which in
the context of TCFU has reduced surgical review waiting lists and helped breast cancer patients to better manage their own health and wellbeing.11 A strategic approach is needed to implement the Recovery Package across all Trusts and cancer types.

3.6 Northern Ireland’s first Cancer Patient Experience Survey (CPES) was conducted in 2015. In England, CPES has happened annually since 2010 and proven effective at encouraging hospitals to implement changes to improve results.12 The NI findings show that, although most patients (92%) rate their overall care highly, some significant variations exist between Trust areas, cancer types and different aspects of the cancer journey.13 It is essential that patient experience is placed at the core of all cancer services, as is happening through cancer plans elsewhere in the UK. Macmillan is funding a second survey in 2018, which should form the basis of a strategy to address any regional gaps evident in the findings.

3.7 Cancer remains the most common cause of death in Northern Ireland (30% of all deaths in 2016).14 It is vital to offer people approaching the end of life choice and control over the things that are important to them. Around 40% of people who die from cancer in Northern Ireland do so in hospital, even though fewer than 4% prefer this to home, hospice or care home settings.15 Macmillan’s research has found that people are more likely to die in the place of their choice when their wishes are recorded and known by their healthcare professionals. We believe a new cancer strategy should include commitments to improving the quality and availability of end of life care. This should start with everyone diagnosed with cancer having an early opportunity to take part in Advance Care Planning discussions.

4 Cancer policy gaps in Northern Ireland

4.1 Northern Ireland is the only part of the UK and Ireland without a current strategy for cancer services. All other jurisdictions launched updated cancer strategies between 2015 and 2017. The Regional Cancer Framework is now 10 years old and the Service Framework for Cancer Prevention, Treatment and Care expired in 2014. A recent paper from the NI Assembly’s Research and Information Service highlighted that there have been no formal performance reviews of the previous policies, making it impossible to assess how much progress was achieved towards their implementation.16

4.2 As indicated by the trends in cancer waiting times and variation in patient experience, there are pressures across the cancer workforce in Northern Ireland. General practice, radiology and surgery are all disciplines with well documented shortages, but similar challenges exist across cancer care. A full government-led review of the cancer workforce could form the basis of a long-term workforce plan to achieve effective recruitment, retention and succession across disciplines and settings. There are also opportunities for greater cross-departmental collaboration, including integration between Health and Social Care and Higher Education to attain a more knowledgeable and skilled workforce. In the absence of devolved government and a strategic focus, this work cannot proceed and Northern Ireland risks falling behind the rest of the UK in achieving good cancer outcomes.

References:


