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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal  
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cymorth Cancer Macmillan

Response from: Macmillan Cancer Support

<b>Purpose:</b>	<b>Macmillan's response to inform the NAFW Health, Social Care &amp; Sport committee priorities</b>
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## 1. Introduction

1.1 Macmillan Cancer Support welcomes the opportunity to support the formulation of priorities of the Health, Social Care & Sport committee during the fifth Assembly.

1.2 Although more people are surviving, there are still too many people dying from cancer in Wales or not living well beyond their treatment. They may have long-term side effects such as fatigue, incontinence or lymphoedema.<sup>1</sup> We need an ambitious approach to match the changing nature of cancer and its treatment, so that many more people survive and many more people live well with and beyond a cancer diagnosis.

1.3 In Wales, 19,000 (WCISU Feb 2015) people are diagnosed with cancer every year and more than 130,000 people are currently living with or beyond cancer, almost 4.5 percent of the population. By 2030 it is expected that 250,000, almost eight percent of the Welsh population, will have been affected by a cancer diagnosis and one in two of us will be affected by cancer at some point in our lives.

1.4 The good news is that survival rates are steadily improving and many people recover. On average 70 percent<sup>2</sup> of Welsh residents diagnosed with cancer can expect to survive at least one year. However, improving survival rates in Wales need to be considered in the context of even better survival rates in many other European countries.

1.5 We know the NHS is struggling now to meet current demand. A transformation in the way we treat and care for patients with and beyond cancer is needed if we are to close the gap between Wales and our European counterparts. This is the challenge we all face. We must change now to meet future demand, increase quality for patients and reduce instances of unacceptable variation.

<sup>1</sup> ["Cured But at What Cost?"](#) Macmillan Cancer Support (2013)

<sup>2</sup> Welsh Cancer Intelligence and Surveillance Unit Official Statistics 2012 data. [Published 10 April 2014](#)

## 2. Previous work with the committee

2.1 During the fourth Assembly we welcomed the opportunity to work in partnership with the Committee to convene a number of focus groups to engage with people affected by cancer. Macmillan is a strong advocate of involving people affected by cancer in the scrutiny, development and refinement of services, utilising their first hand experiences to identify trends and drive improvements increasing consistency across Wales. We hope that this type of engagement will remain a strong feature of how the committee seeks to learn from firsthand experience and expertise during the fifth Assembly.

2.2 We welcomed the committee's exploration of a number of key elements of cancer care in Wales, including:

- Macmillan's tools to support GPs in recognising cancer at an earlier stage
- Recognition that partnerships could be improved to provide a more consistent approach to service provision in Wales
- The challenges experienced by some patients in accessing a Cancer Nurse Specialist

## 3. Priorities identified by the committee

3.1 We welcome the priorities highlighted by the committee at present and feel many of these correspond with Macmillan's work in Wales. In particular the areas of; integration of health and social care, waiting times, primary care, efficiency within the NHS and modern management practices, ambulance services, loneliness and isolation among older people and sport and public health have varying levels of cross-over with both our service delivery and policy work. We look forward to informing the committee on the specific challenges and opportunities in relation to cancer care in Wales within these areas.

## 4. Macmillan's priorities for cancer care in Wales

4.1 In responding to the legacy consultation considering the work of the committee during the fourth Assembly we provided the following feedback on priorities going forward and believe these remain relevant to informing the work of the committee:

- **Cancer must remain a top priority**, underpinned by a refresh of Welsh Government's cancer delivery plan that delivers cancer care and treatment

and outcomes which matches the best in Europe, no matter where the person lives, their age or what type of cancer they have.

- **Person centred care must be embedded** as the cornerstone of this ambition, which ensures every cancer patient receives well co-ordinated holistic care and treatment to live well with and beyond their cancer, or receive high quality end of life care in the most desirable setting for that individual.
- **Strengthened and transparent national leadership and governance** to clearly set out the ambition to deliver on all elements within the cancer delivery plan both locally and nationally linked to robust monitoring and reporting mechanisms.

## 5. Embedding Person Centred Care

5.1 Access to a specialist cancer nurse has been shown to play a vital role in delivering high quality, person-centred care and treatment to people with cancer. Patients allocated a specialist cancer nurse are more positive about the experience of their care. The results of the Wales Cancer Patient Experience Survey evidence this.

5.2 There are a number of factors required in order to deliver person-centred care consistently and to a high quality. These are:

- Personalised and holistic needs assessments and written care planning
- Coordinated and continuity of care
- Good communication
- Timely information and support – including access to Welfare Benefits Advice services.
- Routine signposting to financial, practical and emotional support

5.3 Specialist cancer nurses are central to providing consistent, high quality person centred care. Specialist cancer nurses are part of the cancer multidisciplinary team and are usually recognised as the key worker. They use their skills and expertise in cancer care to provide physical and emotional support, coordinate services and to inform and advise patients on clinical as well as practical issues, leading to better patient outcomes.

## 6. End of Life Care

6.1 Macmillan expects Welsh Government to be committed to the delivery of **high quality palliative and end of life care**. For people who are no longer curative and are dying from cancer, their ongoing care and treatment needs to be planned holistically. With the support of primary care and through advance care planning, every effort should be made to ensure that people are cared for and, wherever possible, are able to die in the place of their choice. Avoidable emergency admissions to hospital during this stage of illness should also be prevented where possible.

6.2 **Advance Care Planning (ACP)** is an important tool to understand people's wishes, needs and preferences at the end of life and facilitates planning to meet them. Sadly, if people are not identified as approaching the end of life, and professionals do not initiate conversations to understand peoples' needs and preferences, it is less likely that plans can be put in place to meet those needs. There is evidence to suggest that the use of processes such as ACP to establish a person's wishes around their care at end of life can increase the likelihood of those wishes being met.

## 7. Enhancing National Leadership and Governance, Accountability

7.1 The Welsh Government's Cancer Delivery Plan should have driven national change and improvement and ensured consistency in services and standards for patients throughout Wales. The Chief Executive of NHS Wales stated in the Foreword ***'I will hold LHBs to account on the outcomes they deliver for their populations'***. This has not happened across Wales across all themes on a consistent basis, producing variation in experiences and outcomes for patients.

7.2 The strategic direction set out in the Cancer Delivery Plan was widely welcomed in 2012 but its operational implementation to date has been limited. Although a number of standards and targets were identified within the plan, monitoring against all of the objectives set out in it have not been met. In addition, there is still no comprehensive national plan which clearly sets out how and when all of the aspirations in the Cancer Delivery Plan will be achieved over time or the milestones which have been set for measuring progress along the way.

7.3 Furthermore, consequences of non-compliance e.g. against NICE guidance, cancer and peer review standards and other policy targets by individual NHS organisations have not been properly addressed (or seen to be addressed) due to lack of clarity about governance, self reporting processes and absence of any real levers that drive action and change. There is insufficient rigour and grit in the current

