

Purpose:	Macmillan Cancer Support response to NAFW H&SC Committee Legacy Consultation
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Date created:	25 September 2015

1. Introduction

1.1 Macmillan Cancer Support welcomes the opportunity to provide information on the work of the Health and Social Care Committee during the fourth Assembly. To provide some background to our interaction and work with the Committee during its term please see the following list of the committee's work where we have provided evidence either written or verbally.

Inquiries

- Progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Legislation

- Regulation & Inspection of Social Services (Wales) Bill
- Safe Nurse Staffing Levels
- Social Services & Well-being (Wales) Bill (and associated guidance)

The Changing Story of Cancer

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.¹ We need a new 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,

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

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 percent² 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.

2. Thinking about the past 5 years, in your view:

- To what extent has the Health and Social Care Committee had an impact on health and social care in Wales?

2.1 We believe the role of the committee has been substantial during its 5 year term. We have welcomed a number of opportunities to provide written and verbal evidence to the committee supporting it in scrutinising a number of key pieces of legislation, guidance and policy.

- What has been the Committee's biggest achievement?

2.2 The successful scrutiny and progress of the Social Services & Well-being (Wales) Act 2014 undoubtedly provided the Committee with a significant challenge in progressing the most substantial piece of legislation through the modern day Welsh Assembly. Although the realisation and impact of this legislation is yet to be fully realised with its implementation due in April 2016, there can be no doubt that it will significantly change the face of health and social care services in Wales. We look forward in continuing our dialogue with the Committee and the Welsh Government to further explore the impacts this legislation will have on how people affected by cancer interact with health and social care services.

2.3 Looking specifically at cancer care the scrutiny undertaken into Welsh Government's progress in implementing the cancer delivery plan highlighted some key areas where service being delivered to people affected by cancer required significant improvement. Importantly, this Inquiry helped raise the profile of the Cancer Delivery Plan and its slow implementation. The Inquiry was unbiased and

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

valuably involved extensive consultation with people affected by cancer, health professionals and the third sector. The Report was published in October 2014 and the thirteen Recommendations were balanced and constructive. One year on, we look forward to an update of progress made in the achievement of these Recommendations especially in relation to the implementation of the Key Worker Guidance, holistic needs assessment of clinical and non clinical needs and care planning (Recommendation 9).

2.4 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.

2.5 With the successful completion of the Wales Cancer Patient Experience Survey in 2014, conducted as a partnership between Welsh Government and Macmillan we hope that the experiences of patients will continue to be held in high regard in future inquiries.

2.6 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. Looking ahead to the next five years, in your view what will be the three biggest challenges for health and social care in Wales?

3.1 We believe that significant progress must be made across three key points. These reflect what Macmillan is calling for the next Welsh Government to progress through the next programme for government. The challenges in relation to cancer care in Wales are set out as follows:

3.2 Cancer remaining a top priority in the next Programme of Government, leading to a new **cancer strategy** 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.

3.3 The cornerstone of this ambition should be embedded in the principle of **person-centred care**, which ensures every cancer patient receives well **co-ordinated holistic care and treatment**.

3.4 Strengthened and transparent **national leadership and governance** to clearly set out the ambition to deliver on the new integrated cancer strategy.

The following sections set out the detail which underpins these challenges:

Matching the best in Europe

3.5 Macmillan believes that cancer should remain a top priority in the next Programme of Government, leading to a new **cancer strategy** that delivers cancer care and treatment which **matches the best in Europe**, no matter where the person lives, their age or what type of cancer they have.

3.6 This ambition can only be achieved by working with partners, including the third sector, to provide national leadership to develop a transformational cancer strategy incorporating a detailed implementation plan which sets out the scale of the challenge and how it will be met by 2021.

Embedding Person Centred Care

3.7 Macmillan believes that to achieve the best outcome following a cancer diagnosis, person-centred care must be at the heart of service delivery. Only by focussing on the whole person, can the patient's experience during their cancer journey be as good as it can possibly be. This is true for those who survive cancer, are living with cancer or someone who is nearing the end of life.

3.8 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.

3.9 Specialist cancer nurses are part of the cancer multidisciplinary team and are usually recognised as the key worker. They hold a clinical caseload, co-ordinate wider care and work to promote health and wellbeing in the patients they care for. 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.

3.10 Person-centred care means that the needs of the person living with cancer are always at the heart of how services are planned, not the needs of the service providers. It means treating people with sensitivity and compassion and ensuring that their care is holistic in its planning and delivery. This care goes beyond the

clinical to also address wider social, financial, emotional, practical, psychological and spiritual concerns.

3.11 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

End of Life Care

3.12 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.

3.13 **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.¹⁶

3.14 Wherever possible, supported by **ACP**, avoidable unscheduled emergency admissions for people at the end of their life should be prevented through good support in the community across both health and social care. This will help to ensure that, wherever possible, the person and their families should be well supported at the end of life and people are supported to die in the place of their choosing.

Enhancing National Leadership and Accountability

3.15 We believe strengthened **national leadership** is needed to accelerate the pace of change in terms of delivering agreed policy plans to improve governance arrangements. Our submission to the Assembly's Health and Social Care Committee's inquiry into the implementation of the Welsh Government's Cancer

Delivery Plan in April 2014, and our response to its report published in October 2014, reinforced our call for this to happen.

3.16 Whilst we want improving cancer care and treatment to remain a top priority for the next Welsh Government, we also want strengthened arrangements for **governance and accountability** at a national level to be implemented. We believe that without this scale and pace of reform, Wales will continue to languish and our aspirations to provide cancer care that matches the best in Europe will not be realised.

3.17 Whilst we recognise the governance arrangements that already exist for individual health boards and NHS Trust, **national scrutiny** of individual organisations must rest with Welsh Government and cannot be delegated to groups such as the Cancer Implementation Group, nor to health boards, their local populations or third sector organisations. This is the **governance gap** and must not continue.

4. Conclusion

4.1 We have welcomed the work of the committee in scrutinising the impact of the Cancer Delivery Plan in Wales, in addition to its broader work in assessing health and social care services, making well-informed recommendations through its term. We look forward to working closely with the committee during the next programme for government as we continue to highlight the steps needed to drive improvements in services for people affected by cancer in Wales.

We would be willing to provide the committee with further evidence at a later date should it be required.

If you would like any further information on any of the content included in this response, please contact Matthew Kennedy, Policy Officer.

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