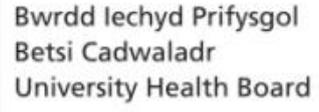


National Assembly for Wales
[Health and Social Care Committee](#)
[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from the Macmillan Health and Wellbeing Project Lead, Betsi Cadwaladr University Health Board – CDP 03

  	
Briefing for:	National Assembly for Wales' Health and Social Care Committee
Purpose:	Response to the inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.
Contact:	Joanne Garzoni, Macmillan Health & Wellbeing Project Lead, Betsi Cadwaladr University Health Board.
Date created:	March 2014.

Introduction

1. I welcome this inquiry into the progress made to date on the implementation of the Welsh Government's (WGs) Cancer Delivery Plan (CDP) by the National Assembly for Wales' Health and Social Care Committee.
2. I have not provided answers to all the questions posed by the inquiry but am looking at 'Whether Wales is on course to achieve the outcomes and performance measures as set out in the Cancer Delivery Plan, by 2016', specifically looking at the 'Meeting People's Need's section and how Macmillan Cancer Support Health and Wellbeing Clinic within Betsi Cadwaladr University Health Board (BCUHB) is supporting people living with cancer.
3. The aim of Health and Wellbeing Clinics is to enable people who have been diagnosed with cancer to lead as healthy and active a life as possible, for as long as possible. To achieve this, survivors are likely to require integrated care and support from a wide range of services, particularly health and social care services and the voluntary sector, but also from other sources such as employers and education services. There is an urgent need to understand the needs of those living with cancer today and to develop models of care which meet their needs.

The changing cancer story

4. In Wales, 120,000 people are currently living with cancer and this number is expected to become 240,000 by 2030.ⁱ Over 17,500 people a year are diagnosed with cancer in Wales and this figure is rising.ⁱⁱ
5. The table below highlights the incidents of cancer in BCUHB and the total number of people living with or beyond cancer in 2010 and the likely number in 2030.

Total population	New cancer diagnoses every year	Number of cancer deaths every year	Total number of people living with or beyond cancer ⁱⁱⁱ	
			2010	2030

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678,500	4,337	2,112	27,100	48,830
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6. There is an urgent need to understand the needs of those living with cancer today and to develop models of care which meet their needs. Services need to be designed in a way which will accommodate the increasing numbers of cancer survivors in the future and in a way which is sustainable.

7. While cancer can be an 'acute illness' which can be cured by initial treatment for some, 'being cured' does not equate necessarily to wellbeing. Chronic consequences of treatment may need to be managed over the following months and years, consequences which often have a devastating impact on daily life. As highlighted within Macmillan Cancer Support report 'Cured - but at what cost?'^{iv} at least 30,000 patients in Wales experienced long-term conditions caused by the disease or its treatment. Those with advanced disease need to be supported to have as active and independent a life as possible. Health and Well-being Clinics are intended as a means to provide such support.

Macmillan Health and Wellbeing Clinics

8. Health and Wellbeing Clinics are a Macmillan Cancer Support development as part of its survivorship work. The vision for the clinic is that everyone who has had a cancer diagnosis and is living with cancer will have access to an innovative Health and Wellbeing Clinic, providing comprehensive and holistic support to enable them to lead as normal a life as possible. The Health and Wellbeing Clinic is a one off event to support people around the end of cancer treatment with the transition between the treatment phase of their care and survivorship.



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9. Currently, not all people affected by cancer have access to a Clinical Nurse Specialist (CNS) or a Key Worker, which we know makes a difference to patient reported outcomes and experience, as highlighted with the Wales Cancer Patient Experience Survey, released in January 2014. The Cancer Patient Experience Survey evidenced that only 66% of the patients surveyed said they were given the name and contact details of their Key Worker, however 91% of patients who had a Key Worker or CNS rated their care as excellent or very good, compared to 74% for those without a CNS. We also know that current models of cancer follow-up are not meeting patients' needs^v and will be unsustainable if the number of people living with and beyond cancer is going to double as projected by 2030.
10. Locally and nationally patients have reported the following problems after cancer treatment has finished, and beyond:
 - a) Effects of treatment (short and long term)
 - b) Abandonment (especially post treatment phase)
 - c) Lack of information
 - d) Lack of support (uncertainty who to contact)
 - e) Emotional difficulties
 - f) Social/relationship difficulties
 - g) Physical/functional changes
11. The Health and Wellbeing Clinics events aim to deal with these issues and to support patients in becoming empowered to identify when they need additional support and how they can access it appropriately.

What's different about health and wellbeing?

12. There is substantial evidence to indicate that Health and Wellbeing Clinics greatly improve patient's feeling of empowerment and self-reported physical wellbeing, as well as raised awareness of what services and resources are available to individuals to facilitate their transition to the new normal.^{vi}
13. The Key differentiators from other forms of service delivery:
 - a) **Supports the transition to survivorship:** health and wellbeing clinics support the transition from active treatment to enabling the patient to resume a normal life as possible.
 - b) **A 'one stop shop':** the concept and format means that the full range of relevant professionals and information can be accessed in one place, at one time (rather than individual appointments to see different clinical and non-clinical staff). Patients are able to access a range of services which are not solely acute or available only in secondary care e.g. clinicians, clinical nurse specialists, allied health professionals, complementary therapists and the voluntary sector.
 - c) **Volunteer and peer support:** volunteers help create a welcoming and relaxed atmosphere which patients value; they also value the opportunity to share experiences of living with cancer with volunteers and other patients. For many

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patients the group setting helped them to access information, by hearing others ask questions that they found relevant to their own experience.

- d) **Reducing unnecessary follow up:** service use reduced almost uniformly following patients' attendance at a clinic; further to the ongoing work on risk stratification of patients, it appears likely that the clinics can form a key part of the care pathway for those patients suitable for 'supported self management'.

14. The added value for patients:

- a) Patients having an increased knowledge of their condition and confidence to self-manage, which reduces their reliance on health and other services.
- b) Patients aware of both the clinical and holistic aspects of cancer and the ongoing management of their disease.
- c) Patients feeling empowered to move on to life after cancer by giving them knowledge and confidence.
- d) Allow people to meet with others who have had a similar experience, one stop shop.
- e) Combat the feeling of isolation that survivors can experience.
- f) Added value for services.
- g) Reduce the need for patients to see GPs, district nurses and other health services.
- h) Give patients information to allow them to refer into relevant services if necessary.
- i) Help improve physical and emotional wellbeing.
- j) Identify potential issues/needs currently not being addressed.
- k) Opportunity to get across health promotion and prevention messages.
- l) Support carers by providing them with information about services they can access for support.
- m) Support for appropriate delivery of follow-up care and changes in patterns of referral.
- n) Part of a scheduled care pathway and whole systems approach to patient needs.

The Health and Wellbeing Clinic Project in BCUHB

15. The Health and Wellbeing Clinic Project in BCUHB became operational on the 31st November 2013. BCUHB are seeking to test, inform and accelerate local change by piloting Health and Wellbeing Clinics with a view to establishing such events as an integral part of the cancer pathway across North Wales.

16. The aim for BCUHB is to establish a rolling programme of Health & Wellbeing Clinics across the three main hospitals in North Wales, to ensure equity of access and flexibility for patients to attend where they prefer. This is to offer a menu of options in the market stalls which include modular type of rehabilitation programmes such as Breast Cancer Care 'moving forward', Expert Patient Programme (Long Term Conditions and Cancer Specific). In addition to support services such as Welfare Benefits, Relate services and Physical Activity.

17. The expected outcomes are to support patients to rehabilitate; helping people to maximise their potential within the limits of their disease and in terms of their physical, emotional, social and economic potential. Following a visit to the Health and Wellbeing Clinic the cancer survivors and their families would be more informed about their disease and treatment and therefore better able to cope with the experience and the challenges

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of returning to as normal a lifestyle as possible. For some this may mean returning to work, for others being able to support their family and for others enjoying their retirement.

Recommendations

18. There is an urgent need to understand the needs of those living with cancer today and to develop models of care which meet their needs. Services need to be designed in a way which will accommodate the increasing numbers of cancer survivors in the future and in a way which is sustainable.

ⁱ Crude estimates made for the end of 2010 and 2030. Estimates assume any increase is consistent across each nation and remains unchanged over the 20 years, as such they are indicative only, are not statistically reliable and could change as more information becomes available. Internal analysis by Intelligence & Research, Macmillan Cancer Support. Analysis based on data from Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009. 101: 541-547

ⁱⁱ Data from WCISU for 2007 to 2009 on all cancers except non melanoma skin cancer.

ⁱⁱⁱ Crude estimates made for the end of 2010 and 2030. Estimates assume any increase is consistent across each nation and remains unchanged over the 20 years, as such they are indicative only, are not statistically reliable and could change as more information becomes available. Internal analysis by Intelligence & Research, Macmillan Cancer Support. Analysis based on data from Maddams J, et al. Cancer prevalence in the United Kingdom: estimates for 2008. British Journal of Cancer. 2009. 101: 541-547

^{iv} 'Cured – but at what cost?' Macmillan Cancer Support 2013

^v National Audit Office, 2005; Picker Institute, 2009

^{vi} Health and Wellbeing Clinics: final report, Macmillan Cancer Support. 2011