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 Breast Cancer Care - CDP 35

David Rees AM
Chair
Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

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Dear Mr Rees

Breast Cancer Care response to the national Assembly for Wales' Health and Social Care Committee's inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

- 1. About Breast Cancer Care
- 1.1 Breast Cancer Care is the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer. For over 40 years we have brought people together, provided information and support, and campaigned for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.
- 1.2 Our vision is that every person affected by breast cancer will get the best treatment, information and support throughout their experience of breast cancer. We reach many thousands of people every year through a wide range of services, some of which are provided by our many volunteers. We also work closely with health and social care professionals to support the delivery and planning of excellent patient care. Last year we were contacted nearly 2.4 million times by members of the public accessing our services.
- 1.3 We have over ten years worth of service delivery experience in Wales as well as our active participation in the Wales Cancer Alliance (WCA).
- 2. General Response
- 2.1 Breast Cancer Care has contributed to the submission forwarded by Wales Cancer Alliance

- Using data more effectively
- · More national planning and leadership and
- Clearer Accountability.

In addition, we would reinforce that it is challenging to respond to the majority of terms of reference as there is no business project plan with SMART objectives and criteria to evidence outcomes with which to measure progress. There is no 'driving group' to ensure

defined performance specific targets are being achieved in order to reach the required outcomes or evidence available in business plan milestones to monitor progress.

- 2.2 Reports from Health Boards need to be open, transparent and consistent. There is limited or out of date data from Health Boards of their baselines or how they intend to improve these achievements, through what actions and by when.
- 2.3 The lack of progress in defining the role of the Keyworker and consistent implementation of the role across all Health Boards is an indication of lack of leadership and drive to deliver the necessary outcomes. Resources to achieve this could be an issue.
- 3. Collaborative working across sectors.
- 3.1 Within some Health Board reports there is strong evidence of collaborative working between NHS and Third Sector eg Aneurin Bevan. There is only limited mention in other Health Board reports (even when collaboration exists). However, on the ground there remains evidence of a reluctance (by some NHS personnel) to delegate areas of information, support and care for patients to the Third Sector, creating duplication and 'competition' when time and financial resources are tight. It would be helpful if this minority felt able to communicate and work with Third Sector more effectively to achieve beneficial outcomes for patients in partnership in this climate of change. At a senior level though there is increased involvement, liaison and communication with Third Sector.

3.2 In the Cancer Plan reference is made

The Welsh Government (WG) strategy Together for Health – Cancer Delivery Plan for NHS in Wales was launched in June 2012. The Delivery Plan places a duty on Local Health Boards to "Plan and deliver co-ordinated services for metastatic cancer patients and measure outcomes." (p. 10) The Cancer Delivery Plan also recognises that:

"Local Health Boards must also place more emphasis on the needs and experience of people with metastatic cancer. Even if such cancer cannot be cured it can be controlled, sometimes for years. Collection of data is crucial to be able to plan services for this patient group and to measure the patients' survival." (p. 10)

In one Health Board report (Velindre) reference is made to metastatic patients, local data collection and a multidisciplinary forum. No other Health Board makes reference to this patient group. It is recognised that collection of data is crucial but it is evident that this is highly unlikely to be achieved by 2016. Patients feel 'invisible' and lack of support and care is evident. There is no indication by any Health Board (except Velindre) of any planning to deliver co-ordinated services for metastatic cancer patients, no measuring of outcomes and no centralised collection of data to measure the patients' survival. The Third Sector can offer advice and support to Health Boards in this essential area.

Yours sincerely,

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Linda J McCarthy Head of Breast Cancer Care Cymru