

Evidence from Wales Cancer Alliance – CDP 18

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

1. Background

The Wales Cancer Alliance (WCA) consists of eleven voluntary organisations dedicated to promoting the best cancer prevention, treatment, research and care for people in Wales. Every year we invest more than £20m in Wales and contribute to the development of cancer policy.

Each member of the WCA will be submitting its own response to this Inquiry; therefore, this response by the WCA will focus on the overarching strategic issues that we believe are fundamental to the successful implementation of the plan. We will focus on the first question, ***“Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016.”***

The Welsh Cancer Delivery Plan published in 2012 set out a vision to achieve a reduction in the impact of cancer on the lives of people and to improve outcomes by 2016 through:

- Preventing cancer
- Detecting cancer quickly
- Delivering fast, effective treatment and care
- Meeting people's needs
- Caring at the end of life
- Improving information
- Targeting research

The plan challenges each Local Health Board (LHBs) to plan and deliver high quality cancer care for their populations.

The Wales Cancer Alliance welcomed the introduction of the Cancer Delivery Plan and the creation of the Cancer Implementation Group (CIG) in June 2012. However, we believe that more work needs to be undertaken in particular in data collection and analysis of the information to inform action; more effective national planning; increased monitoring against performance measures and that more robust accountability structures need to be put in place.

2. Using data more effectively

Data to illustrate whether Wales is on course to achieve the outcomes and performance measures set out in the Cancer Delivery Plan by 2016, is available through the Wales Cancer Intelligence and Surveillance Unit (WCISU) and through other performance monitoring arrangements including the recent Wales Cancer Patient Experience Survey, cancer standards and peer review.

However, we remain concerned that there is not sufficient focus in place in Welsh Government or in the NHS to ensure that the data that is available is being used to drive the actions required to make improvements needed to cancer care consistently across Wales.

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We believe it is unlikely that Wales will achieve the aspirations set out in the Cancer Delivery Plan without much greater and in depth analysis of the data and other information which is available, to identify where the gaps in services and performance are, and where improvements can and must be made.

3. More National Planning and Leadership

We welcomed the requirement set out in the Plan that LHBs have to produce their own annual cancer delivery plans which would help to tailor care to their local services and populations. However, there is significant variation in the content, depth and quality of different LHB plans, and this is likely to lead to greater variation in access to treatments and care from prevention and early diagnosis, through treatment and beyond.

Without national drive to achieve the goals in the plan, the current reliance and focus on planning and implementation at local health board level, will increase rather than reduce inconsistency in access to treatment and care across Wales.

We believe that some services need to be planned nationally on an all-Wales or on a network basis because of the complexity of cancer treatment and because often, patients will need to receive treatment with a number of multi disciplinary teams in a variety of hospitals which span a number of health board boundaries.

The lack of a national planning and support structure has meant that Wales does not have the capacity to manage initiatives on an all-Wales basis, including the project management of key elements of the plan such as taking forward work on early diagnosis which has been identified as a priority.

For example, the lack of a national approach has hindered the implementation of the key worker initiative. Roll out has been slow and the implementation of key worker role has been inconsistently interpreted and applied across health boards.

We recommend that a national planning structure and supporting processes are put in place which incorporate responsibility for better data collection and analysis of the information; for collating progress against the achievements of targets; for advising LHBs where the performance gaps in services are shown to exist; and for delivering the aspects of the plan which require a systematic national focus and commitment. This resource/team should also provide a forum for sharing and developing good and best practice.

Whilst we welcome the creation of the Cancer Implementation Group (CIG), in which the Wales Cancer Alliance has been recognised as a key member, we consider that the group does not have enough resources at present to support its work beyond the meetings particularly with regards to taking forward national initiatives.

A national planning structure and action team to support implementation of the Cancer Delivery Plan would help the CIG to work more effectively by bridging the existing gap between national policy and local implementation. We recommend that the Welsh Government considers the structures and processes that it would need to take forward and implement its ambitions.

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We would like to see more evidence of national leadership, and priority setting which goes beyond a one year timeframe with more robust project planning underpinning each priority and with each clear objective having deadlines/ targets against which progress can be measured.

4. Clearer Accountability

Currently, it is unclear how the accountability structures and process for delivery against health board plans are working or how evidence is gathered which can be used as a tool upon which to benchmark performance.

We welcome the requirement for HBs to publish their individual cancer delivery plans and annual reports on their websites, and welcome the commitment to openness and transparency, which can be a one of the key drivers for change. However, in reality more formal accountability arrangements are also needed with clear expectations on delivery by health boards. Welsh Government must take responsibility for ensuring that where and when the need is identified that performance needs to be improved, that action is taken and additional support is provided.

The WCA believes that the ambitions as set out in the plan will not be achieved without more robust national planning, processes and structures to support implementation to gather informative data; carrying out proper in depth analysis to inform and identifying where action needs to be taken; overseeing national planning and all-Wales initiatives where needed; a more robust monitoring and accountability structure.

There needs to be acknowledgement that a more fundamental shift in thinking is needed about the scale and pace of implementation needed and the level of systems and cultural change required to achieve the ambitions set out in the plan by 2016.

5. Conclusion

In conclusion, the Wales Cancer Alliance welcomes the ambition and direction set out in Together against Cancer – Cancer Delivery Plan which was published in June 2012. We are now two years on from its publication and we are not yet assured that the aspirations set out in the Plan are being achieved at the pace and scale which we had hoped for. There remains significant work to do to ensure that the aims set out for 2016 are achieved across all cancer types and for every cancer patient in Wales. There remains too great a variation in outcomes and patient experience across hospitals and health boards which cannot be justified by local circumstances alone.

We call on Welsh Government to strengthen its approach to national planning and monitoring of progress in implementation. We need to look ahead more than one year with a focus on much greater collaboration across health boards and cancer teams where necessary to ensure patients receive timely and coordinated care.

A shift in thinking and approach is needed to ensure that the direction and ambitions as set out in the Cancer Delivery Plan, which we fully support, can be achieved for every cancer patient, no matter where they live in Wales.

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Membership organisations

Breast Cancer Care

Cancer Research UK

Cancer Research Wales

Clic Sargeant

Independent Hospices Cymru

Macmillan Cancer Support

Maggies

Marie Curie Cancer Care

Prostate Cancer UK

Teenage Cancer Trust

Tenovus

**Wales Cancer Alliance
Priority Policy Calls**

The Wales Cancer Alliance consists of ten voluntary organisations dedicated to promoting the best cancer prevention, treatment, research and care for people in Wales. Every year we invest more than £20m in Wales and contribute to the development of cancer policy.

The Wales Cancer Alliance welcomes the Welsh Government's Cancer Delivery Plan published in June 2012. We recognise the importance of the Delivery Plan in driving improvements in cancer services and call on the government to ensure continued momentum in the implementation of key commitments within the plan.

We believe that the voluntary sector has an important role to play in delivering improvements for people affected by cancer, and we look forward to working in partnership with the Welsh Government, the NHS and others to achieve this.

This document sets out the key areas where we believe further commitment is required and makes suggestions for action.

Preventing Cancer

It is estimated that up to half of all cancers could be prevented by healthy lifestyles. Not smoking, body weight management, active living, healthy food choices, low alcohol intake and staying safe in the sun can all help to reduce cancer risks.

We want to see;

- Improved public awareness of ways to reduce cancer risks and greater partnership working across sectors
- Opportunities for 'teachable moments' for prevention messages to be identified and supported.

A focus on early detection

We warmly welcome the areas that focus on early detection within the Cancer Delivery Plan and look forward to working with the government on their delivery.

We want to see:

- A centrally co-ordinated initiative to improve the early diagnosis of cancers in Wales
- An all-Wales public awareness campaign that highlights the common signs and symptoms of cancers and the importance of presenting promptly to a GP
- Robust evidence provided to Health Boards to guide local action.

Delivering fast effective treatment and care

We know that there are still inequalities in terms of access to services and treatments and that these can lead to inequalities of outcomes.

New processes should improve equity of access to cancer drugs but very little information is available to the public to determine the extent of progress made on this issue. There remains unequal access to treatment more generally; for example, new radiotherapy technologies or surgical techniques; and in both cancer and supportive services.

We want to see:

- Up to date data and more transparency in relation to access to cancer treatment
- Fair, clear and consistent processes across Wales to ensure patients are able to access clinically effective drugs
- People knowing what services are available to them; and
- Have equal access, irrespective of cancer type, geography, age, gender, socio-economic status, ethnicity, faith or disability to cancer specialist multi disciplinary teams
- Compliance with waiting time targets for urgent and non urgent cases
- Specific coordinated services for metastatic cancer patients and measured outcomes

Meeting people's needs

Cancer services should be focused on the individual needs of people and their families. People's holistic needs – physical, emotional, spiritual, financial and practical are not always identified or addressed.

Each person should receive a personal care plan based on a holistic assessment of their needs and this should extend into the post-treatment phase.

People also tell us that they value having a named key worker to act as a coordinator, a touch point for questions and to signpost to services available to support people's individual needs.

These changes would help to support many people to self-manage their condition after treatment and could therefore potentially free up resources and capacity for more complex cases.

We want to see:

- Assessment and care planning implemented for all people living with cancer
- Improved information and support to encourage self-management.
- Consistent interpretation and implementation of the key worker role across Wales

Coordinating care

People tell us they want their care to be effectively coordinated, across the different parts of the statutory sector and the voluntary sector both during and after treatment. To achieve this, we need better coordination of health and social care services and between acute and primary care. Particular attention should be given to transition points such as at diagnosis, at the end of treatment and when patients are nearing end of life.

Clinical Nurse Specialists (CNS) and key workers play an important role in coordinating care. However we know that there is unequal access to CNSs and there is evidence of specialist nurse time being lost. We also know that implementation of the key worker role is patchy and inconsistent and that many patients are unaware of the support they can expect to receive from their key worker.

We want to see:

- A commitment to improved planning of health and social care services.
- Improved joint planning of individual patient care across acute and primary care services including the voluntary sector
- Extra support for people at key transition points.
- Data on specialist nurse provision across Wales.
- Research into the role of CNSs and the extent to which coordination of care needs are being met.
- Monitoring outcome measures on the implementation of the key worker role
- The findings used to inform practice to help assess the best utilisation of resources.

Caring at the End of Life

We know that more than 60% of people express the wish to die at home whilst the reality is that more than 60% of people in Wales die in hospital. We also know that people are concerned that they will experience pain at the end of their lives. Specialist clinical support is critical in ensuring that people's end of life is pain and symptom-free. Carers and families should also receive the support and care they need.

We want to see:

- Increased emphasis on providing services in a community setting with appropriate resources to achieve this
- Greater integration of support across all organisations within and outside the public sector

Improving Information

There is a plethora of audit data collected, however we want to ensure that patients have the information they need to make informed decisions about their cancer treatment and care, and that Health Boards are able to assess and improve their services to cancer patients. Welsh Government also needs data to enable it and the public to hold Local Health Boards to account.

We want to see meaningful data relevant to patient experience, service quality and health outcomes collected, collated and acted upon.

We want to see:

- Local Health Boards acting on the results of the Welsh Government's all-Wales Patient Experience Survey findings to improve care and support for people and their families.
- Identifying dedicated outcome measures for patient experience and incorporating these into the new quality framework.
- Data and information presented in a transparent and easy to understand format so that everyone, including people affected by cancer, can understand the information.
- The creation of a supportive culture within the NHS for learning from patient experience and assessing and improving the quality of services.
- Collection of data on metastatic and recurrent diagnosis to enable effective planning and delivery of treatment and support to this group
- Supporting initiatives to make accessible information available for patients regarding treatment and care

Targeting Research

Wales has been at the forefront of cancer research over the years with several members of the Alliance contributing to key advancements in detection and treatment for the disease. The development of the Wales Cancer Bank and the Wales Gene Park are key achievements that Wales should be proud of.

The Alliance would now like to see a greater focus on developing a cancer research strategy for Wales which gives a clear direction to those in the field of cancer research how they can contribute to the successful implementation of the Cancer Delivery Plan.

We want to see:

- People to be adequately informed and given access to the appropriate clinical trials as this is key

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Wales Cancer Alliance

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