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 Tenovus - CDP 28

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

At Tenovus we want a future where fewer people develop cancer and everyone with cancer has equal access to excellent treatment and support. We offer support, advice and treatment for cancer patients, information on cancer prevention and funding for research to improve the outcomes for people with cancer. We do this where it is needed most - right at the heart of the community.

In 2012 Tenovus welcomed the introduction of the Cancer Delivery Plan and its vision to provide world class health care services to people affected by cancer in Wales. We were also pleased that patient centred care was seen as integral to achieving this aim and that many of the key priorities set out in the Plan matched our own strategic aims and objectives as a service provider to thousands of patients and families affected by cancer in Wales each year.

Below is our response to the progress of the Cancer Delivery Plan to date, focussing on the areas set out in the terms of reference as requested.

1. **Is Wales on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016?**

At this stage it is probably too early to tell if the Cancer Delivery Plan is having a positive effect and whether this will lead to the desired outcomes by 2016. Whilst the Wales Cancer Intelligence Surveillance Unit (WCISU) is an excellent resource for cancer statistics in Wales there needs to be a greater use of this data to drive improvements and identify areas of weakness as soon as they arise. This is symptomatic of a need for greater national planning and leadership in relation to cancer services in Wales.

Whilst the CIG was established to provide some of this oversight and strategic direction it does not have the resources or the authority to do so effectively. Tenovus would welcome a national planning structure with responsibility for better and more expedient data collection and analysis, advising LHBs where the performance gaps in services are shown to exist and delivering the aspects of the plan which require a systematic national focus and commitment.

This would provide clearer leadership and therefore accountability. It would also help us in Wales to plan for long term success that crosses LHB boundaries, with clear deadlines and targets against which progress can be measured.

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2. **Has progress been made in reducing the inequalities gap in cancer incidence and mortality rates?**

Currently in Wales there are approximately 120,000 people who have experienced a diagnosis of cancer, and with around 50 more people diagnosed everyday this is set to double by 2030. In the last 15 years there has been a significant increase in the number of cases of cancer diagnosed each year, but thanks to continuing improvements in our ability to detect and treat cancer the numbers of people who actually lose their lives due to the disease has actually decreased.

However there are still great disparities which determine how likely you are to get cancer and how likely you are to recover from it. For example, in Wales, as in many countries, the poorer you are the more likely you are to develop cancer. In fact if you are a man and live in one of the most deprived areas of Wales you are up to 21% more likely to develop cancer than someone who lives in a more affluent area. If you are a woman you are around 14% more likely to develop cancer.

Even more shockingly, not only are you more likely to develop cancer if you are poor but you are also more likely to die from it compared to someone from a more affluent area. For example, for every 2 individuals who die of cancer in the most affluent group in Wales, 3 die in the poorest [1].

There are also some types of cancer where the outcomes for patients are far more likely to be worse than others. Probably the starkest example of this is lung cancer, a disease which has seen little improvement in survival rates over the last few decades and is today Wales' biggest cancer killer. However, we have made huge strides in successfully treating many other common cancers and improved survival rates dramatically. This has been achieved through a mix of increased public awareness, an established screening service and improvements in treatments and surgery, much of which has been demanded and driven by the patients themselves over a number of years.

We are pleased to see that both 1 year and 5 year survival rates from cancer have improved in Wales however these figures pre-date the implementation of the Cancer Delivery Plan and we may have to wait several years until the data is available to see if the Plan has helped drive these improvements even further.

Also, whilst these improvements are heartening, they are also far overdue and need to continue at a pace if we are to get anywhere near matching the best survival rates in Europe. For example survival rates for lung cancer are the 28th lowest in Europe out of 29 countries. We are also behind the European average in terms of survival for a number of other common cancers [2]. In fact if we just matched the best in Europe in terms of survival across all cancers we would save the lives of over 600 patients per year.

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3. The effectiveness of cancer screening services and the level of take-up across the population of Wales, particularly the harder to reach groups.

We know that early detection (and indeed detection of pre-cancerous conditions) through screening programmes has saved many lives. However we are concerned that the uptake of screening is not meeting national targets in Wales and that the uptake of screening varies greatly between different socioeconomic groups further driving the inequalities seen in incidence and survival described above.

For example, we know that women from more deprived areas are less likely to attend cervical and breast screening [3] and in Wales screening uptake varies hugely by area, for example, patterns of low uptake in breast screening closely match patterns of deprivation in Wales [4]. Despite this little research is being done into targeting socioeconomic groups with a low screening uptake. More funding for research in this area, in-line with the Welsh Government's emphasis on evidence-based policy-making and stronger links between research and policy e.g. through the Knowledge Exchange Trials programme, is essential not only for improving screening uptake but improving it among the socio-economic groups most likely to benefit.

Black Asian Minority Ethnic and Refugee (BAMER) groups and screening is a relatively unexplored area and the links between racial equality and health remain tenuous despite allusions by the Welsh Government to ensuring cultural inclusivity in health care (Ruth Hussey, All Wales Annual Race Equality Conference, 2014). This could be done through stronger links between Local Health Boards and community cohesion programmes within local authorities. In addition working in partnership with organisations such as Communities First and voluntary organisation in a systematic and structured way could improve screening uptake among hard to reach and minority groups.

Wales also has to keeps up with the latest developments in effective screening not just in the UK but also globally. Cervical Screening Wales has announced that they are planning to assess the impact of HPV triage on the screening programme in Wales and will make a recommendation to the Welsh assembly government on any potential plans to adopt HPV triage as a policy. This has already been adopted as common practice in England and should lead to less women being unnecessarily treated for suspected cervical cancer reducing harm to the individual and costs to the health service. If this is found to be the case then we are calling for the screening services to also adopt this as routine practice.

Low awareness and negative beliefs about cancer are likely to contribute to delayed presentation with cancer symptoms, leading to advanced stage at presentation and a smaller chance of survival. In 2011, researchers from Cardiff University's School of Medicine joined forces with Tenovus and the Welsh Government as part of the International Cancer Benchmarking Partnership (ICBP) the largest

international research study designed to examine the root causes of international differences in cancer survival.

Through this study it was shown that Wales and the UK generally had an average knowledge of symptoms relating to cancer, but had a poor knowledge that increasing age was a risk factor and also had the highest level of perceived barriers to symptomatic presentation, in particular being worried about "wasting the doctor's time" [5].

4. Can patients across Wales access the care required (for example, access to diagnostic testing or out-of-hours care) in an appropriate setting and in a timely manner?

Once an individual is told that they have a suspected cancer, whether via a screening route or from GP referral, this is one of the most emotionally distressing times imaginable. The NHS in Wales has set the maximum wait for access to specified diagnostic tests at 8 weeks. However a recent report shows that overall the number of people waiting for diagnostics has increased dramatically over the past two years and as of January this year 41.6% of all people in Wales waiting for diagnostic endoscopy have waited for more than 8 weeks. This is alone represents 5,228 people waiting for a diagnosis relating to a bowel condition, some of which will include cancer [6].

As the population continues to age in Wales, awareness of cancer increases and screening services become more fully utilised, the need for diagnostic testing is going to greatly increase. Therefore much greater investment is needed in this area to ensure that individuals with cancer are treated expeditiously and those who don't have cancer can have their fears alleviated.

There will always be for some specialist services to be centralised to ensure that the right level of expertise or facilities are available. However there are also a number of services that can be taken out into the community alleviating the pressure on already overcrowded waiting rooms whilst also reducing journey times for cancer patients and families at an already stressful time. Since 2009 Tenovus has helped to do this through our mobile chemotherapy and lymphoedema services in partnership with Local Health Boards in Wales.

Technology also provides us with new opportunities, not least telemedicine which can be used to for remote diagnosis, treatment and follow up and is already routinely used in other countries with rurality issues that dwarf ours (e.g. Canada, US, Australia). There have been a number of telemedicine pilots that have taken place in Wales in recent years including a project in Hywel Dda for head and neck cancer patients funded by Tenovus. However there needs to be a coordinated approach to this issue on an all Wales level that brings together the best expertise in Wales with models of global best practice to drive the use of this technology forward.

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5. **Collaborative working across sectors, especially between the NHS and third sector, to ensure patients receive effective person-centred care from multi-disciplinary teams.**

Tenovus has worked closely with the NHS in Wales over a number of years and shares the Cancer Delivery Plan's vision of greater patient centred care and world class treatment, support and care for cancer patients in Wales.

Below are just some of the ways in which Tenovus is already helping to deliver this and some areas where we feel the NHS and third sector could work more closely to provide even greater care and support to a larger number of patients and their families.

Prevention- Over the past 3 years we have delivered more than 3500 cancer specific Health Checks to people in some of the poorest places in Wales. This has led to a partnership with Cardiff University which has secured £150,000 in funding from the National Awareness and Early Detection Initiative (NAEDI) to evaluate its effectiveness as an intervention for promoting healthy living and identification of common cancer symptoms in areas of high social deprivation.

Clinical Trials- Tenovus is currently funding a research project with NISCHR CRC which aims to improve the cancer patient experience of being introduced to research. As is highlighted in the Cancer Delivery Plan Annual Report, only 29% of patients had been asked about participation in research. We hope to use the findings of this study to increase research participation not only in clinical trials but also research that improves vital areas of care such as information provision, psychosocial support and the development of best practice in allied health care services.

Research- Tenovus is one of Wales' largest cancer research funders and will this year invest around £1m in research that covers the whole patient journey. We are also one of the biggest funders of PhD studentships in Wales which not only helps to increase research capacity and training in Wales but also provides some of the newest avenues for research and cutting edge discoveries.

Treatment closer to home- Since 2009 we have worked in partnership with Velindre to deliver chemotherapy in the community closer to where people live. In fact, our mobile units have delivered over 10,000 treatments to date and in 2012/13 saved cancer patients in Wales from traveling over 55,000 miles to and from hospital. Also, since January 2012 we have used our Mobile Units to provide a range of treatments for patients with lymphoedema. In October 2013 we launched our 2nd Mobile Unit which is set to deliver around 6500 treatments for patients affected by this debilitating condition all over Wales, the first mobile service of its kind in the UK.

Practical Advice and Emotional Support- Tenovus provides a wide range of services to cancer patients and their families and can support them from point of diagnosis right through to survivorship or end of life care. Whilst many positives came out of the recent Wales Cancer Patient

Experience Survey [7] carried out by Macmillan and Welsh Government, we were greatly concerned that nearly 1 in 4 patients who would have liked information about emotional support, such as self-help groups, were not offered any information, and half of all patients who would have liked information about financial issues or benefits also did not receive any. This is an example of where the NHS and the third sector could coordinate much more effectively to provide support for cancer patients and families in Wales. The Tenovus Cancer Support Team provides a wide range of services for cancer patients including advice on money matters and benefits, counselling, a nurse led support line available 8am-8pm 7 days a week and a range of innovative and effective support groups such as the Tenovus Sing With Us Choir programme. In 2012 Tenovus received the Advice Quality Standard from the Legal Services Commission in recognition of the quality of our advice services.

We have also developed a proactive telephone support service called Tenovus Cancer Callback through a collaborative project between Tenovus, Velindre and the University of Glamorgan funded by the Burdett Trust for Nursing. The project began in April 2012 and allows Tenovus to implement a schedule of callbacks to any cancer patient in Wales undergoing treatment and to follow those patients up for at least 6 months.

6. **Whether the current level of funding for cancer services is appropriate, used effectively and provides value for money.**

With an ever increasing incidence of cancer and a health and social care system already creaking under we need to think about how we can spend existing budgets more effectively and look at developing new and innovative ways of providing care, treatment and support that will benefit an increasing number of people. In Wales there is a huge opportunity to do this. We have an incredibly skilled and dedicated work force with excellent third sector service providers and a strong track record in research. We feel that they Cancer Delivery Plan is helping cancer care and treatment move in the right direction, but a greater focus on organisational structure, processes and accountability will be needed if we are to reach the bold vision of a world class service by 2016.

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References

[1] Cancer Incidence, Mortality and Survival by Deprivation in Wales, Welsh Cancer Intelligence and Surveillance Unit report, July 2009

[2] De Angelis et al (2014) Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study The Lancet Oncology, Volume 15, Issue 1, Pages 23 - 34, January 2014

[3] Marmot, M. (2010) ‘Fair society, healthy lives: the Marmot review’. http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review, last accessed 31 September 2012.

[4] Breast Test Wales Uptake Mapping by Lower Super Output Area (LSOA): Screening Round 6 (for the approximate period Jun 2003 – Feb 2012), Produced by Screening Informatics, Screening Division, Public Health Wales

[5] Forbes et al (2013) Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (the International Cancer Benchmarking Partnership): do they contribute to differences in cancer survival? British Journal of Cancer, advance online publication 31 January 2013

[6] NHS Wales Diagnostic & Therapy Services Waiting Times: At end January 2014, Statistics for Wales, 13th March 2014 http://wales.gov.uk/docs/statistics/2014/140313-nhs-diagnostic-therapy-service-waiting-times-janaury-2014-en.pdf

[7] Wales Cancer Patient Experience Survey: National Report (2014) Produced by Macmillan Cancer Support, Quality Health and Welsh Government