

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 Public Health Wales – CDP 36

**Public Health Wales evidence submission: Re: 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 Detecting cancer quickly**

### **1 About Our Screening Programmes**

#### **1.1 Cervical Screening Wales**

The aim of the Cervical Screening Programme in Wales (Cervical Screening Wales) is to reduce incidence of and morbidity and mortality from invasive cervical cancer. From the 1<sup>st</sup> September 2013 women aged 25–50 have been invited three yearly and women aged 50–64 are invited five yearly. This reflects the change in WG policy announced in January 2013.

The coverage (proportion of eligible women with an adequate smear result in the past five years) of eligible women aged 25 to 64 years in Wales is good, and for the period 1 April 2012 to 31 March 2013 this was 79.3%. This is just below the target of 80%. In Wales the incidence of cervical cancer has decreased over the last decade to an European Age Standardised Rate of 7.8 new cases per 100,000 women in Wales in 2011. This is the lowest incidence of cervical cancer in the UK.

#### **1.2 Breast Test Wales**

The aim of the Breast Screening Programme in Wales (Breast Test Wales) is to reduce mortality from Breast Cancer. Women aged 50–70 years are invited every three years; women aged over 70 years can self refer. For the period 1 April 2012–31 March 2013, uptake of screening was 71.5%, which meets the standard of 70%. For this period a total of 816 cancers were detected by Breast Test Wales in women screened aged 49 and over. This represents 9.8 cases per 1000 women screened. Breast Test Wales exceeds national performance standards and targets for cancer detection, and has the highest cancer

detection rate of any UK breast screening programme. The overall standardised detection ratio was 1.75 (standard 0.85 and target 1.0).

### **1.3 Bowel Screening Wales**

The aim of the Bowel Screening Programme in Wales (Bowel Screening Wales) is to reduce mortality from bowel cancer by 15% in the group of people invited for screening by 2020. Men and women aged 60 to 74 years are invited for bowel screening every two years. For the period 1 April 2012–31 March 2013 the uptake was 48.2% which was lower than the standard of 60%.

There is evidence of inequity in screening uptake for the cancer screening programmes, where uptake is lower in more deprived groups. For the period 1 April 2012 to 31 March 2013 the uptake for bowel screening was 54.4% in the least deprived groups compared to 39.1% in the most deprived groups. There is a similar pattern in the breast screening with 76.1% uptake in the least deprived compared to 62.9% in the most deprived; and cervical screening with coverage for 25–64 year old of 83.2% in the least deprived group compared to 74.9% in the most deprived group. Reducing inequity is a priority for screening division.

Bowel Screening Wales has the lowest uptake of the cancer programmes and has established an Uptake group to tackle the issue. The group is looking across the population and also at groups where uptake is known to be low. Possible interventions are being considered at strategic level, operational level, and within routine programme activity and will be evaluated.

For example, in February 2014 a bowel screening campaign was launched in Wrexham in partnership with Wrexham Local Service Board aimed at increasing the uptake for bowel screening in the area (current uptake 44%). There was a launch attended by Mayor and Mayoress of Wrexham and the Tenovus Choir on the 14<sup>th</sup> February and the coordinated campaign is being promoted by radio, social media, newspaper and posters including banners on buses. The effectiveness of the intervention will be evaluated.

A literature review has been carried out to explore how best to effectively increase uptake and decrease inequities in uptake. The evidence centres around having should be clear, consistent messages which are delivered in a way that is appropriate to the audience. A set of key messages has been developed for each of the adult programmes, and links made with Communities First groups, Local Public Health Teams, Community Pharmacies and other partners to explore the best way of communicating these messages.

Uptake of bowel screening in Wales has risen consistently over the past five months, and for February 014 stood at 60%– meeting the target for the first time since the programme’s inception.

## 1.4 Screening Engagement

The Screening Engagement Team (SET) works across the cancer screening programmes. Their role is to raise awareness of the screening programmes, promote informed choice by informing the eligible population about the benefits and harms, and encourage people to make an active decision about taking part in screening. The SET work at both a strategic level, engaging with partners and the programmes and providing direction and guidance, but also on an operational level with members actually going out to communities for example and delivering training to the public and health professionals.

The team works extensively with ‘harder to reach’ groups. A summary of current activity is below.

The team is working toward meeting the objectives of the Strategic Equality Plan. There are a number of work streams currently underway:

### 1.4.1 Learning Disabilities

The BTW Packs have been reviewed and are in the process of being uploaded to the BTW Website. The team are working with local Learning Disability (LD) teams to recruit service users with LD to develop digital stories which can be used for health education and service improvement.

#### i) Macmillan Project

Macmillan employs an LD Specialist Nurse to scope, develop and improve services for service users with LD specifically in relation to cancer services. We are members of the steering group for this project. Early discussions are looking to partnership work on the following work streams:

- Developing a standardised bowel desensitization kit which can be used all Wales by LD teams
- Improving information provision for service users with LD
- Developing a suite of LD specific digital stories for health education and service improvement
- Improving links with local teams

These are early stage discussions.

## 1.4.2 Transgender

Work is well underway to support transgender service users. To date:

- An action plan has been developed to support this group
- Members of the transgender community have met with cervical screening nursing team and some Heads of Programme
- Two transgender Digital Stories have been co produced. The female to male (FTM) story has been launched on You tube and is now live. The second male to female (MTF) story has not yet been approved and is currently at the editing stage
- A draft leaflet has been developed. The draft wording is now ready for external review. The team will be meeting with local LGBT and Trans specific networks to get feedback on this resource in the next few weeks
- A set of transgender specific 'Frequently Asked Questions' are in their final stages of development. Once agreed by Core PIG they will go to external groups for review
- A task and finish group will be established by the Centre for Equality and Human Rights to look at developing a resources to support staff. This resource will be developed focussing on acceptable terminology
- The team has been invited to attend the All Wales Gender Dysphoria Partnership Board. This group has only met twice so is in its early stages. However at the last meeting a number of work streams were initiated which may be relevant to division in due course
- The team are improving their links with the different networks and although this work is slow it is improving. The team were invited to attend the annual 'Sparkles' event which enabled the team to network with members from the transgender community. The team delivered a presentation on the work they have undertaken in relation to the trans project at a recent best practice day. It is hoped that some joint event can be delivered to support the Screening for Life Campaign however, no firm plans have been made as yet

## 1.4.3 Black Minority Ethnic (BME) Groups

Working with BME groups is still ongoing with the team accessing information sessions and appropriate events. Two focus groups have been undertaken with BME groups in relation to BSW Uptake work.

#### 1.4.4 Sensory Loss Report

A divisional task and finish group was established to look at the sensory loss provisions for service users within screening. The outcome of this group was that further divisional scoping was needed and that these findings could be taken to the Centre for Equality and Human Rights, stakeholder reference group for consideration. This stakeholder group was instrumental in the development of the initial sensory loss standards which were recently launched. This group consists of key sensory loss stakeholders/organisations. A workshop is scheduled to be held at the end of March to discuss the findings of the scoping and to see if there are any improvements that the division can make to support service users with sensory loss. A report will be presented to the sensory loss task and finish group for consideration.

#### 1.4.5 Homeless Training Pilot

The team has been working with John Bradley from the Public Health Wales, Older Persons and Vulnerable Group Inequalities Team (OPVGIT). The team are developing a training package similar to the one which was developed for use with Harm Reduction Teams across Wales but specific to Homelessness. It is the intention to run a small pilot to train key workers in relation to screening. This will involve basic training on screening covering the different programmes, case studies, frequently asked questions and signposting information. This pilot will initially be run with Cymorth staff which is a national homeless charity. The training package is currently being developed and the training will be scheduled to run in May.

#### 1.4.6 Gypsy and Traveller Project

A project to improve awareness of screening with the Gypsy and Traveller community is currently underway. The team is consulting with Gypsy and Traveller link workers and Gypsy and Traveller communities across Wales to understand what information, training and support is needed to improve knowledge and awareness of screening. The team will also consult with staff from Screening Division to identify if there are any specific training needs in relation to the Gypsy and Traveller community. Following the consultation, an action plan will be drawn up to take forward this work.

## 2 Meeting People's Needs



### Evidence 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

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#### Introduction

1. The National Cancer Patient Information Strategy (NCPIS) Project is a three year partnership project funded by Macmillan Cancer Support and hosted by Public Health Wales exploring how patients can be consistently offered tailored information and support from the point of diagnosis onwards. The project is explicitly referenced within the Welsh Government's Cancer Delivery Plan (CDP) in relation to meeting peoples' needs. This inquiry response is based on learning from the evidence gathered as part of phase 1 of the NCPIS project and specifically refers to two questions
  - Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016;
  - the level of collaborative working across sectors, especially between the NHS and third sector, to ensure patients receive effective person-centred care from multi-disciplinary teams.

#### Background

2. Cancer is changing. Thanks to advances in early diagnosis and treatment, more people are living longer with cancer or beyond it. By 2030, it's estimated that the number of people living with or after cancer in Wales will nearly double to almost a

quarter of a million.<sup>1</sup> This growing cancer population will challenge existing models of cancer care. As more cancer patients experience the disease as a long-term condition, with patterns for many of relapse and remission, there will be a need for ongoing and often long-term support and an increasing drive for cancer survivors to self manage.

3. High quality information and support (by which we mean content – which may be spoken, printed or digital– available at the right time, in the right format, which is quality assured and offered with a level of support required) is an essential component of quality healthcare and a pre-requisite to effective self-care. The case for improving the co-ordination and delivery of cancer patient information in Wales, as a key enabler to the delivery of the CDP and changes to cancer care in Wales, is compelling as is detailed in brief below;
4. **High quality information and support is central to self-care yet the current approach to information provision may widen health inequalities and act as a barrier to effective self-management** – The growing cancer population and financial pressures necessitates greater self-management. However the current issues the project has revealed in relation to the development, co-ordination and delivery of patient information in Wales mean that many people cannot consistently access information and support which meets their individual needs and thus have the tools to self-manage. This is exacerbated by the age and socio-economic profile of the cancer population – a profile which is likely to indicate lower health literacy levels and therefore an increased need for information materials which are accessible and available in a range of formats.
5. *High quality information and support is closely linked to a positive patient experience, yet a number of the poorer scores given by patients in the 2013 Welsh Cancer Patient Experience Survey are in respect of lack of information given to them about key aspects of their condition, treatment and care* – When patients are asked what really matters to them in terms of their healthcare experience, good information is consistently prioritised across conditions and settings<sup>2</sup>. Yet the recent Welsh Cancer Patient Experience Survey revealed significant issues in relation to patient information with particular concerns around the provision of easy to understand written information at diagnosis, information for families

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<sup>1</sup> Macmillan Cancer Support. (2012). *Local Route Maps*. London: Macmillan Cancer Support.

<sup>2</sup> Robert, G. a. (2011). *What matters to patients? Project Report for the Department of Health and NHS Institute for Innovation and Improvement*. Coventry: NHS Institute for Innovation and Improvement.

following discharge and information about the long term side effects of cancer diagnosis and treatment.

**6. High quality information and support underpins the co-creation of healthcare yet the current model of care predominantly views healthcare professionals as information providers rather than enablers, helping people to access information and support** – Research highlights the importance of clinicians and specialist support staff acting as an ‘infomediary’ for their patients/clients – signposting them towards, and helping them to acquire, the high quality health information and support they need<sup>3</sup>. This is key in terms of empowering patients and their families to take responsibility for their own healthcare with growing evidence that more active patients enjoy better health outcomes and incur lower costs<sup>4</sup>. Yet the current model of care predominantly views health care professionals as information providers rather than enablers. Increasingly there will be a need to focus on enabling people to access information and support to help themselves.

**7. The consequences of not providing high quality, co-ordinated information and support are significant leading to poor patient experience, ineffective care, unnecessary interventions, litigation and wasted resources**– Problems relating to poor communications and inadequate information remain one of the most common causes of formal concerns in the health service<sup>5</sup> with the Citizens Advice Bureau suggesting that 1 in 5 of all concerns relate to issues with regards communication and patient information<sup>6</sup> In addition to costs associated with concerns, issues with patient information also impact on service utilisation and health costs. NHS England data suggests that poor understanding of doctors’ instructions and concerns over side-effects cost the NHS approximately £500m per year due to issues with regards adherence to treatment and medication regimens, A&E attendances and unplanned hospital admissions<sup>7</sup>. A recent King’s Fund report has also highlighted how issues with regards clinicians fully informing and involving patients in decisions about their care have a significant impact with the authors arguing that well-informed patients choose fewer treatments, and

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<sup>3</sup> Swain D, Ellins J, Coulter A, Heron P, Howell E, Magee H., (2007). *Accessing Information about Health and Social Services*. London: Picker Institute Europe.

<sup>4</sup> Patient Information Forum. (2013). *Making the Case for Information - the evidence for investing in high quality health information for patients and the public*. London: Patient Information Forum.

<sup>5</sup> Sutherland, L. &. (2008). *The quest for quality: Refining the NHS reforms*. London: Nuffield Trust.

<sup>6</sup> NHS Litigation Authority. (2012). *Factsheet 2: Financial Information*. London: NHS Litigation Authority

<sup>7</sup> Patient Information Forum. (2013). *Making the Case for Information - the evidence for investing in high quality health information for patients and the public*. London: Patient Information Forum.



involving people in decisions about their healthcare helps to reduce unwarranted variations in treatment<sup>8</sup>. The absence of an agreed national approach to patient information provision across all conditions also leads to significant duplication of effort between local and national providers, with cost and resource implications. This is explored further in response to the inquiry terms of reference.

## Response to the inquiry terms of reference

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

8. The Welsh Government Cancer Delivery Plan calls on Local Health Boards to publish an annual report and a detailed local cancer delivery plan each year. The project has analysed the annual reports and local delivery plans available from the perspective of content on patient information and is concerned by the varied nature of documents and the lack of strategic direction in Health Board responses around this key area. Health Boards principally focus on progress on clinical data rather than how they are consistently meeting the information needs of people affected by cancer. It is likely this is related to the lack of clear performance measures governing information for patients and their families or a strategic focus on this important area.
9. The CDP also includes a commitment that ‘people have access to timely information so they understand their condition and what to look out for and what to do and which service to access should problems occur.’ The recent Welsh Cancer Patient Experience Survey (CPES) revealed that a number of the poorer scores given by patients in the survey were in respect of information to them about key aspects of their condition, treatment and care suggesting that this outcome is being inconsistently achieved across Wales. Of the 19 patient and family information questions, there was significant variation between health boards on 16 questions (see Table 1 in Annex A) suggesting wide scale variation at a geographical level. The CPES results also show variation in information and support provision by tumour site with patients with certain tumour sites, such as lung, brain, sarcoma and haematological cancers experiencing a poorer information experience than other patients (see Table 2 in Annex A which details the results of different tumour groups in relation to key information questions).
10. Research shows that people affected by cancer consistently call for information on more holistic aspects of care and this need is explicitly mentioned in the CDP. However, responses to specific questions relating to the availability of

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<sup>8</sup> Mulley, T. &. (2012). *Patients' Preferences Matter: stop the silent misdiagnosis*. Cardiff: King's Fund.

information about relationships, finances and work within the CPES by Health Board highlighted inconsistency and unmet needs in relation to non-clinical information. For example, the percentage of patients who required it given information about emotional support varied from 77% to 58% within health boards. The percentage of respondents wanting and receiving information about the impact of cancer on work or study varied from 74 to 56% and the percentage of patients who would have liked and who were provided with information on financial support varied from 28% to 53%.

11. The CPES findings strongly suggest that Wales is currently not on target to consistently deliver on the outcome ‘people have access to timely information so they understand their condition and what to look out for and what to do and which service to access should problems occur.’ This supports the project findings which highlighted issues with regards the co-ordination and delivery of patient information in Wales and suggests that Wales is lagging behind other UK nations on this key area.

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

12. The extensive evidence review for the Project has highlighted that whilst there is evidence of some good practice in relation to collaboration between the third sector and the NHS in relation to patient information, there are a number of key areas where collaboration is limited and could be significantly enhanced. These primarily relate to information content development and the provision of information and support services. Given the challenging financial situation and growing cancer population, there is a need to co-ordinate and dully utilise all community assets to ensure truly person-centred care.
13. Content – Due to the absence of an agreed national approach to patient information provision and a single portal to host content, there are currently a wide range of producers of health information content in Wales at a local and national level with production varying in terms of format, language, quality and the extent to which it is co-designed by the intended audience, with no common standards in place across Wales. A number of third sector organisations have significant expertise in producing information and undertake stringent quality assurance mechanisms yet content is not consistently utilised or made accessible to professionals and the public. This localised approach has an impact in terms of the ability of services to offer up to date, accessible, quality assured information in other languages and in a range of formats. Currently there is evidence that too

much of the locally produced cancer patient information produced requires a level of literacy not achieved by a significant proportion of the Welsh population<sup>9</sup>. This uncoordinated approach also leads to significant duplication of effort between local and national providers, with cost and resource implications.

14. Third Sector Information and Support Services – An array of information services exist in Wales including telephone, web and face to face support in a variety of settings including hospital, library and community. These services have significant potential to complement information provision by health care professionals and provide additional support to individuals who may struggle to access and understand the information they require. However, evidence suggests that usage of information services is currently limited and raises questions as to the extent to which services are integrated within care pathways and patients are consistently signposted to services by healthcare professionals.

## Recommendations

15. As this response reveals, there are currently significant challenges to the effective provision of high quality supported cancer information in Wales and thus the ability of Local Health Boards to achieve the expected outcomes as stated in the Cancer Delivery Plan. In response to this challenge, the NCPIS project **advocates a strategic all-Wales approach** to cancer patient information in Wales, as a pathfinder for other conditions. This approach should be underpinned by five key areas;
- agreement on sharing content;
  - development of quality standards;
  - development of a cancer information portal;
  - a skills framework to support healthcare professionals enable access to health information; and
  - the integration and consistent usage of community assets such as libraries and community information services within care pathways.
16. The NCPIS project suggest that a national focus on patient information is needed to support the implementation of the recommendations of the project

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<sup>9</sup> Walters, C. (2013). *National Cancer Patient Information Strategy - Current Services Review*. Cardiff: Public Health Wales/Macmillan Cancer Support

and to ensure improved outcomes in this key area for patient engagement, experience and safety.

**ANNEX A Table 1: Results of Welsh Health Boards and Trusts in relation to key patient information questions**

Question	Abertawe Bro Morgannwg	Aneurin Bevan	Betsi Cadwaladr	Cardiff and Vale	Cwm Taf	Hywel Dda	Velindre	Wales
Q14 Given easy to understand information regarding the type of cancer	59%	62%	64%	62%	59%	61%	65%	62%
Q19. Definitely told about future side effects	52%	58%	53%	54%	53%	51%	61%	55%
Q60. Staff definitely gave family all information needed	52%	61%	61%	55%	53%	53%	61%	57%

ANNEX A Table 2: Results in relation to key information questions by tumour type

Question	breast	Colorectal /lower gastro	lung	prostate	Brain /CNS	gynaec ological	Haem atolog ical	Head and neck	Skin	Upper gastro	urologic al	sarcoma
Q13 completely understood the explanation of what was wrong	81%	78%	75%	80%	61%	73%	56%	77%	68%	68%	75%	63%
Q14.Given easy to	69%	62%	57%	78%	32%	49%	66%	50%	60%	48%	57%	34%

understand written information about the type of cancer												
Q19 Definitely told about possible future side effects of treatments	58%	56%	55%	65%	64%	52%	52%	55%	44%	49%	45%	58%

Source: Wales Cancer Patient Experience Survey 2014

### 3 Improving information and working together

#### Progress made in implementing the Cancer Delivery Plan in Wales

#### The Welsh Cancer Intelligence and Surveillance Unit (WCISU)

WCISU is responsible for the national cancer registry for the resident population of Wales wherever diagnosed or treated. Our primary role is to provide Wales with information on the trend and analysis of cancer incidence, mortality and survival. Increasingly we are providing additional analysis such as stage at diagnosis and act in an information and advisory capacity regarding the cancer health intelligence of the Welsh population. The latest official statistics using 2012 diagnosis data was published on 9<sup>th</sup> April 2014. A summary report of population cancer incidence, mortality and survival "*Cancer in Wales*" is attached for information.

#### Incidence

- The number of diagnoses of cancer fell in 2012; however the general trend over the past ten years has been increasing.
- Men continue to have a higher number of cancers diagnosed compared to women.
- Age is a major risk factor for a cancer diagnosis.
- The incidence rate of cancer is a fifth higher in the most deprived areas of Wales compared to the least deprived.
- Lung cancer is one of the most common cancers in Wales. Although it has shown a slight decreasing trend overall, numbers in women increased by over a third in the last ten years. The annual number of lung cancer cases in women is now approaching that in men.

#### Mortality

- Mortality rates for all cancers continue to decrease.



- Lung cancer was the most common cancer death cause in Wales in 2012 and is more than colorectal and breast cancer deaths combined.
- Mortality is now 50% higher in the most deprived areas of Wales compared to the least deprived areas.

## Survival

- Survival is relatively poor for Wales in comparison with Europe; however Wales has shown the fastest improvement in recent survival rates of all the UK countries.
- Cancer survival is worse in men compared to women.
- There is a large gap in five year relative survival rates in Wales for those living in the most deprived areas compared to the least deprived.
- There is large variation in survival rates between different cancer types; the survival rate is very low for cancer of the liver, lung and pancreas and is high for cancer of the testes, breast, melanoma and prostate.
- The EURO CARE 5 study results, published in December 2013, show that the UK and Ireland have amongst the lowest survival rates for most cancers along with Denmark and Eastern European countries. There are particularly poor survival rates for many smoking related cancers across Europe, but especially in Wales and the rest of the UK.

## Stage at diagnosis

- WCISU has provided the stage at diagnosis analysis for the Cancer Delivery Plan annual report using the timeliest data source, Canisc; an activity based clinical management system used by MDTs across Wales.
- Clinical teams across Wales are awaiting the development of Canisc to support the collection of stage at diagnosis for all cancer sites in accordance to the latest international staging classifications.

- There has been an overall improvement in the completeness of stage at diagnosis over the last two years. Completeness is variable across tumour sites; lung, breast and colorectal have high completeness.

### **30 day post treatment mortality**

- WCISU are engaged in the ongoing discussions of the Cancer Implementation Group Information Sub Group to agree and finalise the methodology for 30 day post treatment mortality for a) chemotherapy b) surgery. Resolutions are required to the existing technical difficulties and clinical consensus to move this performance measure forward.

### **Inequalities gap**

- There has been no improvement in decreasing the inequality gap for both cancer incidence and mortality.
- For cancer incidence the deprivation gap increased from 67 per 100,000 population in 2000–2004 to nearly 80 per 100,000 population in 2008 – 2012.
- For cancer mortality the deprivation gap increased from 77 per 100,000 population in 2000–2004 to 79 per 100,000 population in 2007 – 2011.
- Other known risk factors related to deprivation besides age include smoking, alcohol consumption, obesity, low fruit and vegetable intake, low physical activity, sun/UV and sunburn exposure during the life course.