



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

Agencies: Macmillan Cancer Support/Public Health Wales

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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.¹ 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.

¹ Macmillan Cancer Support. (2012). *Local Route Maps*. London: Macmillan Cancer Support.

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 settings². 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 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 need³. 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 costs⁴. 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.

² 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.

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

⁴ 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.

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 service⁵ with the Citizens Advice Bureau suggesting that 1 in 5 of all concerns relate to issues with regards communication and patient information⁶ 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 admissions⁷. 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 involving people in decisions about their healthcare helps to reduce unwarranted variations in treatment⁸. 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

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

⁶ NHS Litigation Authority. (2012). *Factsheet 2: Financial Information*. London: NHS Litigation Authority

⁷ 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.

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

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 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 fully 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 population⁹. 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 and to ensure improved outcomes in this key area for patient engagement, experience and safety.

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

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from National Cancer Patient Information Strategy (NCPIS) Project – CDP 04

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%

Source: Wales Cancer Patient Experience Survey 2014

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

Question	breast	Colorectal/ lower gastro	lung	prostate	Brain/ CNS	gynaeco logical	Haem atologi cal	Head and neck	Skin	Upper gastro	urological	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 understand written information about the type of cancer	69%	62%	57%	78%	32%	49%	66%	50%	60%	48%	57%	34%
Q19	58%	56%	55%	65%	64%	52%	52%	55%	44%	49%	45%	58%

Definitely told about possible future side effects of treatments													
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Source: Wales Cancer Patient Experience Survey 2014