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Committee Clerk,
Health & Social Care Committee,
National Assembly for Wales,
Cardiff Bay, CF99 1NA
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3rd April 2014

Dear Sir / Madam,

Re: Cancer Delivery Plan inquiry

On behalf of Prostate Cancer UK in Wales, please find below a response to the Health & Social Care Committee's inquiry into progress against the Welsh Government's Cancer Delivery Plan.

Prostate Cancer UK is the leading UK charity for men with prostate cancer and prostate problems. We fight to help more men survive prostate cancer and enjoy a better quality of life by:

- **Supporting men and providing information**: Our specialist nurses have time to talk and answer questions about prostate cancer and prostate problems. We provide free printed and downloadable information. Our online community and one-to-one support service connects men and their families with others who know what they're going through.
- **Finding answers by funding research**: We fund research into tests, treatments and the causes of prostate cancer. Over the years, research in this area has been badly underfunded. We are changing this.
- **Leading change to raise awareness and improve care**: With help from our volunteers, we work with the general public, policy-makers and the NHS to raise awareness and get a better deal for men with prostate cancer.

We recently opened our first office in Wales, where we have dedicated staff – including Wales' first prostate cancer specialist nurse – to help men living with prostate cancer. We are working with partner organisations and policy-makers to make sure men in Wales have access to the best treatments available. We are also working with our partners at Movember to fund ground-breaking research led by academics at Cardiff University in a £4.8million study looking at tackling the effects of pelvic radiation.

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

1.1 We have focussed our response to this question on two areas – firstly, the issue of waiting times and performance against waiting time targets for cancer patients, and secondly on some of the specific aspirations set out in the Cancer Delivery Plan and how those aspirations have translated across to prostate cancer.

1.2 **Waiting times**: The Cancer Delivery Plan sets out the aspiration for LHBs to achieve targets for the percentage of people starting definitive cancer treatment. Performance

against the 62- and 31 day targets[1] (for Urgent and Non-Urgent Suspected Cancers respectively) has been reported on regularly, and for urological cancers has often fallen short of the targets (especially for patients on the 31-day route[2]). Concern has also been expressed that the way in which these targets are measured does not always reflect the needs of cancer patients; a concern which we would share.

Prostate Cancer UK welcomes the recent Ministerial Statement[3] setting out a review of the 31-/62-day targets and potential moves towards a "*single patient pathway with waiting times reported from GP referral or from diagnosis depending on the route to diagnosis*". We look forward to contributing to the development of this pathway in due course.

1.3 **Prostate cancer outcome indicators**: The Cancer Delivery Plan sets out a range of outcome indicators in Annex 3, "*Measuring Success*". In our response, Prostate Cancer UK have focussed on those which we consider most important, as follows:

Aspiration in Cancer Delivery Plan	Comments
A slower rise in the rate of increase in the age standardised incidence compared with the projected rise. As many cancers take years to develop following risk factor exposure, there will be a considerable lag in change in risk factor / exposure and change in cancer incidence. (p21)	Prostate Cancer UK are concerned about the fact that incidence rates for prostate cancer in Wales remain significantly higher than they do for the UK as a whole (with an age-standardised incidence rate per 100,000 of 114.0 – compared to the UK average of 104.5). Whilst we recognise that changes to services will take time to deliver results, we would point to the Scottish incidence rate (of just 82.1 cases per 100,000 men) as an example of good practice within the UK.
A reduced gap between the most and least deprived areas of Wales (p21)	See paragraph 2.1 – we do not believe that at present there is sufficient data to make any meaningful comment on this area. We would like to see more information and figures (perhaps provided through WCISU) to give a reflection of prostate cancer levels in different parts of Wales in order to assess the differences in incidence/mortality rates in areas of deprivation.
Incidence rates comparable with the best quartile in Europe (those countries with cancer registration covering whole population) (p22)	For prostate cancer, figures produced by WCISU[4] suggest that Wales compares favourably with other European countries but lies outside of the best quartile in Europe. When examining incidence rates from across Europe, Wales' age-standardised rate by world population (WASR) for is 78.4 (the figure for the UK as a whole is 62.1). Wales therefore has a lower incidence rate (or projected incidence rate) than Ireland (126.3), France (118.3), Norway (115.6) and Sweden (114.2) – but higher than Russia (26.1), Croatia (44.2), Israel (55.0) and Denmark (72.5). However, factors such as access to testing and population demographics can have an impact on incidence rates, so the WASR figures by themselves only tell part of the story.

[1] For full details of the targets and recent performance, see the "NHS cancer waiting times" section of the Welsh Government website: http://wales.gov.uk/statistics-and-research/nhs-cancer-waiting-times/?lang=en

[2] StatsWales (2013) Patients newly diagnosed not via the urgent suspected cancer route starting treatment by tumour site, StatsWales website (accessed 3rd April 2014).

[3] Drakeford, M. (2014) "Written Statement - Improving Cancer Services in Wales", Welsh Government website, published 18th February 2014.

[4] Welsh Cancer Intelligence and Surveillance Unit (2011) *Cancer in Wales, 1995-2009: urological cancers*, Wales: Public Health Wales / WCISU.

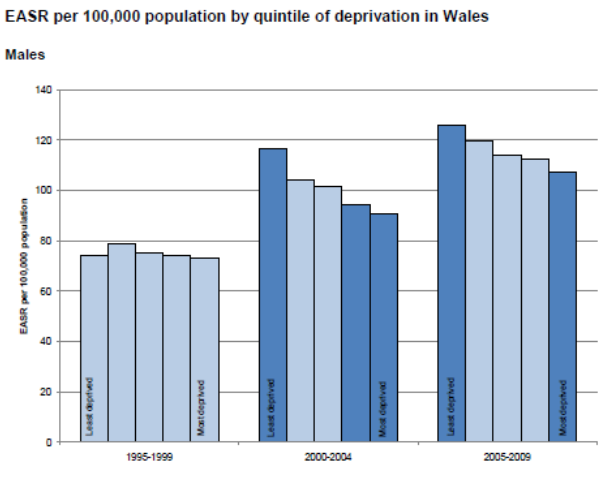
A continued or accelerated fall in death from cancer. (p23)	Mortality rates from prostate cancer in Wales are falling – a trend which has been potentially attributed[5] to better treatment, although improved access to diagnostic measures such as the PSA test (see paragraph 3.2) have also made a contribution.
People of all ages receive well co-ordinated care throughout their cancer journey as a result of being assigned a Key Worker.	See paragraphs 4.2 and 4.3 – we have significant concerns about access to key workers and specialist nurses for men with prostate cancer. The Welsh Cancer Patient Experience Survey highlighted deficiencies in these areas, and we believe that addressing these inconsistencies should be a clear priority for the rest of the lifespan of the Cancer Delivery Plan.

1.4 **LHB cancer delivery plans**: Whilst we welcome the progress being made by LHBs to publish their own cancer delivery plans, we do have concerns about the lack of consistency between the plans. LHBs have all adopted different formats, and the reports go into varying levels of detail; the lack of clarity and consistency makes it difficult to compare the plans. We also believe there is a strong argument that delivery plans should each have a specific section setting out actions which will be taken on major cancers (ie, breast, lung, prostate, bowel) as well as the more general actions which they list overall.

LHBs should adopt the same structure for their cancer delivery plans – and each plan should contain a section on each of the major cancers.

Is progress being made in reducing the inequalities gap in cancer incidence and mortality rates?

2.1 There is insufficient data available to allow detailed comparisons to be made in prostate cancer incidence/mortality rates in the more and less deprived areas of Wales. Information from the Welsh Cancer Intelligence and Surveillance Unit (see graph)[6] suggests that incidence rates between 1995 and 2009 overall have risen, with rates amongst the least deprived groups rising most sharply (a rise which is most likely to be attributable to increased levels of testing), whilst the slowest rise in incidence was amongst the most deprived groups. However, more (and more detailed) data is needed in order to make more meaningful analysis of the situation on deprivation and to draw more detailed conclusions.



We would therefore like to see more information and figures (perhaps provided by WCISU) to give a reflection of prostate cancer levels in different parts of

[5] Welsh Cancer Intelligence and Surveillance Unit (2011) *Cancer in Wales, 1995-2009: urological cancers*, Wales: Public Health Wales / WCISU.

[6] Welsh Cancer Intelligence and Surveillance Unit (2011) *Cancer in Wales, 1995-2009: urological cancers*, Wales: Public Health Wales / WCISU: page 5.

Wales in order to assess the differences in incidence/mortality rates in areas of deprivation.

How effective are cancer screening services and the level of take-up across the population of Wales, particularly the harder to reach groups?

3.1 Our particular interest on this question is in relation to the PSA blood test, which is currently the only tool which could potentially be used to screen for prostate cancer.

3.2 **PSA test**: At present, there is no screening programme for prostate cancer, although men aged 50+ may request a PSA test if they wish. Men with a raised level of PSA in their blood could have a problem with their prostate; this can be a sign of prostate cancer, although it can also be caused by a non-cancerous enlargement of the prostate or an infection or inflammation of the prostate.

Prostate Cancer UK wants to see men being empowered on PSA testing. Men aged 50+ should have all the information they need to make informed decisions on whether a test will benefit them, and should feel able to ask their GP for a PSA test. We also support men over the age of 40 who are at high risk of prostate cancer (men from a BME background, or who have a family history of prostate cancer) being given access to baseline PSA testing so they can monitor any increase in PSA levels. We do not, however, support the introduction of a national screening programme using the PSA test. Although there is evidence[7] that PSA screening can reduce the number of deaths from prostate cancer by around 20%, it has also been shown[8] that around one in six men with a 'normal' PSA level may have prostate cancer, whilst around two-thirds of men with a raised PSA level do not have prostate cancer. These 'false positive' and 'false negative' PSA results can cause men unnecessary anxiety or false reassurance.

We believe that there is not yet enough evidence that the benefits of a national prostate cancer screening programme outweigh the harms. However, we feel that all men at higher risk should be able to choose whether or not to have a PSA test, as long as they have received balanced information about its pros and cons from their GP.

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?

4.1 Our main concern on access to care concerns access to specialist knowledge and information – specifically key workers and specialist nurses. In the recently-published *Wales Cancer Patient Experience Survey*[9], prostate cancer patients reported some very positive experiences. However, the picture was not entirely optimistic.

4.2 **Access to key workers**: On the issue of key workers, only 54% of prostate cancer

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[7] Schröder, F., Hugosson, J., Roobol, M., Tammela, T., Ciatto, S., Nelen, V., Kwiatkowski, M., Lujan, M., Lilja, H., Zappa, M., Denis, L., Recker, F., Berenguer, A., Määttänen, L., Bangma, C., Aus, G., Villers, A., Rebillard, X., van der Kwast, T., Blijenberg, B., Moss, S., de Koning, H. & Auvinen, A. (2012) "Screening and prostate cancer mortality in a randomised European study", *New England Journal of Medicine*, no. 360, pp. 1320-1328.

[8] Thompson, I., Pauler, D., Goodman, P., Tangen, C., Lucia, M., Parnes, H., Minasian, L., Ford, L., Lippman, S., Crawford, E., Crowley, J. & Coltman, C. (2004) "Prevalence of prostate cancer among men with a prostate-specific antigen level ≤ or = 4.0ng per millilitre", *New England Journal of Medicine*, no. 350, pp. 2239-2246.

[9] Welsh Government (2014) *Wales Cancer Patient Experience Survey 2013*, Wales: Welsh Government / Macmillan / Quality Health.

patients were given a name and contact details for their key worker – significantly lower than patients with breast cancer (78%) or lung cancer (80%). Meanwhile, prostate cancer patients also reported the lowest rate (42%) of patients who said they were definitely given enough care/help from health / social services. Prostate cancer patients were also amongst the group least likely to be given information on financial help/benefits by clinical staff, with only 32% of respondents with prostate cancer responding positively to the question. The proportion of positive respondents amongst lung and brain cancer patients was almost double at 62% each.

We therefore have concerns that access to key workers remains poor amongst prostate cancer patients.

4.3 **Access to Clinical Nurse Specialists**: Prostate cancer patients who had access to a Clinical Nurse Specialist were very positive about their experiences, and it is clear that the presence of a CNS makes a substantial positive difference to the perceived quality of cancer services seen by patients, particularly amongst over-75s. Yet the tumour group reporting the lowest levels of CNS support is Urological, where the coverage is only 70%. Moreover, although men with prostate cancer in Wales generally have access to a urology CNS, there is currently only one prostate specialist nurse in Wales.

We would like to see men in Wales given greater access to specialist <u>prostate</u> nurse specialists who can give them detailed expert knowledge on their cancer. Given the extent of prostate cancer incidence across Wales, we believe this is warranted and will have a positive impact on the experiences of men with prostate cancer.

What is 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?

5.1 Whilst examples of good practice exist within Wales with local Health Care Professionals referring patients to our services and information, some reluctance to trust third sector organisations and their ability to deliver quality services still exists. Ensuring patients receive effective person-centred care demands the continual development of key relationships with local HCPs and other third sector organisations which PCUK has set as a priority for its work within Wales.

Is the current level of funding for cancer services appropriate, used effectively and does it provide value for money?

6.1 Paragraphs 4.2 and 4.3 have set out the existing problems Wales faces with helping men to access information and advice services. We believe that additional funding for information, awareness-raising and advice would not only help men with prostate cancer now, but also help to catch future incidences early on and improve outcomes.

Because of the potential health and financial benefits of early diagnosis and support for men with prostate cancer, we would urge the Welsh Government to invest in raising awareness of prostate cancer, particularly amongst men in high-risk groups.

I trust this response is of assistance. I can confirm that Prostate Cancer UK have no objection to our consultation response being made public, and that we would be more than happy to give oral evidence to the Committee if that was felt to be useful. If you require any further information, please do not hesitate to contact me.

Yours faithfully,

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