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 Royal College of Physicians Wales - CDP 08



Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan RCP (Wales) consultation response

About us

The Royal College of Physicians (Wales) plays a leading role in the delivery of high quality patient care by setting standards of medical practice and promoting clinical excellence. We provide physicians across the world with education, training and support throughout their careers. As an independent body representing more than 29,000 fellows and members worldwide, including 1,000 in Wales, we advise and work with government, the public, patients and other professions to improve health and healthcare.

Amdanom ni

Mae Coleg Brenhinol y Meddygon (Cymru) yn arwain y ffordd o ran darparu gofal o ansawdd uchel i gleifion drwy osod safonau ar gyfer arferion meddygol a hybu rhagoriaeth glinigol. Rydym yn darparu addysg, hyfforddiant a chefnogaeth i feddygon ledled y byd drwy gydol eu gyrfa. Fel corff annibynnol sy'n cynrychioli mwy na 29,000 o gymrodorion ac aelodau ym mhedwar ban byd, gan gynnwys 1,000 yng Nghymu, rydym yn cynghori ac yn gweithio gyda'r llywodraeth, y cyhoedd, cleifion, a gweithwyr proffesiynol eraill i wella iechyd a gofal iechyd.

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From the RCP vice president for Wales O'r is-lywydd yr RCP dros Gymru **Dr Alan Rees MD FRCP**

> From the RCP registrar O'r cofrestrydd yr RCP Dr Andrew Goddard FRCP

Friday 04 April 2014

Dear committee,

Thank you for the opportunity to respond to your inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan. We would also like to thank the Association of Cancer Physicians for their help in drawing up this response.

The Royal College of Physicians (RCP) represents doctors in Wales and across the world working medical oncology, that is, physicians trained in the management of cancer. Their main area of expertise is in the systemic or drug treatment of cancer using chemotherapy, hormonal therapy and, increasingly, new molecular targeted therapy. Medical oncology also has a strong research basis: most medical oncologists are involved in clinical trials and many will have an academic post.

Overview

- The RCP strongly welcomes the improvements outlined in the recent Cancer Delivery Plan annual
 report for 2013, especially improved survival rates at 14 per cent for one year, and 15 per cent for
 five year survival, with Wales showing the greatest increase of all four UK nations in recent years.
 However, there is still a great deal more to be done and cancer survival in Wales remains lower
 than the European average for most common cancers. Below we have outlined some of the areas
 from the cancer delivery plan itself which still need further work.
- 2. On preventing cancer, our physicians told us that there had been patchy developments made by local health boards. The overall activity was not overarching or strategic, and not enough work was being done through networks. However, there were some good local examples of best practice. On detecting cancer quickly, our physicians highlighted some capacity and compliance issues for bowel cancer screening at local health board level. Furthermore, we found that on early diagnosis, local health boards had made very little progress, with physicians reporting poor data and information, poor development of primary care oncology, and poor collaboration between primary and secondary care.
- 3. On delivering fast, effective treatment and care, we found that local health boards had made only patchy progress. There were some improvements in some areas, but physicians felt that there had been a lack of strategic planning and delivery for cancer treatment by health boards.
- 4. On **meeting people's needs**, our fellows and members told us that there was very little clarity over policy and strategic planning by local health boards in this area. There was little to no policy on key workers and care planning, and there was huge variation in follow up. Furthermore, our

- physicians judged that Public Health Wales had provided poor support to local health boards to meet the information needs of people affected by cancer.
- 5. On **improving information**, our physicians reported 'frustratingly little progress' by local health boards. They described the progress made by health boards and trusts on data and information, 'patchy at best', and found that Public Health Wales and Velindre NHS Trusts (along with NWIS) had made little progress with providing a cancer clinical information infrastructure, or analysing local health board participation in clinical audit and peer review. Finally, **on targeting research**, they did report some positive work, but argued that this was actually being led by NISCHR, not the health boards or trusts.

Our response to the inquiry terms of reference

6. The Cancer Delivery Plan was published in June 2012. This means that any changes made are highly unlikely to have had sufficient time to be reflected in any of the outcome indicators, so it is very difficult objectively to assess progress. On the terms of reference for the inquiry, it is difficult, if not impossible to answer some of these, either due to short timescales or because of a lack of objective data.

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

- 7. Latest cancer official Welsh Government figures on cancer waiting times show that the 2016 target of 98% of patients starting treatment within 31-days of diagnosis, not via the urgent route, is already being met consistently. Although the target of 95% patients diagnosed via the urgent suspected cancer route, and starting definitive treatment within 62 days of GP referral, has not been attained in any quarter since publication of the cancer delivery plan, data for the latest quarter reached 92%, suggesting progress towards the target, though it is disappointing that only one of 6 LHBs achieved the 95% target.
- 8. We are not aware of any publicly-available statistics on stage-specific data so it is hard to make a worthwhile comment. However, it seems unlikely that there will have been any statistically meaningful downward stage migration in the time since publication of the delivery plan.
- 9. Wales Cancer Research Network figures from September 2013 show that both the 10% and 7.5% targets for cancer trials are already being exceeded in breast and haematological malignancies. Trials in urological cancers are meeting the 10% target, but not the 7.5% interventional target. In colo-rectal cancer trials, the 10% figure is being met overall, though not in two of the three regions of Wales, whilst the 7.5% interventional target is not being met in any of the three. The situation is very similar for lung cancer studies, except that only one of the three regions is not meeting the 10% target. It is disappointing that the details of monitoring of 30-day mortality following chemotherapy and surgery were absent from annex 3 of the cancer delivery plan and we could find no publicly available progress data on these key indicators. We could not find any collated figures, nor trends in the individual tumour types, but overall, there seems to be good, if inconsistent progress, across the main cancer types.
- 10. In the cancer delivery plan, the Wales Cancer Bank was identified as a 'key research facility'. It has played a key role in the success of Cancer Research UK's Stratified Medicine, and is fundamental to continuing to build on Wales' leading role within stratified medicine in the UK. There was an increase in people diagnosed with cancer agreeing to donate to the Wales Cancer Bank from 7.2% in 2011 to 10.6% in 2012 so it is clear that progress is being made towards the target of 20%. However, this is an ambitious number, and we are not convinced that current rates will double by 2016 to meet this target.

11. Furthermore, while this progress has so far been achieved by dedicated research staff, we suggest that achieving the 20% target will require either additional funding and/or a different mechanism for obtaining consent eg introducing an 'opt out' approach of assumed consent to tissue donation for research, or the use of specifically-trained lay consenters.

Progress made in reducing the inequalities gap in cancer incidence and mortality rates

12. This is impossible to assess at this stage. As it is less than two years since the publication of the plan, any changes made have not had enough time to be reflected in any outcome measures. However, cancer service provision is an important determinant of mortality. There have been recent concerns regarding inequality in the provision of medical oncology services for the population of west Wales, and therefore the proposed incorporation of the provision of services for west Wales with Abertawe Bro Morgannwg University Health Board is a welcome prospect which should reduce the inequalities gap.

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

13. We could not find any publicly-available data for the period beyond the publication of the Cancer Delivery Plan. The most recent update of the NSAG for cancer, published in January 2014, contains only data to the end of the 2011/12 period. It would be interesting to know whether figures are available for the take-up of anti-HPV cervical cancer vaccine.

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

14. We are not aware of any systematic barriers to accessing any aspect of cancer services in Wales, aside from expensive novel therapies (see below). We were unable to obtain any official statistics to comment on whether there are inequalities between health boards.

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

15. The work of the third sector (including Tenovus, Cancer Research, Macmillan and Marie Curie Cancer Care) with cancer facilities (such as the Wales Cancer Trials Unit, Wales Cancer Bank and Cardiff Experimental Cancer Medicine Centre) has been crucial in making progress on the cancer delivery plan. The all-Wales Cancer Patient Experience Survey in January 2014 showed very high levels of scores of 'excellent' or 'very good', across the range of services, which suggests a good level of patient-centred care. However, we do have some concerns around the rarer cancers, survivorship issues and disparities between health boards.

Further points to note

16. There is much that is excellent about cancer care in Wales and good progress is being made on a number of fronts. However, we would like to highlight some areas of concern. In particular:

The lack of a Welsh Cancer Drugs Fund

17. Concerns have been raised that inequalities in access to effective novel therapies in Wales may have resulted from the creation of a cancer drugs fund in England since 2010, but not in Wales. The alternative system for accessing in Wales (Individual Patient Funding Requests) is a source of frustration to oncologists in Wales, and our physicians report that it is inconsistently applied by

local health boards. Our physicians asked us to highlight the case of the drug Bevacizumab for patients with ovarian cancer in Wales. In north and south east Wales, the only option for funding is to apply via the IPFR route. Unfortunately, all requests have so far been rejected by these health boards, despite it being widely used throughout Europe and England, and indeed, in south west and west Wales.

Phase I trials

18. In the absence of a cancer drugs fund, Phase I trials are an even more important means for patients to access novel therapies. However, it is disappointing not to have seen any specific mention of Phase I trials of new systemic anti-cancer therapies in the cancer delivery plan. Increasingly, trials are available through Velindre Cancer Centre and UHW, but the numbers are still disproportionately small, relative to comparable major population centres in the UK and to the excellent record of later-phase clinical trials activity in Wales. Phase I cancer trials activity in Wales should be a target for growth, yet there is no specific commitment of public funding for clinical service or clinical research in Phase I cancer trials.

Information technology

19. Accurate, accessible clinical information is crucial to both high quality clinical care and to forefront clinical research. However, the CaNISC electronic record system has failed to keep pace with comparable systems in the UK, and is significantly compromised by being far from universally used in cancer units in Wales. So far, there is no clear evidence that the development of an all-Wales cancer data warehouse has been able to facilitate either research or routine clinical practice.

Acute oncology

20. The provision of acute oncology services is very patchy in Wales and local provision is still almost non-existent in more than one of the larger health boards. There is clearly a long way to go to catch up with equivalent services in England and this must be a target for accelerated progress before 2016.

With best wishes,

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