

National Assembly for Wales
Health and Social Care Committee

**Inquiry into progress made to
date on implementing the Welsh
Government's Cancer Delivery Plan:
Summary**

October 2014



Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales

The National Assembly for Wales is the democratically elected body that represents the interests of Wales and its people, makes laws for Wales and holds the Welsh Government to account.

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The Committee was established on 22 June 2011 with a remit to examine legislation and hold the Welsh Government to account by scrutinising expenditure, administration and policy matters encompassing: the physical, mental and public health of the people of Wales, including the social care system.

Current Committee membership



David Rees (Chair)
Welsh Labour
Aberavon



Alun Davies
Welsh Labour
Blaenau Gwent



Janet Finch-Saunders
Welsh Conservatives
Aberconwy



John Griffiths
Welsh Labour
Newport East



Elin Jones
Plaid Cymru
Ceredigion



Darren Millar
Welsh Conservatives
Clwyd West



Lynne Neagle
Welsh Labour
Torfaen



Gwyn R Price
Welsh Labour
Islwyn



Lindsay Whittle
Plaid Cymru
South Wales East



Kirsty Williams
Welsh Liberal Democrats
Brecon and Radnorshire

Prior to the Committee's consideration of its report, Leighton Andrews AM and Rebecca Evans AM were appointed as members of the Welsh Government.



Leighton Andrews
Welsh Labour
Rhondda



Rebecca Evans
Welsh Labour
Mid and West Wales

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400



WRITTEN CONSULTATION RESPONSES

59

PARTICIPANTS IN
5 REGIONAL
WORKSHOPS

26

PARTICIPANTS IN
5 FOCUS GROUPS
WITH MEMBERS

22

WITNESSES AT **7** FORMAL
ORAL EVIDENCE SESSIONS

13

RECOMMENDATIONS
IN THE REPORT

Chair's introduction

The Health and Social Care Committee looked into the progress that has been made putting into practice the Welsh Government's *Together for Health: Cancer Delivery Plan for the NHS to 2016*. This Plan sets out how the Welsh Government intends to improve cancer prevention, detection, treatment, care and research in Wales.

In the two years since the Plan was prepared, some areas have improved, including research, cancer screening, and caring for people at the end of their lives. However, when we spoke to people who had cancer, their experiences did not always match the aspirations set out in the Plan.

Our report summarises the evidence that we heard during our work. It also makes recommendations to the Minister for Health and Social Services about things that could be done to help make sure that the Plan's goals are achieved and make a difference to people who need cancer services. This summary highlights our recommendations. More detail about each of the recommendations is included in our full report, which is available on our website.¹

I would like to thank everyone who has given their views and their time to the inquiry, especially the cancer patients who told us about their experiences.



David Rees AM
Chair of the Health and Social Care Committee
October 2014

¹ Information about the Committee's inquiry, including a copy of the full report, is on the [inquiry webpage](#).

1. Progress made (recommendations 1 and 2)

What people told us

1. The people and organisations that we talked to about the Plan said that it tried to do the right things to improve cancer care, treatment and outcomes in Wales. However, the cancer patients we spoke to told us that their experiences of cancer services were sometimes very different.
2. Some of the people we spoke to were worried about whether there were enough resources available to do all of the things in the Plan. They were also worried that the deadlines in the Plan might be too short, especially as some of the goals, like improving survival rates, would take a long time to tell if they had been achieved. Others said that there were things missing from the Plan, including surgery and cancer services for children and young people.
3. We also heard that some people had concerns about whether enough was being done to make sure that:
 - health boards are doing what they have committed to do;
 - services do not fall into gaps between health boards' plans or become delayed because of lengthy decision making processes, for example people with less common cancers who may need to access specialised services in another part of Wales;
 - performance management and planning are taking place at a national level to make sure that care and services are available to people across Wales.
4. It can be difficult to find health boards' own plans on their websites, and they are not always written in very plain language, so it can be hard for people to understand what services should be available and how cancer services should work.

What the Minister told us

5. The Minister said that health boards were responsible for doing what they had set out in their plans. He said that he was preparing a standard template for health boards to use in future when setting out their plans for cancer services in their areas. He told us that things were improving, but that people needed to be patient as the Plan was still fairly new.

What we recommended

6. We are concerned about whether there is sufficient leadership to ensure that the Plan's goals are achieved by 2016. We think that if the goals are to be met, there needs to be a body which has clear responsibility, and enough resources, to make sure that the Plan is achieved. Our report recommends that this body, whether a new or existing body, should also be responsible for holding health boards to account on what they have committed to do, and planning ahead for the development of cancer services in the longer term.
7. Our report also recommends that the Minister reminds health boards that they are required to put their plans and reports on their websites and that this information should be easy to find and to understand.
8. For more information, see pages 11 to 16 of our full report.

2. Preventing cancer (recommendation 3)

What people told us

9. The Plan includes a section on preventing people from getting cancer. The people who shared their views with us said that at the moment not enough is done to make sure that people, especially young people and men, know about the risks or symptoms of cancer. Some people said that there was not enough support for the prevention campaigns that had been arranged, including stopping smoking, and encouraging weight loss and exercise.

10. Tenovus told us that there was a link between a lack of awareness of cancer symptoms and people from deprived areas, and that more should be done to encourage people to go to their GP if they were worried.

What the Minister told us

11. The Minister agreed that people did not always go to their GP soon enough, which could be a problem in providing cancer treatment. He said that it was important that people were able to get good information about cancer, and that a website was being thought about to be a single, accurate place to get that information.

What we recommended

12. We were concerned that people were worried about how effective prevention and awareness campaigns were, and think that more should be done to make sure that people know about cancer and feel able to go to their GP. In particular, more needs to be done to raise awareness among men, young people and people from deprived areas.

13. Our report says that the Minister should provide an update after 12 months on how cancer prevention campaigns are being targeted at these harder to reach groups, the timescales, how much they will cost and how he will decide if they have been effective.

14. For more information, see pages 17 to 18 of our full report.

3. Screening (recommendation 4)

What people told us

15. People told us that screening is a good way of identifying people with cancer, and that it can help improve health in a population. There are targets for the numbers of people who should be screened for particular cancers, including breast cancer, cervical cancer and bowel cancer. We were told that the targets are either missed or only just met, but that there were differences in how well the targets are being met for different groups of people. The cancer patients we talked to were worried about the targets being missed. They told us that they thought that more should be done to make sure that people understood why they were being asked to take part in screening and what the benefits could be.

16. Screening programmes in Wales are arranged by Public Health Wales. Public Health Wales told us that it was working with many different organisations to make sure that people knew about screening programmes. It also said that it was working to help people from different backgrounds get access to cancer screening.

What the Minister told us

17. The Minister said that there had been improvements in the uptake of bowel cancer screening, but that it would be challenging to make sure that the progress was sustained. He said that Public Health Wales was working to understand the differences in who took up the opportunities for screening, and why there were differences between men and women, and between people from different backgrounds.

What we recommended

18. We are pleased that the uptake of screening is improving, but concerned that there are still differences between different groups about who accesses screening services. Our report says that the Minister should make sure that Public Health Wales works with as many different organisations as possible to make sure that people can access screening services, and writes to us in 12 months to tell us what has been done.

19. For more information, see pages 19 to 21 of our full report.

4. GP education (recommendation 5)

What people told us

20. We heard that as most GPs do not see very many cancer patients, it can be difficult for them to build up their skills and recognise cancer symptoms. This was worrying for the cancer patients who spoke to us. They said that GPs needed to have good training to recognise symptoms, and to know how to talk to patients about what might be wrong. GPs agreed with this. They said that they do get training at the moment, but it is not often enough, and nurses do not always get the training that they need.

21. Macmillan Cancer Support has prepared tools and information to help GPs spot cancer, and Marie Curie Cancer Care said that it was working with GPs and other medical professionals to make end of life care better.

What the Minister told us

22. The Minister agreed that GPs need to make sure that they keep up to date with developments in diagnosing cancer.

What we recommended

23. Our report says that the Minister should work with the Wales Deanery and the General Medical Council to make sure that awareness of cancer symptoms, early diagnosis and the tools and information available to GPs is included in their training.

24. For more information, see pages 22 to 24 of our full report.

5. Diagnosing cancer (recommendations 6 and 7)

What people told us

25. We were told that it was important for cancer to be diagnosed as early as possible so that it can be treated, and also so that people who do not have cancer do not have to worry. Some cancer patients said they had needed to go to their GP many times or needed to attend Accident & Emergency before they were sent for diagnostic tests, and that they had had to wait too long before they had the tests. The Welsh Cancer Intelligence and Surveillance Unit is doing some work to try to find out more about what happens to patients before they are diagnosed.

26. We were told that some health boards do better than others in meeting waiting time targets. One reason for the difference is that the communication between primary care (GPs) and secondary care (hospitals and specialists) is not always good enough. The Royal College of Nurses said that some health boards had worked together to provide joint services but that not all health boards did this.

27. GPs told us that they did not always know which tests or services were available from different health boards, and that different health boards had different rules about who could get services and how.

What the Minister told us

28. The Minister said that data showed that GPs were referring people for tests in the right way. He told us that early cancer diagnosis was a priority for GPs in 2014-15, and that all GPs were being asked to review their cases of lung and gastrointestinal cancer to see how things could be done better. The Minister also said there would be £6.5million extra in 2014-15 to help improve diagnostic services.

What we recommended

29. Our report says that the Minister should ask each health board to make sure that GPs understand the services available in their areas, and how to refer people. We also say that the Minister should make a statement about cancer diagnosis, to set out his strategy and explain the difference made by the additional money.

30. For more information, see pages 24 to 28 of our full report.

6. Access to new treatments (recommendation 8)

What people told us

31. Cancer patients said it should not be difficult for them to get treatments or medicines they needed. Some had used the Individual Patient Funding Request process (which patients in Wales can use to apply for treatments which are not available to everyone) and said it could be lengthy and confusing, and make inconsistent decisions.

32. Health professionals agreed that the application process was not always good at ensuring fair access to cancer treatments, especially if a small group of patients all applied for the same treatment or new treatments became available. They said that doctors used the process in different ways and health boards made decisions differently which could cause a delay in patients getting treatments and cause anxiety.

33. Some people thought that it would be better to have one national panel to make decisions for everyone in Wales. Others were concerned that this could cause more delays for patients because of the number of requests the panel would need to consider.

What the Minister told us

34. The Minister said that the process for applying for funding for treatments for individual patients had been reviewed earlier this year, and that he had held a public consultation. He planned to set out in the autumn what he would do in response to this review. He told us that the review group did not think that one national decision making panel for Wales was a good idea. Instead, the All Wales Therapeutic and Toxicology Centre² could play a bigger role in making sure that if several people apply for the same medicine, consideration could be given about whether that medicine should be more widely available.

What we recommended

35. Our view is that in order to make sure that applications for individual patient funding from people across Wales are considered fairly, the Minister should establish a national panel.

36. For more information, see pages 32 to 35 of our full report.

² The All Wales Therapeutic and Toxicology Centre provides prescribing and medicine management services to the NHS in Wales.

7. Key workers and care plans (recommendation 9)

What people told us

37. The Plan says that every cancer patient should have a written care plan and a key worker to support them. Very few of the cancer patients that we spoke to had written care plans. Those who had key workers spoke highly of them, but said that they were often overworked. Not all of the patients that we spoke to knew that they were meant to have a key worker or who their key worker might be. People with less common cancers, like neuroendocrine tumours, were less likely to have key workers or clinical nurse specialists (who often fill the key worker role).

38. Health boards and professional organisations were very positive about the role of key workers, but said that there were no structures in place to develop, fund or manage the role. We also heard that there was not enough money or time for training clinical nurse specialists.

What the Minister told us

39. The Minister agreed that having a key worker was often linked to having a good experience of cancer treatment. He did not think that it was always clear enough who should be a key worker, and said that he was going to give more guidance to health boards. He said that a survey of cancer patients showed that most thought that they had enough information about their treatment, even if it was not written down in a care plan. He told us that work was being done to make sure that cancer patients got the information that they needed in the way that they wanted.

What we recommended

40. It is important that cancer patients have a key worker to give them advice, support and information, and we are concerned that is not currently the case. We are also concerned that so few cancer patients say their care plans are written down. Different people will want their information in different ways, but as a minimum, written care plans should be provided. Our report says that the Minister should update us in 12 months on what has been done to make sure that every cancer patient has a key worker and a written care plan.

41. For more information, see pages 39 to 42 of our full report.

8. Aftercare (recommendation 10)

What people told us

42. People said that more people were being diagnosed with, and living with cancer, and that they were concerned that not enough attention has been given to meeting people's on-going medical and non-medical needs after their cancer treatment has finished. Cancer patients told us that in particular they did not think that there was enough understanding of the fear that cancer might come back. They thought that GPs and community nurses could do more to help provide aftercare for people in their own communities.

43. We were told by health care professionals that they are trying to find better ways of meeting people's needs for follow up care and treatment, and to help people get quick access to the care that they need.

What we recommended

44. We think that it is important that good quality aftercare should be available if patients need it following the end of their treatment. Our report says that the Minister should set out what will be done, when and how much it will cost, to improve aftercare services that meet patients' medical and non-medical needs.

45. For more information, see pages 42 to 43 of our full report.

9. End of life care (recommendation 11)

What people told us

46. People said that end of life care in Wales was a good example of the NHS and voluntary organisations working together to meet patients' needs. Health boards told us that the services had got better in recent years because more money had been provided and there was more recognition of the role of end of life care.

47. However, some people were worried that not everyone is able to get end of life care when they need it. Marie Curie Cancer Care told us that people from more deprived areas seem to be less likely to get well-planned end of life care.

What the Minister told us

48. The Minister said that the Welsh Government was already taking action to make sure that everyone could get end of life care if they needed it.

What we recommended

49. We are pleased that progress has been made in making sure that high quality end of life care is available, but concerned that not everyone is able to access the services. Our report says that the Minister should set out what will be done, when, and how much it will cost to make access to end of life care more equal, and that he should write to us in 12 months to tell us what impact the actions have had.

50. For more information, see pages 44 to 45 of our full report.

10. Electronic record system (“CaNISC”) (recommendation 12)

What people told us

51. Health boards said that the systems used to record information about patients do not record information adequately about patients with advanced or secondary diseases. Other people agreed that the system was not good enough, and said that it needed to be updated to meet research needs. The NHS Wales Informatics Service, which is responsible for information technology systems in the NHS in Wales, told us that it was working on upgrading the CaNISC system.

What we recommended

52. We are concerned that the electronic record system cannot record information about secondary diseases or meet the needs of researchers. While we welcome the news that the NHS Wales Informatics Service plans to upgrade the CaNISC system, our report recommends that the Minister should make sure that this is done as a priority.

53. For more information, see pages 47 to 48 of our full report.

11. Stratified medicine (recommendation 13)

What people told us

54. Stratified medicine means treatments which are designed using information about a patient's genetics and the particular tumour they have in order to try to reduce side effects and make the treatments more effective. The Plan says that health boards and NHS trusts should work with universities and researchers to develop this form of medicine. We were told that some progress is being made, but some people said that they were worried that the systems and tests which were needed to support stratified medicine were not included in the Plan. Some said that the Minister needed to have a policy or strategy to make sure that the NHS in Wales planned ahead for the right services to be in place and the right patients chosen to use stratified medicine.

What we recommended

55. We agree that if good use is to be made of stratified medicine, and Wales is to be able to attract people doing research on the medicines and technologies, there needs to be a joint approach. Our report says that the Minister should set out clearly what is going to be done and when to develop and deliver stratified medicine in Wales.

56. For more information, see pages 53 to 54 of our full report.

12. Other issues raised during our inquiry

57. In our full report we also comment on the following issues which were raised with us during our work:

- whether bowel scope screening should be available in Wales (see pages 21 to 22)
- recruitment in the NHS in Wales and the impact on cancer services (see pages 31 to 32);
- the use of new technologies in diagnosing and treating cancer (see page 36);
- the development of a single cancer information hub for Wales to make sure that people can find good quality and easy to understand information about cancer (see pages 37 to 39);
- the changes made to the iWantGreatCare survey (see pages 45 to 46);
- what the draft EU Data Protection Regulation might mean for cancer research in Wales (see pages 49 to 50);
- the targets for involvement in clinical trials in Wales (see pages 51 to 53)
- the effect that the changes to the funding provided by the National Institute for Social Care and Health Research will have on cancer research in Wales (see pages 51 to 53).