National Assembly for Wales
Health and Social Care Committee

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

October 2014

Cynulliad Cenedlaethol Cymru
National Assembly for Wales

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Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

Tel: 029 2089 8403
Fax: 029 2089 8021
Email: HSCCommittee@wales.gov.uk
Twitter: @seneddhealth

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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
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John Griffiths
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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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Chair's foreword

The Welsh Government's *Together for Health: Cancer Delivery Plan for the NHS to 2016* provides a framework of actions for cancer prevention, detection, treatment, care and research, and commits the Government to hold health boards and NHS trusts to account for the outcomes they deliver for their populations and their contribution to the overall health of the people of Wales.

We acknowledge and welcome the progress that has been made in the first two years of the Plan in challenging areas such as research, screening and end of life care. However, we are concerned that the cancer patients we spoke to did not always feel that the Plan's aspirations were translated into the care and support that they received.

Our report makes recommendations to the Minister which, if accepted and implemented, we believe will assist in the achievement of the Plan's aspirations. Perhaps the most important of these responds to the concerns we heard that without stronger national leadership there is a risk that the Plan's aspirations will not be realised by 2016. On that basis we ask the Minister to ensure that there is a body with a clear remit, and the necessary resources, to provide drive and leadership at a national level, and hold health boards to account for the delivery of their local plans. This body must also look ahead, and plan strategically to ensure that the cancer services delivered in years to come meet the needs of an ageing population, make use of the increasing range of medical technologies and treatments, and are sustainable within ever-tightening resources.

I would like to thank all of those who have contributed to our inquiry, and who took the time to provide written and oral evidence. In particular I am grateful to the cancer patients who shared their insight and experience during our workshops and focus groups.

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

The Committee's recommendations

The Committee's recommendations to the Welsh Government are listed below, in the order that they appear in this report. Please refer to the relevant pages of the report to see the supporting evidence and conclusions.

The Committee recommends:

Recommendation 1. That the Minister for Health and Social Services ensures that there is a body which has the remit and resources to drive the delivery of the Welsh Government's Cancer Delivery Plan at a national level, hold health boards to account on the delivery of their local plans and undertake strategic forward planning of cancer services. (Page 15)

Recommendation 2. That the Minister for Health and Social Services reminds health boards of the requirement in the Cancer Delivery Plan for them to publish their local cancer delivery plans and annual reports on their websites to enable the public to hold them to account, and asks health boards to make this information prominent and easy to locate. (Page 16)

Recommendation 3. That the Minister for Health and Social Services provides an update to the Committee after 12 months on the strategy for targeting cancer prevention campaigns at harder to reach groups and socioeconomically deprived areas, to include information on the intended timescales, financial implications and how the effectiveness of campaigns will be measured. (Page 18)

Recommendation 4. That the Minister for Health and Social Services provides an update to the Committee after 12 months on the steps that have been taken to ensure that all opportunities are explored and taken up to promote screening among harder to reach groups, and the impact of such promotion on screening uptake. (Page 21)

Recommendation 5. That the Minister for Health and Social Services works with the Wales Deanery and the General Medical Council to ensure that GPs' training and continuing professional development raises awareness of cancer symptoms, early diagnosis, and the tools and resources available to support GPs in their roles. (Page 24)

Recommendation 6. That the Minister for Health and Social Services requires health boards to take steps to ensure that GPs have clarity about the services available and the referral arrangements in their areas. (Page 27)

Recommendation 7. That the Minister for Health and Social Services makes a statement on cancer diagnosis, to include diagnostic treatments, the Minister's strategy to support diagnostics across Wales, and the impact and value for money resulting from the additional funding provided in 2014-15. (Page 28)

Recommendation 8. That to ensure that there is consistency and equity across Wales, the Minister for Health and Social Services establishes a national panel to consider and make decisions about Individual Patient Funding Requests. (Page 35)

Recommendation 9. That the Minister for Health and Social Services provides an update after 12 months to the Committee on the actions taken, including the guidance he has committed to provide, and progress made by health boards to ensure that the requirements in the Cancer Delivery Plan for all patients to be assigned a key worker and provided with a written care plan are met by 2016. (Page 42)

Recommendation 10. That the Minister for Health and Social Services sets out the actions which will be taken, with associated timescales and financial implications, to address the aftercare needs of the increasing numbers of people living with cancer in the longer term. Such actions should take account of patients' medical and non-medical needs. (Page 43)

Recommendation 11. That the Minister for Health and Social Services sets out the actions which will be taken, with associated timescales and financial implications, to reduce inequities in access to end of life and palliative care, and provides the Committee with an update after 12 months on the impact of those actions. (Page 45)

Recommendation 12. That, as a matter of priority, the Minister for Health and Social Services considers the development or replacement of the Cancer Network Information System Cymru, and ensures that both clinical and research priorities are taken into account, including secondary episodes of care. (Page 48)

Recommendation 13. That the Minister for Health and Social Services sets out the actions which will be taken, with associated timescales, to ensure the development and service delivery of stratified medicine in Wales. (Page 54)

1. Introduction

The Cancer Delivery Plan

1. The Welsh Government published *Together for Health: Cancer Delivery Plan for the NHS to 2016* ("the Plan") in June 2012.[1] The Plan provides a framework for action by health boards ("HBs") and NHS trusts on the outcomes that they deliver for their populations and their contribution to the overall health of the people of Wales. The Plan also outlines NHS performance measures which have been developed to measure how successful cancer detection, treatment and care are for people in Wales.

The Committee's inquiry

2. The Health and Social Care Committee ("the Committee") agreed on 30 January 2014 to undertake an inquiry into progress made to date on implementing the Plan at the halfway stage of its 4-year timescale.[2] In assessing the progress made, the Committee agreed to consider:

- whether Wales is on course to achieve the outcomes and performance measures, as set out in the Plan, by 2016;
- progress made in reducing the inequalities gap in cancer incidence and mortality rates;
- the effectiveness of cancer screening services and the level of take-up across the population of Wales, particularly the harder to reach groups;
- 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;
- 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; and
- whether the current level of funding for cancer services is appropriate, used effectively and provides value for money.

[1] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[2] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-03-14: Minutes*, 30 January 2014

3. The Committee is grateful to all those who contributed to its inquiry through:

- formal oral evidence (a list of those who provided oral evidence may be found at Annex A);
- a public consultation to which 40 responses were received (a list of which may be found at Annex B); and
- informal engagement activity arranged in collaboration with Macmillan Cancer Support, including regional workshops and focus groups with cancer patients and others with direct experience of cancer services (details of the activity undertaken may be found at Annex C).

4. To help those who have contributed keep up to date with the inquiry as it progressed, the Committee made use of social media platforms, including Twitter,[3] YouTube[4] and Storify.[5]

[3] The Committee tweets as @seneddhealth and @iechydsenedd
[4] A playlist of relevant videos is available at AssemblyCynulliad on YouTube.com
[5] A storify of the inquiry is available at @AssemblyWales on Storify.com

2. Progress made on implementing the Cancer Delivery Plan

Progress made on implementing the Plan

> *"The Cancer Delivery Plan sets out [the Minister's] expectations of NHS Wales, working with its partners, in tackling cancer up to 2016."*[6]

5. The evidence that the Committee received demonstrated that the Plan was generally welcomed, and that its aspirations and aims were thought to be appropriate to support improvements in cancer care, treatment and outcomes in Wales.[7] Cancer Research UK ("CRUK") said that the Plan provided "a unique opportunity" to draw together the elements of the cancer pathway, including research, when considering service delivery priorities.[8]

6. Cancer patients who participated in the Committee's focus groups welcomed the aspirations set out in the Plan, but said that those aspirations were not reflected in their experiences as patients.[9] Other witnesses were concerned about whether there was sufficient capability and capacity to support the implementation of the Plan.[10] Some evidence suggested that key elements were missing, such as sufficient detail on diagnosis, treatment and surgery,[11] and cancer services for children and young people.[12]

7. The Committee also heard that some witnesses had concerns about whether enough had been done to ensure HB compliance with the principles set out in the Plan,[13] and whether the timescales were appropriate given the longer term nature of some of the targets, for example cancer survival rates.[14]

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[6] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[7] National Assembly for Wales, Health and Social Care Committee, *RoP, [paras 5, 6, 112, 205, 246, 266, 268, 400]*, 12 June 2014
[8] Ibid, *RoP [para 246]*, 12 June 2014
[9] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[10] Ibid, *RoP [para 5]*, 12 June 2014
[11] Ibid, *RoP [para 112]*, 12 June 2014
[12] Ibid, *Consultation response CDP27 CLIC Sargent*
[13] Ibid, *RoP [para 268]*, 12 June 2014
[14] Ibid, *RoP [para 400]*, 12 June 2014

Leadership

8. Witnesses supported the development of local plans to enable HBs to take account of the particular needs of their populations when planning and delivering cancer services.[15] However, the Committee heard that these local action plans and reports were prepared in isolation, contributing to variation in patient support and care.[16] Witnesses felt that there was a need for greater leadership at a national level to provide clear direction, ensure that HBs work together to share good practice, and provide equal access and services to patients across Wales.[17] HBs agreed with this, saying that the particular nature of cancer meant that there was a need for "a more integrated approach at a national level" in order to overcome clinicians' concerns about unnecessary local variation.[18]

9. In addition, the Royal College of Radiologists ("RCR") told the Committee that there was uncertainty about which of the current structures – the Cancer Implementation Group ("CIG"), the Welsh Health Specialised Services Committee ("WHSSC"), or the cancer networks – was the correct route for ensuring that there was a national response to strategic issues and the elements of cancer services which sit outside the Plan, for example new services or new hospitals.[19]

10. The Wales Cancer Alliance ("WCA") echoed this, and said that it wanted to see a greater degree of national leadership to provide "an overarching drive to implement the plan fully within the time frame".[20] In order to provide drive, performance monitoring and accountability, the WCA thought that there needed to be:

> "another structure, which could be the Cancer Implementation Group, but that Group needs much greater resources in order to deliver the Plan."[21]

11. Tenovus agreed with the establishment of an overarching body, which it said would also assist third sector organisations by providing a single point of contact when operating all-Wales systems and

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[15] National Assembly for Wales, Health and Social Care Committee, *RoP [para 113]*, 12 June 2014
[16] Ibid, *RoP [para 277]*, 12 June 2014
[17] Ibid, *RoP [para 26]*, 12 June 2014
[18] Ibid, *RoP [para 406]*, 12 June 2014
[19] Ibid, *RoP [para 120]*, 12 June 2014
[20] Ibid, *RoP [para 272]*, 12 June 2014
[21] Ibid, *RoP [para 281]*, 12 June 2014

structures.[22] Such an approach was supported by the Wales Cancer Intelligence and Surveillance Unit ("WCISU"), which said that:

> "On an all-Wales basis, I have heard mention of a single cancer network that would perhaps coordinate the health boards. I can see that being sensible and wise."[23]

12. When asked whether a 'cancer czar' approach might be beneficial, Dr Tom Crosby of the South Wales Cancer Network ("SWCN") and Velindre NHS Trust ("VNHST") said that:

> "it certainly is not about a person; it is about having a structure around it. […] What it really needs is to tie in the health boards at a level that has authority, so that, if it is not chief executives, it is directors of planning or directors of finance, who see the benefits of coming together and planning services together, rather than individually, be it for individual medicines, technologies or services, all with the same implications."[24]

13. However, the Minister told the Committee that there was a need for patience, and time to allow the structures and current ways of working under the Plan time to "mature and deliver". He said that the Plan had:

> "drawn out of the service strong clinical leadership in the cancer field, and that you can see the results of that strong leadership in the achievements that there have been against the delivery plan over the two years."[25]

Monitoring and accountability

14. The Committee heard that witnesses had concerns about the structures that are in place to hold HBs to account. The British Association of Surgical Oncologists ("BASO") told the Committee that HBs answered to the CIG on a regular basis in relation to their local

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[22] National Assembly for Wales, Health and Social Care Committee, *RoP [para 356]*, 12 June 2014
[23] Ibid, *RoP [para 7]*, 18 June 2014
[24] Ibid, *RoP [para 422]*, 12 June 2014
[25] Ibid, *RoP [paras 9-10]*, 26 June 2014

plans,[26] but CRUK said that more needed to be done to hold HBs to account.[27]

15. Witnesses were critical of the lack of transparency of HBs' plans, saying that there was insufficient challenge, that the plans were difficult to access on HB websites, and that there was not enough clinical engagement or awareness of the plans.[28] Hamish Laing of Abertawe Bro Morgannwg University Health Board ("ABMUHB") told the Committee that more thought needed to be given to the way in which the plans were written, to ensure that they were accessible and citizen-focused.[29]

16. Mr Laing said that it was important that there was a degree of oversight of HBs' delivery of their plans, but that there should also be local accountability within each health board.[30] BASO welcomed the introduction of peer review in Wales in the last two years. It said that the publication of the review results had been a positive step forward, but that it would like to see the programme expanded to bring in expertise from outside Wales.[31]

17. Macmillan Cancer Support told the Committee that responsibility for holding HBs to account on the delivery of their plans was ultimately a matter for the Welsh Government, but that there was a need for greater accountability at a national level for performance monitoring and for planning ahead, as well as local action planning, scrutiny and transparency.[32]

18. Dr Tom Crosby echoed the need for accountability and forward planning, particularly in the context of an ageing population, asking:

> "Who is planning for the huge epidemic of cancer for the next 20 or 30 years? We are already seeing vacancies in pathology, radiology and now even in oncology, and I do not think that

[26] National Assembly for Wales, Health and Social Care Committee, *RoP [para 113]*, 12 June 2014
[27] Ibid, *RoP [para 249]*, 12 June 2014
[28] Ibid, *RoP [para 465]*, 12 June 2014
[29] Ibid, *RoP [para 468]*, 12 June 2014
[30] Ibid, *RoP [paras 414-5]*, 12 June 2014
[31] Ibid, *RoP [paras 147-8]*, 12 June 2014
[32] Ibid, *RoP [paras 287 and 292]*, 12 June 2014

there is any long-term strategic planning to avoid those for the future."[33]

19. The Minister said that accountability and responsibility for cancer services was "shared and dispersed", and that he:

> "did not want health boards always looking up to somebody apparently above them and reporting to them to find out whether they are doing the right thing."[34]

20. He agreed that there was variation in HBs' plans, and said that a national template was being prepared to support reporting. He told the Committee that this would help to identify whether the variations reported at present were due to inconsistent reporting, or genuine differences in performance.[35]

The Committee's view

21. The Committee notes that stakeholders welcome the Plan and its aspirations. However, the Committee is concerned that witnesses do not consider that there is sufficient leadership to drive the effective delivery of the Plan and achievement of its goals. The introduction of peer review is to be applauded, but the Committee would like to see it extended to draw on expertise from outside Wales.

22. The Committee agrees that there is a need to strengthen the structures for the delivery and implementation of the Plan to ensure that there is adequate leadership, monitoring and accountability to drive progress. The structures must also support cross-health board collaboration and joint planning of services which cannot be delivered at a HB level, for example services for less common cancers.

Recommendation 1: The Committee recommends that the Minister for Health and Social Services ensures that there is a body which has the remit and resources to drive the delivery of the Welsh Government's Cancer Delivery Plan at a national level, hold health boards to account on the delivery of their local plans and undertake strategic forward planning of cancer services.

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[33] National Assembly for Wales, Health and Social Care Committee, *RoP [para 408]*, 12 June 2014
[34] Ibid, *RoP [para 22]*, 26 June 2014
[35] Ibid, *RoP [para 19]*, 26 June 2014

23. The Committee welcomes the planned introduction of a standard national template for HBs' individual plans, but also believes that consideration must be given to ensuring that plans are comprehensible and accessible. The standard template should be drafted so as to help HBs report on nationally identified priorities, as well as their local priorities, and to ensure that no element of cancer services falls between the gaps. The Committee also notes that while the Plan requires HBs to publish their individual local plans, they are frequently difficult to locate on HBs' websites.

Recommendation 2: The Committee recommends that the Minister for Health and Social Services reminds health boards of the requirement in the Cancer Delivery Plan for them to publish their local cancer delivery plans and annual reports on their websites to enable the public to hold them to account, and asks health boards to make this information prominent and easy to locate.

3. Delivery plan area 1: preventing cancer

Public awareness

> *"People are aware of and are supported in minimising their risk of cancer through healthy lifestyle choices."*[36]

24. In written and oral evidence the Committee heard from a number of witnesses that more needed to be done to raise the awareness of cancer symptoms and risks, particularly among young people. In addition, it was felt by some that with regard to stop smoking campaigns, support had been sparse in places, and with regard to weight management, dietetics and exercise on prescription programmes, there had been a significant lack of primary and community support.[37]

25. Cancer patients who participated in the Committee's focus groups told Members that there was a need to do more to raise awareness of cancer symptoms and risks, especially among young people. The patients also said that there could be a disproportionate focus on cancers affecting women, and that men needed to be encouraged to be more proactive about their health.[38]

26. Tenovus stated that international cancer benchmarking had demonstrated that there was a need in Wales to empower patients to go to their GPs when they have concerns, and that:

> "lack of knowledge and health literacy, which is a massive problem in Wales, is compounding the issue of social deprivation and the high instances of cancer in hard-to-reach groups."[39]

27. The Minister acknowledged that late presentation by patients to their GPs was "probably the single largest difficulty in getting effective cancer treatment".[40] To address this, the Minister cited the importance of the prevention agenda, and the provision of authoritative and

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[36] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[37] National Assembly for Wales, Health and Social Care Committee, *Consultation response CDP14 Royal College of General Practitioners*
[38] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[39] Ibid, *RoP [para 362]*, 12 June 2014
[40] Ibid, *RoP [para 52]*, 26 June 2014

accessible information. He told the Committee that the CIG was considering the establishment of a "single cancer hub for Wales" as a source of reliable information and advice.[41]

The Committee's view

28. The Committee notes that some stakeholders had reservations about the implementation and effectiveness of some of the present prevention campaigns. It agrees that there is a need to empower patients, particularly those from harder to reach groups, and to raise their awareness of cancer symptoms.

Recommendation 3: The Committee recommends that the Minister for Health and Social Services provides an update to the Committee after 12 months on the strategy for targeting cancer prevention campaigns at harder to reach groups and socioeconomically deprived areas, to include information on the intended timescales, financial implications and how the effectiveness of campaigns will be measured.

[41] National Assembly for Wales, Health and Social Care Committee, *RoP [para 52]*, 26 June 2014

4. Delivery plan area 2: detecting cancer quickly

Screening programmes

> *"Screening services need to keep pace with the changing evidence of benefit and remain of the highest international standard."*[42]

29. The Plan requires HBs to work with Public Health Wales ("PHW") to deliver screening programmes in line with the recommendations of the Wales Screening Committee, to promote increased uptake of screening, and ensure that there is sufficient capacity in place to treat those referred from screening programmes. The Committee heard that there was a balance to be struck between harm and benefits in relation to screening, both at a population and an individual level.[43]

30. The British Medical Association Cymru Wales recognised the long term benefits of screening for the health of the population. However, it expressed concern about the pressures placed on secondary care treatment services by increasing uptake of screening and identification of diseases. It said that sufficient funding must be targeted to prevent waiting lists building up.[44] Cancer patients shared this concern, and queried whether the system would be able to respond to increasing demand as a result of increased screening or public awareness.[45]

31. The Committee heard that screening uptake targets for breast, cervical and bowel cancers were being missed or only just being met, and that there is significant variation in the uptake of screening services across genders and socioeconomic groups.[46] The cancer patients who took part in the Committee's focus groups were concerned about the low uptake, and thought that more needed to be done to explain to people why they were being asked to take part in screening, and what the benefits could be.[47] CRUK called for work to be undertaken to try to understand the variations in screening uptake,

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[42] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[43] National Assembly for Wales, Health and Social Care Committee, *RoP [paras 23-4]*, 18 June 2014
[44] Ibid, *Consultation response CDP29 British Medical Association Cymru Wales*
[45] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[46] Ibid, *Consultation response CDP36 Public Health Wales*
[47] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014

to identify whether there were any identifiable inequalities or socioeconomic issues, and to plan and carry out targeted public awareness campaigns.[48]

32. PHW told the Committee that it was working with diverse partners including Communities First, HBs, farmers' unions and community pharmacists to promote screening programmes and make sure that people in communities across Wales are aware of the benefits of screening.[49] It said that the PHW Screening Engagement Team was currently working to increase screening uptake among harder to reach groups, including those with learning disabilities, transgender service users, BME groups, individuals with sensory loss, the homeless, and Gypsy and Traveller communities.[50]

33. The Minister acknowledged that the 60% bowel screening uptake target is not being consistently met in Wales, or anywhere else in the UK. He said that annual reporting data showed that the target was met for the first time in February 2014, and that the issue would now be to see whether performance could be sustained.[51] He told the Committee that PHW was currently undertaking work to address the gender and class gradients in the uptake of screening services,[52] and that it was developing a strategy for decreasing inequity in bowel screening uptake across Wales.[53]

The Committee's view

34. The Committee welcomes the increases in the uptake of screening, but notes the continuing inequity across gender and socioeconomic groups. The Committee notes that PHW is carrying out work to understand the underlying reasons for this inequity and to target screening programmes accordingly, and is carrying out a number of campaigns to raise awareness of screening programmes across Wales. The Committee expects that PHW will work with a wide range of groups and partners to develop and deliver such campaigns.

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[48] National Assembly for Wales, Health and Social Care Committee, *RoP [para 215]*, 12 June 2014
[49] Ibid, *RoP [paras 15-7]*, 18 June 2014
[50] Ibid, *Consultation response CDP36 Public Health Wales*
[51] Ibid, *RoP [paras 101-4*], 26 June 2014
[52] Ibid, *RoP [paras 101-4]*, 26 June 2014
[53] Ibid, *HSC(4)-17-14 Paper 1 Evidence from the Minister for Health and Social Services*, 26 June 2014

Recommendation 4: The Committee recommends that the Minister for Health and Social Services provides an update to the Committee after 12 months on the steps that have been taken to ensure that all opportunities are explored and taken up to promote screening among harder to reach groups, and the impact of such promotion on screening uptake.

35. The Committee recognises that in order to ensure equitable access to services, HBs must take account of those entering the treatment and care pathway via the route of screening when planning and delivering their secondary, tertiary and aftercare services. HBs must ensure that sufficient capacity, infrastructure and staffing are in place to deliver an effective and timely service to patients referred from screening.

Bowel scope screening

36. The bowel screening programme currently in place in Wales uses faecal occult blood ("FOB") screening. The Committee heard that bowel scope screening (flexible sigmoidoscopy ("FS")), was being rolled out in England and Scotland, to complement their FOB screening programmes. The majority of polyps and bowel cancers start on the left side of the bowel, which is the side that FS is able to look at. However, in order to cover cancers starting on the right side of the bowel, FOB screening programmes would need to remain.[54] The Committee heard evidence from CRUK and PHW that while bowel scope screening has been shown to be effective, there is currently insufficient capacity and resources to deliver it in Wales.[55]

37. The Minister wrote to the Committee Chair to advise that no decision has yet been taken about whether to introduce bowel scope screening in Wales. He said that PHW was working with Professor Wendy Atkin, who led the UK National Screening Committee trial in 2010 which resulted in pilot programmes in England and Scotland, to identify the impact that a bowel scope screening programme might have in Wales. The Minister advised that he would take account of the outcomes of this work when considering the feasibility of introducing bowel scope screening to complement the existing programme of bowel screening. However, he said that the Wales Screening

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[54] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-20-14 (ptn3) Additional information from the Minister for Health and Social Services*, 18 September 2014

[55] Ibid, *RoP [paras 216-7]*, 12 June 2014/*RoP [para 115]*, 18 June 2014

Committee had discussed this matter at its meeting in June 2014, and had concluded at that time that implementing a bowel scope screening service in Wales would be "challenging given the current low uptake of bowel screening by FOB, and within the current endoscopy provision".[56]

The Committee's view

38. The Committee notes that bowel scope screening has been found to be effective, and that pilot projects have been taken forward in England and Scotland. The Committee also notes that PHW is working with Professor Wendy Atkin to assess the impact bowel scope screening could have in Wales. It welcomes the Minister's intention to take account of this work when considering the feasibility of a bowel scope screening programme in Wales, and expects that he will keep the Committee updated.

GP education

> *"HBs need to raise awareness among public and health professionals about the risks and symptoms of cancer and how to act promptly and appropriately on this knowledge."*[57]

39. The Plan states that a GP typically sees fewer than ten new cancer patients in a year. The WCA told the Committee that this made it challenging to build expertise and skills in primary care in relation to the recognition of symptoms.[58] During the Committee's focus groups, some cancer patients said that they were concerned about the ability of GPs to identify specific cancers. Some also expressed frustration and disappointment that they felt that they had had to fight for their symptoms to be taken seriously by their GP. To address this, they felt that GPs needed access to the right initial and ongoing training, both in terms of symptoms and appropriate ways to communicate with people without providing false reassurance.[59]

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[56] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-20-14 (ptn 3) Additional information from the Minister for Health and Social Services*, 18 September 2014
[57] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[58] National Assembly for Wales, Health and Social Care Committee, *RoP [para 367]*, 12 June 2014
[59] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014

40. The Royal College of General Practitioners ("RCGP") told the Committee that the ageing population was contributing to the increasing complexity of patients' needs, including cancer. It said that GPs' role was to "know a little about a lot", and that it was therefore very important that GPs had access to education and to networking with secondary care colleagues.[60]

41. The RCGP said that GPs do currently receive training in relation to diagnosing cancer, but that it is not sufficiently frequent.[61] BASO told the Committee that nurses also found it difficult to access sufficient professional development, and that the training they did receive was often dependent on third sector funding.[62]

42. To support GPs in diagnosing cancer symptoms, Macmillan Cancer Support told the Committee that it was working on developing electronic risk assessment tools, and cancer decision support tools which would assist them to identify symptoms and make appropriate referrals. Macmillan Cancer Support went on to state that it was working with GPs to provide education sessions on cancer symptoms and referral protocols and guidelines.[63] In addition, Marie Curie Cancer Care said that it was working with GPs and wider community teams on the quality of life at the end of life.[64]

43. The Minister told the Committee that GPs have a "professional responsibility" to ensure that they remain up to date in relation to cancer diagnostics.[65]

The Committee's view

44. The Committee recognises that GPs are, by definition, not specialists, and that they are expected, to "know a little about a lot". However, given the importance of early cancer diagnosis for the individual and the health service, GPs must be supported and assisted to recognise the early signs of cancer, and to make appropriate referrals. Tools such as those prepared by Macmillan Cancer Support may be of assistance in this regard, although such tools should not take the place of effective continuing professional development.

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[60] National Assembly for Wales, Health and Social Care Committee, *RoP [paras 32 and 47]*, 12 June 2014
[61] Ibid, *RoP [para 49]*, 12 June 2014
[62] Ibid, *RoP [para 149]*, 12 June 2014
[63] Ibid, *RoP [para 364]*, 12 June 2014
[64] Ibid, *RoP [para 266]*, 12 June 2014
[65] Ibid, *RoP [para 53]*, 26 June 2014

Recommendation 5: The Committee recommends that the Minister for Health and Social Services works with the Wales Deanery and the General Medical Council to ensure that GPs' training and continuing professional development raises awareness of cancer symptoms, early diagnosis, and the tools and resources available to support GPs in their roles.

Diagnostics and waiting time targets

> *"Rapid diagnosis and treatment improves not only survival but also the quality of life of survivors and lessens their longer term care needs."*[66]

45. In written evidence, CRUK told the Committee that each year 5,600 patients in the UK are diagnosed with cancer at a late stage because of social and health inequalities. This is, in part, due to a lack of awareness of cancer symptoms amongst lower socioeconomic groups.[67]

46. The Plan acknowledges the importance of early diagnosis in achieving good outcomes for cancer patients. In addition, the Committee heard that early diagnosis was beneficial for those patients who prove not to have cancer, as it sets their minds at rest, and for the NHS more generally, as the individuals are then less likely to re-present to other parts of the health service.[68]

47. However, some of the cancer patients who attended the focus groups had to attend their GP repeatedly before being referred for diagnostic tests, and some felt that their GPs had not taken their initial symptoms sufficiently seriously. There was also consensus that once a GP had made the referral, the waiting times for diagnostic tests were too long, particularly in relation to specialised tests or less common cancers. Patients explained to the Committee that long waiting times contributed to the stress they experienced, and could also result in the cancer progressing, or could impact on the period for which they were able to access sick pay.[69]

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[66] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[67] National Assembly for Wales, Health and Social Care Committee, *Consultation response CDP13 Cancer Research UK*
[68] Ibid, *RoP [para 115]*, 12 June 2014
[69] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014

48. Some of the patients said that they had only been referred after presenting at A&E.[70] This was consistent with evidence from CRUK that stated approximately a quarter of patients are diagnosed through emergency routes, whether because they had not presented previously to their GP, or because, in some instances, GPs suggested presenting at A&E as a faster route to accessing diagnostic tests.[71] WCISU told the Committee that it was currently undertaking initial work on a 'route to diagnosis' project in relation to lung cancer to improve understanding of the pathway individual patients follow before receiving a diagnosis through working collaboratively and linking primary and secondary care data.[72]

49. The RCGP explained that it was difficult within the confines of a brief GP appointment to undertake all that was required. It also stated that GPs were being "tasked with reducing our secondary care referrals, so that we do not refer as many patients into secondary care".[73] The Royal College of Physicians ("RCP") said that there was variation in whether or not waiting time targets were achieved, and that better communication was required to address this.[74] Dr Sian Lewis of Hywel Dda Local Health Board ("HDLHB") agreed, saying that there was a need for primary and secondary care to share effective IT systems to enable the scrutiny of referrals by specialists.[75]

50. BASO told the Committee that Wales carried out fewer endoscopies per head of population than other countries, and that opportunities such as the more effective use of the workforce through the provision of training for nurses and other "non-doctor endoscopists" were not taken up. Similarly, access in Wales to diagnostic scans such as MRIs and PET scans was not comparable to other parts of the UK.[76]

51. The RCP told the Committee that the performance across HBs in relation to diagnostic test capacity, waiting times for tests and access to tests was patchy, and that only "one or two of the six major health

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[70] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[71] Ibid, *RoP [para 224]*, 12 June 2014
[72] Ibid, *RoP [paras 61-63]*, 18 June 2014
[73] Ibid, *RoP [para 46]*, 12 June 2014
[74] Ibid, *RoP [para 6]*, 12 June 2014
[75] Ibid, *RoP [para 441]*, 12 June 2014
[76] Ibid, *RoP [paras 126-8]*, 12 June 2014

boards meet the targets either consistently or comfortably".[77] The Committee heard from the Royal College of Nurses ("RCN") that there were examples of good practice and joint working between some HBs and NHS trusts to ensure that the patient was placed at the centre of services, and able to access the services they needed quickly, but that this was not universal.[78]

52. The RCGP told the Committee that one of the barriers to timely and appropriate referrals was the variation in the services available and the referral processes and policies in place across different HBs. It said that:

> "a national directive stating that 'This is going to be available', or a formalised directory of service, would be extremely beneficial."[79]

53. The RCR agreed that there were issues with the referral process, and with the interface between primary and secondary care. In many cases in which patients present with symptoms which could indicate particular cancers, such symptoms prove to be benign, but the number of cases being referred meant that diagnostic clinics are "swamped" and waiting times are long.[80]

54. The Minister told the Committee that 90-95% of patients referred by GPs under the 62 day urgent pathway turn out not to have cancer. He also said that in the last six months, there has been a 16% increase in the number of referrals to the urgent pathway, and a two-thirds increase in the last five years. In his view, this demonstrated GPs' willingness to refer patients in circumstances under which they suspected cancer as a possibility.[81]

55. The Minister said in his written evidence that GPs have a vital role in the early diagnosis of cancer, and that this had been made a priority in the new GP contract arrangements for 2014-15. Under the contract all GPs are required to review diagnoses of lung and gastrointestinal cancer to identify opportunities to improve the system of care and

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[77] National Assembly for Wales, Health and Social Care Committee, *RoP [para 26]*, 12 June 2014
[78] Ibid, *RoP [para 30]*, 12 June 2014
[79] Ibid, *RoP [para 53]*, 12 June 2014
[80] Ibid, *RoP [para 123]*, 12 June 2014
[81] Ibid, *RoP [paras 53-4]*, 26 June 2014

remove barriers to early diagnosis and treatment. The data will then be aggregated through the clusters to an all-Wales level.[82]

56. The Committee asked whether technology was in place to support this review, particularly the aggregation of the data at GP cluster and national level. In a letter to the Chair, the Minister said that the current technology only allowed for the reporting of real time GP data, not the "capture of the analysis of pathways of care though this is the ambition of the cluster work". He went on to say that a workshop had been planned for October 2014 to collate the priorities identified by the GP cluster networks. This would include priorities for information and technology developments to be taken forward with the NHS Wales Informatics Service ("NWIS") and stakeholders. The Minister said that this work would include collaboration with the cancer networks to identify the data required to support continuous learning and service development. On a national level, the themes and actions arising from the GP clusters will be included in the GP cluster network annual report.[83]

57. The Minister told the Committee that he was investing an additional £4million to help HBs achieve their targets in relation to diagnostics,[84] and that the Minister for Finance had announced that £2.5million additional capital funding was being provided in 2014-15 to improve diagnostic services, and that HBs had been tasked with preparing detailed plans for the deployment of that funding.[85]

The Committee's view

58. The Committee notes that there was variation in the referral arrangements, patient pathways and access to diagnostic tests in different HB areas, and that this could create uncertainty for GPs when deciding whether to refer their patients.

Recommendation 6: The Committee recommends that the Minister for Health and Social Services requires health boards to take steps to ensure that GPs have clarity about the services available and the referral arrangements in their areas.

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[82] National Assembly for Wales, Health and Social Care Committee, *RoP [paras 67 and 73]*, 26 June 2014
[83] Ibid, *HSC(4)-20-14 (ptn 3) Additional information from the Minister for Health and Social Services*, 18 September 2014
[84] Ibid, *HSC(4)-17-14 Paper 1 Evidence from the Minister for Health and Social Services*, 26 June 2014
[85] Ibid, *RoP [para 55]*, 26 June 2014

59. The Committee welcomes the requirement in the 2014 GP contract to review all cases of lung and gastrointestinal cancer at GP cluster level, and the aggregation of this data to a national level. However it is concerned that the workshop to identify information and technology developments required to support this work will not take place until October 2014.

60. The Committee notes the additional funding in 2014-15 to improve diagnosis rates, and welcomes the requirement on HBs to prepare detailed plans for the deployment of the funding.

Recommendation 7: The Committee recommends that the Minister for Health and Social Services makes a statement on cancer diagnosis, to include diagnostic treatments, the Minister's strategy to support diagnostics across Wales, and the impact and value for money resulting from the additional funding provided in 2014-15.

5. Delivery plan area 3: delivering fast, effective treatment and care

Provision of services

> *"I expect the NHS to work with ambition - locally, regionally and nationally - to make us amongst the best in Europe for cancer treatment and outcomes."*[86]

61. The Welsh Government's *Cancer Delivery Plan Annual Report 2013* states that "despite improvements in Wales, we are still lagging behind a number of other European countries".[87] Some written evidence received by the Committee questioned whether this is due to the funding levels for cancer services in Wales compared to elsewhere.[88]

62. However, the Committee heard that the development of services was not just an issue of funding, as:

> "it is very difficult for politicians and even for medical people who are not in a particular field to know what the next big thing is. […] it is really about getting the right advice from people who are able to see what is on the horizon and what will be important in terms of delivery."[89]

63. In addition, witnesses said that to ensure the provision of sustainable specialised cancer services in Wales, there needed to be "a bit more of a hub-and-spoke model", which would mean that some people would need to travel further to receive services.[90]

Services for less common cancers

64. Macmillan Cancer Support told the Committee that the *Wales Cancer Patient Experience Survey 2013* ("the Survey") had shown that "the people with the rarer cancers had the worst experience".[91] The Minister explained that HBs cannot reasonably be expected to deliver

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[86] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[87] Ibid, *Together for Health: Cancer Delivery Plan Annual Report 2013*, January 2014
[88] National Assembly for Wales, Health and Social Care Committee, *Consultation response CDP15 Rarer Cancers Foundation*
[89] Ibid, *RoP [para 190]*, 12 June 2014
[90] Ibid, *RoP [para 145]*, 12 June 2014
[91] Ibid, *RoP [para 323]*, 12 June 2014

services for less common forms of cancer, such as neuroendocrine tumours, at a local population level and said that:

> "responsibility for ensuring services across HBs are delivered will fall to either WHSSC or the Cancer Networks."[92]

65. However, Damian Heron of the North Wales Cancer Network ("NWCN") and Betsi Cadwaladr University Health Board ("BCUHB") said that he had concerns about the decision-making process and its impact on patients. In his view the process of commissioning such services through WHSSC was:

> "quite ill-defined at times. I think that the process could be a swifter and simpler one [...] WHSSC is picking up a range of different specialist issues on which – and I do not wish to do it a disservice – it is not necessarily expert, but it has the money. In a way, once again, if that could be delegated to an appropriate group of experts, we might have a better chance of ensuring that there is access for all to the right level of treatment."[93]

66. These comments were echoed by Dr Tom Crosby of the SWCN and VNHST, who said that there was a lack of structures for "cross-health board planning". He told the Committee that it was frequently hard to ensure that funding moved around the NHS with the patient, which could make it difficult to ensure patients across Wales have equitable access to specialist services which may be based in one part of Wales.[94]

The Committee's view

67. The Committee notes that Wales was lagging behind other European countries in the provision of cancer services, and that there is currently inequity of service provision across Wales, particularly for less common cancers. The Committee is concerned that HBs are not currently collaborating effectively to deliver services across HB boundaries, particularly for less common cancers, and believes that this further evidences the importance of stronger leadership at a

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[92] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-20-14 (ptn 3) Additional information from the Minister for Health and Social Services*, 18 September 2014
[93] Ibid, *RoP [para 424]*, 12 June 2014
[94] Ibid, *RoP [para 426]*, 12 June 2014

national level, as recommended in recommendation 1 of this report, to ensure that there is robust commissioning and horizon-scanning.

Recruitment

68. The Committee heard concerns from witnesses about recruitment and the impact that the lack of staff is having on service provision in both primary and secondary care. The RCGP told the Committee that the primary care sector was "currently facing a recruitment and retention crisis".[95] This was echoed for the secondary care sector by the RCR and BASO, which spoke about the difficulties of attracting specialists to fill the funded vacancies in Wales, particularly in west Wales.[96] The Committee heard that there were particular difficulties in recruiting pathologists and radiologists in some parts of Wales, but that this was also a wider UK issue.[97]

69. BASO said that solving the recruitment and retention issues in the NHS in Wales was not just about money, and that increasingly, specialties in Wales were participating in national selection processes to try to attract a wider pool of candidates.[98] The Committee heard that national competition for recruitment could present challenges, as "Wales is always going to have some issues competing with places such as the wealthy south-east of England", but that such challenges could be overcome by ensuring that Wales was an attractive place to work, in which specialists could "practice their craft to the best of their ability".[99] HBs agreed with this, and told the Committee that in order to attract the best trainees, the Welsh NHS must have access to, and use, the latest medical technologies.[100]

70. The RCR told the Committee that there were examples of good practice in making specialties in Wales attractive to applicants, and that, following "a concerted effort among the cancer centres in Wales to promote Wales", clinical oncology trainee vacancies in Wales were now oversubscribed.[101]

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[95] National Assembly for Wales, Health and Social Care Committee, *RoP [para 5]*, 12 June 2014
[96] Ibid, *RoP [para 143]*, 12 June 2014
[97] Ibid, *RoP [paras 241 and 434-5]*, 12 June 2014
[98] Ibid, *RoP [para 137]*, 12 June 2014
[99] Ibid, *RoP [para 141]*, 12 June 2014
[100] Ibid, *RoP [paras 439-40]*, 12 June 2014
[101] Ibid, *RoP [para 141]*, 12 June 2014

71. The Committee heard that the impact of the recruitment difficulties was exacerbated by the ageing workforce population, and, in some fields, there was an insufficient supply of trainees to replace them once they retired. The RCGP suggested that education, networking and support for physicians at all levels were important to ensuring that the issues of retention and recruitment were resolved.[102]

72. The Minister said that he was aware of "some recruitment hotspots in the cancer field", and that he had in place an annual commissioning plan for training to meet the future needs of the NHS. He said that his intention was to "see whether we can put more people into training so that we get more people out to work in the Welsh NHS".[103]

The Committee's view

73. Recruitment and retention in the NHS in Wales, particularly in the west and north of Wales, are issues which frequently arise during the Committee's work. The Committee does not intend to make a specific recommendation in this area at present. It expects however that the Minister will monitor the scale and impact of recruitment difficulties, particularly in rural areas. The Committee may return to this issue in the future.

Access to effective novel therapies

> *"HBs to: determine Individual Patient Funding Requests promptly and equitably across Wales using the All Wales protocol, exceptionality criteria and training."*[104]

74. The Committee heard from cancer patients during its focus groups that patients:

> "should not have to fight for the treatments and drugs that they needed, but that instead there should be recognition that each

[102] National Assembly for Wales, Health and Social Care Committee, *RoP [para 38]*, 12 June 2014
[103] Ibid, *RoP [para 88]*, 26 June 2014
[104] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012

> patient is an individual, who needs to be treated in the best way for their particular cancer and circumstances."[105]

75. The patients were also concerned about the Individual Patient Funding Request ("IPFR") process, which they had found to be frustrating and inconsistent, and, they believed, created a "postcode lottery".[106]

76. Many other witnesses also raised concerns about the IPFR process, saying that it was inappropriate for determining fair access to cancer treatments, particularly for cohorts of patients, and that it was inconsistently applied by clinicians and HBs.[107] BASO agreed, saying that there needed to be equity for patients, and that where treatments had already been National Institute for Health and Care Excellence ("NICE") approved, there should not be a need to "waste patients' time and all of the anxiety of putting them through a long approval process".[108]

77. The representative of the RCR said that he considered the individual IPFR panels to be too isolated at present. He said that as an oncologist he found it difficult that when he was treating patients from different health board areas, he was aware that his IPFR requests would be treated differently by each health board.[109] The RCP said that:

> "between health boards and between patients with very similar situations, you can sometimes get a different answer to more or less the same question. I think that that limits the confidence of both the medical profession and patients in the process."[110]

78. Damian Heron from BCUHB and the NWCN recognised that there were concerns with the IPFR process, and said that it needed "tweaking to an extent", but that he would not support the introduction of an England-style cancer drugs fund, as in his view "a lot of the drugs that

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[105] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[106] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[107] Ibid, *Consultation response CDP11 Sanofi*/*Consultation response CDP15 Rarer Cancers Foundation*/*Consultation response CDP21 Association of the British Pharmaceutical Industry*
[108] Ibid, *RoP [para 174]*, 12 June 2014
[109] Ibid, *RoP [para 168]*, 12 June 2014
[110] Ibid, *RoP [para 102]*, 12 June 2014

are funded will have minimum benefit and they have not been approved".[111]

79. The RCR set out the concerns expressed by many witnesses in relation to exceptionality, saying that it was a "poorly defined concept", and that it introduced variation across the different IPFR panels because each panel interpreted exceptionality differently. The Committee heard that the current IPFR system was ill-equipped to deal with funding for cohorts of patients for whom a new treatment became available because they are not classed as exceptional, and that there was "no clear pathway for a new drug to be cohort-funded".[112]

80. The RCP said that "a more unified approach would probably be better for the patients of Wales, by having a more transparent, standardised process with more clarity".[113] However, some witnesses were concerned about whether a national panel would have the capacity to respond to the volume of requests without creating delays for patients.[114] Dr Sian Lewis of HDLHB suggested that:

> "There could be some pragmatism about it, and some core guidelines so that some things can be done locally. I do not know the practicalities of it. It might be that you do not have a single system and that some are more locally based but, certainly, there needs to be consistency. Variation is a significant issue."[115]

81. In October 2013 the Minister announced a review of the IPFR process, and established a national IPFR review group. The review group's report was published in April 2014.[116] The Minister told the Committee that a consultation had been held on the group's report, which had closed on 25 June, and that he was intending to consider the consultation responses and make further comment in the autumn.[117]

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[111] National Assembly for Wales, Health and Social Care Committee, *RoP [paras 487-8]*, 12 June 2014
[112] Ibid, *RoP [paras 165-6]*, 12 June 2014
[113] Ibid, *RoP [para 7]*, 12 June 2014
[114] Ibid, *RoP [para 498]*, 12 June 2014
[115] Ibid, *RoP [para 496]*, 12 June 2014
[116] National IPFR Review Group, *Review of the individual patient funding request process in Wales*, April 2014
[117] National Assembly for Wales, Health and Social Care Committee, *RoP [paras 96-98]*, 26 June 2014

82. The Minister said that the national IPFR review group had indicated that it did not think that a national panel was the best way to achieve a greater consistency of decision making across Wales. Instead it had recommended that better use be made of the All Wales Therapeutics and Toxicology Centre ("AWTTC").[118] In response to an Oral Assembly Question, the Minister said that the AWTTC would be:

> "put at the heart of the IPFR process. That would mean that it would get notification of all the applications that go through the panel. Where there are multiple applications for the same medicine, that would be identified early, and they would be able to be progressed to full appraisal or an interim evidence-based summary so that an all-Wales consensus could be reached."[119]

The Committee's view

83. The Committee shares the concerns raised by witnesses about the operation and implementation of the IPFR process in Wales. The Committee has heard evidence that there is variation in the interpretation of 'exceptionality', a lack of flexibility to respond to cohorts of patients seeking access to new treatments, inconsistent willingness among clinicians to engage with and access the process and inconsistency in the decisions made by the local IPFR panels.

84. The Committee believes that, to ensure that there is equity of access to novel and innovative treatments across Wales, a national panel should be established for the purpose of considering and making decisions about individual patient funding requests. This would ensure consistency of approach and that HB boundaries do not create barriers for patients.

Recommendation 8: The Committee recommends that to ensure that there is consistency and equity across Wales, the Minister for Health and Social Services establishes a national panel to consider and make decisions about Individual Patient Funding Requests.

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[118] National Assembly for Wales, Health and Social Care Committee, *RoP [paras 96-98]*, 26 June 2014

[119] National Assembly for Wales, *OAQ(4)0467(HSS)*, Supplementary question from David Rees to Mark Drakeford (Minister for Health and Social Services), RoP, 9 July 2014

Access to medical technologies

85. The Committee heard concerns not only about access to cancer drugs, but also in relation to access to new medical technologies. BASO told the Committee that while there were good examples in relation to the uptake of new technologies, for example laparoscopic colorectal surgery,[120] there were also examples in which Wales was slow to adopt new technologies. In part, this was because:

> "We have quite labyrinthine procedures in terms of whether we go through the Welsh Health Specialised Services Committee or whether we go through an IPFR."[121]

86. The RCR said that it also had concerns about the way in which services and infrastructure were developed to take account of emerging technologies, so that once approved they could be swiftly implemented for the benefit of patients.[122]

87. The Committee is currently undertaking an inquiry into access to medical technologies in Wales, and will report on its findings later in the autumn.

[120] National Assembly for Wales, Health and Social Care Committee, *RoP [para 179]*, 12 June 2014
[121] Ibid, *RoP [para 172]*, 12 June 2014
[122] Ibid, *RoP [para 183]*, 12 June 2014

6. Delivery plan area 4: meeting people's needs

Provision of adequate information

> *"Many factors contribute to a positive experience including communication, co-ordination of care, respect of dignity, provision of information, access to psychosocial support and access to financial support."*[123]

88. Macmillan Cancer Support told the Committee that the provision of information was improving, but that it was inconsistent across health boards, services and hospitals, and that HBs were "nowhere near achieving what is set out in [the Plan] yet".[124]

89. The Survey revealed issues in relation to patient information, particularly around the provision of accessible information. The National Cancer Patient Information Strategy Project said in response to the Committee's consultation that there was variation in information provision across Wales, which could "widen health inequalities and act as a barrier to effective self-management". It also said that it was important that healthcare professionals acted as 'infomediaries' for their patients, and that they signposted them towards information and support to enable patients and families to help themselves, but that "the current model of care predominantly views healthcare professionals as information providers rather than enablers".[125]

90. Participants in the Committee's focus groups agreed with this, saying that access to support groups was beneficial, but that more needed to be done to help patients find groups, rather than leaving them to find information and support for themselves. They also said that frequently information was provided to patients at the point of diagnosis, which could be challenging to absorb. The focus groups agreed that it was important for individuals' preferences and needs to be taken into account in the way in which information was provided.[126]

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[123] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[124] National Assembly for Wales, Health and Social Care Committee, *RoP [para 384]*, 12 June 2014
[125] Ibid, *Consultation response CDP04 National Cancer Patient Information Strategy Project*
[126] ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014

91. BASO told the Committee that the health service was "very reliant" on collaboration with the third sector, particularly in relation to advice and information about finances, living with cancer and issues relating to survivorship and quality of life.[127] Focus group participants said that it was very important that such information was provided consistently.[128]

92. The Committee heard that there is evidence of good practice of collaboration between the third sector and NHS in relation to effective person-centred care, such as the health and wellbeing clinics run in collaboration between Macmillan Cancer Support and BCUHB,[129] but that there are areas where collaboration is limited and could be significantly enhanced.[130] Cancer patients were positive about the role of third sector cancer rehabilitation programmes in areas such as occupational and speech therapy, but noted that the provision of such programmes varied across Wales, and said that more should be done to share best practice about such programmes and the provision of information.[131]

93. The Minister recognised the importance of the provision of consistent and accurate information, and told the Committee that the CIG is looking this year at whether a single cancer information hub should be development for Wales, which would provide authoritative information produced by the NHS.[132]

The Committee's view

94. The Committee welcomes the good practice in developing models of effective person-centred care in collaboration with the third sector in some areas, but would like to see these models being implemented more widely.

95. The Committee supports the need for a single authoritative source of information, and welcomes the evidence from the Minister

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[127] National Assembly for Wales, Health and Social Care Committee, *RoP [para 195]*, 12 June 2014
[128] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[129] Ibid, *Consultation response CDP03 Macmillan Health and Wellbeing Project Lead, Betsi Cadwaladr University Health Board*
[130] Ibid, *Consultation response CDP04 National Cancer Patient Information Strategy Project*
[131] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[132] Ibid, *RoP [para 52]*, 26 June 2014

that the CIG is assessing the need for a single cancer information hub for Wales. The Committee expects that the Minister will provide further details about this work in due course, including timescales, financial implications, and how effectiveness and value for money will be assessed.

Key workers

> *"Every patient has a Key Worker who co-ordinates care and support in partnership with them."*[133]

96. The Plan says that cancer patients should have access to a key worker to coordinate their care and support in partnership with them. The Committee heard that in many cases the role of key worker is undertaken by clinical nurse specialists, although the WCA told the Committee that once a patient has been discharged from hospital either GPs, or staff within a GP practice will often take on this role.[134]

97. The Committee heard from cancer patients that their experiences of clinical nurse specialists were very positive, and that, where experiences had been poor, there was frequently a link to high workloads impacting on nurses' capacity and performance.[135]

98. The RCR said that key workers provided "an extraordinary service" and that:

> "They are very good value for money. They make the whole process safer, they co-ordinate the multidisciplinary team and the movement of patients between specialties – they make sure that patients do not fall through the gaps between different specialists. They keep an eye on things, and they provide a point of contact for the patient."[136]

99. However, the Committee also heard that the key worker role had evolved gradually, and that there is no structure in place for developing, funding or managing them.[137] BASO told the Committee that since 2007-08 it had been more difficult to generate new nursing

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[133] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[134] National Assembly for Wales, Health and Social Care Committee, *RoP [para 368]*, 12 June 2014
[135] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[136] Ibid, *RoP [para 153]*, 12 June 2014
[137] Ibid, *RoP [para 154]*, 12 June 2014

posts, and that there was little resource available for training, the funding for which was frequently provided by the third sector or private companies.[138] The RCN agreed that funding for clinical nurse specialists could be challenging.[139]

100. The cancer patients who participated in the Committee's focus groups thought that it was important for patients to "have someone to go to with questions or concerns", but not all of them were aware of the key worker role, or that under the Plan they should have been allocated a key worker.[140] This was consistent with the results of the Survey, which found that 66% of patients stated that they had been given the contact details of their key worker, but there was significant variation between tumour groups, with scores ranging from 80% for lung cancer patients to 39% for urological cancer patients.[141] Macmillan Cancer Support told the Committee that, in particular, patients with rarer cancers frequently lacked access to clinical nurse specialists.[142] This was echoed during the Committee's workshops by members of the NETs Natter Group, a patient support group for individuals with neuroendocrine tumours.[143]

101. The Minister recognised the correlation between patients being allocated key workers and having positive experiences of their cancer treatment. He acknowledged that there was a lack of clarity in some HBs about the roles of key workers and clinical nurse specialists, and said that he intended to issue guidance to HBs, within weeks of the evidence session, which would define the key worker role and who should fulfil it. He reiterated that his ambition was that:

> "every cancer patient in Wales has a key worker and knows who their key worker is, and that the key worker takes an interest in clinical and non-clinical aspects of that patient's care."[144]

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[138] National Assembly for Wales, Health and Social Care Committee, *RoP [paras 151-2]*, 12 June 2014
[139] Ibid, *RoP [para 12]*, 12 June 2014
[140] Ibid, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[141] Welsh Government, *Wales Cancer Patient Experience Survey 2013*, January 2014
[142] National Assembly for Wales, Health and Social Care Committee, *RoP [para 323]*, 12 June 2014
[143] Ibid, *HSC(4)-15-14 (ptn 1) Consolidated note from workshops*, 12 June 2014
[144] Ibid, *RoP [para 87]*, 26 June 2014

Care plans

> *"Care plans are written and shared with the person involved and reviewed on an ongoing basis."*[145]

102. The Survey found that only 22% of patients said that they had been offered a written assessment or care plan. This was echoed in the Committee's focus groups and workshops, in which very few of the participants had a written care plan.[146] One patient from the Singleton Hospital Craft Group said that they had requested a written care plan, but the request had been refused.[147]

103. The Minister acknowledged the Survey's finding, but said that it had also found that 88% of those surveyed said that they felt that they had the information that they needed. He told the Committee that every patient had a care plan, although it might not be in the written format that the Survey described (and the Plan requires). He said that patients may want to receive the information in different formats or through different channels, but recognised that there was a need to improve the level of information available to patients in the format of their preference, and said that work was ongoing in this respect.[148]

The Committee's view

104. The Committee recognises the importance of patients having access to key workers to provide a single point of contact for advice, support and information about their treatment and care. It is concerned to hear that there is inconsistent access and interpretation of the key worker role, and welcomes the Minister's commitment to issue new guidance to HBs in relation to the role of key workers. It is important that this guidance should be clearly communicated to HBs. The Committee expects that the Minister will monitor HBs' compliance with the guidance.

105. The Committee is also concerned to hear about the low levels of patients who report that they have written care plans. The Committee recognises that patients may have different preferences and needs in terms of the ways in which information is provided to them, but

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[145] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[146] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[147] Ibid, *HSC(4)-15-14 (ptn 1) Consolidated note from workshops*, 12 June 2014
[148] Ibid, *RoP [paras 90 and 93]*, 26 June 2014

considers that, as a minimum, all patients must be provided with a written care plan as required by the Plan.

Recommendation 9: The Committee recommends that the Minister for Health and Social Services provides an update after 12 months to the Committee on the actions taken, including the guidance he has committed to provide, and progress made by health boards to ensure that the requirements in the Cancer Delivery Plan for all patients to be assigned a key worker and provided with a written care plan are met by 2016.

Aftercare

> *"Follow up care for people with cancer after treatment must be based on evidence and the individual person's needs".*[149]

106. The number of people being diagnosed with and living with cancer is rising. It was felt by many who gave evidence to the Committee that there was an urgent need to understand the current needs of those living with cancer and to develop sustainable models of care which will also meet the needs of the increasing number of cancer survivors in the future. BASO said that key workers had an important role to play in aftercare and follow up work, building on the rapport that they had developed with the patient during their treatment.[150]

107. Participants in the Committee's focus groups were concerned that aftercare provision is limited and that there is insufficient recognition of the impact that the fear of cancer recurring could have. They also felt that GPs and community nurses should play a greater role in providing aftercare in the community once a patient had been discharged from secondary or tertiary care.[151]

108. The Committee heard that secondary care services recognised that the transition between secondary and primary care was one of the key challenges of implementing the Plan,[152] and that models of follow up care and aftercare were being developed to ensure that patients' individual needs are taken into account. For example, the RCR told the

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[149] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[150] National Assembly for Wales, Health and Social Care Committee, *RoP [para 194]*, 12 June 2014
[151] Ibid, *HSC(4)-15-14 (ptn2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[152] Ibid, *RoP [para 5]*, 12 June 2014

Committee that rather than seeing breast cancer patients every six months for five years, patients were discharged after their initial radiotherapy but with the ability to self-refer between their annual mammograms if needed.[153]

109. The RCR said that the benefits of shifting follow up of patients to primary care services included enabling "the patient's needs from a psychological and spiritual point of view" to be taken into account, and helping to "de-medicalise some of the patients' existence after they have finished their treatment".[154]

The Committee's view

110. The Committee notes the concerns raised by cancer patients and other witnesses about the limitations of current aftercare arrangements in the community. The Committee considers that aftercare, which takes account of the non-clinical and non-medical impacts of cancer, is a key element of the patient pathway, and should be addressed as a matter of priority to ensure that the patient remains at the centre of their care.

Recommendation 10: The Committee recommends that the Minister for Health and Social Services sets out the actions which will be taken, with associated timescales and financial implications, to address the aftercare needs of the increasing numbers of people living with cancer in the longer term. Such actions should take account of patients' medical and non-medical needs.

[153] National Assembly for Wales, Health and Social Care Committee, *RoP [para 197]*, 12 June 2014
[154] Ibid, *RoP [para 198]*, 12 June 2014

7. Delivery plan area 5: caring at the end of life

End of life care

> *"People with cancer approaching the end of life need access to care and support whenever it is needed. […] the right support can transform the end of life experience for everyone – the patient, family, carers and friends."*[155]

111. Witnesses welcomed the Welsh Government's *End of life care delivery plan*, and Marie Curie Cancer Care said that end of life care in Wales was a good example of successful central coordination, and that the service was:

> "something that my colleagues in Marie Curie in England would be envious of in terms of the 24/7 consultant cover, the clinical nurse specialist cover and the coordination between third sector providers."[156]

112. Damian Heron of the NWCN and BCUHB said that progress had been made in the development of end of life and palliative care services in recent years. Such progress was due to investment and emphasis on the service, and the work of the hospice movement and the third sector. However, he said that more progress was needed, particularly because of the ageing population.[157]

113. However, while the service itself was praised by witnesses, there were concerns about equity of access. The Committee heard that 46% of people in the last year of their life in 2012 received specialist palliative care, but that underlying this statistic was correlation between socioeconomic deprivation and emergency, rather than planned or elective, admission.[158] This was echoed by Macmillan Cancer Support, which said that more needed to be done to ensure that there was equitable access to palliative and end of life services,

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[155] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[156] National Assembly for Wales, Health and Social Care Committee, *RoP [para 276]*, 12 June 2014
[157] Ibid, *RoP [para 518]*, 12 June 2014
[158] Ibid, *RoP [para 313-4]*, 12 June 2014

and to help ensure that people were able to die in their place of choice.[159]

114. In a letter to the Chair, the Minister said that the Welsh Government's *Delivering End of Life Care Plan* included a number of actions to ensure equitable end of life care, and set out some of the achievements in this area to date, including:

- a funding formula to ensure a minimum level of specialist services to be provided across Wales;
- the inclusion of healthcare support workers in specialist acute teams to support families and help maintain dignity and respect of patients at the end of life; and
- the development of a GP short course in palliative care.[160]

The Committee's view

115. The Committee recognises the progress that has been made in providing high quality end of life and palliative care services in Wales, and the role of the third sector in the provision of such services. However, it is concerned by the evidence that there are links between socioeconomic deprivation and inequitable access to such services when they are needed.

Recommendation 11: The Committee recommends that the Minister for Health and Social Services sets out the actions which will be taken, with associated timescales and financial implications, to reduce inequities in access to end of life and palliative care, and provides the Committee with an update after 12 months on the impact of those actions.

iWantGreatCare surveys

> *"HBs to: Support participation in cancer patient experience surveys, in particular the iWantGreatCare surveys of palliative care patients and their families."*[161]

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[159] National Assembly for Wales, Health and Social Care Committee, *RoP [para 316]*, 12 June 2014
[160] Ibid, *HSC(4)-20-14 (ptn 3) Additional information from the Minister for Health and Social Services*, 18 September 2014
[161] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012

116. In written evidence Marie Curie Cancer Care stated that there is no satisfactory system in place to ensure that the views of people with terminal cancer, and those of their families and carers, can be effectively heard.[162] The Plan sets an action for HBs to support participation in the iWantGreatCare surveys of palliative care patients and their families. However, Marie Curie Cancer Care told the Committee that it had concerns about the iWantGreatCare surveys as a mechanism for information gathering for a number of reasons, including very low response rates, variations in survey distribution skewing results, and limited scope of questions.[163]

117. In a letter to the Chair, the Minister said that the Marie Curie Palliative Care Research Centre at Cardiff University had recently done a piece of work on the iWantGreatCare survey, as a result of which:

> "a number of changes to the survey are being made to drive up participation and make the survey tool more user friendly. This includes simplifying its user interface and removing complex wording from the document."[164]

The Committee's view

118. The Committee welcomes the Minister's evidence that changes had been made to the iWantGreatCare survey to respond to the concerns raised by Marie Curie Cancer Care. The Committee expects that the Minister will monitor the impact of such changes on the level and quality of information available.

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[162] National Assembly for Wales, Health and Social Care Committee, *Consultation response CDP19 Marie Curie Cancer Care*
[163] Ibid, *Consultation response CDP19 Marie Curie Cancer Care*
[164] Ibid, *HSC(4)-20-14 (ptn 3) Additional information from the Minister for Health and Social Services*, 18 September 2014

8. Delivery plan area 6: improving information

Cancer Network Information System Cymru ("CaNISC")

> *"The priorities for supporting the NHS with access to high quality clinical information up to 2016 [include] to: Develop CaNISC to keep pace with clinical information needs and technology."*[165]

119. Patients who participated in the Committee's focus groups told Members that one of their concerns was a lack of accessible and transparent statistical information.[166] The Plan commits to improvements in access to information across the NHS in Wales, including through the development of CaNISC, and improved processes and data analysis.

120. In oral evidence, Dr Tom Crosby of SWCN and VNHST said that there are weaknesses in the system in some of the support structures around managing patients with advanced disease and that information systems are not set up to collect information about secondary episodes of care. He went on to state:

> "We did have a good system called CaNISC—the Cancer Network Information System Cymru—which collected information about primary diagnoses, but it would not be able to tell you how many patients have metastatic disease or what their outcomes are. So, I would say that the Welsh Government needs to have a tighter relationship and contractual arrangements with the support bodies that support cancer, namely the NHS Wales Informatics Service and Public Health Wales. There is a case to ask them to deliver more for the NHS rather than necessarily their own agendas."[167]

121. The RCP said in written evidence that the CaNISC electronic record system "has failed to keep pace with comparable systems in the UK, and that it is significantly compromised by being far from universally

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[165] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[166] National Assembly for Wales, Health and Social Care Committee, *HSC(4)-15-14 (ptn 2) Note from the focus group event held on 14 May 2014*, 12 June 2014
[167] Ibid, *RoP [para 432]*, 12 June 2014

used in cancer units in Wales".[168] The Wales Cancer Bank agreed with this, saying that while the system had been "a leader in its field [...] it has slipped behind in the last few years" and:

> "It does not always necessarily deliver, and, from a research point of view, because it was set up as a clinical system and the priority is clearly still clinically based, it can be quite difficult to ask for changes to be made to it for a research purpose and to get information from it for research purposes, because they really do not see that as a priority."[169]

122. NWIS said in its written evidence that a business case for a new CaNISC was being progressed, and that interim software upgrades were being carried out where possible. NWIS recognised the importance of the data being accessible to researchers, and advised that:

> "Alongside the technological refresh of CaNISC, options will be explored to identify a reporting tool kit which will provide business intelligence and facilitate clinical reporting requirements."[170]

The Committee's view

123. The Committee is concerned that the CaNISC electronic record system cannot record information about secondary episodes of care, and that the system cannot be adapted for research purposes. It notes the evidence from the NHS Wales Informatics Service that research requirements will be taken into account as part of the future development of the system, but considers that this work should be prioritised.

Recommendation 12: The Committee recommends that, as a matter of priority, the Minister for Health and Social Services considers the development or replacement of the Cancer Network Information System Cymru, and ensures that both clinical and research priorities are taken into account, including secondary episodes of care.

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[168] National Assembly for Wales, Health and Social Care Committee, *Consultation response CDP08 Royal College of Physicians*
[169] Ibid, *RoP [para 256]*, 12 June 2014
[170] Ibid, *Consultation response CDP34 NHS Wales Informatics Service*

EU Data Protection Regulation

> *"Where appropriate, using safeguards to protect patient data, research should be combined with patient data information, to allow researchers to maximise the research resources available for patient benefit."*[171]

124. The Committee heard evidence that the cancer research community in Wales has concerns about the implications of the draft EU Data Protection Regulation. CRUK said that if the Regulation was brought into force as currently drafted:

> "it would essentially mean that we were unable to run most of our population studies. It would make it impossible to collect data through things like cancer registries. It would derail a lot of what we are doing. […] With regard to a lot of what we are talking about around stratified medicine, genomics, and really understanding what is going on with our [cancer] survival rates, if that went through, it would not happen."[172]

125. Similar concerns were raised by the Minister, who said that while he had been supportive of the Regulation as it had originally been drafted, he considered that the amendments recently made by the European Parliament to Articles 81 and 83 "would make much of the research we do in Wales at worst illegal and at best unworkable".[173]

The Committee's view

126. The Committee recognises the importance of protecting individuals' privacy, and of putting in place robust ethical and governance safeguards when personal data is used in the context of research. However, it is concerned that the draft EU Data Protection Regulation, if enacted in its current form, would have damaging implications for valuable research, and put significant Welsh, UK and European investments in research at risk.

127. The Committee notes that officials from the Welsh Government and the UK Ministry of Justice are working together to ensure that concerns about the impact of the draft EU Data Protection Regulation

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[171] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[172] National Assembly for Wales, Health and Social Care Committee, *RoP [para 260]*, 12 June 2014
[173] Ibid, *RoP [para 84]*, 26 June 2014

are raised, and to seek to influence the legislation as it passes through the EU Council and trilogue processes. The Committee is supportive of this work, and has written to the Secretary of State for Justice urging him to do what he can to bring about amendments to Articles 81 and 83 of the draft Regulation, to ensure that a suitable balance is struck between respecting individuals' privacy and protecting valuable research. A copy of this letter is attached at Annex D.

9. Delivery plan area 7: targeting research

Clinical trials

> *"The NHS must continue to promote our research base and ensure access to clinical trials, where appropriate, is well established as this can lead to better outcomes for patients."*[174]

128. The Plan sets targets for the percentage of cancer patients who participate in clinical trials each year. The targets, originally set at 10% of new cancer patients each year to participate in clinical trials, with at least 7.5% of those participants taking part in more complex studies, have since been revised to 15% overall. The National Institute for Social Care and Health Research Clinical Research Centre ("NISCHR CRC") said that it welcomed the revised clinical trials target in the Cancer Delivery Plan, but expressed concern that it may be difficult to sustain the 15% target for overall clinical trials, and challenging to achieve the 7.5% target for more complex interventional studies by 2016.[175]

129. This was echoed by the Wales Cancer Bank, which told the Committee that while progress was being made to meet its targets in the Plan, the sustainability of this work was dependent on resourcing – whether through the current funding from NISCHR, or through alternative models of integrating consenting arrangements into NHS routine practice, although this would require greater ownership by HBs of research activity. Dr Alison Parry Jones of the Wales Cancer Bank told the Committee that there was presently uncertainty about the Wales Cancer Bank's funding as a result of the NISCHR recommissioning and restructuring.[176]

130. When asked about the potential impact of its recommissioning and restructuring on cancer research, NISCHR said that the restructuring was being planned strategically to ensure that the way cancer research, and research generally, are organised in Wales will be done in a more streamlined and cohesive way. NISCHR went on to say that although it has no plans to reduce the funding for cancer research, a number of aspects of the NISCHR infrastructure are

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[174] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012
[175] National Assembly for Wales, Health and Social Care Committee, *Consultation response CDP32 NISCHR Clinical Research Centre Senior Management Team*
[176] Ibid, *RoP [paras 204 and 250]*, 12 June 2014

currently out for commissioning to ensure that "the best research and the most excellent research" was supported.[177]

131. CRUK welcomed the increasing participation in clinical trials in Wales, but was concerned about inequitable access and said that it would welcome greater:

> "collaboration between HBs, trusts and universities and some sort of standardisation across health boards, trusts and universities and some sort of standardisation across health boards so that, when you are trying to run a multi-site trial, you do not have to navigate various different arrangements, depending on which site you go to, so that patients can access trials regardless of where in the country they are based."[178]

132. In addition, CRUK was concerned that there was not always sufficient translation of the outcomes of research into practice, in terms of embedding effective technologies and treatments into NHS services.[179] In its written evidence the Association of the British Pharmaceutical Industry ("ABPI") expressed concern that Wales is missing out on clinical trials placement because new 'gold standard' trial comparator medicines are not already in routine use within the standard care pathways.[180]

133. The Committee also heard evidence, consistent with that submitted to its inquiry on access to medical technologies in Wales, that while drugs trials frequently benefit from the engagement and financial resources of drugs companies, the producers of medical technologies are less likely to be involved in clinical trials. CRUK told the Committee that there was a need for:

> "better integration across planning for research, innovation and integration so that, really, the NHS is looking at these things holistically so that you do not have a situation where you want

[177] National Assembly for Wales, Health and Social Care Committee, *RoP [para 82]*, 26 June 2014
[178] Ibid, *RoP [para 205]*, 12 June 2014
[179] Ibid, *RoP [para 206]*, 12 June 2014
[180] Ibid, *Consultation response CDP21 Association of the British Pharmaceutical Industry*

> to trial your innovations. However, the reality is that the NHS is nowhere near being able to take that forward."[181]

134. The Minister told the Committee that he considered research to be a "real strength" of the NHS in Wales, and that this was something that he was keen to ensure was continued and promoted. He also told the Committee that NISCHR was a partner of the National Cancer Research Initiative, a body consisting of key cancer research funders which set a national direction and coordination at a UK level to seek to gain the maximum effect from research across the UK.[182]

The Committee's view

135. The Committee recognises NISCHR CRC's concerns about whether the targets in the Plan with regard to research will be sustainable and achievable by 2016. In particular, the Committee is concerned by the evidence it heard that research activity is not always well integrated into the work of HBs, and that there is not always a clear translation of the outcomes of research into service developments or benefits for patients.

136. The Committee notes that NISCHR's recommissioning and restructuring is currently creating uncertainty about funding within the cancer research sector, and expects the Minister to provide an update about funding for cancer research once the process has concluded in the autumn.

Stratified medicine

> *"Welsh researchers are actively involved in stratified medicine research and we expect NHS organisations to ensure that clinical trials are linked to existing resources, such as the Wales Cancer Bank, to improve trial design and ensure the correct stratification of patients."*[183]

137. Stratified medicine involves targeting treatments based on genetics and the molecular characteristics of tumours in order to achieve better outcomes with fewer side effects for patients. The Plan includes an action for HBs and NHS trusts to work with universities and

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[181] National Assembly for Wales, Health and Social Care Committee, *RoP [para 244]*, 12 June 2014
[182] Ibid, *RoP [paras 78-80]*, 26 June 2014
[183] Welsh Government, *Together for Health: Cancer Delivery Plan for the NHS to 2016*, June 2012

research organisations to ensure that Wales is involved in the development of stratified medicines. The Wales Cancer Bank told the Committee that progress was being made.[184]

138. However, the ABPI raised concerns that the availability of the new diagnostic systems and molecular tests which would be required to support the use of stratified medicines is not covered in the Plan.[185] Other respondents to the Committee's consultation agreed with this, saying that there was a need for a policy or strategy for the commissioning of the infrastructure required to support stratified medicine, and to ensure that those patients most likely to benefit from the treatment can be selected.[186]

139. Witnesses to the Committee's inquiry recognised the benefits of research and development of stratified medicine, but said that if the benefits were to be achieved it would require suitable investment[187] and a long term strategy for service delivery led by the Welsh Government with involvement from each HB.[188]

The Committee's view

140. The Committee agrees that there is a need to develop an integrated stakeholder approach to stratified medicine, in order to benefit not only patients, but also service providers, regulators and industry, as well as helping to ensure that Wales and the UK are seen as attractive and competitive for research and development in medicines and technologies. Such an approach should support the research and development of stratified medicines, but also plan for the delivery of the requisite infrastructure and services.

Recommendation 13: The Committee recommends that the Minister for Health and Social Services sets out the actions which will be taken, with associated timescales, to ensure the development and service delivery of stratified medicine in Wales.

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[184] National Assembly for Wales, Health and Social Care Committee, *RoP [para 237]*, 12 June 2014
[185] Ibid, *Consultation response CDP21 Association of British Pharmaceutical Industry*
[186] Ibid, Consultation response CDP23 Welsh NHS Confederation/*Consultation response CDP31 Velindre NHS Trust*
[187] Ibid, *RoP [para 239]*, 12 June 2014
[188] Ibid, *RoP [para 247]*, 12 June 2014

Annex A – Witnesses

The following witnesses provided oral evidence to the Committee on the dates noted below. Transcripts of all oral evidence sessions can be viewed on the Committee's website.

12 June 2014

Dr Martin O'Donnell	Royal College of General Practitioners
Ailsa Hayes	Royal College of Nursing
Professor John Chester	Royal College of Physicians
Rachel Hargest FRCS	British Association of Surgical Oncologists
Dr Martin Rolles	Royal College of Radiologists
Emma Greenwood	Cancer Research UK
Dr Alison Parry-Jones	Wales Cancer Bank
Susan Morris	Macmillan Cancer Support
Simon Jones	Marie Curie Cancer Care
Dr Ian Lewis	Tenovus
Linda McCarthy	Wales Cancer Alliance
Dr Hamish Laing	Abertawe Bro Morgannwg University Health Board
Damian Heron	Betsi Cadwaladr University Health Board and the North Wales Cancer Network
Dr Sian Lewis	Hywel Dda University Health Board
Dr Tom Crosby	Velindre NHS Trust and the South Wales Cancer Network

18 June 2014

Sharon Hillier	Public Health Wales
Dr Pat Riordan	Public Health Wales
Dr Dyfed Huws	Wales Cancer Intelligence and Surveillance Unit

26 June 2014

Mark Drakeford AM	Minister for Health and Social Services
Chris Jones	Deputy Chief Medical Officer
Carys Thomas	National Institute for Social Care and Health Research
Grant Duncan	Welsh Government

Annex B – Written evidence

The following people and organisations provided written evidence to the Committee. All consultation responses can be viewed in full on the Committee's website.

Organisation	Reference
Royal College of Anaesthetists Advisory Board in Wales	CDP01
Ms King	CDP02
Macmillan Health and Wellbeing Project Lead, Betsi Cadwaladr University Health Board	CDP03
Macmillan National Cancer Patient Information Strategy Project	CDP04
Macmillan Metastatic Spinal Cord Compression Service Improvement Lead for the South Wales Cancer Network	CDP05
ASH Wales	CDP06
Genomic Health	CDP07
Royal College of Physicians Wales	CDP08
Cwm Taf University Health Board	CDP09
Macmillan Welfare Benefit Service Redesign Project (Wales)	CDP10
Sanofi	CDP11
Prostate Cancer UK	CDP12
Cancer Research UK	CDP13
Royal College of General Practitioners Wales	CDP14
Rarer Cancers Foundation	CDP15
Macmillan Wales	CDP16
Betsi Cadwaladr University Health Board	CDP17
Wales Cancer Alliance	CDP18
Marie Curie Cancer Care	CDP19
Macmillan SACT and AO Development Manager, South Wales Cancer Network	CDP20

Organisation	Reference
ABPI Cymru Wales	CDP21
Hilary Ryan	CDP22
Welsh NHS Confederation	CDP23
GIST Support UK	CDP24
Royal College of Nursing	CDP25
Breaththrough Breast Cancer	CDP26
CLIC Sargent	CDP27
Tenovus	CDP28
British Medical Association Cymru Wales	CDP29
Teenage Cancer Trust	CDP30
Velindre NHS Trust	CDP31
National Cancer Trials Network	CDP32
Standing Welsh Committee of the Royal College of Radiologists	CDP33
NHS Wales Informatics	CDP34
Breast Cancer Care	CDP35
Public Health Wales	CDP36
Dr Gianfilippo Bertelli	CDP37
Annie Mulholland	CDP38
Pancreatic Cancer UK	CDP39
NET Patient Foundation	CDP40

Annex C – Engagement activity

To inform the inquiry, the Committee worked in collaboration with Macmillan Cancer Support to arrange regional workshops and focus groups to ensure that those with direct experience of cancer services were able to share their views. Notes of the Committee's activity have been published, and may be accessed via the links below.

Date	Event
1-12 May 2014	Regional workshops with: – North Wales Cancer Patients Forum; – NETs Natter Group; – Singleton Hospital Craft Group; – North Caerphilly Breast Cancer Support Group; – Bracken Trust Cancer Group.
14 May 2014	Focus groups

Annex D – Letter to the Secretary of State for Justice

Y Pwyllgor Iechyd a Gofal Cymdeithasol
Health and Social Care Committee

Cynulliad Cenedlaethol Cymru
National Assembly for Wales

The Rt Hon Chris Grayling MP
Secretary of State for Justice
Ministry of Justice
102 Petty France
London
SW1H 9AJ

28 July 2014

Dear Secretary of State

EU Data Protection Regulation

During its inquiry into progress made on implementing the Welsh Government's Cancer Delivery Plan, the National Assembly for Wales' Health and Social Care Committee heard concerns about the impact of the proposed EU Data Protection Regulation on the use of data to support NHS service delivery, and health and scientific research in Wales. In particular, witnesses raised concerns about the amendments recently agreed to Articles 81 and 83 of the proposed Data Protection Regulation.

Cancer Research UK gave evidence to the Committee that:

> "As currently drafted, [the draft Regulation] would essentially mean that we were unable to run most of our population studies. It would make it impossible to collect data through things like cancer registries. It would derail a lot of what we are doing. […] With regard to a lot of what we are talking about around stratified medicine, genomics, and really understanding what is going on with our [cancer] survival rates, if that went through, it would not happen".[i]

Similar concerns were raised by the Minister for Health and Social Services, who said that:

> "The draft Regulations were ones that the UK Government supported, and so did we. However, the [European] Parliament has recently

Bae Caerdydd
Cardiff Bay
CF99 1NA

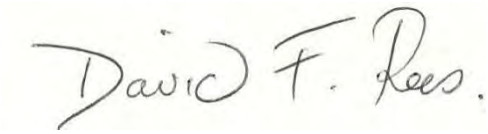
Ffôn / Tel: 029 2089 8403
E-bost / Email: HSCCommittee@wales.gov.uk
Croesewir gohebiaeth yn y Gymraeg a'r Saesneg/We welcome correspondence in both English and Welsh

amended those Regulations significantly, particularly Articles 81 and 83, which, if they go through as currently formulated, would make much of the research we do in Wales at worst illegal and at best unworkable".[ii]

As a Committee, we recognise the importance of protecting individuals' privacy, and of putting in place robust ethical and governance safeguards when personal data is used in the context of research. However, we are concerned that if enacted in its current form, the draft EU Data Protection Regulation would have damaging implications for valuable research, and put significant Welsh, UK and European investments in research at risk.

We note that officials from the Welsh Government and the Ministry for Justice are working together to ensure that concerns about the impact of the draft EU Data Protection Regulation are raised, and to seek to influence the legislation as it passes through the EU Council and trilogue processes. We support this work, and urge you to do what you can to bring about amendments to Articles 81 and 83 of the draft EU Data Protection Regulation, to ensure that a suitable balance is struck between respecting individuals' privacy and protecting valuable research.

Yours sincerely



David Rees AC / AM
Cadeirydd / Chair

cc Mark Drakeford AM, Minister for Health and Social Services

[i] National Assembly for Wales, Health and Social Care Committee, Record of Proceedings [paragraph 260], 12 June 2014
[ii] National Assembly for Wales, Health and Social Care Committee, Record of Proceedings [paragraph 84], 26 June 2014