

Health and Social Care Committee

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

Note of focus group discussion 14 May 2014

1. The Health and Social Care Committee invited people with experiences of cancer services in Wales to participate in focus groups, arranged in partnership with Macmillan Cancer Support and the Wales Cancer Alliance. Members facilitated individual focus groups, seeking participants' views on three main themes, as well as any other points that they wished to raise, and the outcomes of the discussions were captured during a plenary session. This note focuses mainly on the plenary discussions, but also includes some issues raised in individual groups.
2. There was variability in the experiences of patients from across Wales and with different types of cancer. Patients felt that the Cancer Delivery Plan itself sounded good, but that it was not reflected in their experiences as patients.
3. Patients thought that they should not have to fight for the treatments or drugs that they needed, but that instead there should be recognition that each patient is an individual, who needs to be treated in the best way for their particular cancer and circumstances.

Theme 1: what actions need to be taken to ensure that cancer is detected quickly?

Diagnostics

4. Patients had mixed experiences, and expressed concerns about the ability of GPs to identify specific cancers. They said that in many cases repeated visits to GPs were required before receiving an appropriate referral. Some patients expressed frustration and disappointment that

they 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 also appropriate ways to communicate with people without providing false reassurance.

5. Some patients mentioned the role of other primary care services in diagnosis, for example dentists and nurse practitioners.
6. Patients felt that waiting times to access diagnostic tests were too long, particularly in relation to specialised tests or less common cancers. There was frustration that long waiting times could contribute to the stress on an individual, but could also mean that the cancer could progress or metastasise, or impact on the period of sick pay available to the individual. It was also noted in some groups that later diagnosis could lead to higher costs for the NHS due to the increased complexities of treating more developed cancers.
7. Some patients, particularly those referred via the non-urgent route, had paid for private diagnostic tests to avoid lengthy waiting times, but expressed discomfort about having had to do so, and that not all individuals could afford this option. One patient said that had she known cancer was a possibility in her case, she would have paid for a private test. Others said that had they been more aware of the 10-day target to see a consultant they would have chased appointments earlier themselves. They also thought that GPs should have a role in chasing up referrals.
8. Concerns were raised about access to mammograms, particularly that women over 70 are not aware that they have the right to request mammograms, and there was a view that the age at which women are invited for mammograms should be lowered from 50 to 47, as is the case in England. Similar concerns were expressed in relation to prostate-specific antigen tests for men, as many men are unaware that

they have a right to request tests and awareness of the risks of prostate cancer is low.

9. Concerns were also heard that some patients were only diagnosed after attending A&E, which could cause additional stress for patients and additional pressures on services. According to Cancer Research UK approximately a quarter of cancer cases in the UK are diagnosed through emergency admission to hospital.
10. Patients were also unhappy about refusal of applications for genetic testing, which they felt overlooked the preventative role of genetic tests, and about refusals for applications for second opinions.

Theme 2: what improvements can be made to ensure that patients receive fast and effect treatment and care?

Access to treatments

11. The group raised concerns about the consistency of access to cancer medicines, therapies, surgical interventions and clinical trials, and thought that in many cases there was a 'postcode lottery'. There was no general consensus on whether a cancer drugs fund should be established for Wales, but there was a sense that the Individual Patient Funding Request (IPFR) system can be frustrating, and that there is inconsistency about the way that decisions are made by different oncologists and different Local Health Boards (LHBs). There was also a feeling that the clinical reasoning behind decisions to allow or deny treatment was not always communicated clearly to patients. There was a view that an appropriately funded all-Wales approach is required to ensure equity of access, but also that oncologists should have more of a role in the decision making process as they had the best knowledge and understanding of the individual patient.
12. Patients felt that generally, once you were within the system, there was good monitoring of individual cases, but that treatment could sometimes be disjointed and suffer from delays. Some participants

raised the breast cancer treatment pathways, and said that they were too drawn out and lengthy. One suggestion was that there should be a presumption that a patient will wish to proceed with treatment, allowing it to be scheduled at the earliest opportunity to avoid delays once a patient has met with their consultant for the first time.

Access to specialist services

13. Patients' experiences were mixed, particularly in relation to less common cancers. Services could be disparate, and gold standard care was not always available. There was recognition however that cancer specialist centres might be at some distance, or even in England, and patients were content to travel in order to receive the best care. Some patients present had moved from England to Wales, or vice versa, to receive the best care for their particular cancers.
14. There was concern about the availability of radiologists in Wales.

Delivery of treatment

15. There were mixed views on the environment in which services were delivered, with some having had positive experiences while others described negative experiences. One patient said they had had to wait in their car to avoid the stressful environment in which their treatment was being delivered, and other patients referred to a lack of privacy. There were also concerns about the availability and quality of out of hours services.

Access to aftercare

16. Patients felt that aftercare was extremely limited, and that there was not enough recognition of the effects the fear that the cancer would recur could have. They felt that there was a role for GPs and community nurses in providing aftercare in the community once a patient had been discharged from secondary or tertiary care, and said

that this should be built into GP contracts and performance actively monitored. One group felt that cancer should be included in the GP Quality and Outcome Framework.

17. A number of participants felt that there was insufficient information available about continuing screening following treatment, and that screening intervals throughout aftercare should be closer together.
18. Some patients raised the positive effects wellbeing type centres had on their lives during and after diagnosis and treatment. It was felt that the psychological issues of patients were not being adequately addressed and more support in this area was required.
19. Third sector cancer rehabilitation programmes were praised, particularly where interventions such as occupational and speech therapy are required. It was noted that such programmes are not available uniformly across Wales.

Theme 3: are patients being adequately supported and receiving person-centred care?

Patient empowerment

20. There was a feeling that patients needed to be more empowered, with a clearer idea of their patient rights.
21. Patients raised the issue of access to their patient notes, as patients in Wales were not always aware they could request to receive copies.

Care plans

22. Few of the patients present had written care plans. Some patients felt that there was a lack of engagement with social services departments with regard to their care.
23. Given that people are living with cancer longer, and in many cases may have multiple conditions which could impact on each other, the patients felt that their care plans should reflect this, and that medical

professionals should work collaboratively and ensure a joined up approach is taken.

Provision of information for patients

24. The groups were concerned that often a lot of information is provided to patients at the point of diagnosis, when they may not be well placed to take in details, and felt that time needed to be built in to reflect and digest the information. It was noted that individual preferences need to be taken into account when providing information about cancer diagnosis and treatment, and provision adapted accordingly.
25. There was thought to be a lack of financial information and advice in relation to benefits and the impact on cancer patients' earnings.
26. Patients were concerned that good practice on the provision of information is not consistently shared and implemented throughout Wales, for example, the blue book in north Wales is not available in south Wales.
27. Patients found NHS websites in Wales very difficult to navigate, and said that they contained less information than the equivalent sites in England. They said that it could be confusing as to who you would see next and what would happen, and felt that having access to treatment and diagnostic flowcharts could help them to understand their cases and ask questions.

Key workers

28. Patients agreed that it was important to have someone to go to with questions or concerns (whether this was one person throughout the treatment, or a specialist at each stage), but there was mixed understanding and awareness of the role of key workers, and some patients felt that charities were filling this gap. Some patients knew that they had a key worker, others did not know who their key worker was, or if they had one. It was suggested that the provision of a key

worker for each cancer patient was not uniform across Wales. One patient said that he had been given a generic key worker contact card, which had a switchboard number and no individual name. In some cases patients expressed concern about the workload that individual key workers were allocated.

Clinical nurse specialists (CNS)

29. Patients were very positive about the role of specialist nurses, but were concerned that if a nurse changed roles or was off sick then relationships were interrupted. Where individuals had poor experiences of clinical nurse specialists this was often linked to the high workload of the nurses impacting on their capacity and performance

Support groups

30. Access to support groups was felt to be very important, but patients felt that more should be done to signpost them to groups that could provide support, rather than leave patients to find them themselves.

Information and support for patients' families

31. There were mixed views on the role of the NHS in providing information and support to patients' families – some considered this to be very important to the provision of support for the patient, and others felt that services to cancer patients should be prioritised within limited resources. Some patients saw looking after families as the role of the third sector.

Other issues that were raised

Awareness and public education

32. Patients were in agreement about the importance of an early diagnosis, and the need to further raise awareness of symptoms and risks, particularly among young people. Suggestions were made that, given cancer awareness messages are consistent, the UK nations should work more closely together to produce public awareness campaigns, and that more use should be made of social media to target young people in addition to TV campaigns and work in schools.
33. There was concern about the low take-up of screening programmes such as the bowel cancer screening programme, and a feeling that more needed to be done to inform people about the benefits of screening.
34. Patients were interested in the Welsh Government's over-50s health check, but felt that it should include face to face contact with a GP.
35. Some patients felt that conversations about cancer can sometimes be dominated by discussions of female cancers, and that to address the imbalance in cancer gender statistics there was a need to target men to encourage them to be more proactive about their health.
36. Patients were concerned that the system is already at its capacity, and may not be able to respond to an increase in demand as an outcome from public awareness campaigns.

Statistical information

37. Patients were dissatisfied with the availability and transparency of statistical information in relation to cancer, and felt that more transparency would allow patients and politicians to hold the Welsh Government to account. Specific concerns included:
 - a. the way that individuals referred for treatment over the border is recorded in waiting time statistics;

b. a lack of statistical information in relation to secondary tumours.