Review of Cancer Waiting Times Standards

Improving Outcomes: A Strategy for Cancer

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Contact Details	Jane Allberry Cancer Policy Team Department of Health, Wellington House 133-155 Waterloo Road London SE1 8UG 0207 972 1300
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Review of Cancer Waiting Times Standards

Improving Outcomes: A Strategy for Cancer

Prepared by Department of Health Cancer Policy Team

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Executive summary

Background

1. In July 2010 Ministers asked the National Cancer Director, Professor Sir Mike Richards to lead a review of the Cancer Reform Strategy (CRS, 2007) to be completed by Winter 2010. As part of this review, the current set of waiting time standards have been revisited to ensure they retain clinical justification and remain appropriate. This was in line with the Coalition Government's commitment to focus on outcomes rather than process targets, except where the latter are clinically justified.

2. The review has been overseen by the Going Further on Cancer Waits (GFOCW) Advisory Group, chaired by the National Cancer Director. To support the review, the Department of Health Cancer Policy Team has undertaken a range of activities including a literature review and drawing on comparative policy information across the four devolved administrations.

3. The views of a wide range of health professionals, patient groups, charities and NHS managers have been sought through meetings of existing cancer advisory groups, written communication and a dedicated engagement event.

4. Four key questions have been considered:

    - Should cancer waiting time standards be retained i.e. do they remain clinically justified?
    - Should any specific cancer waiting time standards be changed?
    - Should specific cancer types be excluded from the standards?
    - How can the system be improved?

Findings from the review

5. It was noted that all the current cancer waiting time standards (e.g. two week wait; one month (31-day) standard; two month (62-day) standard) are being consistently achieved at a national level. However, some Trusts and local health economies are struggling to achieve the standards.

6. Large scale cancer patient experience surveys involving all acute and specialist NHS Trusts in England were conducted in 2000 and 2010. In the 2010 survey, 68% of cancer patients reported that they had been seen by a hospital doctor within 2 weeks of referral and 91% had been seen within 4 weeks, irrespective of whether they were referred urgently or non urgently. For all tumour groups at least 80% of patients reported being seen within 4 weeks. This represents a considerable improvement over 2000. In 2000, only 66% of all patients surveyed waited less than a month for an appointment with a hospital doctor. For the five tumour groups surveyed other than breast cancer the figure was 57%.

7. The unanimous view of patient groups and cancer charities and the almost unanimous views of clinicians and NHS managers is that the cancer waiting time standards have

helped to drive service improvement and have been beneficial for patients. Although it is impossible to quantify whether the targets have led to improvements in cancer survival, almost everyone we consulted felt that the targets had reduced patient anxiety related to delays in being assessed, diagnosed with and treated for cancer. There was overwhelming support from stakeholders for the retention of cancer waiting time standards.

8. Each of the cancer waiting time standards was carefully considered within the review process to assess whether it was still justified or whether it could now be removed in order to reduce the burden of monitoring and management. The unanimous view of the Advisory Group is that all the targets continue to be justified and should be retained.

9. In general, stakeholders felt that the waiting time standards should apply to all types of cancer. Special consideration was given to the issue of waiting times for patients with prostate cancer, as there are clinical indications for waiting for 4-6 weeks between a prostate biopsy and a subsequent MRI scan. It is also recognised that men with prostate cancer may need time to consider treatment options with very different implications. Options were considered that involved excluding prostate cancer from the two month standard and lengthening the standard to 93 days (i.e. 3 months) for this group of patients. On balance, it was agreed that the two month standard should be retained. However, it was also felt that the Department of Health should re-emphasise to NHS Trusts that the operational standard of 85% of patients being treated within two months (62 days) of an urgent referral for suspected cancer does not mean that this standard has to be achieved for every cancer type.

10. The diagnostic care pathway for some cancers (e.g. breast and skin cancers) is relatively simple and quicker than for others (e.g. colorectal cancer or head and neck cancers). To achieve an overall standard of 85%, it is reasonable to expect that around 95% of breast cancer and skin cancer patients will be treated within two months, whilst only about 80% of those with more complex pathways will be treated in the same timeframe.

11. Several different options for improving the processes surrounding cancer waiting times were considered. These included: reintroducing suspensions (“stopping the clock”), particularly in relation to patients who want time to think about treatment, and the adoption of different processes for allocating responsibility for patients who breach the standard for those cases who are initially referred to one NHS Trust, but then require onward referral to another Trust for treatment (so called Inter Provider Transfers or IPTs).

12. The Advisory Group noted that suspensions (periods where the waiting time clock is stopped) had been used when the cancer waiting time standards were first introduced. The system was changed when the Referral To Treatment (18 week or RTT) target was introduced, as it was felt to be too burdensome on the NHS to run two processes (Cancer and RTT) in parallel locally. As data relating to time from referral to treatment is still a mandatory data collection, the concerns about the potential burden on the NHS of running two systems would remain. It was further noted that the work done to remove the option to ‘suspend’ a patient had reduced the operational standard for the two month standard from 95% to 85%. The Advisory Group unanimously recommended that the current process should continue.

13. It is recognised that the proportion of breaches (patients waiting longer than the specified time) of the 62 day standard is higher for patients who follow a pathway of care including a referral between providers, an IPT, than for those who are treated at the Trust to which they are initially referred. Mainly this is a reflection on the degree of coordination of care across a cancer network. At present when an IPT patient breaches the two month standard responsibility is shared equally between the referring and the receiving Trust. This may act to the disadvantage of large providers of tertiary services.

14. In considering this issue, the Advisory Group were keen to ensure that patients who are required to transfer between NHS Trusts should not be disadvantaged in terms of timeliness of treatment. Members of the group were also keen to take account of the need for equity in the application of performance assessment between Trusts and of the need for processes to be simple to operate within the NHS.

15. One of the methods considered as an appropriate method of ensuring equity is 'breach reallocation', where responsibility for any service failure is identified in an adjustment to the statistics to ensure the responsible provider on a multi-provider pathway of care is the only trust impacted in any statistical assessment of performance. In practice, the issue of breach reallocation is only an issue for a small number of Trusts with very high IPT numbers. Therefore, on balance, it was not considered necessary or appropriate to change the system as a whole to accommodate these local problems. Instead the Advisory Group recommended that local processes should be developed and piloted where necessary. These might well involve collecting data on day of referral from one Trust to another (e.g. from secondary to tertiary care). Local arrangements for breach allocation could then be negotiated.

16. Usability and ease of access to cancer waiting times information is important for both NHS and non-NHS users. The Advisory Group noted the steps undertaken by the Department to ensure the National Statistics on waiting times for suspected and diagnosed cancer patients meet the UK Statistics Authority's 'Code of Practice for Official Statistics' (the subject of a parallel review). The Advisory Group also felt that ongoing lay input into the quality and dissemination of cancer waiting times information would also fulfil the Government's aims of better information to support choice, commissioning and service quality improvement.

Conclusions

17. After careful consideration of a wide range of issues related to the current waiting time standards, the Advisory Group were unanimous in their view that these standards have been beneficial for patients and that they should be retained without any changes at a national level.

Introduction

1. As part of the refresh of the Cancer Reform Strategy (CRS) 2007[1], the Cancer Waiting Time Standards have been revisited to ensure they remain aligned with the Coalition Government's priority to focus on clinically justified outcome measures. This report sets out the findings of this exercise, the conclusions and recommendations.

2. This report has been submitted to Ministers and used to inform the review of the CRS.

[1] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006

Background

Cancer Waiting Times Standards for England

3. Over the last decade, the NHS has been expected to comply with maximum waiting time periods set centrally that determine how long a patient with suspected cancer should wait to be diagnosed and/or treated. Cancer waiting times in England cover the majority of patients and tumour types.

4. The cancer waiting time standards introduced in the NHS Cancer Plan (2000)[2] and the CRS are:

    - Maximum two-week wait for first outpatient appointment for patients referred urgently with suspected cancer by a GP;
    - Maximum one month wait from urgent GP referral to treatment for acute leukaemia and children's and testicular cancers;
    - Maximum one month wait from date of decision to treat to first treatment for breast cancer;
    - Maximum two month wait from urgent GP referral to first treatment breast cancer;
    - Maximum one month wait from date of decision to treat to first treatment for all cancers;
    - Maximum two month wait from urgent GP referral to first treatment for cancer.
    - Maximum 31-day wait for subsequent treatment where the treatment is
    - surgery;
    - Maximum 31-day wait for subsequent treatment where the treatment is an anti-cancer drug regimen;
    - Maximum 62-day wait from a consultant's decision to upgrade a patient's priority to first treatment for all cancers;
    - Maximum 62-day wait from a referral from an NHS screening service to first treatment for all cancers; and
    - Maximum two-week wait for first outpatient appointment for patients referred with breast symptoms, where cancer was not initially suspected.

Assessing the standards

5. NHS achievement is measured using the proportion of patients that are seen or treated within the timeframes identified for the specific waiting times standards that apply to the patient cohort. The waiting times for cancer services, as with all monitored waiting times are not expected to be met in all cases by the NHS. At any one time, there will be a number of patients who are not available for treatment within a waiting time standard because: they elect to delay their treatment (patient choice), are unfit for their treatment or it would be clinically inappropriate to treat them within the standard time.

6. The Department of Health (DH) has published 'operational standards'[3] or performance thresholds that identify an expected level of achievement based on case mix, clinical requirements, potential levels of patients unfit for treatment and patient choice. These

[2] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009609
[3] http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_103436

operational standards are met in most cases for the cancer waiting time standards. The vast majority of cancer providers are achieving the levels expected, with the standards being met at an aggregate level nationally.

Coalition Government priorities

7. The Coalition Government now wants to concentrate on what is most important to patients and their families, and there is a need to ensure that the policies covering cancer services, including those specifically dealing with waiting times are aligned with these priorities.

8. The NHS White Paper, *Equity and excellence: Liberating the NHS*[4], sets out the Government's long-term vision for the future of the NHS. The vision builds on the core values and principles of the NHS - a comprehensive service, available to all, free at the point of use, based on need, not ability to pay. It sets out how the NHS will:

    - put patients at the heart of everything the NHS does;
    - focus on continuously improving those things that really matter to patients - the outcome of their healthcare; and
    - empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services.

[4] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

Review of the cancer waiting time standards

Aims of the review

9. Care Services Minister Paul Burstow announced on 6 July 2010, at the All Party Parliamentary Group on Cancer, that the National Cancer Director, Professor Sir Mike Richards, would lead a review of the *Cancer Reform Strategy*. As part of the review, the current set of cancer waiting time standards put forward in the Cancer Plan (2000) and the Cancer Reform Strategy (2007) were to be revisited by the Department's Cancer Policy Team to ensure they remained clinically justified, focused on clinical outcomes and in the best interests of patients[5].

10. This review was also to determine if any amendments or modifications were required to ensure the cancer waiting times standards best met the needs of patients and the NHS for the future.

11. The Going Further On Cancer Waits (GFOCW) Advisory Group, which oversaw this process, specified in a meeting on the 15th June 2010 that the DH Cancer Team undertaking the review should also:

    - ensure that the cancer waiting time standards were patient-centred and engage with patient groups about what they most value;
    - ensure any revisions to cancer waiting times standards were equitable in terms of service delivery, so for example, revisiting the approach for applying these standards to tertiary cancer providers;
    - tackle specific clinical issues that have arisen, specifically those identified within the diagnostic pathway for prostate cancer and the need for more thinking time for these patients; and
    - consider the impact of any changes to the cancer waiting times standards on the wider systems within local health economies.

12. The information burden placed on the NHS by the need to collect data implement, manage and monitor any revised cancer waiting times standards was also considered within the scope of this review.

13. The scope of this review did not include an impact assessment or assessment of equality as this was undertaken when the cancer waiting times standards were extended as part of the CRS in 2007. Nor was this review intended to identify additional cancer waiting times standards.

Approach

14. As part of this review, the DH Cancer Policy Team undertook to:

[5] http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_117248

- consider the literature covering the evidence for the cancer waiting times standards and any independent studies covering their effectiveness;
- compare policies between the four devolved administrations, particularly the different approaches to implementing and monitoring any cancer waiting times standards;
- engage patient groups, charities, clinical staff and NHS organisations (SHAs, Providers Trusts and Cancer Networks); and
- take account of other developing areas of health policy.

15. In addition to these specific engagement activities any correspondence received during the review of the CRS that is relevant to the review of cancer waiting times standards has been incorporated into the evidence presented to the Advisory Group.

Literature review

16. The aim of the literature review exercise was to investigate published literature concerning cancer waiting times and the standards applied to ensure that there was a rounded approach to the overall review. The scope of the literature covered articles and papers relating to the cancer waiting times standards introduced by the NHS Cancer Plan and CRS that were published between 1999 and 2010.

17. Material was drawn from a range of publications. Of the 25 pieces of literature reviewed, around a third were observational or research studies whilst the remainder were commentaries or articles that drew on the results and conclusions of previous studies. Around half were concerned primarily with the two-week standards (all cancer and symptomatic breast) while the other half could be said to take a more general approach to cancer waiting times as a concept.

Comparative analysis of the cancer waiting times policy between England, Scotland, Wales and Northern Ireland

18. A review of the cancer waiting time policies of the four United Kingdom administrations (England, Scotland, Wales and Northern Ireland) was undertaken to ascertain differences in policies and objectives. This exercise also identified what, if any, changes to cancer service standards or monitoring had been implemented since the 'Comparison of UK Waiting Times Definitions'[6] report was published by the Department of Health, Social Services and Public Safety (Northern Ireland) in 2006, and the publishing of the CRS in 2007.

19. This comparison of policies and statistics between the various administrations focussed on:

- nationally monitored waiting time periods for cancer with reference to published policy documentation;
- coverage in terms of patient groups and tumour types (including those specific groups of patients that are excluded from waiting times monitoring);
- adjustments to calculated waiting times;

[6] http://www.dhsspsni.gov.uk/uk_comparative_waiting_times.pdf

- the responsibility for monitoring the cancer waiting times standards and what systems and/or processes are used to do this; and
- the operational standards (or equivalent processes) set in each administration.

Engagement of patient groups, charities, clinicians and NHS organisations

20. As part of the engagement process the DH Cancer Team sought feedback from a range of stakeholders about the current cancer waiting time standards. Stakeholder groups approached included:

    - patient representative groups
    - cancer charities
    - cancer clinicians
    - NHS and Foundation Trusts providing cancer services;
    - Cancer Networks
    - Strategic Health Authorities

Patients groups and charities

21. Patient representative groups and cancer charities were contacted and asked to respond to a questionnaire. Responses from five national charities were received during the period 28 September 2010 and 26th October 2010.

Clinicians

22. An engagement event was held on 11 October 2010 to seek clinician views. Attendees were asked to consider and respond to four key questions from a clinical viewpoint:

    A. Should cancer waiting times standards be retained?
    B. Do specific targets need changing?
    C. Should specific cancer types be excluded from the scope of the cancer waiting time standards?
    D. How can the system be improved?

    Clinicians who were not able to attend the meeting also had the opportunity to provide written feedback. Thirty clinicians attended the meeting and a further eight gave written feedback.

SHAs, Commissioners and Cancer Providers

23. All ten SHAs have a nominated lead for cancer waiting times. These leads were asked to coordinate contributions to the review within their local health economies. The main tool used in this engagement process was a questionnaire. The SHA responses were the collated views of Provider Trusts, PCTs and Cancer Networks in their region.

24. The outputs of each of these engagement activities were presented to the GFOCW Advisory Group at a meeting on 5 November 2010. The Group was asked to consider all the evidence presented to it, take a view on the key issues that had emerged from these findings as well as revisit the justification for retaining each of the existing cancer waiting times standards, and make their recommendations.

Findings

25. The main findings from each of the review activities are summarised below.

Published evidence

26. The implementation of the cancer waiting times standards introduced by the NHS Cancer Plan and the CRS was supported in many of the published clinical papers. An example of this would be the 'Cancer Waiting Times Audit: Final Report'[7], which indicated that delays with waiting times could influence outcomes, and stated, "*it is undeniable that cancer patients suffer a great deal of worry or anxiety if treatment is delayed*."

27. The conclusions that can be drawn from the published material sourced for the literature review are that the two-week wait standards are more contentious, but not without support. It appears the debate is around the most effective way of triaging patients from primary to secondary care. The one and two month waiting time standards appear to attract far less controversy or debate within the academic and professional community. Here the written material surveyed appears to present a general consensus that longer waiting times increase mortality and reduce the potential for curative treatment. Consequently the one and two month waiting time standards, which concentrate on getting those patients diagnosed with cancer treated as soon as medically appropriate, are geared directly towards that.

28. The published literature, and other evidence, makes a strong case for better patient experience, in that the cancer waiting times standards provides patients with the assurance that they will be dealt with quickly. The National Cancer Patient Experience Survey[8] has shown that for the four common cancers, a higher proportion of patients are now experiencing shorter waiting times for referral to a hospital doctor compared to those surveyed in 2000.

Feedback from stakeholders

29. During the engagement exercises, stakeholder groups gave overwhelming support for maintaining all of the existing cancer waiting time standards. They argued that these had raised standards of cancer care in the NHS. This view was expressed by charities, patient groups, clinicians and managers alike, who felt that whilst the focus on outcomes for cancer was welcomed, the change of emphasis should not be at the expense of the existing cancer waiting times standards.

30. Alongside the support for the existing standards, the stakeholders did identify that improving the quality of cancer waiting times information - making it easier to understand and interpret, whilst improving its timeliness and availability was deemed important.

[7] '*Cancer Waiting Times Audit: Final Report*'. Spurgeon and Barwell, University of Birmingham, March 1999
[8] http://www.dh.gov.uk/en/Healthcare/Cancer/Patientexperience/index.htm

31. There was also a shared view that the way cancer waiting times standards are measured and used for performance management warranted further consideration to better account for the impact of patient choice and "thinking time" and to reflect differences between the requirements of diagnosis and treatment for certain cancers. These are covered in more detail within the following sections.

Comparative analysis

32. All four administrations within the United Kingdom continue to put an emphasis on the access to treatment for cancer services as the focus for setting standards. Each of the countries have one month (31 day) and/or two month (62 day) standards (or targets) which aim to get patients treated as soon as possible following diagnosis. England retains an additional all cancer two week wait standard to get patients into secondary care as soon as possible with the aim of improving 1 year and 5 year survival rates by achieving earlier diagnosis.

Alignment with other policy developments

33. The cancer waiting time standards have been retained in the Operating Framework for the NHS in England 2011/12[9] on the basis that it remains important for patients with cancer or its symptoms, to be seen by the right person, with appropriate expertise, within the current performance standard timescales.

34. The Advisory Group also recognised that the DH will wish to consider their conclusions and recommendations alongside the developments to the NHS in the White Paper, *Equity and Excellence: Liberating the NHS*[10], specifically the commitments to offer greater levels of patient choice, which may pose certain operational problems for critical care services such as the all cancer two week wait.

[9] http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Planningframework/index.htm
[10] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

Conclusions and recommendations

35. The Advisory Group discussed each of the current cancer waiting time standards in detail, with the exception of the all cancer two week wait which is a patient right enshrined within the NHS Constitution[11]. The Advisory Group was also asked for their views on the issues that had emerged within the review.

36. For each section of the Advisory Group discussions, some commentary where relevant, the conclusions reached and any recommendation(s) are set out within the following sections of this report.

Cancer waiting times standards overall

37. The output of all the activities undertaken in this review suggests that cancer waiting time standards continue to fulfil their initial aims, which are to ensure continued progress to achieving cancer outcomes and meeting the needs of patients and their families by guaranteeing timely access to diagnostic investigation and treatment for cancer. There remains strong support for cancer waiting times across all stakeholder groups, including patients and clinicians.

Conclusion

38. There is not sufficient justification to support the discontinuation of the cancer waiting time standards for any of the patient groups currently covered without ensuring that alternative arrangements are in place to ensure that timely access to diagnosis and treatment can be sustained across the NHS. The current cancer waiting time standards continue to support both clinical outcomes and patient benefits.

Recommendation

39. Cancer waiting times standards should be retained.

Consideration of the individual standards

40. The previous Government made a commitment in the CRS to extend the cancer waiting time standards to cover more patients and treatment episodes.

41. Two of these standards were highlighted in the review for further consideration.

42. Maximum 31 day wait for second or subsequent treatment

42.1 The one month standard was extended to cover all cancer treatments, by December 2008 for surgery and anti-cancer drug treatments, and by the end of 2010 for radiotherapy. The implementation date for radiotherapy was delayed to allow for any increases needed in capacity to support a shorter waiting time and

[11] http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113644.pdf

meet the treatment level recommendations of the National Radiotherapy Advisory Group report[12].

42.2 National (England) performance levels have been consistently maintained since the introduction of the standard and are being achieved for all treatment types by the vast majority of providers. Therefore the justification for retaining this set of standards needed to be considered in terms of being the right incentive to drive service improvement.

Conclusion

42.3 The retention of all the subsequent treatment standards remains important in terms of ensuring patients continue to receive timely access to ongoing clinical treatment.

42.4 There is a sound basis supporting the clinical relevance of the maximum wait of 31 days for radiotherapy treatment. The other standards ensure clinical priorities are not distorted for patients requiring subsequent treatments for primary or recurrent cancers at the expense of meeting the one month diagnosis to treatment commitment. Anti-cancer drug or surgical subsequent treatments, together with radiotherapy, can be components of an individual patients' package of care, and it is important to ensure that access to the different treatment components is not compromised by differential standards.

Recommendation

42.5 The benefits for retaining the subsequent treatment standards outweigh the reasons to remove them and therefore they should be retained but kept under close review.

43. Maximum two-week wait for first outpatient appointment for patients urgently referred with breast symptoms, where cancer was not initially suspected

43.1 The standard that all patients urgently referred to a specialist with breast symptoms, whether cancer is suspected or not, to be seen within two weeks of referral was also introduced in the CRS. Not all breast cancers cases are identified by the GP or an NHS Cancer Screening Service. This standard therefore ensures that all patients exhibiting symptoms that could be cancer are referred urgently and seen by a specialist within 14 days. This allows a diagnosis of cancer to be given at the earliest possible opportunity, or for cancer to be excluded, therefore saving the patient the anxiety of waiting longer for a routine appointment and a slower non-urgent diagnostic pathway.

43.2 Feedback indicated there were no concerns with the standard itself, with cancer charities being particularly vocal that it should be retained. However, concerns were raised that the implementation of the 14 day breast symptom standard was not sufficiently flexible to accommodate patient choice. The review suggested that there were circumstances when a patient who might turn out to have a benign condition did not want to attend an appointment within the standard timeframe.

[12] http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_074862

Some cancer service providers have stated that this makes it difficult for them to achieve and sustain the operational standard (93%).

43.3 The NHS Interim Management and Support (IMAS) Intensive Support Team (IST) was commissioned by the National Cancer Action Team (NCAT) and has been working with a number of providers to support them to implement this standard. Feedback from IST members suggests that in the majority of cases the main issues impacting local delivery are related to capacity and demand. This is borne out by the fact that at a national level, over 93% of patients are now being seen within the standard time. NHS internal management information showed that only 10.3%[13] of providers failed to deliver the standard for their patients in three consecutive months (July to September 2010). The IST is aware of instances where the earliest appointment is offered late in the pathway e.g. the 13th day. Where this late date is not convenient the patient inevitably chooses a later appointment, i.e. after the standard waiting time. This in reality is a problem with local capacity management and administration, not patient choice.

Conclusion

43.4 Patient choice may not always be main reason for a patient not being seen within two weeks, though it is an accepted reason for a patient taking longer to be seen and is accounted for in all Departmental assessments of NHS performance.

Recommendations

43.5 The two week breast symptom standard should be retained.

43.6 Those Trusts that are still struggling to meet the operational standard might wish to consider whether this is because there are capacity and demand issues. Better communication with patients should also help to ensure the standard is maintained. The IST and NCAT have produced a 'Top Tips'[14] good practice and guidance document for this standard, which can be shared widely with NHS providers.

44. Maximum one month wait from urgent GP referral to treatment for acute leukaemia and children's and testicular cancers

44.1 The Advisory Group considered the one month wait from urgent GP referral to first definitive treatment standards for acute leukaemia and children's and testicular cancers. They concluded that these remained clinically appropriate and recommended the retention of these standards.

44.2 The Advisory Group also noted that as these patients also fell within the defined "all cancers" cohort used for the maximum two month wait from urgent GP referral to first treatment for cancer, any amendment to this standard would have no impact upon the burden of data collection and management placed on the NHS.

[13] Analysis of data from the Cancer Waiting Times Database, Department of Health, July to September 2010
[14] This is available to the NHS on request and is designed as a local management tool.

45. *Maximum one month wait from date of decision to treat to first treatment for breast cancer; and maximum two month wait target from urgent GP referral to first treatment breast cancer*

45.1 Regarding the one month wait from date of decision to treat to first treatment for breast cancer and the two month wait standard from urgent GP referral to first treatment of breast cancer, the Advisory Group recognised that these were interim steps to the all cancer standards introduced in 2005 and were not currently included in the NHS Operating Framework. However, they concluded and recommended that these indicators should be retained and that the DH should consider incorporating them into a wider tumour level statistical publication, giving greater transparency to the public and allowing more comparative analysis within the NHS.

45.2 The Advisory Group also recommended that publication of national statistics at a more granular level, possibly identifying different types of cancer, would better inform the public and allow greater levels of choice and self determination of care.

46. *Maximum 62-day wait from a referral from an NHS screening service to first treatment for all cancers*

46.1 When looking at the 62-day (two month) wait from a referral from an NHS screening service to first treatment for all cancers, the Advisory Group agreed that the screening standard for bowel screening might be the most problematic to achieve. However, the number of providers affected was too small to justify an immediate revision to the waiting time standards for screening. The Advisory Group recommended that until case ascertainment (data completeness) improves, this waiting time standard should be retained and kept under review.

47. *Maximum 62-day wait from a consultant's decision to upgrade a patient's priority to first treatment for all cancers*

47.1 Regarding the 62-day (two month) waiting time standard following a consultant's decision to upgrade the priority of a patient, the implementation and use of this standard remains a matter for local decision. The Advisory Group concluded and recommended that this standard should remain for local implementation only, although the DH should continue to publish statistics to provide comparative information for the NHS, patients and the public.

The application of cancer waiting times standards for specific cancer types and/or treatment modalities

48. *Prostate cancer and the maximum two month wait from urgent GP referral to first treatment.*

48.1 Prior to and during this review, some members of the clinical community maintained that specific tumour types should be excluded from the cancer waiting time standards. Low Risk Prostate Cancer has been highlighted. This is because:

- The risk of dying from Low Risk Prostate Cancer is about 5% at 10 years and management options include watchful waiting, thus there is no urgency to provide an active treatment in most cases;
- The diagnosis of Low Risk Prostate Cancer is established by the combination of PSA, rectal examination and biopsy, which can cause an extended diagnostic pathway;
- It is considered good practice to include MRI as a further investigation to confirm staging and also to ensure that there are not other areas that may have been missed on the biopsy which would dominate management. MRI is recommended after an interval of at least 6 weeks following biopsy to allow for subsidence of haemorrhage etc;
- Patients with Low Risk Prostate Cancer have a number of different treatment options including active monitoring and may wish to take time to consider these options in detail; and
- This means that once a diagnosis of Low Risk Prostate Cancer has been given patients could be removed from the cancer waits process to allow further detailed assessment and thinking time. Treatment is not urgent.

48.2 The Prostate Cancer Advisory Group were consulted on the exclusion of Low Risk Prostate Cancer from the cancer waiting times standards and in doing so, asked to consider the following options:

Option 1: Retain the two month standard for prostate cancer;
Option 2: Extend the two month standard to allow extra time between TRUS biopsy and MRI;
Option 3: Allow an adjustment for a minimal treatment option (clock stop) in the reporting of cancer waiting times; or
Option 4: Remove prostate cancer from the two month treatment standard.

48.3 The Prostate Cancer Advisory Group was of the firm view that prostate cancer should not be removed from the scope of the cancer waiting times standards, because of the risk that these patients would be de-prioritised. The Group could not reach a consensus as to whether extending the two month standard would benefit these patients. Both Options 2 and 3 were also rejected because of the potential administrative burdens these were likely to introduce as a result of new data requirements.

Conclusion

48.4 The GFOCW Advisory Group concluded that there is a need to ensure performance and activity data are more transparent in order to help clinicians and managers better understand the variations in waiting time by tumour type, including prostate cancer.

Recommendations

48.5 The DH should consider publishing performance data by tumour type to help clinicians and managers monitor the impact of different clinical pathways, including those for prostate cancer on the overall trust performance.

48.6 The DH Cancer Team should undertake further analysis of performance for all prostate cancers (separate from other urological cancers), to establish the number of referrals for this tumour type that come through the two week wait urgent route.

The implementation of cancer waiting time standards

49. Accounting for patient choice and thinking time

49.1 The method of calculating the interval between urgent referral and treatment was revised from 1 January 2009 in order to bring cancer waiting times processes in line with the measurement and management of referral to treatment (18 week) pathways. Until this time it was possible to adjust calculated waiting times to 'suspend' patients during intervals when they wanted time to think about treatment options or were medically unfit to progress to the next stage in the care pathway. This was often referred to by clinicians as 'stopping the clock'. It was decided that it would be too complex and resource intensive for the NHS to run two systems in parallel. In addition there were concerns that some providers might be using suspensions to improve their reported performance.

49.2 This review found that the decision to remove these adjustments has had unintended consequences for the decision-making and planning of cancer treatments. The concern particularly relates to the achievement of the two month standard and the challenge to achieve this without causing a breach. Clinicians reported that they feel under pressure by managers to push patients through a pathway quicker than may be appropriate. The change in the use of adjustments also had consequences for the treatment of specific tumour types e.g. prostate cancer which has been covered earlier in this report.

49.3 To compensate for removing the ability to adjust a patient's calculated waiting time (where appropriate), the operational standard (the level against which local performance is assessed) for the two month standard was revised from 95% to 85%. This change was made so that achievement of the standard would neither be easier nor harder across the NHS.

Conclusion

49.4 Waiting time adjustments to accommodate patient thinking time, patient choice (e.g. decision to go on holiday before a treatment) or patient unfitness should not be reintroduced.

49.5 National performance against the two month standard has been sustained at or above 85% threshold. The majority of cancer providers (over 80%[15]) are achieving the operational standard, which already take the factors previously applied as adjustments into account. For the small number of providers that are failing to meet these standards (in particular the all cancer two week wait and/or the two month standard), the reasons are more likely to be attributed to a lack of capacity, pathway management and administrative issues or more complex clinical pathways.

[15] Cancer Waiting Times Database, Q1 2010/11 (National Statistics)

49.6 Reintroducing a separate system for monitoring cancer waiting times would increase the administrative burden on the NHS and could not be implemented locally or centrally in the short term (it is likely to take at least two years to acquire the necessary permissions to mandate the NHS to submit new cancer reporting information[16]). Any change of this type would also mean that referral to treatment monitoring and cancer waits would no longer be aligned or interoperable locally. The operational standards would also need to be raised to take account of reintroducing these adjustments and could increase the risk of 'gaming' or act as a disincentive for improving Trusts' administrative and clinical pathways.

49.7 However, it is important NHS managers and clinicians understand that only those cancer patients who are willing and able to do so should be treated within the timescales set out by the cancer waiting time standards. The national operational standard is set for performance as a whole i.e. all types of cancer taken together. However, the expected level of achievement within this varies by tumour type and it is not expected that all tumour groups would meet that level of performance. Evidence from the review suggests that it is important that this message is clearly communicated to managers and clinicians again, and shared with patients.

49.8 In addition, better systems are needed to capture the reasons why a patient might wait longer than (breach) a waiting time standard. This would facilitate improvements in administrative systems or care pathway developments by clearly distinguishing between unavoidable breaches (e.g. patient choice and more complex diagnostic pathways) and avoidable breaches due to administrative and capacity issues.

Recommendations

49.9 Provider performance by tumour type together with median waits should be published alongside the Quarterly National Statistics for Cancer Waiting Times[17]. This would enable providers to benchmark themselves with their peers for different tumour type groupings.

49.10 Further guidance for the NHS is required to enable local identification of what are avoidable breaches and how to work towards minimising these by the implementation of efficient pathways of care, to achieve and sustain the current operational standards.

49.11 The Cancer Waiting Times Database (CWT-Db), administered by NHS Connecting for Health, should be further enhanced to collect coded information on the reasons recorded for patient breaches. Currently this is recorded as free text. A change to capturing coded data would enable a better local analysis and benchmarking of nationally consistent breach information.

50. Date of patient transfer between secondary and tertiary providers

[16] Estimate based on guidance published by the Information Standards Board for Health and Social Care: http://www.isb.nhs.uk/how

[17] http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Performancedataandstatistics/HospitalWaitingTimesandListStatistics/CancerWaitingTimes/DH_077389

50.1 Where a patient pathway requires that the patient receive their first definitive treatment at a regional specialist centre (tertiary care provider), rather than the secondary care provider to which they were originally urgently referred with suspected cancer (two week wait), there will be a referral between providers. These referrals to tertiary services are known as Inter-Provider Transfers (IPT).

50.2 From a patient perspective, timeliness of investigation and treatment should not depend on the hospital to which they are initially referred. In practice, however, intervals between urgent referral and treatment are generally longer for patients who require an IPT than for those treated at the hospital to which they were initially referred by their GP. This is independent of tumour type or treatment modality. Across England around 13%[18] of first treatments stopping a two month waiting time period are at the end of a pathway of care containing an IPT.

50.3 Reported activity for IPTs (including breaches) is currently split 50:50 between the secondary and tertiary providers involved. This has had the positive effect of getting secondary and tertiary providers to work much more closely together. However, some tertiary cancer providers are of the view that this arrangement favours the secondary cancer providers, who may delay making referrals for complex treatment. This has caused some specialist providers to raise concerns about the way in which the two month standard is being applied to them.

50.4 The DH Cancer Policy Team investigated the comparative performance analysis of regions in the country where there was a higher concentration of specialist provision in respect of wider national trends for the two month urgent referral to treatment standard. A full report of this analysis was submitted to Ministers. These outputs were also presented to the Advisory Group.

50.5 Comparative analysis of different specialist providers with similar case mix shows that achievement of the two month standard is variable and does not provide sufficient evidence to suggest that the standard is biased against specialist providers. Also, any changes to the measurement of the standard are likely to have an adverse affect on the majority of secondary care providers.

50.6 The DH Cancer Policy Team's analyses indicated that an IPT date around day 38 on the patient pathway might be an appropriate point of transfer. If patients are referred after this day the breach could be allocated exclusively to the secondary provider. The aim is to encourage secondary and tertiary providers to examine and seek to streamline the respective parts of their care pathway.

Conclusion

50.7 The current method for calculating and applying cancer waiting times does appear to be the fairest method for ensuring that the standard is maintained across all providers. With changes in the regulation of Hospital Trusts, the Care Quality Commission no longer operates a breach reallocation procedure. It is important that any revisions to the operational standard are proportionate to the degree or level of regulation that is exercised.

[18] Analysis of data from the Cancer Waiting Times Database, Department of Health, May to December 2009

50.8 Up until now, there have been no steps taken by the DH to set a date for onward referral. This would be complex in terms of the redesign of the CWT-Db and would require the DH to specify timetables to clinically managed pathways. It might also involve an unnecessary level of resources being expended, given that 24 of 28 cancer networks are achieving the operational standard for the two month period. There are however, local arrangements being put in place in some networks to reach a consensus on the appropriate day for onward referral to support management of IPTs.

Recommendation

50.9 The DH Cancer Team should produce further guidance on IPTs to support the development of local arrangements for monitoring day/date of referral from secondary to tertiary care.

50.10 Consideration should be given to piloting a system based around the reallocation of IPT activity based on a day/date threshold in specific areas of the country where there is a concentration of specialist activity. This might help the DH to understand any particular local challenges. Measurement of date of secondary/tertiary referral would enhance local understanding of the problems and should encourage better partnership working.

51. Quality of cancer waiting times information

51.1 Within the review there was significant feedback about the accessibility and quality of cancer information to aid the provision of patient information and support choice, commissioning and service quality improvement.

51.2 At the same time, the DH has been subject to a review of the '*Statistics on Waiting Times for Suspected and Diagnosed Cancer Patients for England*' by the UK Statistics Authority (UKSA)[19].

51.3 The UKSA concluded that since the introduction of the CRS, the DH has worked with the NHS to redesign the administrative data system behind these statistics to ensure that they remain relevant to the changing policy agenda. In addition, it has used this opportunity to harmonise definitions and standards with those underpinning other statistics on hospital waiting times, and actively promoted statistical purposes in the design of the underlying administrative system to enhance its statistical potential.

51.4 It was also the Authority's view that there has been insufficient engagement with users outside the NHS. There was a need to aid non-specialists to interpret and understand what the statistics mean with better commentary and analysis.

51.5 The DH has undertaken a number of steps to address the weaknesses identified by the Authority including:

[19] http://www.statisticsauthority.gov.uk/assessment/assessment/assessment-reports/assessment-report-43---cancer-waiting-times-statistics-for-england.pdf

- o further engagement with the NHS and non-NHS on the utility of and the needs for cancer waiting times information as part of the CRS review;
- o publishing policy on waiting times information on the DH website;
- o publishing a summary of its methods for the production of Cancer Waiting Times Statistics;
- o publishing information about the quality issues associated with the statistics;
- o establishing the feasibility, potential uses and need for comparable statistics across the four UK administrations;
- o publishing the policy for protecting confidentiality in relation to small cell provider counts within these statistics;
- o producing further commentary on the wider policy context for publication alongside these data;
- o revising the presentation of data within the quarterly spreadsheets that are published to ensure that they can be interpreted by non-specialist users; and
- o producing quarterly commentary that includes comparisons of waiting times over time, by treatment type and diagnosis. This will be supplemented by an annual publication of statistics to contain full year data.

51.6 The UKSA has confirmed that the '*Statistics on Waiting Times for Suspected and Diagnosed Cancer Patients for England'* have been designated as National Statistics, following the DH implementing the enhancements required and reporting them to the Authority[20].

Conclusion

51.7 Usability and ease of access to cancer waiting times information is important for both NHS and non-NHS users. The Advisory Group noted the steps undertaken by the DH to meet the specific requirements of the UKSA but was of the view that ongoing lay input into the quality and dissemination of cancer waiting times information would put the requirements set out by The Authority on a sound footing.

Recommendations

51.8 The DH should take further steps to ensure that NHS and non-NHS users are consulted regularly about cancer waiting times statistics to ensure the information supports choice and accountability, and it meets the needs of planning and commissioning cancer services.

51.9 The National Cancer Director should review membership of the Advisory Group to ensure that there is appropriate representation by patient representative groups, cancer charities and GP Consortia (when established).

52. *Addition of median waiting times information to the published Official and National Statistics*

[20] http://www.statisticsauthority.gov.uk/assessment/assessment/assessment-reports/confirmation-of-designation-letters/letter-of-confirmation-as-national-statistics---assessment-report-43.pdf

52.1 The presentation of the cancer waiting times statistics could be further enhanced by including the median number of days patients waited to be treated from referral or the point of diagnosis (as appropriate).

Conclusion

52.2 Adding median waiting time information is not new. Referral to treatment waiting time data are already presented in this way. It provides a useful indicator as to how patients are being managed and gives cancer providers a benchmark by which they can review their administrative and clinical pathways.

Recommendation

52.3 To consider the feasibility of publishing median waiting times information alongside other performance and activity statistics in a way that adds value for the purposes of patient choice and accountability, as well as for service quality improvement.

53. Choice of Consultant Team

53.1 The Advisory Group recognised that there is a Coalition Government commitment in the White Paper, *Equity and Excellence: Liberating the NHS,* to "introduce choice of named consultant-led team by April 2011 where clinically appropriate", and that:

- The consultation *document Liberating the NHS: Greater choice and control*[21] seeks views on implementing this, and the other choice commitments made in the White Paper.
- The consultation document Liberating the NHS: An information revolution[22] seeks views on the information people need to support informed choice, amongst other aspects of giving people greater control over health information.
- The close date of both these public consultations is 14 January 2011.

53.2 The Advisory Group, upon considering the evidence presented felt that larger clinically led teams for cancer, which comprise shared consultant arrangements with a junior doctor team has allowed for the effective management of pooled referrals for cancer. These arrangements have allowed greater flexibility in capacity planning, which has been fundamental to the achievement of shorter waiting times for critical care services such as the two week wait to see a specialist for suspected cancer (or breast symptoms where cancer is not initial suspected).

53.3 The critical nature of the early stages of the diagnostic pathway for cancer patients highlighted within the *The Primary Care Trusts (Choice of Secondary Care Provider) Directions 2009*[23] as a service where the need to progress a diagnosis urgently should not be constrained by all of the choice requirements.

53.4 However, the review process has suggested that patients may want to adapt their pathway of care to personal circumstances after that first outpatient appointment.

[21] http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_119651
[22] http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_120080
[23] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_093004

As such, the Advisory Group suggested there should be no barriers to the availability of choice of appointment (after the first outpatient appointment), admission date, provider or treatment where more than one option is available. ,

Conclusion

53.5 The two week waiting time standard may be compromised as there may not be the scope to allow greater flexibility and accommodation of choice within the current critical care service. However, there are no barriers, except those relating to the local availability of specialist services, that would rule out the provision of choice for later episodes on a patient's pathway of care.

Recommendations

53.6 The DH should

- Work with the NHS to identify where it is possible to offer greater flexibility and choice for patients following a cancer diagnosis and treatment pathway;
- Work with the NHS to investigate how choice and greater flexibility might be offered for the critical care elements of the patient pathway (two week wait); and
- Investigate mechanisms which could ensure that no NHS provider would be penalised for failing to meet a cancer waiting time standard in cases where the delay was due to a patient choosing to wait longer for a particular consultant team.

54. Information monitoring burden for Trusts

53.1 The Advisory Group also considered the administrative burden on the NHS coming from the monitoring and performance management of the cancer waiting time standards.

53.2 There has been an expectation that local provider systems for cancer waiting times information would become better integrated with referral to treatment (18–week) monitoring and the providers central Patient Administration System (PAS), thus reducing the burden of data collected for non-clinical purposes over time.

53.3 Feedback from the engagement exercise suggested that there is still scope to streamline data collection activities (i.e. between cancer waits, cancer registration and cancer clinical audit) and processes between bodies responsible for monitoring or regulating the performance of cancer providers.

Conclusion

53.4 The Advisory Group did not make any specific recommendations but concluded:

- Cancer waiting times monitoring has moved beyond its original remit of performance management to aiding faster cancer registration for surveillance and outcomes monitoring.

- In future, cancer waiting times data will contribute to the Care Quality Commission's Quality Risk Profile (QRP) with no anticipated additional burden on Trusts.
- Locally, cancer data systems are now better integrated with Multi Disciplinary Team (MDT) arrangements, although there is a need to encourage providers to continue to use these systems for proactive patient management.