SCRUTINY BOARD
(ADULT SOCIAL SERVICES, PUBLIC HEALTH, NHS)

CANCER WAITING TIMES IN LEEDS

DRAFT SCRUTINY INQUIRY REPORT

Introduction

1. In June 2015, we[1] identified Cancer Waiting Times as a specific area for inquiry during 2015/16. Part of the basis for this decision was based on advice from the Chief Executive of Leeds Teaching Hospitals NHS Trust (LTHT) that some of the national 'referral to treatment' time targets for suspected cancer were being adversely affected by delays within the patient pathway, particularly in relation to referrals to LTHT[2] from outside the Leeds boundary.

2. However, this report is not solely focused on 'waiting times', as aspects of our work have taken us beyond our original scope and considering wider issues around 'outcomes'.

3. We considered and discussed the matters set out in this report at our Board meetings; while some members also had discussions at the West Yorkshire Joint Health Overview and Scrutiny; and some also attended an 'Improving Cancer Outcomes' workshop (arranged and delivered through LTHT and the University of Leeds). This report seeks to cover the breadth of those discussions and details of the meetings are set out in the appendices.

4. We do not intend to repeat all the evidence and input we have considered as part of this inquiry – but again, those details are summarised in the appendices.

5. As ever, we are grateful to all those who have commented and contributed to our discussions: These have helped form our views and influenced this report and its recommendations, which we hope will help shape the future approach to spotting cancer sooner which will help lead to improved outcomes.

Background

6. The NHS Five Year Forward View[3] refers to a continued focus on improving care, treatment and support for everyone diagnosed with cancer. It sets an ambition to improve outcomes across the whole pathway, including:
    - Better prevention;
    - Swifter diagnosis; and
    - Better treatment, care and aftercare.

7. Following the publication of the Five Year Forward View, NHS England established the Independent Cancer Taskforce, which engaged with a range of stakeholders over a six month period, including:
    - Clinicians

[1] Leeds City Council's Scrutiny Board (Adult Social Services, Public Health, NHS)
[2] Leeds Teaching Hospitals NHS Trust (LTHT) is a regional specialist centre for cancer diagnosis and treatment.
[3] Published in October 2014, the intention of the NHS Five Year Forward View is to set out how the health service needs to change, arguing for a more engaged relationship with patients, carers and citizens in order to promote wellbeing and prevent ill-health.

- Patients
- Charity representatives
- Policy-makers

8. In July 2015, the Cancer Taskforce published its report*, Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020*. The report included over 90 recommendations aimed at organisations across the healthcare system in order to achieve a step change in cancer care across the country.

9. The Cancer Taskforce report aims to guide work on cancer over the coming years and focuses on six key priority areas:

    - Prevention and public health;
    - Early diagnosis;
    - Patient experience;
    - Living with and beyond cancer;
    - Investment in a high-quality, modern service; and
    - Commissioning, accountability and provision.

10. In the summer of 2015, the Office of the Director of Public Health undertook a review of cancer outcomes in Leeds, with a focus on the three Clinical Commissioning Groups (CCGs) in Leeds – namely Leeds North CCG, Leeds West CCG and Leeds South and East CCG. Where possible, the review also sought to compare outcomes across Leeds and against the England average.

Main issues and comments from the Scrutiny Board

11. It is widely recognised that cancer can be a significant cause of anxiety for the public. However, it might be less well known that cancer remains the single greatest cause of death in our population, as well as being both a cause and consequence of health inequalities.

12. At the outset of our inquiry, we were specifically concerned with the waiting times from GP referral to treatment. As mentioned earlier, part of the basis for this decision was following advice from the Chief Executive of Leeds Teaching Hospitals NHS Trust (LTHT) that some of the national 'referral to treatment' time targets for suspected cancer were being adversely affected by delays in referrals to LTHT from outside the Leeds boundary.

13. Given the potential issues, we referred to the matter to the Joint Health Overview and Scrutiny Committee (West Yorkshire), for consideration and heard anecdotally that under performance could also be attributed to issues of capacity at LTHT. As such, it is difficult for us to assess with any certainty the true cause of delays in the referral pathway – although overall, we believe that delays are often likely to be multifaceted. However, given the understandable and significant cause of anxiety that cancer will often bring to members of the public, we believe it is incumbent on the different parts of the NHS and different NHS Trusts to work collaboratively for the benefit of patients and that organisational impacts must be secondary considerations.

14. However, we were heartened to hear during the course of our inquiry that performance against the national targets had improved and that there appeared

to be improved collaboration and communication between different parts of the NHS on a sub-regional (i.e. West Yorkshire) basis.

Recommendation 1

That all local NHS organisations involved in the commissioning and delivery of services for the diagnosis and treatment of cancer continue to work collaboratively for the benefit of patients and that organisational impacts are secondary considerations.

15. We also understand there are arrangements in place to routinely consider performance through a range of different bodies, including the LTHT Cancer Board and the LTHT Contract Management Board (for issues relating to activity, finance or performance). Nonetheless, we are mindful of the significance and importance to the public that the early diagnosis and treatment of cancer have. Therefore, we believe it is important to ensure recent improvements are both embedded and sustainable in the longer-term and that any successor Scrutiny Board should seek to assure itself that performance levels continue to be maintained and improved.

Recommendation 2

That commencing in the new municipal year (2016/17), the Scrutiny Board (Adult Social Services, Public Health, NHS) routinely and regularly considers the key performance indicators associated with the early diagnosis and treatment of cancer.

16. We understand that some of the improvements may be a result of the formal establishment of the West Yorkshire Association of Acute Trusts (WYAAT) – with a key focus of its work being to drive forward a 'model clinical network' that will deliver improved and consistent outcomes for patients by using the latest technology[4]. We see the establishment of the WYAAT as an important and helpful development that is likely to have implications beyond matters associated with the early diagnosis and treatment of cancer. As such, along with the Joint Health Overview and Scrutiny Committee (West Yorkshire), we look forward to receiving further reports on the plans and achievements of the WYAAT.

Recommendation 3

That by December 2016, the Chair of the West Yorkshire Association of Acute Trusts, provides a further report on the achievements to date and future plans of the association.

Prevention, early diagnosis and treatment

17. In order to inform a strategic approach to cancer prevention, early diagnosis and treatment in Leeds, the report from the Director of Public Health that we considered in February 2016, set out the review of cancer intelligence available

[4] As reported to the Joint Health Overview and Scrutiny Committee (West Yorkshire) in December 2015.

to the public health team. The report considered the available evidence under the following areas:

- Risk factors
- Incidence
- Early diagnosis outcomes
- Screening uptake
- Routes to diagnosis
- Stage at diagnosis
- Mortality
- Mortality in all ages
- Mortality in under 75s
- Avoidable Potential Years of Life Lost from Cancer (age under 75)
- Survival

18. The report highlighted the challenges facing Leeds in its approach to the prevention, early diagnosis and treatment of cancer. Issues around the performance of LTHT against the national performance targets for referrals to treatment formed only a part of the matters outlined to us, with some significant matters around health inequality issues across different parts of the City highlighted. Some of the other key issues we feel that have been identified, include:

    - Cancer incidence is generally rising, with a UK incidence modelling study projecting cancers in men and women to increase by 55% and 35%, respectively, between 2007 and 2030.
    - Cancer mortality rates for the under 75s in Leeds are higher than the Yorkshire and Humber and England averages: This being due to higher rates in Leeds South and East CCG and Leeds West CCG.
    - Cancer mortality rates in Leeds are significantly worse than the Yorkshire and Humber and England averages.
    - The higher incidence of prostate cancer in Black men (accounting for over 40% of Black Men's cancer).
    - Cancer screening uptake being lower in more deprived communities, which can worsen health inequalities – highlighted by the differential screening levels for bowel cancer across different CCG areas.
    - Screening uptake for both breast cancer and cervical cancer are currently below the 80% target and falling.
    - Insufficient quality data to present the routes patients use for cancer diagnosis and the stage[5] at which cancers are diagnosed.
    - A mixed picture when considering survival rates across Leeds and comparing these regionally and nationally.

19. The Director of Public Health's report also highlighted a new outcome measure – that of Avoidable Potential Years of Life Lost from Cancer (age under 75). This measure takes account of the age and cause of death. While some of the data used would be suggestive that treatment outcomes in the under 75s are improving, this also highlighted the stark inequalities across areas of the City, particularly in the area of Leeds South and East CCG.

[5] Earlier diagnosis and better planned treatment generally lead to better longer-term outcomes

20. Using the available intelligence to develop the Leeds Cancer Strategy and Improvement Plan is the logical next step. In doing this, we believe one of the challenges will be balancing the need to provide a 'core' or 'standard' offer for all patients from across the City, while recognising and addressing the identified and known aspects of health inequalities across different parts of the Leeds and its communities.

Recommendation 4

That in developing the Leeds Cancer Group due consideration is given to ensuring there is a balance between providing a 'core offer' for all patients from across the City, while recognising and addressing the identified and known aspects of health inequalities across different parts of the Leeds and its communities.

21. Within the report from the Director of Public Health and the available intelligence, it states that this does not cover patient reported outcome measures, measures on the process of care or patient experience of care.

22. As referenced elsewhere in this report, NHS commissioners and providers have a duty to involve the public and patients in developing services. As such, we believe patient experience and any associated data will provide a rich source of intelligence in the development of Leeds Cancer Strategy and improvement plan. As the patient champion and an organisation that aims to present the patient voice, we believe that HealthWatch Leeds could play an important role in helping to capture and report patient experience data and believe further discussions and investigations may be warranted.

Recommendation 5

That by September 2016, the Director of Public Health engages with HealthWatch Leeds to assess the current availability of patient experience data (as it relates to the prevention, early diagnosis and treatment of cancer) and/or the potential future role of HealthWatch Leeds in collating such data.

Leeds Cancer Strategy Group

23. In order to improve cancer outcomes in Leeds, the Director of Public Health's report also made reference to a new Leeds Cancer Strategy Group – setting out the group's Terms of Reference. The Terms of Reference were presented as draft and dated November 2015. The establishment of the Leeds Cancer Strategy Group was also referenced in the report we considered at our November 2015 Scrutiny Board meeting.

24. The Terms of Reference for the Leeds Cancer Strategy Group (LCSG) sets out the group is 'primarily a co-ordinating group', with its outputs feeding into a number of other settings. The LCSG is essentially a partnership group that draws its membership from a range of health and social care partners from across the City, and beyond. These include:

    - The University of Leeds

- Leeds Teaching Hospitals NHS Trust
- Leeds Clinical Commissioning Groups (CCGs)
- Leeds City Council – represented by Public Health and Adult Social Services
- NHS England (Specialist Commissioning)
- West Yorkshire commissioning group (10CC)
- Macmillan

25. However, in the spirit of improving overall involvement and engagement, we question whether or not the public voice is represented through the proposed membership. In addition, given some of the very specific health inequality issues identified with the Director of Public Health's review report, we would also question whether the diverse communities within Leeds are sufficiently represented by the current, proposed membership.

Recommendation 6

That by December 2016, the Chair of the Leeds Cancer Strategy Group reviews its currently proposed membership to ensure this includes:

(a) Appropriate patient and public representation; and,

(b) Appropriate representation to reflect the diverse communities within Leeds, particularly in those areas where specific health inequalities are known to exist.

26. The Terms of Reference for the LCSG also sets out a range of responsibilities for the group, including:

- Ensuring a coordinated plan to deliver the National Cancer Strategy for the population of Leeds and within the LTHT Cancer Centre;
- Defining Leeds' contribution towards National cancer policies through the development of the Leeds Cancer Strategy and plan;
- Ensuring a coordinated response and clarity about responsibilities for delivery of actions agreed by the LCSG;
- Ensuring a focus on cancer inequality reduction and improved outcomes.

27. We welcome the establishment of the LCSG and believe that through partnership working there are opportunities to improve the approach and outcomes for cancer prevention, early diagnosis and treatment in Leeds. We also recognise that through the LTHT Cancer Centre, Leeds also provides services to sub-regional and regional populations: As such, improvements are also likely to impact on a wider Yorkshire and Humber basis. However, what we believe to be less clear are the timescales associated with developing and agreeing an overall Leeds Cancer Strategy and improvement plan; and where these will be presented and agreed.

Recommendation 7

That by July 2016, the Chair of the Leeds Cancer Strategy Group reports back to the Scrutiny Board regarding the timescales associated with developing and agreeing an overall Leeds Cancer Strategy and improvement plan, including details of where these will be presented and agreed.

28. In developing an overall Leeds Cancer Strategy and improvement plan, we would again remind NHS commissioners and other stakeholders of the duty to involve patients and the public, alongside the separate duty and requirement to engage with the Scrutiny Board when considering any proposals to develop and/or changes services in the future. We would also highlight that where any changes are likely to impact on a wider population – such as West Yorkshire – it may also be necessary to engage with the recently established Joint Health Overview and Scrutiny Committee (West Yorkshire), in an appropriate and timely manner.

Recommendation 8

That by July 2016, and as part of the process for developing and agreeing an overall Leeds Cancer Strategy and improvement plan, the Chair of the Leeds Cancer Strategy Group:

(a) Recognises the duty on NHS commissioners and providers to effectively involve and engage patients and the public, setting out plans for public and patient engagement and involvement.

(b) Sets out proposals and timescales for engaging with the appropriate Overview and Scrutiny bodies.

Reaching New Heights: Improving Cancer Outcomes – Spotting Cancer Sooner.

29. As mentioned in our introduction, we are also pleased to report that some members of the Scrutiny Board had the opportunity to be attend and be involved in some of the work being taken forward by the LCSG, through the workshop *Reaching New Heights: Improving Cancer Outcomes – Spotting Cancer Sooner.* The workshop drew together a range of professionals, commissioners, clinicians and patient representatives – both from Leeds and beyond and considered:

- The national context and the national cancer strategy.
- Specifics for Leeds and how these compared nationally.
- An example from Denmark, where changes in the approach and the development of a diagnostics centre had significantly reduced the time taken to provide a definitive diagnosis.

30. Delegates were then engaged in discussions around the challenges and defining 'what good looks like'. We understand the outputs from the session are now being used to inform the strategy for Leeds aimed at improving outcomes for cancer patients. As part of our on-going involvement, we look forward to seeing how this work is used to inform the development of the Leeds Cancer Strategy and improvement plan.

Public Health Grant

31. Our consideration of cancer wait times has included some specific reference to the work around prevention – largely a function of Public Health services. However, through other aspects of our work during the course of the year, we have also considered the general role and pressures on the work of the Council's Public Health teams.

32. Despite a range of national statements of intent about the healthcare system focusing on prevention, over the course of the 2015/16 we have seen central government action to:
    (a) Implement a one-off in-year cut to the local authority public health grants, which had a local impact of around £3M; and,
    (b) Confirm the one-off cut as a longer-term cut to the public health grant.

33. It should also be recognised that cuts to the local public health grant was in addition to the Leeds public health grant being below the target level of funding: With the target level of public health grant being based on the needs assessment used by central government. In our view, the cuts to the local authority public health grant across England have therefore been disproportionate to those local authority arears where that grant is already known to be 'below target' and not sufficient to meet local needs.

34. By the nature of the services provided, public health services focus strongly on prevention of ill-health and health protection. Therefore, it is difficult to understand how any reduction to the public health grant can do anything other than undermine one of the cornerstones of the NHS Five Year Forward View – that of 'Better Prevention'.

35. Concern that a reduction in public health grant might impact negatively and disproportionately on prevention, cancer awareness and early diagnosis work was highlighted in the January 2016 report to the Health and Wellbeing Board – which we also considered in February 2016. We share the concerns about the reduction to the Council's public health grant and expressed our concerns as part of the Department of Health consultation on the in-year cuts earlier in the year.

36. It seems to us that if the need to focus on better prevention is being undermined by reductions to local authority public health grants, the only alternative source of funding is directly through local Clinical Commissioning Groups (CCGs). However, there are already pressures on commissioning budgets and it's likely that the local CCGs will need to make some decisions around the services they will continue to commission and those areas where services might change and/or be decommissioned. We believe the pressure on the preventative work undertaken through public health might, at least in the shorter-term, create further budget pressures elsewhere in the local health and social care economy.

Recommendation 9

That by September 2016, Leeds Clinical Commissioning Groups provide a joint report on the commissioning priorities and intentions for 2016/17, specifically identifying any preventative services and the associated budget allocations, identified within the overall priorities.

37. It is hoped these comments and recommendations further enhance the current focus on the prevention, early diagnosis and treatment of cancer in Leeds and we look forward to a formal response to our comments and recommendations by July 2016.

Cllr Peter Gruen, Chair
On behalf of the Scrutiny Board (Adult Social Services, Public Health, NHS)

May 2016