HEALTH AND WELLBEING BOARD: 20 NOVEMBER 2014

REPORT OF THE DIRECTOR OF PUBLIC HEALTH

2013/14 LEICESTERSHIRE CANCER AUDIT

Purpose of Report

1. The purpose of this report is to highlight the results and lessons from the 2013/14 Leicestershire GP cancer audit.

Policy Framework and Previous Decisions

2. One of the key priorities in the Leicestershire Health and Wellbeing Strategy 2013-16 is to *'reduce the number of people who die prematurely from cancer'*

3. *The HWBS pledges that we will:*

   - Monitor and influence cancer outcomes across the entire cancer pathway from primary prevention to end of life care.
   - Ensure that resources are targeted proportionally (i) across the whole cancer pathway and (ii) in areas of greatest need and particularly in our most vulnerable populations.
   - Facilitate, promote and increase public awareness of cancer symptoms and ensure timely onward referral for people identified as potentially having cancer.

Background

4. In 2013/14 local primary care trusts carried out a GP cancer audit across Leicester, Leicestershire and Rutland **(appendix A)**. The audit's remit was to identify causes of avoidable delays in cancer diagnosis at a local level and to produce recommendations to address such delays. The final report from this audit was published in March 2014 and is the subject of this paper.

5. Cancer causes two fifths of all premature deaths (deaths under 75 years), making it the most common cause of premature mortality in England.[i] Approximately one person in three develops cancer at some point during their life and more than one in four people dies from cancer.

6. Overall cancer services have improved for everyone in recent years. However the progress made in achieving better cancer outcomes has been uneven. We know that inequalities between different groups of people persist in relation to incidence, access to services and treatment, patient experience and outcomes[ii].

7. Between 1993-95 and 2007-09, premature mortality rates from cancer in Leicestershire County and Rutland fell from 132 per 100,000 population to 99 deaths per 100,000

population. However the rates of premature cancer deaths have not decreased to the same extent as heart disease.[iii]

8. For many of the more common cancers, England has poorer survival rates than in comparable developed countries[iv]. A major cause of our lower survival rates is later diagnosis i.e. due to people being diagnosed with cancer when their tumour is at a stage when life-saving (e.g. surgical) treatment will not contain its impact and spread. This delay in diagnosis can happen at a number of points and for a number of reasons including significant variation in public awareness of cancer symptoms and inequalities in referral rates for suspected cancer cases.

9. There is a need for greater focus on earlier diagnosis of cancer through:

   - Raising awareness of several cancer warning signs and risk factors, especially in more deprived and in certain ethnic groups in the UK, to facilitate improvements in early presentation and cancer prevention behaviours
   - Addressing barriers to seeking help, such as fear and lack of confidence to discuss symptoms with GPs
   - Ensuring that primary care is responsive when patients present with signs and symptoms suggestive of possible cancer
   - Increasing awareness of and uptake of National Cancer Screening Programmes

National initiatives to diagnose cancer earlier:

10. The National Awareness Early Diagnosis Initiative (NAEDI) was launched in 2008 to better understand and address reasons for late diagnosis in England. Primary care has a key role to play in the diagnosis of cancer as over 90% of all patient contacts with health care in the UK occur in this setting. The NAEDI work programme produced a national audit of cancer diagnosis in primary care in 2009/10 covering 18,879 cancer patients registered with 1,170 practices[v]. The audit helped develop criteria for best practice, in order to improve future cancer outcomes, by generating insights into the diagnostic pathway.

Local initiatives to diagnose cancer earlier:

11. In 2012/13 local primary care trusts agreed to fund a repeat of the NAEDI GP cancer audit across Leicester, Leicestershire and Rutland. The final report from this repeat audit was published in March 2014 and is the subject of this paper. This report details the results for newly diagnosed cancer patients registered with GPs in the three Leicestershire CCGs (Leicester City, West Leicestershire and East Leicestershire and Rutland).The findings have been shared with GP localities across the county.

12. This report focuses on aspects of the audit data at GP locality level to help CCGs and partners identify any future actions that should be taken to improve the early diagnosis of cancer at a more local level. The audit also helped to assess the extent to which there had been improvements in the early diagnosis of cancer across key stages of the diagnostic pathway.

Key Findings of the local GP cancer audit (2013/14):

13. Across Leicestershire**, 36.1%** of practices participated in the 2013/14 audit. In total **1,377** patients records were examined (compared to 1,702 in 2009/10).

14. The over 70s age group accounted for approximately **50%** of all new cancer diagnoses. The mean age at diagnosis for all Leicestershire cancer patients was 68 years old.

15. The four most common cancers across LLR were breast, colorectal, lung and prostate cancers, with breast cancer being the common cancer for all CCGs accounting for approximately **15%** of all cancers. These findings are in line with national trends.

Cancer Stage at Diagnosis

16. Across Leicestershire, **44%** of cancers identified by the audit were spread beyond the primary organ.

Avoidable delays:

17. From the total number of **1,377** patients GPs identified that there was clear evidence of ‘avoidable’ delay in **211** cases. In a further **160** cases GPs indicated that they were unsure as to whether there had been a delay which could have been avoided. Therefore, GPs considered that **15.3% of all cancer patients included in the audit had experienced some type of avoidable delay in their diagnosis**.

18. Levels of delay varied depending on cancer type e.g. 33% in sarcoma cases, 30% of colorectal cases, 100% of thyroid cases, and in 50% of cases of gallbladder and cancers and cancers of unknown primary. Other cancers more likely to present late included vulval, mesothelioma, ovarian and pancreatic cancers.

Causes of avoidable delays:

19. The results for the three Leicestershire CCGs included:

- Patient factors – e.g. delayed presentation, not attending for tests/appointments
- GP factors – e.g. delay in making referrals or following up urgent referrals
- Secondary Care factors – e.g. delay in finding an appointment slot, failing to follow up patients previously seen etc
- No clear reason for delay
- Incidental finding.

Patient factors:

20. Common reasons related to patient delay in presentation to the GP and patients delaying or failing to attend appointments. Other reasons involved the patient refusing referral or further investigations.

GP factors:

21. Most of the reasons given for delay in this group suggested that the GP could have made the referral sooner or could have made a 2-week wait referral. In a few cases it was suggested that the GP could have ordered a test or performed a more detailed examination. In a couple of cases a referral was made, but rejected by secondary care because, for example, a letter had not been attached or an initial blood test had not been performed.

Secondary care factors:

22. The most common reasons given for an avoidable delay in secondary care related to a delay in performing a test or a delay in making a diagnosis. In a few cases, the delay was caused by a delay in the patient receiving an appointment, the patient not been seen within the 2-week timeframe or a delay in the reporting of test results

No clear reason:

23. Reasons given for delays generally related to complicated or vague symptoms. Other reasons included unclear test results, or another potential cause for the symptoms being investigated on initial presentation.

24. The audit also asked if rapid access to investigations would have altered their management of a case. In **28 (6%)** of 478 cases in e.g. East Leicestershire and Rutland CCG the response was 'yes'. The investigations which would have been useful were reported as CT scan (8 cases), ultrasound (5 cases), endoscopy (5 cases), x-ray (2 cases) and MRI (3 cases). In five cases the additional investigations that may have been useful were not specified.

25. Two groups which had particularly higher risk of delayed referral were housebound patients and patients with communication difficulties.

Comparison with Results of 2009/10 GP Cancer Audit (Leicestershire)

26. The median (average) number of days between the patient first noticing symptoms and presenting to primary/secondary care was the same in the two audits (**7 days**).

27. There was very little change in the median number of days between the patient presenting with symptoms and being seen by a cancer specialist between the two audits - **22 days** in the 2009/10 audit and **23 days** in 2013/14.

28. The percentage of cancer patients with disease spread beyond the organ at the time of diagnosis was similar in the 2013/14 audit and the previous audit (**44% vs 49%**). This difference was not statistically significant different i.e. may have resulted from chance/random variation.

29. Across Leicestershire, there was very little change in the percentage of cases referred as emergencies between the two audits. None of the increases or reductions in the percentage of cancer patients referred as emergencies are statistically significant at the 95% confidence level i.e. differences may be due to chance/random variation.

Resource Implications

30. Public health approaches to raising awareness of cancer symptoms and screening are not cost neutral but overall costs will be reduced by aligning to national campaigns.

31. A repeat of the GP cancer audit should be considered in the future. This would require additional funding

Conclusions/Recommendations

32. Cancer is the now most common cause of premature mortality in Leicestershire.

33. England has poorer survival rates than in comparable developed countries. A major cause of our lower survival rates is later diagnosis.

34. Local commissioners will want to work with patients, primary and secondary care providers and other partners to improve early awareness and diagnosis of cancer.

35. **A local GP cancer audit** in 2013/14 concluded that patient delays in diagnosis were significant across all cancer sites-**15.3%** of all cancer patients included in the audit. This is lower than in the previous audit reported in 2009/10 (**18%)**, although the difference is not statistically significant i.e. it may be due to chance. For the four most common tumour sites (breast, colorectal, lung and prostate), patient factors accounted for **16%** of delays, primary care factors for **20%** and secondary care factors for **25%,** with **7%** of cancers diagnosed as a result of incidental findings and **31%** having no clear reason for delay. The reasons for delay were often complex, nevertheless, common factors amenable to a systematic, organizational approach did emerge. Administrative problems concerning the tracking or management of referrals and/or test results were mentioned in a number of cases indicating that there is scope for checking and reviewing 'fail safe' procedures in both primary and secondary care to ensure that referrals are not 'lost', or that results are not interpreted or followed-up.

Recommendations

36. Reinforcement of 'warning sign' messages for the wider public, e.g. through national or local campaigns, could impact upon patient delays in presentation. CCGs and other partners e.g. local authority and the voluntary sector may wish to consider whether local approaches are required to promote early diagnosis messages. This is especially important to particular groups who may have cultural, language or other barriers to accessing services (including cancer screening programs).

37. Additional interventions which GP practices and CCGs may wish to consider include:

- Analysis of 2 week wait 'urgent' referrals to understand the **55%** of cancer diagnoses referred through this route. This may indicate possible approaches to increasing the proportion of eventual cancer diagnoses referred under the 2 week wait route as these are more likely to lead to earlier diagnosis.
- Establishment of a tracking, review system for 2 week wait 'urgent' referrals to ensure that patients have been seen, have a management plan in place and that it is clear who (consultant or GP) is responsible for any further action.
- Establishment of Significant Event Audit to identify and learn from any untoward events on the cancer referral pathway and ensure referral systems and processes are reviewed in light of the results.
- Ensure management of possible cancer referrals is included in professional development plans for all relevant staff groups. This could include updates on existing and new NICE guidance, embedding of current NICE and local guidelines in referral protocols/proformas and routine use of readily available educational modules.
- Use the results of the 2013/14 audit to refresh any 'key priorities for action' identified from the 2009/10 audit. Consider using data items (and 2013/14 baseline values) to generate key performance indicators for new 'key priorities'.

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Appendix

An Audit of New Cancer Diagnosis in Primary Care in East Leicestershire, Leicester City and West Leicestershire CCGs.

Relevant Impact Assessments

Equality and Human Rights Implications

38. The audit looked at referral patterns and delayed diagnosis in specific socially excluded groups e.g. those who are housebound and those with communication difficulties.

Partnership Working and associated issues

39. Partnership working and effective collaboration across partners are key in terms of diagnosing and treating cancer. The cancer pathway from recognition of symptoms through to treatment creates important opportunities for different partners e.g. clinicians, the local authority and voluntary sector to facilitate earlier diagnosis.

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[i] The NHS Information Centre. Compendium of Population Health Indicators, https://indicators.ic.nhs.uk/webview/

[ii] http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/crukmig_1000ast-3344.pdf

[iii] http://www.lsr-online.org/uploads/2012-leicestershire-jsna-cancer.pdf

[iv] http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70546-1/abstract

[v] https://www.dur.ac.uk/resources/school.health/erdu/NationalAuditofCancerDiagnosisinPrimaryCare.pdf