

LEICESTER CITY HEALTH AND WELLBEING BOARD 29th JUNE 2023

Subject:	Understanding and acting on low 1-year colorectal cancer survival in Leicester City
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EXECUTIVE SUMMARY:

Leicester City had the lowest proportion of people surviving colorectal cancer to one-year post diagnosis at least up to 2019. This situation, which has been developing gradually over a twenty-year period was identified initially by regional public health colleagues. A multidisciplinary, system-wide task and finish group was formed within LLR to investigate. This drew together partners from across public health, community, primary and hospital care and the voluntary sector.

The investigation centred on carrying out a "system diagnostic" based on data and insights to look below the surface of the observed trend and identify (and where possible test) hypotheses about why the difference in survival (in comparison to local and national neighbours) was occurring. The ambition was to remove preconceptions about population or service factors and instead objectively determine possible causes from the triangulation of appropriate datasets.

The process was interrupted by the COVID-19 pandemic, but then by difficulties in obtaining and collating various datasets and other information. This clearly demonstrated opportunities that exist – at every level - for further integration of data plus capacity and capability to interpret and understand it, to build improved intelligence-led system insights.

The picture that now emerges shows that in fact the poor figures for colorectal cancer survival, are set against a picture of colorectal cancer numbers (incidence) that are also falling, driven by the dynamic demographic profile in Leicester City. An important epidemiological study based on Leicester City itself showed that the incidence of colon cancer in the British Indian population is only half that of the white British population. The changing ethnic mix in the City clearly illustrated over successive Censuses, means that an increasing proportion of the colon cancers now emerging are seen to be in a white British (particularly male) population, over 60 years of age and from more disadvantaged parts of the City.

This new intelligence is enabling a much more appropriately and proportionately targeted action plan to be pulled together which plans to identify and manage cases earlier. The plan is coordinating contributions across the sectors and aiming to work with inputs from ICS, Place and PCN connecting into and with communities.

Further investigative work is still ongoing, to fill in remaining gaps and help answer outstanding questions. It will also be necessary to help drive, monitor and evaluate change. UHL-based colorectal cancer surgery achieves good clinical outcomes; a finding validated at an early stage through National Bowel Cancer Programme. Clinicians at UHL are undertaking a detailed audit of several years data to provide more necessary detail, and this is linking in to audit work in primary care, and insight work through public health into the community. A range of policy and resourcing opportunities are already being explored as components of a change programme.

RECOMMENDATIONS:

Members of the Leicester City Health & Wellbeing Board are invited to note the findings of the investigative work and support the next steps and actions set out in the table on slide 16.

Members are asked to raise awareness of this distinctive pattern of disease burden in the City and support the appropriate focus of policy initiatives and resources to enable effective interventions to address this outlier survival status from this serious condition.

This work presents an opportunity for Board members to further discuss (and obtain assurance on):

- how poor outcomes, inequalities and/ or inequities are routinely identified, investigated and acted on based on the particular demographics of the LLR System,
- opportunities to further enable and ensure data integration for intelligence-led system understanding of issues, and for drawing in insight from across partnership networks.

• Leicester City was the worst performing area in the country for colorectal cancer (CRC) 1 year survival.

• The colorectal cancer survival index up to 2019 showed a continuing worsening trend with the proportion surviving CRC to one-year post diagnosis down at 69.7 (decreasing from 70.7% in the previous period and 11% lower than the England average).



Source: <u>https://www.gov.uk/government/statistics/cancer-survival-index-for-clinical-commissioning-groups-2003-to-2018</u>

• As well as being the worst performing area in the country, Leicester City had fallen markedly behind the other CCGs over the last ~15 years.

Variation in survival by CCG relative to England

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The charts here show how the variation of survival by CCG changes over time for the index of cancer survival, breast, colorectal (bowel) and lung cancers separately, which can be selected by choosing from the drop-down menu. The CCGs are coloured and shaped depending on whether their survival was better or worse than the net survival for England in 2004.

Hover over a plot for information about the data points. Click on the camera icon at the top of a plot to save the plot as a .png file.

Select a site to view survival by

Colorectal

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Select the area you want to highlight
NHS Leicester City CCG



Please note that the y-axis for this graph does not start at 0 and varies to automatically to select a good range for comparing survival trends among the selected areas.

Source: https://nhsd-ndrs.shinyapps.io/index_of_cancer_survival/

Leicester City however only had a moderate mortality rate for colorectal cancer, which may have covered up the poor 1-year survival.
This is likely to be driven by another finding - the very low colorectal cancer incidence in comparison to many other CCGs.

Incidence of colorectal cancer per 100,000 population (all ages) - 2017



Leicester City West Leicestershire East Leicestershire/Rutland

Other East Midland CCGs

Source: RightCare Cancer Focus Pack, NHS Leicester City CCG

- The relatively **low and declining incidence** of colon and rectum cancer is part of a long-standing downward trend in Leicester since the 1990s.
- The key question is what is accounting for this low incidence? Is it due to age, ethnic/cultural mix or something else?



- Further adding to this picture is data about the **colon and rectum cancer death rate in** Leicester.
- In comparison to both the England and other areas within the Integrated Care System (ICS) we can observe a longstanding downward trend in deaths per 100,000 due to colon and rectum cancer.



Source: https://vizhub.healthdata.org/gbd-compare/

- A critical key point emerges from the last 3 Censuses, however, which show that the proportionate ethnic make-up of the Leicester population has also followed a continuing trend of change.
- Between 1991 and 2021, Leicester's total population has increased by almost 100,000 from, 270,629 to 368,571.
- Over the last forty years, the number of White residents has decreased while the number of residents from all other broad ethnic groups has increased.



*Due to changes in the census questionnaire, ethnic group categorisation is not entirely consistent. The first census to include a question on ethnicity was 1991. The mixed/multiple ethnic group category was introduced in 2001.

Source: Census/ Leicester City public health team

A high proportion of the Asian population in Leicester are Asian Indians. This is across the age structure, but even more so in the over 60's.
Leicester is now home to the largest number of British Indians of any English city, standing at 6.6% of the national total.



Source: Census/ Leicester City public health team

• This leads us to ask, is there a differential incidence of Colorectal Cancer in ethnic groupings within Leicester City?

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• Evidence (paper below) shows that the incidence rate of colon cancer (but not rectal cancer) in British Indians is around half that of British whites.

	British whites	British Indians	Mumbai Indians		
Male					
Colon	18.2 (1)	9.9 (0.52)	3.0		
Rectum	11.7 (1)	9.8 (1.19)	2.6		
Female					
Colon	15.5 (1)	5.9 (0.38)	2.4		
Rectum	6.5 (1)	7.8 (0.98)	1.8		

Source: British Journal of Cancer (2010) Cancer incidence in British Indians and British whites in Leicester, 2001 – 2006 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2905295/

- The substantial change in the demographic, ethnic make-up of the Leicester population, with an increasing and sizeable proportion shown to have around half the incidence of colon cancer, is likely to account for the decline in incidence and deaths seen over approximately the same period.
- But, what therefore- might account for the prolonged fall in the 1-year survival for colorectal cancer in Leicester in parallel over a similar time trend?

Summary

- Patients diagnosed with colorectal cancer via an emergency admission are more likely to have later-stage disease and are likely then to have a poorer prognosis.
 - Recent Leicester data (for a single year) suggests that such patients were largely white males with age range 60 -79.
 - Over half of patients diagnosed through this route were from the most deprived areas in the city.

Bowel cancer activity for Leicester City CCG (2022) 1st diagnosis emergency admission. Annual rate per 100,000 population









1st Diagnosis: Emergency Admission by Deprivation





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Midlands Cancer Alliance Dashboard Variation in activity by demographics

- While the proportion of white males and females has fallen relative to the Asian population overall, there is still a persistent higher proportion of white males (and females) in the 60 79 age group.
 - This persistent cohort may help to account for an increasing proportion of poor 1-year survivors as the overall number of deaths falls.



Source: Census/ Leicester City public health team

- With these insights in mind, we now need to <u>examine</u> (via secondary care work and planned primary care audit):
 Case mix of people (age, sex, ethnicity, deprivation etc.) diagnosed with colorectal cancer in Leicester city via all routes over time (not just via emergency presentation).
- > The relationship between age, ethnicity and stage of colorectal cancer at diagnosis.

Further work

- >Demographic differences in incidence, presentation and survival between colon and rectal cancers.
- >The contribution of health service factors to this picture e.g., uptake on screening; access to and use of primary care etc.
- This analysis demonstrates the need for us to continue targeted <u>action</u> on colon cancer particularly in the most deprived white British communities and PCNs.
- The consequences of the particular demographics of LLR for better understanding the disease burden, particularly of certain other cancers, e.g., lung, will also be explored

• The Task and Finish Group has therefore pulled together the actions and roles of partners across the System which will contribute to the overall coherent plan, detailed below along the pathway of engagement, treatment and care.

• It has been agreed to extend the timescale for the Task and Finish Group to accommodate the changes resulting from the most recent analysis

1 year survival following Colorectal Cancer (CRC) diagnosis in Leicester City: summary of actions to address high risk of poorer outcomes in identified priority population*

Community	Primary Care	Hospital Care	Patient Support
 Use multi-year data on first diagnosis of CRC via emergency presentation (EP) / admission to expand understanding of high-risk target area/PCN coverage for intervention programme Conduct "attitudes and barriers to screening" focus group work with priority population* Set in place programme management support to focus prevention/ health promotion approach to people diagnosed with CRC in priority population* Explore whether there are any differential issues related to uptake on offer of colonoscopy after a query positive screening/FIT test especially for priority population* Explore possible pilot use of patient symptom attribution awareness measure (in partnership with CRUK) 	 Work in partnership with Leicester PCN leads to: Set in place methods to prioritise early CRC diagnosis as part of DES Explore options for expanding video/text reminders for target population* Embed package of educational support for all PCNs in Leicester City Expand use of E-crest virtual training tool by primary care MDT Conduct "City South PCN CRC audit" using CRUK/PHE tool to learn about common patient pathway improvement opportunities Augment symptomatic FIT pathway for priority population*: Address delays/difficulty in access to kits / explore practice held kits for direct distribution in target practices or PCNs Explore possible arrangements with Lincolnshire hub for test processing Explore possible adjustment in suspicion threshold for testing in priority population* 	 Determine whether access to diagnostics (colonoscopy; imaging) is causing delays in CRC diagnosis/staging Conduct "UHL CRC pathway audit" (underway) with a particular focus on: People diagnosed with CRC from Leicester City (WL and ELR used as 'controls') Expanding to include WL and ELR residents if hypotheses about priority population confirmed Exploring whether priority population pattern extends to other referral sources (than just EP) Providing staging data for correlation Separating analyses by colon and rectal cancers (due to differential incidence rates by ethnicity) Reviewing frequency/importance of differential "DNA" rates Benchmarking risk appetite for surgery Exploring survival of people with CRC on medical care plans 	 Determine whether there are any specific barriers to completing a holistic needs assessment (through Macmillan cancer care or other) and receiving support for people in the priority population Explore possibility of new Community Lead Cancer Nurse to help shape and plan the delivery of community cancer care

Additional slides for information



When the incidence rate is age standardised, we can observe that - although comparatively lower- it has changed little over that period.
We need to explore whether there has been a change in the age structure in Leicester, particularly in the commonest age cohorts presenting with cancer.



Source: https://vizhub.healthdata.org/gbd-compare/

• As with incidence, the falling relative trend disappears when age standardised.

• If this means the incidence and death rates have not changed overall, has the age structure particularly in those age cohorts where cancer incidence and deaths are commonest, altered? To explore this we need to examine population structure data.



- Leicester's population structure remains substantially the same as in 2011. Leicester is still a young city, median age 33 years.
- Adults in most age bands between 35 and 74 now make up a slightly larger proportion of the population, and so will not alone account for falling incidence and deaths from colorectal cancer.



Leicester population structure: 2011 and 2021

Source: Census/ Leicester City public health team