Background

In comparison to other high income countries, England has lower 5-year survival rates for cancer. It has been suggested that this is explained by (1) delayed presentation by patients to general practitioners, (2) delays in referral to the hospital or investigation, and (3) suboptimal treatment at the hospital. Efforts have been made to improve early diagnosis of cancer, including a two-week referral process to hospital, yet rates of detected cancers have not improved.

London Cancer is the integrated cancer system formed by the constituent health organisations within north London and west Essex. In London, figures for emergency route to diagnosis are particularly high. Data from NCIN (2006-2008) shows that 24% of all newly diagnosed cancer patients present as an emergency in England; 28% in North East London; 22% in North London and 24% in Essex. Rates of late diagnosis vary by tumour group and by geographical location and these patients have particularly poor 1-year outcomes. NCIN estimates for emergency presentations (all cancers) in our geography, vary from 16% to 35% for all new cancer diagnoses. This equates to a total 3041 of people being diagnosed by an emergency route in 2011.

Aims

For all cancer patients diagnosed via an emergency route to:

- Combine an analysis of patients’ route to diagnosis across the whole diagnostic pathway, from primary to secondary care, with their own reported behaviour and involvement with the health care system
- Identify the factors which contribute to delay from a patient and organisational perspectives and understand the affect this has on overall health outcomes

Preliminary Results – Secondary Care

Data collection Jan 2013- March 2013

- To date we have identified 218 people
- Men and women were equally represented (109 males and 109 females)
- Median age of women 74 years and for men 71 years
- 98% of patients are registered with a GP
- Emergency admission or attendance most common route to diagnosis (42% of women, 54% for men)
- Main cancers are lung, colorectal and upper GI (hepatic biliary) but haematological in younger people (26-44 yrs)
- 10% of patients had died between date of emergency attendance and time data collected – median time 15 days (range 0-50 days)
- 80% of patients with a treatment intent recorded were given palliative care only

Design and methods

Secondary care

- Data capture in secondary care will be carried out for all patients who have come through the emergency route and who go on to have a cancer diagnosed (1200 patients)

Primary care

- For patients with a significant primary care history, another data capture including significant event audit will be completed at the GP Practice (960 patients)

Patient

- A patient questionnaire (based on the National Cancer Patient Experience Survey) will be offered to all patients identified in secondary care
- In-depth patient interviews will be carried out with 40 patients

Combined analysis

- Working with multidisciplinary primary and secondary care to identify common themes leading to delays in presentation or diagnosis in order to improve local diagnostic and assessment routes

The Evaluation is prospective and patients will be followed in ‘real-time’ from identification to 1-year survival i.e. collection of data in secondary care, followed by patient questionnaire and then collection of primary care data.

It examines routes to diagnosis for all tumour groups across 12 hospitals (9 Acute NHS Trusts) in North Central and North East London and West Essex.

Participating trusts are: Barnet and Chase Farm, Barts Health (including Barts and the Royal London, Whipps Cross and Newham ); Barking, Havering and Redbridge; Homerton; North Middlesex; Princess Alexandra; The Royal Free; UCLH, and The Whittington.

Learning to date:

- Initial identification of cohort challenging due to inability to systematically interrogate hospital IT systems
- Extraction of required data time consuming
- Trusts board level adoption of project not always adequately translated to operational level leading to incomplete and untimely data collection
- Reticence amongst staff to approach this cohort of patients for questionnaire has led to very poor completion rates to date

References

4. Thorne K, Hutchings H, Ewain G. The effects of the two-week rule on NHS colorectal cancer diagnostic services: a systematic literature review. BMC Health Serv Res. 2006;6:43