THAMES VALLEY AUDIT OF PATIENTS DIAGNOSED WITH CANCER FOLLOWING AN EMERGENCY PRESENTATION

Dr Jennifer Yiallouros
RCGP and CRUK workshop
Brighton, March 2017
Acknowledgements

- Thames Valley Strategic Clinical Network commissioned the SEA project
- Project team:

  - Cancer Research UK
  - Jennifer Yiallouros
  - Bridget England
  - Louise Forster
  - Marissa Morriss
  - Allyson Arnold
  - Anna Murray

  - Thames Valley SCN
  - Bernadette Lavery
  - Monique Audifferen
Presentation outline

• Background
  – Why was the audit done

• Methods
  – How was the audit done

• Sample description
  – Which cases were audited

• Findings
  – Using quotes from the respondents
  – GP exercise

• Conclusions
  – GP exercise
Background

• **Emergency presentation (EP) route**
  – England 20-25%

• **Survival**
  – Lower for those with EP

• **Funders**
  – Thames Valley Strategic Clinical Network commissioned Cancer Research UK to undertake the audit
Methods

• Identification of cases
  – Secondary care identified cases diagnosed between April 2012 and March 2014
  – Quarter of 296 TV practices participated

• Data collection tool
  – Significant Event Audits (SEA) for each case
    • What happened
    • Why it happened
    • Lessons learned
    • Actions taken

• Qualitative analysis
Sample description – 172 SEAs

• Demographics -
  – Even split male (49%): female (51%)
  – Average age 69 (range 17-96)
  – Quarter still alive at time of GP SEA

• Tumour sites -
  – Lung cancer (24%)
  – Bowel cancer (22%)
  – Pancreas (8%)
  – ‘The rest’ – haematological, stomach, oesophagus ....
Findings

• Three emerging narratives -
  – EP was unavoidable
  – Potential earlier diagnosis, but same prognosis
  – Missed opportunities
Route to diagnosis, prognosis and potential impact

**Prognosis**
- Better
  - Due to improvements in treatment
- Same
  - EP unavoidable
  - EP potentially avoidable

**Potential for improved patient and family experience**
- Due to improvements in underlying causal mechanisms

**Route to diagnosis**
Findings

• Underlying factors -
  – Tumour
  – Person
  – System and Health Care Professionals
Factors affecting path to diagnosis

- Tumour (65%)
- Person (25%)
- System (72%)

Venn Diagram:
- Tumour: 23% overlap with Person, 23% overlap with System, 9% overlap with all three.
- Person: 3% overlap with Tumour, 10% overlap with System, 2% overlap with all three.
- System: 2% overlap with Tumour, 29% overlap with Person, 23% overlap with all three.
Tumour factors

- No symptoms before EP
- Vague, atypical, non-red flag symptoms
- Complex symptoms
- Very quick deterioration
- Symptoms suggesting alternative diagnosis
- Symptoms prompting referral to wrong specialty / not timely
No symptoms before EP

“Some cancers do present late and it can be impossible to find them earlier in their illness course.”
(F, 86, Liver)

• Three people did not attend their GP
• Some had no relevant symptoms
• Incidental findings (15%)
• Reporting ‘no symptoms’
Vague, atypical or non red flag symptoms

“We would like a 2WW referral for people who are unwell but we don’t know which system they are unwell with.”

(F, 82, Brain & CNS)

- Not associated with cancer
- Explained by current condition
- Pain associated with injury
- Where to send person
Complex symptoms

“his admission for abdominal pain highlighted several medical issues that were unrelated to his eventual diagnosis of myeloma including a likely renal carcinoma, gallstones and an abdominal aortic aneurysm.”

(M, 75, Multiple Myeloma)

• Masked by co-morbidities
• Initial improvement with treatment
• Multiple diagnoses
Very quick deterioration

“Difficult case. From time of reported abnormal bowel habit 12th July to death 2nd Oct was 3 months so rapid deterioration.”

(M, 78, Pancreas)

• Little time to act
• Should set alarm bells ringing; “3 times and your in”
Symptoms suggesting alternative diagnosis

“It would appear that GP3 was considering Osteoporosis as a cause for the fracture and pain.”
(F, 64, Multiple Myeloma)

- Existing condition
- New condition
Symptoms prompting referral to wrong specialty / not timely

“Delays can arise when a 2WW referral results in a ‘negative’ diagnosis for cancer and the patient is referred back to the GP. Often the patient and the GP are falsely reassured that there is no cancer (anywhere).”

(M, 54, Multiple Myeloma)

• ‘Incorrect’ specialisation
• Correct referral but EP preceded
• Non urgent referral
Exercise 1 – match the symptoms to the cancer site

- represents SEAs where there was a symptom mentioned in any consultation.

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<tr>
<th>Respiratory symptoms</th>
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Exercise 1 – match the symptoms to the cancer site

- Bowel
- Brain and CNS
- Breast
- CUP & other
- Gynaecological
- Haematological

- Lip, oral cavity, pharynx
- Lung & other respiratory
- Male genital
- Upper GI
- Urological
Exercise 1 – match the symptoms to the cancer site - answer

<table>
<thead>
<tr>
<th>Respiratory symptoms</th>
<th>Lung &amp; other nasp (47)</th>
<th>Gynae (7)</th>
<th>Bowel (39)</th>
<th>Upper GI (42)</th>
<th>CUP &amp; other (11)</th>
<th>Male genital (3)</th>
<th>Brain &amp; CNS (6)</th>
<th>Breast (3)</th>
<th>Haematological (11)</th>
<th>Urological (9)</th>
<th>Lip, oral cavity &amp; pharynx (1)</th>
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Person factors

- Symptom experienced for a long time
- Symptoms concealed / denied
- Being a difficult historian
- Declining medical advice
- Reluctance to come to GP surgery
- Failing to attend appointments
- Slow to re-present or go for investigations
- Reluctance to be tested
Symptom experienced for a long time

“It is difficult to say if there had been much delay on the part of the patient presenting with symptoms as no symptom duration is mentioned at the initial consultation”
(M, 45, Lung)

- Days
- Weeks
- Months
- Years
“Suspect patient was somewhat stoical and not entirely honest about symptoms, family subsequently revealed to me that she had been concealing how ill she was feeling at her appointments with me.”
(F, 68, Stomach)

- Stoical
- Not wanting medical intervention
- Not known
“Patient did not engage and ETOH meant that his presentation was possibly masked and maybe medical practitioners whom he came into contact with did not fully take in to account/take him seriously due to the repetitive nature and presentation of ETOH.”

(M, 78, Lung)

- Mental health problems
- Lifestyle, ie alcohol
- Language difficulties
- Too many problems for one consultation
Declining medical advice

“Patient still autonomous and if declined referral with knowledge that symptoms could suggest cancer then inevitably will be delay in diagnosis.” (M, 60, Oesophagus)

- Engagement with health care
- On occasions supported by GP due to frailty or co-morbidities
Reluctance to come to GP surgery

“Patient took no responsibility for his own health. All contacts were initiated by wife or son.”
(M, 78, lung)

- Anxiety about attending surgery
- Use of other services ie OOH
Failing to attend appointments

“Patient was already referred but as due to his severe depression, he did not attend the appointments and was actually followed up by the psychiatrist also.”
(M, 58, Bowel)

- Infrequent attendees
- Lifestyle / co-morbidities
- Referral not attended due to holiday
Slow to re-present or go for investigations

“To get doctor of choice
• Not appreciating seriousness of condition / symptom

“Safety netting was generally rather non-specific and may have contributed to the delay in the patient returning.”

(F, 39, Bowel)
Reluctance to be tested

“Consider a barium swallow or CT in patient who does not want an OGD.”
(M, 76, Stomach)

- Some people refuse tests
- Consider offering alternatives
Findings

• Factors effecting path to diagnosis

Tumour

Person

System & Health Care Professionals
Findings

- System and Health Care Professionals

Events during the consultation

Processes in the GP practice

Primary care

Secondary care

Cancer community
Events during the consultation

Communication
“This gentleman is not a native English speaker, he may not have understood the referral or use of hospital services.”
(M, 44, Mesothelioma)

Examinations
“Never weighed—this may be an objective marker of deterioration.”
(M, 63, Bowel)

Medical histories
“importance of taking clear history and starting afresh when dealing with patients who attend regularly”
(M, 78, Prostate)

Referrals
“This patient met criteria for two separate 2 week wait pathways, neither of these actually picked up her cancer. We need to not be limited by specific pathways if we have concerns.”
(F, 63, Lung)
Events during the consultation

Follow-up & documenting

“Documentation is vital. This is not only for medico-legal reasons but also for best patient care and continuity of care – if it’s not in the notes then it didn’t happen.”
(F, 64, Multiple myeloma)

“Sometimes cancer presents without classic symptoms and vigilance and diligence in the presence of abnormal results is imperative.”
(M, 73, Prostate)

Diagnostics

“When a patient presents repeatedly she needs to be clinically assessed again.”
(F, 68, Lung)

“Normal CXR does not exclude cancer diagnosis”
(M, 87, Lung)

Re-assessing the working diagnosis
Processes within the practice

Responsibility
“At his previous practice there appeared to be no ownership of the patient or sense of urgency of referral.”
(M, 28, Brain & CNS)

Vigilance
“Mental health patients are just as likely as the general population to develop cancer but this can sometimes be forgotten”
(F, 47, Ovary)

Holistic approach
“Although very unusual this clinical presentation reminded staff of the need to consider alternative diagnoses.”
(M, 32, Bowel)

Continuity of care
“Continuity leads to greater patient satisfaction and smoother management.”
(F, 67, Ovary)
Processes within the practice

**Difficult cases**

“Improved awareness of ways to share difficult cases and allow early reflection may assist in prompting earlier and speedier referrals”

(F, 58, Brain & CNS)

“Better communication between all the DRs who saw this patient may have resulted in an earlier referral.”

(M, 82, Bowel)

“Then urgent CT scan still not reported after 10 days. Total delay; 33 days. We got no answer to our complaint letter.”

(F, 75, Lung)

“Clinical handover is weak point in medical practice”

(M, 75, Bowel)

**Communication in the practice**

**Communication with secondary care**
System factors

- Secondary care
  - Tests
  - Ownership
  - Referrals / pathway (incl. the role of guidelines)
  - Communication
  - Holistic approach
Availability of the test

“We could manage patients better if we had access to urgent USS”
(M, 63, Bowel)

• Not all GPs have access to certain tests
• Not all GPs want access to all tests
• GP to decide whether to test first or refer straight away
Appropriateness / adequacy of the test

“It would appear that the chest x-ray was not the best investigation for her particular case but it is the standard available investigation in primary care to investigate ongoing respiratory symptoms,” (F, 62, Lung)

• PSA, CA125, ESR
• Some cancers not seen on CT scan or x-rays
Timing of the test

“Following the upper GI endoscopy, the patient had been waiting almost another 4 weeks and still had not received an appointment for an ultrasound scan.”
(F, 89, Liver)

- How long a wait is acceptable
- Some tests in secondary care took too long
Receiving the results of the test

“It also goes against the concept of the clinician requesting a test being responsible for following up the result.”
(M, 42, Bowel)

- Filing of the results by the practice
- Relaying results to the patient
Interpretation of results

“Should have been followed up regardless as if abnormal needed treatment and if normal needed further investigation”.
(F, 72, Ovarian)

• False reassurance of normal test result
• When normal results should prompt further action
• Normal results can show a change in trend
• Response to abnormal results
• Abnormal results can lead to other condition masking cancer
Ownership of the patient

“This patient’s CT scan was arranged by the hospital and should they therefore have followed up and investigated potential causes of vertebral collapse?”
(M, 74, Multiple Myeloma)

- After referral to secondary care confusion over responsibility for chasing appointments / results
- How is responsibility handed back to GP when patient referred back to primary care.
Referrals / pathways (including role of guidelines)

“In April 2013, the patient had three appointments where malignancy was suspected but the site was unknown so a two week referral was delayed.” (M, 78, Bladder)

- Multiple referrals to different specialties can lead to delays
- Symptoms don’t always meet 2WW criteria
- Sometimes guidelines are unhelpful / irrelevant
- Some cancers don’t have guidelines
- Lack of clarity for some
- GP awareness
“Some pathways are already different 2 years down the line, some are in evolution, but themes of handover and communication seem to persist!”

(F, 86, Bowel)

• With primary care
  – Reports missing information / not received in timely manner
    • Discharge summaries
  – Referring
    • 2WW bounced
    • Choose and book system

• Within secondary care
  – Record keeping
  – Between departments
Holistic approach

“Difficulty lies within liaison with and follow up within secondary care, seen as separate issues, not addressing single cause, and reminded to think of bigger picture when presented with several new symptoms.”
(F, 52, Breast)

- Specialties to think outside of their own specialty
- Atypical presentations of cancer
- Lifestyle factors
- Co-morbidities
- Don’t focus on the obvious problem - reassess
Conclusions

• Not all emergency presentations can be prevented
• Some cases have missed opportunities
• Important to diagnose earlier -
  – survival
  – patient experience
• There are many factors which impact the route to diagnosis
Exercise 2 – prioritising actions

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<th>Impact on early diagnosis</th>
<th>Length of project</th>
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Placing actions on impact / length of time parameters

- High
- Low

- Short
- Long
Exercise 2 – prioritising actions

Placing actions on impact / length of time parameters

- **High**
  - Impact on early diagnosis
  - Length of project

- **Low**
  - Impact
  - Length of project
Exercise 2 – prioritising actions

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