

New Skin for the Old Ceremony: time to revisit the cancer diagnosis paradigm?

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*Themes of conflict and division,
life changes and mortality*

- The model of early diagnosis that we have been working in
- How evidence is expanding but also challenging this model
- Is a new model for cancer diagnosis emerging



An Address on the IMPORTANCE OF EARLY DIAGNOSIS WITH A VIEW TO SUCCESSFUL TREATMENT

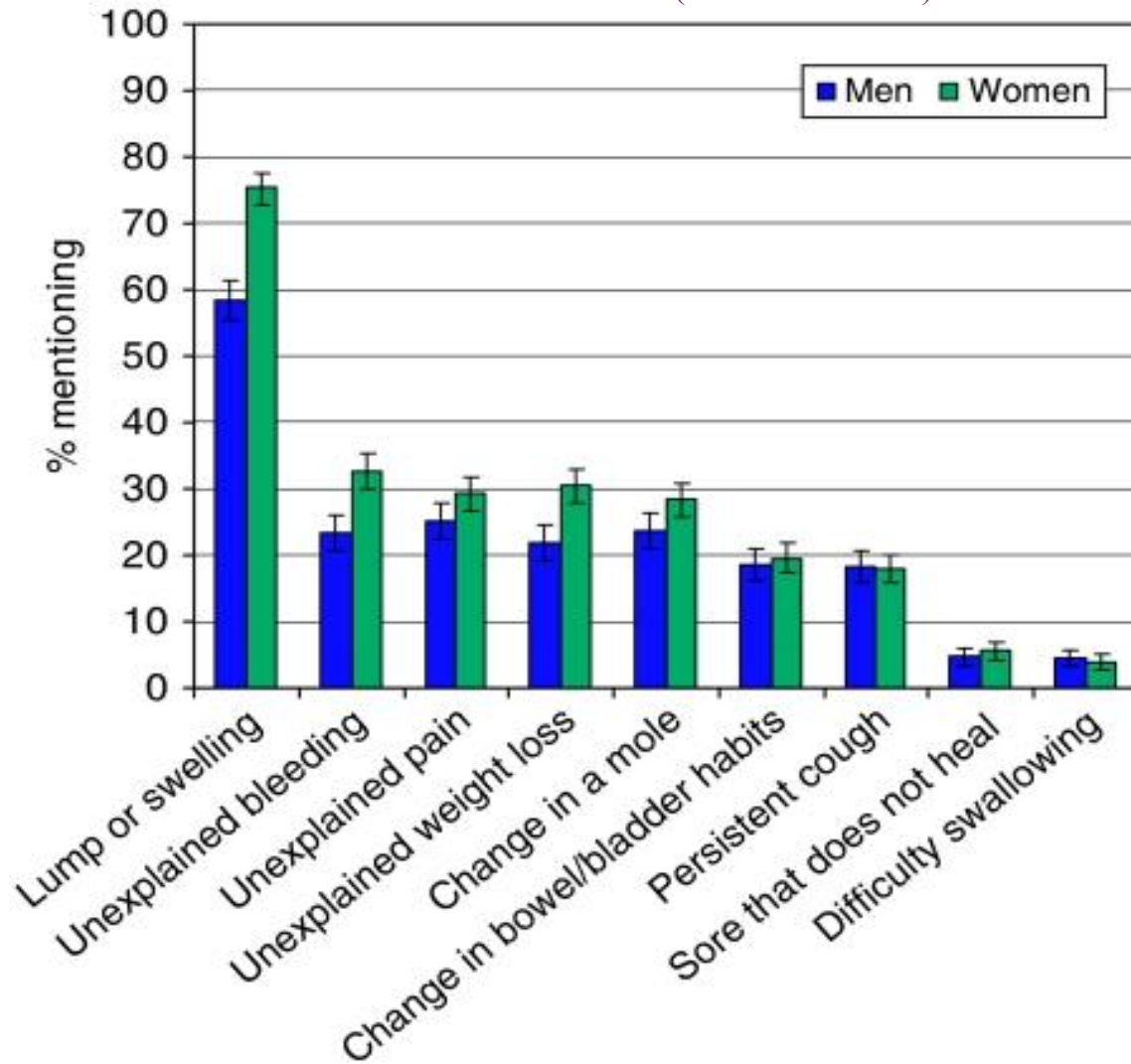
- Are there not many cases seen by all of us in which early symptoms, though definite and pronounced enough to enable a diagnosis to be made, are treated by palliative remedies simply for the relief of symptoms and only at a later stage.....is the importance of radical treatment insisted upon?
- The blame for procrastination.....must often be laid at the door of the patient.....though we cannot always exonerate ourselves.

What has been the prevailing paradigm for achieving earlier diagnosis?

- Patients don't recognise or act on symptoms that could be cancer
- A key problem in diagnosing symptomatic cancer is avoidable delay, most often in primary care
 - This is primarily a GP performance issue, remediable through education and remediation, but also better access to diagnostics
- Cancer Reform Strategy 2007
 - Raise public awareness and encourage people to seek help sooner
 - 'We also want to understand more about the nature and extent of delays in cancer diagnosis. A national audit in primary care of newly diagnosed cancers will be used to make decisions about how best to provide more support to primary care professionals to ensure the early diagnosis of cancer.'
- Common approaches to common problems
 - cancer diagnosis as a homogenous problem in primary care
 - Studies of individual cancers assumed to be generalisable to all
 - Cancer diagnosis as a linear process
 - Decision support

Variation in recall of warning signs of cancer

(Robb et al 2009)



NAEDI Regional Bowel Cancer Pilot 2010/11

- Campaign ran in East of England and South West England for 7 weeks from end of Jan 2011.
- Social marketing campaign using regional TV, radio and print media, face-to-face events and partnership activity.



Dr Terry Bowley



Just tell me

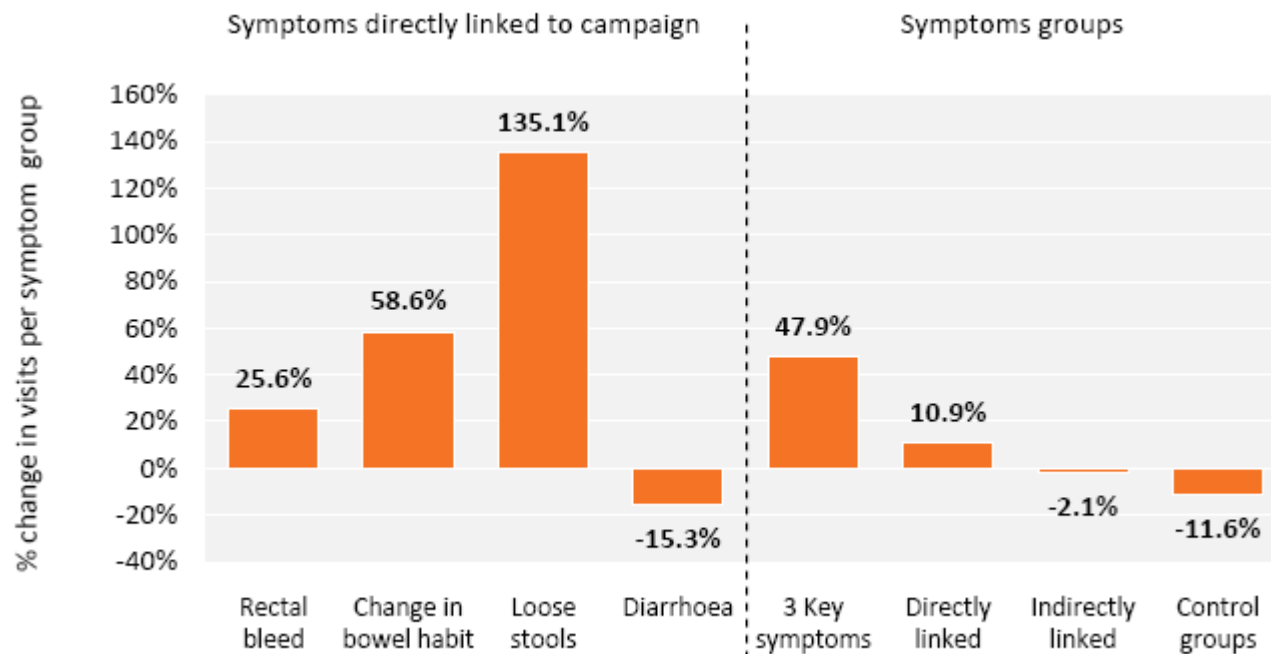
**If you've had blood
in your poo or looser
poo for 3 weeks, your
doctor wants to know.**

Chances are it's nothing to worry about, but it could be the early signs of bowel cancer, so tell your doctor. Finding it early makes it more treatable and could save your life.

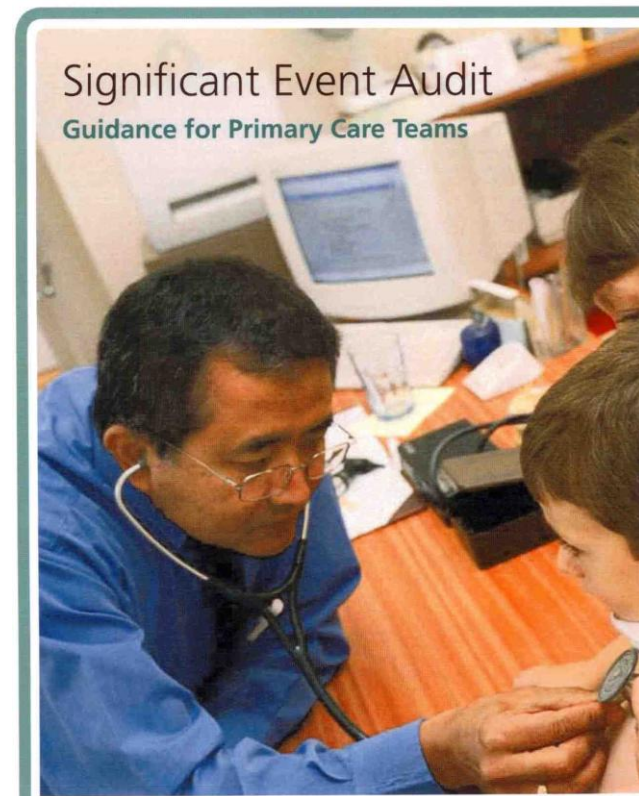
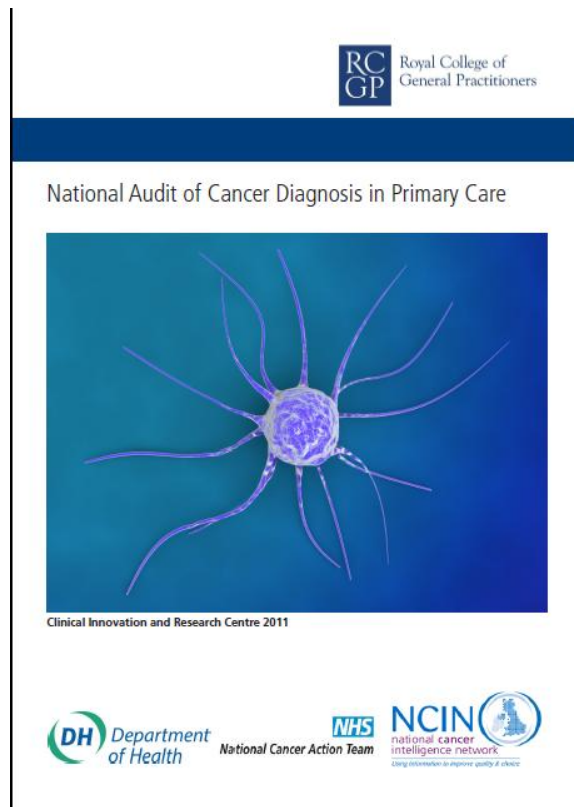
**BE CLEAR
ON CANCER**

nhs.uk/bowelcancer

Change in GP consultations during bowel awareness campaign, compared to 12 months earlier



NAEDI and Primary Care



Number of GP consultations before specialist referral

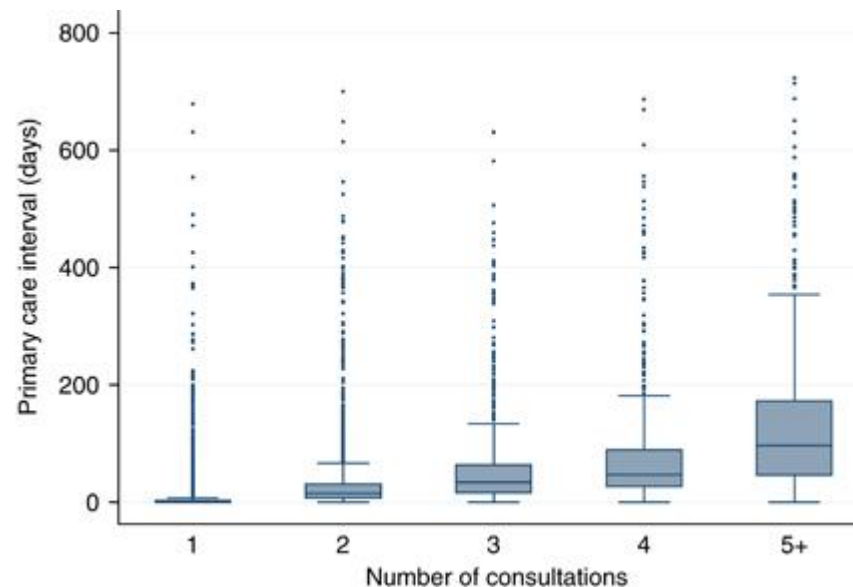
Sex	0	1	2	3	4	5+	Not known	Total	n
Male	9.2%	41.8%	23.9%	8.2%	3.3%	4.1%	9.5%	100%	9759
Female	9.7%	51.2%	15.7%	6.8%	3.2%	3.9%	9.4%	100%	9066
Not Known	9.3%	42.6%	13.0%	0.0%	1.9%	5.6%	27.8%	100%	54
Total	9.4%	46.3%	20.0%	7.5%	3.2%	4.0%	9.5%	100%	18879

- Excluding those with 0 consultations, 73.2% of patients consulted 1 or 2 times before referral
- Cancer sites for which >20% of patients had 3 or more consultations:
 - Lung, lymphoma, ovary, pancreas, and stomach

Promptness of cancer diagnosis

Among 13 035 patients with any of 18 different cancers, most (82%) were referred after 1 (58%) or 2 (25%) consultations (median intervals 0 and 15 days, respectively) while 9%, 4% and 5% patients required 3, 4 or 5+ consultations (median intervals 34, 47 and 97 days, respectively) (Spearman's $r=0.70$).

Box plot for primary care interval by category of number of pre-referral consultations (1, 2, 3, 4 and '5+') for patients with any of 18 cancers ($n=13\ 035$).



Investigations ordered

Fraction of patients diagnosed with each tumour type that have specified investigation (i.e. 74.1% of prostate cancer patients have a blood test).

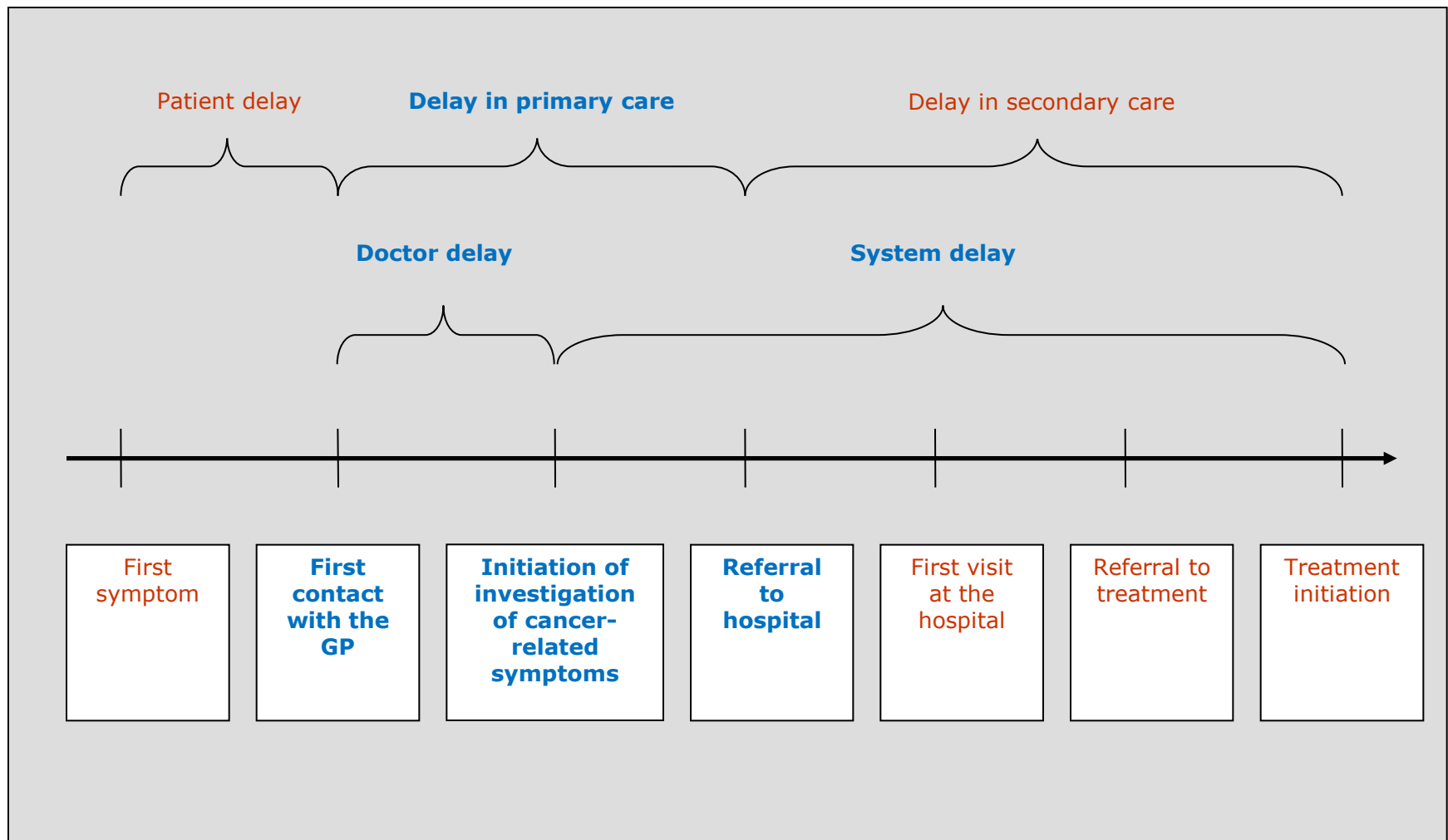
	All	Breast	Colorectal	Lung	Prostate	Haematology	Other
Blood Test	33.1%	2.0%	41.5%	24.6%	74.0%	52.3%	24.4%
CT	1.1%	0.2%	0.8%	4.0%	0.2%	0.7%	1.2%
CXR	10.3%	1.7%	2.5%	61.0%	3.0%	14.8%	4.1%
Endoscopy	1.1%	0.0%	3.5%	0.4%	0.1%	0.5%	1.4%
MRI	0.2%	0.1%	0.0%	0.3%	0.2%	0.6%	0.3%
USS	6.7%	0.5%	5.4%	2.2%	3.2%	6.1%	12.9%

(Multiple investigations in a single patient may be counted more than once.)

Cancer stage at diagnosis

	Confined to organ	Local spread	Distant spread	Not Known	n
All persons	45.5%	25.1%	18.0%	11.3%	18879
Communication difficulty	36.7%	27.6%	22.1%	13.7%	1142
Housebound	31%	26%	27%	16%	1298
Non-white	43.7%	28.2%	16.1%	12.0%	1159
Emergency	34.1%	24.8%	28.3%	12.7%	2432
2 week referral	47.1%	27.5%	16.5%	8.9%	10175

Sub-divisions of delay in diagnosis



Improving access to diagnostic tests

Department of Health

Public health, adult social care, and the NHS

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Guidance on direct access to diagnostic tests for cancer published

12 April, 2012

Guidance on direct referral by GPs to specific diagnostic tests for the assessment of particular symptoms where cancer may be suspected but the urgent GP referral (two week wait) process is not applicable, has been published.

The guidance aims to help GPs in determining which patients would be suitable for direct referral to local services providing the diagnostic tests.

It deals specifically with the circumstances and symptoms that may warrant such referrals and is aimed at health care professionals across primary and secondary

Related content

- ▶ Plans to improve cancer intelligence published
- ▶ Assessment of strategy for improving cancer outcomes published
- ▶ Second stage of board governance guidance for aspirant foundation trusts published
- ▶ Choice of GP practice guidance published
- ▶ Quality Accounts audit guidance published

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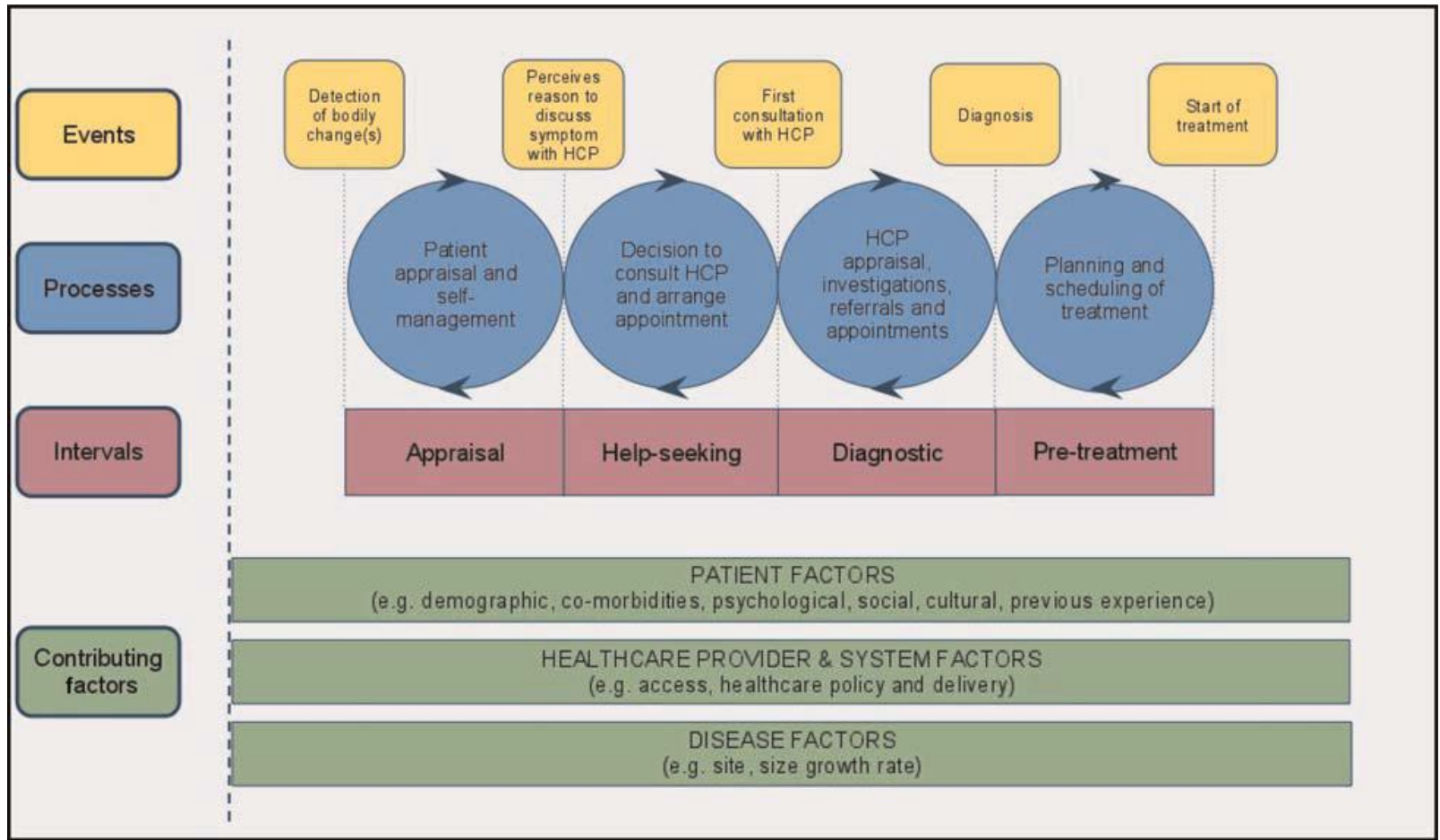
Latest press releases

- ▶ More help to follow a healthy diet – front of pack food labelling consultation launched

Evidence that is inconsistent with current paradigm

- The iterative, non-linear nature of diagnosis
- The nature of symptomatic presentation
- The variation in intervals between cancers
- Uptake of decision support tools
- The impact of GP diagnostics
- Poor performance is inherently implausible as the principal problem

Model of patient pathways to treatment



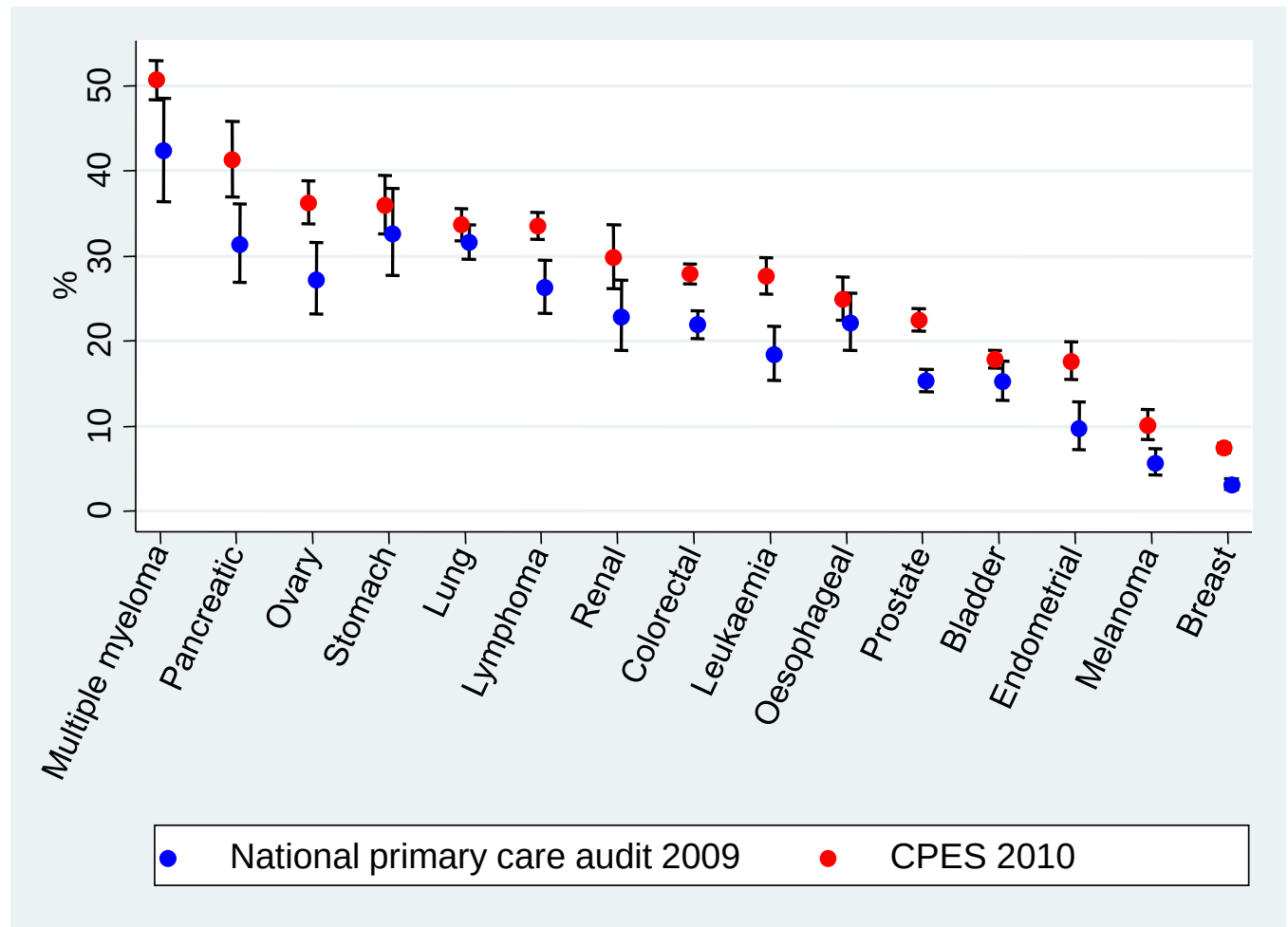
Significant event analysis of cancer diagnosis: findings from 2 large scale studies

TABLE 3: FACTORS INFLUENCING THE REFERRAL PATHWAY

Explanatory factor	Lung	Upper GI	Ovarian	TYA
Complexity of presentation				
Presence of co-existing morbidity	●	●	●	
Symptom suggests different initial diagnosis	●	●	●	●
Symptom suggests different malignancy	●	●		
Patient-mediated factors				
Time to re-present with ongoing symptoms	●	●	●	●
Time to re-present after initial treatment	●	●	●	
Declining investigation or examination		●	●	
Declining referral or admission	●			
Not attending for follow-up (GP or hospital)	●	●		
Diagnostic process				
Reassurance from negative investigation	●	●	●	
Investigation suggests benign cause	●			

GP consultations prior to referral

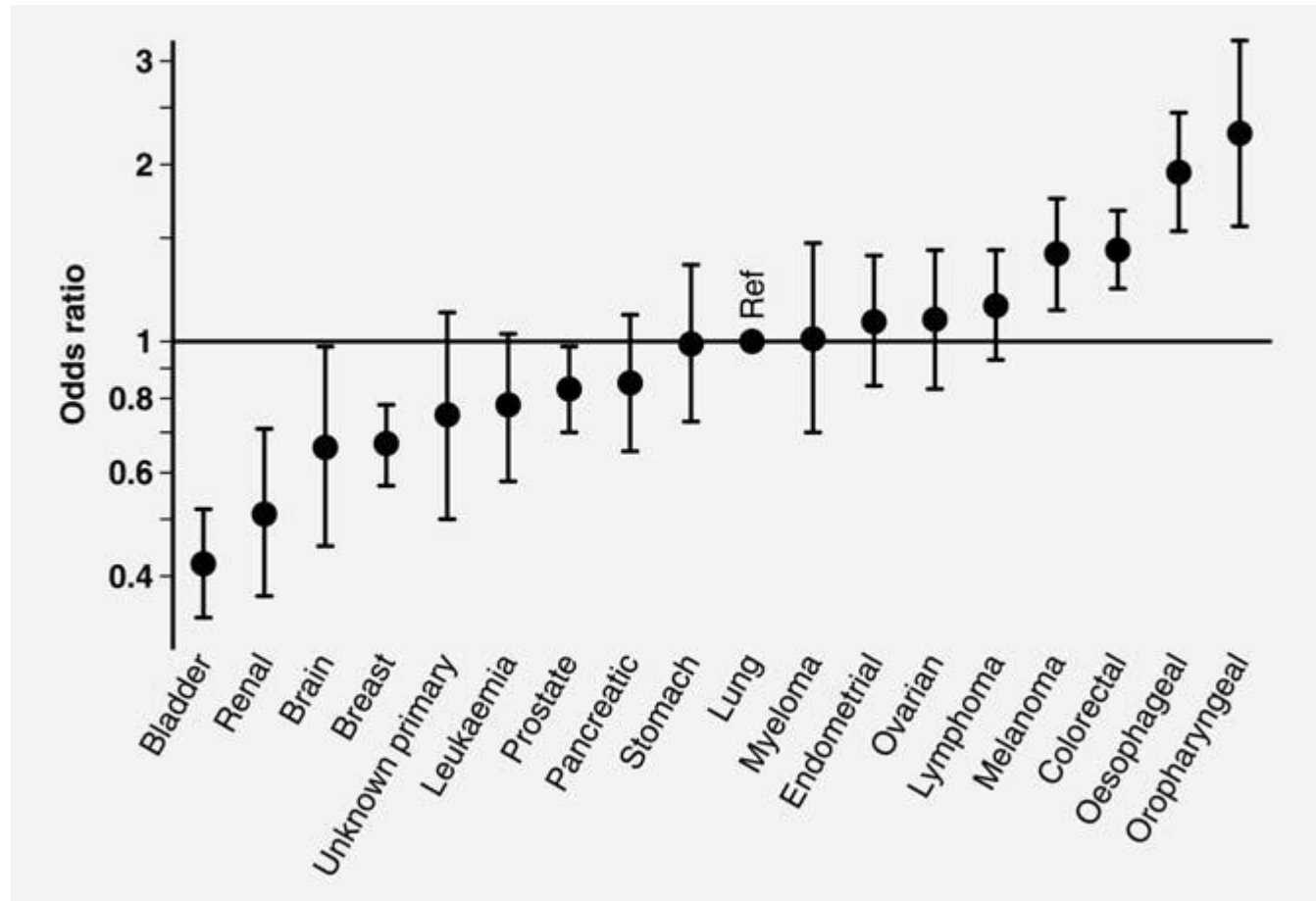
Comparison of crude (unadjusted) proportion of patients with three or more general practitioner consultations before hospital referral between the NHS Cancer Patient Survey 2010 and the National Audit of Cancer Diagnosis in Primary Care



Non-prompt presentation of symptomatic cancer to primary care

Keeble et al IJC 2014

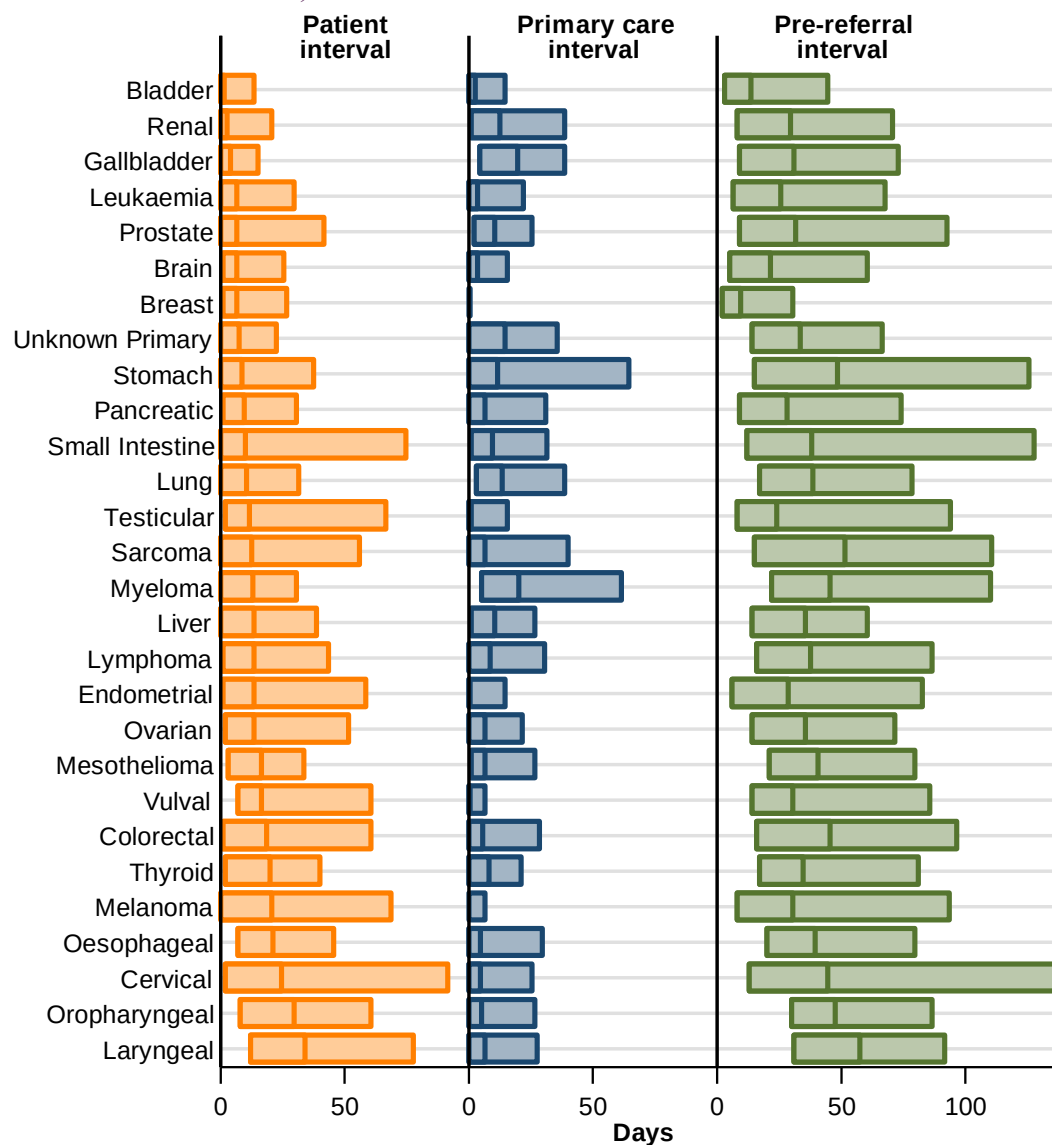
Non-prompt presentation
= >14 days



Awareness and barriers to help seeking

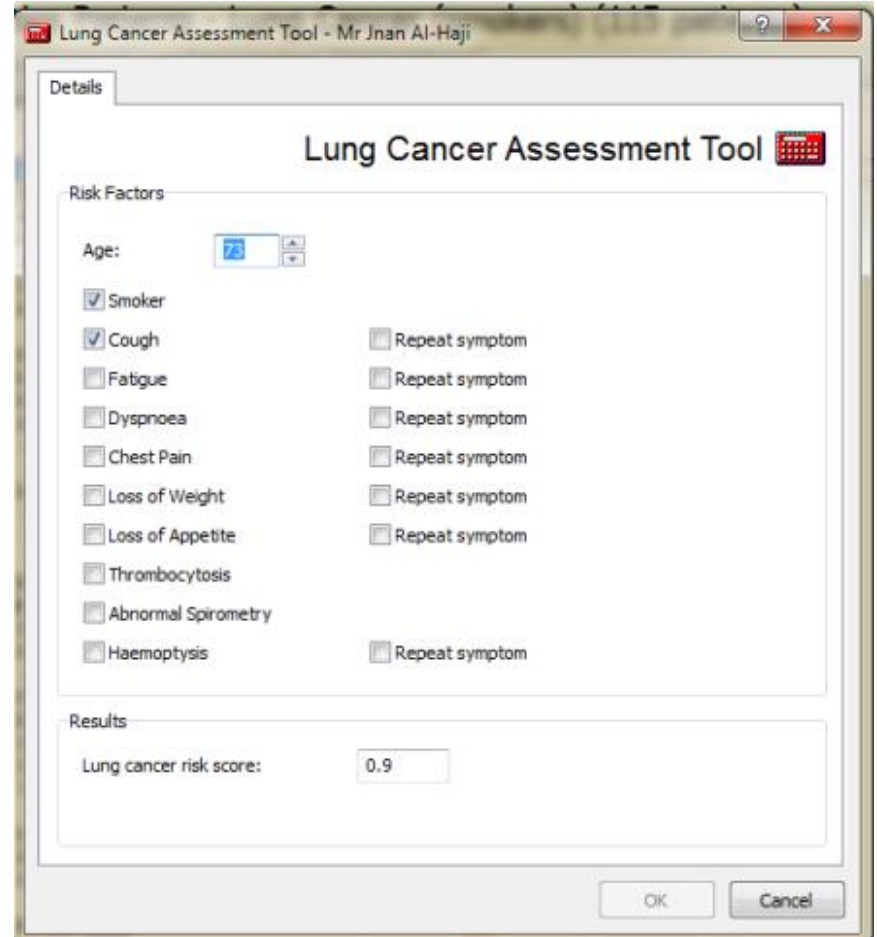
- BCOC campaigns associated with increased public awareness of symptoms but barriers to visiting the GP were not reduced (Power and Wardle, BJC 2015)
- Elements other than knowledge contribute to symptom appraisal and help seeking, including attention, expectation and identity. The notion of candidacy (for cancer and/ or for health care) may help explain differential uptake of health care (Whitaker et al, BJC 2015)

Contribution of patient and primary care to the pre-referral interval (Lyratzopoulos et al BJC 2015)



The Macmillan eCDS tool

- Evaluation by CRUK in 2014
- Report only publicly available in summary form
- Substantial minority of GPs in participating practices did not use the tool
- Use by most GPs was infrequent to rare
- Context in which eCDS tools are used remains incompletely understood



The screenshot shows a software window titled "Lung Cancer Assessment Tool - Mr Jnan Al-Haji". Inside, there is a tab labeled "Details". The main heading is "Lung Cancer Assessment Tool" with a small calendar icon. Below this is a section titled "Risk Factors". It contains a list of checkboxes for various symptoms and risk factors, arranged in two columns. The first column includes "Age:" with a numeric input field, "Smoker", "Cough", "Fatigue", "Dyspnoea", "Chest Pain", "Loss of Weight", "Loss of Appetite", "Thrombocytosis", "Abnormal Spirometry", and "Haemoptysis". The second column includes "Repeat symptom" repeated eight times. At the bottom of the "Risk Factors" section is a "Results" section with a label "Lung cancer risk score:" and a text box containing the value "0.9". At the very bottom of the window are "OK" and "Cancel" buttons.

Risk Factors	
Age:	
☒ Smoker	☐ Repeat symptom
☒ Cough	☐ Repeat symptom
☐ Fatigue	☐ Repeat symptom
☐ Dyspnoea	☐ Repeat symptom
☐ Chest Pain	☐ Repeat symptom
☐ Loss of Weight	☐ Repeat symptom
☐ Loss of Appetite	☐ Repeat symptom
☐ Thrombocytosis	☐ Repeat symptom
☐ Abnormal Spirometry	☐ Repeat symptom
☐ Haemoptysis	☐ Repeat symptom

Results

Lung cancer risk score:

OK Cancel

The impact of investigations in primary care on time to referral

	n	% investigated	Mean additional primary care interval in days (95% CI)
Colorectal	2111	54.2	25.7 (19.5-31.7)
Ovarian	345	69.6	18.4 (12.2-25.5)
Lung	1494	80.3	23.6 (16.8-30.0)
Oesophageal	513	42.9	22.3 (13.2-32.4)
Pancreatic	327	75.2	17.1 (-1.9-30.6)
Stomach	246	60.2	29.3 (14.0-45.8)

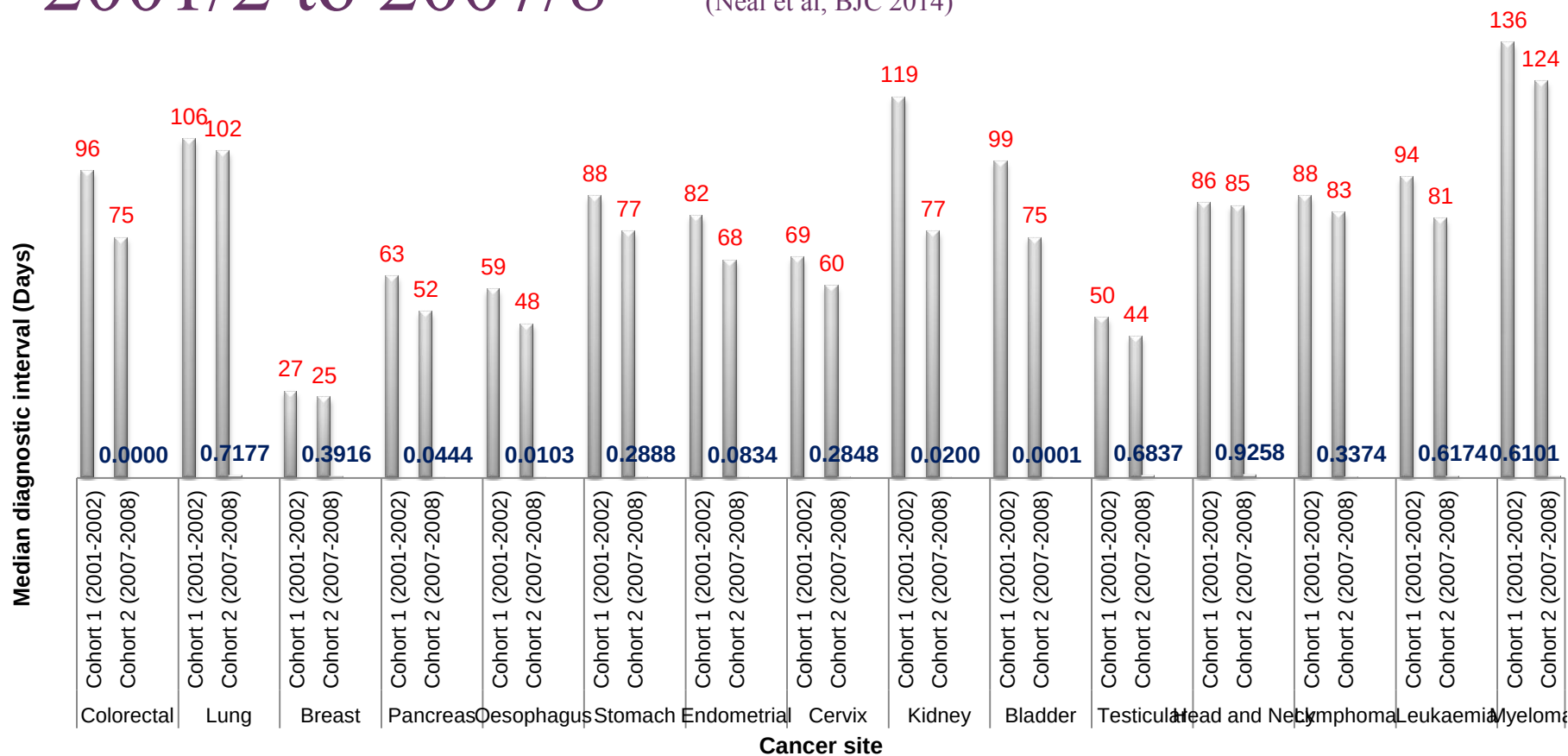
After adjustment for age, sex and NICE guideline referral category).
P<0.0001 for all except pancreatic cancer

Poor performance is not the main cause of diagnostic delay (Lyratzopoulos et al BMJ 2014)

- The proportion of patients with 3+ consultations before referral varies by cancer site
- Cancers with a high proportion of 3+ consults before referral tend to have higher emergency presentation rates
- 20% of all patients with newly diagnosed cancer in England experience multiple consultations. It seems improbable that these thousands of patients are seen by a few 'poorly performing' general practitioners.
- The main driver for multiple consultations is diagnostic difficulty and appropriate primary care-led investigations of poorly differentiated symptoms, rather than poor diagnostic reasoning or sub-optimal professional practice.

Change in diagnostic intervals, 2001/2 to 2007/8

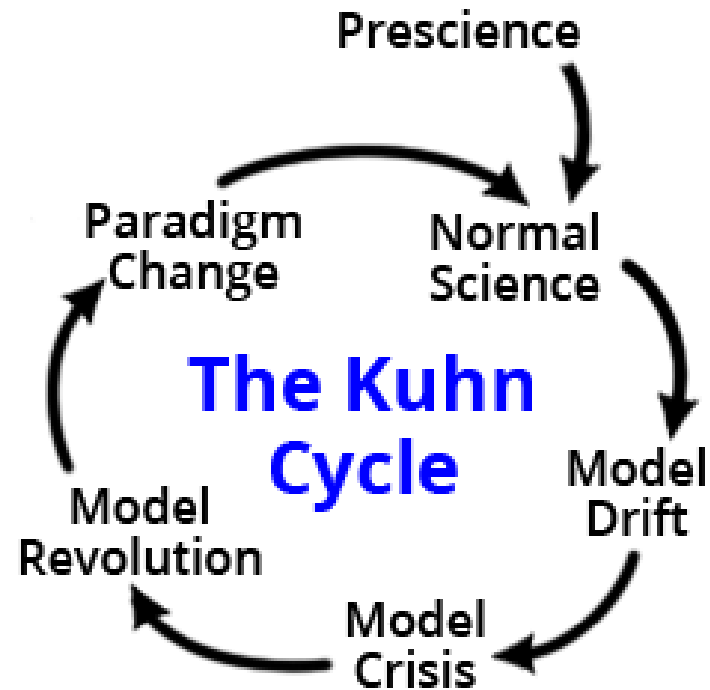
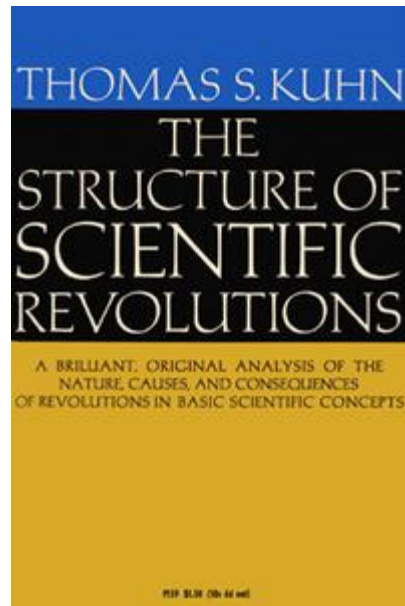
(Neal et al, BJC 2014)



Symptoms and their significance

- The Symptom study: lung cancer (Walter et al BJC 2015)
 - Haemoptysis as a first symptom in <5% of patients with lung cancer (22% at any stage)
 - 51% have multiple first symptoms
 - Diagnostic intervals shorter for those with more advanced stage
- Fewer than 50% of patients with cancer have alarm symptoms (Nielsen 2010, Neal et al, 2014)

Time for a new paradigm?



What might be different in a new paradigm?

- Symptoms act as a trigger to investigation, not as a filter
- For doctors, models of decision support will be more sophisticated,. They will work in real time, utilise artificial intelligence and address cognitive error.
- Systems based on patient safety principles will be used
- Actions to hasten help-seeking will address behavioural and attitudinal as well as cognitive domains.
- Improvement strategies are tailored to cancer site
- Symptom emergence in relation to stage is poorly understood but almost certainly differs by cancer. Some cancers will need a step change in diagnostic technology to achieve significant improvement in outcomes.

Investigating symptoms: pros and cons

- NICE CG17 (2015) likely to advocate investigation at 3% risk level.
- Current CWT data on conversion rates indicate that overall urgent referral carries an 8% risk of cancer
- High levels of patient preference for investigation, even at 1% level of risk (Banks et al TLO 2014)
- ACE initiatives include some intended to meet need for assessment at sub-NICE levels of risk.

BUT

- Demand for resources will be considerably increased, while investigation at these levels of risk carries significant risk of overdiagnosis
- Over half of patients in a Danish trial of low dose CT for suspected lung cancer required further evaluation (Gulbrandt et al PLOS One 2014)

Investigating symptoms

- The driver for assessment should be suspicion of serious disease
- Suspicion is a complex construct, incorporating objective (risk values) and subjective (sixth sense) dimensions.
- This will require a culture change in diagnostic and specialist services, to accept that they predominantly exclude cancer and other serious disease, and in general practice, that this is acceptable.

Next generation eCDS

Relationship between salient features underpinned by complex mathematics

Intelligent prompts to refine each patient model

Dynamic 'learning' system



Safety-netting

In the consultation:

- Communicating the existence of uncertainty
- Outlining exactly what the patient needs to look out for
- How to seek further help
- What to expect about time course

Outwith the consultation

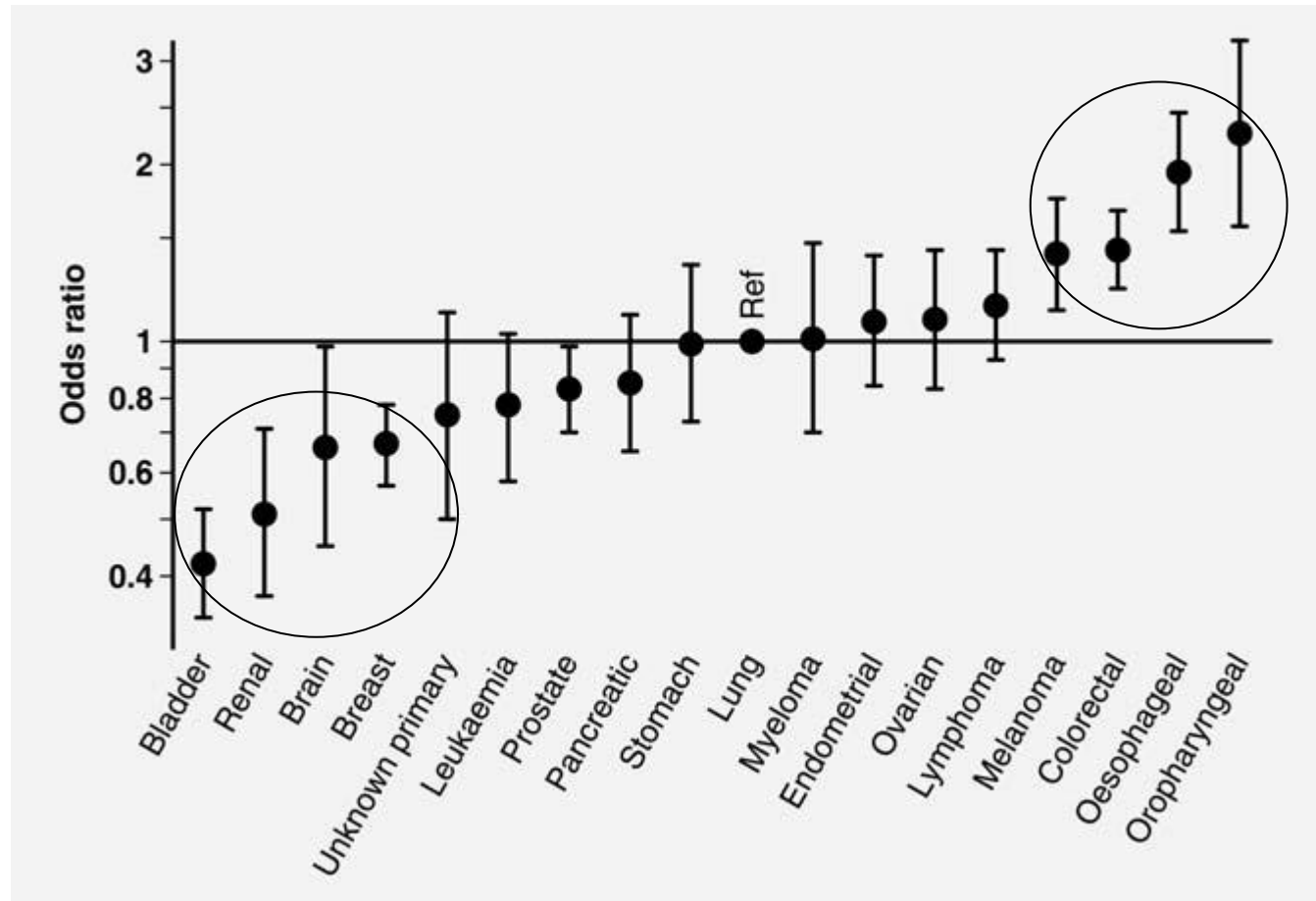
- Checklists



Non-prompt presentation of symptomatic cancer to primary care

Keeble et al IJC 2014

Non-prompt presentation
= >14 days



Attitudes and help seeking

- Notions of candidacy develop and become acceptable
- Perceptions of primary care services change to no longer be seen as demand-managing
- Attitudes to accessing health care change

Thinking differently about cancer diagnosis

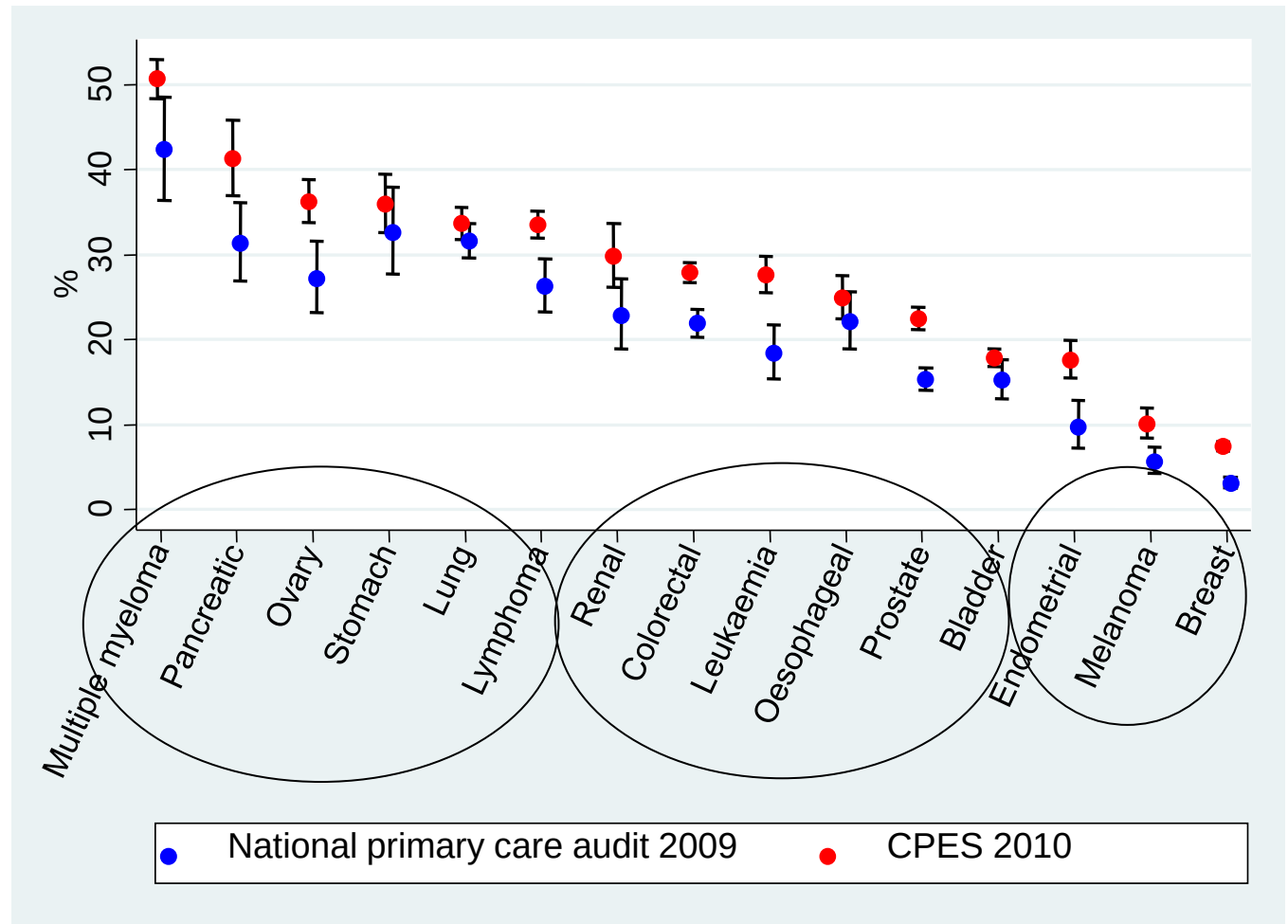
(% of patients with 3+ consultations prior to referral)

Cancers that may need a step change in diagnostic approach, e.g. new biomarkers

Cancers where decision support and better access to tests can be of benefit

Cancers where delayed diagnosis is a patient safety problem

(Lyratzopoulos, Wardle and Rubin, BMJ 2014)



The end game?

‘Depending on the criteria, an estimated 27–48% of symptoms in individuals with as yet undiagnosed lung cancer, and 12–32% with undiagnosed colorectal cancer *are not caused by the cancer.*’ (Ades et al, BJC 2014)



Are we edging towards a scenario where our dominant strategy effectively becomes to screen based on propensity?

What is society able to afford, or willing to pay more for?



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