EARLY DIAGNOSIS: CHALLENGES AND OPPORTUNITIES FOR GPs

In the second part of our special series on the GP's role in cancer care, the authors consider the challenge of diagnosing cancer at an earlier stage and approaches GPs may consider to achieve a more timely diagnosis.

Dr Bridget Gwynne
Dr Steven R Beaven
Dr Cathy Burton
Macmillan GP Advisers

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The problem in the UK

Cancer survival in the UK is improving, but it is also improving in other countries and the UK still lags behind.[1] In the UK, one and five year survival rates are lower than in many countries with equivalent health economies to our own. One year survival is seen as a proxy for cancer staging at diagnosis and we need to understand why patients in the UK are more likely to have advanced disease at diagnosis.[2]

Later staging at diagnosis may account for an excess of 6,000-7,000 deaths a year in the UK.[3]

Delays in diagnosis can occur at different stages, and therefore efforts to achieve earlier diagnosis need to target these stages (Figure 1). GPs can best address delays once a patient presents in primary care.[4]

Patient Factors

Many cancer symptoms are non-specific, common and often caused by non-malignant conditions. The National Primary Care Cancer audit[5] and the Cancer Awareness Measure[6] tell us that patients may delay visiting their GP with early symptoms of cancer for various reasons, including a lack of awareness of the potential significance of the symptoms.

The International Cancer Benchmarking Partnership is examining the patient journey to diagnosis in breast, colon, lung and prostate cancers across a number of equivalent health economies. It reveals that people in the UK:

- Are more concerned about wasting doctors' time (34% vs. 9% in Sweden)
- Are embarrassed to see a doctor with symptoms that may be serious (15% vs. 8% in Denmark)
- Worry about what the doctor might find (28% vs. 20% in Norway)
- Have the lowest level of knowledge about age related risk of cancer (14% vs. 38% in Sweden)[7]

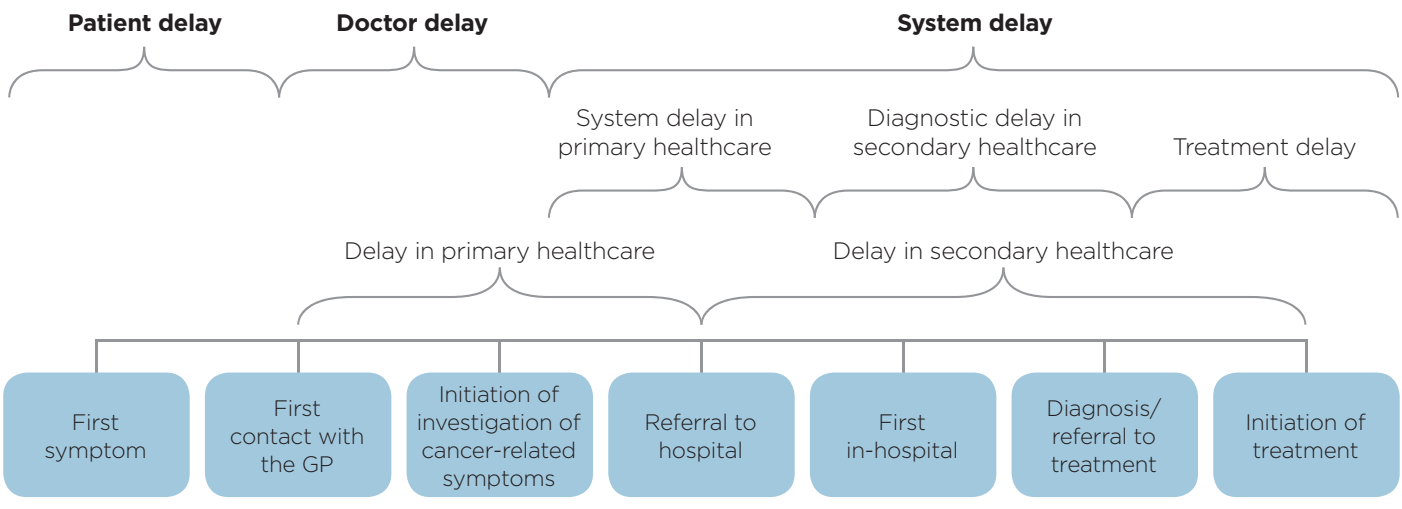
GPs need to ensure their practice policies and consultations are sensitive to these barriers.

Population awareness campaigns

In recent years, public health campaigns to raise awareness of cancer symptoms in the general population have had measurable effects.

The *Don't get scared get checked* campaign in Scotland raised confidence in half the population aged 40-65 approaching a GP about their worries.[8] The *Be Clear on Cancer* lung campaign in England in May-June 2012 led to statistically significant improvements in patient awareness of symptoms (30%), cases of cancer diagnosed (9%), lowering of staging at

FIGURE 1: CATEGORY OF DIAGNOSIS DELAY (NPSA)



diagnosis in non-small cell cancers, and increased resection of tumours (2.3%), the only curative treatment available.[9]

It is estimated that these campaigns increased consultations by 2-3 per week in an average practice and that the earlier diagnoses reflected a lowering of the threshold for investigation.[10]

The GP perspective

Diagnosing cancer early is not easy. As GPs, we worry about missing cancer. We see patients whose symptoms may be attributable to cancer on a daily basis but relatively rarely see a new cancer. We are urged to diagnose cancer earlier, requiring more investigation and referrals, while being responsible for using NHS resources wisely.

A Danish study found an association between poorer one year survival rates for cancer patients and a primary care structure where GPs have a gatekeeper role.[11] If these findings were replicated in the UK, there would be a major challenge to GPs to review work patterns and reconsider how we manage risk.

The International Cancer Benchmarking Partnership is at present examining primary care attitudes, behaviours and systems for cancer referral.

Resources and tools to help GPs

1. Cancer referral guidelines and urgent referral systems

There are referral guidelines for suspected cancer in the different nations within the UK, and cancer services may have local plans for implementing these guidelines.[12, 13] A desktop format based on NICE guidance is available from Macmillan (visit www.macmillan.org.uk/Documents/AboutUs/Health_professionals/PCCL/Rapidreferralguidelines.pdf). However, referral guidelines are not perfect. Many patients fitting the referral criteria do not have cancer and many of those with cancer do not have symptoms that "fit" the guidelines.

Cancers diagnosed as emergencies have a significantly worse prognosis than those diagnosed through the urgent GP route.[14]

Evidence that the urgent cancer referral systems impact positively on outcomes is weak.[15,16,17] A review of two week referrals and patients treated for cancer across 8049 English GP practices found that practices with higher proportions of two week wait (2WW) referrals that are found to have cancer (i.e. a higher "conversion rate") also detected more of their patients with cancer through this urgent referral system. This finding suggests that efficient use of the 2WW pathway is key to early detection, with potentially better outcomes for patients.[18]

2. Decision support tools

Tools which calculate the risk of a patient having an undiagnosed cancer can support the GP in making decisions about referral and investigation.

Two tools have been developed to assist UK GPs in decision making.

QCancer

QCancer is a computerised risk calculator tool, developed for GPs and academics by Professor Julia Hippisley Cox, an academic GP at the University of Nottingham, using data from Q Research database. Risk is expressed as a percentage across 12 cancer types (Figure 2).[19]

Risk Assessment Tool (RAT)

This primary care risk assessment resource was developed by Professor Willie Hamilton from the CAPER (Cancer Prediction in Exeter) programme – a series of case control studies which identified symptoms of common cancers seen in general practice and quantified the risk of cancer associated.[20] The tools produce a "positive predictive value (PPV)", i.e. the chance of a patient having the disease of interest, based on a reported symptom, group of symptoms, signs or test result. Originally developed in a paper format, there is now a computer tool (Figures 3a-3b). Both of these resources are currently being evaluated as GP desk-top tools for bowel, lung, upper GI, ovarian and pancreatic cancers.

GPs are accustomed to scoring systems to aid decision making, for example in cardiovascular and osteoporosis risk. Cancer decision support tools have been shown to raise GPs' awareness of cancer and aid clinical decision making. They may lend support to an urgent referral when risk appears to be high but patients do not have symptoms that fit the referral criteria.[21, 22]

When used in pilots, a threshold of >2% has suggested considering urgent referral, and one of 5% has advised urgent referral. There is however no clear consensus on these thresholds.

FIGURE 2: QCANCER RISK CALCULATOR

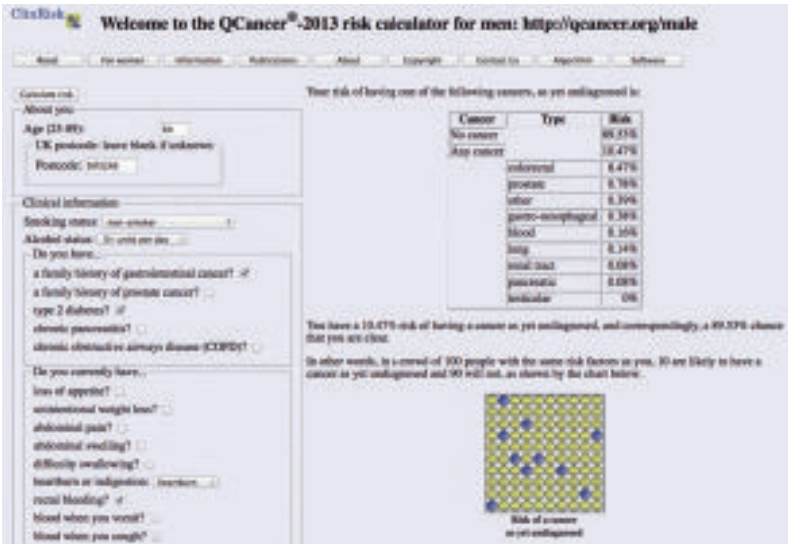
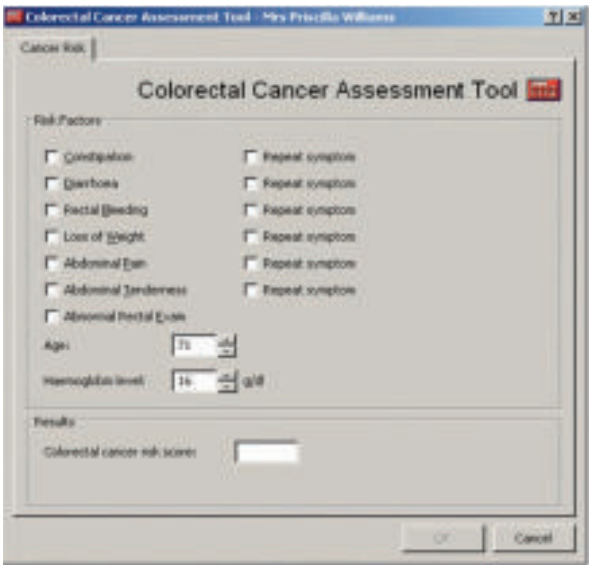


Figure 3: Paper (a) and electronic (b) RAT for bowel cancer

a

Constipation	Diarrhoea	Rectal Bleeding	Loss of Weight	Abdominal Pain	Abdominal Tenderness	Abnormal Rectal Exam	Haemoglobin 10-13g/dl	Haemoglobin <10 g/dl	
0.4	0.9	2.4	1.2	1.1	1.1	1.5	0.97	2.3	PPV as a single symptom
0.8	1.1	2.4	3.0	1.5	1.7	2.6	1.2	2.6	Constipation
	1.5	3.4	3.1	1.9	2.4	11	2.2	2.9	Diarrhoea
		6.8	4.7	3.1	4.5	8.5	3.6	3.2	Rectal Bleeding
			1.4	3.4	6.4	7.4	1.3	4.7	Loss of Weight
				3.0	1.4	3.3	2.2	6.9	Abdominal Pain
					1.7	5.8	2.7	>10	Abdominal Tenderness

b



3. Access to diagnostics

Open access to investigations (specifically CXR, abdominal/pelvic USS, lower bowel endoscopies and brain MRI) may enable GPs to achieve some earlier diagnoses.[23]

Normal tests do not necessarily exclude cancers, however. For example, a lung cancer may be present with a normal chest x-ray, so referral for CT scan may be indicated if the clinical picture is suspicious.[24]

4. Safety netting

GPs need to provide safety nets for patients so that:

- Patients know when to return if symptoms have not resolved
- Patients understand how they will be informed of test results
- The GP makes unequivocal arrangements to follow up patients about whom they have concerns
- The patient understands the reasons and hence importance of any referral

Effective safety netting requires a practice to have robust systems, for example regarding action on results and correspondence.[25,26]

Patients at increased risk of cancer

1. Lifestyle

Everyone needs to recognise and understand factors that are associated with an increased risk of cancer. Patients and health professionals are aware of the increased risk of lung cancer in smokers but may be less aware of increased risk of myeloid leukaemia, oro-pharyngeal, upper gastro-intestinal, prostate, bladder, kidney, cervical and ovarian cancers. The risk from

MACMILLAN CANCER DECISION SUPPORT TOOL: NEXT STEPS

In 2013 Macmillan Cancer Support successfully piloted the use of an electronic Cancer Decision Support Tool in over 550 GP practices across England, Scotland and Wales. Following successful completion of the pilot, and building on the early evaluation findings, Macmillan is now working to improve the functionality of the tool, with a view to making it available to all GP practices across the UK.

The tool comprises a reactive prompt, alerting GPs to potential cancer risks, an easy to use symptom checker that can be called up during consultation, and a risk stratification function that enables practices to list their practice population in order of risk.

Macmillan is continuing to work alongside BMJ Informatica, who have led on the software development, with the objective of creating an easy to use, downloadable version of the tool. Taking this approach will simplify the installation process as well as improve usability. Macmillan is also in the process of developing different versions of the tool that will sit on a number of IT platforms.

Cancer Research UK is undertaking the formal evaluation of work, with the final evaluation report due in the summer of 2014. Early evaluation data has already shown that use of the tool has influenced GPs in their clinical decision making when referring for cancer. The prompt feature acts as a reminder to GPs to consider the possibility of cancer where a risk has been calculated.

A typical comment from one participating GP hailed the resource as "a useful tool to have. It identifies cases one might not have picked up on and helps with making a decision in borderline cases."

Formal training and support will be available, with a selection of interactive training resources available on www.macmillan.org.uk/earlydiagnosis.

For more information on the Cancer Decision Support Tool or any other projects within Macmillan's Early Diagnosis Programme of work, contact Phil Hall, Macmillan Early Diagnosis Programme Coordinator at **phall@macmillan.org.uk**, or visit the Early Diagnosis page at **www.macmillan.org.uk/earlydiagnosis**

smoking diminishes slowly on stopping, so we must remain vigilant with ex-smokers.[28] Excessive alcohol consumption, sun exposure or use of sunbeds, physical inactivity and obesity are all associated with increased cancer risk.[27]

2. Genetic risk of cancer

Patients may worry about their risk of developing cancer following a diagnosis in a family member. Often these fears are groundless, but assessment requires a detailed family history. Local cancer genetic services will provide further assessment, provided that referrals meet local guidelines.

Some genetic risks are widely recognised, for example in breast, ovarian, bowel and prostate cancers. Advances in mapping genes will lead to an increased understanding of genetic risk of cancer.

Patients may assess their risk using publicly available tools, such as Macmillan's OPERA tool (www.macmillan.org.uk/Aboutus/Healthprofessionals/Cancer_genetics/OPERA.aspx) for ovarian and breast cancer. [28]

3. Other risk factors

One of the most important risk factors for cancer is older age.[29] A study from Scotland reviewing urgent suspected cancer referrals found that younger patients were over-referred and older patients under-referred when compared with their relative incidence of cancer.[30]

Deprivation is a risk factor both for developing cancer and for having more advanced disease at the time of diagnosis.[31]

Patients with difficulty accessing services (e.g. those who are housebound, or who have language difficulties, cognitive and sensory impairment, a chaotic lifestyle or severe mental illness) are significantly more likely to have advanced disease at diagnosis.[5]

Screening

Patients diagnosed through screening have better overall outcomes than those diagnosed through other routes.[14] It is of concern that the uptake of cervical screening (particularly among younger women) has been falling nationally and the uptake of bowel cancer screening remains significantly below the target of 70% in many parts of the UK, with an association between greater levels of deprivation and poorer uptake of screening.

PSA testing does not meet the criteria of a useful screening test. It is neither sensitive nor specific and does not reliably identify those patients at risk of aggressive prostate cancer. Further investigation of raised PSA levels is invasive, has significant associated morbidity and can lead to over-diagnosis, as discussed in the first article (*BJFM* Jan/Feb). There is now a broad consensus recommending against screening using PSA testing.[32]

Figure 4 shows key examples from the evidence base of benefit derived from screening for cancer.

Suggested actions for GP practices

The RCGP toolkit *Improving Cancer Diagnosis* illustrated how significant event analysis (SEA) encouraged GPs to think about practice issues. The resource can be found at www.rcgp.org.uk/clinical-and-research/clinical-resources/~/media/Files/CIRC/Cancer/Improving%20Cancer%20Diagnosis%20-%20A%20Toolkit%20for%20General%20Practice%20(2).ashx

Key messages highlighted:

- The importance of investigating vague persistent symptoms
- Negative tests do not necessarily reassure
- The need for a high index suspicion in older patients
- Co-morbidity clouds the picture
- The importance of continuity of care and good safety netting.

At a practice organisational level it illustrated the importance of robust result follow-up and good quality note keeping, and ensured completion of delegated tasks.[25]

Other reviews a practice may consider include:

- Urgent suspected cancer referrals
- Cancers diagnosed by non-urgent referral routes
- Patients with metastatic disease at diagnosis or diagnosed after emergency admission. Were there missed opportunities for an earlier diagnosis?
- Patients not attending for screening – what actions can the practice take to promote or increase uptake?

The Macmillan Revalidation Toolkit provides a framework that GPs and practices can use to look at

Figure 4: Evidence of benefit derived from screening for cancer

Cancer type	Screening protocol	Outcomes	Reference
Cervical	10,000 screened age 20-64	10 deaths prevented	*BMJ* Volume 326 26 April 2003
Breast	10,000 screened age 50 for 20 yrs	43 deaths prevented	*Lancet* 2012:380:1778
Colorectal	2 yearly tests age 60-69	Reduces colorectal mortality by 16%	NHS Bowel Cancer Screening Programme

their cancer care, with many suggestions for audits and reviews.[33]

GPs in England have access to their practice cancer profile data through the Cancer commissioning Toolkit (cancertoolkit.co.uk) and can use the data to benchmark themselves against both local and national colleagues.

SUMMARY OF KEY POINTS

1. Survival from earlier stage cancers is significantly better than at later stages of the disease.[14]
2. Treatments are also likely to be less taxing for the patient, with subsequent return to previous life and activity.
3. Earlier diagnosis remains a challenge to primary care, because GPs see many patients with symptoms that are potentially cancerous, although most are not.
4. Earlier diagnosis is a challenge to administrators, because reaching earlier diagnoses would require referral and investigation of more patients.
5. Earlier diagnosis is seen as cost effective.[34] The international benchmarking project is currently providing insights into differences between the UK and countries with better cancer outcomes.
6. Public health messages to encourage reporting of significant symptoms, tools to assist assessment of the risk of cancer, urgent referral pathways, referral guidelines and GP access to relevant investigations are the key levers to assist the UK to improve outcomes

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