

Early diagnosis: empowering and educating patients

Patients have to choose to make that initial appointment to discuss a symptom that could be cancer. What influences them, and how can we, and public health measures, influence them to present sooner? One of the great joys of primary care is working out why different patients behave differently – that is the art. Here, we consider a summary of evidence from recent years:

Promptness of initial presentation

Barriers for patients	What can we do?
<p>Awareness of cancer symptoms</p> <p>Lower in the UK than in other similar countries, particularly in men, ethnic minorities and the more socially deprived.</p> <p>Poorer awareness of:</p> <ul style="list-style-type: none"> • Persistent cough. • Swallowing difficulties. • Weight loss. <p>(BJC 2013,108:292, Eur J Cancer 2015;51:2473)</p>	<p><i>The ‘Be Clear on Cancer’ campaign was designed by Macmillan to tackle this issue. We can support these public health campaigns by publicising them in our surgeries.</i></p> <p><i>We can discuss the context of these symptoms when we are safety-netting, e.g. explaining why we don’t think it is cancer on this occasion <u>but what would concern us and when to re-consult.</u></i></p>
<p>Perception of ‘wasting GP time’</p> <p>Up to 15% of patients delay presentation for fear of wasting GP time. Factors that make this more likely:</p> <ul style="list-style-type: none"> • Visible reminders of time constraints, e.g. ‘One consultation, one problem’ posters. • Difficulty making an appointment. • Long waiting times in the surgery. • Dismissive or disinterested interactions. • Perception that symptoms were not serious enough, e.g. not life-threatening. <p>(BJGP 2016;66(648):e474)</p>	<p><i>Factors which reassured patients were:</i></p> <ul style="list-style-type: none"> • <i>Friendly GP interactions.</i> • <i>GP-initiated follow-up appointments.</i> <p><i>Clearly, more resource is also crucial in this issue!</i></p>
<p>Health beliefs</p>	<p><i>Public health education, including ‘Be Clear on Cancer’ and CRUK advertising, have worked to</i></p>

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A US study looking at fatalistic health beliefs and lung/colorectal cancer found that they are associated with a greater chance of having stage IV cancer at diagnosis.
(Cancer Epidemiol Biomarkers Prev 2015;24(4):720)

dispel the myth that cancer is a death sentence and promote the view that early diagnosis is worthwhile.

When do patients want to be investigated?

A UK-based study assessed the level of cancer risk at which patients would choose to be referred to secondary care for further investigation (Lancet Onc 2014;15:232).

It designed case history vignettes of symptoms which corresponded to 1%, 2%, 5% and 10% risk of lung, colorectal and pancreatic carcinoma. The vignettes also contained the proposed diagnostic route, its risks and benefits, treatment options if cancer was identified, and possible prognosis. Patients were asked to indicate if they would choose to be referred for investigation. 3500 patients in UK primary care completed more than 6000 case vignettes.

- 88% of patients opted for immediate referral for investigation, regardless of the level of risk.
- The association between risk and choosing referral was greater when colorectal cancer was analysed alone.
- Age had an effect – those aged between 60 and 69 were most likely to opt for immediate referral, while younger patients and those over 70 were less likely.

The authors concluded that patients showed a willingness and desire to be referred for investigation at risk levels well below those captured by the 2005 2ww guidelines, which equate to a risk level of not less than 5%. This factored into the decision-making process for the 2015 NICE referral guidelines discussed elsewhere.

Shared decision-making about referral

A further UK qualitative study looked at the extent to which patients were involved in the decision to be referred for symptoms which may be related to cancer (BJGP 2014;DOI:10.3399/bjgp14X682849). Patients were recruited from secondary care at sites in the north and north-east of England. They had been referred via 2ww or via routine clinic pathway for symptoms possibly suggestive of lung or colorectal cancer.

The main themes identified were:

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- Most patients described their GP as 'taking the decision to refer' – this was not perceived negatively, but rather as a 'trusted expert'.
- Greater involvement occurred when patients' expectations were not met, e.g. they wanted further investigation but their GP appeared unwilling/offered an explanation they found implausible.
- The reason for referral was often discussed in vague terms, even when a patient was referred on a cancer pathway.
- The subject of cancer only seemed to be raised if patients explicitly raised it as a concern, and it was often presented as a 'rule-out' test rather than the possibility that a cancer might actually be found.
- For patients on the 2ww pathway, this sometimes caused anxiety; things moved fast, creating alarm, but there had been no explicit discussion of cancer. Some saw the words 'cancer referral' and found this upsetting.
- Some patients also raised the disparity between public health campaigns that prompted them to see the doctor urgently about their symptoms, and then receiving reassurance from the GP with no mention of cancer!

What does this mean in practice?

The authors remind us that embedded in the NICE guidelines for referral is the importance of communication and shared decision-making with patients. They suggest there may be benefits to more overt discussion about the reasons for referral when symptoms may be suggestive of cancer, especially if using the 2ww system. It is also important for us to remember the 'Be Clear on Cancer' campaign, and address these patient concerns and expectations in the consultation

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