Urgent referral to specialist services for patients with cancer symptoms: a cause for concern or oversimplifying a complex issue?

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Prompt diagnosis of cancer is crucial, as it saves lives. In some primary healthcare systems, such as New Zealand (NZ) or the UK, patients with suspicious symptoms or signs normally require a referral from their general practitioner (GP) before accessing diagnostic services.[1] Thus, primary care in such systems has a key role in facilitating early diagnosis of cancer and reducing diagnostic delay.[2–4]

Early diagnosis of cancer in primary care is difficult because most presenting symptoms are common and overlap with other, benign, conditions. The GP's task is to assess the diagnostic probability of cancer and decide if further investigation and/or referral for specialist assessment is indicated.[2] Here, the supporting evidence base has moved over the past 20 years from expert consensus to diagnostic studies using electronic primary care data to provide estimates of the positive predictive values of different symptoms, signs and common laboratory tests for a broad range of cancers.[2] This evidence formed the basis for the UK's National Institute for Health and Care Excellence (NICE) updated 2015 clinical guideline on the recognition and referral of suspected cancer in primary care.[5]

The NICE 2015 guideline aims to promote early diagnosis and reduce diagnostic delay.[5] It promotes the latter by explicitly setting a risk of cancer threshold (positive predictive value) at which certain combinations of symptoms, signs and investigations—'alarm' features—merit urgent referral to secondary care (to be assessed and/or investigated within 2 weeks). Previous (2005) NICE guidelines had set this risk at 5%, the updated 2015 guidelines set this risk at 3%.[5] The NICE guideline

development group considered that a slight reduction of the threshold would improve the timeliness of cancer diagnosis without overwhelming clinical services or greatly increasing the possible harms to patients from overinvestigation.[5 6]

In this issue of *BMJ Quality and Safety*, Wiering *et al* present the findings of a UK-based study which aimed to assess the concordance between real-world GP referral practices and the 2015 NICE guideline.[7] Specifically, they wished to determine how often GPs follow the guidelines, whether certain patients are less likely to be referred and how many patients were diagnosed with cancer within 1 year of non-referral. They undertook a retrospective cohort study using linked primary care records in patients presenting with any of six 'alarm' features of possible cancer (haematuria, breast lump, dysphagia, iron-deficiency anaemia, postmenopausal bleeding, rectal bleeding) during 2014 and 2015. They found that a minority (40%) of patients received an urgent referral within 14 days of presentation, with wide variation by feature type, and that of these 9.9% went on to be diagnosed with cancer within 1 year. The probability of having an urgent referral also varied by patient characteristics with young patients and those with comorbidities less likely to receive a referral. Among patients presenting with a breast lump, those from more deprived areas were less likely to receive a referral. A total of 3.6% of the unreferred patients were diagnosed with cancer within 1 year.

This study uses a large, longitudinal, validated linked dataset that has been used in a number of previous cancer diagnostic studies, including a before and after study

that suggested that implementation of the previous 2005 NICE guidelines led to a reduction in cancer diagnostic intervals.[8] Its key finding, that guideline-recommended actions were not followed for the majority of patients presenting with alarm features, is consistent with previous research.[9] Nonetheless, the data relate to 2014/2015 and may not be consistent with current referral practice. Some support for this hypothesis is provided by UK research, using more recent data, which shows that from 2009/2010 to 2018/2019, the number of 2-week referrals has increased by 10% each year and that this has led to an increase in cancer detection.[10] The study's other findings regarding variation in urgent referral rates by age, multimorbidity and by deprivation[10] are also consistent with previous research. While the authors found no variation in urgent referral rates by ethnicity, this is often not the case internationally, particularly with respect to indigenous populations.[11] Indigenous people continue to have worse health outcomes than the majority group as a result of entrenched social inequities and racism as a result of colonisation.[12] NZ research (PIPER Project) has explored this issue using indicators of deficiencies in diagnostic delay in colorectal cancer.[13] Overall, 31% of patients were diagnosed following emergency department presentation and 19% with obstruction. These indicators were worse for Māori (the Indigenous people of NZ) patients living in areas with high deprivation,[13] findings confirmed by other NZ studies.[14] Thus, inequities for Māori in access to primary care and cancer diagnostic services exist in NZ, leading to poor cancer outcomes.[14 15] It is noted that Wiering et al did not consider geographical location (urban/rural) in their study, and this may also be an important determinant of delayed access to diagnostic services.[16]

The recommendation of Wiering et al that better adherence to the NICE guidelines may increase cancer detection, even for alarm features with already high referral rates, merits further discussion. It is important to highlight that GPs made the right decision for those patients who were appropriately referred, with about 1 in 10 of patients being diagnosed with cancer within 1 year. This is clearly above both the old and updated NICE guideline risk threshold. Among patients not receiving an urgent referral, the NICE 3% risk threshold was exceeded for patients presenting with anaemia of whom 5.5% were diagnosed with colorectal cancer within 1 year, and patients presenting with a breast lump of whom 3.5% were diagnosed with breast cancer within 1 year. However, for the other 'alarm' features, the percentage of patients diagnosed with a specific cancer within 1 year was below the NICE 3% risk threshold. It could therefore be argued that the guidelines are ensuring that the correct patients are being referred for some 'alarm' features.

Further, we suggest there is merit in considering implementation of cancer referral guidelines, at both patient–practitioner and health system levels. Looking at the entire process through a complexity lens can help us reflect on how the clinical interaction is not a simple linear process.[17] While the temptation is to think that simply having a symptom or sign should trigger an immediate referral or action, it does not account for other factors. It is vital to understand how cancer referral guidelines are actually used by GPs in their day-to-day practice, as there may be valid clinical and organisational reasons for non-referral and this may help to gain insight into why patients presenting with 'alarm' features are not referred in some situations.

There is a body of UK qualitative research exploring how GPs use cancer referral guidelines.[18–21] Lack of knowledge of guideline recommendations, while noted for some clinical areas,[19] was not seen as a major barrier to making an urgent referral. Rather, the difficulties in applying the referral criteria to individual patients, given that not all patients present with typical 'alarm symptoms',[18] lead some clinicians to prioritise clinical acumen and 'gut feeling' over strict adherence to guidelines in referral decision-making.[21] The desire not to make patients more anxious by over-referring[19] and the need to manage clinical uncertainty by observing patients over time, using safety-netting as a strategy to get patients to reattend should symptoms change, have also been previously discussed.[20] Thus, educational interventions at the GP–patient level to promote better adherence to the NICE guideline, a strategy suggested by Wiering et al, are unlikely to be effective unless they are tailored to the complexity of GP diagnostic and referral decision-making.

Moving onto understanding how healthcare system attributes influence GP referral decisions, the GPs in these studies emphasised the need not to refer unnecessarily, as this likely would lead to delays further down the diagnostic pathway given the resource constraints of a publicly funded health system (National Health Service).[18 19] Such concerns are borne out by the fact that the rise in UK 2-week wait referrals[10] has put pressure on diagnostic services with an attendant increase in diagnostic intervals.[22] Similarly in NZ, GPs and patients report delays in accessing diagnostic and specialist services for patients with suspected cancer.[23] It is interesting to note that a recent UK ecological analysis of national data found that a substantial proportion of the variation between general practices in referral rates and cancer detection rates is attributable at local health service level (primary care commissioning organisations and diagnostic service providers).[24] Moreover, diagnostic service providers accounted for the majority of variation attributable to local health services. These findings suggest that GPs in different geographical areas are referring into different local health systems that are performing differently in terms of their diagnostic and specialist provision, an area that merits further investigation.

To conclude, Wiering et al have identified that NICE clinical guideline recommendations were not followed for the majority of patients presenting with common cancer features in 2014/2015.[7] Nonetheless, the patients whom GPs referred were well above

the guideline's threshold, and for the most part those patients not referred immediately had a low risk of cancer. Rather than seeing this as a failure of adherence to clinical guideline recommendations, it is important that we first understand, and address, system factors such as local diagnostic and specialist provision and local organisational culture as it relates to primary and secondary care. This can then inform subsequent strategies to reduce diagnostic delay in patients with suspected cancer that goes beyond guideline adherence by GPs. These strategies must focus on achieving equitable health outcomes for cancer for Indigenous people, other ethnic minorities and in particular those living in areas of high deprivation, as these groups are most likely to experience diagnostic delay.

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