

Patient perspectives on delays in diagnosis and treatment of cancer:

a qualitative analysis of free-text data

Abstract

Background

Earlier cancer diagnosis is crucial in improving cancer survival. The International Cancer Benchmarking Partnership Module 4 (ICBP4) is a quantitative survey study that explores the reasons for delays in diagnosis and treatment of breast, colorectal, lung, and ovarian cancer. To further understand the associated diagnostic processes, it is also important to explore the patient perspectives expressed in the free-text comments.

Aim

To use the free-text data provided by patients completing the ICBP4 survey to augment the understanding of patients' perspectives of their diagnostic journey.

Design and setting

Qualitative analysis of the free-text data collected in Wales between October 2013 and December 2014 as part of the ICBP4 survey. Newly-diagnosed patients with either breast, ovarian, colorectal, or lung cancer were identified from registry data and then invited by their GPs to participate in the survey.

Method

A thematic framework was used to analyse the free-text comments provided at the end of the ICBP4 survey. Of the 905 patients who returned a questionnaire, 530 included comments.

Results

The free-text data provided information about patients' perspectives of the diagnostic journey. Analysis identified factors that acted as either barriers or facilitators at different stages of the diagnostic process. Some factors, such as screening, doctor-patient familiarity, and private treatment, acted as both barriers and facilitators depending on the context.

Conclusion

Factors identified in this study help to explain how existing models of cancer diagnosis (for example, the Pathways to Treatment Model) work in practice. It is important that clinicians are aware of how these factors may interact with individual clinical cases and either facilitate, or act as a barrier to, subsequent cancer diagnosis. Understanding and implementing this knowledge into clinical practice may result in quicker cancer diagnoses.

Keywords

early detection of cancer; patients; qualitative research; surveys and questionnaires; Wales.

INTRODUCTION

In the UK, cancer survival rates are poorer than in many similar countries.¹ Later stage at diagnosis is a contributor to this.² Despite an expanding evidence base surrounding the role of primary care in cancer diagnosis,^{3,4} there is still much to understand, and to improve, regarding the diagnosis of cancer through primary care. One widely accepted model of the diagnostic process is the Model of Pathways to Treatment.⁵ This proposes a series of interconnected phases that patients move through in the process from first recognising symptoms to diagnosis and treatment.

The International Cancer Benchmarking Partnership (ICBP) aims to compare cancer survival rates and to examine why there may be variations in cancer survival between similar health systems in different countries.⁶ More specifically, module 4 of the ICBP aims to explore and compare the reasons for delays in diagnosis and treatment of four cancers (breast, colorectal, lung, and ovarian) in 10 participating jurisdictions (Denmark, England, Manitoba, Northern Ireland, Norway, Ontario, Scotland, Sweden, Victoria, and Wales).⁶

This survey study of around 800 patients in each jurisdiction included patients recently diagnosed with one of the four cancers and contained factual questions about symptoms, consultations, investigations, and referrals. At the end of the survey, a free-text question asked patients: 'Please

add anything else that you would like to tell us about your cancer diagnosis or treatment', leaving one side of A5 as space for a response.

Free-text comments at the end of questionnaires differ in two ways from open questions. Not only do they have potential to expand to fit the space supplied, but they can also cover a wide range of topics that are important to and determined by the responder. Such responses may or may not be of relevance to the research questions being addressed. Free-text comments may be used in thematic analysis as a tool to understand replies to closed questions, for identifying new issues, to obtain feedback on the research process, and in the development of new survey questions.⁷

If systematically analysed, free-text comments from surveys may provide valuable data and can often be a neglected information source.⁸ Written sources are often seen as an underutilised source of data,⁹ and may give additional insight into quantitative responses.¹⁰ Previous studies have found that analysis of qualitative free-text comments in questionnaire studies can provide valuable information about individual expectations, knowledge, and understanding of health services.¹¹

The aim of this work was to use the qualitative free-text data from the recently conducted ICBP survey between October 2013 and December 2014 to investigate the patient's journey through cancer diagnosis

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Submitted: 31 May 2016; **Editor's response:** 28 June 2016; **final acceptance:** 17 August 2016.

©British Journal of General Practice

This is the full-length article (published online 22 Nov 2016) of an abridged version published in print. Cite this version as: **Br J Gen Pract 2016; DOI: 10.3399/bjgp16X688357**

How this fits in

There are known factors affecting the cancer diagnostic pathway. This study highlights that some factors, such as doctor–patient familiarity, can act as both a barrier and a facilitator to timely diagnosis. The findings also highlight the importance of patients' 'gut feelings' about their symptoms, the cyclical nature of some diagnostic journeys, and the barriers that can prevent timely diagnosis. It is important for clinicians to be aware of these further potential influences on the diagnostic journey for patients.

from their own perspective.

METHOD

Study design and participants

The main methods for the ICBP Module 4 survey are reported elsewhere.⁶ Data were collected between October 2013 and December 2014. Patients were newly diagnosed, having received their diagnosis 3–6 months prior to their identification for this study through the cancer registry. All eligible patients were sequentially invited, with the aim of recruiting at least 200 patients diagnosed with each cancer, within the time period.

Completed paper surveys were received and the free-text comments transcribed verbatim. A total of 905 patients in Wales returned surveys that were included in the analysis presented in this study. Of the 905 returned questionnaires, 530 (58.6%) contained free-text comments. Of these, 166/277 (59.9%) were made by patients with breast cancer, 181/306 (59.1%) with colorectal cancer, 121/224 (54.0%) with lung cancer, and 62/98 (63.2%) with ovarian cancer. In all, 352/587 (60.0%) females added comments, and 178/318 (56.0%) males added comments. The mean age of those who commented was 66.1 years, with a range of 23.6–90.8 years, and the mean age of those who did not add comments was 68.0 years, with a range of 22.1–93.9 years.

The socioeconomic status (Welsh Index of Multiple Deprivation) was also similar. Where a score of 1 indicates the least deprived and 5 indicates the most deprived, 23.8% of those who commented scored 1, compared with 24.8% of those who did not comment, 23.6% versus 23.5% scored 2, 22.5% versus 19.7% scored 3, 18.3% versus 18.7% scored 4, and 11.9% versus 13.3% scored 5. In addition, 53.6% of those who commented and 45.9% of those who did not comment with breast cancer were

screen-detected, and 30.9% of those who commented and 28.0% of those who did not comment with colorectal cancer were screen-detected (self-reported). The free-text data for Wales were analysed separately from data for other UK countries because of the devolved nature of the health services.

Analysis

A thematic framework was used to analyse the free-text data. This is consistent with approaches used in other studies of free-text survey data.¹⁰ However, in contrast to other studies,¹² it was decided to treat the data as wholly qualitative, as the free-text contributions were unstructured and unguided. The Framework approach was chosen to organise and analyse the data. Framework analysis is a systematic, matrix-based system that encourages analysis both by theme and by case.^{13–15} The five stages of Framework were conducted: data familiarisation, inductive development of a framework, index of themes and subthemes, synthesising the data, and data interpretation. As GPs, two of the researchers brought a clinical perspective to the analysis. Due to the brevity of free-text data, the layout of the Framework charts (the matrix displaying the data) was condensed to ensure it was easy to identify patterns and associations in the data, and also to ensure the authors maintained links to each individual responder so that comments by individual responders could be visibly and easily traced, and their characteristics (cancer type, age, sex) identified to facilitate the interpretative process.

All authors were involved in the interpretation stage through individual interpretative work and data interrogation, interspersed with an iterative process of team data interpretation workshops. During these workshops, the data and interpretations were discussed, emerging explanations formulated and reformulated, and alternative explanations debated with reference to the data (charts). It was during this process that the authors identified a pattern within the data that related to barriers and facilitators to diagnosis and treatment. The decision was made to focus on barriers and facilitators, in terms of what they were, and how and why they worked. Only data pertaining to the diagnosis, as opposed to treatment, were considered.

RESULTS

The free-text comments covered a range of views pertaining to time points across the diagnostic journeys of the patients. The following section describes the emerging

themes relating to the barriers and facilitators to cancer diagnosis and how they interact. The qualitative findings are arranged in a sequential order, with issues pertaining to screening followed by appraisal and help-seeking, interactions with primary care, and interactions with secondary care. All quotes are presented verbatim. Those in the third person were completed by carers.

Screening

From the patient's perspective, screening was usually considered to be a facilitator to cancer diagnosis, with many patients describing screening as a positive aspect of their journey, which usually indicated abnormalities that were previously unknown. However, in some instances, screening was regarded by patients as a barrier to detection of cancer. One reason for this was that recent screening had not picked up their cancer, and, in one case, a participant did not present their suspicious symptoms because they were due to attend a screening session. Had this participant not been involved in the screening programme, they may have presented earlier to their GP with suspicious symptoms. Others had difficulty scheduling a screening appointment:

'My treatment started with the bowel screening in [name of hospital]. For this reason I did not visit my GP with symptoms.' (Female, age 67 years, colorectal cancer diagnosis)

'I missed my first mammogram due to a poorly child, and had problems rearranging a new appointment.' (Female, age 52 years, breast cancer diagnosis)

Appraisal and help-seeking

Patients described various barriers and facilitators to help-seeking that occurred before their cancer diagnosis. For some patients, life events impeded diagnostic tests. Some patients described the phenomenon of not having any specific symptoms, just a 'gut feeling'. For some, this was the only initial indicator that prompted help-seeking. For others, help-seeking was delayed until more obvious symptoms were found.

Whether the 'gut feeling' acted as a barrier or a facilitator appeared to depend largely upon the decision of the patient's GP to initiate further investigation:

'Had mammogram and then vacuum assisted biopsy May 2013. Consulted doctor Nov 2012. Had no symptoms, just a gut feeling.' (Female, age 54 years, breast cancer diagnosis)

'Three days later I was told I had cancer. I knew that a year before.' (Male, age 69 years, lung cancer diagnosis)

Patients themselves often requested further investigations even when previous results were clear of abnormalities. Such requests often acted as facilitators, aided by their GP taking further action:

'Asked for another X-ray December. Cough was bad. Found cancer. A mass.' (Female, age 77 years, lung cancer diagnosis)

Those patients who had had previous malignancies described a sense of feeling entitled to further investigations or treatment due to an impression that they were high risk. Having a previous malignancy was regarded as a facilitator in this situation:

'I was diagnosed with thyroid cancer in Dec 2013, and because of this I was able to push for further investigation of my bowel problems.' (Female, age 43 years, colorectal cancer diagnosis)

Other patients described not noticing or acting upon their symptoms until they were influenced by other people. Although this was sometimes due to cognitive impairment, this input from others was seen as a facilitator to diagnosis:

'I have Alzheimer's disease and my wife noticed the change in bowel habits. I had no other signs or symptoms.' (Male, age 79 years, colorectal cancer diagnosis)

'P.S. I must thank my granddaughter as she said: "Nanna you have been coughing more than a month — go to the doctor's", as the TV ad had shown. So I did. Thanks to her I am getting better.' (Female, age 75 years, lung cancer diagnosis)

Some patients stated that they put the initial symptoms that they were experiencing down to other conditions. These acted as barriers to early diagnosis. Such conditions included pre-existing conditions, such as bowel problems, and psychological issues, such as stress:

'In 2012, I experienced extreme levels of stress in work. The difficulties began in January when I started to sleep badly and experienced high levels of anxiety about my job. By July 2012 I started to feel very run down, stressed, and unable to recover from colds etc. I had myalgia in Sept/Oct and

then took 2 weeks off to rest. This coincided with a very stressful period of bullying in work. After my hysterectomy I felt very well. (Female, age 58 years, ovarian cancer diagnosis)

However, although most patients indicated that vague symptoms were usually a barrier, in some cases these symptoms facilitated the speed of diagnosis. There was also some confusion about seemingly obvious symptoms, with some patients not realising the significance of 'alarm' symptoms, and others recognising them and seeking help. This appears to be dependent on individual patient knowledge and awareness of potential cancer symptoms:

'The only symptom was an annoying cough which I had for a few months before.' (Male, age 69 years, lung cancer diagnosis)

Paying for private health services

Some patients described how they had paid privately for accessing health services. This was usually because patients saw NHS waiting times as being unreasonably long. Paying privately was usually viewed by patients as a facilitator to a quicker diagnosis or treatment:

'Due to waiting list (NHS) 36 weeks, paid to see a private consultant.' (Female, age 54 years, colorectal cancer diagnosis)

However, paying privately for further investigations also acted as a barrier. One reason was because the tests ordered failed to detect their cancer:

'Since July '09 I have had four colonoscopies, two endoscopies and two scans, one sigmoid endoscopy (in Jan '13). As a result of poor bowel habits, diagnosed as a coeliac July '09 and had polyps removed. All on private sector. The sigmoid endoscopy in Jan '13 was clear.' (Male, age 62 years, colorectal cancer diagnosis)

Thus, although private patients may expect further investigations or treatment to result in a quicker route to cancer diagnosis or treatment, this may not always be the case.

Interaction with primary care

On contact with primary care, the most common barriers to cancer diagnosis included being treated for other conditions, misdiagnosis with another condition, or not appearing to be taken seriously by health professionals.

For example, if a patient has a chronic condition, there may be no indication to initiate further investigations:

'I first visited my doctor about my symptoms around Aug 2012. I was not examined. I was told the pain was coming from my back (I had a back problem for years).' (Female, age 72 years, ovarian cancer diagnosis)

'They even referred me to a psychiatrist with cancer anxiety as they just didn't seem to believe how ill I felt and what was happening when I went to the toilet.' (Female, age 43 years, colorectal cancer diagnosis)

Being investigated for another condition acted in some situations as a facilitator to diagnosis and treatment. Sometimes this was based on incidental findings from investigations regarding pre-existing conditions, and at other times it was as a result of regular checks:

'The cancer was only found on annual chest check for COPD [chronic obstructive pulmonary disease].' (Male, age 69 years, lung cancer diagnosis)

'The lump that I felt initially that led me to go to GP, on ultrasound turned out to be a cyst. This was localised below nipple L breast. However, incidental finding of a mass found on mammogram L lateral aspect of breast.' (Female, age 47 years, breast cancer diagnosis)

Another mediating factor was the reaction of health professionals to patient symptoms. Most patients found their health professional's reaction to their symptoms to be a facilitator. However, others found it to be a barrier. The quote below demonstrates how different health professionals acted as either barriers or facilitators to making a cancer diagnosis:

'At yearly check up with the nurse, despite high weight loss, this was considered a positive effect (June). However, a different nurse noticed him in the surgery waiting for his wife and was concerned at his obvious weight loss and made an emergency appointment with the GP (late August).' (Male, age 82 years, lung cancer diagnosis)

Some younger patients reported a sense that their GP had not taken their symptoms seriously, potentially due to their age and the rare likelihood of malignancy:

'... had a number of visits to the doctors

to which I was told nothing was wrong and wouldn't listen to me.' (Female, age 24 years, ovarian cancer diagnosis)

Others felt that their GP took their symptoms seriously and they were referred appropriately:

'2013 Jan — blood test at surgery. Anaemia result. Doctor referred me to have tests at hospital. Doctor wanted to know why, [cause of anaemia] not treat.' (Female, age 85 years, colorectal cancer diagnosis)

Some patients described familiarity with their GP as a barrier to treatment. This appears to be an important concept where it is possible for intervention:

'I feel I have been very lucky with my diagnosis, as when I attend [sic] my surgery my doctor was away on holiday and saw a locum doctor. Had I seen my normal doctor she may have thought my symptoms were due to my COPD. However the locum, not knowing me, he immediately sent me for an X-ray and re-referred me to the chest clinic and my diagnosis was very swift.' (Female, age 62 years, lung cancer diagnosis)

Although patients described how some health professionals inadvertently gave false reassurance, others investigated patients further despite inconclusive or negative tests:

'My GP was concerned and initiated further tests which indicated that I did in fact have bowel cancer!' (Male, age 67 years, colorectal cancer diagnosis)

'Back to GP as had hip pain that was concerning me as well as the fatigue. By October I found a lump on my left breast as well as some pain on the side of both breasts. The GP found the lump and referred me to [name of hospital] even though he believed I just had lumpy breast.' (Female, age 39 years, breast cancer diagnosis)

Lastly, there were views regarding the need for all patients to be referred urgently, and general views about potentially bypassing general practice altogether when it comes to cancer diagnosis:

'I think all cases should be referred, as England, within 2 weeks, irrespective of whether GP thinks it is cancer or not — they are not the experts. I knew it was a lump — whether it was cancer or not is up to specialist.' (Female, age 46 years, breast

cancer diagnosis)

Interaction with secondary care

Although some patients described waiting a long time and being delayed, others felt that their cancer diagnosis had been swift, sometimes due to the quick-thinking actions of their GP or their own persistence:

'NHS see urgent as within 2 weeks. This is a very long time in those early days. I made my appointments by persistently waiting for cancellations so managed to bring my treatment forwards.' (Female, age 59 years, ovarian cancer diagnosis)

Others described the sense of disappointment that they felt due to waiting in the system for what they perceived to be a long time:

'Although the treatment I am getting now is second to none, I feel I could have [been] investigated a lot sooner if the gastroenterologist in [name of hospital] had agreed to see me in February as my GP requested. The secondaries in my liver might not have been so serious.' (Female, age 72 years, colorectal cancer diagnosis)

'Test results for type of cancer and treatment needed: Really needs to be faster. Most people think they are going to die — I waited around 4 weeks to hear that "actually" I would need chemo. Chemotherapy.' (Female, age 51 years, breast cancer diagnosis)

In secondary care-initiated investigations, as in primary care, some patients reported that specific diagnostic tests missed their cancer:

'As a result of the bowel screening on 03/12, I was diagnosed with ischaemic colitis and under a gastroenterologist 30/1/13. I had a CT [computed tomography] angiography scan. Scan showed a thickening of bowel wall 25/2/2013. I had a sigmoidoscopy as cancer was suspected, where it was ruled out. I was then referred to a surgeon to remove part of the colon.' (Female, age 64 years, colorectal cancer diagnosis)

For others, their cancer was an incidental finding in secondary care while undergoing investigations for other health problems, or from other screening or primary care testing (see previous section):

'I went into hospital for a double heart bypass and a chest X-ray identified a lump

in my left lung, which was confirmed by a PET [positron emission tomography] scan as cancer. The top lobe of my left lung was removed and no further treatment was needed, so far.' (Male, age 66 years, lung cancer diagnosis)

'My cancer was detected by a wonderful accident. I was undergoing tests and scans because my yearly check-up showed I was anaemic. It was only the scan on my abdomen caught my right lung.' (Female, age 77 years, lung cancer diagnosis)

Some patients explained how that they had never accessed their GP initially. Although some patients were diagnosed via accident and emergency attendance, others found novel methods of accessing secondary care services:

'Didn't go to GP — I work in the hospital and was seen in breast clinic.' (Female, age 51 years, breast cancer diagnosis)

Others reported cases that appeared to indicate negligence on the part of the healthcare system. Although having a scan for a specific symptom would be expected to be a facilitator to diagnosis, it can sometimes act as a barrier:

'09/2012 I did have a scan, and was told I had two small cysts on my ovaries, but nothing to worry about, apparently no one did report filed and forgotten.' (Female, age 73 years, ovarian cancer diagnosis)

DISCUSSION

Summary

This study provides an insight into the journeys of patients with cancer through their cancer diagnosis, by demonstrating the range of factors that can act as barriers and facilitators to diagnosis, and how some factors can act as both.

The study also highlights that physicians and patients need to be mindful of factors that may affect the diagnostic journey, such as involvement in a screening programme, continuity of care, and the efficiency of diagnostic tests. There is potential for patient education on issues such as the accuracy of screening and diagnostic testing, the implications of vague recurring symptoms, and navigating through the diagnostic pathway.

These findings help to further explain how existing models of cancer diagnosis work in practice and offer further information to aid in the development and evaluation of interventions to expedite and avoid

unnecessary delays in diagnosis.

Strengths and limitations

The free-text comments analysed in this study add to the quantitative knowledge about patients' diagnostic journey providing insight and understanding from the patients' perspectives.

However, it is also important to be aware that free-text comments may not represent the survey population. Because more than two-fifths of the sample did not write anything in the free-text box, there was only limited demographic data for those that did.

Furthermore, just because an issue is raised by one participant does not mean it is not important to others who did not raise it.

Lastly, when analysing qualitative comments, the authors have no way of understanding the mood or circumstances of the patients at the time of completion, and how this has impacted on the free-text comments.

Comparison with existing literature

The existing literature supports many of the findings from this study. The authors found evidence of patients delaying before presenting symptoms after a previous 'all-clear' message, which confirms similar results reported after symptomatic presentation.^{16,17} Furthermore, the finding that some patients may wait for their next round of screening instead of seeking more immediate help from their GP regarding symptoms resonates with similar results presented by Solbjør and colleagues.¹⁸ Patient knowledge of cancer symptoms was shown in this study to be an important mediating factor in initiating help-seeking behaviour. This appeared true irrespective of whether the symptoms were common or uncommon. Issues relating to the variation in the public awareness of cancer symptoms and the effectiveness of awareness campaigns have also recently been reported.^{19,20} This builds on, and has implications for, knowledge about the effectiveness and importance of public awareness campaigns.

The authors' findings extend the literature by adding to the understanding of the complexities of the path to cancer diagnosis. Recent research has highlighted the range of biopsychosocial, contextual, and cultural influences on the ways in which people recognise, interpret, and act on symptoms.²¹ The findings of this study add to this by suggesting that further influences, such as comorbidity, can complicate the diagnosis, as patients may not recognise symptoms as indicative of cancer and GPs

Funding

Module 4 was organised by the International Cancer Benchmarking Partnership (ICBP) with funding from Cancer Research UK. This study was funded in Wales by Cancer Research Wales.

Ethical approval

This study was approved by the National Research Ethics Service Committee East Midlands — Derby 2 Research Ethics Committee, REC No: 11/EM/0420.

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

Acknowledgements

The authors would like to thank all the patients for taking the time to contribute to this international study. We are also grateful to the ICBP 4 central team led by Professor Peter Vedsted, Aarhus University Denmark, Professor David Weller, Edinburgh University, and Professor Usha Menon, University College London. We also acknowledge all members of the ICBP Programme Board: Ole Andersen (Danish Health and Medicines Authority, Copenhagen, Denmark), Søren Brostrøm (Danish Health and Medicines Authority, Copenhagen, Denmark), Heather Bryant (Canadian Partnership Against Cancer, Toronto, Canada), David Currow (Cancer Institute New South Wales, Sydney, Australia), Dhali Dhaliwal (Cancer Care Manitoba, Winnipeg, Canada), Anna Gavin (Northern Ireland Cancer Registry, Queen's University, Belfast, UK), Gunilla Gunnarsson (Swedish Association of Local Authorities and Regions, Stockholm, Sweden), Jane Hanson (Welsh Cancer National Specialist Advisory Group, Cardiff, UK), Nicola Quin (Cancer Council Victoria, Carlton, Australia), Stein Kaasa (University Hospital of Trondheim, Trondheim, Norway), Linda Rabeneck (Cancer Care Ontario, Toronto, Canada), Michael A Richards (Care Quality Commission, London, UK), Michael Sherar (Cancer Care Ontario, Toronto, Canada), and Robert Thomas (Department of Health and Human Services, Victoria, Melbourne, Australia).

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may not act on them due to the known comorbidity. The authors also found that some patients experienced a 'gut feeling' that further influenced their diagnosis pathway. This finding reinforces the recent report from Whitaker and colleagues of 'just instinct' by patients regarding cancer alarm symptoms.²²

Importantly, this study highlights how certain factors can act as either barriers or facilitators to diagnosis in different contexts. A similar observation was reported by McLachlan and colleagues²³ in their study of help-seeking behaviour prior to lung and colorectal cancer diagnosis. They observed how health professionals may act as both a barrier and a facilitator to diagnosis. The current study highlights that some factors (for example, doctor-patient familiarity) are commonly presumed to be a facilitator but are reported to be barriers, and factors that are commonly presumed to be barriers (for example, the presence of comorbidity) are also reported as facilitators.

Lastly, this study also begins to explain some of the detail underpinning current models of cancer diagnosis. The findings (except the data relating to screening) map very closely onto the Model of Pathways to Treatment.⁵ This study adds some complexity to this model, demonstrating how and why some patients go 'backwards' as well as 'forwards' in the model. It also shows how patients may be able to enter the model at different points in time; for example, by bypassing primary care and entering their diagnostic journey via secondary care.

Implications for research and practice

There are a number of implications from this analysis of patient descriptions of their diagnostic journey. The findings suggest that models encompassing cancer diagnosis and treatment need to incorporate the possibility that patients may not travel along a predefined pathway of initially accessing primary care, and therefore should account for the potential for less common diagnostic pathways. Screening programmes need to promote awareness of the issues of

symptomatic cancers presenting soon after a negative screen, and of patients ignoring symptoms if they have an upcoming screen. There also remains the need for effective awareness campaigns regarding common and potentially less common symptoms. The study provides reminders for GPs of the potential negative consequences of multimorbidity, the reality that some tests will come back as false-negative, and how easy it is for health professionals' actions to be perceived as not taking patients' symptoms seriously.

GPs should be aware that some factors may act as barriers or facilitators, depending on the context. In addition, although doctor-patient familiarity and continuity of care are considered important and positive aspects of high-quality primary care,²⁴ a 'fresh pair of eyes' may also be a worthwhile consideration that may expedite the diagnostic pathway.

In secondary care, there must be an awareness of the possibility of false-negative tests, and of the risk of excessive waiting times and of not acting on GP requests to expedite. It is important for patients to realise that cancer may not always present in a typical manner; for example, not all cancers cause 'red-flag' symptoms such as lumps or bleeding. To assist with this, physicians need to explore patients' understanding of their symptoms. This finding is echoed by McLachlan and colleagues,²³ who found that prompting patients for further information within a consultation may give important details about the context of their symptoms, later aiding physician decision making. The authors further suggest that a more inclusive approach should be taken by physicians to encompass vague symptoms (for example, not just those presented in media campaigns, such as coughs and rectal bleeding) when considering the investigation of patients for potential malignancy.

The main implication for future research is the continued need to develop and evaluate interventions to expedite the diagnosis of cancer and avoid unnecessary delays in treatment.

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