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## Non-attendance at urgent referral appointments for suspected cancer:

a qualitative study to gain understanding from patients and GPs

### Abstract

#### Background

The 2-week-wait urgent referral policy in the UK has sought to improve cancer outcomes by accelerating diagnosis and treatment. However, around 5–7% of symptomatic referred patients cancel or do not attend their hospital appointment. While subsequent cancer diagnosis was less likely in non-attenders, those with a diagnosis had worse early mortality outcomes.

#### Aim

To examine how interpersonal, communication, social, and organisational factors influence a patient's non-attendance.

#### Design and setting

Qualitative study in GP practices in one Northern English city.

#### Method

In-depth, individual interviews were undertaken face-to-face or by telephone between December 2016 and May 2018, followed by thematic framework analysis.

#### Results

In this study 21 GPs, and 24 patients who did not attend or had cancelled their appointment were interviewed, deriving a range of potential explanations for non-attendance, including: system flaws; GP difficulties with booking appointments; patient difficulties with navigating the appointment system, particularly older patients and those from more deprived areas; patients leading 'difficult lives'; and patients' expectations of the referral, informed by their beliefs, circumstances, priorities, and the perceived prognosis. GPs recognised the importance of communication with the patient, particularly the need to tailor communication to perceived patient understanding and anxiety. GPs and practices varied in their responses to patient non-attendance, influenced by time pressures and perceptions of patient responsibility.

#### Conclusion

Failure to be seen within 2 weeks of urgent referral resulted from a number of patient and provider factors. The urgent referral process in general practice and cancer services should accommodate patient perceptions and responses, facilitate referral and attendance, and enable responses to patient non-attendance.

#### Keywords

cancer; communication; diagnosis; no-show patients; primary health care; socioeconomic factors.

### INTRODUCTION

Introduced in 2000, the 2-week-wait (2WW) policy sought to improve cancer outcomes by accelerating diagnosis and treatment. All NHS patients in England and Wales with suspected cancer should be seen within 2 weeks of GP referral.<sup>1</sup> Though intended to reduce waiting times, the policy also had potential to reduce social inequalities and geographical variation in outcomes.<sup>2</sup>

More than 1.9 million 2WW referrals are made annually.<sup>3</sup> Almost half of all cancers are identified through this route, though for 92% of patients, referral will exclude cancer.<sup>4</sup> Hospital trusts face penalties if <93% of referred patients are seen within 2 weeks. This is commonly caused by patient appointment non-attendance, including repeated non-attendance. Around 5–7% of symptomatic referred patients cancel or do not attend their hospital appointment.<sup>5</sup>

Help-seeking with symptoms and patient non-attendance have been investigated extensively in other patient pathways,<sup>6–10</sup> revealing sociodemographic patterning of non-attendance. It has not yet been researched in the 2WW pathway, despite referred patients being symptomatic and the potential impact of non-attendance on diagnostic interval<sup>11</sup> and cancer outcomes. Recent quantitative research by the current authors, using a dataset of 109 433 patients (including 5673 non-attenders), found both patient and practice factors predicted non-

attendance.<sup>5</sup> Rates were highest in the youngest (aged 18–28 years) and oldest (aged >85 years) patients; in males; in patients living in more deprived areas or further from the hospital; and in those with specific suspected cancers (highest among upper gastrointestinal [GI] referrals). While cancer diagnosis was less likely in non-attenders, early mortality outcomes were worse in this group compared to attenders.

With this in mind, this study sought to gain an in-depth understanding of patients' and referring GPs' experiences of non-attendance for urgent referral appointments using qualitative research methods to examine how interpersonal, communication, social, and organisational factors can mediate decision making and influence non-attendance. By triangulating patient and GP views, the authors aimed to identify and understand a range of possible barriers to attendance in this patient group and identify potential solutions.

### METHOD

This was a qualitative study that interviewed patients referred for suspected cancer and GPs. All practices in one large Northern English city were invited to help recruit participants and identify GP interviewees.

### Sampling

While a purposive sampling strategy was planned, to gain maximum variation

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### How this fits in

Previous research into patient non-attendance at appointments has mostly focused on primary care, with a concern about wasted time and resources. To the authors knowledge, this is the first study of non-attendance by symptomatic patients referred owing to suspected cancer. The study found that a range of patient and provider factors were associated with non-attendance, including several to which healthcare organisations and individual practitioners may be able to respond.

in key factors (rates of 2WW referral and non-attendance, practice Index of Multiple Deprivation [IMD],<sup>12</sup> location, GP sex, and years of experience), difficulties in recruiting these hard-to-reach patients meant that opportunistic sampling was used. Opportunistic sampling is often necessary for recruiting difficult-to-reach patients, such as those who do not attend appointments.<sup>13</sup> The authors selected 24 patients for interview from the 29 consenting and eligible patients (Figure 1). The hospital trust identified, on a weekly basis, patients from participating practices who had not attended their appointment without warning ('did not

attend': DNA) or cancelled it (cancelled at least two appointments or cancelled referral completely) to achieve this pool of patients. Patients dissenting from the use of their health records for research were excluded. Practices determined patient eligibility according to mental health problems, learning disability, limited English, or any other known factor potentially affecting ability to consent and/or undertake an interview.

### Participant recruitment

The authors wrote to all 105 general practices in the city, requesting one or both forms of participation: assistance with patient recruitment and GP interview participation.

Eligible patients were invited by personalised GP letter and recruitment pack. GPs opting for further information about participation were invited by personalised letter from the study team and recruitment pack.

Patients were contacted for in-depth face-to-face interviews; interviews were held within 12 weeks of cancellation or DNA. GP interviews were conducted face-to-face or by telephone ( $n=2$ ). Patients were given a 25 GBP honorarium. Practices were reimbursed for GP time at National Institute of Health Research Comprehensive Regional Network rates.

### Data collection

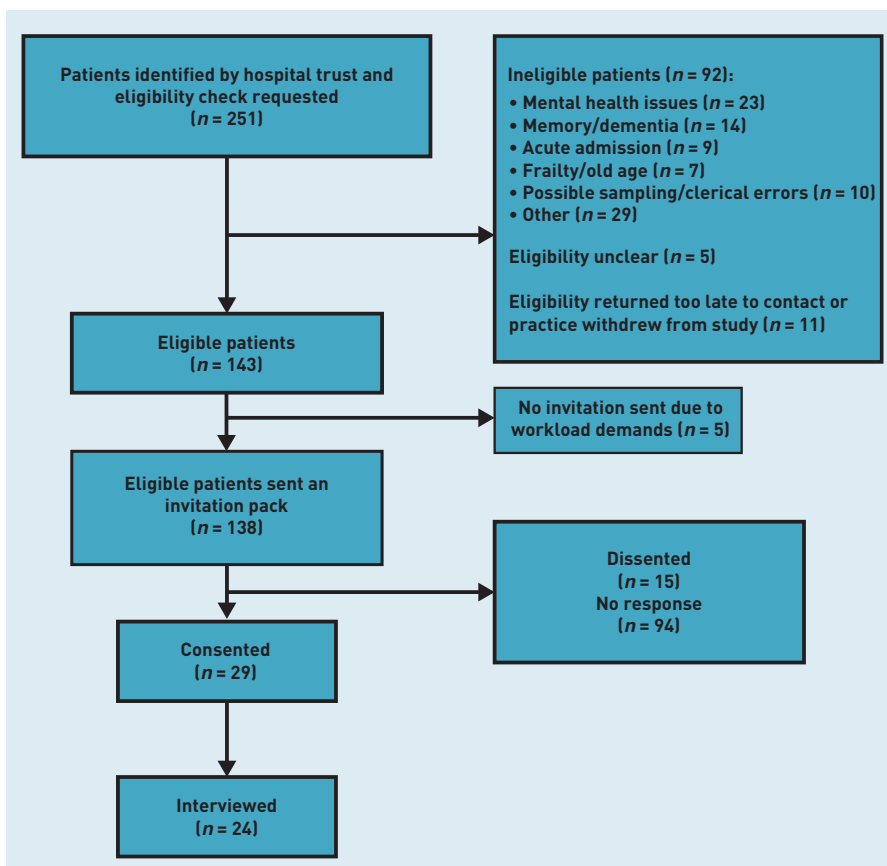
Participants were interviewed between December 2016 and May 2018 by one of two experienced researchers using a topic guide [available from the authors on request], which had been informed by relevant published research, the study Patient and Public Involvement Group, and aspects of the quantitative analysis.<sup>5</sup> Patient interviews focused on the following: recollection of symptoms provoking the GP appointment; how the referral was explained; and reasons for not attending. GP interviews focused on: 2WW referral decisions; why some patients do not attend; and how non-attendance is managed by the practice. GPs were asked to discuss 2WW referrals both generally and with reference to individual scenarios. Potential interventions were discussed with both groups.

Recordings were transcribed verbatim and all transcriptions checked for accuracy.

### Data analysis

Framework analysis was used.<sup>14</sup> Following data familiarisation, a coding framework was developed for emergent themes and subthemes by two experienced qualitative researchers using a grounded theory approach.<sup>15</sup> GP and patient data were

Figure 1. Patient recruitment.



analysed concurrently to draw comparisons and enrich interpretations from multiple viewpoints (Figure 2). Elements of consensus and differences between individual patients and individual GPs, as well as between demographic groups were explored. This particularly focused on exploring the effect of participant age, sex, GP years' experience, level of deprivation and, to some extent, suspected cancer pathway, though this was limited owing to the large number of categories. Analysis continued until saturation occurred within the evolving themes, a concept Saunders *et al* term 'inductive thematic saturation'.<sup>16</sup> Investigator triangulation was employed whereby a random sample of 20% of transcriptions was second-coded and independently checked to ensure consistency in the use of the coding framework and interpretations made.

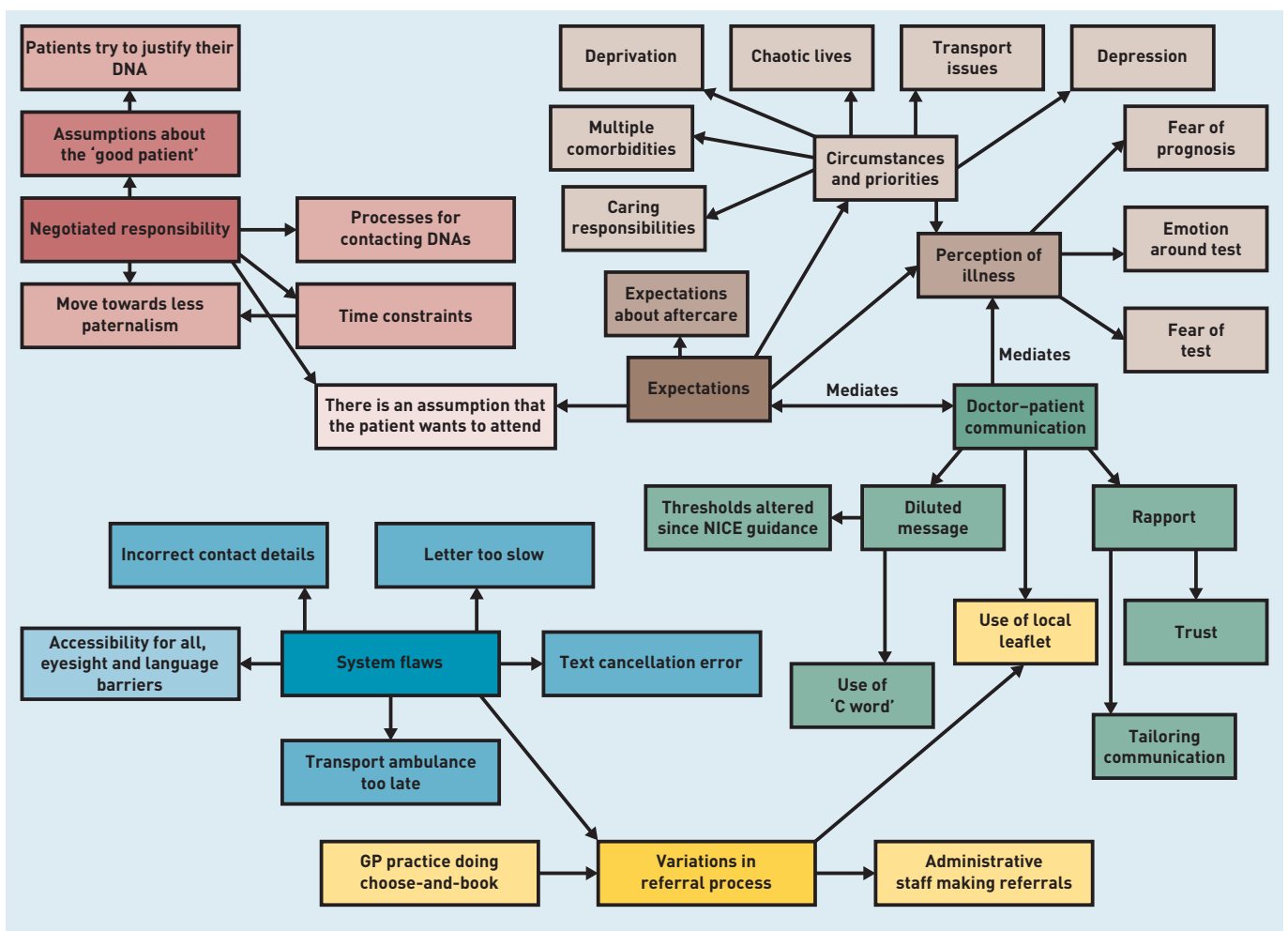
### RESULTS

A total of 34 practices participated in patient identification, from which 21 GPs were interviewed (from 16 different practices). GPs had a wide range of experience (Table 1), and

three were current or former local clinical cancer leads. Out of 251 patient eligibility checks requested, 143 (57%) were eligible for interview and 138 patients were contacted (consented 29; dissented 15; no response 94 (Figure 1, Tables 1 and 2) and 24 were interviewed. Patients had been referred with a range of suspected cancers, though patients with suspected skin cancer were over-represented and the authors were only able to interview one patient with suspected breast cancer. Patients with suspected lung cancer were not included as these are not routinely referred via the 2WW process in the city in which this study was based. As would be expected in this patient group, most patients tended to be older (median age 60.5 years), though several younger patients were also interviewed (age range 22–77 years). There was socioeconomic variation in patients, across all national IMD deciles. Most patients were white British (18 out of 24).

There were some relatively straightforward explanations for non-attendance. However, other reasons were complex and related

Figure 2. Mind map of analytical themes. C= cancer. DNA = did not attend. NICE = National Institute for Health and Care Excellence.



**Table 1. Participant characteristics**

Characteristics	n(%) <sup>a</sup>
<b>Patients (N= 24)</b>	
<b>Sex</b>	
Male	13 (54)
Female	11 (46)
<b>Age, median years</b>	60.5 (22–77)
<b>Suspected cancer referral pathway</b>	
Skin	8 (33)
Head and neck	5 (21)
Lower gastrointestinal	5 (21)
Gynaecology	3 (13)
Urology	2 (8)
Breast	1 (4)
<b>2WW circumstances of non-attendance</b>	
Did not attend	14 (58)
Cancelled by patient	7 (29)
Recorded on system as DNA but patient states it was CBP	3 (13)
<b>SES, median IMD quintile (range)<sup>b</sup></b>	4 (1–5)
<b>Ethnicity</b>	
White British	18 (75)
Pakistani	1 (4)
Other Asian background	1 (4)
Missing	4 (17)
<b>GPs (N= 21)</b>	
<b>Sex</b>	
Male	11 (52)
Female	10 (48)
<b>Age, median years (range)</b>	47.5 (33–61)
<b>GP experience, median years (range)</b>	18.5 (4–27)
<b>Status</b>	
Partner	21 <sup>c</sup>
<b>Practice list size, median, n (range)</b>	9010 (4700–24 235)
<b>Practice national IMD decile, median (range)<sup>b</sup></b>	3 (1–7)

<sup>a</sup>Percentages shown unless stated otherwise.

<sup>b</sup>IMD quintile, 1 = most deprived. <sup>c</sup>1 single handed.

2WW = 2-week-wait. CBP = cancelled by patient.

DNA = did not attend. IMD = Index of Multiple

Deprivation. SES = socioeconomic status.

to patient expectations and social context, in addition to communication within the consultation (Figure 2). This study explored referral processes and how they impacted on attendance, and how patients and GPs balanced notions of personal responsibility and paternalistic care. Finally, the authors summarise themes arising.

### System flaws

The requirement to be seen within 2 weeks of referral presented logistical challenges that impacted attendance. Patients described receiving appointment letters after the intended appointment date or with 1 day's notice. One patient was registered blind and needed an interpreter to read the letter; this was not possible in the timeframe. Other examples included incorrect patient contact details; errors in the hospital's mobile phone text cancellation system; and a transport ambulance arriving several hours late.

### Expectations

Patients' beliefs about their symptoms, understanding of tests for which they have been referred, and prognostic expectations were key, often interrelated and mutually reinforcing. This may be further mediated by the communication with the GP, itself influenced by the doctor's expectations about the symptoms and possible diagnosis. Patient and GP interviews identified three interacting factors that mediated attendance: patients' circumstances and priorities; patients' beliefs (including emotions, such as fear); and perceived severity.

*Patients' circumstances and priorities.* Some patients are disproportionately exposed to challenging social factors, creating further barriers to health care.<sup>17</sup> Patients often had multiple comorbidities or significant caring responsibilities. Patients with multiple health conditions described confusion over appointment times and sometimes had difficulty recalling specific circumstances of missed appointments, suggesting they may find their lives difficult to manage. Patients also described how mental health and financial problems created difficulties when prioritising competing demands.

Several doctors commented on the broader difficulties faced by patients (GP01, GP10, GP22):

*'Bizarre as it might be, [cancer] isn't the be all and end all for a lot of my patients ... then they actually get cancer thrown into the mix and it's just yet another big issue. Whereas for a lot of people that have got good health*

*of course it's a major issue.'* (GP10, male [M], age 45 years, 16 years' GP experience)

Against this background, some patients judged their referral as not particularly serious or urgent. Patient 65 (Pt65) illustrates the complex factors mediating decision making, having declined testing despite transfer to hospital for emergency blood transfusion and referral for urgent colonoscopy and laryngoscopy. Coupled with some anxiety about the test, the patient had chronic pain, diabetes, a history of alcoholism, and depression:

*'They think that I might have cancer of the bowel like; I said "Well if I have I have, but you're still not sticking a camera up my arse, you can go away ... I'm not bothered ... sick of living anyway".'* (Patient [Pt]65, M, age 62 years)

This patient was also receiving financial benefits and lived in an area in the lowest IMD quintile nationally.

GP and patient interviews suggested that deprivation may be strongly related to patients' decisions. Two-thirds (8 out of 12) of patients commenting on these wider life struggles lived in areas ranked in the lowest IMD quintile. GPs described some possible effects:

*'[Some patients] lead such chaotic lives and we do have a significant number of patients who, people are really down, they're kind of at the bottom of the chaos ladder of life who literally are in so much debt that they will just not open any letters.'* (GP01, M, age 45 years, 15 years' experience)

Deprivation may also lead to more immediate difficulties; patients may struggle to negotiate time away from work and transport costs can be prohibitive.

Navigating the appointment system appeared a particular problem for older patients and those of lower socioeconomic status; all patients who described navigation difficulties were from areas ranked on the lowest quintile of the IMD and aged >60 years. GPs suggested that patients from minority ethnicities and cultures may struggle to navigate the system, partly owing to language barriers, but also their expectations of the NHS, which may differ to other health systems.

Many GPs commented on how time constraints within consultations prevented them from discussing details. Some, however, considered the practicalities of patient attendance:

**Table 2. Characteristics of patients who declined interview or did not reply to request for interview**

Characteristics	n (%) <sup>a</sup>
<b>Patients who declined interview (N= 16)</b>	
<b>Sex</b>	
Male	7 (44)
Female	9 (56)
<b>Age, median years (range)</b>	60.5 (27–94)
<b>Suspected cancer referral pathway<sup>b</sup></b>	
Skin	6 (38)
Head and neck	4 (25)
Lower gastrointestinal	2 (13)
Urology	1 (7)
Breast	3 (19)
<b>2WW circumstances of non-attendance</b>	
Did not attend	11 (69)
Cancelled by patient	5 (31)
<b>SES, median IMD quintile (range)<sup>b</sup></b>	3.5 (1–5)
<b>Ethnicity</b>	
White British	14 (88)
Missing	2 (12)
<b>Patients who did not reply to request to interview (N= 94)</b>	
<b>Sex</b>	
Male	34 (36)
Female	60 (64)
<b>Age, median years (range)</b>	47 (20–93)
<b>Suspected cancer referral pathway</b>	
Head and neck	19 (20)
Lower gastrointestinal	11 (12)
Upper gastrointestinal	2 (2)
Gynaecology	7 (7)
Breast	21 (22)
Skin	28 (30)
Testicular	1 (1)
Urology	5 (5)
<b>2WW circumstances of non-attendance</b>	
Did not attend	62 (66)
Cancelled by patient	32 (34)
<b>SES, median IMD quintile (range)<sup>c</sup></b>	3 (1–5)
<b>Ethnicity</b>	
White British	61 (65)
Pakistani	4 (4)
Other Asian background	2 (2)
White Irish	2 (2)
Black African	1 (1)
Black Caribbean	2 (2)
Other ethnic background	7 (7)
Missing	15 (16)

<sup>a</sup>Percentages shown unless stated otherwise.

<sup>b</sup>Percentages add up to >100% due to rounding.

<sup>c</sup>IMD quintile, 1 = most deprived. 2WW = 2-week-wait. IMD = Index of Multiple Deprivation. SES = socioeconomic status.

*'You cannot give an appointment to a 92 year-old at 9 o'clock ... in general they are obviously in pain and they usually have arthritis and they're slow in the morning. Afternoon is best.'* (GP09, female [F], age 52 years, 20 years' experience)

**Emotional responses to testing.** Most patients described relief that they would be seen quickly. For some patients, however, fear and anxiety affected attendance, describing (at times extreme) hesitation about further testing because they feared the procedure and/or a potential cancer diagnosis. GPs commonly cited this as a reason for patients not attending for investigative tests (12 out of 21 GPs). Fear was especially common among patients referred through upper and lower GI routes, reflecting the invasive tests. Other emotions, potentially influencing attendance, such as embarrassment or disgust, were also touched on, for example the earlier quote regarding colonoscopy from Pt65.

By discussing these concerns, patients may become more informed about the test. However, this relies on them being sufficiently confident or being able to raise concerns. If raised, GPs could prescribe medication for anxiety or discuss alternative scenarios:

*'I do remember cancelling one [gynaecological test] because I was scared ... So that was when I went back to the GP and then they fast tracked me and I agreed to have it under general [anaesthetic].'* (Pt72, F, age 67 years)

It was clear that some patients were not aware that sedatives could be provided for invasive tests, such as colonoscopy. Hospitals are using 'straight-to-test' (STT) appointments to reduce the total number of appointments along with guidance that GPs should assess the patient's fitness to do this; however the STT route may inhibit opportunities to allay fears and correct misconceptions. Fear may also relate to the patient's broader concerns about cancer diagnosis and prognosis. Missing an appointment can protect them from the stress of a potential diagnosis. By presenting with symptoms it may seem that patients are actively engaging in managing their health. However, they may also be seeking reassurance and do not expect a cancer referral. Some GPs described this as a form of denial:

*'That's news that they didn't want to hear and they don't want to process that and so they just kind of put the shutters up and*

*ignore it.'* (GP03, F, age 43 years, 15 years' experience)

Some patients revealed instances of denial. They were adamant that they did not have cancer and their personal or relatives' wider experiences of illness influenced these judgements. Avoiding assessment for cancer was a means of coping with these stressful events:

*'I'm telling you it's not cancer ... I says, don't complicate matters.'* (Pt106, M, age 65 years)

Some older patients may not want to seek diagnosis or treatment for potential cancer. This was commented on by some GPs:

*'They accept that there's something wrong, they accept they've probably got cancer, but actually they're not sure they really want to do anything about it.'* (GP28, F, age 55 years, 27 years' experience)

**Perceived severity.** Patients' perception of symptom severity shaped decision making. While perceptions may be complex and influenced by previous experiences and beliefs, doctor-patient communication was influential. Some patients were unaware of the potential appointment urgency and reported that their GP did not explain:

*'[The GP] didn't sort of explain that much. I didn't really know what it was all about.'* (Pt111, F, age 22 years)

Many patients were surprised by the speed of the referral letter and appointment; consequently several were not available for appointments. This is surprising since local digital systems prompt GPs to confirm that referred patients are available for the next 14 days. Few GPs, however, reported completing this because of time constraints:

*'If they've got a cancer I don't want it to be the fact their holiday delays their diagnosis. I've told [the hospital trust] they're on holiday, they need an appointment when they get back.'* (GP34, F, age 39 years, 10 years' experience)

#### Doctor-patient communication

Many GPs commented on how conversations with patients had become more difficult as National Institute for Health and Care Excellence guidance for certain cancer referrals had lowered referral thresholds.<sup>18</sup> GPs believed this may dilute messages given to patients and held concerns about increased pressure on hospitals:

*'Basically you can't get an ultrasound scan and you can't get gastroscopies. We've had MRIs now stopped for GPs ... because the whole system has been swamped by this 2-week increased guidelines.'* (GP10, M, age 45 years, 16 years' experience)

There was a sense that referral thresholds were often lower among more recently qualified GPs, described as a 'tick-box generation'. Some GPs suggested that a growing fear of litigation (GP05, GP08, GP21) may create 'soft' referrals, used to reduce uncertainty.

Most GPs acknowledged the careful negotiation required, when balancing the potential cancer risk with patient anxiety, but felt this may be misunderstood:

*'It's quite a difficult balance to say, you must attend, it could be cancer but it's probably not ... it's a quite hard, a hard kind of dynamic for the patient to grasp.'* (GP21, M, age 35 years, 7 years' experience)

GPs described the importance of rapport, particularly when a patient held concerns about a procedure or perhaps misunderstood the implication of symptoms. Patients may be less open to raising concerns unless trust has been established:

*'[The patient will] give you the bombshell at the end, you know .... oh by the way whilst I'm here and then they say, oh I've had altered bowel habit.'* (GP26, F, age 46 years, 18 years' experience)

Four GPs, all female, said they actively chose not to use the 'C [Cancer] word' with some referred patients:

*'Sometimes I don't mention the word cancer ... that's deliberate and it's normally with somebody who is already so anxious ... we still talk about the fact that it could be something very serious or it could be something sinister.'* (GP28, F, age 55 years, 27 years' experience)

All GPs described tailoring communication to patients, with prior knowledge of a patient being key. Most commented on the importance of being clear and expressing risks, partly to ensure 2WW attendance and partly to prepare patients for a potential cancer diagnosis:

*'It's a real shock if a patient goes for a 2-week-wait appointment and they're suddenly hit with it could be cancer, well, "Why didn't you*

*say that when you referred?'"* (GP02, M, age 55 years, 27 years' experience)

### **Negotiating responsibility**

GPs described moves away from paternalism, with increased onus on the patient to take responsibility for their health and health care. However, this varied. Some practices used 'fail safes' whereby administrative staff checked appointments that had been made within 2-week timeframes, whereas other GPs emphasised to patients to contact the practice if they did not receive an appointment. This onus of responsibility was not always well understood by patients; some were surprised there was no GP follow-up, despite ongoing symptoms. A GP reflected on the challenges:

*'I think nowadays we have to, unfortunately, rely more on the patients telling us they do rather than checking that they do or don't. They have to take some responsibility for their health care, I suppose.'* (GP36, F, age 43 years, 16 years' experience)

To encourage 2WW attendance, some GPs delayed referrals if patients were about to go on holiday, while GP28 described collecting an older patient from home and attending the hospital appointment with them thinking that fear of the test would otherwise prevent attendance.

Many patients were concerned about wasted resources through non-attendance, related to a sense of complying with normative assumptions of a 'good patient'. Some described being concerned that non-attendance would be noted as a 'black mark' on their health records:

*'I would hate for people to then slow down or, think oh he's already cancelled once or whatever, so I just want to do things right.'* (Pt95, M, age 44 years)

GPs described similar 'good patient' notions and the potential guilt that patients may feel for non-attendance, to encourage patients to attend rearranged appointments. Most GPs described follow-up whereby practice receptionists telephoned non-attending patients and at times GPs made these calls themselves; partly to enable medical discussion and to reflect the greater respect patients were felt to have for GPs. This could be seen as an example of 'safety netting',<sup>19</sup> though none of the GP participants used that term. Meanwhile, some GPs felt that the onus should be on the patient to attend and an informed decision not to attend should be respected:

*'If they don't take you up on that offer and they've already been offered an appointment for a test and they've declined that, then I think at some point you might need to respect the patient's autonomy.'* (GP05, M, age 38 years, 10 years' experience)

### Referral processes

GPs described struggling to undertake appointments involving suspected cancer referrals in 10-minute timeslots. This explains why online referrals were either completed at the end of a clinic or by practice administrators. A few GPs completed the referral online themselves during the consultation and, in some instances, completed a choose-and-book appointment booking with the patient:

*'So you can actually do [a choose-and-book appointment] on the system with the patient in the room and they walk out with the date ... I personally do that, but I'm the only one in my practice that does, my colleagues use our secretaries.'* (GP22, M, age 40 years, 12 years' experience)

Within the city in which this study took place, an information leaflet had been developed for patients being referred on the 2WW pathway. It had been agreed between the hospital trust, local clinical commissioning group, practices, and a patient representative group, but only 7 out of 21 participating GPs used it. Two patients (Pt23, Pt94) commented that they would have found a leaflet useful.

The online 2WW referral includes a prompt to ensure the GP has given this leaflet, however, since GPs rarely complete the referral process during a consultation, this may not be done. Some GPs deliberately did not give the leaflet as they felt the reference to cancer would worry patients:

*'It's treading that fine line, isn't it, between wanting them to know it's important they get followed up and not wanting to scare.'* (GP36, F, age 43 years, 16 years' experience)

### Interventions

Potential interventions to increase attendance were raised by patients and GPs. These tended to be relatively straightforward. For example, making appointments with patients by phone rather than letter could reduce communication delays, and ensure patient availability. Administrative support was used in some practices to check contact details and help patients navigate the choose-and-book system, and some GPs booked appointments with the patient during the consultation. Text messaging is being used increasingly to send

appointment and reminder notifications. Increased vigilance in ensuring patients were suitable for STT appointments was suggested, particularly a need for further discussions around investigations that patients would find acceptable.

Practices varied in responses to information from the hospital about non-attendance of urgent referral appointments; while some GPs described telephoning non-attending patients to stress the importance of re-referral and attendance, others did not follow-up.

## DISCUSSION

### Summary

Interviews with patients and GPs offer several potential explanations for non-attendance at urgent referral appointments for suspected cancer. System flaws explained some instances. GPs talked about practical difficulties experienced with booking appointments and time pressures that restrict them.<sup>20</sup> Patients' expectations of referral were complex, informed by beliefs, circumstances and priorities, and the perceived prognosis. These were often mediated by communication with the GP. GPs' recognition of the importance of communication was evident when acknowledging the need to tailor communication to perceived patient need and worry. GPs have the inherently difficult task of communicating the importance of the referral and also not causing unnecessary anxiety.<sup>21</sup> GPs and practices varied in their responses to non-attendance, influenced by time pressures and perceptions of patient responsibility.

### Strengths and limitations

This qualitative study design allowed the generation of in-depth accounts of participants' experiences. Drawing on the two sets of accounts (GPs and patients) enabled greater contextual understanding of the various factors that may influence non-attendance, with triangulation both across these groups and also between researchers improving the rigour of this study. The authors expected patient recruitment to be challenging and wrote to many potential interviewees to achieve their sample. Patients living in the most deprived areas were particularly hard to recruit and several cancelled on the day of the interview, highlighting the difficulties these patients face. However the achieved samples were sufficiently diverse to suggest that some of the identified themes are potentially universal.

The authors planned patient sampling criteria but finally applied only one sample limitation (not to recruit any more patients

who had cancelled rather than not attended appointments). Relatively few patients from ethnic minorities were recruited and only one whose first language was not English. Youngest and oldest age groups were also relatively under-represented, given that they have the highest rates of non-attendance,<sup>5</sup> though many older potential participants were assessed by GPs as not fit for interview.

Given the complex, various reasons for non-attendance at appointments, this relatively small study may not have enabled some explanations to be reported. Indeed there may have been common determinants of decisions not to engage with the health care and research interview, and so an important subset of patient views was possibly unavailable. However, the accounts and explanations generated by patient and GP participants were diverse.

### Comparison with existing literature

This is the first reported qualitative investigation of patient non-attendance at urgent referral appointments for suspected cancer. Some findings are consistent with studies of non-attendance and use of services in other healthcare settings, such as the influences of deprivation and 'difficult lives';<sup>17,22</sup> the effects of health literacy on ability to understand and navigate healthcare systems;<sup>23-25</sup> and diagnostic and procedure fear as determinants of patient behaviour.<sup>6,26,27</sup> Varied notions of paternalism, largely as a result of workload pressures, have also been reported in a qualitative study of GPs' practice of 'safety netting' for potential cancer presentations.<sup>19</sup>

The range of explanations for non-attendance and their potential to increase the diagnostic interval were consistent with elements of the Andersen model of total patient delay.<sup>11</sup> The importance of system flaws is magnified by time pressures within an urgent referral process with performance targets. Thresholds for referral have reduced over the past decade;<sup>18</sup> intended to reduce rates of late cancer diagnoses, resulting in increased referrals and a greater proportion without cancer. This may impact on GP communication and patients' receipt of referral news. Practices varied in their response to non-attendance; some actively monitored attendance, while this was not judged feasible by others owing to many other demands.

A local patient information leaflet had been developed to communicate the importance of attending as cancer was suspected. A significant minority of GPs did not use the leaflet, some because they forgot but others had decided not to use it, questioning the

value of universal information that cannot be adjusted to patient needs and circumstances, or provider preferences.

Patients' and GPs' accounts suggest that the challenging circumstances of some patients' lives mean that they may not treat a referral for suspected cancer as a priority. It may be possible for GPs, practices, and hospitals to provide support to improve the chances of these patients attending. Recent research exploring patients' views of the planned introduction of the Faster Diagnosis Standard (FDS) for cancer also highlights the perceived importance of GPs' offering reassurance and support to patients being referred.<sup>28</sup> Remedies to help patients struggling to navigate the healthcare system have been previously suggested,<sup>29-32</sup> however such interventions are 'downstream' and may fail to address substantive causes of difficult circumstances, which require 'upstream' interventions.

Furthermore, patient agency is expressed through choices and preferences as they make sense of the possibility of a cancer diagnosis.<sup>33</sup> Individual agency is realised socially<sup>34</sup> and experience is defined and realised through social negotiation, which includes social and economic barriers.<sup>35</sup> Overcoming these is important in facilitating the success of 2WW. Patients must understand that the referral is urgent and about suspected cancer, as some GPs attempted to reduce patient anxiety by not using the 'C word'. Effective communication is key, in which individual responses to what is happening can be appropriately negotiated, to achieve a desirable outcome.<sup>36</sup>

### Implications for research and practice

This study of the 2WW urgent referral system and the linked quantitative study<sup>5</sup> illustrate the importance of policy evaluation, particularly the need to examine its implications through the lens of users, whether patients or practitioners. While this qualitative study provides in-depth accounts and explanations across a relatively broad group of patients and GPs, further research would be valuable in other locations and with patients from minority ethnic groups, those without English as their first language, and older patients. The authors did not explore patients' previous attendance and engagement with health care; it would be useful to know if these patterns and explanations are specific to suspected cancer referrals or more general. Lastly, interviews concerned referrals across all suspected cancers and some disaggregation in future would be helpful, not least to permit the development and evaluation of targeted interventions.



Non-attendance of urgent referral appointments affects a small proportion of patients but within a high volume patient pathway, and could result from a range of patient and provider factors.<sup>5</sup> It may impact on short-term mortality outcomes.<sup>5</sup> Patient responses, and especially the provoked worry, influence decision making, and occur within a social context and need to be negotiated by referring GPs. Further barriers include low levels of health literacy, lack of patient access to material resources, practical demands

of travelling to hospital, comorbidities (particularly among older patients), and fear of the diagnostic procedure (particularly among patients with suspected GI cancer). The urgent referral process, therefore, needs to accommodate patient circumstances, perceptions, and responses, while ensuring an appropriate infrastructure in both general practice and cancer services to facilitate referral, patient attendance, and responses to non-attendance.

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### Ethical approval

Approvals were obtained for this study from: NHS research ethics committee (16/NE/0146), HRA (IRAS ID:201398), HRA Confidentiality Advisory Group (16/CAG/0060) and the University of York departmental research ethics committee.

### Provenance

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The authors have declared no competing interests.

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