



Complexity, continuity & conflict: a qualitative study of primary care staff views of initiatives to promote cancer early detection and referral

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-004820
Article Type:	Research
Date Submitted by the Author:	09-Jan-2014
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Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Public health, General practice / Family practice
Keywords:	QUALITATIVE RESEARCH, PUBLIC HEALTH, Epidemiology < ONCOLOGY

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10 **Complexity, continuity & conflict: a qualitative study of primary care staff views of**
11 **initiatives to promote cancer early detection and referral**
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46 **Key Words:** primary health care, general practice, neoplasms, qualitative research, early detection of
47 cancer.
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53 Word count: 3760
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ABSTRACT

Background

In the UK, there have been a number of national initiatives to promote earlier detection and prompt referral of patients presenting to primary care with signs and symptoms of cancer.

Objective

To explore the barriers and facilitators, in primary care, to early detection and prompt referral of patients with symptoms suggestive of cancer.

Design

Qualitative, descriptive interview study.

Setting

Six practices in North West England.

Participants

Primary care staff.

Method

A random sample of primary care practices, stratified by level of previous engagement with early detection and referral initiatives, were invited to take part in individual or group-based interviews. Interviews were audio-recorded and transcribed. A thematic network analysis approach was used with independent coding by two researchers and consensual validation of themes.

Results

Thirty-nine participants recruited from six practices took part in individual (n=4) or group interviews (n=5). The global theme to emerge from the interviews was that 'managing risk' in primary care was not well understood by those introducing primary care-based cancer initiatives. Three underpinning organising themes were identified: 'complexity', 'continuity' and 'conflict' which reflected issues such as complex symptoms and care systems, patient-led factors and target focused care.

Conclusion

To improve the successful implementation of early detection and referral initiatives, practice capacity, complexities related to cancer diagnosis, communication issues associated with the care pathways and conflicting opinions about staff roles need to be addressed.

ARTICLE SUMMARY**Strengths and limitations of this study**

- The study is, to the best of our knowledge, the first to investigate the attitudes and opinions of primary care staff towards the implementation of cancer early detection and awareness initiatives.
- Findings revealed a number of issues in primary care related to managing risk.
- The sample consisted of individuals from a range of job roles and practices in rural and urban areas.
- The sample was small and drawn from a single area of the country, which may limit the generalisability of findings.

INTRODUCTION

Two decades of concerted effort to expedite access to proven effective cancer treatments in the UK has led to improvements in cancer survival rates.[1] Primary care has a key role in improving cancer survival through earlier detection and referral of patients with cancer symptoms. National referral guidelines for suspected cancer have been published and there is a national system for urgent referral (two-week waiting-time initiative).[2] However, evidence suggests that there is further room for improvement.[3] There is practice variation in the use of the 'two-week' initiative, and some patients are seen several times in primary care before referral.[4-7] A significant proportion of patients also present through emergency routes and have poorer survival.[5, 8]

To further support primary care, resources were developed and/or disseminated by the Department of Health's National Awareness and Early Diagnosis Initiative (NAEDI), established in 2008, and the Royal College of General Practitioners (RCGP), including: audit and significant events analysis tools,[4, 5] general practitioner (GP) level cancer profile data, safety netting recommendations and referral prompts.

To understand whether and how primary care-based cancer initiatives could be more effective, we need to understand the barriers and facilitators to the promotion of earlier consultation, detection and referral at individual (GP) and organisational (primary care practice) level. Key initiatives have mainly focused on GPs, but other members of the primary care team may have key roles: an area which has been largely unexplored. We report the findings of a qualitative study of the views and experiences of a range of primary care staff in one region of England, which at that time was covered by the Lancashire and South Cumbria Cancer Network (LSCCN). In this paper we focus on the experiences of practice staff in implementing cancer detection and referral initiatives and the perceived barriers and facilitators to earlier consultation, detection and referral of those with symptoms suggestive of cancer.

METHODS

This was a qualitative descriptive study utilising both individual and group-based interviews. It aimed to recruit staff in six practices with differing levels of engagement (high, medium and low) with cancer early diagnosis initiatives. Information on the level of engagement was collated via the LSCCN at the end of June 2012.

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3 High engagers had participated in at least one of the following: RCGP cancer audit, attendance at a
4 course on early diagnosis or face-to-face meetings to discuss GP cancer profiles and action planning.
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6 Medium engagers had attended at least one regional meeting about cancer awareness. Low
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8 engagers were not known to have engaged in any initiatives.
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10 GP practices in LSSCN were stratified into these three groups and a random sample of 10 practices in
11 each group were sent a letter about the study, followed up with a phone call from the research team
12 after one week. Practices were offered participation in a practice-based group interview, or
13 individual interviews if preferred. The aim was to recruit two practices in each stratum. Due to low
14 uptake, two strata (medium and low engagers) were merged and a random sample of a further 15
15 practices were sent letters.
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20 In practices agreeing to take part, semi-structured, audio-recorded interviews, attended by two
21 researchers, were undertaken between September and October 2012. All transcribed data were
22 entered into NVivo 10 and analysed using a Thematic Network Analysis approach.[9] This involved
23 an iterative and cyclical process of reading and analysis to identify basic, organising and global
24 themes within the dataset. Analysis was undertaken by two authors (GT and NC) independently on
25 six transcripts initially followed by an in-depth discussion, and consensual validation of key themes.
26 A further cycle of independent and collaborative analysis was then undertaken on a further sub-set
27 of transcripts to ensure rigour and authenticity of the themes generated. All thematic decisions
28 were discussed with the third author (PD). The study was approved by the University of Central
29 Lancashire STEM ethics committee and individual written informed consent was obtained from all
30 participants.
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41 RESULTS

42 Six practices agreed to participate; three 'high engagers' and three 'low/medium engagers'.
43 Practices were geographically spread across the region in urban and rural areas. Thirty-nine
44 participants took part in group (n=5) or individual (n=4) interviews. Job roles included GP (n=9,
45 23.1%), receptionist (n=7, 17.9%), nurse (n=6, 15.4%), manager (n=6, 15.4%), secretary (n=5, 12.8%),
46 health care assistant (n=3, 7.7%), medical student (n=2, 5.1%) and phlebotomist (n=1, 2.6%).
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52 Overall, practice staff were aware of the two-week waiting-time initiative. There was also good
53 knowledge about the national 'Be Clear on Cancer' public cancer awareness campaigns, but less
54 awareness about other initiatives specifically targeted at primary care. The key global theme to
55 emerge from the interviews related to 'managing risk' within primary care:
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3 *"It's quite a tricky, nebulous area [...]. The nature of general practice is that we're dealing*
4 *every day with uncertainty..."* (Interview 6, Participant 3)
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8 A key concern of staff was that policymakers and those implementing cancer initiatives within
9 primary care did not fully understand how risk was managed within primary care. Cancer was only
10 one priority within primary care and there was an abundance of initiatives for a variety of conditions
11 which primary care staff were expected to implement. Three underpinning organising themes (and
12 associated basic themes) of 'complexity', 'continuity' and 'conflict' reflected the tensions and
13 difficulties that primary care face in managing risk whilst dealing with complex symptoms and care
14 systems, patient-led factors and target-focused care. An overview of the organising and basic
15 themes is presented in figure 1. These themes are described and discussed, contextualised by
16 participant quotes below.
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25 Complexity

26 *Cancer disease and symptoms:* Cancer diagnosis was considered an important priority. However,
27 whilst some symptoms were straightforwardly associated with cancer, e.g. breast lump, other
28 symptoms commonly presenting in practice, compared with the relative infrequency of cancer in a
29 practice population, provided greater challenges:
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34 *"How often do we see them [...] most cancers you, sort of, see so infrequently, that it's*
35 *actually quite difficult to then keep up-to-date with, you know, what you're supposed to be*
36 *doing and the referral pathways and all that sort of thing, when you might see one or two a*
37 *year."* (Interview 4, Participant 1)
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43 *Fragmentation and access to diagnostic services:* Primary care staff expressed difficulties accessing
44 diagnostic services due to fragmented systems and multiple agencies. Rigid referral criteria led to
45 cases being 'bounced back' if they failed to meet these criteria. However, concerns about patients
46 led many participants to 'fudge', 'embellish' or 'bend-the-rules' to ensure assessment:
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50 *"I think, sometimes [...] even though it says on the form, don't fill out this form unless they*
51 *tick any boxes but you find a box to tick, and usually for very good reason. And I think you'd*
52 *only go, slightly over egging the presentation if you were pretty sure there was something*
53 *there, something going on."* (Interview 4, Participant 4)
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3 Several participants felt frustrated by restricted access to diagnostics for certain conditions:
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6 *"I can send people for a CT scan if I have a concern about them, for some conditions, but not*
7 *others. Well why not? I'm the one who's initiating the referral in the first place. You trust me*
8 *to initiate the referral to pick the patient and prepare them so that you can come along and*
9 *just arrange the scan and look at it."* (Interview 4, Participant 3)
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14 Access restrictions were felt to reflect 'empire building' and 'preservation', rather than a 'logical'
15 service delivery model. Whilst some GPs wanted more direct access to diagnostics, this was not
16 universal, and others highlighted the need for appropriate 'training'.
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21 *Guidelines content and information overload:* Participants referred to the usefulness of guidelines to
22 help symptom differentiation. Knowledge was felt to be experientially derived; referral guidelines
23 were considered useful for less experienced doctors. Guidance that expressed the statistical
24 probabilities that someone had cancer was less preferred to guidance on what symptoms or signs
25 raise concern or require further investigation:
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30 *"I mean, you see, from a GPs point of view, if somebody comes in who is fifty-five years of*
31 *age, and passes blood in his stool, you need to exclude a cancer. Now, I don't want to know*
32 *how many, percentage of those people pass blood in the motion will have cancer, or how*
33 *many will have piles or, inflammatory bowel disease or what have you [...]. Text books don't*
34 *help you there, NICE guidelines do not help you in that sort of situation."* (Interview 4,
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39 Participant 3)
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42 Concerns were expressed about the number of guidelines available for different conditions and
43 inconsistencies between different sources:
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46 *"And that's the problem 'cause last year there was a big campaign, "if you have a cough for*
47 *more than three weeks you need to go and see a doctor", but NICE guidelines is six weeks,*
48 *[...] so there is no uniformity."* (Interview 6, Participant 4)
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53 Participants described a 'tsunami' of new guidelines, care plans and initiatives inducing guideline
54 'negativity' and difficulties keeping up-to-date:
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3 *“And I thought that’s probably a squamous cell carcinoma. That needs a two-week wait*
4 *referral. Then, I actually checked the guidelines, the guidelines say that “it’s got to be over*
5 *one centimetre and you’ve got to wait more than eight weeks really for it to grow” etcetera,*
6 *etcetera [...] and those things will change on a regular basis. Now, how do you expect an*
7 *entire network of primary care physicians to stay current with all those guidelines and apply*
8 *them religiously?” (Interview 2, Participant 3).*
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13 14 Continuity

15 *Patient-practice relationships:* Continuity-of-care could not always be achieved in practice, even
16 though patients preferred it and its absence could contribute to diagnostic delay:
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21 *“People have been hopping around from one clinician to another and that, and you [...] don’t*
22 *see the evolution of the story until [...] it hits you in the face [...]. Patients book on the day,*
23 *they don’t necessarily get in the person they normally see, they get in with the available, so*
24 *that can disjoint things....” (Interview 3, Participant 4)*
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29 It was felt that smaller, rural practices had closer relationships with patients and their community,
30 which would lead to earlier consultation. However, others felt awareness of cancer deaths was
31 heightened in close-knit communities, which could reinforce negative views.
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35 *Primary care and secondary care interface:* Expedited assessment following GP referral of patients
36 through the two-week wait initiative was perceived to work well, but delays following patients’
37 initial appointment were reported. Some staff worried about the impact on patients:
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42 *“And, well, it’s very difficult from our point of view, ‘cause we’re saying, “look, you know this*
43 *may be nothing serious, however, I want to refer you on the system, you’ll get an*
44 *appointment in two weeks”, and they do get seen, but then there’s a massive delay, so, you*
45 *know, then they’re kinda all heightened up because they’re thinking, “{whispered} the doctor*
46 *thinks I’ve got cancer” and then nothing happens for ages, and it’s really hard for the*
47 *patients...” (Interview 3, Participant 5)*
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53 Delays in hospital communication were also identified:
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56 *“You know, a letter takes, takes two or three days or four days to be produced, then you have*
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3 *to wait a fortnight for a consultant to sign it, because they're away, then it has to go in the*
4 *internal post to the next department, then it has to go into the system. I mean you just wait, I*
5 *mean you just see waits stretch ahead.” (Interview 2, Participant 3)*
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10 There were concerns that centralising services negatively affected assessment uptake among low
11 income patients. In some rural locations, transport was provided, with financial implications:
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14 *“I mean, up here, if you haven't got your own transport, you can use the transport service,*
15 *that again is a cost to the National Health, how much is that costing?” (Interview 2,*
16 *Participant 2)*
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21 *Practice-based follow-up:* Practices were divided on whether they should follow patients up if they
22 failed to attend for cancer screening; the debate centred on whether the practice or the patient was
23 responsible:
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27 *“When we got these figures out we did bash that around quite a bit[...], and we felt that*
28 *patients had had quite a lot of letters, quite a lot of information, and it would, certainly for*
29 *the bowel screening and the breast screening, we felt that they actually made their own*
30 *decisions.” (Interview 3, Participant 4)*
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35 *“Yeah, you can bet your bottom dollar that one of those people who doesn't turn up or*
36 *refuses to have them done, [...] statistically one of these people, over the following three*
37 *years is going to develop a bowel cancer, and if they suddenly discover that there was the*
38 *screening and the doctor was aware that he didn't turn up, he's gonna take legal action,*
39 *because he'll say the doctor must have an obligation to remind me.” (Interview 4, Participant*
40 *3)*
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48 Conflict

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50 *Prevention versus target driven care:* Cancer was considered a public health priority but many
51 participants considered that there was a tension between preventative approaches and achieving
52 Quality and Outcomes Framework (QOF) targets:
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3 *“There is a real public health disconnect in primary care, how we’re funded, what we do, and*
4 *we’re not as good as with public health, with local public health initiatives, as maybe we*
5 *should be necessarily [...]. It’s just time to do things, [...] and those things aren’t required of*
6 *our core business, and when you have a very detailed contract that tells you what you will be*
7 *paid for doing...”* (Interview 2, Participant 3)
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12 The routine review of patients with long-term conditions had major resource implications for
13 primary care, particularly small practices. However, others felt that this could present an
14 opportunity:
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19 *“You’ve got the long-term condition nurses who are going into a different clientele to those*
20 *from the district nurses...”* (Interview 2, Participant 2)
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24 Even when QOF focussed on public health issues, there were concerns about the focus on target
25 attainment. For example, GPs repeatedly asking patients opportunistically if they have attended
26 screening led to concerns that this may ‘*put patients off*’ coming to see them because they become
27 ‘*fed up*’ with being asked. Participants also felt they needed to be careful about pushing patients ‘*too*
28 *hard*’ in case they raised anxiety because they then believed the doctor ‘*knows something*’.
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33 *Staff roles:* There were conflicting views around the role of other practice staff in cancer awareness,
34 in particular with regard to reception staff. Some staff viewed the reception role as a health advisor,
35 whereas others perceived their role to be purely administrative. Additionally, there were
36 reservations about the ability of reception staff to provide these messages and how the public might
37 feel about receiving health information from a member of reception staff:
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43 *“You’re passing clinical responsibility to people who are non-clinical. It’s alright for patients*
44 *to speak to them, and that’s fine, but, I’m not gonna use the receptionists as a source of*
45 *information [...]. I think anything clinical should be passed to the doctor full stop. I don’t think*
46 *there is any other role for the receptionist.”* (Interview 4, Participant 3)
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51 There were also concerns about potential litigation issues if reception staff were to give advice and
52 how this could impact on the practice:
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56 *“I think it’s also worth mentioning that at this point, because of our roles, how they are, we*
57 *get a lot of patients not happy about us supplying information, because we’re not allowed to*
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3 *diagnose, obviously for obvious reasons, but if you was to imply something, that could come*
4 *back on us twice as hard because you'd implied something that could be wrong, and*
5 *therefore it is now your fault."* (Interview 1, Participant 1)
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10 A further issue associated with staff roles was the identified benefits of having a chain of
11 communication between all practice members. For example, receptionists being able to 'raise issues'
12 with the doctor if they know someone is coming in who has symptoms the doctor should be aware
13 of but the patient 'may not say anything'. This can also work the other way:
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17 *"Patients that I worry about, I will leave messages. I'll mention to reception or mention to*
18 *people that I want to follow them up."* (Interview 6, Participant 3)
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22 Some could see a role for other members of the wider practice team, particularly to support
23 screening uptake:
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27 *"We'd say well who are the district nurses already going out to? You know, maybe they carry*
28 *packs with them [those] they're regularly going into and it's given by word of mouth.you*
29 *know, you can work with your local pharmacists."* (Interview 2, Participant 2)
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34 *Cancer awareness:* Although cancer fear was commonly acknowledged, staff were divided as to
35 whether patients were afraid to consult the GP with cancer symptoms. Some felt that unhealthy
36 lifestyle choices contributed to patient reluctance to present with cancer symptoms:
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40 *"The cancers where they feel that they may have contributed to it, like smoking, they tend to*
41 *ignore because they don't want to be told that it may be their fault in a certain way, and they*
42 *don't want to give up the lifestyle."* (Interview 6, Participant 4)
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47 Cancer awareness campaigns were felt to be important, but those who presented to the practice
48 following the campaign were more likely to be those at least risk:
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52 *"It's the people who never come to the doctors that you want to hit, not the people that were*
53 *already coming in anyway, and they tend to be ones that see those adverts. But then if you*
54 *can get one person who wouldn't normally come in and you catch them, then... it's better."*
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56 (Interview 5, Participant 1)
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4 Campaigns were also felt to create extra work for all practice members. There were complaints that
5 cancer awareness campaigns tend to run without consideration of other local or national campaigns
6 which may be running simultaneously:
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11 *"It's like it's alright saying putting in place to get them in, but it's the sheer volume, isn't it?*
12 *You can only cope with so much can't you?"* (Interview 5, Participant 1)
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15 16 17 **DISCUSSION**

18 To the best of our knowledge, this is the first study which has qualitatively explored the attitudes
19 and opinions of a range of primary care staff about early consultation, detection and referral
20 initiatives to reduce cancer diagnostic delay. The core theme identified by the study was that of the
21 tensions and difficulties in managing risk in primary care.
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24 The study was small, descriptive and exploratory. However, it covered a diverse geographical area
25 and practices with varying levels of engagement with awareness and early detection initiatives.
26 Furthermore, although exploratory, the findings highlight key issues for cancer diagnosis in primary
27 care, which warrant further investigation and consideration and which can be used to develop
28 theoretical perspectives for larger studies.
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31 Diagnosing cancer in primary care is difficult. Diagnostic errors in cancer are frequent and primary
32 care malpractice claims common.[10] To support practitioners, national referral guidelines have
33 been published.[2] There is limited evidence to suggest that these have, in part, contributed to
34 diagnostic delay reduction in the UK.[3] There is also increasing interest in risk assessment tools, to
35 aid decision-making, with algorithms and probabilities of risk based on demographic characteristics,
36 lifestyle factors, symptoms and/or attendance frequency.[11] Some have been disseminated
37 nationally, with limited evidence of effectiveness.[12] A number of practitioners in our study felt
38 these aids introduced rules which failed to encapsulate practitioners' tacit concerns about patients.
39 Previous work in primary care decision-making emphasised the analytical over intuition, but recent
40 work, including in cancer diagnosis, suggests the experiential knowledge may have a role and may be
41 more responsive to individual patients.[13-16] Further research into general practitioner's diagnostic
42 reasoning in cancer is warranted with particular emphasis on the relationship between analytical
43 and tacit approaches and the implications for further development of risk assessment tools in
44 routine practice.
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3 Practice staff highlighted that patient-doctor relationships were increasingly being eroded,
4 particularly in large practices. Others suggest that fragmentation of primary care and shorter
5 consultation times has led to a lack of continuity-of-care, which may hinder early diagnosis as cancer
6 presentation can be complex in those with multiple co-morbidities.[4, 17, 18] A recent analysis of
7 significant event audits in lung cancer highlighted how cancer can mimic other diagnoses and have
8 atypical presentation.[4] Other practice team members may be in contact with the patients more
9 regularly. Nurses undertaking regular review of patients with long-term conditions could raise
10 symptom awareness or be more alert to changes in, or new, symptoms suggestive of cancer.
11 Receptionists could act as navigators directing patients with symptoms to see the GP.[19] Low levels
12 of knowledge about some cancer symptoms has been demonstrated in non-medical staff and
13 training needs should be addressed.[20] However, this study highlighted that professional
14 boundaries and concerns about litigation could impede such whole-system working. Research
15 within primary care suggests that facilitation of communities of practice and interdisciplinary
16 knowledge sharing may reduce some of these barriers.[21]

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26 Our findings also suggest that the primary/secondary care interface needs strengthening; an
27 observation supported by others who highlighted the role of poor communication between primary
28 and secondary care in diagnostic delay.[4] While there was almost universal support for the two-
29 week waiting-time initiative, concerns were expressed about patient delays after their first
30 assessment and the time taken for patient information to be sent back to the practice. Practice staff
31 felt it was difficult to support patients during this time and that they could be lost to the system,
32 particularly when hospital services were fragmented. For some, increasing direct access to
33 diagnostic services from primary care was seen as a key mechanism for reducing some of these
34 delays and supporting early referral, but the need for training in referral criteria was also
35 highlighted.

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44 For there to be greater success, initiatives aimed at primary care need to take into account GP
45 practice workload and organisation. A 'one-size-fits-all' approach is unlikely to succeed as
46 practitioners expressed a range of views and opinions on the benefits of different initiatives.
47 Practices vary in size, population demography, community interactions, organisation and staff
48 expectations, which can affect their capacity to enact different initiatives and/or whether their
49 patients can access services. Lack of implementation of initiatives in primary care is not always
50 because of resistance to the initiatives themselves, but sometimes because of the sheer number of
51 initiatives across a range of priority areas that practices are expected to implement, often
52 simultaneously. Policymakers should consider more carefully how new initiatives in cancer early
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3 detection impact on primary care, how these can be embedded into practice systems and emphasise
4 and exploit synergies with other disease conditions. On the other hand, they also need to consider
5 the impact of primary care policies, designed to benefit other patient groups, on the earlier
6 consultation and referral of patients with signs and symptoms of cancer. A greater appreciation and
7 understanding of these issues by commissioners and policymakers could lead to greater gains in
8 cancer survival.
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16 **ACKNOWLEDGEMENTS:** Our thanks to the practices who participated in this study and to the staff
17 of the Lancashire and South Cumbria Cancer Network who assisted us.

18
19 **COMPETING INTERESTS:** PD was public health lead for LSCCN and NC is part-funded by a grant from
20 LSCCN.
21

22 **FUNDING:** This work was supported by Lancashire and South Cumbria Cancer Network (LSCCN) as
23 part of the National Cancer Awareness and Early Detection initiative (NAEDI) funding ‘cancer
24 networks supporting primary care’.
25

26 **CONTRIBUTIONS:**

27
28 NC recruited participants, carried out interviews, transcribed the interviews, coded the transcripts,
29 contributed to the development of the coding framework, and contributed to the writing of the
30 manuscript.
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33 GT carried out interviews, coded the transcripts, contributed to the development of the coding
34 framework and contributed to the writing of the manuscript .
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37 PD designed the study, collated practice engagement data, contributed to the development of the
38 coding of the framework and contributed to the writing of the manuscript.
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40 **DATA SHARING:** No further data are available
41

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Figure 1: organising themes of complexity, continuity and conflict with their associated basic themes, centred around the global theme of managing risk in primary care

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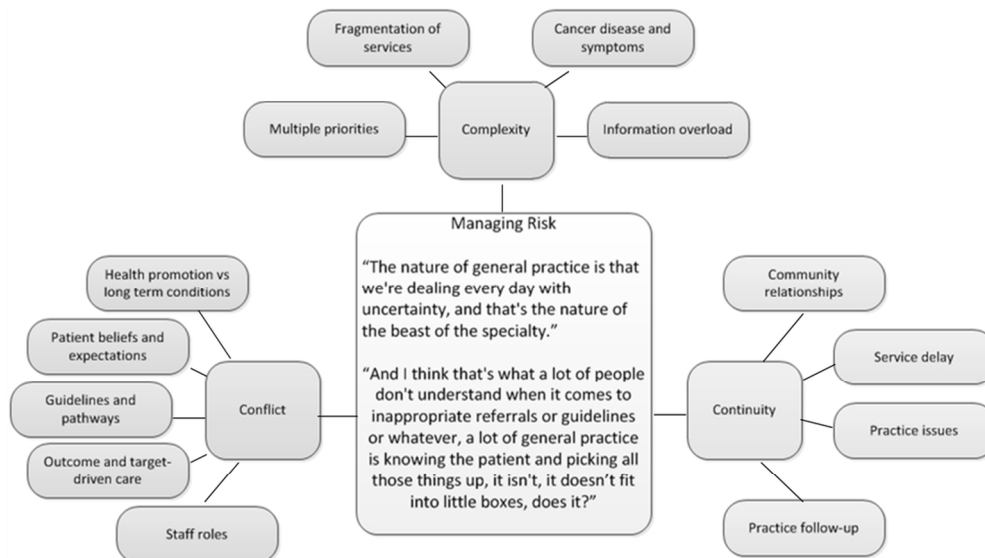


Figure 1: organising themes of complexity, continuity and conflict with their associated basic themes, centred around the global theme of managing risk in primary care

97x54mm (300 x 300 DPI)

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BMJ Open

Managing risk in cancer presentation, detection and referral: a qualitative study of primary care staff views

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-004820.R1
Article Type:	Research
Date Submitted by the Author:	16-Apr-2014
Complete List of Authors:	Cook, Neil; University of Central Lancashire, School of Medicine and Dentistry Thomson, Gillian; University of Central Lancashire, School of Health Dey, Maria; University of Central Lancashire, School of Medicine and Dentistry
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Public health, General practice / Family practice
Keywords:	QUALITATIVE RESEARCH, PUBLIC HEALTH, Epidemiology < ONCOLOGY

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Managing risk in cancer presentation, detection and referral: a qualitative study of primary care staff views

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Key Words: primary health care, general practice, neoplasms, qualitative research, early detection of cancer.

Word count: abstract- 232, manuscript - 4,504

ABSTRACT

Objectives: In the UK, there have been a number of national initiatives to promote earlier detection and prompt referral of patients presenting to primary care with signs and symptoms of cancer. The aim of the study was to explore the experiences of a range of primary care staff in promoting earlier presentation, detection and referral of patients with symptoms suggestive of cancer.

Setting: Six primary care practices in North West England.

Participants: Thirty-nine primary care staff from a variety of disciplines took part in five group and four individual interviews.

Results: The global theme to emerge from the interviews was ‘managing risk’, which had three underpinning organising themes: ‘complexity’, relating to uncertainty of cancer diagnoses, service fragmentation and plethora of guidelines; ‘continuity’, relating to relationships between practice staff and their patients and between primary and secondary care; ‘conflict’ relating to policy drivers and staff role boundaries. A key concern of staff was that policymakers and those implementing cancer initiatives did not fully understand how risk was managed within primary care.

Conclusion: Primary care staff expressed a range of views and opinions on the benefits of cancer initiatives. National initiatives did not appear to wholly resolve issues in managing risk for all practitioners. Staff were concerned about the number of guidelines and priorities

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3 they were expected to implement. These issues need to be considered by policymakers when
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5 developing and implementing new initiatives.
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8 9 **ARTICLE SUMMARY**

10 11 12 13 **Strengths and limitations of this study**

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15
16 • The study investigates the experiences of a range of primary care staff around
17
18 implementing initiatives for the earlier diagnosis of cancer.
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21 • The underlying concern in primary care is related to managing risk.
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24 • The sample included a mix of practices with different practice characteristics and
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26 included those known to be engaged in national and regional initiatives and those who
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28 were less engaged.
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31 • The sample was drawn from a single English region.
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INTRODUCTION

Studies in the 1990s showed that UK cancer survival rates were worse than many other European countries, following which there has been two decades of concerted effort to expedite access to proven effective cancer treatments.[1] While there have been improvements in cancer survival latterly, the UK still lags behind many other countries with similar health care systems, which may be partly due to later stage of disease at presentation. [2]

Both nationally and internationally, primary care is seen to have a key role in improving cancer survival by reducing delays in diagnosis through promoting earlier presentation and through earlier detection and referral of those with symptoms for further specialist assessment.[3, 4] In the UK, national campaigns extol those with symptoms to see their general practitioner earlier; there are national referral guidelines for suspected cancer and a national system for urgent referral from primary to secondary care (two-week waiting-time initiative).[5] However, evidence suggests that there may be further room for improvement:[6] there is practice variation in the use of the 'two-week' initiative and some patients are seen several times in primary care before referral.[7-9] A significant proportion of patients also present through emergency routes and have poorer survival.[10]

To further support primary care in the UK, resources were developed and/or disseminated by the Department of Health's National Awareness and Early Diagnosis Initiative (NAEDI), established in 2008, and the Royal College of General Practitioners (RCGP) including: audit and significant events analysis tools,[7, 8] general practitioner (GP) level cancer profile data, safety netting recommendations and risk assessment tools.[11] Key initiatives have mainly

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3 focused on GPs, but other members of the primary care team may have key roles: an area
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5 which has been largely unexplored.
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10 A number of international studies have been undertaken in attempts to understand the reasons
11 behind delay in cancer diagnosis. Qualitative studies have mostly focussed on patient
12 perspectives.[12-14] Only a few have explored primary care experiences and these have been
13 mainly limited to decision-making processes or referral pathways [11, 15, 16] and from the
14 perspective of the general practitioner. [3, 11, 15,16] In order to understand how a range of
15 initiatives across the patient pathway in primary care could be more effective and the role of
16 other members of the practice team, we explored the experiences of a range of primary care
17 staff in supporting earlier presentation, detection and referral of those with symptoms
18 suggestive of cancer. The study was undertaken in one region of England, which at that time
19 was covered by the Lancashire and South Cumbria Cancer Network (LSSCN).
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36 **METHODS**

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40 This was a qualitative descriptive study utilising both individual and group-based interviews.
41
42 It aimed to recruit staff from six practices who were differentially engaged with the national
43 awareness and early diagnosis of cancer agenda. GP practices within LSSCN were stratified
44 into one of three groups at the end of June 2012. High engagers had participated in at least
45 one of the following: RCGP cancer audit, attendance at a course on early diagnosis or face-
46 to-face meetings to discuss GP cancer profiles and action planning. Medium engagers had
47 attended at least one regional meeting about cancer awareness. Low engagers were not
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3 known to have engaged in any initiatives. Of 254 practices in the geographical area, there
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5 were 51 high engagers, 69 medium engagers and 134 low engagers.
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10 Within each group, a random sample of 10 practices were sent a letter about the study,
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12 followed up with a phone call from the research team one week later. The initial aim was to
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14 recruit at least two practices in each stratum. Due to low uptake within the medium and low
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16 engager strata, these categories were merged and a random sample of a further 15 practices
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18 sent letters. Practices were offered a choice of either group or individual interviews as it was
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20 recognised that time constraints prevent some practice staff from taking part in group
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22 interviews and some may feel uncomfortable discussing the issues with colleagues.
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24 Individual interviews were the preferred method in only one practice. Interviews (group and
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26 individual) were held on only one occasion in each practice.
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32 Six practices agreed to take part in semi-structured, audio-recorded interviews, which were
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34 attended by two researchers, between September and October 2012. We recruited three
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36 practices in the high stratum and three practices in the merged medium and low stratum (a
37
38 mix of low and medium engagers). The topic guide is outlined in Box 1. Thirty-nine
39
40 participants took part in group (n=5) or individual (n=4) interviews. Job roles included GP
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42 (n=9), receptionist (n=7), nurse (n=6), manager (n=6), secretary (n=5), health care assistant
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44 (n=3), medical student (n=2) and phlebotomist (n=1). Practice characteristics are shown in
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46 table 1.
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Table 1: Practice and interview characteristics

Practice characteristic	No. of practices
No of partners	
4 or more	3
3 or less	3
Deprivation Quintile*	
5 or 4 (more deprived)	3
2 or 3	3
1 (most affluent)	0
Population Density**	
<15%	2
15 to 39%	2
>=40%	2

*based on index of multiple deprivation of practice location 2010 (source: Department for Communities and Local Government, Indices of Deprivation 2010)

** Person per hectare based on practice location (source: ONS Neighbourhood Statistics)

The interviews took between 38 and 67 minutes to complete, and between four and eleven staff took part in each practice. All transcribed data were entered into NVivo 10 and analysed using a Thematic Network Analysis approach.[17] This involved an iterative and cyclical process of reading and analysis to identify basic, organising and global themes within the dataset. Analysis was undertaken by two authors (GT and NC) independently on six transcripts initially, followed by an in-depth discussion and consensual validation of key themes. A further cycle of independent and collaborative analysis was then undertaken on a further sub-set of transcripts to ensure rigour and authenticity of the themes generated. All thematic decisions were discussed with the third author (PD). The study was approved by the University of Central Lancashire 'STEMH' ethics committee and individual written informed consent was obtained from all participants.

RESULTS

Overall, practice staff were well aware of the two-week waiting-time initiative and had good knowledge about the national ‘Be Clear on Cancer’ cancer awareness public campaigns, but had less awareness about other initiatives specifically targeted at primary care. The key global theme to emerge from the interviews related to ‘managing risk’ within primary care:

“It's quite a tricky, nebulous area [...]. The nature of general practice is that we're dealing every day with uncertainty...” (Interview 6, Participant 3)

A key concern of staff was that policymakers and those implementing cancer initiatives did not fully understand how risk was managed within primary care. Cancer was only one priority and there was an abundance of initiatives for a variety of conditions which primary care staff were expected to implement. Three underpinning organising themes (and associated basic themes) of ‘complexity’, ‘continuity’ and ‘conflict’ highlighted the tensions and difficulties that primary care face in managing the risk of early detection and referral for cancer symptoms whilst dealing with complex symptoms and care systems, patient-led factors and target-focused care. An overview of the organising and basic themes is presented in figure 1. These themes are described and discussed, contextualised by participant quotes below.

Complexity

This theme highlighted the complexity of managing risk in early cancer diagnosis because of external factors including cancer symptom differentiation and the restrictions imposed by referral criteria; the multitude of services and professionals involved in diagnostic and

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3 assessment services and the plethora of policies and initiatives targeted at primary care
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5 practice.
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10 *Cancer disease and symptoms:* Cancer diagnosis was an important priority area in primary
11 care but diagnosis presented complex challenges. Cancer was a rare diagnosis in primary
12 care although symptoms associated with cancer were common.
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18 *“We get lots of sore throats, and yet we get one tonsillar cancer every three [years] so*
19 *sorting out the wheat from the chaff is a real challenge.”* (Interview 3, Participant 3)
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25 These complexities of diagnosis were compounded by what were considered rigid referral
26 criteria, based on disease prevalence amongst those with symptoms, which led to cases being
27 ‘bounced back’ if they failed to meet diagnostic criteria. In attempts to manage what they
28 considered was a risk to patients, some participants said, on occasion, they had to ‘fudge’,
29 ‘embellish’ or ‘bend-the-rules’ to ensure assessment of patients for whom they had concerns:
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38 *“Even though it says on the form, “don't fill out this form unless they tick any boxes”*
39 *but you find a box to tick, and usually for very good reason. And I think you'd only go,*
40 *slightly over egging the presentation if you were pretty sure there was something*
41 *there, something going on.”* (Interview 4, Participant 4)
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50 *Fragmentation and access to diagnostic services:* Primary care staff expressed difficulties
51 accessing diagnostic services due to on-going service re-configurations and the involvement
52 of multiple agencies. This led to fragmentation in terms of staff not always knowing who, or
53 to which services, referrals could be made.
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5 There were also some concerns about fragmented relationships between primary and
6
7 secondary care with several participants feeling frustrated by restricted access to diagnostics
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9 for certain conditions. Some participants considered this was due to 'empire building' by
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11 professionals justifying and 'preserving' their service by retaining ownership of who was
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13 qualified to make referrals:
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18 *"I can send people for a CT scan if I have a concern about them, for some conditions,*
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20 *but not others. Well why not? I'm the one who's initiating the referral in the first*
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22 *place. You trust me to initiate the referral to pick the patient and prepare them so that*
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24 *you can come along and just arrange the scan and look at it."* (Interview 4,
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27 Participant 3)
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32 Whilst some GPs wanted more direct access to diagnostics, this was not universal, and others
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34 highlighted the need for 'training' prior to referrals being made.
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38 *Guidelines content and information overload:* Participants referred to the usefulness of
39
40 guidelines to help symptom differentiation and manage risk. Knowledge was felt to be
41
42 experientially derived and referral guidelines only considered useful for less experienced
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44 doctors. Risk assessment tools were occasionally considered unnecessarily complex when
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46 patients had 'red flag' symptoms and, as previously mentioned, sometimes restrictive for use
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48 in primary care:
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54 *"I mean, you see, from a GPs point of view, if somebody comes in who is fifty-five*
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56 *years of age, and passes blood in his stool, you need to exclude a cancer. Now, I don't*
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3 *want to know how many percentage of those people pass blood in the motion will*
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5 *have cancer, or how many will have piles, or inflammatory bowel disease or what*
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7 *have you.” (Interview 4, Participant 3)*
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12 Concerns were expressed about the number of guidelines available for different conditions
13
14 and inconsistencies between different sources:
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18 *“And that’s the problem ‘cause last year there was a big campaign, “if you have a*
19 *cough for more than three weeks you need to go and see a doctor”, but NICE*
20 *guidelines is six weeks.” (Interview 6, Participant 4)*
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27 Participants described how the ‘tsunami’ of new guidelines, care plans and initiatives meant it
28
29 was difficult to keep up-to-date:
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34 *“And I thought ‘that’s probably a squamous cell carcinoma. That needs a two-week*
35 *wait referral’. Then, I actually checked the guidelines, the guidelines say that “it’s got*
36 *to be over one centimetre and you’ve got to wait more than eight weeks really for it to*
37 *grow” etcetera, etcetera [...] and those things will change on a regular basis. Now,*
38 *how do you expect an entire network of primary care physicians to stay current with*
39 *all those guidelines and apply them religiously?” (Interview 2, Participant 3).*
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51 52 Continuity

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54 Practice staff expressed concern that a lack of continuity increased the risk of missing
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56 diagnoses and/or supporting the patient through a difficult period. This was highlighted
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3 through discussions about relationships between patients and clinicians; delays in information
4 sharing across the primary and secondary care interface and patient follow-up after initial
5 consultation.
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11 *Patient-practice relationships:* Continuity-of-carer could not always be achieved in practice,
12 even though it was felt that patients preferred it and its absence was thought to possibly
13 contribute to diagnostic delay:
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21 *“People have been hopping around from one clinician to another and that, and you*
22 *don't see the evolution of the story until it hits you in the face. Patients book on the*
23 *day, they don't necessarily get in the person they normally see, they get in with the*
24 *available, so that can disjoint things.” (Interview 3, Participant 4)*
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32 Staff felt that smaller, rural practices had closer relationships with their patients and their
33 community, which would lead to earlier consultation. However, others felt awareness of
34 cancer deaths was heightened in close-knit communities, which could reinforce negative
35 views towards cancer and cancer survivorship amongst the local population and delay access
36 to services.
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45 *Primary care and secondary care interface:* Expedited assessment following GP referral of
46 patients through the two-week wait initiative was perceived to work well by practice staff,
47 but delays further on in the assessment process, and outside of primary care control, were felt
48 to put patients at risk again and exacerbated their concerns:
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3 *“And, well, it's very difficult from our point of view, ‘cause we're saying, ‘look, you*
4 *know this may be nothing serious, however, I want to refer you on the system, you'll*
5 *get an appointment in two weeks”, and they do get seen, but then there's a massive*
6 *delay, so, you know, then they're kinda all heightened up because they're thinking,*
7 *“{whispered} the doctor thinks I've got cancer” and then nothing happens for ages,*
8 *and it's really hard for the patients.”* (Interview 3, Participant 5)
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21 *Practice-based follow-up:* Patients themselves were also considered to cause delays if they
22 failed to attend. Practices debated the extent to which they should chase these patients up and
23 the risks if they did not:
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29 *“In the back of their mind they know they should, but if they face the fact that they're*
30 *going back, are they are going to be faced with something else? You also have to be*
31 *responsible for the fact that if that doesn't stop, you must persist, and accept the fact*
32 *that, if you don't, then you could, somewhere down the line end up with something so*
33 *serious that it's only going to be palliative.”* (Interview 2, Participant 1)
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44 Conflict

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46 Within this theme, managing risk was related to primary care focus on targets; conflicting
47 opinions about the role of non-clinical staff and about the worries and tensions generated by
48 cancer awareness campaigns.
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55 *Prevention versus target driven care:* It is recognised that primary care can make a significant
56 contribution to public health through promotion, in the practice population, of healthier
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3 lifestyles and earlier presentation of symptoms of diseases, where early intervention reduces
4 morbidity and mortality, such as cancer. Primary care staff considered cancer a public health
5 priority but some felt that there was a tension between adopting preventative approaches in
6 the practice such as promoting cancer awareness and early presentation and the way that
7 primary care is currently funded through achieving specific targets mainly relating to the
8 management of long-term conditions (Quality and Outcomes Framework):
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“We’re not as good with public health, with local public health initiatives, as maybe we should be necessarily. It’s just time to do things, and those things aren’t required of our core business, and when you have a very detailed contract that tells you what you will be paid for doing...” (Interview 2, Participant 3)

Staff roles: There were conflicting views around the role of other practice staff in managing the risk of cancer detection and awareness, in particular with regard to reception staff. Some staff viewed the reception role as a health advisor, whereas others perceived their role to be purely administrative. Additionally, there were reservations about the ability of reception staff to relay cancer messages and how the public might feel about receiving health information from them:
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“You’re passing clinical responsibility to people who are non-clinical. It’s alright for patients to speak to them, and that’s fine, but, I’m not gonna use the receptionists as a source of information [...]. I think anything clinical should be passed to the doctor full stop. I don’t think there is any other role for the receptionist.” (Interview 4, Participant 3)

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5 There were also concerns about potential litigation issues if reception staff were to give
6
7 advice and how this could impact on the practice:
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10
11 *“I think it's also worth mentioning at this point, because of our roles, how they are,*
12 *we get a lot of patients not happy about us supplying information, because we're not*
13 *allowed to diagnose, obviously for obvious reasons, but if you was to imply*
14 *something, that could come back on us twice as hard because you'd implied*
15 *something that could be wrong, and therefore it is now your fault.”* (Interview 1,
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23 Participant 1)
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27 A further issue associated with staff roles in helping to manage risk was the identified
28
29 benefits of having a chain of communication between all practice members. For example,
30
31 receptionists being able to ‘raise issues’ with the doctor if they know someone is coming in
32
33 who has symptoms the doctor should be aware of but the patient ‘may not say anything’. This
34
35 can also work the other way:
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40 *“Patients that I worry about, I will leave messages. I'll mention to reception or*
41 *mention to people that I want to follow them up.”* (Interview 6, Participant 3)
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47 Others felt that the focus on the long-term conditions might provide opportunities for practice
48
49 nurses to be more involved as they were often seeing patients who might be at higher risk of
50
51 cancer because of their age, disease condition or lifestyle behaviours:
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55
56 *“Chronic disease, yeah, so diabetic, high blood pressure, chronic kidney disease,*
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3 *asthma, most patients will come and see the practice nurses for routine bloods, blood*
4
5 *pressure, weight, everything like that. So often, GPs don't always see them, I mean*
6
7 *they do the medication reviews, but, we flag to them anything that we're worried*
8
9 *about.*” (Interview 2, Participant 4)
10
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14 Some could also see a role for members of the wider practice team:

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18 *“We'd say 'well who are the district nurses already going out to?' You know, you can*
19 *work with your local pharmacists.*” (Interview 2, Participant 2)
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24
25 *Cancer awareness:* Although cancer fear was commonly acknowledged, staff were divided as
26
27 to whether patients were afraid to consult the GP with cancer symptoms. Some felt that
28
29 unhealthy lifestyle choices contributed to patient reluctance to present with cancer symptoms:
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33
34 *“The cancers where they feel that they may have contributed to it, like smoking, they*
35 *tend to ignore because they don't want to be told that it may be their fault in a certain*
36 *way, and they don't want to give up the lifestyle.*” (Interview 6, Participant 4)
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43 Cancer awareness campaigns were felt to be important, even though those who presented to
44
45 the practice following the campaign were more likely to be those at least risk:
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49
50 *“It's the people who never come to the doctors that you want to hit, not the people*
51 *that were already coming in anyway, and they tend to be ones that see those adverts.*
52 *But then if you can get one person who wouldn't normally come in and you catch*
53 *them, then it's better.*” (Interview 5, Participant 1)
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5 Campaigns were also felt to create extra work for all practice members. There were
6
7 complaints that cancer awareness campaigns tend to run without consideration of other local
8
9 or national campaigns which may be running simultaneously which increased the risk that
10
11 practice capacity to safely respond to patients was compromised:
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16 *“It's like it's alright saying putting in place to get them in, but it's the sheer volume,*
17
18 *isn't it? You can only cope with so much can't you?”* (Interview 5, Participant 1)
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25 **DISCUSSION**

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29 This study provides insights into the experiences of primary care staff who manage patients
30
31 with symptoms suggestive of cancer. The overarching theme to emerge was the need to
32
33 manage risk so that cancer patients had a timely diagnosis and were assessed appropriately.
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35 The associated subthemes of complexity, continuity and conflict highlighted the tensions and
36
37 difficulties faced by staff when attempting to manage these risks in modern practice.
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43 The study was small, descriptive and exploratory. However, it covered a diverse geographical
44
45 area and included practices with varying levels of engagement with awareness and early
46
47 diagnosis initiatives. We stratified on engagement to ensure we had a balance of perspectives
48
49 so as to better inform policymakers of the possible barriers and drivers to the uptake of
50
51 initiatives. The stratification was based on known engagement with the range of national and
52
53 regional initiatives to promote earlier presentation, detection and referral of patients with
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55 symptoms suggestive of cancer available to the practices at that time.
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5 The findings of our study suggest that national initiatives did not appear to wholly resolve
6
7 issues in managing risk for all practitioners. Rather, in some cases, these initiatives were felt
8
9 to introduce inherent risks which staff had to find ways to overcome. This included cancer
10
11 awareness campaigns which, while felt to be very important to encourage patients who would
12
13 otherwise delay diagnosis, also appeared to increase consultation rates from those at lesser
14
15 risk. This placed additional burden on the practice.

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17
18 There were also concerns about initiatives introduced to directly support practices.

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21 Participants highlighted timely diagnosis as an essential part of their role in cancer care. A
22
23 finding reported in an Australian study.[16] This study also identified that the resources spent
24
25 gaining timely access to specialist opinion were a major issue. In our study this appeared to
26
27 be less of a problem because of the two-week waiting-time initiative. This initiative was
28
29 universally embraced by participants as it was felt to work well in facilitating timely
30
31 assessment. However, there were still concerns that lack of direct access to diagnostic
32
33 investigations and poor communication between primary and secondary care put patients at
34
35 risk due to extended delays, as reported in a study undertaken in Ireland.[3] Some
36
37 participants in our study felt that the referral criteria for the two-week waiting-time initiative
38
39 were too restrictive and this led to practitioners, on occasion, subverting the referral system to
40
41 ensure that patients they considered were at risk, but who did not fit the referral criteria, could
42
43 be assessed in a timely manner. Such concerns are not unfounded; one study has shown that
44
45 8% of cancer patients do not have symptoms which fit referral criteria.[18] This may be
46
47 because the presenting signs and symptoms had a lower predictive value for cancer than those
48
49 included in the guidelines. Nevertheless, there is high compliance with guidelines and some
50
51 limited evidence that referral guidelines contribute, in part, to diagnostic delay reduction.[6,
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5 Diagnostic errors leading to primary care malpractice claims are common.[19] Researchers
6
7 suggest that although GPs are more likely to correctly diagnose patients with cancer than
8
9 miss cases, there are a disproportionate number of deaths amongst the latter.[20, 21]
10
11 Diagnostic complexity is compounded by the frequency of consultations for symptoms
12
13 associated with cancer, [21, 22] a fear highlighted by practitioners in this study. A study in
14
15 Norway, which followed up patients presenting with cancer warning signs to their GP,
16
17 suggests that patients with cancer may be missed if multiple warning signs and symptoms are
18
19 not considered.[21] Retrospective studies of practice-based data have identified
20
21 combinations of warning signs and symptoms which may be associated with increasing the
22
23 likelihood of cancer.[23-24] These have been used to inform risk assessment tools to aid
24
25 decision-making, with algorithms and probabilities of risk based on demographic
26
27 characteristics, lifestyle factors, symptoms and/or attendance frequency.[11] Some have been
28
29 disseminated nationally, and there is evidence from both quantitative and qualitative studies
30
31 that they affect GPs' decisions to refer.[11] However, in our study, some participants had
32
33 similar concerns about these tools as they did guidelines. A recent analysis of significant
34
35 event audits in lung cancer highlighted how cancer can mimic other diagnoses and have
36
37 atypical presentation.[7] Guidelines and risk assessment tools are analytical tools, and
38
39 although statistical probabilities are based on uncertainty, they may be perceived to introduce
40
41 a level of certainty which fails to encapsulate practitioners' tacit concerns about patients.
42
43 Previous work in primary care decision-making has emphasised the analytical over the
44
45 experiential, but recent research , including cancer diagnosis, suggests that experiential
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47 knowledge may have a role and may be more responsive to individual patients.[15, 25-27]
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49 Others have found that better diagnostic decisions appear to be made by older doctors [22]
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51 and, as commented on by some of our participants, that guidelines and risk assessment tools
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3 may be more useful for newer practitioners who have yet to develop problem solving
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5 strategies.[28]
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10 It has also been observed that, unlike in acute care, decision-making in primary care partly
11 involves an understanding of the patient context and perspective.[29] Our study participants
12 highlighted concerns that lack of continuity of carer may lead to diagnostic delays. Relational
13 continuity was felt to be a particular problem in larger practices and urban settings. Others
14 suggest that fragmentation of primary care and shorter consultation times has led to a lack of
15 continuity-of-care or carer, which may hinder early diagnosis as cancer presentation can be
16 complex in those with multiple co-morbidities.[16, 30, 31] In a qualitative study of lung
17 cancer patients in New Zealand, patients felt that not always seeing the same GP could lead
18 to delays in diagnosis due to poor follow up.[32] In a study in Denmark, perceived lack of
19 accessibility and the doctor-patient relationship were associated with patient delay in seeking
20 advice about cancer symptoms.[33] Others have found that confidence and trust in a doctor
21 were more important predictors of cancer detection than ease of access and choice of
22 preferred doctor.[34]
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40 In our study, participants highlighted how other practice team members, such as nurses who
41 are in more regular contact with patients with long-term conditions, could raise symptom
42 awareness or be more alert to changes in, or new, symptoms suggestive of cancer. In the US
43 and Canada, patient navigators are being used to support patients through the complex
44 systems found in cancer management and care. It has also been suggested that these roles
45 could be extended to support patients during the diagnostic, referral and assessment processes
46 and ensure appropriate follow up of investigative results.[35] In our study, some staff felt that
47 receptionists could act as navigators in terms of directing patients with symptoms to see the
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3 GP.[36] Low levels of knowledge about some cancer symptoms has been demonstrated in
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5 non-medical staff.[37] However, our study highlighted that professional boundaries and
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7 concerns about litigation which might impede such initiatives; disclosures or discussions of
8
9 diagnostic issues within a public reception location also raised ethical concerns. Research
10
11 within primary care suggests that facilitation of communities of practice and interdisciplinary
12
13 knowledge sharing may help to identify the role of other practice team members in promoting
14
15 earlier cancer presentation and diagnosis;[38] although training needs should be
16
17 addressed.[37]
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23 This study has highlighted that a ‘one-size-fits-all’ approach to implementing initiatives is
24
25 unlikely to succeed as practitioners expressed a range of views and opinions on the benefits
26
27 of different initiatives. Lack of implementation of initiatives in primary care is not always
28
29 because of resistance to the initiatives themselves, but sometimes because of the sheer
30
31 number across a range of priority areas that practices are expected to implement, often
32
33 simultaneously. Policymakers should consider more carefully how these impact on primary
34
35 care, how they can be embedded into practice systems and emphasise and exploit synergies
36
37 with other disease conditions.
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43 For there to be greater success of initiatives aimed at promoting earlier presentation, detection
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45 and referral in primary care, there needs to be further work on understanding how primary
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47 care manage risk in the face of inherent uncertainty, organisational changes and competing
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49 priorities.
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3 **ACKNOWLEDGEMENTS:** Our thanks to the practices who participated in this study and
4
5 to the staff of the Lancashire and South Cumbria Cancer Network who assisted us.
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10 **COMPETING INTERESTS:** PD was public health lead for LSCCN and NC is part-funded
11
12 by a grant from LSCCN; PD was also funded by LSCCN to undertake evaluative work.
13

14
15
16 **FUNDING:** This work was supported by Lancashire and South Cumbria Cancer Network
17
18 (LSCCN) as part of the National Cancer Awareness and Early Detection initiative (NAEDI)
19
20 funding ‘cancer networks supporting primary care’.
21
22

23 24 25 **CONTRIBUTIONS:**

26
27 NC recruited participants, carried out interviews, transcribed the interviews, coded the
28
29 transcripts, contributed to the development of the coding framework, and contributed to the
30
31 writing of the manuscript.
32

33
34 GT carried out interviews, coded the transcripts, contributed to the development of the coding
35
36 framework and contributed to the writing of the manuscript.
37

38
39 PD designed the study, collated practice engagement data, contributed to the development of
40
41 the coding of the framework and contributed to the writing of the manuscript.
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45 **DATA SHARING:** No further data are available
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48 49 50 51 52 53 54 55 56 **REFERENCES** 57 58 59 60

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3 **Figure 1: organising themes of complexity, continuity and conflict with their associated**
4 **basic themes, centred around the global theme of managing risk in primary care**
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For peer review only

Box 1: Semi-structured interview schedule

- Why do you think people with symptoms suggestive of cancer do not present, get seen or diagnosed or referred earlier?
- What do you know about the initiatives that concern the earlier presentation, diagnosis and referral of cancer symptoms?
 - Prompts around specific tools/initiatives/referral criteria
- Have you accessed any local training events concerning the identification, referral of cancer patients?
 - Prompts around specific training attended, and how learning is usually undertaken
- Overall, what is working well in terms of the implementation and use of these initiatives?
- Overall, have you experienced any/or what do you consider to be the main barriers in the implementation/access/use of these various initiatives?
- Are there any practice based issues that may affect the early identification and referral for cancer patients?
 - Prompts around staff and practice issues, communication, administration
- Overall, what do you think local practices could do to help promote and diagnose cancer symptoms?
 - Prompts around team roles and other practice issues
- Do you know about the Lancashire and South Cumbria Cancer Network and what their role is?
 - Prompts around extent of engagement, attitudes and areas for improvement
- What is your opinion concerning the forthcoming 'access to diagnostics' initiative (initiative for practices to make direct referrals to diagnostics such as x-rays, CT scans, ultrasound)?
 - Prompts around who should make the referral
- Are there any additional support mechanisms/external to the practice that need to be in place to help with promotion/diagnosis and referral?
- Any further issues or concerns you would like to raise about this work?

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9 **Managing the risk of cancer earlier presentation, detection and referral: a qualitative**
10 **study of primary care staff views**
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51 **Key Words:** primary health care, general practice, neoplasms, qualitative research, early
52 detection of cancer.
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57 Word count: abstract- 232, manuscript - 4,504
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ABSTRACT

Objectives: In the UK, there have been a number of national initiatives to promote earlier detection and prompt referral of patients presenting to primary care with signs and symptoms of cancer. The aim of the study was to explore the experiences of a range of primary care staff in promoting earlier presentation, detection and referral of patients with symptoms suggestive of cancer.

Setting: Six primary care practices in North West England.

Participants: Thirty-nine primary care staff from a variety of disciplines took part in five group and four individual interviews.

Results: The global theme to emerge from the interviews was 'managing risk', which had three underpinning organising themes: 'complexity', relating to uncertainty of cancer diagnoses, service fragmentation and plethora of guidelines; 'continuity', relating to relationships between practice staff and their patients and between primary and secondary care; 'conflict' relating to policy drivers and staff role boundaries. A key concern of staff was that policymakers and those implementing cancer initiatives did not fully understand how risk was managed within primary care.

Conclusion: Primary care staff expressed a range of views and opinions on the benefits of cancer initiatives. National initiatives did not appear to wholly resolve issues in managing risk for all practitioners. Staff were concerned about the number of guidelines and priorities

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3 they were expected to implement. These issues need to be considered by policymakers when
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5 developing and implementing new initiatives.
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8 9 10 **ARTICLE SUMMARY**

11 12 13 14 **Strengths and limitations of this study**

- 15
16 • The study investigates the experiences of a range of primary care staff around
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18 implementing initiatives for the earlier diagnosis of cancer.
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- 20
21 • The underlying concern in primary care is related to managing risk.
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24 • The sample included a mix of practices with different practice characteristics and
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26 included those known to be engaged in national and regional initiatives and those who
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28 were less engaged.
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31 • The sample was drawn from a single English region.
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INTRODUCTION

Studies in the 1990s showed that UK cancer survival rates were worse than many other European countries, following which there has been two decades of concerted effort to expedite access to proven effective cancer treatments.[1] While there have been improvements in cancer survival latterly, the UK still lags behind many other countries with similar health care systems, which may be partly due to later stage of disease at presentation. [2]

Both nationally and internationally, primary care is seen to have a key role in improving cancer survival by reducing delays in diagnosis through promoting earlier presentation and through earlier detection and referral of those with symptoms for further specialist assessment.[3, 4] In the UK, national campaigns extol those with symptoms to see their general practitioner earlier; there are national referral guidelines for suspected cancer and a national system for urgent referral from primary to secondary care (two-week waiting-time initiative).[5] However, evidence suggests that there may be further room for improvement:[6] there is practice variation in the use of the 'two-week' initiative and some patients are seen several times in primary care before referral.[7-9] A significant proportion of patients also present through emergency routes and have poorer survival.[10]

To further support primary care in the UK, resources were developed and/or disseminated by the Department of Health's National Awareness and Early Diagnosis Initiative (NAEDI), established in 2008, and the Royal College of General Practitioners (RCGP) including: audit and significant events analysis tools,[7, 8] general practitioner (GP) level cancer profile data, safety netting recommendations and risk assessment tools.[11] Key initiatives have mainly

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3 focused on GPs, but other members of the primary care team may have key roles: an area
4
5 which has been largely unexplored.
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10 A number of international studies have been undertaken in attempts to understand the reasons
11 behind delay in cancer diagnosis. Qualitative studies have mostly focussed on patient
12 perspectives.[12-14] Only a few have explored primary care experiences and these have been
13
14 mainly limited to decision-making processes or referral pathways [11, 15, 16] and from the
15
16 perspective of the general practitioner. [3, 11, 15,16] In order to understand how a range of
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18 initiatives across the patient pathway in primary care could be more effective and the role of
19
20 other members of the practice team, we explored the experiences of a range of primary care
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22 staff in supporting earlier presentation, detection and referral of those with symptoms
23
24 suggestive of cancer. The study was undertaken in one region of England, which at that time
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26 was covered by the Lancashire and South Cumbria Cancer Network (LSSCN).
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36 METHODS

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40 This was a qualitative descriptive study utilising both individual and group-based interviews.
41
42 It aimed to recruit staff from six practices who were differentially engaged with the national
43
44 awareness and early diagnosis of cancer agenda. GP practices within LSSCN were stratified
45
46 into one of three groups at the end of June 2012. High engagers had participated in at least
47
48 one of the following: RCGP cancer audit, attendance at a course on early diagnosis or face-
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50 to-face meetings to discuss GP cancer profiles and action planning. Medium engagers had
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52 attended at least one regional meeting about cancer awareness. Low engagers were not
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3 known to have engaged in any initiatives. Of 254 practices in the geographical area, there
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5 were 51 high engagers, 69 medium engagers and 134 low engagers.
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10 Within each group, a random sample of 10 practices were sent a letter about the study,
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12 followed up with a phone call from the research team one week later. The initial aim was to
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14 recruit at least two practices in each stratum. Due to low uptake within the medium and low
15
16 engager strata, these categories were merged and a random sample of a further 15 practices
17
18 sent letters. Practices were offered a choice of either group or individual interviews as it was
19
20 recognised that time constraints prevent some practice staff from taking part in group
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22 interviews and some may feel uncomfortable discussing the issues with colleagues.
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24 Individual interviews were the preferred method in only one practice. Interviews (group and
25
26 individual) were held on only one occasion in each practice.
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32 Six practices agreed to take part in semi-structured, audio-recorded interviews, which were
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34 attended by two researchers, between September and October 2012. We recruited three
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36 practices in the high stratum and three practices in the merged medium and low stratum (a
37
38 mix of low and medium engagers). The topic guide is outlined in Box 1. Thirty-nine
39
40 participants took part in group (n=5) or individual (n=4) interviews. Job roles included GP
41
42 (n=9), receptionist (n=7), nurse (n=6), manager (n=6), secretary (n=5), health care assistant
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44 (n=3), medical student (n=2) and phlebotomist (n=1). Practice characteristics are shown in
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46 table 1.
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Table 1: Practice and interview characteristics

Practice characteristic	No. of practices
No of partners	
4 or more	3
3 or less	3
Deprivation Quintile*	
5 or 4 (more deprived)	3
2 or 3	3
1 (most affluent)	0
Population Density**	
<15%	2
15 to 39%	2
>=40%	2

*based on index of multiple deprivation of practice location 2010 (source: Department for Communities and Local Government, Indices of Deprivation 2010)

** Person per hectare based on practice location (source: ONS Neighbourhood Statistics)

The interviews took between 38 and 67 minutes to complete, and between four and eleven staff took part in each practice. All transcribed data were entered into NVivo 10 and analysed using a Thematic Network Analysis approach.[17] This involved an iterative and cyclical process of reading and analysis to identify basic, organising and global themes within the dataset. Analysis was undertaken by two authors (GT and NC) independently on six transcripts initially, followed by an in-depth discussion and consensual validation of key themes. A further cycle of independent and collaborative analysis was then undertaken on a further sub-set of transcripts to ensure rigour and authenticity of the themes generated. All thematic decisions were discussed with the third author (PD). The study was approved by the University of Central Lancashire 'STEMH' ethics committee and individual written informed consent was obtained from all participants.

RESULTS

Overall, practice staff were well aware of the two-week waiting-time initiative and had good knowledge about the national 'Be Clear on Cancer' cancer awareness public campaigns, but had less awareness about other initiatives specifically targeted at primary care. The key global theme to emerge from the interviews related to 'managing risk' within primary care:

"It's quite a tricky, nebulous area [...]. The nature of general practice is that we're dealing every day with uncertainty..." (Interview 6, Participant 3)

A key concern of staff was that policymakers and those implementing cancer initiatives did not fully understand how risk was managed within primary care. Cancer was only one priority and there was an abundance of initiatives for a variety of conditions which primary care staff were expected to implement. Three underpinning organising themes (and associated basic themes) of 'complexity', 'continuity' and 'conflict' highlighted the tensions and difficulties that primary care face in managing the risk of early detection and referral for cancer symptoms whilst dealing with complex symptoms and care systems, patient-led factors and target-focused care. An overview of the organising and basic themes is presented in figure 1. These themes are described and discussed, contextualised by participant quotes below.

Complexity

This theme highlighted the complexity of managing risk in early cancer diagnosis because of external factors including cancer symptom differentiation and the restrictions imposed by

1
2
3 referral criteria; the multitude of services and professionals involved in diagnostic and
4
5 assessment services and the plethora of policies and initiatives targeted at primary care
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7 practice.
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11 *Cancer disease and symptoms:* Cancer diagnosis was an important priority area in primary
12
13 care but diagnosis presented complex challenges. Cancer was a rare diagnosis in primary
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15 care although symptoms associated with cancer were common.
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21 *“We get lots of sore throats, and yet we get one tonsillar cancer every three [years] so*
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23 *sorting out the wheat from the chaff is a real challenge.” (Interview 3, Participant 3)*
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27 These complexities of diagnosis were compounded by what were considered rigid referral
28
29 criteria, based on disease prevalence amongst those with symptoms, which led to cases being
30
31 ‘bounced back’ if they failed to meet diagnostic criteria. In attempts to manage what they
32
33 considered was a risk to patients, some participants said, on occasion, they had to ‘fudge’,
34
35 ‘embellish’ or ‘bend-the-rules’ to ensure assessment of patients for whom they had concerns:
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40 *“Even though it says on the form, “don't fill out this form unless they tick any boxes”*
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42 *but you find a box to tick, and usually for very good reason. And I think you'd only go,*
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44 *slightly over egging the presentation if you were pretty sure there was something*
45
46 *there, something going on.” (Interview 4, Participant 4)*
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52 *Fragmentation and access to diagnostic services:* Primary care staff expressed difficulties
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54 accessing diagnostic services due to on-going service re-configurations and the involvement
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3 of multiple agencies. This led to fragmentation in terms of staff not always knowing who, or
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5 to which services, referrals could be made.
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10 There were also some concerns about fragmented relationships between primary and
11
12 secondary care with several participants feeling frustrated by restricted access to diagnostics
13
14 for certain conditions. Some participants considered this was due to 'empire building' by
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16 professionals justifying and 'preserving' their service by retaining ownership of who was
17
18 qualified to make referrals:
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23 *"I can send people for a CT scan if I have a concern about them, for some conditions,*
24
25 *but not others. Well why not? I'm the one who's initiating the referral in the first*
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27 *place. You trust me to initiate the referral to pick the patient and prepare them so that*
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29 *you can come along and just arrange the scan and look at it."* (Interview 4,
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31 Participant 3)
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36 Whilst some GPs wanted more direct access to diagnostics, this was not universal, and others
37
38 highlighted the need for 'training' prior to referrals being made.
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43 *Guidelines content and information overload:* Participants referred to the usefulness of
44
45 guidelines to help symptom differentiation and manage risk. Knowledge was felt to be
46
47 experientially derived and referral guidelines only considered useful for less experienced
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49 doctors. Risk assessment tools were occasionally considered unnecessarily complex when
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51 patients had 'red flag' symptoms and, as previously mentioned, sometimes restrictive for use
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53 in primary care:
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3 *“I mean, you see, from a GPs point of view, if somebody comes in who is fifty-five*
4 *years of age, and passes blood in his stool, you need to exclude a cancer. Now, I don’t*
5 *want to know how many percentage of those people pass blood in the motion will*
6 *have cancer, or how many will have piles, or inflammatory bowel disease or what*
7 *have you.”* (Interview 4, Participant 3)
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16 Concerns were expressed about the number of guidelines available for different conditions
17 and inconsistencies between different sources:
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23 *“And that’s the problem ‘cause last year there was a big campaign, “if you have a*
24 *cough for more than three weeks you need to go and see a doctor”, but NICE*
25 *guidelines is six weeks.”* (Interview 6, Participant 4)
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32 **Participants described how the ‘tsunami’ of new guidelines, care plans and initiatives meant it**
33 **was difficult to keep up-to-date:**
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38 *“And I thought ‘that’s probably a squamous cell carcinoma. That needs a two-week*
39 *wait referral’. Then, I actually checked the guidelines, the guidelines say that “it’s got*
40 *to be over one centimetre and you’ve got to wait more than eight weeks really for it to*
41 *grow” etcetera, etcetera [...] and those things will change on a regular basis. Now,*
42 *how do you expect an entire network of primary care physicians to stay current with*
43 *all those guidelines and apply them religiously?”* (Interview 2, Participant 3).
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56 Continuity
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3 Practice staff expressed concern that a lack of continuity increased the risk of missing
4 diagnoses and/or supporting the patient through a difficult period. This was highlighted
5 through discussions about relationships between patients and clinicians; delays in information
6 sharing across the primary and secondary care interface and patient follow-up after initial
7 consultation.
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16 *Patient-practice relationships:* Continuity-of-carer could not always be achieved in practice,
17 even though it was felt that patients preferred it and its absence was thought to possibly
18 contribute to diagnostic delay:
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25 *“People have been hopping around from one clinician to another and that, and you*
26 *don't see the evolution of the story until it hits you in the face. Patients book on the*
27 *day, they don't necessarily get in the person they normally see, they get in with the*
28 *available, so that can disjoint things.” (Interview 3, Participant 4)*
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36 Staff felt that smaller, rural practices had closer relationships with their patients and their
37 community, which would lead to earlier consultation. However, others felt awareness of
38 cancer deaths was heightened in close-knit communities, which could reinforce negative
39 views towards cancer and cancer survivorship amongst the local population and delay access
40 to services.
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49 *Primary care and secondary care interface:* Expedited assessment following GP referral of
50 patients through the two-week wait initiative was perceived to work well by practice staff,
51 but delays further on in the assessment process, and outside of primary care control, were felt
52 to put patients at risk again and exacerbated their concerns:
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5 “And, well, it's very difficult from our point of view, ‘cause we're saying, “look, you
6 know this may be nothing serious, however, I want to refer you on the system, you'll
7 get an appointment in two weeks”, and they do get seen, but then there's a massive
8 delay, so, you know, then they're kinda all heightened up because they're thinking,
9 “{whispered} the doctor thinks I've got cancer” and then nothing happens for ages,
10 and it's really hard for the patients.” (Interview 3, Participant 5)
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23 *Practice-based follow-up:* Patients themselves were also considered to cause delays if they
24 failed to attend. Practices debated the extent to which they should chase these patients up and
25 the risks if they did not:
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32 “In the back of their mind they know they should, but if they face the fact that they're
33 going back, are they are going to be faced with something else? You also have to be
34 responsible for the fact that if that doesn't stop, you must persist, and accept the fact
35 that, if you don't, then you could, somewhere down the line end up with something so
36 serious that it's only going to be palliative.” (Interview 2, Participant 1)
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46 Conflict

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48 Within this theme, managing risk was related to primary care focus on targets; conflicting
49 opinions about the role of non-clinical staff and about the worries and tensions generated by
50 cancer awareness campaigns.
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57 *Prevention versus target driven care:* It is recognised that primary care can make a significant
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3 contribution to public health through promotion, in the practice population, of healthier
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5 lifestyles and earlier presentation of symptoms of diseases, where early intervention reduces
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7 morbidity and mortality, such as cancer. Primary care staff considered cancer a public health
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9 priority but some felt that there was a tension between adopting preventative approaches in
10
11 the practice such as promoting cancer awareness and early presentation and the way that
12
13 primary care is currently funded through achieving specific targets mainly relating to the
14
15 management of long-term conditions (Quality and Outcomes Framework):
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21 *“We’re not as good with public health, with local public health initiatives, as maybe*
22 *we should be necessarily. It’s just time to do things, and those things aren’t required*
23 *of our core business, and when you have a very detailed contract that tells you what*
24 *you will be paid for doing...” (Interview 2, Participant 3)*
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34 *Staff roles:* There were conflicting views around the role of other practice staff in managing
35
36 the risk of cancer detection and awareness, in particular with regard to reception staff. Some
37
38 staff viewed the reception role as a health advisor, whereas others perceived their role to be
39
40 purely administrative. Additionally, there were reservations about the ability of reception
41
42 staff to relay cancer messages and how the public might feel about receiving health
43
44 information from them:
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50 *“You’re passing clinical responsibility to people who are non-clinical. It’s alright for*
51 *patients to speak to them, and that’s fine, but, I’m not gonna use the receptionists as a*
52 *source of information [...]. I think anything clinical should be passed to the doctor*
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3 *full stop. I don't think there is any other role for the receptionist.*” (Interview 4,
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5 Participant 3)
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10 There were also concerns about potential litigation issues if reception staff were to give
11
12 advice and how this could impact on the practice:
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16 *“I think it's also worth mentioning at this point, because of our roles, how they are,*
17
18 *we get a lot of patients not happy about us supplying information, because we're not*
19
20 *allowed to diagnose, obviously for obvious reasons, but if you was to imply*
21
22 *something, that could come back on us twice as hard because you'd implied*
23
24 *something that could be wrong, and therefore it is now your fault.”* (Interview 1,
25
26 Participant 1)
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32 A further issue associated with staff roles in helping to manage risk was the identified
33
34 benefits of having a chain of communication between all practice members. For example,
35
36 receptionists being able to ‘*raise issues*’ with the doctor if they know someone is coming in
37
38 who has symptoms the doctor should be aware of but the patient ‘*may not say anything*’. This
39
40 can also work the other way:
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45 *“Patients that I worry about, I will leave messages. I'll mention to reception or*
46
47 *mention to people that I want to follow them up.”* (Interview 6, Participant 3)
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52 **Others felt that the focus on the long-term conditions might provide opportunities for practice**
53
54 **nurses to be more involved as they were often seeing patients who might be at higher risk of**
55
56 **cancer because of their age, disease condition or lifestyle behaviours:**
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5 *“Chronic disease, yeah, so diabetic, high blood pressure, chronic kidney disease,*
6 *asthma, most patients will come and see the practice nurses for routine bloods, blood*
7 *pressure, weight, everything like that. So often, GPs don’t always see them, I mean*
8 *they do the medication reviews, but, we flag to them anything that we’re worried*
9 *about.” (Interview 2, Participant 4)*
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19 Some could also see a role for members of the wider practice team:

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23 *“We’d say ‘well who are the district nurses already going out to?’ You know, you can*
24 *work with your local pharmacists.” (Interview 2, Participant 2)*
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29 *Cancer awareness:* Although cancer fear was commonly acknowledged, staff were divided as
30 to whether patients were afraid to consult the GP with cancer symptoms. Some felt that
31 unhealthy lifestyle choices contributed to patient reluctance to present with cancer symptoms:
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38 *“The cancers where they feel that they may have contributed to it, like smoking, they*
39 *tend to ignore because they don’t want to be told that it may be their fault in a certain*
40 *way, and they don’t want to give up the lifestyle.” (Interview 6, Participant 4)*
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47 Cancer awareness campaigns were felt to be important, even though those who presented to
48 the practice following the campaign were more likely to be those at least risk:
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54 *“It’s the people who never come to the doctors that you want to hit, not the people*
55 *that were already coming in anyway, and they tend to be ones that see those adverts.*
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3 *But then if you can get one person who wouldn't normally come in and you catch*
4 *them, then it's better.”* (Interview 5, Participant 1)
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10 Campaigns were also felt to create extra work for all practice members. There were
11 complaints that cancer awareness campaigns tend to run without consideration of other local
12 or national campaigns which may be running simultaneously **which increased the risk that**
13 **practice capacity to safely respond to patients was compromised:**
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21 *“It's like it's alright saying putting in place to get them in, but it's the sheer volume,*
22 *isn't it? You can only cope with so much can't you?”* (Interview 5, Participant 1)
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29 **DISCUSSION**

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34 **This study provides insights into the experiences of primary care staff who manage patients**
35 **with symptoms suggestive of cancer.** The overarching theme to emerge was the need to
36 manage risk so that cancer patients had a timely diagnosis and were assessed appropriately.
37 The associated subthemes of complexity, continuity and conflict highlighted the tensions and
38 difficulties faced by staff when attempting to manage these risks in modern practice.
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47 The study was small, descriptive and exploratory. However, it covered a diverse geographical
48 area and included practices with varying levels of engagement with awareness and early
49 diagnosis initiatives. **We stratified on engagement to ensure we had a balance of perspectives**
50 **so as to better inform policymakers of the possible barriers and drivers to the uptake of**
51 **initiatives. The stratification was based on known engagement with the range of national and**
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3 regional initiatives to promote earlier presentation, detection and referral of patients with
4
5 symptoms suggestive of cancer available to the practices at that time.
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10 The findings of our study suggest that national initiatives did not appear to wholly resolve
11
12 issues in managing risk for all practitioners. Rather, in some cases, these initiatives were felt
13
14 to introduce inherent risks which staff had to find ways to overcome. This included cancer
15
16 awareness campaigns which, while felt to be very important to encourage patients who would
17
18 otherwise delay diagnosis, also appeared to increase consultation rates from those at lesser
19
20 risk. This placed additional burden on the practice.
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23 There were also concerns about initiatives introduced to directly support practices.

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25 Participants highlighted timely diagnosis as an essential part of their role in cancer care. A
26
27 finding reported in an Australian study.[16] This study also identified that the resources spent
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29 gaining timely access to specialist opinion were a major issue. In our study this appeared to
30
31 be less of a problem because of the two-week waiting-time initiative. This initiative was
32
33 universally embraced by participants as it was felt to work well in facilitating timely
34
35 assessment. However, there were still concerns that lack of direct access to diagnostic
36
37 investigations and poor communication between primary and secondary care put patients at
38
39 risk due to extended delays, as reported in a study undertaken in Ireland.[3] Some
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41 participants in our study felt that the referral criteria for the two-week waiting-time initiative
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43 were too restrictive and this led to practitioners, on occasion, subverting the referral system to
44
45 ensure that patients they considered were at risk, but who did not fit the referral criteria, could
46
47 be assessed in a timely manner. Such concerns are not unfounded; one study has shown that
48
49 8% of cancer patients do not have symptoms which fit referral criteria.[18] This may be
50
51 because the presenting signs and symptoms had a lower predictive value for cancer than those
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53 included in the guidelines. Nevertheless, there is high compliance with guidelines and some
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3 limited evidence that referral guidelines contribute, in part, to diagnostic delay reduction.[6,
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10 Diagnostic errors leading to primary care malpractice claims are common.[19] Researchers
11 suggest that although GPs are more likely to correctly diagnose patients with cancer than
12 miss cases, there are a disproportionate number of deaths amongst the latter.[20, 21]
13
14 Diagnostic complexity is compounded by the frequency of consultations for symptoms
15 associated with cancer, [21, 22] a fear highlighted by practitioners in this study. A study in
16 Norway, which followed up patients presenting with cancer warning signs to their GP,
17 suggests that patients with cancer may be missed if multiple warning signs and symptoms are
18 not considered.[21] Retrospective studies of practice-based data have identified
19 combinations of warning signs and symptoms which may be associated with increasing the
20 likelihood of cancer.[23-24] These have been used to inform risk assessment tools to aid
21 decision-making, with algorithms and probabilities of risk based on demographic
22 characteristics, lifestyle factors, symptoms and/or attendance frequency.[11] Some have been
23 disseminated nationally, and there is evidence from both quantitative and qualitative studies
24 that they affect GPs' decisions to refer.[11] However, in our study, some participants had
25 similar concerns about these tools as they did guidelines. A recent analysis of significant
26 event audits in lung cancer highlighted how cancer can mimic other diagnoses and have
27 atypical presentation.[7] Guidelines and risk assessment tools are analytical tools, and
28 although statistical probabilities are based on uncertainty, they may be perceived to introduce
29 a level of certainty which fails to encapsulate practitioners' tacit concerns about patients.
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31 Previous work in primary care decision-making has emphasised the analytical over the
32 experiential, but recent research, including cancer diagnosis, suggests that experiential
33 knowledge may have a role and may be more responsive to individual patients.[15, 25-27]
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3 Others have found that better diagnostic decisions appear to be made by older doctors [22]
4 and, as commented on by some of our participants, that guidelines and risk assessment tools
5 may be more useful for newer practitioners who have yet to develop problem solving
6 strategies.[28]
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14 It has also been observed that, unlike in acute care, decision-making in primary care partly
15 involves an understanding of the patient context and perspective.[29] Our study participants
16 highlighted concerns that lack of continuity of carer may lead to diagnostic delays. Relational
17 continuity was felt to be a particular problem in larger practices and urban settings. Others
18 suggest that fragmentation of primary care and shorter consultation times has led to a lack of
19 continuity-of-care or carer, which may hinder early diagnosis as cancer presentation can be
20 complex in those with multiple co-morbidities.[16, 30, 31] In a qualitative study of lung
21 cancer patients in New Zealand, patients felt that not always seeing the same GP could lead
22 to delays in diagnosis due to poor follow up.[32] In a study in Denmark, perceived lack of
23 accessibility and the doctor-patient relationship were associated with patient delay in seeking
24 advice about cancer symptoms.[33] Others have found that confidence and trust in a doctor
25 were more important predictors of cancer detection than ease of access and choice of
26 preferred doctor.[34]
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45 In our study, participants highlighted how other practice team members, such as nurses who
46 are in more regular contact with patients with long-term conditions, could raise symptom
47 awareness or be more alert to changes in, or new, symptoms suggestive of cancer. In the US
48 and Canada, patient navigators are being used to support patients through the complex
49 systems found in cancer management and care. It has also been suggested that these roles
50 could be extended to support patients during the diagnostic, referral and assessment processes
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3 and ensure appropriate follow up of investigative results.[35] In our study, some staff felt that
4
5 receptionists could act as navigators in terms of directing patients with symptoms to see the
6
7 GP.[36] Low levels of knowledge about some cancer symptoms has been demonstrated in
8
9 non-medical staff.[37] However, our study highlighted that professional boundaries and
10
11 concerns about litigation which might impede such initiatives; disclosures or discussions of
12
13 diagnostic issues within a public reception location also raised ethical concerns. Research
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15 within primary care suggests that facilitation of communities of practice and interdisciplinary
16
17 knowledge sharing may help to identify the role of other practice team members in promoting
18
19 earlier cancer presentation and diagnosis;[38] although training needs should be
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21 addressed.[37]
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27 This study has highlighted that a 'one-size-fits-all' approach to implementing initiatives is
28
29 unlikely to succeed as practitioners expressed a range of views and opinions on the benefits
30
31 of different initiatives. Lack of implementation of initiatives in primary care is not always
32
33 because of resistance to the initiatives themselves, but sometimes because of the sheer
34
35 number across a range of priority areas that practices are expected to implement, often
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37 simultaneously. Policymakers should consider more carefully how these impact on primary
38
39 care, how they can be embedded into practice systems and emphasise and exploit synergies
40
41 with other disease conditions.
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47 For there to be greater success of initiatives aimed at promoting earlier presentation, detection
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49 and referral in primary care, there needs to be further work on understanding how primary
50
51 care manage risk in the face of inherent uncertainty, organisational changes and competing
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53 priorities.
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5 **ACKNOWLEDGEMENTS:** Our thanks to the practices who participated in this study and
6
7 to the staff of the Lancashire and South Cumbria Cancer Network who assisted us.
8
9

10
11 **COMPETING INTERESTS:** PD was public health lead for LSCCN and NC is part-funded
12
13 by a grant from LSCCN; PD was also funded by LSCCN to undertake evaluative work.
14
15

16
17 **FUNDING:** This work was supported by Lancashire and South Cumbria Cancer Network
18
19 (LSCCN) as part of the National Cancer Awareness and Early Detection initiative (NAEDI)
20
21 funding 'cancer networks supporting primary care'.
22
23
24

25 26 27 **CONTRIBUTIONS:**

28
29 NC recruited participants, carried out interviews, transcribed the interviews, coded the
30
31 transcripts, contributed to the development of the coding framework, and contributed to the
32
33 writing of the manuscript.
34

35
36 GT carried out interviews, coded the transcripts, contributed to the development of the coding
37
38 framework and contributed to the writing of the manuscript.
39

40
41 PD designed the study, collated practice engagement data, contributed to the development of
42
43 the coding of the framework and contributed to the writing of the manuscript.
44
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47 **DATA SHARING:** No further data are available
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Figure 1: organising themes of complexity, continuity and conflict with their associated basic themes, centred around the global theme of managing risk in primary care

For peer review only

Box 1: Semi-structured interview schedule

- Why do you think people with symptoms suggestive of cancer do not present, get seen or diagnosed or referred earlier?
- What do you know about the initiatives that concern the earlier presentation, diagnosis and referral of cancer symptoms?
 - Prompts around specific tools/initiatives/referral criteria
- Have you accessed any local training events concerning the identification, referral of cancer patients?
 - Prompts around specific training attended, and how learning is usually undertaken
- Overall, what is working well in terms of the implementation and use of these initiatives?
- Overall, have you experienced any/or what do you consider to be the main barriers in the implementation/access/use of these various initiatives?
- Are there any practice based issues that may affect the early identification and referral for cancer patients?
 - Prompts around staff and practice issues, communication, administration
- Overall, what do you think local practices could do to help promote and diagnose cancer symptoms?
 - Prompts around team roles and other practice issues
- Do you know about the Lancashire and South Cumbria Cancer Network and what their role is?
 - Prompts around extent of engagement, attitudes and areas for improvement
- What is your opinion concerning the forthcoming ‘access to diagnostics’ initiative (initiative for practices to make direct referrals to diagnostics such as x-rays, CT scans, ultrasound)?
 - Prompts around who should make the referral
- Are there any additional support mechanisms/external to the practice that need to be in place to help with promotion/diagnosis and referral?
- Any further issues or concerns you would like to raise about this work?

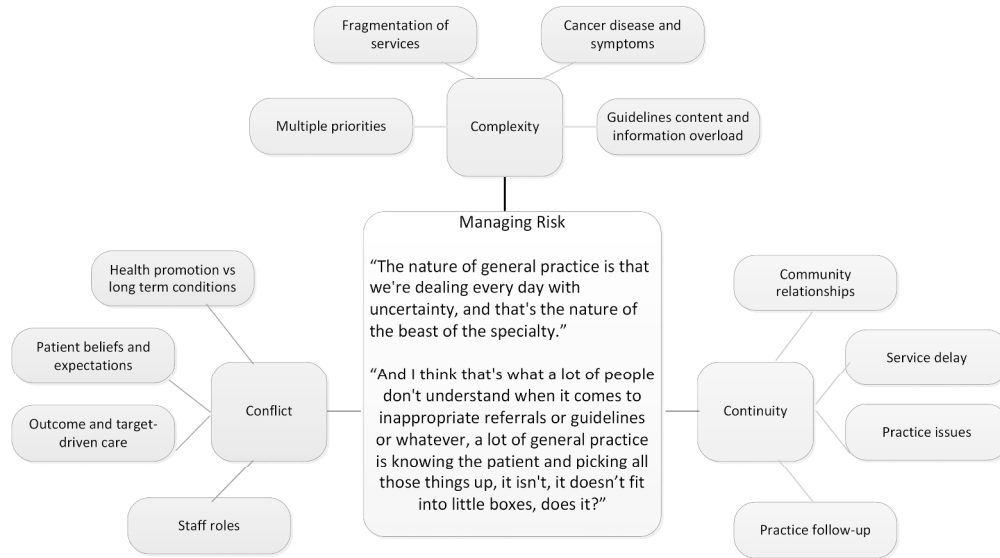


Figure 1: organising themes of complexity, continuity and conflict with their associated basic themes, centred around the global theme of managing risk in primary care
233x130mm (300 x 300 DPI)

review only

BMJ Open

Managing risk in cancer presentation, detection and referral: a qualitative study of primary care staff views

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2014-004820.R2
Article Type:	Research
Date Submitted by the Author:	19-May-2014
Complete List of Authors:	Cook, Neil; University of Central Lancashire, School of Medicine and Dentistry Thomson, Gillian; University of Central Lancashire, School of Health Dey, Maria; University of Central Lancashire, School of Medicine and Dentistry
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Public health, General practice / Family practice
Keywords:	QUALITATIVE RESEARCH, PUBLIC HEALTH, Epidemiology < ONCOLOGY

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8 **Managing risk in cancer presentation, detection and referral: a qualitative study of**
9 **primary care staff views**
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18 Lancashire, Preston, England*
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50
51 **Key Words:** primary health care, general practice, neoplasms, qualitative research, early
52 detection of cancer.
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57 Word count: abstract- 232, manuscript - 4,645
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ABSTRACT

Objectives: In the UK, there have been a number of national initiatives to promote earlier detection and prompt referral of patients presenting to primary care with signs and symptoms of cancer. The aim of the study was to explore the experiences of a range of primary care staff in promoting earlier presentation, detection and referral of patients with symptoms suggestive of cancer.

Setting: Six primary care practices in North West England.

Participants: Thirty-nine primary care staff from a variety of disciplines took part in five group and four individual interviews.

Results: The global theme to emerge from the interviews was ‘managing risk’, which had three underpinning organising themes: ‘complexity’, relating to uncertainty of cancer diagnoses, service fragmentation and plethora of guidelines; ‘continuity’, relating to relationships between practice staff and their patients and between primary and secondary care; ‘conflict’ relating to policy drivers and staff role boundaries. A key concern of staff was that policymakers and those implementing cancer initiatives did not fully understand how risk was managed within primary care.

Conclusion: Primary care staff expressed a range of views and opinions on the benefits of cancer initiatives. National initiatives did not appear to wholly resolve issues in managing risk for all practitioners. Staff were concerned about the number of guidelines and priorities

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3 they were expected to implement. These issues need to be considered by policymakers when
4
5 developing and implementing new initiatives.
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8 9 **ARTICLE SUMMARY**

10 11 12 13 **Strengths and limitations of this study**

- 14
15 • The study investigates the experiences of a range of primary care staff around
16
17 implementing initiatives for the earlier diagnosis of cancer.
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- 20
21 • The underlying concern in primary care is related to managing risk.
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- 23
24 • The sample included a mix of practices with different practice characteristics and
25
26 included those known to be engaged in national and regional initiatives and those who
27
28 were less engaged.
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- 30
31 • The sample was drawn from a single English region.
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INTRODUCTION

Studies in the 1990s showed that UK cancer survival rates were worse than many other European countries, following which there has been two decades of concerted effort to expedite access to proven effective cancer treatments.[1] While there have been improvements in cancer survival latterly, the UK still lags behind other countries with similar health care systems, which may be partly due to later stage of disease at presentation.[2]

Both nationally and internationally, primary care is seen to have a key role in improving cancer survival by reducing delays in diagnosis through promoting earlier presentation and through earlier detection and referral of those with symptoms for further specialist assessment.[3, 4] In the UK, national campaigns extol those with symptoms to see their general practitioner earlier; there are national referral guidelines for suspected cancer and a national system for urgent referral from primary to secondary care (two-week waiting-time initiative).[5] While these appear to have contributed to improved survival, evidence also suggests that there may be further room for improvement:[6] there is practice variation in the use of the ‘two-week’ initiative and some patients are seen several times in primary care before referral.[7-9] A significant proportion of patients also present through emergency routes and have poorer survival.[10]

To further support primary care in the UK, resources were developed and/or disseminated by the Department of Health’s National Awareness and Early Diagnosis Initiative (NAEDI), established in 2008, and the Royal College of General Practitioners (RCGP) including: audit and significant events analysis tools,[7, 8] general practitioner (GP) level cancer profile data, safety netting recommendations and risk assessment tools.[11] Key initiatives have mainly

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3 focused on GPs, but other members of the primary care team may have key roles: an area
4
5 which has been largely unexplored.
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10 A number of international studies have been undertaken in attempts to understand the reasons
11 behind delay in cancer diagnosis. Qualitative studies have mostly focussed on patient
12 perspectives.[12-14] Only a few have explored primary care experiences and these have been
13 mainly limited to decision-making processes or referral pathways [11, 15, 16] and from the
14 perspective of the general practitioner.[3, 11, 15, 16] In order to understand how a range of
15 initiatives across the patient pathway in primary care could be more effective and the role of
16 other members of the practice team, we explored the experiences of a range of primary care
17 staff in supporting earlier presentation, detection and referral of those with symptoms
18 suggestive of cancer. The study was undertaken in one region of England, which at that time
19 was covered by the Lancashire and South Cumbria Cancer Network (LSSCN).
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36 **METHODS**

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40 This was a qualitative descriptive study utilising both individual and group-based interviews.
41
42 It aimed to recruit staff from six practices who were differentially engaged with the national
43 awareness and early diagnosis of cancer agenda. GP practices within LSSCN were stratified
44 into one of three groups at the end of June 2012. High engagers had participated in at least
45 one of the following: RCGP cancer audit, attendance at a course on early diagnosis or face-
46 to-face meetings to discuss GP cancer profiles and action planning. Medium engagers had
47 attended at least one regional meeting about cancer awareness. Low engagers were not
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3 known to have engaged in any initiatives. Of 254 practices in the geographical area, there
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5 were 51 high engagers, 69 medium engagers and 134 low engagers.
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10 Within each group, a random sample of 10 practices were sent a letter about the study,
11
12 followed up with a phone call from the research team one week later. The initial aim was to
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14 recruit at least two practices in each stratum. Due to low uptake within the medium and low
15
16 engager strata, these categories were merged and a random sample of a further 15 practices
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18 sent letters. Practices were offered a choice of either group or individual interviews as it was
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20 recognised that time constraints prevent some practice staff from taking part in group
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22 interviews and some may feel uncomfortable discussing the issues with colleagues. Five
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24 practices agreed to a group interview; with one group interview undertaken in each practice.
25
26 Individual interviews were the preferred method in only one practice: with four interviews
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28 undertaken in this setting.
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34 The semi-structured, audio-recorded interviews, which were attended by two researchers,
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36 occurred between September and October 2012. We recruited three practices in the high
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38 stratum and three practices in the merged medium and low stratum (a mix of low and medium
39
40 engagers). The topic guide is outlined in Box 1. Thirty-nine participants took part in the
41
42 study; 35 took part in one of the five group interviews and four took part in individual
43
44 interviews. Job roles included GP (n=9), receptionist (n=7), nurse (n=6), manager (n=6),
45
46 secretary (n=5), health care assistant (n=3), medical student (n=2) and phlebotomist (n=1). In
47
48 each practice, GPs, other clinical staff and administrative staff were involved in the
49
50 interviews. Practice characteristics are shown in table 1.
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Table 1: Practice and interview characteristics

Practice characteristic	No. of practices
No of partners	
4 or more	3
3 or less	3
Deprivation Quintile*	
5 or 4 (more deprived)	3
2 or 3	3
1 (most affluent)	0
Population Density**	
<15%	2
15 to 39%	2
>=40%	2

*based on index of multiple deprivation of practice location 2010 (source: Department for Communities and Local Government, Indices of Deprivation 2010)

** Person per hectare based on practice location (source: ONS Neighbourhood Statistics)

Further detail at practice level is not presented due to the level of confidentiality agreed with our participants.

The interviews took between 38 and 67 minutes to complete, and between four and eleven staff took part in each practice. All transcribed data were entered into NVivo 10 and analysed using a Thematic Network Analysis approach.[17] This involved an iterative and cyclical process of reading and analysis to identify basic, organising and global themes within the dataset. Analysis was undertaken by two authors (GT and NC) independently on six transcripts initially, followed by an in-depth discussion and consensual validation of key themes. A further cycle of independent and collaborative analysis was then undertaken on a further sub-set of transcripts to ensure rigour and authenticity of the themes generated. All thematic decisions were discussed with the third author (PD). The study was approved by the

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3 University of Central Lancashire 'STEMH' ethics committee and individual written informed
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5 consent was obtained from all participants.
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8 9 **RESULTS**

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14 Overall, practice staff were well aware of the two-week waiting-time initiative and had good
15
16 knowledge about the national 'Be Clear on Cancer' cancer awareness public campaigns, but
17
18 had less awareness about other initiatives specifically targeted at primary care. The key
19
20 global theme to emerge from the interviews related to 'managing risk' within primary care:
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25 *"It's quite a tricky, nebulous area [...]. The nature of general practice is that we're*
26
27 *dealing every day with uncertainty..."* (Interview 6, Participant 3)
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32 A key concern of staff was that policymakers and those implementing cancer initiatives did
33
34 not fully understand how risk was managed within primary care. Cancer was only one
35
36 priority and there was an abundance of initiatives for a variety of conditions which primary
37
38 care staff were expected to implement. Three underpinning organising themes (and
39
40 associated basic themes) of 'complexity', 'continuity' and 'conflict' highlighted the tensions
41
42 and difficulties that primary care face in managing the risk of early detection and referral for
43
44 cancer symptoms whilst dealing with complex symptoms and care systems, patient-led
45
46 factors and target-focused care. An overview of the organising and basic themes is presented
47
48 in figure 1. These themes are described and discussed, contextualised by participant quotes
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50 below.
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56 **Complexity**
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3 This theme highlighted the complexity of managing risk in early cancer diagnosis because of
4
5 external factors including cancer symptom differentiation and the restrictions imposed by
6
7 referral criteria; the multitude of services and professionals involved in diagnostic and
8
9 assessment services and the plethora of policies and initiatives targeted at primary care
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11 practice.
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16 *Cancer disease and symptoms:* Cancer diagnosis was an important priority area in primary
17
18 care but diagnosis presented complex challenges. Cancer was a rare diagnosis in primary
19
20 care although symptoms associated with cancer were common.
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25 *“We get lots of sore throats, and yet we get one tonsillar cancer every three [years] so*
26
27 *sorting out the wheat from the chaff is a real challenge.” (Interview 3, Participant 3)*
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31
32 These complexities of diagnosis were compounded by what were considered rigid referral
33
34 criteria, based on disease prevalence amongst those with symptoms, which led to cases being
35
36 ‘*bounced back*’ if they failed to meet diagnostic criteria. In attempts to manage what they
37
38 considered was a risk to patients, some participants said, on occasion, they had to ‘*fudge*’,
39
40 ‘*embellish*’ or ‘*bend-the-rules*’ to ensure assessment of patients for whom they had concerns:
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45 *“Even though it says on the form, “don't fill out this form unless they tick any boxes”*
46
47 *but you find a box to tick, and usually for very good reason. And I think you'd only go*
48
49 *slightly over egging the presentation if you were pretty sure there was something*
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51 *there, something going on.” (Interview 4, Participant 4)*
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3 *Fragmentation and access to diagnostic services:* Primary care staff expressed difficulties
4
5 accessing diagnostic services due to on-going service re-configurations and the involvement
6
7 of multiple agencies. This led to fragmentation in terms of staff not always knowing who, or
8
9 to which services, referrals could be made.
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14 There were also some concerns about fragmented relationships between primary and
15
16 secondary care with several participants feeling frustrated by restricted access to diagnostics
17
18 for certain conditions. Some participants considered this was due to *'empire building'* by
19
20 professionals justifying and *'preserving'* their service by retaining ownership of who was
21
22 qualified to make referrals:
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26
27 *"I can send people for a CT scan if I have a concern about them, for some conditions,*
28
29 *but not others. Well why not? I'm the one who's initiating the referral in the first*
30
31 *place. You trust me to initiate the referral to pick the patient and prepare them so that*
32
33 *you can come along and just arrange the scan and look at it."* (Interview 4,
34
35
36 Participant 3)
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41 Whilst some GPs wanted more direct access to diagnostics, this was not universal, and others
42
43 highlighted the need for *'training'* prior to referrals being made.
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48 *Guidelines content and information overload:* Participants referred to the usefulness of
49
50 guidelines to help symptom differentiation and manage risk. Knowledge was felt to be
51
52 experientially derived and referral guidelines only considered useful for less experienced
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54 doctors. Risk assessment tools were occasionally considered unnecessarily complex when
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3 patients had ‘red flag’ symptoms and, as previously mentioned, sometimes restrictive for use
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5 in primary care:
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10 *“I mean, you see, from a GPs point of view, if somebody comes in who is fifty-five*
11 *years of age, and passes blood in his stool, you need to exclude a cancer. Now, I don’t*
12 *want to know how many percentage of those people pass blood in the motion will*
13 *have cancer, or how many will have piles, or inflammatory bowel disease or what*
14 *have you.”* (Interview 4, Participant 3)
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23 Concerns were expressed about the number of guidelines available for different conditions
24 and inconsistencies between different sources:
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29 *“And that’s the problem ‘cause last year there was a big campaign, “if you have a*
30 *cough for more than three weeks you need to go and see a doctor”, but NICE*
31 *guidelines is six weeks.”* (Interview 6, Participant 4)
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39 Participants described how the ‘tsunami’ of new guidelines, care plans and initiatives meant it
40 was difficult to keep up-to-date:
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45 *“And I thought ‘that’s probably a squamous cell carcinoma. That needs a two-week*
46 *wait referral’. Then, I actually checked the guidelines, the guidelines say that “it’s got*
47 *to be over one centimetre and you’ve got to wait more than eight weeks really for it to*
48 *grow” etcetera, etcetera [...] and those things will change on a regular basis. Now,*
49 *how do you expect an entire network of primary care physicians to stay current with*
50 *all those guidelines and apply them religiously?”* (Interview 2, Participant 3).
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5 Continuity
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7 Practice staff expressed concern that a lack of continuity increased the risk of missing
8 diagnoses and/or supporting the patient through a difficult period. This was highlighted
9 through discussions about relationships between patients and clinicians; delays in information
10 sharing across the primary and secondary care interface and patient follow-up after initial
11 consultation.
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21 *Patient-practice relationships:* Continuity-of-carer could not always be achieved in practice,
22 even though it was felt that patients preferred it and its absence was thought to possibly
23 contribute to diagnostic delay:
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30 *“People have been hopping around from one clinician to another and that, and you*
31 *don't see the evolution of the story until it hits you in the face. Patients book on the*
32 *day, they don't necessarily get in the person they normally see, they get in with the*
33 *available, so that can disjoint things.” (Interview 3, Participant 4)*
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40 Staff felt that smaller, rural practices had closer relationships with their patients and their
41 community, which would lead to earlier consultation. However, others felt awareness of
42 cancer deaths was heightened in close-knit communities, which could reinforce negative
43 views towards cancer and cancer survivorship amongst the local population and delay access
44 to services.
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54 *Primary care and secondary care interface:* Expedited assessment following GP referral of
55 patients through the two-week wait initiative was perceived to work well by practice staff,
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3 but delays further on in the assessment process, and outside of primary care control, were felt
4
5 to put patients at risk again and exacerbated their concerns:
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10 *“And, well, it's very difficult from our point of view, ‘cause we're saying, ‘look, you*
11 *know this may be nothing serious, however, I want to refer you on the system, you'll*
12 *get an appointment in two weeks”, and they do get seen, but then there's a massive*
13 *delay, so, you know, then they're kinda all heightened up because they're thinking,*
14 *“{whispered} the doctor thinks I've got cancer” and then nothing happens for ages,*
15 *and it's really hard for the patients.”* (Interview 3, Participant 5)
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25 *Practice-based follow-up:* Patients themselves were also considered to cause delays if they
26 failed to attend. Practices debated the extent to which they should chase these patients up and
27 the risks if they did not:
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34 *“In the back of their mind they know they should, but if they face the fact that they're*
35 *going back, are they are going to be faced with something else? You also have to be*
36 *responsible for the fact that if that doesn't stop, you must persist, and accept the fact*
37 *that, if you don't, then you could, somewhere down the line end up with something so*
38 *serious that it's only going to be palliative.”* (Interview 2, Participant 1)
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48 Conflict

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50 Within this theme, managing risk was related to primary care focus on targets; conflicting
51 opinions about the role of non-clinical staff and about the worries and tensions generated by
52 cancer awareness campaigns.
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3 *Prevention versus target driven care:* Primary care staff considered cancer a public health
4
5 priority but some felt that there was a tension between adopting preventative approaches in
6
7 the practice such as promoting cancer awareness and early presentation and the way that
8
9 primary care is currently funded through achieving specific targets mainly relating to the
10
11 management of long-term conditions (Quality and Outcomes Framework):
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16 *“We’re not as good with public health, with local public health initiatives, as maybe*
17
18 *we should be necessarily. It’s just time to do things, and those things aren’t required*
19
20 *of our core business, and when you have a very detailed contract that tells you what*
21
22 *you will be paid for doing” (Interview 2, Participant 3)*
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27 *Staff roles:* There were conflicting views around the role of other practice staff in managing
28
29 the risk of cancer detection and awareness, in particular with regard to reception staff. Some
30
31 staff viewed the reception role as a health advisor, whereas others perceived their role to be
32
33 purely administrative. Additionally, there were reservations about the ability of reception
34
35 staff to relay cancer messages and how the public might feel about receiving health
36
37 information from them:
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43 *“You’re passing clinical responsibility to people who are non-clinical. It’s alright for*
44
45 *patients to speak to them, and that’s fine, but, I’m not gonna use the receptionists as a*
46
47 *source of information [...]. I think anything clinical should be passed to the doctor*
48
49 *full stop. I don’t think there is any other role for the receptionist.” (Interview 4,*
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51 *Participant 3)*
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3 There were also concerns about potential litigation issues if reception staff were to give
4
5 advice and how this could impact on the practice:
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10 *“I think it's also worth mentioning at this point, because of our roles, how they are,*
11 *we get a lot of patients not happy about us supplying information, because we're not*
12 *allowed to diagnose, obviously for obvious reasons, but if you was to imply*
13 *something, that could come back on us twice as hard because you'd implied*
14 *something that could be wrong, and therefore it is now your fault.”* (Interview 1,
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21 Participant 1)
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25 A further issue associated with staff roles in helping to manage risk was the identified
26
27 benefits of having a chain of communication between all practice members. For example,
28
29 receptionists being able to ‘raise issues’ with the doctor if they know someone is coming in
30
31 who has symptoms the doctor should be aware of but the patient ‘may not say anything’. This
32
33 can also work the other way:
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38 *“Patients that I worry about, I will leave messages. I'll mention to reception or*
39 *mention to people that I want to follow them up.”* (Interview 6, Participant 3)
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46 Others felt that the focus on the long-term conditions might provide opportunities for practice
47
48 nurses to be more involved as they were often seeing patients who might be at higher risk of
49
50 cancer because of their age, disease condition or lifestyle behaviours:
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54 *“Chronic disease, yeah, so diabetic, high blood pressure, chronic kidney disease,*
55 *asthma, most patients will come and see the practice nurses for routine bloods, blood*
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3 *pressure, weight, everything like that. So often, GPs don't always see them, I mean*
4
5 *they do the medication reviews, but, we flag to them anything that we're worried*
6
7 *about.” (Interview 2, Participant 4)*
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12 Some could also see a role for members of the wider practice team:

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16 *“We'd say 'well who are the district nurses already going out to?' You know, you can*
17
18 *work with your local pharmacists.” (Interview 2, Participant 2)*
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23 *Cancer awareness:* Although cancer fear was commonly acknowledged, staff were divided as
24
25 to whether patients were afraid to consult the GP with cancer symptoms. Some felt that
26
27 unhealthy lifestyle choices contributed to patient reluctance to present with cancer symptoms:
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31
32 *“The cancers where they feel that they may have contributed to it, like smoking, they*
33
34 *tend to ignore because they don't want to be told that it may be their fault in a certain*
35
36 *way, and they don't want to give up the lifestyle.” (Interview 6, Participant 4)*
37
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41 Cancer awareness campaigns were felt to be important, even though those who presented to
42
43 the practice following the campaign were more likely to be those at least risk:
44
45

46
47 *“It's the people who never come to the doctors that you want to hit, not the people*
48
49 *that were already coming in anyway, and they tend to be ones that see those adverts.*
50
51 *But then if you can get one person who wouldn't normally come in and you catch*
52
53 *them, then it's better.” (Interview 5, Participant 1)*
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3 Campaigns were also felt to create extra work for all practice members. There were
4
5 complaints that cancer awareness campaigns tend to run without consideration of other local
6
7 or national campaigns which may be running simultaneously which increased the risk that
8
9 practice capacity to safely respond to patients was compromised:
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14 *“It's like it's alright saying putting in place to get them in, but it's the sheer volume,*
15
16 *isn't it? You can only cope with so much can't you?”* (Interview 5, Participant 1)
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23 **DISCUSSION**

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27 This study provides insights into the experiences of primary care staff who manage patients
28
29 with symptoms associated with cancer. The overarching theme that emerged was the need to
30
31 manage risk so that cancer patients had a timely diagnosis and were assessed appropriately.
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33 The associated subthemes of complexity, continuity and conflict highlighted the tensions and
34
35 difficulties faced by staff when attempting to manage these risks in modern practice.
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41 The study was small, descriptive and exploratory. However, it covered a diverse geographical
42
43 area and included practices with varying levels of engagement with awareness and early
44
45 diagnosis initiatives. We undertook stratified sampling of the practices to ensure we had a
46
47 balance of perspectives so as to better inform policymakers of the possible barriers and
48
49 drivers to the uptake of initiatives. The stratification was based on known engagement with a
50
51 range of national and regional initiatives to promote earlier presentation, detection and
52
53 referral of patients with symptoms suggestive of cancer available to the practices at that time.
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3 The findings of our study suggest that national initiatives did not appear to wholly resolve
4 issues around managing risk for all practitioners. Rather, in some cases, these initiatives
5 were felt to introduce inherent risks which staff had to find ways to overcome. For example,
6 national cancer awareness campaigns were felt to be very important to encourage patients
7 who would otherwise delay diagnosis. However, as these campaigns appeared to increase
8 consultation rates from those at lesser risk, this was perceived to place additional burden on
9 the practice.
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21 There were also concerns amongst our participants about practice-based initiatives. The
22 International Cancer Benchmarking Partnership observed lower survival rates in Denmark
23 and the UK compared to other countries in their study, and raised concerns about the role of
24 primary care gatekeeping in delayed diagnosis.[2] This observation appears to be supported
25 by a wider study of European countries which also demonstrated lower cancer survival in
26 those with primary care based gatekeeper systems.[18] Primary care gatekeeping may reduce
27 the burden on specialist care but may also contribute to diagnostic delay through the
28 restriction of access to these services. In the UK, national referral guidelines and the two-
29 week waiting-time initiative should help alleviate this problem for those with symptoms
30 associated with cancer. Participants in our study considered that timely diagnosis was as an
31 essential part of their role in cancer care. An Australian study had a similar finding,[16] but
32 highlighted that the resources spent gaining timely access to specialist opinion were a major
33 issue for their practitioners. In our study this was universally considered less of a problem
34 because of the two-week waiting-time initiative, but concerns were expressed that lack of
35 direct access to diagnostic investigations and poor communication between primary and
36 secondary care put patients at risk of extended delays. Similar concerns were reported in a
37 study undertaken in Ireland.[3] Some participants in our study felt that the referral criteria for
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3 the two-week waiting-time initiative were too restrictive. This led to practitioners, on
4
5 occasion, subverting the referral system to ensure that patients they considered were at risk,
6
7 but who did not fit the referral criteria, could be assessed in a timely manner. Such concerns
8
9 are not unfounded; one study has shown that 8% of patients felt by GPs to have cancer, but
10
11 who did not have symptoms which fit referral criteria for cancer, were subsequently
12
13 diagnosed with cancer.[19] This may be because the presenting signs and symptoms had a
14
15 lower predictive value for cancer than those included in the guidelines. Nevertheless, there is
16
17 high compliance with guidelines and some limited evidence that referral guidelines
18
19 contribute, in part, to diagnostic delay reduction.[6, 19]
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25 Diagnostic errors leading to primary care malpractice claims are common.[20] Researchers
26
27 suggest that although GPs are more likely to correctly diagnose patients with cancer than
28
29 miss cases, there are a disproportionate number of deaths amongst the latter.[21,22]
30
31 Diagnostic complexity is compounded by the frequency of consultations for symptoms
32
33 associated with cancer,[22, 23] a fear highlighted by practitioners in this study. A study in
34
35 Norway, which followed up patients presenting with cancer warning signs to their GP,
36
37 suggests that patients with cancer may be missed if multiple warning signs and symptoms are
38
39 not considered.[22] Retrospective studies of practice-based data have identified
40
41 combinations of warning signs and symptoms which may be associated with increasing
42
43 likelihood of cancer.[24-25] These have been used to inform risk assessment tools to aid
44
45 decision-making, with algorithms and probabilities of risk based on demographic
46
47 characteristics, lifestyle factors, symptoms and/or attendance frequency.[11] Some have been
48
49 disseminated nationally, and there is evidence from both quantitative and qualitative studies
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51 that they affect GPs' decisions to refer.[11] However, in our study, some participants had
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53 similar concerns about these tools as they did about guidelines. A recent analysis of
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3 significant event audits in lung cancer highlighted how cancer can mimic other diagnoses and
4 have atypical presentation.[7] Guidelines and risk assessment tools are analytical tools, and
5
6 although statistical probabilities are based on uncertainty, some participants in our study felt
7 they may introduce a level of certainty which fails to encapsulate practitioners' tacit concerns
8 about patients. Previous work in primary care decision-making has emphasised the analytical
9 over the experiential, but recent research , including in cancer diagnosis, suggests that
10 experiential knowledge may have a role and may be more responsive to the patient as a
11 person.[15, 26-28] Others have found that better diagnostic decisions about urgent referrals
12 appear to be made by older doctors [23] and, as commented on by some of our participants,
13 that guidelines and risk assessment tools may be more useful for newer practitioners who
14 have yet to develop problem solving strategies.[29]
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29 It has also been observed that, unlike in acute care, decision-making in primary care partly
30 involves an understanding of the patient context and perspective.[30] Our study participants
31 highlighted concerns that lack of continuity of carer may lead to diagnostic delays. Relational
32 continuity was felt to be a particular problem in larger practices and urban settings. Other
33 studies suggest that fragmentation of primary care and shorter consultation times has led to a
34 lack of continuity-of-care or carer, which may hinder early diagnosis as cancer presentation
35 can be complex in those with co-morbidities.[16, 31, 32] In a qualitative study of lung cancer
36 patients in New Zealand, patients felt that not always seeing the same GP could lead to delays
37 in diagnosis due to poor follow up.[33] In a study in Denmark, the authors suggest that
38 perceived lack of accessibility and doctor-patient relationship were associated with patient
39 delay in seeking advice about cancer symptoms.[34] Others have found that confidence and
40 trust in a doctor were more important predictors of cancer detection than ease of access and
41 choice of preferred doctor.[35]
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5 In our study, participants highlighted how other practice team members, such as nurses who
6 are in more regular contact with patients with long-term conditions, could raise symptom
7 awareness or be more alert to symptoms suggestive of cancer. In the US and Canada, patient
8 navigators are being used to support patients through the complex systems found in cancer
9 management and care.[36] It has also been suggested that these roles could be extended to
10 support patients during the diagnostic, referral and assessment processes and ensure
11 appropriate follow up of investigations.[37] In our study, some staff felt that receptionists
12 could act as navigators in terms of directing patients with symptoms to see the GP. Low
13 levels of knowledge about some cancer symptoms has been demonstrated in non-medical
14 staff.[38] However, our study highlighted that professional boundaries and concerns about
15 litigation might impede such initiatives. Disclosures or discussions of diagnostic issues
16 within a public reception location also raised ethical concerns. Research within primary care
17 suggests that facilitation of communities of practice and interdisciplinary knowledge sharing
18 may help to identify the role of other practice team members in promoting earlier cancer
19 presentation and diagnosis;[39] although training needs should be addressed.[38]
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41 This study has highlighted that a 'one-size-fits-all' approach to implementing initiatives is
42 unlikely to succeed as practitioners expressed a range of views and opinions on the benefits
43 of different initiatives. Lack of implementation of initiatives in primary care is not always
44 because of resistance to the initiatives themselves, but sometimes because of the sheer
45 number across a range of priority areas that practices are expected to implement, often
46 simultaneously. Policymakers should consider more carefully how these impact on primary
47 care, how they can be embedded into practice systems and emphasise and exploit synergies
48 with other disease conditions.
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5 For there to be greater success of initiatives aimed at promoting earlier presentation, detection
6 and referral in primary care, there needs to be further work on understanding how primary
7 care manage risk in the face of inherent uncertainty, organisational changes and competing
8 priorities.
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18 **ACKNOWLEDGEMENTS:** Our thanks to the practices who participated in this study and
19 to the staff of the Lancashire and South Cumbria Cancer Network who assisted us.
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25 **COMPETING INTERESTS:** PD was public health lead for LSCCN and NC is part-funded
26 by a grant from LSCCN; PD was also funded by LSCCN to undertake evaluative work.
27
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31
32 **FUNDING:** This work was supported by Lancashire and South Cumbria Cancer Network
33 (LSCCN) as part of the National Cancer Awareness and Early Detection initiative (NAEDI)
34 funding 'cancer networks supporting primary care'.
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39 40 **CONTRIBUTIONS:**

41
42 NC recruited participants, carried out interviews, transcribed the interviews, coded the
43 transcripts, contributed to the development of the coding framework, and contributed to the
44 writing of the manuscript.
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47

48
49 GT carried out interviews, coded the transcripts, contributed to the development of the coding
50 framework and contributed to the writing of the manuscript.
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53
54 PD designed the study, collated practice engagement data, contributed to the development of
55 the coding of the framework and contributed to the writing of the manuscript.
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5 **DATA SHARING:** No further data are available
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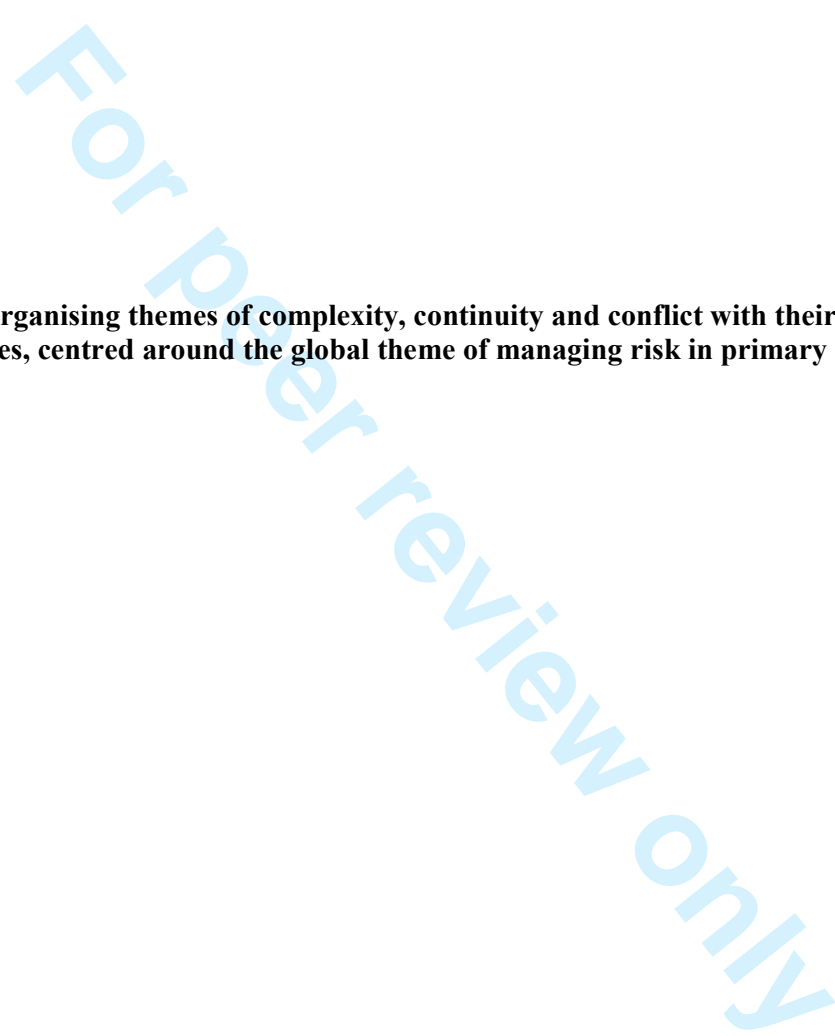
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23 **Figure 1: organising themes of complexity, continuity and conflict with their associated**
24 **basic themes, centred around the global theme of managing risk in primary care**
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Box 1: Semi-structured interview schedule

- Why do you think people with symptoms suggestive of cancer do not present, get seen or diagnosed or referred earlier?
- What do you know about the initiatives that concern the earlier presentation, diagnosis and referral of cancer symptoms?
 - Prompts around specific tools/initiatives/referral criteria
- Have you accessed any local training events concerning the identification, referral of cancer patients?
 - Prompts around specific training attended, and how learning is usually undertaken
- Overall, what is working well in terms of the implementation and use of these initiatives?
- Overall, have you experienced any/or what do you consider to be the main barriers in the implementation/access/use of these various initiatives?
- Are there any practice based issues that may affect the early identification and referral for cancer patients?
 - Prompts around staff and practice issues, communication, administration
- Overall, what do you think local practices could do to help promote and diagnose cancer symptoms?
 - Prompts around team roles and other practice issues
- Do you know about the Lancashire and South Cumbria Cancer Network and what their role is?
 - Prompts around extent of engagement, attitudes and areas for improvement
- What is your opinion concerning the forthcoming ‘access to diagnostics’ initiative (initiative for practices to make direct referrals to diagnostics such as x-rays, CT scans, ultrasound)?
 - Prompts around who should make the referral
- Are there any additional support mechanisms/external to the practice that need to be in place to help with promotion/diagnosis and referral?
- Any further issues or concerns you would like to raise about this work?

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11 **Managing risk in cancer presentation, detection and referral: a qualitative study of**
12 **primary care staff views**
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19 Neil Cook, Research Assistant, School of Medicine and Dentistry, University of Central
20 Lancashire, Preston, England*

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25 Gillian Thomson, Senior Research Fellow, School of Health, University of Central
26 Lancashire, Preston, England

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31 Paola Dey, Professor of Public Health Epidemiology, School of Medicine and Dentistry,
32 University of Central Lancashire, Preston, England

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43 Email: NCook2@uclan.ac.uk Phone: 01772 893409
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48 **Key Words:** primary health care, general practice, neoplasms, qualitative research, early
49 detection of cancer.
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54 | Word count: abstract- 232, manuscript - [4,504,645](#)
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ABSTRACT

Objectives: In the UK, there have been a number of national initiatives to promote earlier detection and prompt referral of patients presenting to primary care with signs and symptoms of cancer. The aim of the study was to explore the experiences of a range of primary care staff in promoting earlier presentation, detection and referral of patients with symptoms suggestive of cancer.

Setting: Six primary care practices in North West England.

Participants: Thirty-nine primary care staff from a variety of disciplines took part in five group and four individual interviews.

Results: The global theme to emerge from the interviews was 'managing risk', which had three underpinning organising themes: 'complexity', relating to uncertainty of cancer diagnoses, service fragmentation and plethora of guidelines; 'continuity', relating to relationships between practice staff and their patients and between primary and secondary care; 'conflict' relating to policy drivers and staff role boundaries. A key concern of staff was that policymakers and those implementing cancer initiatives did not fully understand how risk was managed within primary care.

Conclusion: Primary care staff expressed a range of views and opinions on the benefits of cancer initiatives. National initiatives did not appear to wholly resolve issues in managing risk for all practitioners. Staff were concerned about the number of guidelines and priorities

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6 they were expected to implement. These issues need to be considered by policymakers when
7
8 developing and implementing new initiatives.
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10 11 12 **ARTICLE SUMMARY** 13

14 15 16 **Strengths and limitations of this study** 17

- 18 • The study investigates the experiences of a range of primary care staff around
19 implementing initiatives for the earlier diagnosis of cancer.
20
- 21 • The underlying concern in primary care is related to managing risk.
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- 23 • The sample included a mix of practices with different practice characteristics and
24 included those known to be engaged in national and regional initiatives and those who
25 were less engaged.
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- 27 • The sample was drawn from a single English region.
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INTRODUCTION

Studies in the 1990s showed that UK cancer survival rates were worse than many other European countries, following which there has been two decades of concerted effort to expedite access to proven effective cancer treatments.[1] While there have been improvements in cancer survival latterly, the UK still lags behind ~~many~~ other countries with similar health care systems, which may be partly due to later stage of disease at presentation. [2]

Both nationally and internationally, primary care is seen to have a key role in improving cancer survival by reducing delays in diagnosis through promoting earlier presentation and through earlier detection and referral of those with symptoms for further specialist assessment.[3, 4] In the UK, national campaigns extol those with symptoms to see their general practitioner earlier; there are national referral guidelines for suspected cancer and a national system for urgent referral from primary to secondary care (two-week waiting-time initiative).[5] While these appear to have contributed to improved survival However, evidence also suggests that there may be further room for improvement:[6] there is practice variation in the use of the ‘two-week’ initiative and some patients are seen several times in primary care before referral.[7-9] A significant proportion of patients also present through emergency routes and have poorer survival.[10]

To further support primary care in the UK, resources were developed and/or disseminated by the Department of Health’s National Awareness and Early Diagnosis Initiative (NAEDI), established in 2008, and the Royal College of General Practitioners (RCGP) including: audit and significant events analysis tools,[7, 8] general practitioner (GP) level cancer profile data,

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7 safety netting recommendations and risk assessment tools.[11] Key initiatives have mainly
8 focused on GPs, but other members of the primary care team may have key roles: an area
9 which has been largely unexplored.
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14 A number of international studies have been undertaken in attempts to understand the reasons
15 behind delay in cancer diagnosis. Qualitative studies have mostly focussed on patient
16 perspectives.[12-14] Only a few have explored primary care experiences and these have been
17 mainly limited to decision-making processes or referral pathways [11, 15, 16] and from the
18 perspective of the general practitioner.-[3, 11, 15, 16] In order to understand how a range of
19 initiatives across the patient pathway in primary care could be more effective and the role of
20 other members of the practice team, we explored the experiences of a range of primary care
21 staff in supporting earlier presentation, detection and referral of those with symptoms
22 suggestive of cancer. The study was undertaken in one region of England, which at that time
23 was covered by the Lancashire and South Cumbria Cancer Network (LSCCN).
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37 **METHODS**

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41 This was a qualitative descriptive study utilising both individual and group-based interviews.
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43 It aimed to recruit staff from six practices who were differentially engaged with the national
44 awareness and early diagnosis of cancer agenda. GP practices within LSCCN were stratified
45 into one of three groups at the end of June 2012. High engagers had participated in at least
46 one of the following: RCGP cancer audit, attendance at a course on early diagnosis or face-
47 to-face meetings to discuss GP cancer profiles and action planning. Medium engagers had
48 attended at least one regional meeting about cancer awareness. Low engagers were not
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7 known to have engaged in any initiatives. Of 254 practices in the geographical area, there
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9 were 51 high engagers, 69 medium engagers and 134 low engagers.

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12 Within each group, a random sample of 10 practices were sent a letter about the study,
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14 followed up with a phone call from the research team one week later. The initial aim was to
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16 recruit at least two practices in each stratum. Due to low uptake within the medium and low
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18 engager strata, these categories were merged and a random sample of a further 15 practices
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20 sent letters. Practices were offered a choice of either group or individual interviews as it was
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22 recognised that time constraints prevent some practice staff from taking part in group
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24 interviews and some may feel uncomfortable discussing the issues with colleagues. [Five](#)
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26 [practices agreed to a group interview; with one group interview was undertaken in each](#)
27
28 [practice.](#) Individual interviews were the preferred method in only one practice: [with four](#)
29
30 [interviews were undertaken in this setting practice.](#)

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32 ~~Interviews (group and individual) were held on only one occasion in each practice.~~

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36 ~~Six practices agreed to take part in~~ The semi-structured, audio-recorded interviews, which
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38 were attended by two researchers, [occurred](#) between September and October 2012. We
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40 recruited three practices in the high stratum and three practices in the merged medium and
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42 low stratum (a mix of low and medium engagers). The topic guide is outlined in Box 1.

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44 Thirty-nine participants took part in [group \(n=5\) or individual \(n=4\) the study; 35 took part in](#)
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46 [one of the five group interviews and four took part in individual](#) interviews. Job roles
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48 included GP (n=9), receptionist (n=7), nurse (n=6), manager (n=6), secretary (n=5), health
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50 care assistant (n=3), medical student (n=2) and phlebotomist (n=1). [Within In each practice,](#)
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52 [GPs, other clinical staff and administrative staff were involved in the interviews.](#) Practice
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54 characteristics are shown in table 1.

Table 1: Practice and interview characteristics

Practice characteristic	No. of practices
No of partners	
4 or more	3
3 or less	3
Deprivation Quintile*	
5 or 4 (more deprived)	3
2 or 3	3
1 (most affluent)	0
Population Density**	
<15%	2
15 to 39%	2
>=40%	2

*based on index of multiple deprivation of practice location 2010 (source: Department for Communities and Local Government, Indices of Deprivation 2010)

** Person per hectare based on practice location (source: ONS Neighbourhood Statistics)

[Further detail at practice level is not presented due to the level of confidentiality agreed with our participants.](#)

~~[we are unable to present further detail at practice level.](#)~~

The interviews took between 38 and 67 minutes to complete, and between four and eleven staff took part in each practice. All transcribed data were entered into NVivo 10 and analysed using a Thematic Network Analysis approach.[17] This involved an iterative and cyclical process of reading and analysis to identify basic, organising and global themes within the dataset. Analysis was undertaken by two authors (GT and NC) independently on six transcripts initially, followed by an in-depth discussion and consensual validation of key themes. A further cycle of independent and collaborative analysis was then undertaken on a further sub-set of transcripts to ensure rigour and authenticity of the themes generated. All thematic decisions were discussed with the third author (PD). The study was approved by the

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7 University of Central Lancashire 'STEMH' ethics committee and individual written informed
8 consent was obtained from all participants.
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10 11 12 **RESULTS** 13

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16 Overall, practice staff were well aware of the two-week waiting-time initiative and had good
17 knowledge about the national 'Be Clear on Cancer' cancer awareness public campaigns, but
18 had less awareness about other initiatives specifically targeted at primary care. The key
19 global theme to emerge from the interviews related to 'managing risk' within primary care:
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26 *"It's quite a tricky, nebulous area [...]. The nature of general practice is that we're*
27 *dealing every day with uncertainty..."* (Interview 6, Participant 3)
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31 A key concern of staff was that policymakers and those implementing cancer initiatives did
32 not fully understand how risk was managed within primary care. Cancer was only one
33 priority and there was an abundance of initiatives for a variety of conditions which primary
34 care staff were expected to implement. Three underpinning organising themes (and
35 associated basic themes) of 'complexity', 'continuity' and 'conflict' highlighted the tensions
36 and difficulties that primary care face in managing the risk of early detection and referral for
37 cancer symptoms whilst dealing with complex symptoms and care systems, patient-led
38 factors and target-focused care. An overview of the organising and basic themes is presented
39 in figure 1. These themes are described and discussed, contextualised by participant quotes
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53 Complexity
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7 This theme highlighted the complexity of managing risk in early cancer diagnosis because of
8 external factors including cancer symptom differentiation and the restrictions imposed by
9 referral criteria; the multitude of services and professionals involved in diagnostic and
10 assessment services and the plethora of policies and initiatives targeted at primary care
11 practice.
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18 *Cancer disease and symptoms:* Cancer diagnosis was an important priority area in primary
19 care but diagnosis presented complex challenges. Cancer was a rare diagnosis in primary
20 care although symptoms associated with cancer were common.
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26 *“We get lots of sore throats, and yet we get one tonsillar cancer every three [years] so*
27 *sorting out the wheat from the chaff is a real challenge.”* (Interview 3, Participant 3)
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31 These complexities of diagnosis were compounded by what were considered rigid referral
32 criteria, based on disease prevalence amongst those with symptoms, which led to cases being
33 ‘bounced back’ if they failed to meet diagnostic criteria. In attempts to manage what they
34 considered was a risk to patients, some participants said, on occasion, they had to ‘fudge’,
35 ‘embellish’ or ‘bend-the-rules’ to ensure assessment of patients for whom they had concerns:
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43 *“Even though it says on the form, “don't fill out this form unless they tick any boxes”*
44 *but you find a box to tick, and usually for very good reason. And I think you'd only go-*
45 *slightly over egging the presentation if you were pretty sure there was something*
46 *there, something going on.”* (Interview 4, Participant 4)
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7 *Fragmentation and access to diagnostic services:* Primary care staff expressed difficulties
8 accessing diagnostic services due to on-going service re-configurations and the involvement
9 of multiple agencies. This led to fragmentation in terms of staff not always knowing who, or
10 to which services, referrals could be made.
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16 There were also some concerns about fragmented relationships between primary and
17 secondary care with several participants feeling frustrated by restricted access to diagnostics
18 for certain conditions. Some participants considered this was due to *'empire building'* by
19 professionals justifying and *'preserving'* their service by retaining ownership of who was
20 qualified to make referrals:
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28 *"I can send people for a CT scan if I have a concern about them, for some conditions,*
29 *but not others. Well why not? I'm the one who's initiating the referral in the first*
30 *place. You trust me to initiate the referral to pick the patient and prepare them so that*
31 *you can come along and just arrange the scan and look at it."* (Interview 4,
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35 Participant 3)
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39 Whilst some GPs wanted more direct access to diagnostics, this was not universal, and others
40 highlighted the need for *'training'* prior to referrals being made.
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45 *Guidelines content and information overload:* Participants referred to the usefulness of
46 guidelines to help symptom differentiation and manage risk. Knowledge was felt to be
47 experientially derived and referral guidelines only considered useful for less experienced
48 doctors. Risk assessment tools were occasionally considered unnecessarily complex when
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6 patients had 'red flag' symptoms and, as previously mentioned, sometimes restrictive for use
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8 in primary care:
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12 *"I mean, you see, from a GPs point of view, if somebody comes in who is fifty-five*
13 *years of age, and passes blood in his stool, you need to exclude a cancer. Now, I don't*
14 *want to know how many percentage of those people pass blood in the motion will*
15 *have cancer, or how many will have piles, or inflammatory bowel disease or what*
16 *have you."* (Interview 4, Participant 3)
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24 Concerns were expressed about the number of guidelines available for different conditions
25 and inconsistencies between different sources:
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30 *"And that's the problem 'cause last year there was a big campaign, "if you have a*
31 *cough for more than three weeks you need to go and see a doctor", but NICE*
32 *guidelines is six weeks."* (Interview 6, Participant 4)
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37 Participants described how the 'tsunami' of new guidelines, care plans and initiatives meant it
38 was difficult to keep up-to-date:
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43 *"And I thought 'that's probably a squamous cell carcinoma. That needs a two-week*
44 *wait referral'. Then, I actually checked the guidelines, the guidelines say that "it's got*
45 *to be over one centimetre and you've got to wait more than eight weeks really for it to*
46 *grow" etcetera, etcetera [...] and those things will change on a regular basis. Now,*
47 *how do you expect an entire network of primary care physicians to stay current with*
48 *all those guidelines and apply them religiously?"* (Interview 2, Participant 3).
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12 Continuity

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14 Practice staff expressed concern that a lack of continuity increased the risk of missing
15 diagnoses and/or supporting the patient through a difficult period. This was highlighted
16 through discussions about relationships between patients and clinicians; delays in information
17 sharing across the primary and secondary care interface and patient follow-up after initial
18 consultation.
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26 *Patient-practice relationships:* Continuity-of-carer could not always be achieved in practice,
27 even though it was felt that patients preferred it and its absence was thought to possibly
28 contribute to diagnostic delay:
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34 *“People have been hopping around from one clinician to another and that, and you*
35 *don't see the evolution of the story until it hits you in the face. Patients book on the*
36 *day, they don't necessarily get in the person they normally see, they get in with the*
37 *available, so that can disjoint things.” (Interview 3, Participant 4)*
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43 Staff felt that smaller, rural practices had closer relationships with their patients and their
44 community, which would lead to earlier consultation. However, others felt awareness of
45 cancer deaths was heightened in close-knit communities, which could reinforce negative
46 views towards cancer and cancer survivorship amongst the local population and delay access
47 to services.
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7 *Primary care and secondary care interface:* Expedited assessment following GP referral of
8 patients through the two-week wait initiative was perceived to work well by practice staff,
9 but delays further on in the assessment process, and outside of primary care control, were felt
10 to put patients at risk again and exacerbated their concerns:
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16 *“And, well, it's very difficult from our point of view, ‘cause we're saying, “look, you*
17 *know this may be nothing serious, however, I want to refer you on the system, you'll*
18 *get an appointment in two weeks”, and they do get seen, but then there's a massive*
19 *delay, so, you know, then they're kinda all heightened up because they're thinking,*
20 *“{whispered} the doctor thinks I've got cancer” and then nothing happens for ages,*
21 *and it's really hard for the patients.” (Interview 3, Participant 5)*
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30 *Practice-based follow-up:* Patients themselves were also considered to cause delays if they
31 failed to attend. Practices debated the extent to which they should chase these patients up and
32 the risks if they did not:
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37 *“In the back of their mind they know they should, but if they face the fact that they're*
38 *going back, are they are going to be faced with something else? You also have to be*
39 *responsible for the fact that if that doesn't stop, you must persist, and accept the fact*
40 *that, if you don't, then you could, somewhere down the line end up with something so*
41 *serious that it's only going to be palliative.” (Interview 2, Participant 1)*
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7 Within this theme, managing risk was related to primary care focus on targets; conflicting
8 opinions about the role of non-clinical staff and about the worries and tensions generated by
9 cancer awareness campaigns.
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14 *Prevention versus target driven care:* ~~It is recognised that primary care can make a significant~~
15 ~~contribution to public health through promotion, in the practice population, of healthier~~
16 ~~lifestyles and earlier presentation of symptoms of diseases, where early intervention reduces~~
17 ~~morbidity and mortality, such as cancer.~~ Primary care staff considered cancer a public health
18 priority but some felt that there was a tension between adopting preventative approaches in
19 the practice such as promoting cancer awareness and early presentation and the way that
20 primary care is currently funded through achieving specific targets mainly relating to the
21 management of long-term conditions (Quality and Outcomes Framework):
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32 *“We’re not as good with public health, with local public health initiatives, as maybe*
33 *we should be necessarily. It’s just time to do things, and those things aren’t required*
34 *of our core business, and when you have a very detailed contract that tells you what*
35 *you will be paid for doing—.”* -(Interview 2, Participant 3)
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41 *Staff roles:* There were conflicting views around the role of other practice staff in managing
42 the risk of cancer detection and awareness, in particular with regard to reception staff. Some
43 staff viewed the reception role as a health advisor, whereas others perceived their role to be
44 purely administrative. Additionally, there were reservations about the ability of reception
45 staff to relay cancer messages and how the public might feel about receiving health
46 information from them:
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“You’re passing clinical responsibility to people who are non-clinical. It’s alright for patients to speak to them, and that’s fine, but, I’m not gonna use the receptionists as a source of information [...]. I think anything clinical should be passed to the doctor full stop. I don’t think there is any other role for the receptionist.” (Interview 4, Participant 3)

There were also concerns about potential litigation issues if reception staff were to give advice and how this could impact on the practice:

“I think it’s also worth mentioning at this point, because of our roles, how they are, we get a lot of patients not happy about us supplying information, because we’re not allowed to diagnose, obviously for obvious reasons, but if you was to imply something, that could come back on us twice as hard because you’d implied something that could be wrong, and therefore it is now your fault.” (Interview 1, Participant 1)

A further issue associated with staff roles in helping to manage risk was the identified benefits of having a chain of communication between all practice members. For example, receptionists being able to ‘raise issues’ with the doctor if they know someone is coming in who has symptoms the doctor should be aware of but the patient ‘may not say anything’. This can also work the other way:

“Patients that I worry about, I will leave messages. I’ll mention to reception or mention to people that I want to follow them up.” (Interview 6, Participant 3)

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7 Others felt that the focus on the long-term conditions might provide opportunities for practice
8 nurses to be more involved as they were often seeing patients who might be at higher risk of
9 cancer because of their age, disease condition or lifestyle behaviours:
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14 *“Chronic disease, yeah, so diabetic, high blood pressure, chronic kidney disease,*
15 *asthma, most patients will come and see the practice nurses for routine bloods, blood*
16 *pressure, weight, everything like that. So often, GPs don't always see them, I mean*
17 *they do the medication reviews, but, we flag to them anything that we're worried*
18 *about.”* (Interview 2, Participant 4)
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26 Some could also see a role for members of the wider practice team:
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30 *“We'd say 'well who are the district nurses already going out to?' You know, you can*
31 *work with your local pharmacists.”* (Interview 2, Participant 2)
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35 *Cancer awareness:* Although cancer fear was commonly acknowledged, staff were divided as
36 to whether patients were afraid to consult the GP with cancer symptoms. Some felt that
37 unhealthy lifestyle choices contributed to patient reluctance to present with cancer symptoms:
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43 *“The cancers where they feel that they may have contributed to it, like smoking, they*
44 *tend to ignore because they don't want to be told that it may be their fault in a certain*
45 *way, and they don't want to give up the lifestyle.”* (Interview 6, Participant 4)
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51 Cancer awareness campaigns were felt to be important, even though those who presented to
52 the practice following the campaign were more likely to be those at least risk:
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“It’s the people who never come to the doctors that you want to hit, not the people that were already coming in anyway, and they tend to be ones that see those adverts. But then if you can get one person who wouldn’t normally come in and you catch them, then it’s better.” (Interview 5, Participant 1)

Campaigns were also felt to create extra work for all practice members. There were complaints that cancer awareness campaigns tend to run without consideration of other local or national campaigns which may be running simultaneously which increased the risk that practice capacity to safely respond to patients was compromised:

“It’s like it’s alright saying putting in place to get them in, but it’s the sheer volume, isn’t it? You can only cope with so much can’t you?” (Interview 5, Participant 1)

DISCUSSION

This study provides insights into the experiences of primary care staff who manage patients with symptoms ~~suggestive of~~ associated with cancer. The overarching theme ~~that~~ emerged was the need to manage risk so that cancer patients had a timely diagnosis and were assessed appropriately. The associated subthemes of complexity, continuity and conflict highlighted the tensions and difficulties faced by staff when attempting to manage these risks in modern practice.

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7 The study was small, descriptive and exploratory. However, it covered a diverse geographical
8 area and included practices with varying levels of engagement with awareness and early
9 diagnosis initiatives. We undertook stratified sampling of the practices based on the level of
10 on engagement to ensure we had a balance of perspectives so as to better inform
11 policymakers of the possible barriers and drivers to the uptake of initiatives. The stratification
12 was based on known engagement with at the range of national and regional initiatives to
13 promote earlier presentation, detection and referral of patients with symptoms suggestive of
14 cancer available to the practices at that time.

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24 The findings of our study suggest that national initiatives did not appear to wholly resolve
25 issues in-around managing risk for all practitioners. Rather, in some cases, these initiatives
26 were felt to introduce inherent risks which staff had to find ways to overcome. eFor
27 example, national cancer awareness campaigns This included cancer awareness campaigns.
28 However, these campaigns which, while felt were felt to be very important to encourage
29 patients who would otherwise delay diagnosis. However, as these also campaigns appeared
30 to increase consultation rates from those at lesser risk, this was perceived to placed. This
31 placed additional burden on the practice.

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41 There were-were also concerns amongst our participants about practice-based initiatives
42 introduced to directly support practices. The International Cancer Benchmarking Partnership
43 has observed lower survival rates in Denmark and the UK compared to other countries in
44 their study, which has and raised concerns about the role of primary care gatekeeping in
45 delayed diagnosis. [2] This observation appears to be supported by a wider study of
46 European countries which also demonstrated lower cancer survival in those with primary care
47 based gatekeeper systems. [18] Primary care gatekeeping may reduce the burden on specialist

care but may also contribute to diagnostic delay through the restriction of access to these services. In the UK, national referral guidelines and the two-week waiting-time initiative should help alleviate this problem for those with symptoms associated with cancer.

Participants in our study considered ~~highlighted that~~ timely diagnosis was as an essential part of their role in cancer care. ~~This An Australian study had a similar finding was A finding reported in an Australian study, [16], but highlighted that who~~ This study also identified that ~~the~~ resources spent gaining timely access to specialist opinion were a major issue for their practitioners. In our study this was universally ~~appeared to be considered~~ less of a problem because of the two-week waiting-time initiative. ~~This initiative was universally embraced by participants as it was felt to work well in facilitating timely assessment. However, but there were still~~ concerns were expressed that lack of direct access to diagnostic investigations and poor communication between primary and secondary care put patients at risk due to of extended delays. Similar concerns were as reported in a study undertaken in Ireland.[3]

Some participants in our study felt that the referral criteria for the two-week waiting-time initiative were too restrictive. ~~This might, and this, lead~~ to practitioners, on occasion, subverting the referral system to ensure that patients they considered were at risk, but who did not fit the referral criteria, could be assessed in a timely manner. Such concerns are not unfounded; one study has shown that 8% of patients felt by GPs to have cancer, but who did not have symptoms which fit referral criteria for cancer, were subsequently diagnosed with cancer ~~cancer patients do not have symptoms which fit referral criteria.~~[189] This may be because the presenting signs and symptoms had a lower predictive value for cancer than those included in the guidelines. Nevertheless, there is high compliance with guidelines and some limited evidence that referral guidelines contribute, in part, to diagnostic delay reduction.[6, 189]

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7 Diagnostic errors leading to primary care malpractice claims are common.[1920] Researchers
8 suggest that although GPs are more likely to correctly diagnose patients with cancer than
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10 miss cases, there are a disproportionate number of deaths amongst the latter.[201,-2224]
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12 Diagnostic complexity is compounded by the frequency of consultations for symptoms
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14 associated with cancer,-[212, 223] a fear highlighted by practitioners in this study. A study in
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16 Norway, which followed up patients presenting with cancer warning signs to their GP,
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18 suggests that patients with cancer may be missed if multiple warning signs and symptoms are
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20 not considered.[242] Retrospective studies of practice-based data have identified
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22 combinations of warning signs and symptoms which may be associated with increasing ~~the~~
23
24 likelihood of cancer.[234-245] These have been used to inform risk assessment tools to aid
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26 decision-making, with algorithms and probabilities of risk based on demographic
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28 characteristics, lifestyle factors, symptoms and/or attendance frequency.[11] Some have been
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30 disseminated nationally, and there is evidence from both quantitative and qualitative studies
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32 that they affect GPs' decisions to refer.[11] However, in our study, some participants had
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34 similar concerns about these tools as they did [about](#) guidelines. A recent analysis of
35
36 significant event audits in lung cancer highlighted how cancer can mimic other diagnoses and
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38 have atypical presentation.[7] Guidelines and risk assessment tools are analytical tools, and
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40 although statistical probabilities are based on uncertainty, [some participants in our study felt](#)
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42 [they may be perceived to-they may](#) introduce a level of certainty which fails to encapsulate
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44 practitioners' tacit concerns about patients. Previous work in primary care decision-making
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46 has emphasised the analytical over the experiential, but recent research , including [in](#) cancer
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48 diagnosis, suggests that experiential knowledge may have a role and may be more responsive
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50 to ~~individual-the~~ patient [as a person](#). [15, 256-287] Others have found that better diagnostic
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52 decisions [about urgent referrals](#) appear to be made by older doctors_- [223] and, as commented
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7 on by some of our participants, that guidelines and risk assessment tools may be more useful
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9 | for newer practitioners who have yet to develop problem solving strategies.[289]

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12 It has also been observed that, unlike in acute care, decision-making in primary care partly
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14 | involves an understanding of the patient context and perspective.[2930] Our study
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16 | participants highlighted concerns that lack of continuity of carer may lead to diagnostic
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18 | delays. Relational continuity was felt to be a particular problem in larger practices and urban
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20 | settings. Other studies suggest that fragmentation of primary care and shorter consultation
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22 | times has led to a lack of continuity-of-care or carer, which may hinder early diagnosis as
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24 | cancer presentation can be complex in those with multiple co-morbidities.[16, 301, 312] In a
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26 | qualitative study of lung cancer patients in New Zealand, patients felt that not always seeing
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28 | the same GP could lead to delays in diagnosis due to poor follow up.[323] In a study in
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30 | Denmark, the -authors suggest that perceived lack of accessibility and the doctor-patient
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32 | relationship were associated with patient delay in seeking advice about cancer
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34 | symptoms.[334] Others have found that confidence and trust in a doctor were more
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36 | important predictors of cancer detection than ease of access and choice of preferred
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38 | doctor.[345]

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41 In our study, participants highlighted how other practice team members, such as nurses who
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43 | are in more regular contact with patients with long-term conditions, could raise symptom
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45 | awareness or be more alert to changes in, or new, symptoms suggestive of cancer. In the US
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47 | and Canada, patient navigators are being used to support patients through the complex
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49 | systems found in cancer management and care.[36] It has also been suggested that these
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51 | roles could be extended to support patients during the diagnostic, referral and assessment
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53 | processes and ensure appropriate follow up of investigative resultsons.[357] In our study,
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7 some staff felt that receptionists could act as navigators in terms of directing patients with
8 symptoms to see the GP.[36] Low levels of knowledge about some cancer symptoms has
9 been demonstrated in non-medical staff.[378] However, our study highlighted that
10 professional boundaries and concerns about litigation-which might also impede such
11 initiatives. Disclosures or discussions of diagnostic issues within a public reception
12 location also raised ethical concerns. Research within primary care suggests that facilitation
13 of communities of practice and interdisciplinary knowledge sharing may help to identify the
14 role of other practice team members in promoting earlier cancer presentation and
15 diagnosis;[398] although training needs should be addressed.[387]

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26 This study has highlighted that a 'one-size-fits-all' approach to implementing initiatives is
27 unlikely to succeed as practitioners expressed a range of views and opinions on the benefits
28 of different initiatives. Lack of implementation of initiatives in primary care is not always
29 because of resistance to the initiatives themselves, but sometimes because of the sheer
30 number across a range of priority areas that practices are expected to implement, often
31 simultaneously. Policymakers should consider more carefully how these impact on primary
32 care, how they can be embedded into practice systems and emphasise and exploit synergies
33 with other disease conditions.

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43 For there to be greater success of initiatives aimed at promoting earlier presentation, detection
44 and referral in primary care, there needs to be further work on understanding how primary
45 care manage risk in the face of inherent uncertainty, organisational changes and competing
46 priorities.

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7 **ACKNOWLEDGEMENTS:** Our thanks to the practices who participated in this study and
8 to the staff of the Lancashire and South Cumbria Cancer Network who assisted us.
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12 **COMPETING INTERESTS:** PD was public health lead for LSCCN and NC is part-funded
13 by a grant from LSCCN; PD was also funded by LSCCN to undertake evaluative work.
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18 **FUNDING:** This work was supported by Lancashire and South Cumbria Cancer Network
19 (LSCCN) as part of the National Cancer Awareness and Early Detection initiative (NAEDI)
20 funding 'cancer networks supporting primary care'.
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23

24 25 **CONTRIBUTIONS:**

26
27 NC recruited participants, carried out interviews, transcribed the interviews, coded the
28 transcripts, contributed to the development of the coding framework, and contributed to the
29 writing of the manuscript.
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33 GT carried out interviews, coded the transcripts, contributed to the development of the coding
34 framework and contributed to the writing of the manuscript.
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38 PD designed the study, collated practice engagement data, contributed to the development of
39 the coding of the framework and contributed to the writing of the manuscript.
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43 **DATA SHARING:** No further data are available
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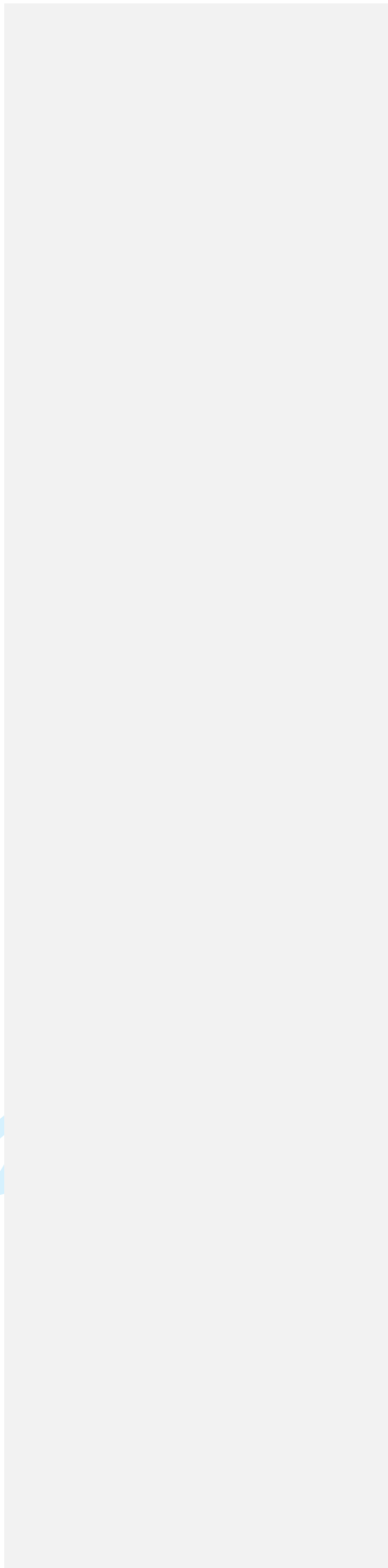
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Figure 1: organising themes of complexity, continuity and conflict with their associated basic themes, centred around the global theme of managing risk in primary care



Box 1: Semi-structured interview schedule

- Why do you think people with symptoms suggestive of cancer do not present, get seen or diagnosed or referred earlier?
- What do you know about the initiatives that concern the earlier presentation, diagnosis and referral of cancer symptoms?
 - Prompts around specific tools/initiatives/referral criteria
- Have you accessed any local training events concerning the identification, referral of cancer patients?
 - Prompts around specific training attended, and how learning is usually undertaken
- Overall, what is working well in terms of the implementation and use of these initiatives?
- Overall, have you experienced any/or what do you consider to be the main barriers in the implementation/access/use of these various initiatives?
- Are there any practice based issues that may affect the early identification and referral for cancer patients?
 - Prompts around staff and practice issues, communication, administration
- Overall, what do you think local practices could do to help promote and diagnose cancer symptoms?
 - Prompts around team roles and other practice issues
- Do you know about the Lancashire and South Cumbria Cancer Network and what their role is?
 - Prompts around extent of engagement, attitudes and areas for improvement
- What is your opinion concerning the forthcoming ‘access to diagnostics’ initiative (initiative for practices to make direct referrals to diagnostics such as x-rays, CT scans, ultrasound)?
 - Prompts around who should make the referral
- Are there any additional support mechanisms/external to the practice that need to be in place to help with promotion/diagnosis and referral?
- Any further issues or concerns you would like to raise about this work?

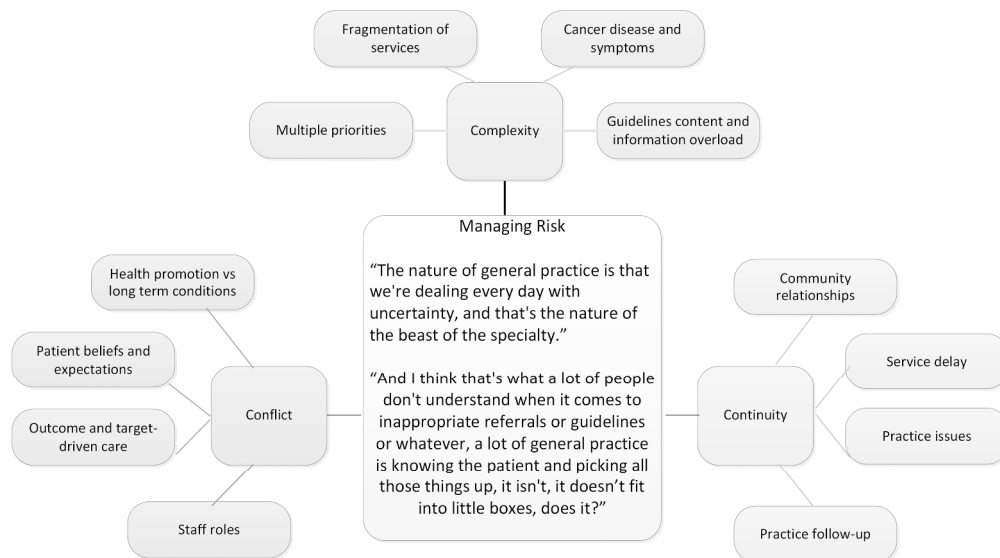


Figure 1: organising themes of complexity, continuity and conflict with their associated basic themes, centred around the global theme of managing risk in primary care
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review only

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