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How European primary care practitioners think the timeliness of cancer diagnosis can be improved – a thematic analysis

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How European primary care practitioners think the timeliness of cancer diagnosis can be improved – a thematic analysis

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Word count

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Abstract

Background

National European cancer survival rates vary widely. Prolonged diagnostic intervals are thought to be a key factor in explaining these variations. Primary Care Practitioners (PCPs) frequently play a crucial role during initial cancer diagnosis; their knowledge could be used to improve the planning of more effective approaches to earlier cancer diagnosis.

Objectives

This study sought the views of PCPs from across Europe on how they thought the timeliness of cancer diagnosis could be improved.

Design

In an online survey, an open-ended question asked PCPs how they thought the speed of diagnosis of cancer in primary care could be improved. Thematic analysis was used to analyse the data.

Setting

A primary care study, with participating centres in twenty European countries.

Participants

A total of 1,352 PCPs answered the survey question, with a median of 48 per country.

Results

The main themes identified were: patient-related factors, including health education; care provider-related factors, including continuing medical education; improving communication and inter-professional partnership, particularly between primary and secondary care; factors relating to health system organization and policies, including improving access to health care;

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easier primary care access to diagnostic tests; and use of information technology. Re-allocation of funding to support timely diagnosis was seen as an issue affecting all of these.

Conclusions

To achieve more timely cancer diagnosis, health systems need to facilitate earlier patient presentation through education and better access to care, have well-educated clinicians with good access to investigations and better information technology, and adequate primary care cancer diagnostic pathway funding.

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Article Summary

Strengths and limitations of this study

- This this is the first trans-European study to explore PCPs' perceptions of how timeliness of cancer diagnosis can be improved.
- Variation in geography, health systems and levels of healthcare spending was provided recruiting PCPs from 20 European countries, four countries from each of the Northern, Southern, Eastern, Western and Central European geographical areas.
- The survey had only one question that related directly to our research question.
- Neither patients, secondary care nor other primary care health professionals were included in the survey, and these groups may have had other insights to offer.

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Introduction

Cancer survival rates vary widely in Europe [1], leading to considerable additional mortality in some countries. Data from the European Cancer Registry-based Study on Survival and Care of Cancer Patients (EUROCARE-5) show that the national 1-year relative survival rates for all cancer sites vary from 58.2% to 81.1% [2]. Poorer 1-year relative survival is thought to be indicative of diagnostic delay [3 4] and more advanced disease at diagnosis [5 6], although it can be affected by differences in registration, as well as overdiagnosis and lead-time biases [7 8]. There may also be geographical differences in incidence of cancers that have a poorer prognosis [9], as well as national variations in access to effective cancer treatment [10], and in levels of poverty, which in itself has been linked with more advanced disease stage at diagnosis [11-13]. More advanced cancers are more difficult to treat successfully [14] and, for many cancers, the stage of disease at diagnosis is related to survival [15 16]. There is considerable evidence that longer time to diagnosis and treatment has an adverse impact on cancer mortality [17-23]. Timely care also adds to patients' quality of life and emotional well-being [24]. In addition, patients' descriptions of the quality of their care are closely related to the speed of their diagnosis and treatment; this is because they are concerned that longer waits might allow time for their cancers to grow [25].

Timely diagnosis of cancer has therefore been an important aim of healthcare providers across Europe [25]. However, the challenge in deciding where and how to achieve this is substantial [26]. In countries where a comparatively low 1-year cancer survival suggests that late diagnosis may be a major factor, it is uncertain whether this is due to patients presenting later to health-care, whether they are not being referred quickly enough by those in primary care, or whether they are not being investigated and managed efficiently in secondary care [14]. This may be a particular problem where patients with cancer present without red-flag symptoms, as how their primary care practitioners (PCPs) act depends on how their health systems are organised [27].

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Doctors and their patients recognise that general practitioners (GPs) and other PCPs have a key role in cancer detection [28-30]. It has been suggested that PCPs' knowledge of their patient populations can be used to improve health service design [31] and the planning for more effective approaches to earlier cancer recognition and referral [32]. There has been a call for research in this field [15]; although PCPs' experience of their own health systems could potentially help to improve the planning of more effective approaches to earlier cancer recognition and referral, their perceptions have not been previously evaluated.

The Örenäs Research Group, a European group of primary care researchers that studies the primary care factors that relate to cancer survival, therefore decided to elicit the views of GPs and other PCPs from across Europe on how they thought the timeliness of cancer diagnosis could be improved.

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Methods and design

Design

Between November 2015 and December 2016, we performed an online survey of PCPs in 20 European countries. The methodology of the study is described in our published protocol paper [33].

Development of the questionnaire

After a literature review, Örenäs Research Group investigators developed a questionnaire designed to elicit PCPs' referral decisions on patients that could have cancer, and their degree of agreement with items relating to health system aspects that could affect their decision to refer patients with potential cancer symptoms for further investigation. The final, open-ended question asked: 'How do you think the speed of diagnosis of cancer in primary care could be improved?' The answers to this question are used in this analysis.

The questionnaire was piloted twice by PCPs in 16 Örenäs Research Group centres. No changes were made to the final, open-ended question after either of the piloting stages. Örenäs Research Group leads arranged for translations of the questionnaire into their local languages where these were not English, a total of 19 translations from the original English. Translation, validation by back-translation to assess semantic and conceptual equivalence, and cultural adaptation [34] of the survey were done in a standardised way [35] and are described elsewhere [36]. The questionnaires were put online using SurveyMonkey (SurveyMonkey, California, USA).

Participants and recruitment

The study was conducted in 25 Örenäs Research Group centres in 20 countries across Europe: Bulgaria, Croatia, Denmark, England, Finland, France, Germany, Greece, Israel, Italy, Netherlands, Norway, Poland, Portugal, Romania, Scotland, Slovenia, Spain, Sweden and

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Switzerland. Local study leads were asked to either gain ethical approval or obtain a statement that formal ethical approval was not needed in their jurisdiction (see supplementary file).

Criterion sampling was used [37], with subjects being eligible for the survey if they were doctors working mainly in primary care. These doctors, referred to collectively here as 'Primary Care Practitioners', consisted of GPs as well as other doctors who had specialist training but worked in the community and could be accessed directly by patients without referral.

Each Örenäs Research Group local lead was asked to email a survey invitation to the PCPs in their local health district, and to recruit at least 50 participants. This allowed recruitment of a varied sample with regards to gender, years since graduation, site of practice (urban, rural, remote), and size of practice. Consent was implied by agreeing to take part in the survey.

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Data analysis

Local Örenäs Research Group leads translated the responses from their own languages into English and sent them to MH, who asked them for more information where the translation or context was unclear.

We used inductive thematic analysis [38], an approach in which codes and themes are suggested by the data rather than by a theoretical framework. The phases of analysis included coding, followed by the identification and clustering of themes and sub-themes, and the production of a descriptive thematic summary. Two researchers (MH and SH) independently coded the data from three countries and compared their analyses for inconsistencies and agreement. MH then coded the data from the other countries. Team members from seven participating countries (ME, MH, RH, TK, ALN, DP, HT, all PCPs) then independently considered themes and sub-themes, discussed these and came to a consensus over the course of two meetings. The themes and sub-themes were grouped to construct an interpretative narrative across the dataset and depicted diagrammatically. Apart from SH, a Masters psychology student, all authors involved in the coding and thematic analysis were experienced general practitioners who were also active in primary care research.

Patient and public involvement

There was no patient or public involvement in this study.

Results

A total of 1,833 PCPs completed the full questionnaire, with a median response rate per country of 24.8% (range 7.1% to 65.6%). All participating centres received at least 50 responses, with a median of 61 PCPs per country. In all, 1,352 PCPs (73.8% of completers) gave an answer to the final, open-ended survey question on “how could the speed of diagnosis of cancer in primary care could be improved?”, with a median of 48 per country (Table 1). The demographic distributions of the PCPs answering this question are shown in Table 2. Towards the end of the analysis, no new themes emerged.

We identified four main themes organising the content of the responses to the question: patient-related factors, care provider-related features, improving communication and inter-professional partnership, and aspects of health system organisation and health policies. Two structural facets transcended the four themes: accessing diagnostic tests and using information technology. The issue of allocating funding to support timely diagnosis fed into all the other themes. The themes are shown diagrammatically in Figure 1. Themes and subthemes are described below, with participant quotations identified by country and a participant number.

(Place Figure 1 here)

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Patient-related factors

This theme included ideas on education and training to improve patient knowledge. Many PCPs advocated the use of health education and media campaigns to improve patient awareness of alarm symptoms and signs:

> ‘By giving patients better information about when to go to a doctor - reduce patient delay.’ (Denmark, PCP69)
>
> ‘Improve health literacy of patients regarding the detection of early symptoms that might indicate oncological disease.’ (Portugal, PCP37)

Targeting advice on cancer risks was also considered important:

> ‘Informing patients about cancer risks related to their age groups.’ (Italy, PCP28)

However, public health messages could be seen as unworkable:

> ‘Stop public campaigns telling everyone with a particular symptom they need seen eg chest X-ray after 3 weeks of cough – inappropriately blocking the service.’ (Scotland, PCP16)

Care provider-related factors

PCPs had suggestions on how to improve their own knowledge and that of other caregivers, by both increasing the amount of the training and improving the teaching content. Improving the training of PCPs and other health care professionals was considered by many respondents to be important:

> ‘By educating health care professionals. When to suspect and when to do further tests?’ (Finland, PCP33)
>
> ‘CME [continuing medical education] on early signs and up-to-date investigation processes.’ (Sweden, PCP52)

Alertness in their role was also considered key:

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> ‘Often the presence of alarm signs is too late ... Be alert and listen to the patients.’ (Spain, PCP46)

Primary care doctors also need to be aware of the relevant clinical pathways:

> ‘Training of GPs … taking into account the entire pathway from symptom to diagnosis.’ (Poland, PCP17)

PCPs thought it important that cancer screening and referral guidelines should be clear, and that they themselves should be involved in designing them.

> ‘Clear guidelines regarding cancer alarm signs and referral indications.’ (Finland, PCP37)

> ‘GPs who design guidelines together with specialists.’ (Sweden, PCP21)

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Improving communication and inter-professional partnership

Patient-PCP communication improvements and enhancements to inter-professional partnerships were frequently suggested by the PCP respondents. Improving communication with patients was considered important, though this implied having longer consultations:

> ‘GPs should pay more attention when they speak to patients.’ (Italy, PCP26)

> ‘Longer consultations to allow more thorough assessment without pressure of time.’ (Scotland, PCP5)

Improving the interaction within the practice team could also be helpful:

> ‘Discussion in the team about recent referrals so the team benchmarks itself.’ (England, PCP22)

> ‘A lot can be learnt from colleagues' experiences of missed diagnoses.’ (Netherlands, PCP40)

Improving partnership between PCPs and other primary health care professionals, for example nurses and health-care assistants, with adequate training, was also considered important:

> 'Involve the nurses in gathering the patient's medical history.' (Poland, PCP20)
>
> 'Good training of health-care assistant to identify risk symptoms.' (Norway, PCP1)

Improving the relationship between primary and secondary care doctors, with easier and reliable communication between the two, was highlighted:

> 'Easy communication with specialists (and, in my case, preferably email contact).' (Netherlands, PCP85)
>
> 'It is essential to establish a communication channel between primary health care and specialist health care so that critical patients would not get lost in the system.' (Croatia, PCP36)

Joint working with public health departments was also considered valuable:

> 'With the cooperation between the National Institute of Public Health and family medicine specialists, who know their patients best.' (Croatia, PCP38)

Many doctors commented on the importance of continuity of care:

> 'Knowing your patient well. Consequently, not having three different GPs for one patient.' (Netherlands, PCP69)

Strengthening system organisation and improving health policy

Strengthening how health systems are organised and implementing health policies that allow timely cancer diagnosis were key recommendations from many PCPs. Enhancing patient access to primary care, particularly for vulnerable or more remote groups, was considered important by some:

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> ‘Shorter queues to GP appointment in order to start assessments without delay.’ (Finland, PCP33)

> ‘In some places (rural, inland) inaccessibility to MCDTs [screening examinations] can be an obstacle.’ Portugal, PCP43)

Practical steps to improve access to secondary care were also seen as key, particularly those relating to costs to the patient:

> ‘Access to specialists must be cheaper.’ (Romania, PCP99)

> ‘Patient friendly hospital services - so that the appointments are not too stressful or expensive (travel and parking).’ (England, PCP19)

Many PCPs commented on the need for better working conditions, a larger workforce, a reduced workload and less bureaucracy:

> ‘A sufficient number of healthcare professionals so that there is not too much workload for a few.’ (Croatia, PCP5)

> ‘Reduction of the workload at the family medicine doctor office.’ (Croatia, PCP31)

> ‘By decreasing bureaucracy! So we will have more time for a real consultation!’ (Romania, PCP49)

The adoption of financial incentives schemes was also suggested:

> ‘Allocating additional financial resources and stimulating the GP in this direction.’ (Romania, PCP78)

> ‘Financial incentives for preventative care of most common malignant conditions.’ (Bulgaria, PCP4)

PCPs felt that guidelines and protocols needed to be clear and relevant to them:

> ‘Clear guidelines regarding cancer alarm signs and referral indications.’ (Finland, PCP37)

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> 'By developing a more specific GP protocol for the various types of cancer.' (Netherlands, PCP51)

Fast-track systems for patients with cancer were requested by many respondents:

> 'Create a fast-track unit for patients with high cancer suspicion.' (Spain, PCP51)

> 'Preferential appointments for cases with cancer suspicion in all hospital specialities.' (Spain, PCP6)

In countries where fast-track systems already existed, these were seen as a success:

> 'Cancer diagnostics have priority in the Norwegian health care system since fast track referral was introduced last year. Functions well.' (Norway, PCP5)

> 'I actually think that the introduction of the "2-week wait" urgent referral system has greatly improved the speed of diagnosis for those with obvious red flag symptoms.' (England, PCP11)

Some PCPs felt that there should be more uptake of national screening programmes:

> 'Encourage patients to use existing prevention programmes.' (Germany, PCP7)

> 'All physicians should adhere to screening guidelines.' (Switzerland, PCP8)

Accessing diagnostic tests

This theme suggesting improvements to diagnostic structures dealt mainly with easier and quicker access to testing. Easier PCP access to diagnostic testing was cited by many respondents:

> 'Increasing the range of diagnostics available; also making them easier to refer for.' (Netherlands, PCP79)

> 'Facilitating family doctors to request tests and investigations that he/she considers necessary for the diagnosis.' (Spain, PCP39)

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Many felt that they should have direct access to cancer-specific testing:

> ‘GPs should be able to recommend any investigation without reference to other specialist doctors.’ (Romania, PCP44)

> ‘Give GPs the ability to refer patients to more diagnostic tests e.g. CT, tumour markers.’ (Poland, PCP26)

The speed of access to diagnostic tests was also seen as key:

> ‘Faster access/fast track to imaging diagnostics could help us exclude a number of cases and so could relieve specialist services.’ (Norway, PCP18)

> ‘Reduction of the delay in getting special tests.’ (France, PCP 2)

However, some PCPs were worried that the increase in investigation of patients needed to diagnose cancers earlier could also lead to overdiagnosis and overtreatment:

> ‘Cancer diagnostics are a difficult balancing act between under- and overdiagnosis. Faster cancer diagnostics will also give more overdiagnosis.’ (Norway, PCP 31)

> ‘Depends on the type of cancer, but there is a trade-off between diagnosing a few cancers earlier by referring lots more patients to specialist clinics and the increased stress, anxiety, expense and risk of physical harm from unnecessary ionizing radiation and treatments.’ (England, PCP 7)

Using information technology

This theme was about using electronic information and communication to improve diagnostic capability and enhance partnership working. Some PCPs thought that more decision support aids should be included in electronic health records:

> ‘Automatic decision support/diagnostic support in the GP electronic information system based on symptoms.’ (Netherlands, PCP10)

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> 'The 29 Norwegian guidelines regarding 'fast track referral for cancer' could be included into our electronic patient files as a real decision aid with extraction of clinical information for the referral.' (Norway, PCP3)

Information technology could also be used to help identify those who would benefit from screening, and provide reminders relating to individual patients where needed:

> 'Select specific age groups from healthcare databases and identify the individuals that haven't had the screening.' (Portugal, PCP11)
>
> 'Using an automatic reminder system for cancer screening for each patient.' (Greece, PCP15)

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Some PCPs were keen on the option to have 'virtual consultations' with specialists:

> 'Allow virtual consultations with specialists in specific subjects to validate malignancy diagnosis (radiologists/pulmonologists/gastroenterologists/surgeons, etc.) (Israel, PCP18)

Allocating funding to support timely diagnosis

Adequate resources for primary care and targeted funding for investigations were frequently recommended by participants. This theme wove through the whole cancer diagnostic process. An increase in primary care financing was considered to be necessary if PCPs were to improve access to care:

> 'By increasing resources in primary care in order to improve the access to care.' (Finland, PCP34)

Adequate funds were also seen to be needed for screening and diagnostic tests:

> 'Increase funding of screening tests.' (Poland, PCP20)
>
> 'A higher budget for diagnostic tests, covering … some higher costs related to the investigation and early diagnosis of cancer.' (Romania, PCP59)

In some countries, there was a need for an increase in the budget for diagnostic tests and referrals:

> ‘Increase funding for cancer diagnostic tests (tumour markers, colonoscopy, gastroscopy, radiographs) - currently, the funding is insufficient.’ (Poland, PCP29)

> ‘Unlimited lab tests and unlimited referrals to specialist services if malignant conditions are suspected.’ (Bulgaria, PCP11)

Funding limitations could be an issue for patients:

> ‘Many patients refuse the investigations because of the costs (tumour markers, MRI, extra payment to the specialist doctor, ineffective collaboration between specialities).’ (Romania, PCP12)

This could also affect the finances of the PCPs themselves:

> ‘Ensure adequate financial support – at present there are penalties if the number of consultations exceeds the limit, even if the consultations are clinically indicated.’ (Bulgaria, PCP25)

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Discussion

Principal findings

In this primary care study, participants were able to use their experience situated in their own healthcare systems to provide a rich variety of suggestions for the improvements needed to allow more timely diagnosis of cancer. These covered the whole diagnostic pathway, from recommendations on how to help patients to present earlier with their symptoms, through continuing medical education that would help PCPs to recognise and act on symptoms that could be due to cancer, to improving communication and inter-professional partnership between and within primary and secondary care. Improving health system organisation and health policies is essential for achieving these goals. Facilitating patients’ access to health care was also considered important, as was enabling fast and direct PCP access to diagnostic tests. Respondents saw funding allocation as an underlying component of most of these issues. They also identified a risk that reducing delays in cancer diagnosis in some patients could lead to overdiagnosis in others.

Strengths and weaknesses of the study

To our knowledge, this is the first trans-European study to explore PCPs' perceptions of how timeliness of cancer diagnosis can be improved, offering a unique insight into the operational and administrative challenges. This could be invaluable for the evaluation and revision of current healthcare policies and practices.

Variation in geography, health systems and levels of healthcare spending was provided by having four participating countries from each of the Central, Eastern, Northern, Southern and Western European geographical areas. The sample size was large and diverse, with participants varying in terms years of clinical practice, gender, and site and size of practice. The study successfully recruited participants in countries in which PCPs are underrepresented in research.

The survey had only one, short question that related directly to our research question. However, it may be that this format prompted participants to focus on writing down only what, for them, was the most important point. Neither patients, secondary care nor other primary care health professionals were included in the survey, and these groups may have had other insights to offer. There is a risk that the translators and investigators misunderstood some of the nuances of the twenty different languages, cultures and healthcare organisations involved in this study. While themes were identified from responses from PCPs in 20 European countries, not all of the themes identified will be equally relevant to each of the participating countries.

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Comparison with other studies

Our findings map across to those of a survey of GPs in Ireland, which identified that barriers to early cancer diagnosis included lack of direct GP access to diagnostic tests, difficulties with referral to secondary care, poor clarity relating to cancer screening, unequal patient access to secondary services, and a need for further training and guidelines [39]. GPs' views on the importance of closer links between primary and secondary care were identified in that study, and also in a United Kingdom (UK) study [29]. Our PCPs' call for improved patient education and better access to diagnostic testing specialist care were also prioritised by GPs in another UK study [40]. An Australian study of GPs' perceptions identified a need to reduce system barriers and workforce pressures in general practice [30].

The need for healthcare systems to support PCPs' quick and easy access to investigations has been proposed before [41]. While investigation in primary care has been linked with later referral for specialist assessment, reducing the waiting time for tests would be expected to shorten the primary-care intervals associated with investigation use [42]. Despite this, another study found that some patients received a delayed cancer diagnosis, even when they had presented with typical cancer symptoms to a GP who had access to relevant diagnostic tests [43].

Possible implications for clinicians and policymakers

PCP respondents from each participating country had specific recommendations on the changes that are needed to facilitate more timely diagnosis of cancer. Those responsible for the organisation of healthcare in their countries need to put this study's findings into the context of their own systems, so that they can identify which recommendations are particularly relevant in their own jurisdictions. Some recommendations, for instance health education campaigns and development of relevant guidelines, may need central direction, albeit with the input of PCPs. Others, for example improving the way PCP communicate with

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secondary care specialists, and PCPs' ability to access to cancer-specific tests, may need local agreement. Aspects such as PCPs' own communication skills, their own accessibility to patients and their continuing medical education, are more likely to be under PCPs' own control. However, a consideration of how funding is best reallocated is crucial if PCPs and their health systems are able to make these changes.

Unanswered questions and future research

Further analysis is needed to help identify which recommendations are most relevant to different existing models of healthcare, for example as to whether some are particularly relevant to systems in which the PCP has more of a 'gatekeeper' role, or to those in which PCP practises are large or smaller than average. A longitudinal study would give evidence on the trends on PCP opinions and how they are impacted by changes in health policies and public health initiatives. There is a need to consider how to get the best balance between achieving early cancer diagnosis and minimising overdiagnosis of cancer. Our study gives the basic elements for the international primary care cancer research agenda, which would provide a knowledgebase for developing and improving cancer diagnosis and prognosis internationally.

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Conclusions

This research has identified key features that PCPs believe would be necessary to improve the timeliness of cancer diagnosis in their patients, and a need for re-allocation of health system funding to allow these to happen. Health systems need to facilitate earlier patient presentation through health education and better access to care, have well-educated clinicians with good access to investigations and better information technology, and adequate primary care cancer diagnostic pathway funding.

Many PCPs play a crucial role at the centre of their patients' care, and the breadth of their experience is reflected in their wide range of suggestions. This understanding should help to inform health service policy and research towards better cancer outcomes.

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List of abbreviations

CME	Continuing medical education
GP	General practitioner
PCP	Primary Care Physician
UK	United Kingdom

Declarations

Ethics approval

Ethical approval for the study was given by the University of Bath Research Ethics Approval Committee for Health (approval date: 24th November 2014; REACH reference number: EP 14/15 66). Other countries' study leads either achieved local ethical approval or gave statements that formal ethical approval was not needed in their jurisdictions.

Competing interests

The authors declare that they have no competing interests.

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Data sharing statement

The Örenäs survey data that support the findings of this study are available from the corresponding author, Harris M, upon reasonable request.

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Author contributions

K Buczkowski, M Brekke, N Buono, E Costiug, G-J Dinant, M Esteva, G Foreva, M Harris, R Hoffman, E Jakob, T Koskela, M Marzo-Castillejo, P Murchie, AL Neves, DP Petek, J Sawicka-Powierza, A Schneider, E Smyrnakis, S Streit, H Thulesius, P Vedsted and B Weltermann participated in the study design, piloting and data collection. G Taylor participated in the study design. S Harker coded some of the data. M Esteva and S Harker assisted in validated the coding. M Esteva, M Harris, R Hoffman, T Koskela, AL Neves, D Petek and H Thulesius worked together to agree the themes. M Harris had overall responsibility for the study design, recruitment of local leads, analysis of data and interpretation of results. All authors contributed to the writing and review of the manuscript and approved the final version.

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Table 1. *National distribution of PCPs who responded to the question 'How do you think the speed of diagnosis of cancer in primary care could be improved?'*

Country	Number of PCPs who completed the survey	Number who answered the open-ended question (% of all survey completers)
Bulgaria	52	45 (86.5)
Croatia	56	42 (75.0)
Denmark	92	71 (77.2)
England	62	25 (40.3)
Finland	61	39 (63.9)
France	52	35 (67.3)
Germany	91	31 (34.1)
Greece	59	50 (84.7)
Israel	58	42 (72.4)
Italy	60	52 (86.7)
Netherlands	108	84 (77.8)
Norway	81	46 (56.8)
Poland	135	103 (76.3)
Portugal	59	46 (78.0)
Romania	146	132 (90.4)
Scotland	62	55 (88.7)

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Slovenia	91	52 (57.1)
Spain	380	332 (87.4)
Sweden	68	55 (80.9)
Switzerland	60	15 (25.0)
Total	1,833	1,352 (73.8)

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Table 2. *Demographic distribution of PCPs who responded to the question 'How do you think the speed of diagnosis of cancer in primary care could be improved?'*

Demographic	Number (%)
Gender	
Female	833 (61.6)
Male	513 (38.0)
Not stated	5 (0.4)
Years since graduation	
<10	192 (14.2)
10–19	356 (26.4)
20–29	416 (30.8)
30–39	336 (24.9)
40 or over	47 (3.5)
Not stated	4 (0.3)
Site of practice	
Urban	816 (60.4)
Rural	314 (23.2)
Island	25 (1.9)

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Mixed	194 (14.4)
Not stated	2 (0.1)
Number of doctors in practice	
1-2	337 (24.9)
3-5	344 (25.5)
6-9	290 (21.5)
10 or more	374 (27.7)
Not stated	6 (0.4)

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Figure legends

Figure 1. *Diagrammatic representation of themes emerging from responses to the question:*

'How do you think the speed of diagnosis of cancer in primary care could be improved?'

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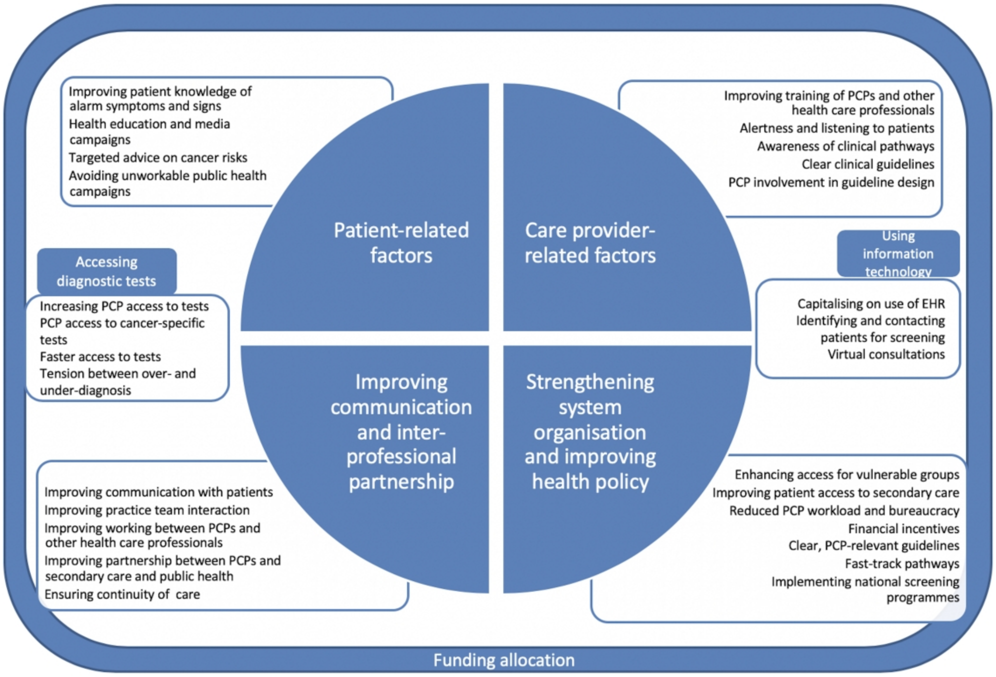

Figure 1. Diagrammatic representation of themes emerging from responses to the question: 'How do you think the speed of diagnosis of cancer in primary care could be improved?'

292x200mm (300 x 300 DPI)

Supplementary file. Ethical and other approvals obtained in each Örenäs Research Group participating jurisdiction

	Date of Ethics Approval	Approvals obtained	Reference
Bulgaria	29 October 2015	Medical University Plovdiv Ethical Commission	P-7820
Croatia	16 December 2016	Nastavni Zovod Za Javno Zdravstvo	08-820-61/31-15
Denmark	7 May 2016	Danish Data Protection Agency; according to Danish law and the Central Denmark Region Committees on Health Research Ethics, approval by the National Committee on Health Research Ethics was not required as no biomedical intervention was performed.	2009-41-3471
Finland	16 November 2016	Academic Ethics Committee of the Tampere Region	16 November 2016
France	N/A	In France, research ethics approval was not required as no biomedical intervention was performed.	
Germany	15 January 2016	Ethik-Kommission Universität Duisberg-Essen	16-6747-BO
Greece	N/A	In Greece, research ethics approval was not required as no biomedical intervention was performed.	
Israel	N/A	In Israel, research ethics approval was not required as no biomedical intervention was performed.	
Italy	N/A	In Italy the approval of the ethical committee is not required when a study is neither an interventional nor an observational study on pharmacological treatment.	Decreto Legislativo n. 211 (24 giugno 2003)<2001/20/EC
Netherlands	27 June 2016	medisch-ethischetoetsingscommissie (METC) azM/UM Maastricht UMC+	METC 16-4-113
Norway	N/A	In Norway, research ethics approval was not required as no biomedical intervention was performed.	
Poland	28 January 2016	Komisja Bioetyczena Uniwersytetu Medycznego w Bialymstoku	R_I_022/10/2016

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Portugal	N/A	In Portugal, research ethics approval was not required as no biomedical intervention was performed.	
Romania	N/A	In Romania, research ethics approval was not required as no biomedical intervention was performed.	
Slovenia	8 December 2014	Komisija Republike Slovenije Medicinsko Etiko	KME 113/08/14
Spain	25 October 2015 23 Decmber 2015	Comissio d'Investigacio Govern de les Illes Balears Informe del Comite Etic d'Investigacio Clinica	Palma 27oct15 P15/159
Sweden	N/A	In Sweden, research ethics approval was not required as no biomedical intervention was performed. It does not fall under the law of research on human subjects to ask professionals about their work and how they perceive it.	
Switzerland	N/A	Swiss law on human research (Humanforschungsgesetz, HFG) does not require that an ethics committee approve collection and analysis of non-medical and anonymous data.	
United Kingdom	24 November 2014	Research Ethics Approval Committee for Health, University of Bath	EP 14/15 66

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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		Reporting Item	Page Number
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	4-5
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	7-8
Purpose or research question	#4	Purpose of the study and specific objectives or questions	8
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also	9-10

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		recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	10-11
Context	#7	Setting / site and salient contextual factors; rationale	9-10
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	10
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	10; 24
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	9-10
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	9
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	11
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	10

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Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	10
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	10
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	11-19
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11-19
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	19-21
Limitations	#19	Trustworthiness and limitations of findings	20
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	24
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	24

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BMJ Open

How European primary care practitioners think the timeliness of cancer diagnosis can be improved – a thematic analysis

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	Investigación
Primary Subject Heading:	General practice / Family practice
Secondary Subject Heading:	Oncology, Qualitative research, Public health
Keywords:	Delivery of Health Care, Primary Health Care, General Practitioners, Cancer, Diagnosis, Consultation and Referral

How European primary care practitioners think the timeliness of cancer diagnosis can be improved – a thematic analysis

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Delivery of Health Care; Primary Health Care; General Practitioners; Cancer; Diagnosis; Consultation and Referral.

Word count

3,182 (excluding data/quotes)

Abstract

Background

National European cancer survival rates vary widely. Prolonged diagnostic intervals are thought to be a key factor in explaining these variations. Primary Care Practitioners (PCPs) frequently play a crucial role during initial cancer diagnosis; their knowledge could be used to improve the planning of more effective approaches to earlier cancer diagnosis.

Objectives

This study sought the views of PCPs from across Europe on how they thought the timeliness of cancer diagnosis could be improved.

Design

In an online survey, a final open-ended question asked PCPs how they thought the speed of diagnosis of cancer in primary care could be improved. Thematic analysis was used to analyse the data.

Setting

A primary care study, with participating centres in twenty European countries.

Participants

A total of 1,352 PCPs answered the final survey question, with a median of 48 per country.

Results

The main themes identified were: patient-related factors, including health education; care provider-related factors, including continuing medical education; improving communication

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and inter-professional partnership, particularly between primary and secondary care; factors relating to health system organization and policies, including improving access to health care; easier primary care access to diagnostic tests; and use of information technology. Re-allocation of funding to support timely diagnosis was seen as an issue affecting all of these.

Conclusions

To achieve more timely cancer diagnosis, health systems need to facilitate earlier patient presentation through education and better access to care, have well-educated clinicians with good access to investigations and better information technology, and adequate primary care cancer diagnostic pathway funding.

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Article Summary

Strengths and limitations of this study

- We recruited PCPs from 20 European countries, four countries from each of the Northern, Southern, Eastern, Western and Central European geographical areas, to provide variation in geography, health systems and levels of healthcare spending.
- The recruitment method allowed participation of physicians in countries in which PCPs are underrepresented in research.
- The survey had only one question that related directly to PCPs' views on the timeliness of cancer diagnosis.
- Neither patients, secondary care nor other primary care health professionals were included in the survey, and these groups may have had other insights to offer.

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Introduction

Cancer survival rates vary widely in Europe [1], leading to considerable additional mortality in some countries. Data from the European Cancer Registry-based Study on Survival and Care of Cancer Patients (EUROCARE-5) show that the national 1-year relative survival rates for all cancer sites vary from 58.2% to 81.1% [2]. Poorer 1-year relative survival is thought to be indicative of diagnostic delay [3 4] and more advanced disease at diagnosis [5 6], although it can be affected by differences in registration, as well as overdiagnosis and lead-time biases [7 8]. There may also be geographical differences in incidence of cancers that have a poorer prognosis [9], as well as national variations in access to effective cancer treatment [10], and in levels of poverty, which in itself has been linked with more advanced disease stage at diagnosis [11-13]. More advanced cancers are more difficult to treat successfully [14] and, for many cancers, the stage of disease at diagnosis is related to survival [15 16]. There is considerable evidence that longer time to diagnosis and treatment has an adverse impact on cancer mortality [17-23]. Timely care also adds to patients' quality of life and emotional well-being [24]. In addition, patients' descriptions of the quality of their care are closely related to the speed of their diagnosis and treatment; this is because they are concerned that longer waits might allow time for their cancers to grow [25].

Timely diagnosis of cancer has therefore been an important aim of healthcare providers across Europe [25]. However, the challenge in deciding where and how to achieve this is substantial [26]. In countries where a comparatively low 1-year cancer survival suggests that late diagnosis may be a major factor, it is uncertain whether this is due to patients presenting later to health-care, whether they are not being referred quickly enough by those in primary care, or whether they are not being investigated and managed efficiently in secondary care [14]. This may be a particular problem where patients with cancer present without red-flag symptoms, as how their primary care practitioners (PCPs) act depends on how their health systems are organised [27].

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Doctors and their patients recognise that general practitioners (GPs) and other PCPs have a key role in cancer detection [28-30]. It has been suggested that PCPs' knowledge of their patient populations can be used to improve health service design [31] and the planning for more effective approaches to earlier cancer recognition and referral [32]. There has been a call for research in this field [15]; although PCPs' experience of their own health systems could potentially help to improve the planning of more effective approaches to earlier cancer recognition and referral, their perceptions have not been previously evaluated.

The aim of this study was to elicit the views of GPs and other PCPs from across Europe on how they thought the timeliness of cancer diagnosis could be improved.

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Methods and design

Design

Between November 2015 and December 2016, we performed an online survey of PCPs in 20 European countries. The methodology of the study is described in our published protocol paper [33].

Development of the questionnaire

The Örenäs Research Group is a European group of primary care researchers that studies the primary care factors that relate to cancer survival. After a literature review, Örenäs Research Group investigators developed a questionnaire designed to elicit PCPs' referral decisions on patients that could have cancer, and their degree of agreement with items relating to health system aspects that could affect their decision to refer patients with potential cancer symptoms for further investigation. The final, open-ended question asked: 'How do you think the speed of diagnosis of cancer in primary care could be improved?' The answers to this question are used in this analysis.

The questionnaire was piloted twice by PCPs in 16 Örenäs Research Group centres. No changes were made to the final, open-ended question after either of the piloting stages. Örenäs Research Group leads arranged for translations of the questionnaire into their local languages where these were not English, a total of 19 translations from the original English. Translation, validation by back-translation to assess semantic and conceptual equivalence, and cultural adaptation [34] of the survey were done in a standardised way [35] and are described elsewhere [36]. The questionnaires were put online using SurveyMonkey (SurveyMonkey, California, USA).

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Participants and recruitment

The study was conducted in 25 Örenäs Research Group centres in 20 countries across Europe: Bulgaria, Croatia, Denmark, England, Finland, France, Germany, Greece, Israel, Italy, Netherlands, Norway, Poland, Portugal, Romania, Scotland, Slovenia, Spain, Sweden and Switzerland. Local study leads were asked to either gain ethical approval or obtain a statement that formal ethical approval was not needed in their jurisdiction (see supplementary file).

Criterion sampling was used [37], with subjects being eligible for the survey if they were doctors working mainly in primary care. These doctors, referred to collectively here as 'Primary Care Practitioners', consisted of GPs as well as other doctors who had specialist training but worked in the community and could be accessed directly by patients without referral.

Each Örenäs Research Group local lead was asked to email a survey invitation to the PCPs in their local health district, and to recruit at least 50 participants, with no maximum limit. This allowed recruitment of a varied sample with regards to gender, years since graduation, site of practice (urban, rural, remote), and size of practice. Consent was implied by agreeing to take part in the survey.

Data analysis

Local Örenäs Research Group leads translated the responses from their own languages into English and sent them to MH, who asked them for more information where the translation or context was unclear.

We used inductive thematic analysis [38], an approach in which codes and themes are suggested by the data rather than by a theoretical framework. The phases of analysis included coding, followed by the identification and clustering of themes and sub-themes, and the production of a descriptive thematic summary. Two researchers (MH and SH) independently coded the data from three countries and compared their analyses for inconsistencies and agreement. MH

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then coded the data from the other countries. Team members from seven participating countries (ME, MH, RH, TK, ALN, DP, HT, all PCPs) then independently considered themes and sub-themes, discussed these and came to a consensus over the course of two meetings. The themes and sub-themes were grouped to construct an interpretative narrative across the dataset and depicted diagrammatically. Apart from SH, a Masters psychology student, all authors involved in the coding and thematic analysis were experienced general practitioners who were also active in primary care research.

Patient and public involvement

There was no patient or public involvement in this study.

Results

A total of 1,833 PCPs completed the full questionnaire, with a median response rate per country of 24.8% (range 7.1% to 65.6%). All participating centres received at least 50 responses, with a median of 61 PCPs per country. In all, 1,352 PCPs (73.8% of completers) gave an answer to the final, open-ended survey question 'How could the speed of diagnosis of cancer in primary care could be improved?', with a median of 48 per country (Table 1). To reduce the risk of bias from countries with larger numbers of respondents, we coded a maximum of 100 respondents' comments, randomly sampled, per country. The demographic distributions of the PCPs answering this final survey question are shown in Table 2. Towards the end of the analysis, no new themes emerged.

We identified four main themes organising the content of the responses to the final survey question: patient-related factors, care provider-related features, improving communication and inter-professional partnership, and aspects of health system organisation and health policies. Two structural facets transcended the four themes: accessing diagnostic tests and using information technology. The issue of allocating funding to support timely diagnosis fed into all the other themes. The themes are shown diagrammatically in Figure 1. Themes and

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subthemes are described below, with participant quotations identified by country and a participant number.

(Place Figure 1 here)

Patient-related factors

This theme included ideas on education and training to improve patient knowledge. Many PCPs advocated the use of health education and media campaigns to improve patient awareness of alarm symptoms and signs:

> ‘By giving patients better information about when to go to a doctor - reduce patient delay.’ (Denmark, PCP69)

> ‘Improve health literacy of patients regarding the detection of early symptoms that might indicate oncological disease.’ (Portugal, PCP37)

Targeting advice on cancer risks was also considered important:

> ‘Informing patients about cancer risks related to their age groups.’ (Italy, PCP28)

However, public health messages could be seen as unworkable:

> ‘Stop public campaigns telling everyone with a particular symptom they need e.g. a chest X-ray after 3 weeks of cough – inappropriately blocking the service.’ (Scotland, PCP16)

Care provider-related factors

PCPs had suggestions on how to improve their own knowledge and that of other caregivers, by both increasing the amount of the training and improving the teaching content. Improving the training of PCPs and other health care professionals was considered by many respondents to be important:

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> ‘By educating health care professionals. When to suspect and when to do further tests?’ (Finland, PCP33)

> ‘CME [continuing medical education] on early signs and up-to-date investigation processes.’ (Sweden, PCP52)

Alertness in their role was also considered key:

> ‘Often the presence of alarm signs is too late ... Be alert and listen to the patients.’ (Spain, PCP46)

Primary care doctors also need to be aware of the relevant clinical pathways:

> ‘Training of GPs … taking into account the entire pathway from symptom to diagnosis.’ (Poland, PCP17)

PCPs thought it important that cancer screening and referral guidelines should be clear, and that they themselves should be involved in designing them.

> ‘Clear guidelines regarding cancer alarm signs and referral indications.’ (Finland, PCP37)

> ‘GPs who design guidelines together with specialists.’ (Sweden, PCP21)

Improving communication and inter-professional partnership

Patient-PCP communication improvements and enhancements to inter-professional partnerships were frequently suggested by the PCP respondents. Improving communication with patients was considered important, though this implied having longer consultations:

> ‘GPs should pay more attention when they speak to patients.’ (Italy, PCP26)

> ‘Longer consultations to allow more thorough assessment without pressure of time.’ (Scotland, PCP5)

Improving the interaction within the practice team could also be helpful:

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> ‘Discussion in the team about recent referrals so the team benchmarks itself.’ (England, PCP22)

> ‘A lot can be learnt from colleagues' experiences of missed diagnoses.’ (Netherlands, PCP40)

Improving partnership between PCPs and other primary health care professionals, for example nurses and health-care assistants, with adequate training, was also considered important:

> ‘Involve the nurses in gathering the patient’s medical history.’ (Poland, PCP20)

> ‘Good training of health-care assistant to identify risk symptoms.’ (Norway, PCP1)

Improving the relationship between primary and secondary care doctors, with easier and reliable communication between the two, was highlighted:

> ‘Easy communication with specialists (and, in my case, preferably email contact).’ (Netherlands, PCP85)

> ‘It is essential to establish a communication channel between primary health care and specialist health care so that critical patients would not get lost in the system.’ (Croatia, PCP36)

Joint working with public health departments was also considered valuable:

> ‘With the cooperation between the National Institute of Public Health and family medicine specialists, who know their patients best.’ (Croatia, PCP38)

Many doctors commented on the importance of continuity of care:

> ‘Knowing your patient well. Consequently, not having three different GPs for one patient.’ (Netherlands, PCP69)

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Strengthening system organisation and improving health policy

Strengthening how health systems are organised and implementing health policies that allow timely cancer diagnosis were key recommendations from many PCPs. Enhancing patient access to primary care, particularly for vulnerable or more remote groups, was considered important by some:

> 'Shorter queues to GP appointment in order to start assessments without delay.' (Finland, PCP33)

> 'In some places (rural, inland) inaccessibility to MCDTs [screening examinations] can be an obstacle.' Portugal, PCP43)

Practical steps to improve access to secondary care were also seen as key, particularly those relating to costs to the patient:

> 'Access to specialists must be cheaper.' (Romania, PCP99)

> 'Patient friendly hospital services - so that the appointments are not too stressful or expensive (travel and parking).' (England, PCP19)

Many PCPs commented on the need for better working conditions, a larger workforce, a reduced workload and less bureaucracy:

> 'A sufficient number of healthcare professionals so that there is not too much workload for a few.' (Croatia, PCP5)

> 'Reduction of the workload at the family medicine doctor office.' (Croatia, PCP31)

> 'By decreasing bureaucracy! So we will have more time for a real consultation!' (Romania, PCP49)

The adoption of financial incentives schemes was also suggested:

> 'Allocating additional financial resources and stimulating the GP in this direction.' (Romania, PCP78)

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> 'Financial incentives for preventative care of most common malignant conditions.' (Bulgaria, PCP4)

PCPs felt that guidelines and protocols needed to be clear and relevant to them:

> 'Clear guidelines regarding cancer alarm signs and referral indications.' (Finland, PCP37)

> 'By developing a more specific GP protocol for the various types of cancer.' (Netherlands, PCP51)

Fast-track systems for patients with cancer were requested by many respondents:

> 'Create a fast-track unit for patients with high cancer suspicion.' (Spain, PCP51)

> 'Preferential appointments for cases with cancer suspicion in all hospital specialities.' (Spain, PCP6)

In countries where fast-track systems already existed, these were seen as a success:

> 'Cancer diagnostics have priority in the Norwegian health care system since fast track referral was introduced last year. Functions well.' (Norway, PCP5)

> 'I actually think that the introduction of the "2-week wait" urgent referral system has greatly improved the speed of diagnosis for those with obvious red flag symptoms.' (England, PCP11)

Some PCPs felt that there should be more uptake of national screening programmes:

> 'Encourage patients to use existing prevention programmes.' (Germany, PCP7)

> 'All physicians should adhere to screening guidelines.' (Switzerland, PCP8)

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Accessing diagnostic tests

This theme suggesting improvements to diagnostic structures dealt mainly with easier and quicker access to testing. Easier PCP access to diagnostic testing was cited by many respondents:

> 'Increasing the range of diagnostics available; also making them easier to refer for.' (Netherlands, PCP79)

> 'Facilitating family doctors to request tests and investigations that he/she considers necessary for the diagnosis.' (Spain, PCP39)

Many felt that they should have direct access to cancer-specific testing:

> 'GPs should be able to recommend any investigation without reference to other specialist doctors.' (Romania, PCP44)

> 'Give GPs the ability to refer patients to more diagnostic tests e.g. CT, tumour markers.' (Poland, PCP26)

The speed of access to diagnostic tests was also seen as key:

> 'Faster access/fast track to imaging diagnostics could help us exclude a number of cases and so could relieve specialist services.' (Norway, PCP18)

> 'Reduction of the delay in getting special tests.' (France, PCP 2)

However, some PCPs were worried that the increase in investigation of patients needed to diagnose cancers earlier could also lead to overdiagnosis and overtreatment:

> 'Cancer diagnostics are a difficult balancing act between under- and overdiagnosis. Faster cancer diagnostics will also give more overdiagnosis.' (Norway, PCP 31)

> 'Depends on the type of cancer, but there is a trade-off between diagnosing a few cancers earlier by referring lots more patients to specialist clinics and the increased stress,

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> anxiety, expense and risk of physical harm from unnecessary ionizing radiation and treatments.' (England, PCP 7)

Using information technology

This theme was about using electronic information and communication to improve diagnostic capability and enhance partnership working. Some PCPs thought that more decision support aids should be included in electronic health records:

> 'Automatic decision support/diagnostic support in the GP electronic information system based on symptoms.' (Netherlands, PCP10)

> 'The 29 Norwegian guidelines regarding 'fast track referral for cancer' could be included into our electronic patient files as a real decision aid with extraction of clinical information for the referral.' (Norway, PCP3)

Information technology could also be used to help identify those who would benefit from screening, and provide reminders relating to individual patients where needed:

> 'Select specific age groups from healthcare databases and identify the individuals that haven't had the screening.' (Portugal, PCP11)

> 'Using an automatic reminder system for cancer screening for each patient.' (Greece, PCP15)

Some PCPs were keen on the option to have 'virtual consultations' with specialists:

> 'Allow virtual consultations with specialists in specific subjects to validate malignancy diagnosis (radiologists/pulmonologists/gastroenterologists/surgeons, etc.) (Israel, PCP18)

Allocating funding to support timely diagnosis

Adequate resources for primary care and targeted funding for investigations were frequently recommended by participants. This theme wove through the whole cancer diagnostic process.

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An increase in primary care financing was considered to be necessary if PCPs were to improve access to care:

> 'By increasing resources in primary care in order to improve the access to care.' (Finland, PCP34)

Adequate funds were also seen to be needed for screening and diagnostic tests:

> 'Increase funding of screening tests.' (Poland, PCP20)

> 'A higher budget for diagnostic tests, covering … some higher costs related to the investigation and early diagnosis of cancer.' (Romania, PCP59)

In some countries, there was a need for an increase in the budget for diagnostic tests and referrals:

> 'Increase funding for cancer diagnostic tests (tumour markers, colonoscopy, gastroscopy, radiographs) - currently, the funding is insufficient.' (Poland, PCP29)

> 'Unlimited lab tests and unlimited referrals to specialist services if malignant conditions are suspected.' (Bulgaria, PCP11)

Funding limitations could be an issue for patients:

> 'Many patients refuse the investigations because of the costs (tumour markers, MRI, extra payment to the specialist doctor, ineffective collaboration between specialities).' (Romania, PCP12)

This could also affect the finances of the PCPs themselves:

> 'Ensure adequate financial support – at present there are penalties if the number of consultations exceeds the limit, even if the consultations are clinically indicated.' (Bulgaria, PCP25)

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Discussion

Principal findings

In this primary care study, participants from twenty countries were able to use their experience situated in their own healthcare systems to provide a rich variety of suggestions for the improvements needed to allow more timely diagnosis of cancer. These covered the whole diagnostic pathway, from recommendations on how to help patients to present earlier with their symptoms, through continuing medical education that would help PCPs to recognise and act on symptoms that could be due to cancer, to improving communication and inter-professional partnership between and within primary and secondary care. Improving health system organisation and health policies is essential for achieving these goals. Facilitating patients' access to health care was also considered important, as was enabling fast and direct PCP access to diagnostic tests. Respondents saw funding allocation as an underlying component of most of these issues. They also identified a risk that reducing delays in cancer diagnosis in some patients could lead to overdiagnosis in others.

Strengths and weaknesses of the study

This is the first trans-European study to explore PCPs' perceptions of how timeliness of cancer diagnosis can be improved, offering a unique insight into the operational and administrative challenges. This could be invaluable for the evaluation and revision of current healthcare policies and practices. Cancer diagnosis is a complex process and the diagnostic behaviour of PCPs working under the influences of their native health care systems is a key determinant. A key strength of our work is that we have gathered the views of PCPs from 20 countries on this process; our analysis examines systemic influences on PCP cancer diagnostic activity across Europe.

Variation in geography, health systems and levels of healthcare spending was provided by having four participating countries from each of the Central, Eastern, Northern, Southern and

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Western European geographical areas. The sample size was large and diverse, with participants varying in terms years of clinical practice, gender, and site and size of practice. The study successfully recruited participants in countries in which PCPs are underrepresented in research.

The survey had only one, short question that related directly to our research question. However, it may be that this format prompted participants to focus on writing down only what, for them, was the most important point. Neither patients, secondary care nor other primary care health professionals were included in the survey, and these groups may have had other insights to offer. There is a risk that the translators and investigators misunderstood some of the nuances of the twenty different languages, cultures and healthcare organisations involved in this study. While themes were identified from responses from PCPs in 20 European countries, not all of the themes identified will be equally relevant to each of the participating countries.

The data collection was completed in December 2016, and participating countries' health systems will have continued to develop since then. However, each of the themes results from PCPs' comments on healthcare is situated in a society and culture which changes very slowly, as is also seen for implementation of new knowledge. The findings are therefore likely to continue to be relevant.

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Comparison with other studies

Our findings map across to those of a survey of GPs in Ireland, which identified that barriers to early cancer diagnosis included lack of direct GP access to diagnostic tests, difficulties with referral to secondary care, poor clarity relating to cancer screening, unequal patient access to secondary services, and a need for further training and guidelines [39]. GPs' views on the importance of closer links between primary and secondary care were identified in that study, and also in a United Kingdom (UK) study [29]. Our PCPs' call for improved patient education and better access to diagnostic testing specialist care were also prioritised by GPs in another UK study [40]. Our findings map across to the findings from qualitative research on patient-perceived barriers to early presentation and diagnosis of cancer, which have identified the need for better access to services for patients [41 42] and better patient awareness of cancer symptoms [42] as key issues.

The need for healthcare systems to support PCPs' quick and easy access to investigations has been proposed before [43]. While investigation in primary care has been linked with later referral for specialist assessment, reducing the waiting time for tests would be expected to shorten the primary-care intervals associated with investigation use [44]. Despite this, another study found that some patients received a delayed cancer diagnosis, even when they had presented with typical cancer symptoms to a GP who had access to relevant diagnostic tests [45].

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Possible implications for clinicians and policymakers

PCP respondents had specific recommendations on the changes that are needed to facilitate more timely diagnosis of cancer. Some recommendations, for instance health education campaigns and development of relevant guidelines, may need central direction, albeit with the input of PCPs. Others, for example improving the way PCP communicate with secondary care specialists, and PCPs' ability to access to cancer-specific tests, may need local agreement. Aspects such as PCPs' own communication skills, their own accessibility to patients and their continuing medical education, are more likely to be under PCPs' own control. However, a consideration of how funding is best reallocated is crucial if PCPs and their health systems are able to make these changes.

Unanswered questions and future research

Further analysis is needed to help identify which recommendations are most relevant to different existing models of healthcare, for example as to whether some are particularly relevant to systems in which the PCP has more of a 'gatekeeper' role, or to those in which PCP practises are large or smaller than average. A longitudinal study would give evidence on the trends on PCP opinions and how they are impacted by changes in health policies and public health initiatives. Research using interviews would give in-depth ideas on how changes resulting from the study findings could be implemented. A mixed-methods approach, comparing PCPs' views from different countries, would allow recommendations that are relevant to individual countries. In the study we have focused on the view of PCPs, as they have a key role in cancer diagnosis throughout Europe; however, the views of other stakeholders, such as patients and policy makers, are also important and should be included in future qualitative research.

There is a need to consider how to get the best balance between achieving early cancer diagnosis and minimising overdiagnosis of cancer. Our study gives the basic elements for the international primary care cancer research agenda, which would provide a knowledgebase for developing and improving cancer diagnosis and prognosis internationally.

Conclusions

This research has identified key features that PCPs believe would be necessary to improve the timeliness of cancer diagnosis in their patients, and a need for re-allocation of health system funding to allow these to happen. Health systems need to facilitate earlier patient presentation through health education and better access to care, have well-educated clinicians with good access to investigations and better information technology, and adequate primary care cancer diagnostic pathway funding.

Many PCPs play a crucial role at the centre of their patients' care, and the breadth of their experience is reflected in their wide range of suggestions. This understanding should help to inform health service policy and research towards better cancer outcomes.

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List of abbreviations

CME	Continuing medical education
GP	General practitioner
PCP	Primary Care Physician
UK	United Kingdom

Declarations

Ethics approval

Ethical approval for the study was given by the University of Bath Research Ethics Approval Committee for Health (approval date: 24th November 2014; REACH reference number: EP 14/15 66). Other countries' study leads either achieved local ethical approval or gave statements that formal ethical approval was not needed in their jurisdictions.

Competing interests

The authors declare that they have no competing interests.

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Data sharing statement

The Örenäs survey data that support the findings of this study are available from the corresponding author, M Harris, on reasonable request.

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Author contributions

K Buczkowski, M Brekke, N Buono, E Costiug, G-J Dinant, M Esteva, G Foreva, M Harris, R Hoffman, E Jakob, T Koskela, M Marzo-Castillejo, P Murchie, AL Neves, DP Petek, J Sawicka-Powierza, A Schneider, E Smyrnakis, S Streit, H Thulesius, P Vedsted and B Weltermann participated in the study design, piloting and data collection. G Taylor participated in the study design. S Harker coded some of the data. M Esteva and S Harker assisted in validated the coding. M Esteva, M Harris, R Hoffman, T Koskela, AL Neves, D Petek and H Thulesius worked together to agree the themes. M Harris had overall responsibility for the study design, recruitment of local leads, analysis of data and interpretation of results. All authors contributed to the writing and review of the manuscript and approved the final version.

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Table 1. *National distribution of PCPs who responded to the question 'How do you think the speed of diagnosis of cancer in primary care could be improved?'*

Country	Number of PCPs who completed the survey	Number who answered the open-ended question (% of all survey completers)
Bulgaria	52	45 (86.5)
Croatia	56	42 (75.0)
Denmark	92	71 (77.2)
England	62	25 (40.3)
Finland	61	39 (63.9)
France	52	35 (67.3)
Germany	91	31 (34.1)
Greece	59	50 (84.7)
Israel	58	42 (72.4)
Italy	60	52 (86.7)
Netherlands	108	84 (77.8)
Norway	81	46 (56.8)
Poland	135	103 (76.3)
Portugal	59	46 (78.0)
Romania	146	132 (90.4)
Scotland	62	55 (88.7)

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Slovenia	91	52 (57.1)
Spain	380	332 (87.4)
Sweden	68	55 (80.9)
Switzerland	60	15 (25.0)
Total	1,833	1,352 (73.8)

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Table 2. *Demographic distribution of PCPs who responded to the question 'How do you think the speed of diagnosis of cancer in primary care could be improved?'*

Demographic	Number (%)
Gender	
Female	833 (61.6)
Male	513 (38.0)
Not stated	5 (0.4)
Years since graduation	
<10	192 (14.2)
10–19	356 (26.4)
20–29	416 (30.8)
30–39	336 (24.9)
40 or over	47 (3.5)
Not stated	4 (0.3)
Site of practice	
Urban	816 (60.4)
Rural	314 (23.2)
Island	25 (1.9)

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Mixed	194 (14.4)
Not stated	2 (0.1)
Number of doctors in practice	
1-2	337 (24.9)
3-5	344 (25.5)
6-9	290 (21.5)
10 or more	374 (27.7)
Not stated	6 (0.4)

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Figure legends

Figure 1. *Diagrammatic representation of themes emerging from responses to the question:*

'How do you think the speed of diagnosis of cancer in primary care could be improved?'

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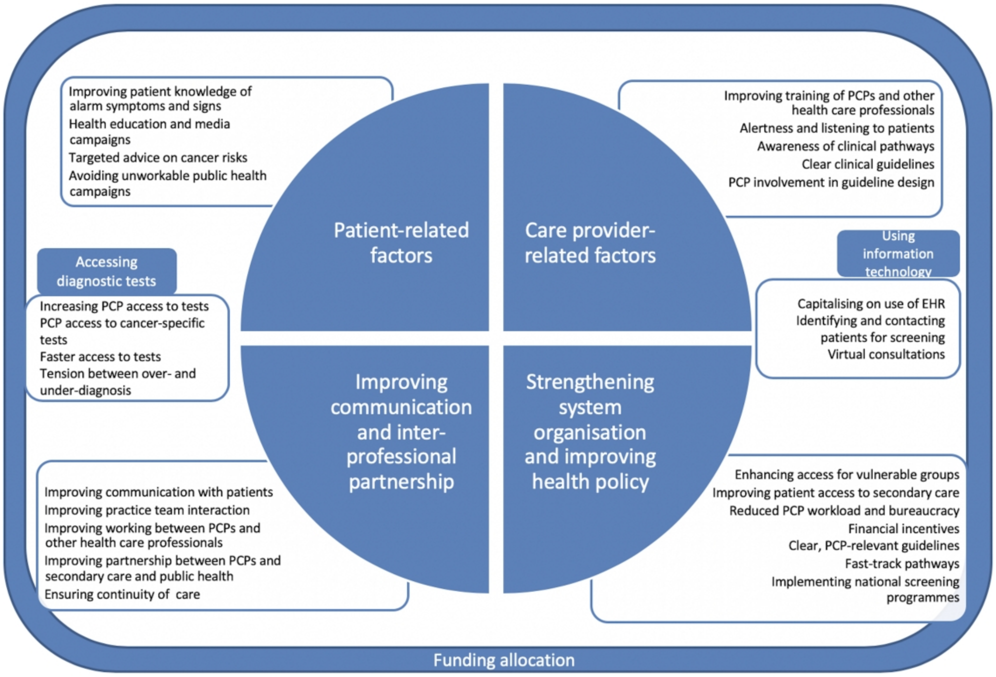

Figure 1. Diagrammatic representation of themes emerging from responses to the question: ‘How do you think the speed of diagnosis of cancer in primary care could be improved?’

292x200mm (300 x 300 DPI)

Supplementary file. Ethical and other approvals obtained in each Örenäs Research Group participating jurisdiction

	Date of Ethics Approval	Approvals obtained	Reference
Bulgaria	29 October 2015	Medical University Plovdiv Ethical Commission	P-7820
Croatia	16 December 2016	Nastavni Zovod Za Javno Zdravstvo	08-820-61/31-15
Denmark	7 May 2016	Danish Data Protection Agency; according to Danish law and the Central Denmark Region Committees on Health Research Ethics, approval by the National Committee on Health Research Ethics was not required as no biomedical intervention was performed.	2009-41-3471
Finland	16 November 2016	Academic Ethics Committee of the Tampere Region	16 November 2016
France	N/A	In France, research ethics approval was not required as no biomedical intervention was performed.	
Germany	15 January 2016	Ethik-Kommission Universität Duisberg-Essen	16-6747-BO
Greece	N/A	In Greece, research ethics approval was not required as no biomedical intervention was performed.	
Israel	N/A	In Israel, research ethics approval was not required as no biomedical intervention was performed.	
Italy	N/A	In Italy the approval of the ethical committee is not required when a study is neither an interventional nor an observational study on pharmacological treatment.	Decreto Legislativo n. 211 (24 giugno 2003)<2001/20/EC
Netherlands	27 June 2016	medisch-ethischetoetsingscommissie (METC) azM/UM Maastricht UMC+	METC 16-4-113
Norway	N/A	In Norway, research ethics approval was not required as no biomedical intervention was performed.	
Poland	28 January 2016	Komisja Bioetyczena Uniwersytetu Medycznego w Bialymstoku	R_I_022/10/2016

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Portugal	N/A	In Portugal, research ethics approval was not required as no biomedical intervention was performed.	
Romania	N/A	In Romania, research ethics approval was not required as no biomedical intervention was performed.	
Slovenia	8 December 2014	Komisija Republike Slovenije Medicinsko Etiko	KME 113/08/14
Spain	25 October 2015 23 Decmber 2015	Comissio d'Investigacio Govern de les Illes Balears Informe del Comite Etic d'Investigacio Clinica	Palma 27oct15 P15/159
Sweden	N/A	In Sweden, research ethics approval was not required as no biomedical intervention was performed. It does not fall under the law of research on human subjects to ask professionals about their work and how they perceive it.	
Switzerland	N/A	Swiss law on human research (Humanforschungsgesetz, HFG) does not require that an ethics committee approve collection and analysis of non-medical and anonymous data.	
United Kingdom	24 November 2014	Research Ethics Approval Committee for Health, University of Bath	EP 14/15 66

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

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		Reporting Item	Page Number
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	4-5
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	7-8
Purpose or research question	#4	Purpose of the study and specific objectives or questions	8
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also	9-10

		recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	10-11
Context	#7	Setting / site and salient contextual factors; rationale	9-10
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	10
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	10; 24
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	9-10
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	9
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	11
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	10

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Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	10
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	10
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	11-19
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11-19
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	19-21
Limitations	#19	Trustworthiness and limitations of findings	20
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	24
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	24

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BMJ Open

How European primary care practitioners think the timeliness of cancer diagnosis can be improved – a thematic analysis

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	Investigación
Primary Subject Heading:	General practice / Family practice
Secondary Subject Heading:	Oncology, Qualitative research, Public health
Keywords:	Delivery of Health Care, Primary Health Care, General Practitioners, Cancer, Diagnosis, Consultation and Referral

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Manuscripts

How European primary care practitioners think the timeliness of cancer diagnosis can be improved – a thematic analysis

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Delivery of Health Care; Primary Health Care; General Practitioners; Cancer; Diagnosis; Consultation and Referral.

Word count

3,182 (excluding data/quotes)

Abstract

Background

National European cancer survival rates vary widely. Prolonged diagnostic intervals are thought to be a key factor in explaining these variations. Primary Care Practitioners (PCPs) frequently play a crucial role during initial cancer diagnosis; their knowledge could be used to improve the planning of more effective approaches to earlier cancer diagnosis.

Objectives

This study sought the views of PCPs from across Europe on how they thought the timeliness of cancer diagnosis could be improved.

Design

In an online survey, a final open-ended question asked PCPs how they thought the speed of diagnosis of cancer in primary care could be improved. Thematic analysis was used to analyse the data.

Setting

A primary care study, with participating centres in twenty European countries.

Participants

A total of 1,352 PCPs answered the final survey question, with a median of 48 per country.

Results

The main themes identified were: patient-related factors, including health education; care provider-related factors, including continuing medical education; improving communication

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and inter-professional partnership, particularly between primary and secondary care; factors relating to health system organization and policies, including improving access to health care; easier primary care access to diagnostic tests; and use of information technology. Re-allocation of funding to support timely diagnosis was seen as an issue affecting all of these.

Conclusions

To achieve more timely cancer diagnosis, health systems need to facilitate earlier patient presentation through education and better access to care, have well-educated clinicians with good access to investigations and better information technology, and adequate primary care cancer diagnostic pathway funding.

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Article Summary

Strengths and limitations of this study

- We recruited PCPs from 20 European countries, four countries from each of the Northern, Southern, Eastern, Western and Central European geographical areas, to provide variation in geography, health systems and levels of healthcare spending.
- The recruitment method allowed participation of physicians in countries in which PCPs are underrepresented in research.
- The survey had only one question that related directly to PCPs' views on the timeliness of cancer diagnosis.
- Neither patients, secondary care nor other primary care health professionals were included in the survey, and these groups may have had other insights to offer.

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Introduction

Cancer survival rates vary widely in Europe [1], leading to considerable additional mortality in some countries. Data from the European Cancer Registry-based Study on Survival and Care of Cancer Patients (EUROCARE-5) show that the national 1-year relative survival rates for all cancer sites vary from 58.2% to 81.1% [2]. Poorer 1-year relative survival is thought to be indicative of diagnostic delay [3 4] and more advanced disease at diagnosis [5 6], although it can be affected by differences in registration, as well as overdiagnosis and lead-time biases [7 8]. There may also be geographical differences in incidence of cancers that have a poorer prognosis [9], as well as national variations in access to effective cancer treatment [10], and in levels of poverty, which in itself has been linked with more advanced disease stage at diagnosis [11-13]. More advanced cancers are more difficult to treat successfully [14] and, for many cancers, the stage of disease at diagnosis is related to survival [15 16]. There is considerable evidence that longer time to diagnosis and treatment has an adverse impact on cancer mortality [17-23]. Timely care also adds to patients' quality of life and emotional well-being [24]. In addition, patients' descriptions of the quality of their care are closely related to the speed of their diagnosis and treatment; this is because they are concerned that longer waits might allow time for their cancers to grow [25].

Timely diagnosis of cancer has therefore been an important aim of healthcare providers across Europe [25]. However, the challenge in deciding where and how to achieve this is substantial [26]. In countries where a comparatively low 1-year cancer survival suggests that late diagnosis may be a major factor, it is uncertain whether this is due to patients presenting later to health-care, whether they are not being referred quickly enough by those in primary care, or whether they are not being investigated and managed efficiently in secondary care [14]. This may be a particular problem where patients with cancer present without red-flag symptoms, as how their primary care practitioners (PCPs) act depends on how their health systems are organised [27].

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Doctors and their patients recognise that general practitioners (GPs) and other PCPs have a key role in cancer detection [28-30]. It has been suggested that PCPs' knowledge of their patient populations can be used to improve health service design [31] and the planning for more effective approaches to earlier cancer recognition and referral [32]. There has been a call for research in this field [15]; although PCPs' experience of their own health systems could potentially help to improve the planning of more effective approaches to earlier cancer recognition and referral, their perceptions have not been previously evaluated.

The aim of this study was to elicit the views of GPs and other PCPs from across Europe on how they thought the timeliness of cancer diagnosis could be improved.

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Methods and design

Design

Between November 2015 and December 2016, we performed an online survey of PCPs in 20 European countries. The methodology of the study is described in our published protocol paper [33].

Development of the questionnaire

The Örenäs Research Group is a European group of primary care researchers that studies the primary care factors that relate to cancer survival. After a literature review, Örenäs Research Group investigators developed a questionnaire designed to elicit PCPs' referral decisions on patients that could have cancer, and their degree of agreement with items relating to health system aspects that could affect their decision to refer patients with potential cancer symptoms for further investigation. The final, open-ended question asked: 'How do you think the speed of diagnosis of cancer in primary care could be improved?' The answers to this question are used in this analysis.

The questionnaire was piloted twice by PCPs in 16 Örenäs Research Group centres. No changes were made to the final, open-ended question after either of the piloting stages. Örenäs Research Group leads arranged for translations of the questionnaire into their local languages where these were not English, a total of 19 translations from the original English. Translation, validation by back-translation to assess semantic and conceptual equivalence, and cultural adaptation [34] of the survey were done in a standardised way [35] and are described elsewhere [36]. The questionnaires were put online using SurveyMonkey (SurveyMonkey, California, USA).

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Participants and recruitment

The study was conducted in 25 Örenäs Research Group centres in 20 countries across Europe: Bulgaria, Croatia, Denmark, England, Finland, France, Germany, Greece, Israel, Italy, Netherlands, Norway, Poland, Portugal, Romania, Scotland, Slovenia, Spain, Sweden and Switzerland. Local study leads were asked to either gain ethical approval or obtain a statement that formal ethical approval was not needed in their jurisdiction (see supplementary file).

Criterion sampling was used [37], with subjects being eligible for the survey if they were doctors working mainly in primary care. These doctors, referred to collectively here as 'Primary Care Practitioners', consisted of GPs as well as other doctors who had specialist training but worked in the community and could be accessed directly by patients without referral.

Each Örenäs Research Group local lead was asked to email a survey invitation to the PCPs in their local health district, and to recruit at least 50 participants, with no maximum limit. This allowed recruitment of a varied sample with regards to gender, years since graduation, site of practice (urban, rural, remote), and size of practice. Consent was implied by agreeing to take part in the survey.

Data analysis

Local Örenäs Research Group leads translated the responses from their own languages into English and sent them to MH, who asked them for more information where the translation or context was unclear.

We used inductive thematic analysis [38], an approach in which codes and themes are suggested by the data rather than by a theoretical framework. The phases of analysis included coding, followed by the identification and clustering of themes and sub-themes, and the production of a descriptive thematic summary. Two researchers (MH and SH) independently coded the data from three countries and compared their analyses for inconsistencies and agreement. MH

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then coded the data from the other countries. Team members from seven participating countries (ME, MH, RH, TK, ALN, DP, HT, all PCPs) then independently considered themes and sub-themes, discussed these and came to a consensus over the course of two meetings. The themes and sub-themes were grouped to construct an interpretative narrative across the dataset and depicted diagrammatically. Apart from SH, a Masters psychology student, all authors involved in the coding and thematic analysis were experienced general practitioners who were also active in primary care research.

Patient and public involvement

There was no patient or public involvement in this study.

Results

A total of 1,833 PCPs completed the full questionnaire, with a median response rate per country of 24.8% (range 7.1% to 65.6%). All participating centres received at least 50 responses, with a median of 61 PCPs per country. In all, 1,352 PCPs (73.8% of completers) gave an answer to the final, open-ended survey question ‘How could the speed of diagnosis of cancer in primary care could be improved?’, with a median of 48 per country (Table 1). To reduce the risk of bias from countries with larger numbers of respondents, we coded a maximum of 100 respondents’ comments, randomly sampled, per country. The demographic distributions of the PCPs answering this final survey question are shown in Table 2. Towards the end of the analysis, no new themes emerged.

We identified four main themes organising the content of the responses to the final survey question: patient-related factors, care provider-related features, improving communication and inter-professional partnership, and aspects of health system organisation and health policies. Two structural facets transcended the four themes: accessing diagnostic tests and using information technology. The issue of allocating funding to support timely diagnosis fed into all the other themes. The themes are shown diagrammatically in Figure 1. Themes and

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subthemes are described below, with participant quotations identified by country and a participant number.

(Place Figure 1 here)

Patient-related factors

This theme included ideas on education and training to improve patient knowledge. Many PCPs advocated the use of health education and media campaigns to improve patient awareness of alarm symptoms and signs:

> ‘By giving patients better information about when to go to a doctor - reduce patient delay.’ (Denmark, PCP69)

> ‘Improve health literacy of patients regarding the detection of early symptoms that might indicate oncological disease.’ (Portugal, PCP37)

Targeting advice on cancer risks was also considered important:

> ‘Informing patients about cancer risks related to their age groups.’ (Italy, PCP28)

However, public health messages could be seen as unworkable:

> ‘Stop public campaigns telling everyone with a particular symptom they need e.g. a chest X-ray after 3 weeks of cough – inappropriately blocking the service.’ (Scotland, PCP16)

Care provider-related factors

PCPs had suggestions on how to improve their own knowledge and that of other caregivers, by both increasing the amount of the training and improving the teaching content. Improving the training of PCPs and other health care professionals was considered by many respondents to be important:

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> ‘By educating health care professionals. When to suspect and when to do further tests?’ (Finland, PCP33)

> ‘CME [continuing medical education] on early signs and up-to-date investigation processes.’ (Sweden, PCP52)

Alertness in their role was also considered key:

> ‘Often the presence of alarm signs is too late ... Be alert and listen to the patients.’ (Spain, PCP46)

Primary care doctors also need to be aware of the relevant clinical pathways:

> ‘Training of GPs … taking into account the entire pathway from symptom to diagnosis.’ (Poland, PCP17)

PCPs thought it important that cancer screening and referral guidelines should be clear, and that they themselves should be involved in designing them.

> ‘Clear guidelines regarding cancer alarm signs and referral indications.’ (Finland, PCP37)

> ‘GPs who design guidelines together with specialists.’ (Sweden, PCP21)

Improving communication and inter-professional partnership

Patient-PCP communication improvements and enhancements to inter-professional partnerships were frequently suggested by the PCP respondents. Improving communication with patients was considered important, though this implied having longer consultations:

> ‘GPs should pay more attention when they speak to patients.’ (Italy, PCP26)

> ‘Longer consultations to allow more thorough assessment without pressure of time.’ (Scotland, PCP5)

Improving the interaction within the practice team could also be helpful:

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> ‘Discussion in the team about recent referrals so the team benchmarks itself.’ (England, PCP22)

> ‘A lot can be learnt from colleagues' experiences of missed diagnoses.’ (Netherlands, PCP40)

Improving partnership between PCPs and other primary health care professionals, for example nurses and health-care assistants, with adequate training, was also considered important:

> ‘Involve the nurses in gathering the patient’s medical history.’ (Poland, PCP20)

> ‘Good training of health-care assistant to identify risk symptoms.’ (Norway, PCP1)

Improving the relationship between primary and secondary care doctors, with easier and reliable communication between the two, was highlighted:

> ‘Easy communication with specialists (and, in my case, preferably email contact).’ (Netherlands, PCP85)

> ‘It is essential to establish a communication channel between primary health care and specialist health care so that critical patients would not get lost in the system.’ (Croatia, PCP36)

Joint working with public health departments was also considered valuable:

> ‘With the cooperation between the National Institute of Public Health and family medicine specialists, who know their patients best.’ (Croatia, PCP38)

Many doctors commented on the importance of continuity of care:

> ‘Knowing your patient well. Consequently, not having three different GPs for one patient.’ (Netherlands, PCP69)

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Strengthening system organisation and improving health policy

Strengthening how health systems are organised and implementing health policies that allow timely cancer diagnosis were key recommendations from many PCPs. Enhancing patient access to primary care, particularly for vulnerable or more remote groups, was considered important by some:

> ‘Shorter queues to GP appointment in order to start assessments without delay.’ (Finland, PCP33)

> ‘In some places (rural, inland) inaccessibility to MCDTs [screening examinations] can be an obstacle.’ Portugal, PCP43)

Practical steps to improve access to secondary care were also seen as key, particularly those relating to costs to the patient:

> ‘Access to specialists must be cheaper.’ (Romania, PCP99)

> ‘Patient friendly hospital services - so that the appointments are not too stressful or expensive (travel and parking).’ (England, PCP19)

Many PCPs commented on the need for better working conditions, a larger workforce, a reduced workload and less bureaucracy:

> ‘A sufficient number of healthcare professionals so that there is not too much workload for a few.’ (Croatia, PCP5)

> ‘Reduction of the workload at the family medicine doctor office.’ (Croatia, PCP31)

> ‘By decreasing bureaucracy! So we will have more time for a real consultation!’ (Romania, PCP49)

The adoption of financial incentives schemes was also suggested:

> ‘Allocating additional financial resources and stimulating the GP in this direction.’ (Romania, PCP78)

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> ‘Financial incentives for preventative care of most common malignant conditions.’ (Bulgaria, PCP4)

PCPs felt that guidelines and protocols needed to be clear and relevant to them:

> ‘Clear guidelines regarding cancer alarm signs and referral indications.’ (Finland, PCP37)

> ‘By developing a more specific GP protocol for the various types of cancer.’ (Netherlands, PCP51)

Fast-track systems for patients with cancer were requested by many respondents:

> ‘Create a fast-track unit for patients with high cancer suspicion.’ (Spain, PCP51)

> ‘Preferential appointments for cases with cancer suspicion in all hospital specialities.’ (Spain, PCP6)

In countries where fast-track systems already existed, these were seen as a success:

> ‘Cancer diagnostics have priority in the Norwegian health care system since fast track referral was introduced last year. Functions well.’ (Norway, PCP5)

> ‘I actually think that the introduction of the “2-week wait” urgent referral system has greatly improved the speed of diagnosis for those with obvious red flag symptoms.’ (England, PCP11)

Some PCPs felt that there should be more uptake of national screening programmes:

> ‘Encourage patients to use existing prevention programmes.’ (Germany, PCP7)

> ‘All physicians should adhere to screening guidelines.’ (Switzerland, PCP8)

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Accessing diagnostic tests

This theme suggesting improvements to diagnostic structures dealt mainly with easier and quicker access to testing. Easier PCP access to diagnostic testing was cited by many respondents:

> 'Increasing the range of diagnostics available; also making them easier to refer for.' (Netherlands, PCP79)

> 'Facilitating family doctors to request tests and investigations that he/she considers necessary for the diagnosis.' (Spain, PCP39)

Many felt that they should have direct access to cancer-specific testing:

> 'GPs should be able to recommend any investigation without reference to other specialist doctors.' (Romania, PCP44)

> 'Give GPs the ability to refer patients to more diagnostic tests e.g. CT, tumour markers.' (Poland, PCP26)

The speed of access to diagnostic tests was also seen as key:

> 'Faster access/fast track to imaging diagnostics could help us exclude a number of cases and so could relieve specialist services.' (Norway, PCP18)

> 'Reduction of the delay in getting special tests.' (France, PCP 2)

However, some PCPs were worried that the increase in investigation of patients needed to diagnose cancers earlier could also lead to overdiagnosis and overtreatment:

> 'Cancer diagnostics are a difficult balancing act between under- and overdiagnosis. Faster cancer diagnostics will also give more overdiagnosis.' (Norway, PCP 31)

> 'Depends on the type of cancer, but there is a trade-off between diagnosing a few cancers earlier by referring lots more patients to specialist clinics and the increased stress,

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> anxiety, expense and risk of physical harm from unnecessary ionizing radiation and treatments.' (England, PCP 7)

Using information technology

This theme was about using electronic information and communication to improve diagnostic capability and enhance partnership working. Some PCPs thought that more decision support aids should be included in electronic health records:

> 'Automatic decision support/diagnostic support in the GP electronic information system based on symptoms.' (Netherlands, PCP10)
>
> 'The 29 Norwegian guidelines regarding 'fast track referral for cancer' could be included into our electronic patient files as a real decision aid with extraction of clinical information for the referral.' (Norway, PCP3)

Information technology could also be used to help identify those who would benefit from screening, and provide reminders relating to individual patients where needed:

> 'Select specific age groups from healthcare databases and identify the individuals that haven't had the screening.' (Portugal, PCP11)
>
> 'Using an automatic reminder system for cancer screening for each patient.' (Greece, PCP15)

Some PCPs were keen on the option to have 'virtual consultations' with specialists:

> 'Allow virtual consultations with specialists in specific subjects to validate malignancy diagnosis (radiologists/pulmonologists/gastroenterologists/surgeons, etc.) (Israel, PCP18)

Allocating funding to support timely diagnosis

Adequate resources for primary care and targeted funding for investigations were frequently recommended by participants. This theme wove through the whole cancer diagnostic process.

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An increase in primary care financing was considered to be necessary if PCPs were to improve access to care:

> 'By increasing resources in primary care in order to improve the access to care.' (Finland, PCP34)

Adequate funds were also seen to be needed for screening and diagnostic tests:

> 'Increase funding of screening tests.' (Poland, PCP20)

> 'A higher budget for diagnostic tests, covering … some higher costs related to the investigation and early diagnosis of cancer.' (Romania, PCP59)

In some countries, there was a need for an increase in the budget for diagnostic tests and referrals:

> 'Increase funding for cancer diagnostic tests (tumour markers, colonoscopy, gastroscopy, radiographs) - currently, the funding is insufficient.' (Poland, PCP29)

> 'Unlimited lab tests and unlimited referrals to specialist services if malignant conditions are suspected.' (Bulgaria, PCP11)

Funding limitations could be an issue for patients:

> 'Many patients refuse the investigations because of the costs (tumour markers, MRI, extra payment to the specialist doctor, ineffective collaboration between specialities).' (Romania, PCP12)

This could also affect the finances of the PCPs themselves:

> 'Ensure adequate financial support – at present there are penalties if the number of consultations exceeds the limit, even if the consultations are clinically indicated.' (Bulgaria, PCP25)

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Discussion

Principal findings

In this primary care study, participants from twenty countries were able to use their experience situated in their own healthcare systems to provide a rich variety of suggestions for the improvements needed to allow more timely diagnosis of cancer. These covered the whole diagnostic pathway, from recommendations on how to help patients to present earlier with their symptoms, through continuing medical education that would help PCPs to recognise and act on symptoms that could be due to cancer, to improving communication and inter-professional partnership between and within primary and secondary care. Improving health system organisation and health policies is essential for achieving these goals. Facilitating patients' access to health care was also considered important, as was enabling fast and direct PCP access to diagnostic tests. Respondents saw funding allocation as an underlying component of most of these issues. They also identified a risk that reducing delays in cancer diagnosis in some patients could lead to overdiagnosis in others.

Strengths and weaknesses of the study

This is the first trans-European study to explore PCPs' perceptions of how timeliness of cancer diagnosis can be improved, offering a unique insight into the operational and administrative challenges. This could be invaluable for the evaluation and revision of current healthcare policies and practices. Cancer diagnosis is a complex process and the diagnostic behaviour of PCPs working under the influences of their native health care systems is a key determinant. A key strength of our work is that we have gathered the views of PCPs from 20 countries on this process; our analysis examines systemic influences on PCP cancer diagnostic activity across Europe.

Variation in geography, health systems and levels of healthcare spending was provided by having four participating countries from each of the Central, Eastern, Northern, Southern and

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Western European geographical areas. The sample size was large and diverse, with participants varying in terms years of clinical practice, gender, and site and size of practice. The study successfully recruited participants in countries in which PCPs are underrepresented in research.

The survey had only one, short question that related directly to our research question. However, it may be that this format prompted participants to focus on writing down only what, for them, was the most important point. Neither patients, secondary care nor other primary care health professionals were included in the survey, and these groups may have had other insights to offer. There is a risk that the translators and investigators misunderstood some of the nuances of the twenty different languages, cultures and healthcare organisations involved in this study. While themes were identified from responses from PCPs in 20 European countries, not all of the themes identified will be equally relevant to each of the participating countries.

The data collection was completed in December 2016, and participating countries' health systems will have continued to develop since then. However, each of the themes results from PCPs' comments on healthcare is situated in a society and culture which changes very slowly, as is also seen for implementation of new knowledge. The findings are therefore likely to continue to be relevant.

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Comparison with other studies

Our findings reflect those of a survey of GPs in Ireland, which identified that barriers to early cancer diagnosis included lack of direct GP access to diagnostic tests, difficulties with referral to secondary care, poor clarity relating to cancer screening, unequal patient access to secondary services, and a need for further training and guidelines [39]. GPs' views on the importance of closer links between primary and secondary care were identified in that and other studies [29 30]. Our PCPs' call for improved patient education and better access to diagnostic testing specialist care were also prioritised by GPs in another UK study [40]. Our findings map across to the findings from qualitative research on patient-perceived barriers to early presentation and diagnosis of cancer, which have identified the need for better access to services for patients [41 42] and better patient awareness of cancer symptoms [42] as key issues. Our PCPs' call for an improved partnership with other primary health care professionals is one that has been successfully implemented before, though not specifically in relation to cancer diagnosis [43]. Their recommendation for better cancer awareness among primary care staff is confirmed by evidence from other research that there is a need for this [44].

GPs in other studies have identified issues that were not raised by PCPs in our study, including the perception that late presentation of cancer symptoms often relates to patients' socio-economic and socio-cultural circumstances [15 30], a concern that fragmentation of health services adversely affects timeliness of cancer diagnosis [15 45], and a need for mentoring of doctors unfamiliar with their health systems [30].

The need for healthcare systems to support PCPs' quick and easy access to investigations has been proposed before [46]. While investigation in primary care has been linked with later referral for specialist assessment, reducing the waiting time for tests would be expected to shorten the primary-care intervals associated with investigation use [47]. Despite this, another study found that some patients received a delayed cancer diagnosis, even when they had presented with typical cancer symptoms to a GP who had access to relevant diagnostic tests [48].

Possible implications for clinicians and policymakers

PCP respondents had specific recommendations on the changes that are needed to facilitate more timely diagnosis of cancer. Some recommendations, for instance health education campaigns and development of relevant guidelines, may need central direction, albeit with the input of PCPs. Others, for example improving the way PCP communicate with secondary care

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specialists, and PCPs’ ability to access to cancer-specific tests, may need local agreement. Aspects such as PCPs’ own communication skills, their own accessibility to patients and their continuing medical education, are more likely to be under PCPs’ own control. However, a consideration of how funding is best reallocated is crucial if PCPs and their health systems are able to make these changes.

Unanswered questions and future research

Further analysis is needed to help identify which recommendations are most relevant to different existing models of healthcare, for example as to whether some are particularly relevant to systems in which the PCP has more of a ‘gatekeeper’ role, or to those in which PCP practises are large or smaller than average. A longitudinal study would give evidence on the trends on PCP opinions and how they are impacted by changes in health policies and public health initiatives. Research using interviews would give in-depth ideas on how changes resulting from the study findings could be implemented. A mixed-methods approach, comparing PCPs’ views from different countries, would allow recommendations that are relevant to individual countries. In the study we have focused on the view of PCPs, as they have a key role in cancer diagnosis throughout Europe; however, the views of other stakeholders, such as patients and policy makers, are also important and should be included in future qualitative research.

There is a need to consider how to get the best balance between achieving early cancer diagnosis and minimising overdiagnosis of cancer. Our study gives the basic elements for the international primary care cancer research agenda, which would provide a knowledgebase for developing and improving cancer diagnosis and prognosis internationally.

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Conclusions

This research has identified key features that PCPs believe would be necessary to improve the timeliness of cancer diagnosis in their patients, and a need for re-allocation of health system funding to allow these to happen. Health systems need to facilitate earlier patient presentation through health education and better access to care, have well-educated clinicians with good access to investigations and better information technology, and adequate primary care cancer diagnostic pathway funding.

Many PCPs play a crucial role at the centre of their patients' care, and the breadth of their experience is reflected in their wide range of suggestions. This understanding should help to inform health service policy and research towards better cancer outcomes.

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List of abbreviations

CME	Continuing medical education
GP	General practitioner
PCP	Primary Care Physician
UK	United Kingdom

Declarations

Ethics approval

Ethical approval for the study was given by the University of Bath Research Ethics Approval Committee for Health (approval date: 24th November 2014; REACH reference number: EP 14/15 66). Other countries' study leads either achieved local ethical approval or gave statements that formal ethical approval was not needed in their jurisdictions.

Competing interests

The authors declare that they have no competing interests.

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Data sharing statement

The Örenäs survey data that support the findings of this study are available from the corresponding author, M Harris, on reasonable request.

Author contributions

K Buczkowski, M Brekke, N Buono, E Costiug, G-J Dinant, M Esteva, G Foreva, E Jacob, M Harris, R Hoffman, E Jakob, T Koskela, M Marzo-Castillejo, P Murchie, AL Neves, DP Petek, J Sawicka-Powierza, A Schneider, E Smyrnakis, S Streit, H Thulesius, P Vedsted and B Weltermann participated in the study design, piloting and data collection. G Taylor participated in the study design. S Harker coded some of the data. M Esteva and S Harker assisted in validated the coding. M Esteva, M Harris, R Hoffman, T Koskela, AL Neves, D Petek and H Thulesius worked together to agree the themes. M Harris had overall responsibility for the study design, recruitment of local leads, analysis of data and interpretation of results. All authors contributed to the writing and review of the manuscript and approved the final version.

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Table 1. *National distribution of PCPs who responded to the question 'How do you think the speed of diagnosis of cancer in primary care could be improved?'*

Country	Number of PCPs who completed the survey	Number who answered the open-ended question (% of all survey completers)
Bulgaria	52	45 (86.5)
Croatia	56	42 (75.0)
Denmark	92	71 (77.2)
England	62	25 (40.3)
Finland	61	39 (63.9)
France	52	35 (67.3)
Germany	91	31 (34.1)
Greece	59	50 (84.7)
Israel	58	42 (72.4)
Italy	60	52 (86.7)
Netherlands	108	84 (77.8)
Norway	81	46 (56.8)
Poland	135	103 (76.3)
Portugal	59	46 (78.0)
Romania	146	132 (90.4)
Scotland	62	55 (88.7)

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Slovenia	91	52 (57.1)
Spain	380	332 (87.4)
Sweden	68	55 (80.9)
Switzerland	60	15 (25.0)
Total	1,833	1,352 (73.8)

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Table 2. *Demographic distribution of PCPs who responded to the question 'How do you think the speed of diagnosis of cancer in primary care could be improved?'*

Demographic	Number (%)
Gender	
Female	833 (61.6)
Male	513 (38.0)
Not stated	5 (0.4)
Years since graduation	
<10	192 (14.2)
10–19	356 (26.4)
20–29	416 (30.8)
30–39	336 (24.9)
40 or over	47 (3.5)
Not stated	4 (0.3)
Site of practice	
Urban	816 (60.4)
Rural	314 (23.2)
Island	25 (1.9)

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Mixed	194 (14.4)
Not stated	2 (0.1)
Number of doctors in practice	
1-2	337 (24.9)
3-5	344 (25.5)
6-9	290 (21.5)
10 or more	374 (27.7)
Not stated	6 (0.4)

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Figure legends

Figure 1. *Diagrammatic representation of themes emerging from responses to the question:*

'How do you think the speed of diagnosis of cancer in primary care could be improved?'

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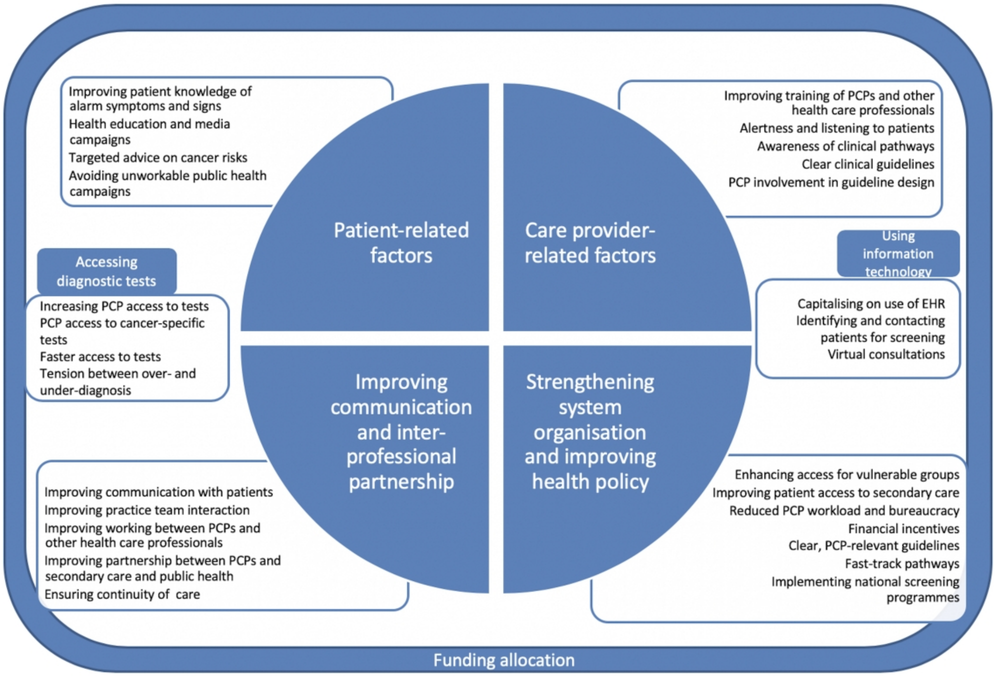

Figure 1. Diagrammatic representation of themes emerging from responses to the question: ‘How do you think the speed of diagnosis of cancer in primary care could be improved?’

292x200mm (300 x 300 DPI)

Supplementary file. Ethical and other approvals obtained in each Örenäs Research Group participating jurisdiction

	Date of Ethics Approval	Approvals obtained	Reference
Bulgaria	29 October 2015	Medical University Plovdiv Ethical Commission	P-7820
Croatia	16 December 2016	Nastavni Zovod Za Javno Zdravstvo	08-820-61/31-15
Denmark	7 May 2016	Danish Data Protection Agency; according to Danish law and the Central Denmark Region Committees on Health Research Ethics, approval by the National Committee on Health Research Ethics was not required as no biomedical intervention was performed.	2009-41-3471
Finland	16 November 2016	Academic Ethics Committee of the Tampere Region	16 November 2016
France	N/A	In France, research ethics approval was not required as no biomedical intervention was performed.	
Germany	15 January 2016	Ethik-Kommission Universität Duisberg-Essen	16-6747-BO
Greece	N/A	In Greece, research ethics approval was not required as no biomedical intervention was performed.	
Israel	N/A	In Israel, research ethics approval was not required as no biomedical intervention was performed.	
Italy	N/A	In Italy the approval of the ethical committee is not required when a study is neither an interventional nor an observational study on pharmacological treatment.	Decreto Legislativo n. 211 (24 giugno 2003)<2001/20/EC
Netherlands	27 June 2016	medisch-ethischetoetsingscommissie (METC) azM/UM Maastricht UMC+	METC 16-4-113
Norway	N/A	In Norway, research ethics approval was not required as no biomedical intervention was performed.	
Poland	28 January 2016	Komisja Bioetyczena Uniwersytetu Medycznego w Bialymstoku	R_I_022/10/2016

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Portugal	N/A	In Portugal, research ethics approval was not required as no biomedical intervention was performed.	
Romania	N/A	In Romania, research ethics approval was not required as no biomedical intervention was performed.	
Slovenia	8 December 2014	Komisija Republike Slovenije Medicinsko Etiko	KME 113/08/14
Spain	25 October 2015 23 Decmber 2015	Comissio d'Investigacio Govern de les Illes Balears Informe del Comite Etic d'Investigacio Clinica	Palma 27oct15 P15/159
Sweden	N/A	In Sweden, research ethics approval was not required as no biomedical intervention was performed. It does not fall under the law of research on human subjects to ask professionals about their work and how they perceive it.	
Switzerland	N/A	Swiss law on human research (Humanforschungsgesetz, HFG) does not require that an ethics committee approve collection and analysis of non-medical and anonymous data.	
United Kingdom	24 November 2014	Research Ethics Approval Committee for Health, University of Bath	EP 14/15 66

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

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		Reporting Item	Page Number
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	4-5
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	7-8
Purpose or research question	#4	Purpose of the study and specific objectives or questions	8
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also	10-11

		recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	11
Context	#7	Setting / site and salient contextual factors; rationale	10
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	10
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	10; 24
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	9
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	9
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	11
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	10

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Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	10
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	10-11
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	11-19
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11-19
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	20-23
Limitations	#19	Trustworthiness and limitations of findings	20-21
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	25
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	25

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