Do I refer this patient on?

European family doctors swap notes on how they decide who should be tested for cancer

Symptomatic cancers are diagnosed quicker in some countries than others. A group of European primary care physicians recently set out to discover why this is, by gathering information about the different factors that influence decision–making. **Janet Fricker** talked to one of them, to find out what they learned.

For the great majority of cancers, diagnosing early is the single most important factor in determining whether the patient survives, and does so with a good quality of life. It might be seen as somewhat surprising, therefore, that more effort has not been put into learning how to configure primary healthcare systems in a way most likely to facilitate early diagnosis.

Important new information that could throw a light on this topic is now beginning to make its way into the literature thanks to the determined efforts of Michael Harris, a now-retired English primary care physician (PCP), together with a group of European colleagues.

Harris remembers that his 'Road-to-Damascus' moment occurred in 2011 when reading a paper in the *British Journal of General Practice*. The study, by Peter Vedsted and Frede Olesen from Aarhus University, Denmark, suggested that European countries with strong primary care gatekeeping systems had much poorer one-year relative cancer survival than countries with weaker gatekeeping systems (*Br J Gen Pract* 2011, 61:512–3).

Gatekeeping is about controlling referral to specialist services, and the results showed that, for the 12 countries with gatekeeping roles for PCPs, the one-year relative cancer survival was 67.8%, compared with 73.4% for the seven countries that did not have gatekeeping (*P*= 0.004).

The study used data taken from the EUROCARE-5 study, which had demonstrated wide disparities in one-year cancer survival rates across Europe, ranging from 81.1% in Sweden to 58.2% in Bulgaria.

"For me the publication really struck home, because up until that point I had been telling my European colleagues how marvellous the UK gatekeeping system was," said Harris, who at the time was a PCP in Bath, England, with a visiting academic post in Bern, Switzerland, advising on PCP training.

Gatekeepers, typically PCPs, are the doctor of first contact for patients, coordinating the care of their patients and controlling their access to secondary care.

What had particularly appealed to Harris about the gatekeeping system was that it helped prevent over-investigation of patients, and identified

The Swedish system

"In Sweden, although the primary care practitioner (PCP) has no formal gate-keeping role, two-thirds of cancer patients present first to general practice. The Swedish system allows patients to write their own referral letters directly to the hospital, although of course such patients will not be prioritised for appointments.

"The reality of the Swedish system is, perhaps, that the gatekeeping role is undertaken by the practice nurse, who 'triages' which patients should be seen by the PCP. This can lead to delays of a few days before patients are able to get an appointment with their PCP.

"Swedish PCPs don't use any cut-off values for deciding who to refer for cancer testing, and can directly arrange their own tests, including CT and MRI scans, without going through the hospital.

"Despite Sweden's cancer survival rates being among the highest in the world, long waiting times still exist. In 2015 the Swedish government started a new national programme to standardise cancer care pathways, with the aim of reducing waiting times, increasing patient satisfaction and reducing regional inequalities. Once cancer is suspected, the PCP can tick a box on a form that directs patients along up to 20 different 'standard care pathways'.

"The biggest bottleneck for cancer diagnosis is in pathology departments"

"Maximum waiting times are specified for every step along these pathways, from specialist appointments, to each pre-treatment diagnostic procedure, the pathological and other analysis and multidisciplinary team meetings. The idea is that providers should stick to each 'time slot', creating 'time-bound' clinical guidelines.

"In Sweden, the biggest bottleneck for cancer diagnosis is in pathology departments, where tissue specimens are processed for histopathological analysis for all cancers, to help plan treatment."

Hans Thulesius, Associate Professor of Family Medicine, Lund University, Malmö, Sweden

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the most appropriate management and specialist care – and in doing so controlled healthcare costs. "I was shocked to discover that, while the gatekeeping system may well ensure optimal care for most patients, it appears to work badly for patients whose symptoms are due to cancer," said Harris, who now undertakes primary care research at the University of Bath.

The need for action was further brought home to him when he saw that more than 6,000 premature deaths from cancer – i.e. 6–7% of cancer-related mortality – would have been avoided each year, if Britain had achieved the mean survival rate in Europe.

For Harris, the Vedsted and Olesen study was a 'call to arms' to undertake research to see how different healthcare structures in countries across Europe impact on timeliness of cancer diagnosis. He decided to enlist collaborative help from European

There were clear differences between where PCPs do diagnostic investigations, such as ultrasound, and where access is solely by referral

partners, which he did by 'googling' for primary care researchers exploring cancer disparities.

In 2012 Harris secured an EU grant of €11,000 to run an exploratory three-day workshop with 18 colleagues from 12 different European countries. From the workshop, which was hosted at Örenäs Castle, Sweden, they established the Örenäs Research Group, with the remit to investigate how health system factors affect the timeliness of cancer diagnosis in primary care.

Achieving more timely cancer diagnoses in primary care poses considerable challenges, said Harris, as PCPs only see a small number of new cancers each year, and half of patients with malignancies present with evolving and undifferentiated symptoms

that can be interpreted as something other than cancer.

At another Örenäs workshop, held in 2014, eight PCP researchers from six European countries came together

How easy it is to telephone or email a specialist for informal discussion and advice was key

to identify system-related and other non-clinical factors that could affect a PCP's decision-making when faced with a patient who might have cancer. The workshop identified 50 different system factors that could have

an effect (*J Cancer Res Ther* 2016, 4:7–10).

Notably, the group highlighted clear differences in decision-making between systems that have some special investigations done by PCPs themselves, for instance diagnostic ultrasound, and those that have access to them solely by referral. When investigations are undertaken by PCPs "the investigation is facilitated because it is seen as a quick, easy, and possibly income-generating way of making (or ruling out) a sinister diagnosis."

The Örenäs group also found that relationships with specialist colleagues, including how easy it is to telephone or email a specialist for informal discussion and advice, was key. Systems where the PCP is prevented from referring to a named specialist – which is the case in countries

such as Croatia, Slovenia, Spain and the UK – may have an inhibitory effect on referrals, the group suggested.

The intensity of PCP workload was also seen as an important factor, with high workloads potentially making PCPs more likely to refer, in an attempt to reduce follow-up appointments. However, if there is an expectation that the PCP will write detailed referral letters (as in the UK), the time taken to do this may discourage the PCP from making that referral.

"Overall, the workshop gave us an awareness of the range of factors that may influence how PCPs act on concerns that cancer may be present, and it helped us to highlight future studies," said Harris.

Next, came the 'vignettes' study, with the Örenäs group aiming to find out where patients with possible cancer

The Dutch system

"In The Netherlands we have a really strict gate-keeping system, where the primary care physician (PCP) decides who should be referred to secondary care. The PCP does not use risk-assessment tools, but instead uses guidelines developed by the Dutch College of General Practice. Overall, we have 110 guidelines on different clinical areas that flag alarm symptoms known to indicate an increased risk of cancer.

"I would like a model where a number of PCP practices come together to form community diagnostic centres"

"PCPs feel real ownership of these guidelines, because they know that they were written by PCP colleagues, and were not just imposed upon them.

"An important aspect of the Dutch system is that PCPs have really good personal communications with their secondary care colleagues. If I suspect cancer in a patient, I will pick up the phone to my specialist colleagues and ask them to see the patient within a week.

"In The Netherlands we have a system of practice assistants, who answer the telephones and triage how quickly patients should see the PCP. The practice assistant has the flexibility to book longer appointments if they feel this will be necessary. In some areas PCPs can order MRI scans, colonoscopies, or other imaging tests directly, but this is by no means universal.

"The patients who concern me most are those with 'low risk', but not 'no risk' symptoms, who can get lost in the system. I would like to see a new model where a number of PCP practices come together to form community diagnostic centres. Such centres would give PCPs easy access to all testing, and allow consultants to hold regular sessions to advise on results. People considered to be at high risk of cancer would still go directly to the hospital."

Niek de Wit, Professor of General Practice at the University of Utrecht, The Netherlands

The Spanish system

"Primary care practition- ers (PCPs) in Spain use their clinical judgement to decide when to refer patients for cancer test- ing, and don't use tables for determining risk. No guidelines are available systematically across all regions to say how quickly patients with suspected cancer should be seen.

"Several years ago there was an initiative to develop fast-track pathways for breast and colon cancer, where patients were expected to be seen within 15 days. The system was abandoned, however, due to lack of funding.

"Much of the current variability in waiting times for cancer diagnosis in Spain is due to hospitals rather than PCPs, as most of the tests and diagnostic imaging are done in hospitals. There are also delays for outpatient appointments.

"The thing that works well in the Spanish system is that PCPs are very available, and keep free appointments during the day for emergency consultations. But to arrange for most cancer tests, PCPs then need to go through hospitals, and this is where the delays come in. "It helps when the PCP knows the hospital specialists personally and can pick up the phone to flag up that it is important to see the patient urgently. Otherwise, it is common for hospital clerks (who are not medically qualified) to undertake the medical triage, and decide how quickly patients should be seen. Sometimes PCPs refer patients to emergency services to get around waiting lists.

> "Sometimes PCPs refer patients to emergency services to get around waiting lists"

There are multiple delays in the Spanish cancer diag- nosis system, but this is not completely reflected in our cancer survival statistics, which are compara- tively good compared to other countries in Europe. It seems that we manage to compensate by giving our patients good access to treatment once diagnosed."

Magdalena Esteva, primary care researcher, from Mallorca, Spain

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symptoms would be most likely to make initial contact with the health service in different European countries, and how this correlated with national one-year relative cancer survival (*Scand J Primary Health Care* 2017, 35:1–8).

For the study, 78 PCPs from 14 countries were given 'vignettes' of a symptomatic patient with possible lung cancer, one with possible ovarian can- cer, another patient with possible breast cancer, and one with possible colorectal cancer.

In contrast to Vedsted and Olesen's findings, the Örenäs analysis found no significant correlation between overall national one-year relative cancer sur- vival rates and the probability of ini- tial presentation to a PCP ($r= –0.16$, 95%CI = –0.39 to 0.08). There was, however, poorer lung cancer survival in countries where patients were more likely to initially present to a PCP ($r= –0.57$, 95%CI = –0.83 to –0.12). "Our hypothesis was that most pri- mary care doctors don't have in-house access to radiology, so if people see a specialist first they may be more likely to get an immediate chest X-ray," said Harris.

Next, Örenäs members delved more deeply into the 50 system factors that had been identified in the explor- atory workshop as affecting decision- making by PCPs in relation to patients who may have cancer. After a pilot study had identified the 20 factors that varied most across Europe, 2,086 PCPs from 20 European countries took part in an online survey using a Likert scale (with answers ranging from 'strongly disagree' to 'strongly agree'), to rate how each of those fac- tors influenced their referral decisions for the four clinical vignettes.

Such European surveys are labori- ous, explained Harris, as they involve collaborators translating question- naires into each local language, with linguistic validation undertaken by independent 'back-translation' into English, to identify and then correct any important differences from the original.

From the results, a statistical 'exploratory factor analysis' identi- fied that five factors between them explained half the variation in the sur- vey responses:

- □ Ability to refer (this factor was about barriers to specialist referral),
- □ Patient access (financial and geographical barriers to healthcare),
- □ Pressure on the PCP from outside (workload, demands from patient,

The UK system

"In the UK most patients with cancer present first to primary care, with no direct access to specialists, although a proportion of them are so ill that they take themselves to A&E.

"In 2015 the National Institute for Health and Care Excellence (NICE) developed a cancer risk threshold of 3% (calculated from tables based on the patient's symptoms) for entry into a fast–track scheme where patients would be seen by consultants in two weeks.

"The cut–off value of 3% was a complex judgement that took into account the needs of patients and the risks of over–investigation. Children are deemed to be a special case, although no special cut–offs were specified for them.

"In the UK, when deciding who to refer outside of the fast–track system, PCPs can use these risk assessment tools to alert them to the possibility of cancer, and then add in their own clinical judgement. Medical delays most commonly occur for patients with low–risk symptoms, where the PCP initially decides against investigation, only to refer later for testing, when the situation is unresolved or has worsened.

"Oddly, the people who tend to do worst in the UK system are those with conditions other than cancer, since the system deprioritises them once cancer is ruled out.

"Expanding access to cancer testing remains key for improving cancer survival in the UK"

"PCPs in the UK increasingly have direct access to testing such brain scans, CT scans, endoscopy and blood tests. The CanTest programme, funded by Cancer Research UK, is looking into how this can be expanded. Expanding access to cancer testing remains key for improving cancer survival in the UK."

Willie Hamilton, Professor of Primary Care Diagnostics at University of Exeter, UK

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public or health system),
- ☐ Role of the PCP (level of expectations of PCP-centred care), and
- ☐ Quality versus cost (influence of financial aspects on decision-making by PCPs).

The results, presented at the 2017 European General Practitioner Research Network (EGPRN) meeting in Riga, Latvia, in May, revealed positive correlations between better one-year relative cancer survival and systems that focus on quality rather than cost ($r=0.65$) and lower barriers to specialist referral ($r=0.46$), and a negative association between one-year relative cancer survival and systems in which there is higher pressure on primary care ($r=-0.40$).

However, further analysis showed that these factors varied according to national healthcare spend per capita. For those European countries in the highest national healthcare spend tercile (Denmark, France, Germany, the Netherlands, Norway, Sweden and Switzerland), better national cancer survival was associated with closer relationships between PCPs and specialists, and less of a gatekeeping role and less pressure on primary care.

For countries in the middle tercile for per capita healthcare spend (Finland, Italy, Portugal, Slovenia, Spain and the United Kingdom), better national cancer survival was also associated with less of a PCP-as-gatekeeper role and with less pressure on primary care, but also with a higher likelihood of PCPs organising investigations at the initial consultation.

Conversely, for the lowest tercile (Bulgaria, Poland and Croatia), better national cancer survival was associated with being more PCP-centred: more active PCP involvement in referral decision-making, with less easy access to specialists.

"These data suggest that how system factors affect PCP decision-making varies according to the level of national per capita healthcare spend. It seems that poorer countries have better cancer survival when GPs [PCPs] have stronger decision-making roles, but in wealthier countries the opposite is true," said Harris.

The Örenäs Research Group now plans a health systems analysis, so that it can explore in more detail how each European country's health system affects cancer survival. It also plans qualitative work to compare decision-making in different European countries by PCPs when faced with patients who could have cancer.