

International exchange

European differences in cancer survival: report of an international symposium of general practitioners from three countries exploring primary and secondary care delay

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ABSTRACT

Background There are several potential delays in the cancer diagnostic pathway: patient delay, primary care delay and secondary care delay. People in the UK have poorer five-year survival from many cancers compared with people in European countries with similar healthcare systems. The reasons for this are not clear, although it has been postulated that UK patients may present with cancer at a later stage. We are conducting a study to investigate the feasibility of comparing diagnostic delays in different European countries.

Methods (conduct of the symposium) A half-day, round-table symposium was convened with seven general practitioners (GPs) and single primary care researchers from Sweden (Malmö), the Netherlands (Maastricht) and Scotland (Aberdeen). In Session

One the group had a broad-ranging discussion comparing and contrasting their different working contexts and how these might impact on the cancer diagnostic pathway. In Session Two the group considered two case studies from Scotland, applying their own local experience and the insights generated in Session One to identify common and divergent issues. When it had finished the facilitator drafted a detailed report of the symposium which was supported by reference to the individual participants' notes which had been collected at the end of the symposium.

Results (consensus views reached) Sweden, the Netherlands and Scotland have strong traditions of primary care acting in a gate-keeping role.

People with cancer in the three countries following a broadly similar cancer diagnostic pathway.

In Sweden and the Netherlands GPs have direct unscreened access to a greater range of investigations than in Scotland.

In Scotland there is a greater reliance on specialist guidelines than in the Netherlands or Sweden.

Future research in the UK could explore the potential contribution of increased GP access to investigations and revised referral guidelines.

Keywords: primary care, cancer, diagnosis

Introduction

There are useful models for describing the diagnostic pathway experienced by people with cancer.^{1–3} Generally these describe patient delay (time between symptoms developing and the patient presenting to primary care), primary care delay (time between presentation to a general practitioner (GP) and being referred to secondary care) and secondary care delay (the delay between referral to secondary care and the diagnosis being achieved). In the UK in particular such models are a focus of much current interest, largely due to the NAEDI (National Early Diagnosis Initiative) which recognises the need to achieve the earliest possible diagnosis of cancer.³ Policy initiatives such as NAEDI are driven in large part by the recognition of poorer cancer outcomes in the UK compared with elsewhere in Europe.^{4,5}

In the most recent EURO CARE study people with cancer in the UK continued to have poorer five-year survival than their counterparts in many other western European countries.^{4,5} Why this should be is not entirely clear, but some have suggested that longer diagnostic and treatment delays, including primary care delay, in the UK compared to elsewhere are contributory factors.^{6,7} It has been further suggested that it would be important, although highly challenging, to meaningfully compare the diagnostic pathway experienced by people with cancer in different countries.⁸

These views have provoked considerable interest among participants of the first cohort of the Brisbane Initiative, an international primary care leadership programme which includes delegates from several European countries.⁹ Initial discussions focused on striking differences in five-year survival for most of the

major cancers between Scotland and the Netherlands, and this discussion was expanded to include colleagues from Sweden who similarly perform considerably better than Scotland (Table 1).^{4,5} Colleagues in the three settings agreed that most cases of cancer diagnosis will be achieved via a similar pathway, corresponding to the model of 'delay in seeking a cancer diagnosis' described by Andersen and Cacioppo.¹

In order to explore the feasibility of meaningfully comparing cancer diagnostic pathways between different European countries the group secured funding from Cancer Research UK for an exploratory study. To initiate the study a half-day round-table symposium was held at the University of Aberdeen in October 2009. The aim of the symposium was to identify any obvious differences in healthcare systems which could begin to explain disparities in five-year survival from cancer. These consensus findings are presented in this paper.

Methods (conduct of the symposium)

Participants

Seven GPs and one primary care researcher participated in the symposium. Their characteristics are summarised in Table 2.

Facilitation and structure

One participant (PM) facilitated the symposium which was run in two halves. A copy of the Andersen and Cacioppo¹ and four EURO CARE papers had been

Table 1 Comparison of five-year survival for five cancers (1995–1999) between Scotland, the Netherlands and Sweden (Eurocare 4)

	Colorectal % (SD)	Lung % (SD)	Melanoma % (SD)	Breast % (SD)	Prostate % (SD)
Scotland	51.5 (1.0)	8.0 (0.5)	88.4 (1.8)	75.0 (1.1)	67.8 (1.9)
Netherlands	57.0 (1.3)	14.3 (0.8)	89.8 (2.0)	82.7 (1.2)	80.9 (2.0)

Table 2 Characteristics of consensus group participants

Country of practice	Region of practice	Gender	GP experience (years)	Practice size (approximate)	Practice setting	Cancers diagnosed in past 5 years
Scotland	Aberdeen City	Female	5	12 000	Urban	2
Scotland	Suburban Aberdeenshire	Female	3	11 000	Suburban/rural	6
Scotland	Suburban Aberdeenshire	Male	11	7000	Suburban	2
Netherlands	Rural Limburg	Male	23	5000	Urban	10
Netherlands*		Male	0	–	–	–
Sweden	Urban Malmö	Male	5	12 300	Urban	4
Sweden	Suburban Skane	Male	10	12 300	Urban	10

* Physiotherapist by training and now full-time primary care researcher. No direct patient contact

circulated to all participants beforehand.^{4,5,7,10} PM began session one with a brief (five-minute) presentation summarising the Andersen and Cacioppo model and the five-year survival data for five common cancers in the participants' three countries (Table 1).¹ The purpose of this presentation was to generate a general and free-flowing discussion which lasted approximately 70 minutes. PM had a brief schedule of topics, not issued to the participants, which he used to ensure that the discussion touched on all major topic areas. At this stage PM introduced two case studies (Appendix 1), which were anonymised real life examples from his own practice. PM presented Case Study 1 (Appendix 1) which was followed by approximately 30 minutes of discussion. PM then presented Case Study 2 (Appendix 1) which was followed by approximately 15 minutes of discussion.

Recording the discussion

All participants were issued with a single sheet of blank A4 paper and a single sheet of A4 paper illustrating the Andersen and Cacioppo model.¹ PM informed the participants at the beginning of the symposium that these should be used for making notes and annotations and would be collected at the end. In addition, PM specifically asked both University of Aberdeen colleagues to note key issues that particularly struck them as important during the discussion in the form of bullet points. During the symposium PM also kept

notes. At the end PM collected all of the participants' notes and wrote detailed notes about the issues discussed during the whole symposium.

Achieving consensus

These notes were subsequently circulated to participants for agreement and annotation prior to drafting this report.

Results (consensus views reached)

Comparing and contrasting contexts

Funding primary care

All three countries have strong primary care systems with the GP being the first point of contact when health issues arise. In all three countries the GP acts as a gate-keeper to specialist care and investigations. In all three countries primary care services are readily accessible. In Scotland and Sweden services are government funded. In Scotland they are free at the point of use. In Sweden there is a small charge (approximately €11) to the patient for each visit, although many patients will not be required to pay this. In the Netherlands all primary care services are provided by insurance companies with minimal government in-

volvement and funded through a combination of mandatory and voluntary top-up insurance schemes. In Sweden, and to a lesser extent in the Netherlands, there are privately run primary care facilities. This does not happen to any extent in Scotland.

Cancer screening programmes

All three countries have screening programmes for breast and cervical cancer. Since 2007 Scotland has also implemented a colorectal cancer screening programme amongst people aged 50 to 74 years. The Netherlands is considering implementation of a similar programme, although this is unlikely to be before 2019. The Swedish participants were not aware of plans to implement a colorectal cancer screening programme in their country.

The primary–secondary care interface

In all three countries GPs have three main lines of access to secondary care on behalf of their patients: referral, admission and contacting the specialist for advice. Also, in all three countries there appeared to be similar subtleties within these pathways, for example using admission as a short-circuit when a GP was concerned about a patient, and more established GPs having a personal network of specialists from whom they feel empowered to seek advice or urgent appointments for their patients.

The Dutch participant identified a particular problem with poor integration of secondary care specialties. He gave the example of a patient with breathlessness being referred to a cardiologist, who on concluding negative cardiac investigations would send the patient back to the GP – ‘this patient’s breathlessness is not cardiac’. The Swedish and Scottish participants felt it considerably more likely that a similar patient would be referred on within the hospital system.

Compared with GPs in Scotland, Dutch and Swedish GPs appeared to have more direct access to hospital investigations. In Scotland, direct referrals could be made for basic radiological tests. GPs could also refer directly for some other investigations including upper GI endoscopy and sigmoidoscopy, but these were subject to screening by a consultant, and all of the Grampian participants had had experience of such referrals being deemed inappropriate and not completed as requested. This contrasts with the Netherlands and Sweden, where GPs have direct unscreened access to investigations including MRI, CT scans and upper GI endoscopy. It is noteworthy, however, that in the Netherlands GP access to investigations is subject to geographical variation. Furthermore, although in Scotland and the Netherlands there is an emerging trend of GPs with special interests, raising the possibility of horizontal referrals for investigation within primary care, Swedish GPs appear to generally undertake a greater number of

investigative procedures within their own practices, for example rectoscopy and direct laryngoscopy.

In border areas of Holland GPs will sometimes refer to Belgian and German hospitals for quicker service. Despite a similar proximity of Scandinavian countries, this does not appear to happen there. Similarly, in Scotland it would be very rare for a patient to be referred outside their own regional health board area.

Comparing the cancer diagnostic pathway

Participants from all three countries agreed that the model of cancer delay proposed by Andersen and Cacioppo is relevant within their healthcare systems.¹

Getting an appointment

In all three countries patients will generally be offered an ‘on the day’ emergency appointment for symptoms strongly associated with cancer. In terms of routine GP appointments, however, the situation differs. In Scotland, patients will usually receive a routine appointment within 48 hours, although they may wait longer to see a specific GP. In the Netherlands patients will usually be seen within three days for routine matters. In Sweden waiting time for routine appointments varies considerably, with urban patients typically waiting between three and four weeks, compared with much shorter waits in rural areas. In the last decade or so waiting times for routine GP appointments has tended to decrease in Scotland, increase in the Netherlands and remain stable in Sweden.

In both Scotland and the Netherlands GPs will offer ten-minute appointments and will see up to 40 patients per day in two- to three-hour surgery sessions. In both countries GPs will also undertake home visits. By contrast, Swedish GPs tend to see fewer patients for longer (15 to 20 patients for 15- or 30-minute appointments). In Sweden, home visits are increasingly being undertaken by a separate organisation.

How referrals are made

Once the decision has been made to make an onward referral to secondary care, GPs in the Netherlands have access to a well-established electronic referral system. Dutch GPs will also receive investigation results and consultant letters by this route. In Scotland, most referrals are now made electronically although this is a very recent development, whereas in Sweden an electronic primary care referral system is still nascent. In both Scotland and Sweden, with the exception of blood results in Scotland, investigation results and consultant replies arrive in hard copy sent by post.

In Scotland, there is a strong culture of GPs being guided by and adhering to referral guidelines, based on cancer alarm symptoms, that have been produced

by specialists with strictly limited input from GPs. Scottish participants agreed that there would be circumstances when their clinical suspicion of cancer had been aroused but the existence of guidelines focusing on alarm symptoms relating to advanced cancer would constrain them from making an urgent referral at that time. Both Swedish and Dutch participants suggested that such formal guidelines were less common in their countries and, they felt, would be less likely to be acceptable to and adhered to by themselves and colleagues, unless they had been produced with major input from GPs. Furthermore, there was general agreement that a potential problem of guidelines was to discourage urgent referral when clinical suspicion was aroused by symptoms which were subtle or atypical.

How are referrals managed?

In Scotland most patients will be referred for an initial consultation with a specialist at an outpatient clinic. In most instances the GP will designate the referral as 'routine' or 'urgent – suspected cancer', a decision based on symptoms and examination findings and influenced by clinical guidelines. At this point the GP is essentially handing over responsibility for the patient since the specialist will arrange subsequent investigations and act upon the results. The hospital specialist will screen all referrals and will not necessarily agree with the GP's assessment of urgency.

This contrasts markedly to the situation in Sweden where, although direct referral to specialists does occur, it is most likely that the GP will refer the patient directly for investigation first. The results of these investigations will in most cases be sent back to the referring GP for interpretation and further action. The waiting time for different investigations can vary widely and their prioritisation will sometimes be downgraded following specialist triage. On the basis of investigation results, Swedish GPs will then refer to a specialist, and delay can be introduced by the referral being returned to the GP for clarification or a request for further investigation before the patient is seen. When Swedish GPs refer direct to a specialist they do not explicitly categorise the urgency of referrals, but by this time the diagnosis has usually been established by earlier investigations.

In the Netherlands, where a GP suspects cancer they can initially refer the patient to a diagnostic centre. These are discrete diagnostic facilities run by insurance companies and staffed by visiting hospital specialists. At a single visit the patient will receive a suite of investigations tailored to the cancer suspected by the GP. The investigating specialist or biochemist will act on results but will also give very detailed feedback, including all results, to GPs. In addition or alternatively, the patient will be referred to a specialist outpatient clinic at a hospital, where a triage system is used to assess the level of urgency, similar to the system prevalent in Scotland. Diagnostic centres do not deliver any treatment.

Issues emerging from the discussion of cases

Most of the issues emerging during the case study discussion have been incorporated above. In each case, however, a few additional points are worth highlighting.

Case 1

Swedish and Dutch participants could think of no compelling reason why the 35-day delay between the patient presenting with symptoms and the GP deciding that further investigation would be required would be any less in Sweden or the Netherlands. On the other hand, both Dutch and Swedish participants stated that in these circumstances in their systems an endoscopy would undoubtedly have been performed in the first instance. Participants speculated on the possibility that this reflected subtle differences in the relationship between GPs and specialists in the different systems, with Scottish GPs perhaps being less empowered in the relationship. Of note, both Dutch and Swedish colleagues believed that the seven-day delay between diagnosis and oesophagectomy was less than would be the case in their systems.

Case 2

Dutch participants agreed that this diagnostic pathway, encapsulating a horizontal referral to a 'GP with a special interest' (GPwSI) colleague could occur in Holland. On the other hand, in Sweden the GP would most probably do the biopsy themselves at the initial visit. It was agreed that the process of delay in receiving and acting upon the pathology report would be similar in all three systems.

Discussion

Strengths and weaknesses of our approach

The strength of this symposium resides principally in its value in generating hypotheses. It has permitted primary care physicians from three different European countries to formally compare and contrast their experiences of diagnosing cancer. As a result, several factors have been highlighted which could feasibly contribute to key differences in the diagnostic pathways experienced by patients in different European countries with, on the face of it, broadly similar healthcare systems. We would argue that such discussions are a crucial prelude to any form of comparative research on cancer delay. Specifically, our views could inform the design of future large-scale comparative European

studies of cancer delay since they highlight many of the process variables that such a study must consider if meaningful comparisons are to be made.

On the other hand, we do not attempt to escape the fact that this is an extremely small, discursive piece of qualitative work that draws on the experience and anecdotes of seven healthcare professionals. In particular, we must acknowledge that the small number of GPs involved means that geographical variations within countries cannot be accounted for. Nevertheless, we present the distillation of a fascinating discussion between committed GPs from different countries, written up in the hope of stimulating further discourse and enquiry on the issue of different rates of cancer survival across Europe. From the UK perspective, this is surely one of the most perplexing and challenging issues facing academic primary care in the early 21st Century.

Summary of key consensus views

In all three countries the GP is generally the first point of contact for symptomatic patients and acts as a gatekeeper to investigations and secondary care specialists. GPs in Sweden and the Netherlands have direct access to a greater range of investigations than their counterparts in Scotland, where a patient is more usually required to be seen by a specialist first. Swedish GPs appear to conduct a greater number of investigations themselves in primary care. In all three systems patients with alarm symptoms will be seen rapidly by a GP. Routine appointments of ten-minutes duration are generally available within a few days to patients in Scotland and the Netherlands. In Sweden, a patient may wait several weeks for a routine appointment but it will last up to 30 minutes. In Scotland GPs tend to make referrals based upon guidelines written for them by specialists. In Scotland, the traditional route of referral is to a specialist for initial assessment and this specialist will then initiate investigations. This contrasts with the Netherlands where referral to a diagnostic centre where a suite of investigations are performed at a single visit is usual, and Sweden where the GP has direct access to a wider range of investigations. It is possible that Scottish GPs are less empowered in their relationship with secondary care colleagues than their counterparts in Sweden and the Netherlands.

Applying our views to the literature

The most recent EURO CARE data continue to show poorer outcomes for people with cancer in Britain compared to elsewhere in Europe.^{4,5} It is likely that some of this difference may be explained by differences in cancer registry coverage and case ascertainment between European countries.¹⁰ Nevertheless, striking differences remain even when Scotland is

compared to countries with similar data quality, prosperity and healthcare systems, such as Sweden and the Netherlands.^{4,5} In a recent sub-analysis of the Eurocare-4 results, Moller *et al* concluded that a pronounced difference in survival between the UK and Nordic countries is most likely due to less favourable distribution of stage at diagnosis in the UK.¹⁰ They acknowledge, however, that their analysis is superficial and does not exclude possible functions for other factors relating to the organisation and quality of cancer care services.¹⁰ At the current time it is not clear whether cancer presents later in Scotland than in comparable European countries, and research comparing cancer diagnostic pathways and delays between different European countries has been advocated.⁸

Against this background of uncertainty our data offer two key insights. First, Swedish and Dutch GPs have direct access to a larger range of radiological and other imaging procedures than their counterparts in Scotland. Despite evidence from earlier UK studies that direct GP access can shorten investigation times, reduce waiting times and does not result in an increased number of normal investigations, these systems have not been widely implemented in the UK.¹¹⁻¹³ Indeed, direct GP access to investigations continues to be limited in the UK and continues to be viewed negatively by many specialists.¹⁴ Second, compared with Sweden and the Netherlands our data suggest that Scotland has a far stronger culture of and reliance upon specialist guidelines which are generally based upon cancer alarm symptoms.¹⁵⁻¹⁷ This should be a cause for concern since in a recent audit the most common explanation given by Scottish GPs for delayed referral was that the symptoms did not fit the classic pattern described in guidelines.¹⁸

Implications of our consensus views

It is clear that Scotland, the Netherlands and Sweden have strong traditions of primary care and that the diagnostic pathway experienced by people with cancer, in terms of the key stages passed through, is broadly similar. On the other hand, it appears that GPs in the Netherlands and Sweden have a degree of autonomy with regard to ordering and conduct of investigations that are not enjoyed to the same extent by their colleagues in Scotland. Furthermore, there seems to be a greater reliance in Scotland on guidelines written by specialists for GPs, which are frequently based on alarm symptoms indicative of more advanced cancer. It also seems that the screening of referrals by specialists in Scotland adds a further layer of complexity to the cancer diagnostic pathway in that country, introducing the possibility that GP referrals may be downgraded or investigation requests questioned and delayed.

Signposts to the future

The fruits of our symposium are important hypotheses which signpost further research. It would appear that priority should be given to research exploring the potential of more direct access to investigations by UK GPs to impact on the stage at which cancer is diagnosed. Additionally, research in the UK should consider the potential impact of current specialist-produced referral guidelines on diagnostic pathways.

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CONTRIBUTORS

Peter Murchie, Lennart Johansson, Elizabeth K Delaney, Geert-Jan Dinant, Piötr Röllano, Mark Spigt and Lucy Wisely participated in the symposium. Peter Murchie wrote the manuscript with comments from all participants. Peter Murchie is the guarantor of findings. The University of Aberdeen acts as sponsor for the finding of this international symposium.

ETHICAL APPROVAL

Ethical approval was not required for this symposium.

PEER REVIEW

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CONFLICTS OF INTEREST

None.

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Appendix 1 Case studies presented during consensus group

Case 1 56-year-old male

A 56-year-old male with long-standing dyspepsia presents to GP with worsening symptoms.

- At first appointment GP takes full history (no alarm features) and arranges full blood count.
- Patient returns for review in one week – slightly anaemic but feeling a bit better.
- Returns four weeks later – symptoms much worse.
- GP refers routinely to gastroenterology, requesting endoscopy.
- Gastroenterologist writes back six weeks later stating that based on history he feels malignancy is very unlikely and that patient should have dose of omeprazole increased.
- Patient has three subsequent GP consults over next five months for other issues.
- Patient presents with dysphagia.
- Admitted two weeks later for endoscopy. Endoscopy reveals circumferential tumour in lower third of oesophagus. Biopsies taken.
- Patient has radical oesophagectomy one week later.

Delay from presentation to GP referral	35 days
Delay from referral to first hospital appointment	196 days
Delay to definitive diagnosis	0 days
Delay until initial treatment	0 days
Delay until definitive treatment	7 days
TOTAL SCHEDULING AND TREATMENT DELAY	238 days

Case 2 67-year-old female

Lady who has lived abroad in the tropics for 20 years presents with a long-standing mole on the left shin which she says has changed recently. GP examines and is not unduly concerned via ABCDE criteria. In view of history both agree should be excised. GP refers to minor surgery partner.

- Minor surgery partner sees ten days later and performs excision biopsy.
- Pathology report received at surgery two weeks later confirming completely excised superficial spreading melanoma.
- Duty doctor telephones duty plastic surgeon who agrees to see patient the following day.
- Patient admitted following day.
- Next day has wide local excision and sentinel node biopsy.

Delay from presentation to GP referral	24 days
Delay from referral to first hospital appointment	1 day
Delay to definitive diagnosis	24 days
Delay until first treatment	10 days
Delay until definitive treatment	25 days
TOTAL SCHEDULING AND TREATMENT DELAY	25 days