BMJ Open

Identifying important health system factors that influence primary care practitioners' referrals for cancer suspicion: a European cross-sectional survey

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-022904
Article Type:	Research
Date Submitted by the Author:	14-Mar-2018
Complete List of Authors:	Harris, Michael; University of Bath, Department for Health Vedsted, Peter; Research Unit for General Practice, University of Aarhus Esteva, Magdalena; Majorca Primary Health Care Department, Balearic Islands Health Research Institute (IdISBa), Research Unit Murchie, Peter; University of Aberdeen, Division of Applied Health Sciences - Academic Primary Care Aubin-Auger, Isabelle; Universite Paris Diderot UFR de Medecine, General Practice Azuri, Joseph; Tel Aviv University, Sackler Faculty of Medicine Brekke, Mette; University of Oslo, Department of General Practice and General Practice Research Unit Buczkowski, Krzysztof; Nicolaus Copernicus University, Department of Family Medicine Buono, Nicola; National Society of Medical Education in General Practice (SNaMID), Department of General Practice Costiug, Emiliana; Iuliu Hatieganu University of Medicine and Pharmacy, Family Medicine Department Dinant, Geert-Jan; Maastricht University, Department of General Practice Foreva, Gergana; Medical Center BROD Gašparović Babić, Svjetlana; The Teaching Institute of Public Health of Primorsko-goranska County, Odjel Socijalne Medicine Hoffman, Robert; Tel Aviv University, Department of Family Medicine Jakob, Eva; Centro de Saúde Sarria, Primary Health Centre Koskela, Tuomas; University of Tampere, Department of General Practice Marzo, Mercè; Institut Catala De La Salut, Unitat de Suport a la Recerca, IDIAP Jordi Gol Neves, Ana Luísa; Imperial College London, Centre for Health Policy; University of Porto , Center for Health Technology and Services Research Petek, Davorina; University of Ljubljana, Associate Professor Ster, Marija Petek; University of Ljubljana, Department of Family Medicine Sawicka-Powierza, Jolanta; Medical University of Bialystok, Department of Family Medicine Schneider, Antonius; Technische Universität München, Institut für Allgemeinmedizin Smyrnakis, Emmanouil; Aristotle University of Thessaloniki , Laboratory of Primary Health Care, General Practice and Health Services Research Streit, Sven; University of Bern, Institute of Primary Health Care Bern (BIHAM) Thulesius, Hans; Lund University, Department of Clinical Sciences Weltermann, Birgitta; University of Bonn, Institut für Hausarztmedizin

	Taylor, Gordon; University of Bath, Department for Health
Keywords:	Delivery of Health Care, Primary Health Care, General Practitioners, Cancer, Decision Making, Consultation and Referral

Identifying important health system factors that influence primary care practitioners' referrals for cancer suspicion: a European cross-sectional survey

Authors

Michael Harris (corresponding author), Department for Health, University of Bath, Claverton Down, Bath BA2 7AY, UK; telephone: +44 1761 241366; fax: none. michaelharris681@btinternet.com

Peter Vedsted, The Research Unit for General Practice, Aarhus University, Aarhus, Denmark. p.vedsted@alm.au.dk

Magdalena Esteva, Research Unit, Majorca Primary Health Care Department, Balearic Islands Health Research Institute (IdISBa), Palma, Spain. mesteva@ibsalut.caib.es

Peter Murchie, Division of Applied Health Sciences - Academic Primary Care, University of Aberdeen, Aberdeen, UK. p.murchie@abdn.ac.uk

Isabelle Aubin-Auger, Department of General Practice, Université Paris Diderot, Paris, France. isabelle.auger-aubin@univ-paris-diderot.fr

Joseph Azuri, Sackler Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel. azuri_yo@mac.org.il

Mette Brekke, Department of General Practice and General Practice Research Unit, University of Oslo, Oslo, Norway. mette.brekke@medisin.uio.no

Krzysztof Buczkowski, Department of Family Medicine, Nicolaus Copernicus University, Toruń, Poland. buczkowskik@cm.umk.pl

Nicola Buono, Department of General Practice, National Society of Medical Education in General Practice (SNaMID), Caserta, Italy. buono.nicola2@gmail.com

Emiliana Costiug, Associate Teaching Assistant, Family Medicine Department,Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania. dr.costiug@gmail.com

Geert-Jan Dinant, Department of General Practice, Maastricht University, Maastricht, Netherlands. geertjan.dinant@maastrichtuniversity.nl

Gergana Foreva, Medical Center BROD, Plovdiv, Bulgaria gerganaforeva@gmail.com

Svjetlana Gašparović Babić, Odjel Socijalne Medicine, The Teaching Institute of Public Health of Primorsko-goranska County, Rijeka, Croatia. svjetlana@zzjzpgz.hr

Hoffman Robert, Department of Family Medicine,Tel Aviv University, Tel Aviv, Israel. Hofman_r@mac.org.il

Eva Jakob, Primary Health Centre, Centro de Saúde Sarria, Sarria, Lugo, Spain. Eva.Jacob.Gonzalez@sergas.es

Tuomas Koskela, Department of General Practice University of Tampere, Tampere, Finland. Tuomas.Koskela@staff.uta.fi

Mercè Marzo-Castillejo, Unitat de Suport a la Recerca, IDIAP Jordi Gol, Institut Català de la Salut, Barcelona, Spain. mmarzoc@gencat.cat

Ana Luísa Neves, Centre for Health Policy, Imperial College, London, UK; also Center for Health Technology and Services Research, University of Porto, Porto, Portugal. ana.luisa.neves@gmail.com

Davorina Petek, Department of Family Medicine, University of Ljubljana, Ljubljana, Slovenia. davorina.petek@gmail.com

Marija Petek Ster, Department of Family Medicine, University of Ljubljana, Ljubljana, Slovenia. marija.petek-ster@mf.uni-lj.si

Jolanta Sawicka-Powierza, Department of Family Medicine, Medical University of Bialystok, Bialystok, Poland. jolasawicka@gmail.com

Antonius Schneider, Institut für Allgemeinmedizin, Technische Universität München, Munich, Germany. antonius.schneider@tum.de

Emmanouil Smyrnakis, Laboratory of Primary Health Care, General Practice and Health Services Research, Aristotle University of Thessaloniki, Thessaloniki, Greece. smyrnak@auth.gr

Sven Streit, Institute of Primary Health Care Bern (BIHAM), University of Bern, Bern, Switzerland. sven.streit@biham.unibe.ch

Hans Thulesius Department of Clinical Sciences, Lund University, Malmö, Sweden. hansthulesius@gmail.com

Birgitta Weltermann, Institut für Hausarztmedizin, University of Bonn, Bonn, Germany. Birgitta.Weltermann@ukbonn.de

Gordon Taylor, Department for Health, University of Bath, Bath, UK. g.j.taylor@bath.ac.uk

Keywords

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

Word count

3,109

Abstract

Objectives

Cancer survival and stage of disease at diagnosis and treatment vary widely across Europe. These differences may be partly due to variations in access to investigations and specialists. However, evidence to explain how different national health systems influence Primary Care Practitioners' (PCPs') referral decisions is lacking.

This study analyses health system factors potentially influencing PCPs' referral decision-making when consulting with patients who may have cancer, and how these vary between European countries.

Design

Based on a content-validity consensus, a list of 45 items relating to a PCP's decisions to refer patients with potential cancer symptoms for further investigation was reduced to 20 items. An online questionnaire with the 20 items was answered by PCPs on a five-point Likert scale, indicating how much each item affected their own decision-making in patients that could have cancer. An exploratory factor analysis identified the factors underlying PCPs' referral decision-making.

Setting

A primary care study; 25 participating centres in 20 European countries

Participants

1,830 PCPs completed the survey. The median response rate for participating centres was 20.7%

Outcome measures

The factors derived from items related to PCPs' referral decision-making. Mean factor scores were produced for each country, allowing comparisons.

Results

Factor analysis identified five underlying factors: PCPs' ability to refer; degree of direct patient access to secondary care; PCPs' perceptions of being under pressure; expectations of PCPs' role; and extent to which PCPs believe that quality comes before cost in their health systems. These accounted for 47.4% of the observed variance between individual responses.

Conclusions

Five healthcare system factors which influence PCPs' referral decision-making were identified. The factors varied considerably between European countries. Knowledge of these factors could assist development of health service policies to produce better cancer outcomes, and inform future research to compare national cancer diagnostic pathways and outcomes.

Article Summary

Strengths and limitations of this study

- The questionnaire was developed using content validity reduction and factor analysis of a consensus item pool, and therefore grounded in PCPs' clinical experience.
- PCPs were recruited from 20 European countries, four countries from each of the Central, Eastern, Northern, Southern and Western European geographical areas.
- Most samples were taken from each local lead's own locality, and these may not have been representative of their nations as a whole.
- The response rate was low but comparable to that of other equivalent surveys of primary care doctors.

Background

There is wide variation in cancer survival rates across Europe [1]. EUROCARE-5 data show that the 1-year relative survival rate for all cancer sites varies from 58.2% to 81.1% between countries [1] (Table 1). Although 1-year relative survival can be affected by differences in registration (e.g. completeness and use of death certificates), and lead-time and over-diagnosis biases [2, 3], it is generally taken to be an indicator of more advanced disease at diagnosis [4, 5]. Survival differences in the subsequent four-year period (known as '5|1-year conditional survival') are narrower, suggesting that earlier diagnosis could reduce the one-year relative survival gap [6]. This is supported by increasing evidence that longer time to diagnosis and treatment may adversely affect mortality [7-13]. While recent overall cancer survival trends show improvements [14], there is little narrowing in the between-country survival differences [15].

The challenge of where and how to achieve more timely diagnosis is considerable [16]. A General Practitioner (GP) will see only a small number of new cancers each year, for example a GP in the UK will on average have a new cancer diagnosed in one of his or her patients each month [17]. The majority of cancers are identified because the patient has been experiencing symptoms. However, most patients present with evolutionary and undifferentiated symptoms that are much more likely to be interpreted as something other than cancer [16].

GP gatekeeping is the cornerstone of many European medical systems [18]. There is evidence that stronger gatekeeper systems are linked with lower one-year relative cancer survival than systems without such gatekeeper functions [19]. This may be because gatekeeping systems can impose cost and resource decisions which impede early referral for investigation [20]. However, there are wide variations in the degree of gatekeeping between countries, with no simple binary model as to whether or not a

country has a "GP-as-gatekeeper" system, and a European study found no link between a higher probability of initial consultation with a GP and poorer cancer survival [21].

The way in which different healthcare systems support primary care in cancer diagnosis by quick and easy access to investigations may also be a factor in timeliness of cancer diagnosis [22]. It has been suggested that GPs need faster routes to diagnostic tests and/or specialist opinion for all patients with a suspicious symptom, above a certain threshold [20]. An International Cancer Benchmarking Partnership (ICBP) study demonstrated a correlation between the readiness of Primary Care Practitioners (PCPs) to investigate suspicious symptoms and cancer survival rates [23]. However, there was no exploration of how individual doctors felt that health system factors affected their decision-making.

The Örenäs Research Group is a European group of primary care researchers that studies the primary care factors that relate to cancer survival. It has identified a large variety of non-clinical factors that are likely to have a considerable impact on PCPs' referral decision-making [24]. These include levels of gatekeeping responsibility, funding systems, access to investigations, and relationships with specialist colleagues. However, there has been little research done to explain how these vary between countries [16].

This study investigated the health system factors potentially influencing European PCPs' decision-making with regards to investigating patients who may have cancer, and how these vary between European countries.

Methods and design

Design

We performed an international online survey of PCPs in twenty European countries between November 2015 and December 2016.

Development of the questionnaire

Seven Örenäs Research Group investigators developed and agreed by consensus a list of 45 items, each relating to predefined aspects/concepts that may affect a PCP's decision to refer patients with potential cancer symptoms for further investigation. A questionnaire based on these items was piloted by sixteen members of the Örenäs Research Group to assess content validity. Six of the items were removed due to low content validity. An English-language questionnaire with the remaining 39 items was piloted by 49 PCPs in 16 Örenäs Research Group member countries. Nineteen items were found to show little or no variation between countries and were removed from the questionnaire, leaving 20 items.

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 and validation were done in a standardised way [25]: native speakers of the local languages who were fluent in English and were medically qualified did the 'forward' translations. 'Backward' translations into English were then made by translators who were fluent in both English and their local language. The forward translations were then compared with the backward ones, to assess semantic and conceptual equivalence [26]. Discrepancies between the forward and backward translations were resolved by discussion with the translators, following which the final

translation was agreed on. Finally, in each country the corrected versions were piloted in a small sample of PCPs to evaluate the instructions, response format and the items for clarity, and to ensure cultural adaptation [26].

The questionnaire and distribution

The final questionnaire sought demographic information (Table 2) and presented the twenty health system factor items (listed in Table 3). Respondents were asked to rate how much they agreed with each item in relation to their referral decision-making for patients who could have cancer. A five-point Likert rating scale was provided for participants, with response options ranging from 'Strongly disagree' to 'Strongly agree'. The questionnaires were put on-line using SurveyMonkey. Online methodology was used to aid the logistics of survey administration; on-line surveys have been successfully used in research involving cancer care professionals [27].

Study population

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.

Subjects were eligible for the survey if they were doctors working mainly in primary care. These doctors, here referred to collectively as 'Primary Care Practitioners', included GPs and other doctors who had had specialist training but worked in the community and could be accessed directly by patients without referral.

Sample size

A total sample size of 1,000 or more responses was calculated to be sufficient to obtain stable factor estimates within the exploratory factor analysis [28], based on each jurisdiction recruiting at least 50 respondents. This provided a 95% confidence interval (CI) ±14% for equally distributed responses, and a 95% CI ±13% for less equally distributed responses.

Recruitment of participants

Each Örenäs Research Group local lead was asked to email an invitation to take part in the survey to the PCPs in their local health district, and to recruit at least 50 participants. In six countries (Denmark, Norway, Portugal, Romania, Slovenia, Sweden), the invitation was distributed to a national sample. Any local leads who had difficulty in achieving the required sample sizes were asked to increase the number of responses by using snowballing [29]. Consent was implied by agreeing to take part in the survey.

Statistical analysis

The demographic characteristics of the respondents were explored using descriptive statistics. Likert scale responses were converted to numerical scores ('Strongly disagree' = 1, 'Strongly agree' = 5). An exploratory factor analysis was undertaken on these responses, to identify underlying factors and to test the predefined constructs.

We used a principal components method [30], with a direct oblimin rotation to allow for correlated factors. The number of components was defined by inspection of the scree plot and the Kaiser criterion (eigenvalue ≥1). Between-country variation in these factors was then examined and presented as means with 95% CIs. Calculations were performed using IBM SPSS Version 22.

Patient and public involvement

There was not patient or public involvement in this study.

Results

A total of 1,830 PCPs completed the questionnaire. All participating centres received at least 50 responses, with a median of 72 respondents per centre. PCPs' demographic distributions are shown in Table 2. The median response rate per country was 20.8% (range 6.7% to 57.8%).

The mean national Likert-scale values for each of the 20 questions are given in Table 3.

The factor loadings for each of the 20 items are shown in Table 4. The factor analysis identified five factors which accounted for 47.4% of the variance of individual responses. The factor means for each participating country and their 95% CIs are given in Table 5.

Factor 1: Primary care practitioners' ability to refer

This factor contained six items. A higher score on this factor indicated lower barriers to specialist referral, more time during the consultation to consider whether the patient needs a referral, and absence of criticism from colleagues over referrals that were perceived to be unnecessary. This factor explained 15.5% of the variance of individual responses. A comparison of national scores for Factor 1 is shown in Figure 1.

(Place Figure 1 here)

Factor 2: Degree of direct patient access to secondary care

This factor contained six items. A higher score for this factor was linked with items relating to direct patient access to secondary care: the absence of a GP gate-keeping role, with higher financial and geographical barriers to healthcare for some patients, and in some cases the presence of a quota for diagnostic tests. Higher scores for this factor were also linked with less likelihood of having a fast-track specialist appointment system for patients with suspected cancer. Factor 2 explained 10.8% of the variance of individual responses, and the comparison of national scores for this factor is shown in Figure 2.

(Place Figure 2 here)

Factor 3: Primary care practitioners' perceptions of being under pressure

This factor contained four items. A higher score was linked with perceptions of pressure on the PCP from a high workload, as well as demands from patients, the

public and the health system. It explained 7.6% of the variance of individual responses. A comparison of national scores for Factor 3 is shown in Figure 3.

(Place Figure 3 here)

Factor 4: Expectations of the primary care practitioners' role

This factor contained two items. A higher score for this factor was associated with higher expectations of PCP-centred care, and the presence of guidelines to support PCP decision-making. It explained 6.7% of the variance of individual responses, and a comparison of national scores for this factor is shown in Figure 4.

(Place Figure 4 here)

Factor 5: Quality before cost

This factor contained two items. A higher score was linked with PCP perceptions that in their systems high quality care for patients was more important than costs, and that financial aspects had less effect on their referral decision-making. This factor explained 6.4% of the variance of individual responses. A comparison of national scores for Factor 5 is shown in Figure 5.

(Place Figure 5 here)

Discussion

Principal findings

Based on a content validity process, a 45-item pool on referral decision-making for patients who could have cancer was reduced to a 20-item questionnaire. From the responses of 1,830 PCPs, five key factors were identified: PCPs' ability to refer; degree of direct patient access to secondary care; PCP perceptions of being under pressure; expectations of the PCPs' role; and the extent to which PCPs believe that, in their systems, quality comes before cost. The factors showed significant variation between the 20 European participant countries. This supports the use of the questionnaire to analyse associations with national cancer outcomes, for example survival, stage at diagnosis and patient evaluation.

Interpretation of the results

Based on the content validity and the significant variation between countries, the survey can be regarded as relevant for studying aspects of the referral and investigation of patients with symptoms that could be due to cancer. Thus, the developed questionnaire could be used in further research to evaluate associations with cancer outcomes, and could also be used to evaluate changes in healthcare systems regarding referring patients who could have cancer.

Factor 1. Primary care practitioners' ability to refer: the variation in PCPs' ability to refer was linked to structural differences like barriers to specialist referrals (including waiting times), the degree of criticism of PCPs relating to their referrals, the quality and amount of relationships between PCPs and specialists, and the length of the PCPs'

consultations with patients. This was the most important factor, carrying most of the explained variation. Thus, such experienced abilities appear to be particularly important in explaining between-country differences in primary care cancer diagnosis.

Factor 2. Degree of direct patient access to secondary care: this important factor was related to the extent to which GPs were gatekeepers and to which public systems provided universal access to healthcare, whether self-referral to specialists was possible outside the public health system, patients' ability to travel to and fund specialist consultations, and whether fast-track referral systems were in place for patients with suspected cancer.

Factor 3. Primary care practitioners' perceptions of being under pressure: variations in PCP perceptions of being under pressure were linked with PCP workloads, patient expectations and their level of trust in their doctors, and the extent to which health systems expected PCPs to refer patients.

Factor 4. Expectations of the primary care practitioners' role: differing expectations of the PCPs' role were related to whether there had been a shift of work and responsibility between secondary and primary care, and the extent to which patient care was from specialists rather than from PCPs.

Factor 5. Quality before cost: the variation in the extent to which PCPs perceived the balance between quality of care and cost was linked with how much PCPs themselves were directly affected by considerations of cost.

Strengths and weaknesses of the study

There were participating centres in four countries from each of the Central, Eastern, Northern, Southern and Western European geographical areas, providing variation in

geography, health systems and levels of healthcare spending. It included the views of PCPs who are not usually involved in research. The questionnaire was carefully developed and piloted by GPs and other PCPs, and therefore grounded in their clinical experience. While low survey response rates are common in primary care [31] and are known to vary between countries, the response rates in our study were comparable to those of a recent ICBP survey, in which response rates varied from 5.5% to 45.6% [23].

Most samples were taken from each local lead's own locality, and these may not have been representative of their nations as a whole [32]. While this makes it difficult to generalise the findings to each country, the variation between countries is relevant and valid. The recruitment method used in this study resulted in variable response rates, leading to a risk of non-response bias and loss of power [31]. However, the goal of 50 survey participants per centre and more than 1000 respondents in total was achieved.

Participants' responses may have been influenced by previous questions, and there may have been country-level differences in response styles, for instance choosing or avoiding the 'extreme' options on the scale [33]. As the translation also included a cultural adaptation we believe this bias was minimised, and the differences between countries cannot simply be explained by differences in response styles.

The five factors accounted for 47.4% of the variance in PCPs' responses, and it is acceptable consider a solution that accounts for 60% or less of the total variance as satisfactory [34]. Two of the factors only included two items each, which makes them vulnerable to missing responses and stochastic variation.

Comparison with other studies

To our knowledge, this is the first study that has been designed to identify the factors underlying PCPs' referral decision-making, and provide international comparisons of

the extent to which PCPs themselves perceive these as important. An ICBP narrative review compared the characteristics of healthcare systems of six countries (Australia, Canada, Denmark, Norway, Sweden and the United Kingdom), aiming to identify characteristics that could possibly modify the diagnostic pathway [35]. However, unlike our study, it only explored the systems of relatively wealthy countries, and it did not examine PCPs' own perceptions of how their systems affected their decision-making. Our finding that PCPs in different European countries perceive different levels of access to investigations and specialist opinions may be relevant to the finding of varying referral delays in three European countries (Scotland, the Netherlands and Sweden) [36].

Possible implications for clinicians and policymakers

Five health system factors were able to explain nearly half of the variation in the PCPs' responses to the items. This indicates that a relatively large part of the variation may be explained by differences between the health systems. Our study indicates the policy domains where countries might be able to modify their systems to better support their GPs and other PCPs in the timely referral and investigation of patients who could have cancer.

The most important of these factors were the ease of PCPs' ability to refer, and the degree of direct patient access to secondary care. These factors are key in supporting earlier and expedited cancer diagnosis and may thus be linked with cancer outcomes. It therefore seems plausible that some countries could improve their cancer outcomes by providing better access to investigations and secondary care when cancer is suspected.

Unanswered questions and future research

The five factors and their related scores should be compared with national cancer outcomes. These outcomes could include mortality, stage distribution and patient evaluations. An additional area of study could be to relate the factors and scores to national health system costs.

Conclusions

This research has developed a 20-item questionnaire with good content and construct validity, and has identified five factors that PCPs perceive to affect their referral decision-making in patients that could have cancer. We have demonstrated that these vary depending on the different European models of primary care. This understanding of the interaction between health system variables and PCP decision-making can help in an exploration of the differences in national cancer diagnostic pathways and cancer outcomes, and could help to inform health service policy and research toward better cancer outcomes.

List of abbreviations

CI	Confidence interval
GP	General Practitioner
ICBP	International Cancer Benchmarking Partnership
PCP	Primary Care Practitioner

Declarations

Ethics approval

Ethical approval for the study was been 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.

Funding

This study received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Data sharing

The Örenäs survey data used in this study is available at https://doi.org/10.15125/BATH-00486

Author contributions

BW, EC, ES, GF, G-JD, IA-A, JS-P, KB, ME, MH, MM-C, NB, PM, PV, RH, SG-B, and HT participated in the study design and piloting. All authors except GT were involved in the data collection. All authors contributed to the writing and review of the manuscript and approved the final version. MH had overall responsibility for the study design, recruitment of local leads, analysis of data and interpretation of results. GT advised on the study design and the statistical analysis.

Acknowledgements

The authors would like to thank all the PCPs who piloted the questionnaire and those who completed the survey. They are also grateful to Prof. Barbara Silverman and Prof. Lital Keinan for the data on cancer survival rates in Israel.

References

1. EUROCARE. EUROCARE-5. In: Istituto Nazionale Tumori (Milan IaISdSR, Italy), editor. Milan and Rome 2014.

2. Carter JL, Coletti RJ, Harris RP. Quantifying and monitoring overdiagnosis in cancer screening: a systematic review of methods. BMJ. 2015;350:g7773.(doi):10.1136/bmj.g7773.

3. Zahl PH, Jorgensen KJ, Gotzsche PC. Overestimated lead times in cancer screening has led to substantial underestimation of overdiagnosis. Br J Cancer. 2013;109(7):2014-9. doi: 10.1038/bjc.2013.427. Epub Aug 20.

4. Richards MA. The size of the prize for earlier diagnosis of cancer in England. Br J Cancer. 2009;101:S125–S9.

5. Woods LM, Coleman MP, Lawrence G, Rashbass J, Berrino F, Rachet B. Evidence against the proposition that "UK cancer survival statistics are misleading": simulation study with National Cancer Registry data. BMJ. 2011;342:d3399.(doi):10.1136/bmj.d3399.

6. Thomson CS, Forman D. Cancer survival in England and the influence of early diagnosis: what can we learn from recent EUROCARE results? Br J Cancer. 2009;101:S102–S9.

7. McLaughlin JM, Anderson RT, Ferketich AK, Seiber EE, Balkrishnan R, Paskett ED. Effect on survival of longer intervals between confirmed diagnosis and treatment initiation among low-income women with breast cancer. J Clin Oncol. 2012;30(36):4493-500.

8. Yun YH, Kim YA, Min YH, Park S, Won YJ, Kim DY, et al. The influence of hospital volume and surgical treatment delay on long-term survival after cancer surgery. Ann Oncol. 2012;23(10):2731-7.

9. Elit LM, O'Leary EM, Pond GR, Seow HY. Impact of wait times on survival for women with uterine cancer. J Clin Oncol. 2014;32(1):27-33.

10. Nanthamongkolkul K, Hanprasertpong J. Longer waiting times for early stage cervical cancer patients undergoing radical hysterectomy are associated with diminished long-term overall survival. J Gynecol Oncol. 2015;26(4):262-9.

11. Neal RD, Tharmanathan P, France B, Din NU, Cotton S, Fallon-Ferguson J, et al. Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic review. Br J Cancer. 2015;112 Suppl 1:S92-107.

12. Torring ML, Frydenberg M, Hansen RP, Olesen F, Vedsted P. Evidence of increasing mortality with longer diagnostic intervals for five common cancers: a cohort study in primary care. Eur J Cancer. 2013;49(9):2187-98.

13. Gobbi PG, Bergonzi M, Comelli M, Villano L, Pozzoli D, Vanoli A, et al. The prognostic role of time to diagnosis and presenting symptoms in patients with pancreatic cancer. Cancer Epidemiol. 2013;37(2):186-90.

14. De Angelis R, Sant M, Coleman MP, Francisci S, Baili P, Pierannunzio D, et al. Cancer survival in Europe 1999-2007 by country and age: results of EUROCARE-5 - a population-based study. Lancet Oncol. 2014;15(1):23-34.

15. Coleman MP, Forman D, Bryant H, Butler J, Rachet B, Maringe C, et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. Lancet. 2011;377(9760):127-38.

16. Foot C, Harrison T. How to improve cancer survival: explaining England's relatively poor rates. London: The King's Fund; 2011. p. 30 January 2012.

17. Hamilton W. Cancer diagnosis in primary care. Br J Gen Pract. 2010;60(571):121-8.

18. Masseria C, Irwin R, Thomson S, Gemmill M, Mossialos E. Primary care in Europe. In: Science TLSoEaP, editor.: European Commission; 2009.

19. Vedsted P, Olesen F. Are the serious problems in cancer survival partly rooted in gatekeeper principles? Br J Gen Pract. 2011;61(589):512-3.

20. Neal RD. Commentary. Cancer diagnosis - the role of urgent referral guidelines. Br J Gen Pract. 2010;60(571):127.

21. Harris M, Frey P, Esteva M, Gašparović Babić S, Marzo-Castillejo M, Petek D, et al. How the probability of presentation to a primary care clinician correlates with cancer survival rates: a European survey using vignettes. Scand J Prim Health Care. 2017:1-8.

22. Rubin G, Vedsted P, Emery J. Improving cancer outcomes: better access to diagnostics in primary care could be critical. Br J Gen Pract. 2011;61(586):317-8.

23. Rose PW, Rubin G, Perera-Salazar R, Almberg SS, Barisic A, Dawes M, et al. Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. BMJ Open. 2015;5(5):e007212. doi: 10.1136/bmjopen-2014-.

24. Harris M, Frey P, Esteva M, Gašparović-Babić S, Marzo-Castillejo M, Petek D, et al. How health system factors influence referral decisions in patients that may have cancer: European symposium report. J Cancer Res Ther.2016. p. 7-10.

25. Maneesriwongul W, Dixon JK. Instrument translation process: a methods review. J Adv Nurs. 2004;48(2):175-86.

26. Center for Aging in Diverse Communities. Guidelines for Translating Surveys in Cross-Cultural Research. San Francisco: University of California; 2007.

27. Dobrow MJ, Orchard MC, Golden B, Holowaty E, Paszat L, Brown AD, et al. Response audit of an Internet survey of health care providers and administrators: implications for determination of response rates. J Med Internet Res. 2008;10(4):e30.

28. van Belle G. Statistical Rules of Thumb, 2nd Edition. Hoboken, N.J.: Wiley; 2008.

29. Shaghaghi A, Bhopal RS, Sheikh A. Approaches to Recruiting 'Hard-To-Reach' Populations into Re-search: A Review of the Literature. Health Promot Perspect. 2011;1(2):86-94.

30. Hotelling H. Analysis of a complex of statistical variables into principal components. . J Educ Psychol. 1933;24(6):417-41.

31. Pit SW, Vo T, Pyakurel S. The effectiveness of recruitment strategies on general practitioner's survey response rates - a systematic review. BMC Med Res Methodol. 2014;14:76.

32. Greenacre Z. The Importance of Selection Bias in Internet Surveys. OJS. 2016;6:397-404.

33. Harzing A-W. Response styles in cross-national survey research: a 26-country study. Int J Cross Cult Manag. 2006;6(2).

34. Hair J, Black W, Babin B, Anderson R. Multivariate Data Analysis. 7th ed: Pearson; 2009.

35. Brown S, Castelli M, Hunter D, Erskine J, Vedsted P, Foot C, et al. How might healthcare systems influence speed of cancer diagnosis: A narrative review. Soc Sci Med. 2014;116:56–63.

36. Murchie P, Campbell NC, Delaney EK, Dinant GJ, Hannaford PC, Johansson L, et al. Comparing diagnostic delay in cancer: a cross-sectional study in three European countries with primary care-led health care systems. Fam Pract. 2012;29(1):69-78.

Table 1. EUROCARE 5 1-year relative and 5|1-year conditional cancer survival rates for European countries [1], with ranks given.

Country	1-year relative survival (%)	1-year relative survival: rank	5|1-year conditional survival (%)	5|1-year conditional survival: rank
Austria	75.9	11	60.1	7
Belgium	78.9	3	60.4	6
Bulgaria	58.2	28	38.7	28
Croatia	62.1	25	46.2	22
Czech Republic	68.3	19	50.7	19
Denmark	69.8	18	50.9	18
Estonia	65.9	22	46.0	24
Finland	76.9	8	61.4	4
France	77.8	7	58.6	10
Germany	76.7	9	59.1	9
Greece	(not available)		(not available)	
Iceland	78.3	6	61.2	5
Ireland	70.3	16	54.0	15
Israel (Arabs) *	78.6	4	61.4	3
Israel (Jews) *	82.8	1	68.9	1
Italy	74.9	12	56.8	12
Latvia	60.9	27	41.7	26
Lithuania	63.8	24	46.1	23
Malta	70.0	17	52.9	16

Netherlands	73.0	14	54.6	14
Norway	76.1	10	58.6	11
Poland	61.7	26	40.6	27
Portugal	74.0	13	56.4	13
Romania	(not available)		(not available)	
Slovakia	65.4	23	44.8	25
Slovenia	67.7	21	47.8	21
Spain	71.5	15	52.8	17
Sweden	81.1	2	64.8	2
Switzerland	78.3	5	59.2	8
United Kingdom	67.9	20	50.1	20
European mean	72.5		54.2	

* Calculated from data provided by B. Silverman, Israel Ministry of Health (personal communication, 7 September 2017)

Table 2. Number of respondents per country and demographic distributions.

		Number of respondents (% of all respondents)
Respondents per country	Bulgaria	51 (2.8)
	Croatia	56 (3.1)
	Denmark	92 (5.0)
	England	62 (3.4)
	Finland	61 (3.3)
	France	52 (2.8)
	Germany	91 (5.0)
	Greece	59 (3.2)
	Israel	58 (3.2)
	Italy	60 (3.3)
	Netherlands	107 (5.8)
	Norway	81 (4.4)
	Poland	135 (7.4)
	Portugal	59 (3.2)
	Romania	146 (8.0)
	Scotland	62 (3.4)
	Slovenia	91 (5.0)
	Spain	379 (20.7)
	Sweden	68 (3.7)
	Switzerland	60 (3.3)
	Total	1830 (100)

Respondent gender	Female	1108 (60.5)
	Male	708 (38.7)
	Not stated	14 (0.8)
	Total	1830 (100)
Years since graduation	<10 years	284 (15.5)
	10-19 years	492 (26.9)
	20-29 years	535 (29.2)
	30-39 years	442 (24.2)
	40 years or over	69 (3.8)
	Not stated	8 (0.4)
	Total	1830 (100)
Site of practice	Urban	1086 (59.6)
	Rural	426 (23.3)
	Island	50 (2.7)
	Mixed	268 (14.6)
	Total	1830 (100)
Number of doctors in practice	1	252 (13.8)
	2	210 (11.5)
	3	196 (10.7)
	4-5	304 (16.6)

6-7	235 (12.8)
8-9	153 (8.4)
10 or more	470 (25.7)
Not stated	10 (0.5)
Total	1830 (100)

Table 3. Mean national Likert-scale values for each of the 20 questions

	Bulgaria	Croatia	Denmark	England	Finland	France	Germany	Greece	Israel	Italy	Netherlands	Norway	Poland	Portugal	Romania	Scotland	Slovenia	Spain	Sweden	Switzerland
Common presentations are covered by local or national guidelines that usually give advice on which patients to refer	2.76	3.22	3.96	3.92	4.00	3.04	3.35	3.59	3.64	3.40	3.96	3.26	3.44	3.12	3.37	3.89	3.73	3.90	3.59	3.37
The local health system encourages us to refer any patients with possible cancer early, even if there is a low risk of cancer.	2.78	3.00	3.91	3.29	2.97	3.29	3.79	3.37	3.60	3.05	2.84	3.20	3.18	2.97	3.68	3.31	3.28	3.07	2.91	4.05
In my practice, patients often have to travel a long way to see a specialist.	1.91	2.45	2.02	2.44	1.62	1.98	1.76	3.24	2.40	2.83	1.79	1.89	2.54	1.90	2.78	2.74	2.34	1.99	2.59	1.68
I am able to refer directly to a named specialist.	3.80	2.73	4.28	2.10	1.95	4.55	4.60	3.90	4.49	3.24	3.92	3.84	2.73	2.81	3.83	2.35	2.73	3.79	2.31	4.90
I am able to refer to a specialist that I know personally.	4.14	2.89	3.38	2.02	2.00	4.24	4.39	3.86	4.26	3.41	3.74	2.67	2.77	2.27	3.81	2.34	2.92	2.52	2.29	4.87
I can easily telephone (or email) a specialist for informal discussion and advice.	3.36	2.52	3.68	3.16	3.90	3.80	4.21	3.07	3.82	3.13	4.18	3.25	1.69	2.71	3.25	3.23	2.51	3.39	4.04	4.73
Here, specialists usually welcome referrals.	4.37	2.85	3.36	3.35	3.48	4.18	3.89	3.31	3.88	3.21	4.02	3.79	2.29	3.14	3.01	3.06	2.21	2.68	3.37	4.70
Seeing a specialist can be a problem for some of my patients because of the financial cost to them.	3.22	2.82	1.74	2.28	2.64	4.06	1.74	4.36	2.21	3.70	3.90	2.15	3.13	2.71	3.80	2.02	2.70	2.12	2.04	2.32
We have a budget or quota (maximum limit) for diagnostic tests.	4.36	3.02	1.68	1.87	1.92	1.60	3.18	3.63	2.21	2.44	2.03	1.34	3.52	3.22	3.09	1.51	2.88	2.72	2.07	1.35

Here, high quality care for an individual patient is always more important than costs.	3.20	3.53	3.95	3.85	3.77	3.75	3.23	3.51	3.91	3.48	3.76	3.59	3.38	3.95	3.87	3.89	3.74	3.67	4.03	4.08
Referring or not referring doesn't affect me at all financially.	2.69	3.13	4.41	4.07	4.20	4.67	4.18	3.68	4.33	3.31	4.28	4.46	3.52	4.29	3.99	4.43	4.04	3.63	4.26	4.27
Referral costs are usually paid by insurance companies, not hospital or primary care budgets.	2.76	3.41	1.00	1.63	1.33	2.88	3.56	2.10	2.84	1.94	4.00	1.78	2.71	1.63	3.70	1.66	4.13	1.84	1.41	4.48
My colleagues sometimes criticise me if I have referred a patient to them, but they think that I should have been able to manage the patient myself.	2.08	2.76	1.90	2.39	2.51	2.19	1.48	2.92	2.11	2.63	2.29	2.58	3.38	2.53	2.72	2.40	3.24	2.41	2.65	1.27
In general, patients prefer a GP, rather than a specialist, to look after them.	3.12	3.09	3.40	3.00	2.61	3.00	3.67	3.56	3.52	3.30	3.53	2.99	2.98	3.12	3.53	3.23	3.49	3.22	3.12	3.65
We have access to a fast-track specialist appointment system for patients with suspected cancer.	2.71	3.22	4.75	4.66	4.08	3.46	2.87	2.45	3.33	3.22	4.30	4.67	3.63	3.42	2.58	4.37	3.22	4.06	3.31	2.27
Patients can self-refer to specialists, so GPs don't need to act as gatekeepers.	2.39	2.04	1.41	1.39	1.92	2.29	3.19	2.58	3.10	2.65	1.61	1.59	1.83	1.86	2.38	1.38	1.55	1.45	2.75	3.02
I am usually very busy, so I sometimes refer to help reduce my workload.	2.73	2.16	2.61	2.53	2.59	2.48	1.98	2.24	2.98	2.56	2.51	2.40	2.82	2.12	1.96	1.92	3.01	2.43	2.15	1.97
I usually have enough time in the consultation to think carefully about whether the patient needs a referral.	3.32	3.52	3.43	3.02	3.15	3.77	3.86	3.49	3.16	3.67	3.59	3.75	2.64	2.58	3.90	3.29	2.91	2.83	3.16	3.69
I am likely to refer if the patient says that she/he would like to be referred, even if there are no “red flags”.	3.10	2.59	3.02	3.20	2.51	2.96	3.62	3.42	3.69	3.36	2.92	3.11	3.63	3.05	2.80	3.00	3.30	2.88	3.06	3.52
We are under media (newspaper, television) or public pressure to refer earlier.	3.84	3.04	3.38	3.97	2.82	2.81	4.16	2.69	3.16	3.42	3.10	3.80	3.61	2.42	2.65	3.92	3.36	3.23	2.50	2.77

A response of ‘Strongly disagree’ was given a score of 1; ‘Disagree’ = 2; ‘Neither agree nor disagree’ = 3; ‘Agree’ = 4; ‘Strongly agree’ = 5.

Table 4. Health system items and their factor analysis loadings.

Health system item	Component				
Factor 1	1	2	3	4	5
I am able to refer to a specialist that I know personally.	0.68	0.42	0.09	0.03	-0.14
Here, specialists usually welcome referrals.	0.68	0.02	0.12	-0.04	-0.11
I can easily telephone (or email) a specialist for informal discussion and advice.	0.68	-0.12	0.11	0.17	-0.12
I am able to refer directly to a named specialist.	0.62	0.22	0.22	0.13	-0.26
I usually have enough time in the consultation to think carefully about whether the patient needs a referral.	0.57	-0.02	-0.32	0.07	0.12
My colleagues sometimes criticise me if I have referred a patient to them, but they think that I should have been able to manage the patient myself.	-0.51	0.25	0.14	0.12	0.31
Factor 2					
Seeing a specialist can be a problem for some of my patients because of the financial cost to them.	-0.08	0.59	-0.17	0.27	0.24
We have access to a fast-track specialist appointment system for patients with suspected cancer.	0.05	-0.54	0.34	0.34	-0.03
We have a budget or quota (maximum limit) for diagnostic tests.	-0.27	0.54	-0.06	0.25	-0.26
Referral costs are usually paid by insurance companies, not hospital or primary care budgets.	0.30	0.46	-0.05	-0.19	0.23
Patients can self-refer to specialists, so GPs don't need to act as gatekeepers.	0.34	0.44	0.04	-0.30	0.11

In my practice, patients often have to travel a long way to see a specialist.	-0.26	0.38	-0.09	0.37	0.36
Factor 3					
I am usually very busy, so I sometimes refer to help reduce my workload.	-0.32	0.19	0.60	-0.09	-0.01
I am likely to refer if the patient says that she/he would like to be referred, even if there are no “red flags”.	-0.02	0.29	0.53	-0.34	0.16
We are under media (newspaper, television) or public pressure to refer earlier.	-0.20	0.08	0.51	-0.09	-0.16
The local health system encourages us to refer any patients with possible cancer early, even if there is a low risk of cancer.	0.26	0.11	0.36	0.23	0.20
Factor 4					
Common presentations are covered by local or national guidelines that usually give advice on which patients to refer	0.05	-0.25	0.33	0.55	0.15
In general, patients prefer a GP, rather than a specialist, to look after them.	0.25	0.19	-0.02	0.41	0.08
Factor 5					
Here, high quality care for an individual patient is always more important than costs.	0.30	-0.26	0.01	0.05	0.57
Referring or not referring doesn't affect me at all financially.	0.31	-0.29	0.08	-0.34	0.55

Table 5. Factor means for each country with 95% confidence intervals

	Number of respondents	**Factor 1** Mean (95% CI)	**Factor 2** Mean (95% CI)	**Factor 3** Mean (95% CI)	**Factor 4** Mean (95% CI)	**Factor 5** Mean (95% CI)
Bulgaria	52	0.62 (0.43 - 0.82)	0.58 (0.34 - 0.82)	0.23 (-0.12 - 0.59)	-1.11 (-1.50 - -0.72)	-1.43 (-1.74 - -1.11)
Croatia	56	-0.47 (-0.70 - -0.24)	0.42 (0.21 - 0.62)	-0.48 (-0.74 - -0.21)	-0.46 (-0.78 - -0.14)	-0.53 (-0.81 - -0.25)
Denmark	92	0.39 (0.25 - 0.54)	-1.04 (-1.15 - -0.93)	0.15 (-0.04 - 0.35)	0.59 (0.43 - 0.76)	0.41 (0.26 - 0.57)
England	62	-0.65 (-0.85 - -0.45)	-0.90 (-1.09 - -0.71)	0.29 (0.06 - 0.51)	0.31 (0.12 - 0.50)	0.34 (0.16 - 0.52)
Finland	61	-0.52 (-0.70 - -0.34)	-0.83 (-0.97 - -0.68)	-0.34 (-0.59 - -0.10)	-0.07 (-0.31 - 0.17)	0.38 (0.19 - 0.56)
France	52	0.76 (0.57 - 0.95)	0.58 (0.41 - 0.75)	-0.23 (-0.50 - 0.04)	-0.27 (-0.51 - -0.03)	0.58 (0.42 - 0.74)
Germany	91	1.41 (1.26 - 1.55)	0.40 (0.22 - 0.57)	0.43 (0.25 - 0.62)	-0.64 (-0.87 - -0.42)	0.02 (-0.23 - 0.27)
Greece	59	0.03 (-0.18 - 0.24)	1.40 (1.21 - 1.60)	-0.21 (-0.46 - 0.03)	0.35 (0.03 - 0.67)	-0.61 (-0.86 - -0.37)
Israel	58	0.89 (0.73 - 1.05)	0.48 (0.29 - 0.68)	0.67 (0.39 - 0.95)	-0.05 (-0.31 - 0.21)	0.49 (0.25 - 0.72)
Italy	60	-0.18 (-0.44 - 0.08)	0.52 (0.32 - 0.73)	-0.07 (-0.38 - 0.25)	-0.06 (-0.34 - 0.21)	-0.45 (-0.82 - -0.09)
Netherlands	108	0.60 (0.50 - 0.70)	0.23 (0.12 - 0.33)	-0.24 (-0.40 - -0.08)	0.44 (0.33 - 0.55)	0.29 (0.16 - 0.41)
Norway	81	0.11 (-0.06 - 0.28)	-0.77 (-0.92 - -0.62)	0.16 (-0.04 - 0.36)	-0.18 (-0.35 - 0.00)	0.52 (0.36 - 0.68)
Poland	135	-1.00 (-1.15 - -0.84)	0.40 (0.26 - 0.55)	0.70 (0.52 - 0.88)	-0.15 (-0.36 - 0.06)	-0.59 (-0.77 - -0.40)
Portugal	59	-0.63 (-0.84 - -0.42)	-0.09 (-0.31 - 0.13)	-0.32 (-0.57 - -0.06)	-0.48 (-0.76 - -0.19)	0.01 (-0.20 - 0.22)

Romania	146	0.16 (0.01 - 0.31)	1.30 (1.17 - 1.43)	-0.69 (-0.86 - -0.52)	0.11 (-0.05 - 0.28)	-0.03 (-0.19 - 0.13)
Scotland	62	-0.54 (-0.72 - -0.37)	-0.71 (-0.88 - -0.53)	-0.14 (-0.33 - 0.05)	0.34 (0.14 - 0.55)	0.57 (0.39 - 0.75)
Slovenia	91	-0.71 (-0.87 - -0.56)	0.53 (0.40 - 0.67)	0.48 (0.30 - 0.66)	0.08 (-0.13 - 0.28)	0.01 (-0.18 - 0.20)
Spain	380	-0.27 (-0.35 - -0.19)	-0.67 (-0.75 - -0.60)	-0.03 (-0.13 - 0.07)	0.21 (0.12 - 0.31)	-0.36 (-0.46 - -0.26)
Sweden	68	-0.35 (-0.52 - -0.18)	-0.11 (-0.27 - 0.06)	-0.42 (-0.64 - -0.20)	-0.21 (-0.45 - 0.03)	0.56 (0.34 - 0.79)
Switzerland	60	1.79 (1.66 - 1.91)	0.78 (0.63 - 0.94)	-0.08 (-0.36 - 0.20)	-0.55 (-0.79 - -0.31)	0.91 (0.69 - 1.12)
Total	1,833					

Figure legends

Figure 1. *Comparison of national scores for Factor 1: Primary care practitioner's ability to refer.*

Figure 2. *Comparison of national scores for Factor 2: Degree of direct patient access to secondary care.*

Figure 3. *Comparison of national scores for Factor 3: pressure on PCP from outside.*

Figure 4. *Comparison of national scores for Factor 4: Expectations of the PCP's role.*

Figure 5. *Comparison of national scores for Factor 5: Quality before cost.*

Figure 1. *Comparison of national scores for Factor 1: Primary care practitioner's ability to refer.*

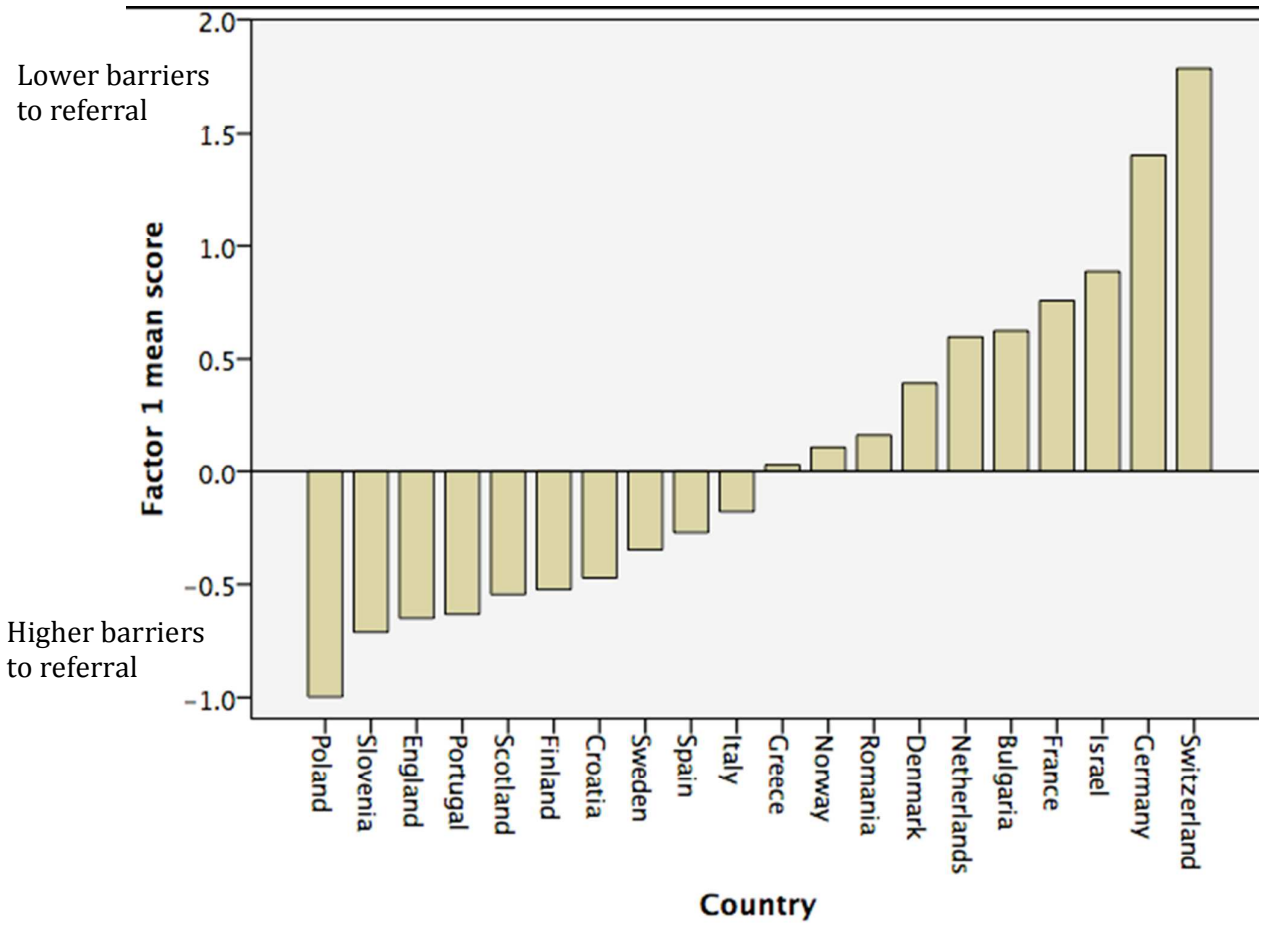


Figure 2. *Comparison of national scores for Factor 2: Degree of direct patient access to secondary care.*

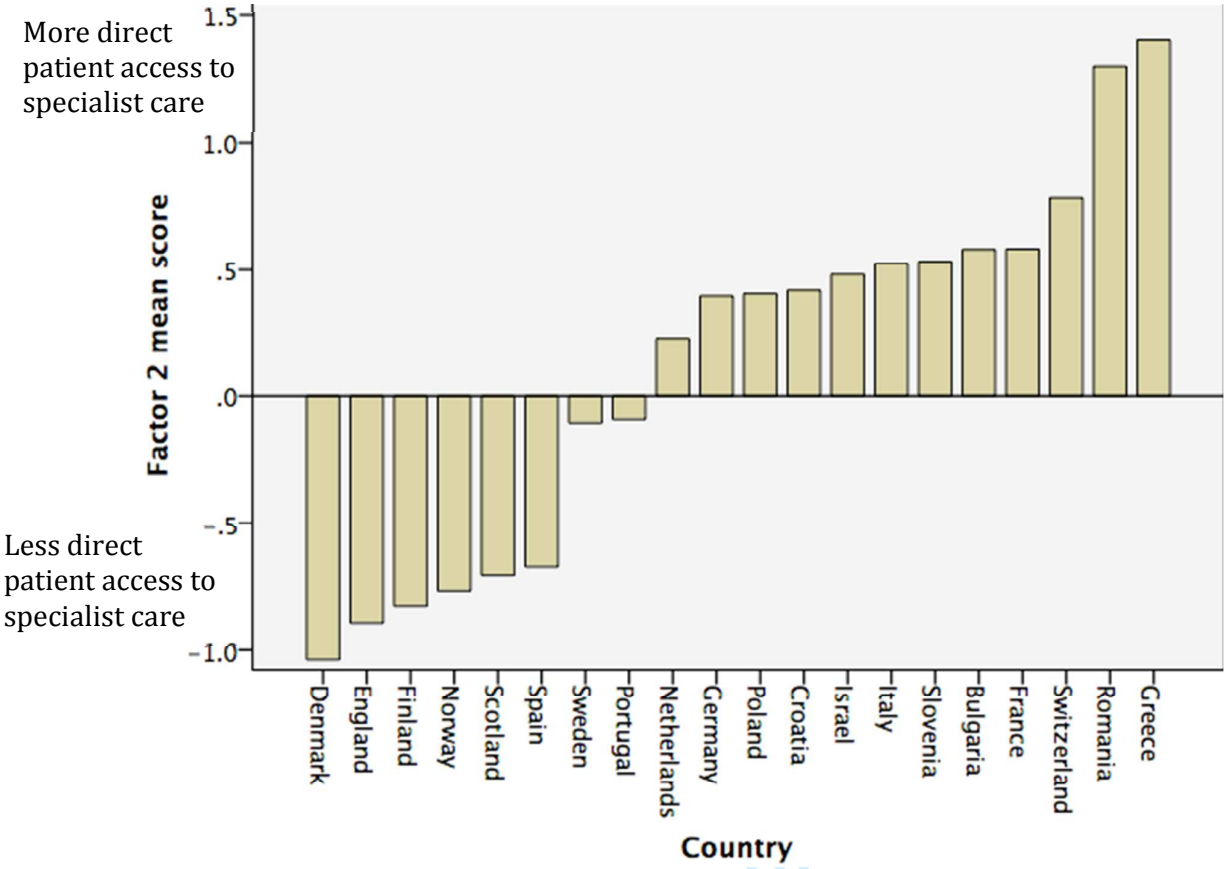


Figure 3. *Comparison of national scores for Factor 3: pressure on PCP from outside.*

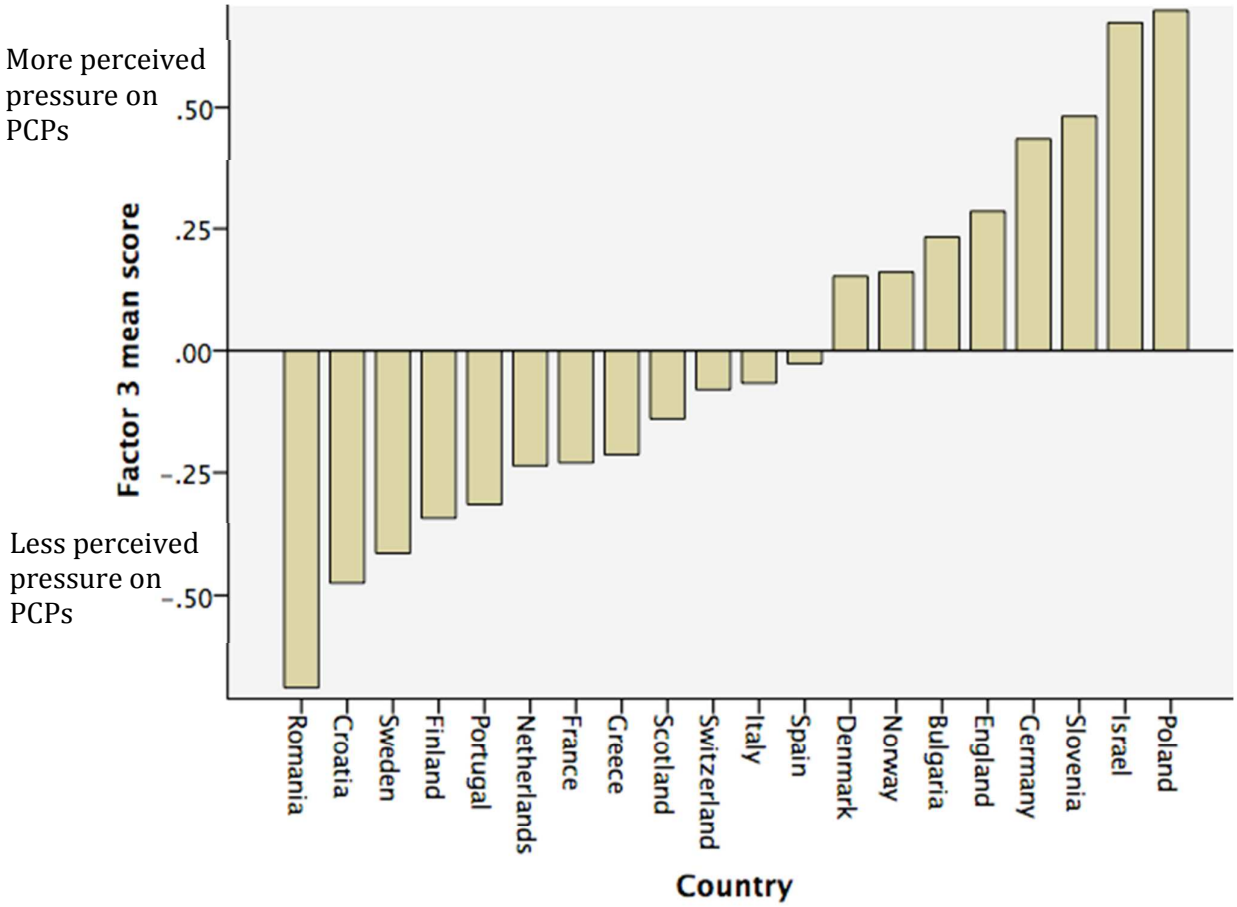


Figure 4. *Comparison of national scores for Factor 4: Expectations of the PCP's role.*

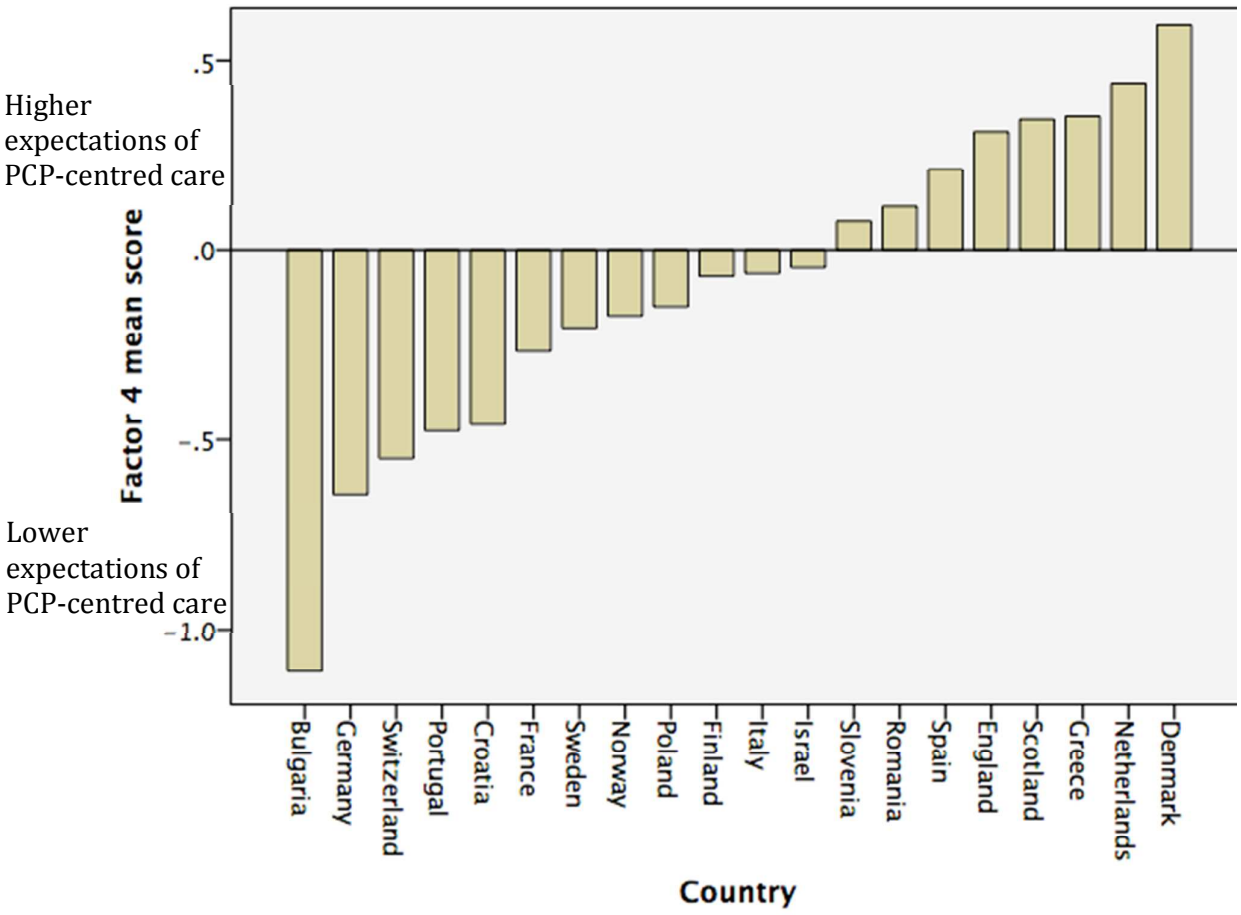
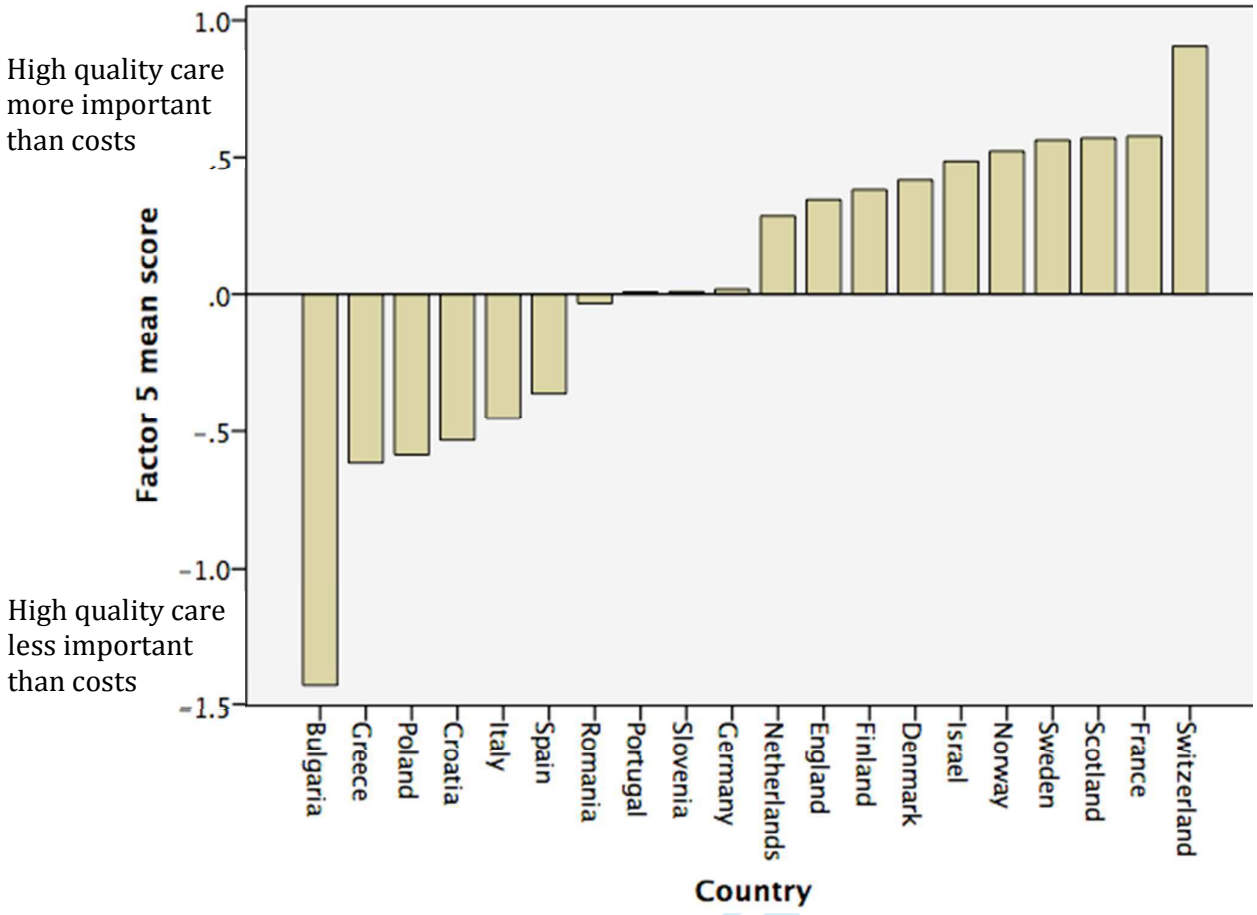


Figure 5. *Comparison of national scores for Factor 5: Quality before cost.*



BMJ Open

Identifying important health system factors that influence primary care practitioners' referrals for cancer suspicion: a European cross-sectional survey

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-022904.R1
Article Type:	Research
Date Submitted by the Author:	09-Jun-2018

Complete List of Authors:	Harris, Michael; University of Bath, Department for Health Vedsted, Peter; Research Unit for General Practice, University of Aarhus Esteva, Magdalena; Majorca Primary Health Care Department, Balearic Islands Health Research Institute (IdISBa), Research Unit Murchie, Peter; University of Aberdeen, Division of Applied Health Sciences - Academic Primary Care Aubin-Auger, Isabelle; Universite Paris Diderot UFR de Medecine, General Practice Azuri, Joseph; Tel Aviv University, Sackler Faculty of Medicine Brekke, Mette; University of Oslo, Department of General Practice and General Practice Research Unit Buczkowski, Krzysztof; Nicolaus Copernicus University, Department of Family Medicine Buono, Nicola; National Society of Medical Education in General Practice (SNaMID), Department of General Practice Costiug, Emiliana; Iuliu Hatieganu University of Medicine and Pharmacy, Family Medicine Department Dinant, Geert-Jan; Maastricht University, Department of General Practice Foreva, Gergana; Medical Center BROD Gašparović Babić, Svjetlana; The Teaching Institute of Public Health of Primorsko-goranska County, Odjel Socijalne Medicine Hoffman, Robert; Tel Aviv University, Department of Family Medicine Jakob, Eva; Centro de Saúde Sarria, Primary Health Centre Koskela, Tuomas; University of Tampere, Department of General Practice Marzo, Mercè; Institut Catala De La Salut, Unitat de Suport a la Recerca, IDIAP Jordi Gol Neves, Ana Luísa; Imperial College London, Centre for Health Policy; University of Porto , Center for Health Technology and Services Research Petek, Davorina; University of Ljubljana, Associate Professor Ster, Marija Petek; University of Ljubljana, Department of Family Medicine Sawicka-Powierza, Jolanta; Medical University of Bialystok, Department of Family Medicine Schneider, Antonius; Technische Universität München, Institut für Allgemeinmedizin Smyrnakis, Emmanouil; Aristotle University of Thessaloniki , Laboratory of Primary Health Care, General Practice and Health Services Research Streit, Sven; University of Bern, Institute of Primary Health Care Bern (BIHAM) Thulesius, Hans; Lund University, Department of Clinical Sciences Weltermann, Birgitta; University of Bonn, Institut für Hausarztmedizin

	Taylor, Gordon; University of Bath, Department for Health
Primary Subject Heading:	General practice / Family practice
Secondary Subject Heading:	Health services research
Keywords:	Delivery of Health Care, Primary Health Care, General Practitioners, Cancer, Decision Making, Consultation and Referral

Identifying important health system factors that influence primary care practitioners' referrals for cancer suspicion: a European cross-sectional survey

Authors

Michael Harris (corresponding author), Department for Health, University of Bath, Claverton Down, Bath BA2 7AY, UK; telephone: +44 1761 241366; fax: none. michaelharris681@btinternet.com

Peter Vedsted, The Research Unit for General Practice, Aarhus University, Aarhus, Denmark. p.vedsted@alm.au.dk

Magdalena Esteva, Research Unit, Majorca Primary Health Care Department, Balearic Islands Health Research Institute (IdISBa), Palma, Spain. mesteva@ibsalut.caib.es

Peter Murchie, Division of Applied Health Sciences - Academic Primary Care, University of Aberdeen, Aberdeen, UK. p.murchie@abdn.ac.uk

Isabelle Aubin-Auger, Department of General Practice, Université Paris Diderot, Paris, France. isabelle.auger-aubin@univ-paris-diderot.fr

Joseph Azuri, Sackler Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel. azuri_yo@mac.org.il

Mette Brekke, Department of General Practice and General Practice Research Unit, University of Oslo, Oslo, Norway. mette.brekke@medisin.uio.no

Krzysztof Buczkowski, Department of Family Medicine, Nicolaus Copernicus University, Toruń, Poland. buczkowskik@cm.umk.pl

Nicola Buono, Department of General Practice, National Society of Medical Education in General Practice (SNaMID), Caserta, Italy. buono.nicola2@gmail.com

Emiliana Costiug, Associate Teaching Assistant, Family Medicine Department,Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania. dr.costiug@gmail.com

Geert-Jan Dinant, Department of General Practice, Maastricht University, Maastricht, Netherlands. geertjan.dinant@maastrichtuniversity.nl

Gergana Foreva, Medical Center BROD, Plovdiv, Bulgaria gerganaforeva@gmail.com

Svjetlana Gašparović Babić, Odjel Socijalne Medicine, The Teaching Institute of Public Health of Primorsko-goranska County, Rijeka, Croatia. svjetlana@zzjzpgz.hr

Hoffman Robert, Department of Family Medicine,Tel Aviv University, Tel Aviv, Israel. Hofman_r@mac.org.il

Eva Jakob, Primary Health Centre, Centro de Saúde Sarria, Sarria, Lugo, Spain. Eva.Jacob.Gonzalez@sergas.es

Tuomas Koskela, Department of General Practice University of Tampere, Tampere, Finland. Tuomas.Koskela@staff.uta.fi

Mercè Marzo-Castillejo, Unitat de Suport a la Recerca, IDIAP Jordi Gol, Institut Català de la Salut, Barcelona, Spain. mmarzoc@gencat.cat

Ana Luísa Neves, Centre for Health Policy, Imperial College, London, UK; also Center for Health Technology and Services Research, University of Porto, Porto, Portugal. ana.luisa.neves@gmail.com

Davorina Petek, Department of Family Medicine, University of Ljubljana, Ljubljana, Slovenia. davorina.petek@gmail.com

Marija Petek Ster, Department of Family Medicine, University of Ljubljana, Ljubljana, Slovenia. marija.petek-ster@mf.uni-lj.si

Jolanta Sawicka-Powierza, Department of Family Medicine, Medical University of Bialystok, Bialystok, Poland. jolasawicka@gmail.com

Antonius Schneider, Institut für Allgemeinmedizin, Technische Universität München, Munich, Germany. antonius.schneider@tum.de

Emmanouil Smyrnakis, Laboratory of Primary Health Care, General Practice and Health Services Research, Aristotle University of Thessaloniki, Thessaloniki, Greece. smyrnak@auth.gr

Sven Streit, Institute of Primary Health Care Bern (BIHAM), University of Bern, Bern, Switzerland. sven.streit@biham.unibe.ch

Hans Thulesius Department of Clinical Sciences, Lund University, Malmö, Sweden. hansthulesius@gmail.com

Birgitta Weltermann, Institut für Hausarztmedizin, University of Bonn, Bonn, Germany. Birgitta.Weltermann@ukbonn.de

Gordon Taylor, Department for Health, University of Bath, Bath, UK. g.j.taylor@bath.ac.uk

Keywords

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

Word count

3,109

Abstract

Objectives

Cancer survival and stage of disease at diagnosis and treatment vary widely across Europe. These differences may be partly due to variations in access to investigations and specialists. However, evidence to explain how different national health systems influence Primary Care Practitioners' (PCPs') referral decisions is lacking.

This study analyses health system factors potentially influencing PCPs' referral decision-making when consulting with patients who may have cancer, and how these vary between European countries.

Design

Based on a content-validity consensus, a list of 45 items relating to a PCP's decisions to refer patients with potential cancer symptoms for further investigation was reduced to 20 items. An online questionnaire with the 20 items was answered by PCPs on a five-point Likert scale, indicating how much each item affected their own decision-making in patients that could have cancer. An exploratory factor analysis identified the factors underlying PCPs' referral decision-making.

Setting

A primary care study; 25 participating centres in 20 European countries

Participants

1,830 PCPs completed the survey. The median response rate for participating centres was 20.7%

Outcome measures

The factors derived from items related to PCPs' referral decision-making. Mean factor scores were produced for each country, allowing comparisons.

Results

Factor analysis identified five underlying factors: PCPs' ability to refer; degree of direct patient access to secondary care; PCPs' perceptions of being under pressure; expectations of PCPs' role; and extent to which PCPs believe that quality comes before cost in their health systems. These accounted for 47.4% of the observed variance between individual responses.

Conclusions

Five healthcare system factors influencing PCPs' referral decision-making in twenty European countries were identified. The factors varied considerably between European countries. Knowledge of these factors could assist development of health service policies to produce better cancer outcomes, and inform future research to compare national cancer diagnostic pathways and outcomes.

Article Summary

Strengths and limitations of this study

- The questionnaire was developed using content validity reduction and factor analysis of a consensus item pool, and therefore grounded in PCPs' clinical experience.
- PCPs were recruited from 20 European countries, four countries from each of the Central, Eastern, Northern, Southern and Western European geographical areas.
- Most samples were taken from each local lead's own locality, and these may not have been representative of their nations as a whole.
- The response rate was low but comparable to that of other equivalent surveys of primary care doctors.

Background

There is wide variation in cancer survival rates across Europe [1]. EUROCARE-5 data show that the 1-year relative survival rate for all cancer sites varies from 58.2% to 81.1% between countries [1] (Table 1). Although 1-year relative survival can be affected by differences in registration (e.g. completeness and use of death certificates), and lead-time and over-diagnosis biases [2, 3], it is generally taken to be an indicator of more advanced disease at diagnosis [4, 5]. Survival differences in the subsequent four-year period (known as '5|1-year conditional survival') are narrower, suggesting that earlier diagnosis could reduce the one-year relative survival gap [6]. This is supported by increasing evidence that longer time to diagnosis and treatment may adversely affect mortality [7-13]. While recent overall cancer survival trends show improvements [14], there is little narrowing in the between-country survival differences [15].

The challenge of where and how to achieve more timely diagnosis is considerable [16]. A General Practitioner (GP) will see only a small number of new cancers each year, for example a GP in the UK will on average have a new cancer diagnosed in one of his or her patients each month [17]. The majority of cancers are identified because the patient has been experiencing symptoms. However, most patients present with evolving and undifferentiated symptoms that are much more likely to be interpreted as something other than cancer [16].

GP gatekeeping, in which patients' access to specialists, hospital care and diagnostic tests needs to be authorised by GPs [18], is the cornerstone of many European medical systems [19]. There is evidence that stronger gatekeeper systems are linked with lower one-year relative cancer survival than systems without such gatekeeper functions [20]. This may be because gatekeeping systems can impose cost and resource decisions which impede early referral for investigation [21]. However, there are wide variations

in the degree of gatekeeping between countries, with no simple binary model as to whether or not a country has a "GP-as-gatekeeper" system, and a European study found no link between a higher probability of initial consultation with a GP and poorer cancer survival [22].

The way in which different healthcare systems support primary care in cancer diagnosis by quick and easy access to investigations may also be a factor in timeliness of cancer diagnosis [23]. It has been suggested that GPs need faster routes to diagnostic tests and/or specialist opinion for all patients with a suspicious symptom, above a certain threshold [21]. In the UK, use of an urgent cancer referral pathway has been found to be associated with reduced mortality [24] and a reduction in the proportion of cancers diagnosed through emergency presentations [25]. An International Cancer Benchmarking Partnership (ICBP) study demonstrated a correlation between the readiness of Primary Care Practitioners (PCPs) to investigate suspicious symptoms and cancer survival rates [26]. No consistent associations were found between how likely practitioners were to investigate and PCP demographics, practice or health system variables. However, there was no exploration of how individual doctors felt that health system factors affected their decision-making.

The Örenäs Research Group is a European group of primary care researchers that studies the primary care factors that relate to cancer survival. It has identified a large variety of non-clinical factors that are likely to have a considerable impact on PCPs' referral decision-making [27]. These include levels of gatekeeping responsibility, funding systems, access to investigations, and relationships with specialist colleagues. However, there has been little research done to explain how these vary between countries [16].

This study investigated the health system factors potentially influencing European PCPs' decision-making with regards to investigating patients who may have cancer, and how these vary between European countries.

Methods and design

Design

We performed an international online survey of PCPs in twenty European countries between November 2015 and December 2016. Some of the methodology described here reproduces information already reported in our published protocol paper [28].

Development of the questionnaire

Following a literature review, seven Örenäs Research Group investigators developed and agreed by consensus a list of 45 items, each relating to predefined aspects/concepts that may affect a PCP's decision to refer patients with potential cancer symptoms for further investigation. A questionnaire based on these items was piloted by sixteen members of the Örenäs Research Group to assess content validity. Six of the items were removed due to low content validity. An English-language questionnaire with the remaining 39 items was piloted by 49 PCPs in 16 Örenäs Research Group member countries (Table 2). Nineteen items were found to show little or no variation between countries and were removed from the questionnaire, leaving 20 items.

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 and validation were done in a standardised way [29]: native speakers of the local languages who were fluent in English and were medically

qualified did the 'forward' translations. 'Backward' translations into English were then made by translators who were fluent in both English and their local language. The forward translations were then compared with the backward ones, to assess semantic and conceptual equivalence [30]. Discrepancies between the forward and backward translations were resolved by discussion with the translators, following which the final translation was agreed on. Finally, in each country the corrected versions were piloted in a small sample of PCPs to evaluate the instructions, response format and the items for clarity, and to ensure cultural adaptation [30].

The questionnaire and distribution

The final questionnaire sought demographic information (Table 3) and presented the twenty health system factor items (listed in Table 4). Respondents were asked to rate how much they agreed with each item in relation to their referral decision-making for patients who could have cancer. A five-point Likert rating scale was provided for participants, with response options ranging from 'Strongly disagree' to 'Strongly agree'. The questionnaires were put on-line using SurveyMonkey. Online methodology was used to aid the logistics of survey administration; on-line surveys have been successfully used in research involving cancer care professionals [31].

Study population

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).

Subjects were eligible for the survey if they were doctors working mainly in primary care. These doctors, here referred to collectively as 'Primary Care Practitioners', included GPs and other doctors who had had specialist training but worked in the community and could be accessed directly by patients without referral.

Sample size

A total sample size of 1,000 or more responses was calculated to be sufficient to obtain stable factor estimates within the exploratory factor analysis [32], based on each jurisdiction recruiting at least 50 respondents. This provided a 95% confidence interval (CI) of at most ±14%.

Recruitment of participants

Each Örenäs Research Group local lead was asked to email an invitation to take part in the survey to the PCPs in their local health district, and to recruit at least 50 participants. In six countries (Denmark, Norway, Portugal, Romania, Slovenia, Sweden), the invitation was distributed to a national sample. Any local leads who had difficulty in achieving the required sample sizes were asked to increase the number of responses by using snowballing [33]. Consent was implied by agreeing to take part in the survey. All data were collected anonymously.

Statistical analysis

The demographic characteristics of the respondents were explored using descriptive statistics. Likert scale responses were converted to numerical scores ('Strongly disagree' = 1, 'Strongly agree' = 5). An exploratory factor analysis was undertaken on these responses, to identify underlying factors and to test the predefined constructs.

We used a principal components method [34], with a direct oblimin rotation to allow for correlated factors. The number of components was defined by inspection of the scree plot and the Kaiser criterion (eigenvalue ≥1). Between-country variation in these factors was then examined and presented as means with 95% CIs. We made a sensitivity analysis with weighting of the responses to adjust for the differing numbers of respondents per country. Calculations were performed using IBM SPSS Version 22.

Patient and public involvement

There was no patient or public involvement in this study.

Results

A total of 1,830 PCPs completed the questionnaire. All participating centres received at least 50 responses, with a median of 72 respondents per centre. PCPs' demographic distributions are shown in Table 3. The median response rate per country was 20.8% (range 6.7% to 57.8%).

The mean national Likert-scale values for each of the 20 questions are given in Table 4.

The factor loadings for each of the 20 items are shown in Table 5. The factor analysis identified five factors which accounted for 47.4% of the variance of individual responses. The factor means for each participating country and their 95% CIs are given in Table 6.

Factor 1: Primary care practitioners' ability to refer

This factor contained six items. A higher score on this factor indicated lower barriers to specialist referral, more time during the consultation to consider whether the patient needs a referral, and absence of criticism from colleagues over referrals that were perceived to be unnecessary. This factor explained 15.5% of the variance of individual responses. A comparison of national scores for Factor 1 is shown in Figure 1.

(Place Figure 1 here)

Factor 2: Degree of direct patient access to secondary care

This factor contained six items. A higher score for this factor was linked with items relating to direct patient access to secondary care: the absence of a GP gate-keeping role, with higher financial and geographical barriers to healthcare for some patients, and in some cases the presence of a quota for diagnostic tests. Higher scores for this factor were also linked with less likelihood of having a fast-track specialist appointment system for patients with suspected cancer. Factor 2 explained 10.8% of the variance of individual responses, and the comparison of national scores for this factor is shown in Figure 2.

(Place Figure 2 here)

Factor 3: Primary care practitioners' perceptions of being under pressure

This factor contained four items. A higher score was linked with perceptions of pressure on the PCP from a high workload, as well as demands from patients, the

public and the health system. It explained 7.6% of the variance of individual responses. A comparison of national scores for Factor 3 is shown in Figure 3.

(Place Figure 3 here)

Factor 4: Expectations of the primary care practitioners' role

This factor contained two items. A higher score for this factor was associated with higher expectations of PCP-centred care, and the presence of guidelines to support PCP decision-making. It explained 6.7% of the variance of individual responses, and a comparison of national scores for this factor is shown in Figure 4.

(Place Figure 4 here)

Factor 5: Quality before cost

This factor contained two items. A higher score was linked with PCP perceptions that in their systems high quality care for patients was more important than costs, and that financial aspects had less effect on their referral decision-making. This factor explained 6.4% of the variance of individual responses. A comparison of national scores for Factor 5 is shown in Figure 5.

(Place Figure 5 here)

Sensitivity analysis

In a sensitivity analysis with weighting of the responses to adjust for the differing numbers of respondents per country, only one statement moved to a different factor:

the statement 'In my practice, patients often have to travel a long way to see a specialist' moved from Factor 2 to Factor 4.

Discussion

Principal findings

Based on a content validity process, a 45-item pool on referral decision-making for patients who could have cancer was reduced to a 20-item questionnaire. From the responses of 1,830 PCPs, from 25 primary care centres in 20 European countries, five key factors were identified: PCPs' ability to refer; degree of direct patient access to secondary care; PCP perceptions of being under pressure; expectations of the PCPs' role; and the extent to which PCPs believe that, in their systems, quality comes before cost. The factors showed significant variation between the participant countries.

Interpretation of the results

Based on the content validity and the significant variation between countries, the survey can be regarded as relevant for studying aspects of PCPs' perceptions of what affects their referral and investigation of patients with symptoms that could be due to cancer. Thus, the developed questionnaire could be used in further research to evaluate associations with cancer outcomes, and could also be used to evaluate changes in healthcare systems regarding referring patients who could have cancer.

Factor 1. Primary care practitioners' ability to refer: the variation in PCPs' ability to refer was linked to structural differences like barriers to specialist referrals (including waiting times), the degree of criticism of PCPs relating to their referrals, the quality and amount of relationships between PCPs and specialists, and the length of the PCPs' consultations with patients. This was the most important factor, carrying most of the

explained variation, and consequently it appears to be particularly important in explaining between-country differences in primary care cancer diagnosis.

Factor 2. Degree of direct patient access to secondary care: this important factor was related to the extent to which GPs were gatekeepers and to which public systems provided universal access to healthcare, whether self-referral to specialists was possible outside the public health system, patients' ability to travel to and fund specialist consultations, and whether fast-track referral systems were in place for patients with suspected cancer.

Factor 3. Primary care practitioners' perceptions of being under pressure: variations in PCP perceptions of being under pressure were linked with PCP workloads, patient expectations and their level of trust in their doctors, and the extent to which health systems expected PCPs to refer patients.

Factor 4. Expectations of the primary care practitioners' role: differing expectations of the PCPs' role were related to whether there had been a shift of work and responsibility between secondary and primary care, and the extent to which patient care was from specialists rather than from PCPs.

Factor 5. Quality before cost: the variation in the extent to which PCPs perceived the balance between quality of care and cost was linked with how much PCPs themselves were directly affected by considerations of cost.

Strengths and weaknesses of the study

There were participating centres in four countries from each of the Central, Eastern, Northern, Southern and Western European geographical areas, providing variation in geography, health systems and levels of healthcare spending. It included the views of

PCPs who are not usually involved in research. The questionnaire was carefully developed and piloted by GPs and other PCPs, and therefore grounded in their clinical experience. The sensitivity analysis suggested that the factor structure is robust and not driven by countries with larger numbers of respondents.

While low survey response rates are common in primary care [35] and are known to vary between countries, the response rates in our study were comparable to those of a recent ICBP survey, in which response rates varied from 5.5% to 45.6% [26]. As the survey was anonymous, we have no data on non-responders. It is possible that the PCPs with the most interest in this subject were the most likely to respond. However, while this selection bias may have affected the factor loadings, it is unlikely to have changed the factor structure itself.

While the demographic data that we collected included the gender of participants and the number of years that they had been in practice, we have found no equivalent data on national PCP populations that would allow us to assess how representative our samples were.

Most samples were taken from each local lead's own locality, and these may not have been representative of their nations as a whole [36]. While this makes it difficult to generalise the findings to each country, the variation between countries is relevant and valid. The recruitment method used in this study resulted in variable response rates, leading to a risk of non-response bias and loss of power [35]. However, the goal of 50 survey participants per centre and more than 1000 respondents in total was achieved.

Participants' responses may have been influenced by previous questions, and there may have been country-level differences in response styles, for instance choosing or avoiding the 'extreme' options on the scale [37]. As the translation also included a

cultural adaptation we believe this bias was minimised, and the differences between countries cannot simply be explained by differences in response styles.

The five factors accounted for 47.4% of the variance in PCPs' responses, and it is acceptable consider a solution that accounts for 60% or less of the total variance as satisfactory [38]. Two of the factors only included two items each, which makes them vulnerable to missing responses and stochastic variation.

Comparison with other studies

To our knowledge, this is the first study that has been designed to identify the factors underlying PCPs' referral decision-making, and provide international comparisons of the extent to which PCPs themselves perceive these as important. An ICBP narrative review compared the characteristics of healthcare systems of six countries (Australia, Canada, Denmark, Norway, Sweden and the United Kingdom), aiming to identify characteristics that could possibly modify the diagnostic pathway [39]. However, unlike our study, it only explored the systems of relatively wealthy countries, and it did not examine PCPs' own perceptions of how their systems affected their decision-making. Our finding that PCPs in different European countries perceive different levels of access to investigations and specialist opinions may be relevant to the finding of varying referral delays in three European countries (Scotland, the Netherlands and Sweden) [40].

Possible implications for clinicians and policymakers

Five health system factors were able to explain nearly half of the variation in the PCPs' responses to the items. This indicates that a relatively large part of the variation may be explained by differences between the health systems. Our study indicates the policy domains where countries might be able to modify their systems to better support their

GPs and other PCPs in the timely referral and investigation of patients who could have cancer.

The most important of these factors were the ease of PCPs' ability to refer, and the degree of direct patient access to secondary care. These factors are key in supporting earlier and expedited cancer diagnosis and may thus be linked with cancer outcomes. It therefore seems plausible that some countries could improve their cancer outcomes by providing better access to investigations and secondary care when cancer is suspected.

Unanswered questions and future research

The five factors and their related scores should be compared with national cancer outcomes. These outcomes could include mortality, stage distribution and patient evaluations. An additional area of study could be to relate the factors and scores to national health system costs.

Conclusions

This research has developed a 20-item questionnaire with good content and construct validity, and has identified five factors that PCPs perceive to affect their referral decision-making in patients that could have cancer. These appear to vary depending on the different European models of primary care. This understanding of the interaction between health system variables and PCP decision-making can help in an exploration of the differences in national cancer diagnostic pathways and cancer outcomes, and could help to inform health service policy and research toward better cancer outcomes.

List of abbreviations

CI	Confidence interval
GP	General Practitioner
ICBP	International Cancer Benchmarking Partnership
PCP	Primary Care Practitioner

Declarations

Ethics approval

Ethical approval for the study was been 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.

Funding

This study received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Data sharing

The Örenäs survey data used in this study is available at https://doi.org/10.15125/BATH-00486

Author contributions

IA-A, JA, KB, BB, EC, G-JD, ME, GF, SBG, MH, RH, MM-C, PM, DP, MPS, JS-P, ES, GT, HT, PV and BW participated in the study design and piloting. All authors except GT were involved in the data collection. All authors contributed to the writing and to the review of the manuscript and approved the final version. MH had overall responsibility for the study design, recruitment of local leads, analysis of data and interpretation of results. GT advised on the study design and the statistical analysis.

Acknowledgements

The authors would like to thank all the PCPs who piloted the questionnaire and those who completed the survey. They are also grateful to Prof. Barbara Silverman and Prof. Lital Keinan for the data on cancer survival rates in Israel.

References

1. EUROCARE. EUROCARE-5. In: Istituto Nazionale Tumori (Milan IaISdSR, Italy), editor. Milan and Rome 2014.

2. Carter JL, Coletti RJ, Harris RP. Quantifying and monitoring overdiagnosis in cancer screening: a systematic review of methods. BMJ. 2015;350:g7773.(doi):10.1136/bmj.g7773.

3. Zahl PH, Jorgensen KJ, Gotzsche PC. Overestimated lead times in cancer screening has led to substantial underestimation of overdiagnosis. Br J Cancer. 2013;109(7):2014-9. doi: 10.1038/bjc.2013.427. Epub Aug 20.

4. Richards MA. The size of the prize for earlier diagnosis of cancer in England. Br J Cancer. 2009;101:S125–S9.

5. Woods LM, Coleman MP, Lawrence G, Rashbass J, Berrino F, Rachet B. Evidence against the proposition that "UK cancer survival statistics are misleading": simulation study with National Cancer Registry data. BMJ. 2011;342:d3399.(doi):10.1136/bmj.d3399.

6. Thomson CS, Forman D. Cancer survival in England and the influence of early diagnosis: what can we learn from recent EUROCARE results? Br J Cancer. 2009;101:S102–S9.

7. McLaughlin JM, Anderson RT, Ferketich AK, Seiber EE, Balkrishnan R, Paskett ED. Effect on survival of longer intervals between confirmed diagnosis and treatment initiation among low-income women with breast cancer. J Clin Oncol. 2012;30(36):4493-500.

8. Yun YH, Kim YA, Min YH, Park S, Won YJ, Kim DY, et al. The influence of hospital volume and surgical treatment delay on long-term survival after cancer surgery. Ann Oncol. 2012;23(10):2731-7.

9. Elit LM, O'Leary EM, Pond GR, Seow HY. Impact of wait times on survival for women with uterine cancer. J Clin Oncol. 2014;32(1):27-33.

10. Nanthamongkolkul K, Hanprasertpong J. Longer waiting times for early stage cervical cancer patients undergoing radical hysterectomy are associated with diminished long-term overall survival. J Gynecol Oncol. 2015;26(4):262-9.

11. Neal RD, Tharmanathan P, France B, Din NU, Cotton S, Fallon-Ferguson J, et al. Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic review. Br J Cancer. 2015;112 Suppl 1:S92-107.

12. Torring ML, Frydenberg M, Hansen RP, Olesen F, Vedsted P. Evidence of increasing mortality with longer diagnostic intervals for five common cancers: a cohort study in primary care. Eur J Cancer. 2013;49(9):2187-98.

13. Gobbi PG, Bergonzi M, Comelli M, Villano L, Pozzoli D, Vanoli A, et al. The prognostic role of time to diagnosis and presenting symptoms in patients with pancreatic cancer. Cancer Epidemiol. 2013;37(2):186-90.

14. De Angelis R, Sant M, Coleman MP, Francisci S, Baili P, Pierannunzio D, et al. Cancer survival in Europe 1999-2007 by country and age: results of EUROCARE-5 - a population-based study. Lancet Oncol. 2014;15(1):23-34.

15. Coleman MP, Forman D, Bryant H, Butler J, Rachet B, Maringe C, et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. Lancet. 2011;377(9760):127-38.

16. Foot C, Harrison T. How to improve cancer survival: explaining England's relatively poor rates. London: The King's Fund; 2011. p. 30 January 2012.

17. Hamilton W. Cancer diagnosis in primary care. Br J Gen Pract. 2010;60(571):121-8.

18. Franks P, Clancy CM, Nutting PA. Gatekeeping revisited--protecting patients from overtreatment. N Engl J Med. 1992;327(6):424-9.

19. Masseria C, Irwin R, Thomson S, Gemmill M, Mossialos E. Primary care in Europe. In: Science TLSoEaP, editor.: European Commission; 2009.

20. Vedsted P, Olesen F. Are the serious problems in cancer survival partly rooted in gatekeeper principles? Br J Gen Pract. 2011;61(589):512-3.

21. Neal RD. Commentary. Cancer diagnosis - the role of urgent referral guidelines. Br J Gen Pract. 2010;60(571):127.

22. Harris M, Frey P, Esteva M, Gašparović Babić S, Marzo-Castillejo M, Petek D, et al. How the probability of presentation to a primary care clinician correlates with cancer survival rates: a European survey using vignettes. Scand J Prim Health Care. 2017:1-8.

23. Rubin G, Vedsted P, Emery J. Improving cancer outcomes: better access to diagnostics in primary care could be critical. Br J Gen Pract. 2011;61(586):317-8.

24. Moller H, Gildea C, Meechan D, Rubin G, Round T, Vedsted P. Use of the English urgent referral pathway for suspected cancer and mortality in patients with cancer: cohort study. BMJ. 2015;351:h5102.

25. National Cancer Intelligence Network. Routes to Diagnosis 2006-2013, preliminary results. London: Public Health England, 2015.

26. Rose PW, Rubin G, Perera-Salazar R, Almberg SS, Barisic A, Dawes M, et al. Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. BMJ Open. 2015;5(5):e007212. doi: 10.1136/bmjopen-2014-.

27. Harris M, Frey P, Esteva M, Gašparović-Babić S, Marzo-Castillejo M, Petek D, et al. How health system factors influence referral decisions in patients that may have cancer: European symposium report. J Cancer Res Ther.2016. p. 7-10.

28. Harris M, Taylor G, The Örenäs Research Group. How health system factors affect primary care practitioners' decisions to refer patients for further investigation: protocol for a pan-European ecological study. BMC Health Serv Res. 2018;18(1):338.

29. Maneesriwongul W, Dixon JK. Instrument translation process: a methods review. J Adv Nurs. 2004;48(2):175-86.

30. Center for Aging in Diverse Communities. Guidelines for Translating Surveys in Cross-Cultural Research. San Francisco: University of California; 2007.

31. Dobrow MJ, Orchard MC, Golden B, Holowaty E, Paszat L, Brown AD, et al. Response audit of an Internet survey of health care providers and administrators: implications for determination of response rates. J Med Internet Res. 2008;10(4):e30.

32. van Belle G. Statistical Rules of Thumb, 2nd Edition. Hoboken, N.J.: Wiley; 2008.

33. Shaghaghi A, Bhopal RS, Sheikh A. Approaches to Recruiting 'Hard-To-Reach' Populations into Re-search: A Review of the Literature. Health Promot Perspect. 2011;1(2):86-94.

34. Hotelling H. Analysis of a complex of statistical variables into principal components. J Educ Psychol. 1933;24(6):417-41.

35. Pit SW, Vo T, Pyakurel S. The effectiveness of recruitment strategies on general practitioner's survey response rates - a systematic review. BMC Med Res Methodol. 2014;14:76.

36. Greenacre Z. The Importance of Selection Bias in Internet Surveys. Open J Stat. 2016;6:397-404.

37. Harzing A-W. Response styles in cross-national survey research: a 26-country study. Int J Cross Cult Manag. 2006;6(2).

38. Hair J, Black W, Babin B, Anderson R. Multivariate Data Analysis. 7th ed: Pearson; 2009.

39. Brown S, Castelli M, Hunter D, Erskine J, Vedsted P, Foot C, et al. How might healthcare systems influence speed of cancer diagnosis: A narrative review. Soc Sci Med. 2014;116:56–63.

40. Murchie P, Campbell NC, Delaney EK, Dinant GJ, Hannaford PC, Johansson L, et al. Comparing diagnostic delay in cancer: a cross-sectional study in three European countries with primary care-led health care systems. Fam Pract. 2012;29(1):69-78.

Table 1. EUROCARE 5 1-year relative and 5|1-year conditional cancer survival rates for European countries [1], with ranks given.

Country	1-year relative survival (%)	1-year relative survival: rank	5|1-year conditional survival (%)	5|1-year conditional survival: rank
Austria	75.9	11	60.1	7
Belgium	78.9	3	60.4	6
Bulgaria	58.2	28	38.7	28
Croatia	62.1	25	46.2	22
Czech Republic	68.3	19	50.7	19
Denmark	69.8	18	50.9	18
Estonia	65.9	22	46.0	24
Finland	76.9	8	61.4	4
France	77.8	7	58.6	10
Germany	76.7	9	59.1	9
Greece	(not available)		(not available)	
Iceland	78.3	6	61.2	5
Ireland	70.3	16	54.0	15
Israel (Arabs) *	78.6	4	61.4	3
Israel (Jews) *	82.8	1	68.9	1
Italy	74.9	12	56.8	12
Latvia	60.9	27	41.7	26
Lithuania	63.8	24	46.1	23
Malta	70.0	17	52.9	16

Netherlands	73.0	14	54.6	14
Norway	76.1	10	58.6	11
Poland	61.7	26	40.6	27
Portugal	74.0	13	56.4	13
Romania	(not available)		(not available)	
Slovakia	65.4	23	44.8	25
Slovenia	67.7	21	47.8	21
Spain	71.5	15	52.8	17
Sweden	81.1	2	64.8	2
Switzerland	78.3	5	59.2	8
United Kingdom	67.9	20	50.1	20
European mean	72.5		54.2	

* Calculated from data provided by B. Silverman, Israel Ministry of Health (personal communication, 7 September 2017)

Table 2. Results of questionnaire pilot.

Response	Number of countries in which piloting PCPs agreed with statement	Number of countries in which piloting PCPs were unsure	Number of countries in which piloting PCPs disagreed with statement
Even if there are no "red-flag" symptoms, we usually refer if we have a feeling that something is wrong. *	11	4	0
Here, high quality care for an individual patient is always more important than costs.	5	6	5
If we have "over-referred", our own income may be reduced. *	1	3	12
If we organise any investigations, we pay for that themselves. *	1	2	13
In some practices, patients often have to travel a long way to see a specialist.	9	5	2
Long waiting lists for specialists or tests mean that we sometimes delay a referral/special investigation until it's really necessary. *	1	10	5
Many primary care doctors have special investigations (e.g. diagnostic ultrasound) in their practices. *	1	5	10
Missing a diagnosis of cancer is something that we particularly worry about. *	15	0	0
Patients can self-refer to specialists, so we don't need to act as a gate-keeper.	5	1	10
Patients sometimes criticise us if they think we delayed a cancer diagnosis because of a late referral. *	13	3	0
Paying for a specialist can be a problem for some our patients.	5	4	7
Referral costs are usually paid by insurance companies, not primary care or hospital budgets.	6	3	7
Referring or not referring doesn't affect our income at all.	10	3	3
Some of our referral systems (e.g. on-line referral systems) make the referral process more difficult. *	1	4	11
Specialists often try to reduce referrals to them. *	1	5	10
Specialists often welcome referrals.	6	7	3
Specialists sometimes criticise us if they think that a cancer diagnosis was slow because of a late referral. *	12	3	1
Specialists sometimes criticise us if they think that we should have been able to look after the patient ourselves.	7	5	4
There is a special, quick specialist appointment system for patients with suspected cancer.	8	3	5

Usually, patients prefer a GP (rather than a specialist) to look after them.	6	6	4
We are asked not to refer patients with a low risk of cancer. *	1	4	11
We are asked to refer any patients with possible cancer early, even if there is a low risk of cancer.	6	7	3
We are likely to refer if the patient is very worried that he/she has cancer, even if there are no "red flag" symptoms. *	12	2	1
We are likely to refer if the patient says that she/he would like to be referred, even if there are no red flags.	8	3	4
We are often worried about the risk of unnecessary (and possibly harmful) investigations. *	12	2	1
We are under media (newspaper, television) or public pressure to refer earlier.	5	4	6
We are under media (newspaper, television) or public pressure to refer less. *	1	3	11
We are usually very busy, so we sometimes refer to help reduce our workload.	6	5	5
We can easily email a specialist for advice.	5	3	8
We can easily telephone a specialist for advice.	5	5	6
We can refer directly to a named specialist.	8	4	4
We have a budget for patient care costs, but we share it with secondary care. *	0	2	14
We have a budget or quota (maximum limit) for referrals. *	1	3	12
We have a budget or quota (maximum limit) for special tests.	4	2	9
We have guidelines that help us decide which patients to refer.	7	2	7
We often refer to a specialist that we know personally.	8	6	2
We usually have enough time in the consultation to think carefully about whether the patient needs a referral.	6	6	4
We worry about the possibility of legal action or a formal complaint if we refer late. *	8	7	1
Writing a good referral letter takes time, and as we are usually very busy we sometimes delay making a referral. *	1	2	13

* These statements were removed from the final questionnaire because either (a) one or no piloting countries agreed with the statement, or (b) one or no piloting countries disagreed with the statement.

Table 3. Number of respondents per country and demographic distributions.

		Number of respondents (% of all respondents)
Respondents per country	Bulgaria	51 (2.8)
	Croatia	56 (3.1)
	Denmark	92 (5.0)
	England	62 (3.4)
	Finland	61 (3.3)
	France	52 (2.8)
	Germany	91 (5.0)
	Greece	59 (3.2)
	Israel	58 (3.2)
	Italy	60 (3.3)
	Netherlands	107 (5.8)
	Norway	81 (4.4)
	Poland	135 (7.4)
	Portugal	59 (3.2)
	Romania	146 (8.0)
	Scotland	62 (3.4)
	Slovenia	91 (5.0)
	Spain	379 (20.7)
	Sweden	68 (3.7)
	Switzerland	60 (3.3)
	Total	1830 (100)

Respondent gender	Female	1108 (60.5)
	Male	708 (38.7)
	Not stated	14 (0.8)
	Total	1830 (100)
Years since graduation	<10 years	284 (15.5)
	10-19 years	492 (26.9)
	20-29 years	535 (29.2)
	30-39 years	442 (24.2)
	40 years or over	69 (3.8)
	Not stated	8 (0.4)
	Total	1830 (100)
Site of practice	Urban	1086 (59.6)
	Rural	426 (23.3)
	Island	50 (2.7)
	Mixed	268 (14.6)
	Total	1830 (100)
Number of doctors in practice	1	252 (13.8)
	2	210 (11.5)
	3	196 (10.7)
	4-5	304 (16.6)

6-7	235 (12.8)
8-9	153 (8.4)
10 or more	470 (25.7)
Not stated	10 (0.5)
Total	1830 (100)

Table 4. Mean national Likert-scale values for each of the 20 questions

	Bulgaria	Croatia	Denmark	England	Finland	France	Germany	Greece	Israel	Italy	Netherlands	Norway	Poland	Portugal	Romania	Scotland	Slovenia	Spain	Sweden	Switzerland
Common presentations are covered by local or national guidelines that usually give advice on which patients to refer	2.76	3.22	3.96	3.92	4.00	3.04	3.35	3.59	3.64	3.40	3.96	3.26	3.44	3.12	3.37	3.89	3.73	3.90	3.59	3.37
The local health system encourages us to refer any patients with possible cancer early, even if there is a low risk of cancer.	2.78	3.00	3.91	3.29	2.97	3.29	3.79	3.37	3.60	3.05	2.84	3.20	3.18	2.97	3.68	3.31	3.28	3.07	2.91	4.05
In my practice, patients often have to travel a long way to see a specialist.	1.91	2.45	2.02	2.44	1.62	1.98	1.76	3.24	2.40	2.83	1.79	1.89	2.54	1.90	2.78	2.74	2.34	1.99	2.59	1.68
I am able to refer directly to a named specialist.	3.80	2.73	4.28	2.10	1.95	4.55	4.60	3.90	4.49	3.24	3.92	3.84	2.73	2.81	3.83	2.35	2.73	3.79	2.31	4.90
I am able to refer to a specialist that I know personally.	4.14	2.89	3.38	2.02	2.00	4.24	4.39	3.86	4.26	3.41	3.74	2.67	2.77	2.27	3.81	2.34	2.92	2.52	2.29	4.87
I can easily telephone (or email) a specialist for informal discussion and advice.	3.36	2.52	3.68	3.16	3.90	3.80	4.21	3.07	3.82	3.13	4.18	3.25	1.69	2.71	3.25	3.23	2.51	3.39	4.04	4.73
Here, specialists usually welcome referrals.	4.37	2.85	3.36	3.35	3.48	4.18	3.89	3.31	3.88	3.21	4.02	3.79	2.29	3.14	3.01	3.06	2.21	2.68	3.37	4.70
Seeing a specialist can be a problem for some of my patients because of the financial cost to them.	3.22	2.82	1.74	2.28	2.64	4.06	1.74	4.36	2.21	3.70	3.90	2.15	3.13	2.71	3.80	2.02	2.70	2.12	2.04	2.32
We have a budget or quota (maximum limit) for diagnostic tests.	4.36	3.02	1.68	1.87	1.92	1.60	3.18	3.63	2.21	2.44	2.03	1.34	3.52	3.22	3.09	1.51	2.88	2.72	2.07	1.35

Here, high quality care for an individual patient is always more important than costs.	3.20	3.53	3.95	3.85	3.77	3.75	3.23	3.51	3.91	3.48	3.76	3.59	3.38	3.95	3.87	3.89	3.74	3.67	4.03	4.08
Referring or not referring doesn't affect me at all financially.	2.69	3.13	4.41	4.07	4.20	4.67	4.18	3.68	4.33	3.31	4.28	4.46	3.52	4.29	3.99	4.43	4.04	3.63	4.26	4.27
Referral costs are usually paid by insurance companies, not hospital or primary care budgets.	2.76	3.41	1.00	1.63	1.33	2.88	3.56	2.10	2.84	1.94	4.00	1.78	2.71	1.63	3.70	1.66	4.13	1.84	1.41	4.48
My colleagues sometimes criticise me if I have referred a patient to them, but they think that I should have been able to manage the patient myself.	2.08	2.76	1.90	2.39	2.51	2.19	1.48	2.92	2.11	2.63	2.29	2.58	3.38	2.53	2.72	2.40	3.24	2.41	2.65	1.27
In general, patients prefer a GP, rather than a specialist, to look after them.	3.12	3.09	3.40	3.00	2.61	3.00	3.67	3.56	3.52	3.30	3.53	2.99	2.98	3.12	3.53	3.23	3.49	3.22	3.12	3.65
We have access to a fast-track specialist appointment system for patients with suspected cancer.	2.71	3.22	4.75	4.66	4.08	3.46	2.87	2.45	3.33	3.22	4.30	4.67	3.63	3.42	2.58	4.37	3.22	4.06	3.31	2.27
Patients can self-refer to specialists, so GPs don't need to act as gatekeepers.	2.39	2.04	1.41	1.39	1.92	2.29	3.19	2.58	3.10	2.65	1.61	1.59	1.83	1.86	2.38	1.38	1.55	1.45	2.75	3.02
I am usually very busy, so I sometimes refer to help reduce my workload.	2.73	2.16	2.61	2.53	2.59	2.48	1.98	2.24	2.98	2.56	2.51	2.40	2.82	2.12	1.96	1.92	3.01	2.43	2.15	1.97
I usually have enough time in the consultation to think carefully about whether the patient needs a referral.	3.32	3.52	3.43	3.02	3.15	3.77	3.86	3.49	3.16	3.67	3.59	3.75	2.64	2.58	3.90	3.29	2.91	2.83	3.16	3.69
I am likely to refer if the patient says that she/he would like to be referred, even if there are no “red flags”.	3.10	2.59	3.02	3.20	2.51	2.96	3.62	3.42	3.69	3.36	2.92	3.11	3.63	3.05	2.80	3.00	3.30	2.88	3.06	3.52
We are under media (newspaper, television) or public pressure to refer earlier.	3.84	3.04	3.38	3.97	2.82	2.81	4.16	2.69	3.16	3.42	3.10	3.80	3.61	2.42	2.65	3.92	3.36	3.23	2.50	2.77

A response of ‘Strongly disagree’ was given a score of 1; ‘Disagree’ = 2; ‘Neither agree nor disagree’ = 3; ‘Agree’ = 4; ‘Strongly agree’ = 5.

Table 5. Health system items and their factor analysis loadings. The highest-scoring component for each item is underlined.

Health system item	Component				
Factor 1	1	2	3	4	5
I am able to refer to a specialist that I know personally.	<u>0.68</u>	0.42	0.09	0.03	-0.14
Here, specialists usually welcome referrals.	<u>0.68</u>	0.02	0.12	-0.04	-0.11
I can easily telephone (or email) a specialist for informal discussion and advice.	<u>0.68</u>	-0.12	0.11	0.17	-0.12
I am able to refer directly to a named specialist.	<u>0.62</u>	0.22	0.22	0.13	-0.26
I usually have enough time in the consultation to think carefully about whether the patient needs a referral.	<u>0.57</u>	-0.02	-0.32	0.07	0.12
My colleagues sometimes criticise me if I have referred a patient to them, but they think that I should have been able to manage the patient myself.	<u>-0.51</u>	0.25	0.14	0.12	0.31
Factor 2					
Seeing a specialist can be a problem for some of my patients because of the financial cost to them.	-0.08	<u>0.59</u>	-0.17	0.27	0.24
We have access to a fast-track specialist appointment system for patients with suspected cancer.	0.05	<u>-0.54</u>	0.34	0.34	-0.03
We have a budget or quota (maximum limit) for diagnostic tests.	-0.27	<u>0.54</u>	-0.06	0.25	-0.26
Referral costs are usually paid by insurance companies, not hospital or primary care budgets.	0.30	<u>0.46</u>	-0.05	-0.19	0.23
Patients can self-refer to specialists, so GPs don't need to act as	0.34	<u>0.44</u>	0.04	-0.30	0.11

gatekeepers.					
In my practice, patients often have to travel a long way to see a specialist.	-0.26	0.38	-0.09	0.37	0.36
Factor 3					
I am usually very busy, so I sometimes refer to help reduce my workload.	-0.32	0.19	0.60	-0.09	-0.01
I am likely to refer if the patient says that she/he would like to be referred, even if there are no “red flags”.	-0.02	0.29	0.53	-0.34	0.16
We are under media (newspaper, television) or public pressure to refer earlier.	-0.20	0.08	0.51	-0.09	-0.16
The local health system encourages us to refer any patients with possible cancer early, even if there is a low risk of cancer.	0.26	0.11	0.36	0.23	0.20
Factor 4					
Common presentations are covered by local or national guidelines that usually give advice on which patients to refer	0.05	-0.25	0.33	0.55	0.15
In general, patients prefer a GP, rather than a specialist, to look after them.	0.25	0.19	-0.02	0.41	0.08
Factor 5					
Here, high quality care for an individual patient is always more important than costs.	0.30	-0.26	0.01	0.05	0.57
Referring or not referring doesn't affect me at all financially.	0.31	-0.29	0.08	-0.34	0.55

Table 6. Factor means for each country with 95% confidence intervals

	Number of respondents	**Factor 1** Mean (95% CI)	**Factor 2** Mean (95% CI)	**Factor 3** Mean (95% CI)	**Factor 4** Mean (95% CI)	**Factor 5** Mean (95% CI)
Bulgaria	52	0.62 (0.43 - 0.82)	0.58 (0.34 - 0.82)	0.23 (-0.12 - 0.59)	-1.11 (-1.50 - -0.72)	-1.43 (-1.74 - -1.11)
Croatia	56	-0.47 (-0.70 - -0.24)	0.42 (0.21 - 0.62)	-0.48 (-0.74 - -0.21)	-0.46 (-0.78 - -0.14)	-0.53 (-0.81 - -0.25)
Denmark	92	0.39 (0.25 - 0.54)	-1.04 (-1.15 - -0.93)	0.15 (-0.04 - 0.35)	0.59 (0.43 - 0.76)	0.41 (0.26 - 0.57)
England	62	-0.65 (-0.85 - -0.45)	-0.90 (-1.09 - -0.71)	0.29 (0.06 - 0.51)	0.31 (0.12 - 0.50)	0.34 (0.16 - 0.52)
Finland	61	-0.52 (-0.70 - -0.34)	-0.83 (-0.97 - -0.68)	-0.34 (-0.59 - -0.10)	-0.07 (-0.31 - 0.17)	0.38 (0.19 - 0.56)
France	52	0.76 (0.57 - 0.95)	0.58 (0.41 - 0.75)	-0.23 (-0.50 - 0.04)	-0.27 (-0.51 - -0.03)	0.58 (0.42 - 0.74)
Germany	91	1.41 (1.26 - 1.55)	0.40 (0.22 - 0.57)	0.43 (0.25 - 0.62)	-0.64 (-0.87 - -0.42)	0.02 (-0.23 - 0.27)
Greece	59	0.03 (-0.18 - 0.24)	1.40 (1.21 - 1.60)	-0.21 (-0.46 - 0.03)	0.35 (0.03 - 0.67)	-0.61 (-0.86 - -0.37)
Israel	58	0.89 (0.73 - 1.05)	0.48 (0.29 - 0.68)	0.67 (0.39 - 0.95)	-0.05 (-0.31 - 0.21)	0.49 (0.25 - 0.72)
Italy	60	-0.18 (-0.44 - 0.08)	0.52 (0.32 - 0.73)	-0.07 (-0.38 - 0.25)	-0.06 (-0.34 - 0.21)	-0.45 (-0.82 - -0.09)
Netherlands	108	0.60 (0.50 - 0.70)	0.23 (0.12 - 0.33)	-0.24 (-0.40 - -0.08)	0.44 (0.33 - 0.55)	0.29 (0.16 - 0.41)
Norway	81	0.11 (-0.06 - 0.28)	-0.77 (-0.92 - -0.62)	0.16 (-0.04 - 0.36)	-0.18 (-0.35 - 0.00)	0.52 (0.36 - 0.68)
Poland	135	-1.00 (-1.15 - -0.84)	0.40 (0.26 - 0.55)	0.70 (0.52 - 0.88)	-0.15 (-0.36 - 0.06)	-0.59 (-0.77 - -0.40)
Portugal	59	-0.63 (-0.84 - -0.42)	-0.09 (-0.31 - 0.13)	-0.32 (-0.57 - -0.06)	-0.48 (-0.76 - -0.19)	0.01 (-0.20 - 0.22)

Romania	146	0.16 (0.01 - 0.31)	1.30 (1.17 - 1.43)	-0.69 (-0.86 - -0.52)	0.11 (-0.05 - 0.28)	-0.03 (-0.19 - 0.13)
Scotland	62	-0.54 (-0.72 - -0.37)	-0.71 (-0.88 - -0.53)	-0.14 (-0.33 - 0.05)	0.34 (0.14 - 0.55)	0.57 (0.39 - 0.75)
Slovenia	91	-0.71 (-0.87 - -0.56)	0.53 (0.40 - 0.67)	0.48 (0.30 - 0.66)	0.08 (-0.13 - 0.28)	0.01 (-0.18 - 0.20)
Spain	380	-0.27 (-0.35 - -0.19)	-0.67 (-0.75 - -0.60)	-0.03 (-0.13 - 0.07)	0.21 (0.12 - 0.31)	-0.36 (-0.46 - -0.26)
Sweden	68	-0.35 (-0.52 - -0.18)	-0.11 (-0.27 - 0.06)	-0.42 (-0.64 - -0.20)	-0.21 (-0.45 - 0.03)	0.56 (0.34 - 0.79)
Switzerland	60	1.79 (1.66 - 1.91)	0.78 (0.63 - 0.94)	-0.08 (-0.36 - 0.20)	-0.55 (-0.79 - -0.31)	0.91 (0.69 - 1.12)
Total	1,833					

Figure legends

Figure 1. *Comparison of national scores for Factor 1: Primary care practitioner's ability to refer.*

Figure 2. *Comparison of national scores for Factor 2: Degree of direct patient access to secondary care.*

Figure 3. *Comparison of national scores for Factor 3: pressure on PCP from outside.*

Figure 4. *Comparison of national scores for Factor 4: Expectations of the PCP's role.*

Figure 5. *Comparison of national scores for Factor 5: Quality before cost.*

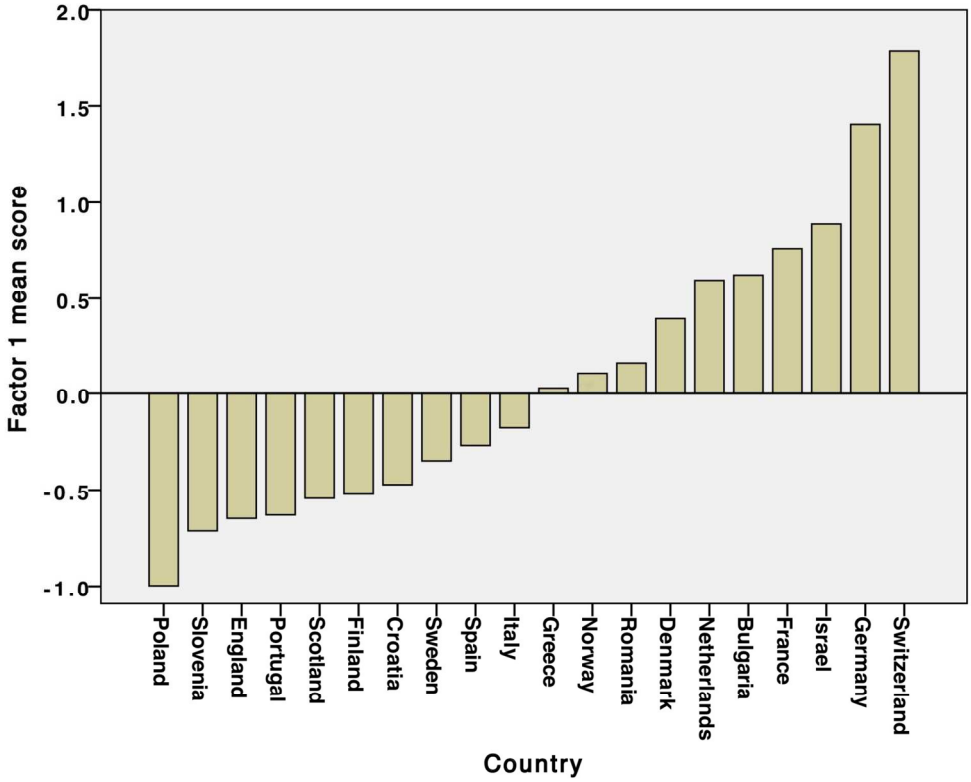


Figure 1. Comparison of national scores for Factor 1: Primary care practitioner's ability to refer.

166x133mm (300 x 300 DPI)

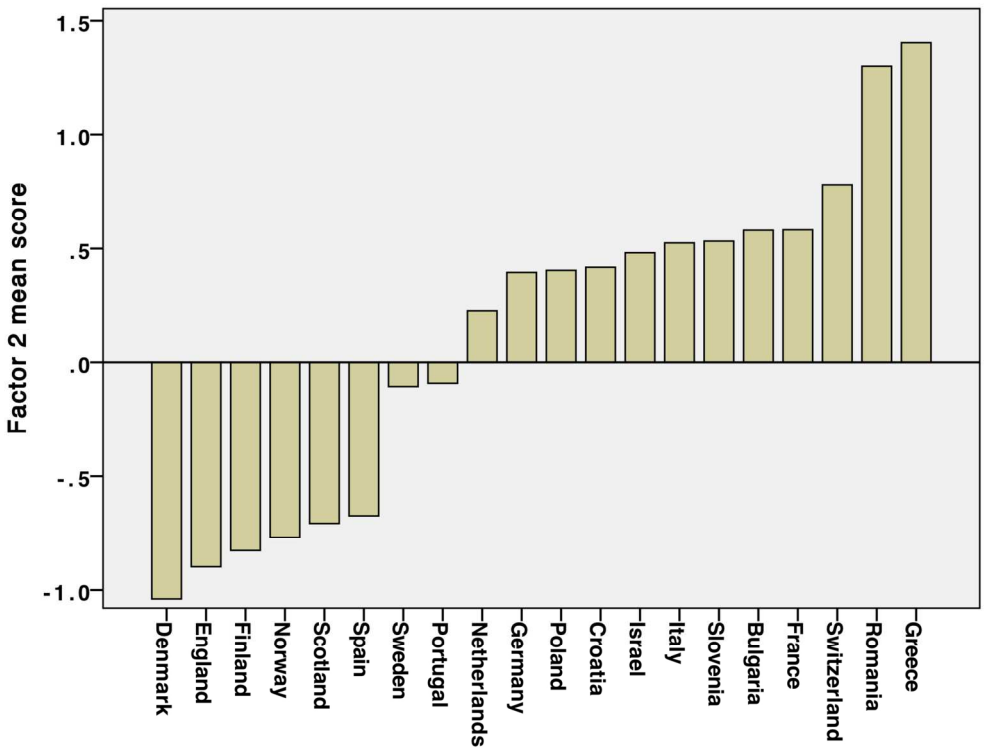


Figure 2. Comparison of national scores for Factor 2: Degree of direct patient access to secondary care.

195x145mm (300 x 300 DPI)

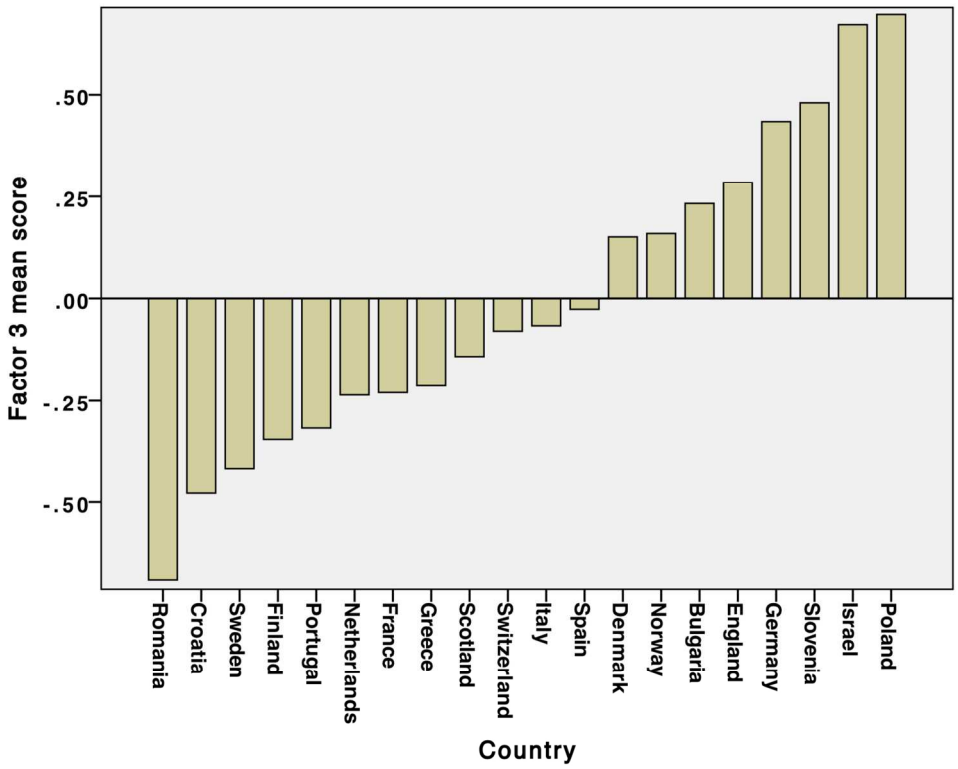


Figure 3. Comparison of national scores for Factor 3: pressure on PCP from outside.

176x137mm (300 x 300 DPI)

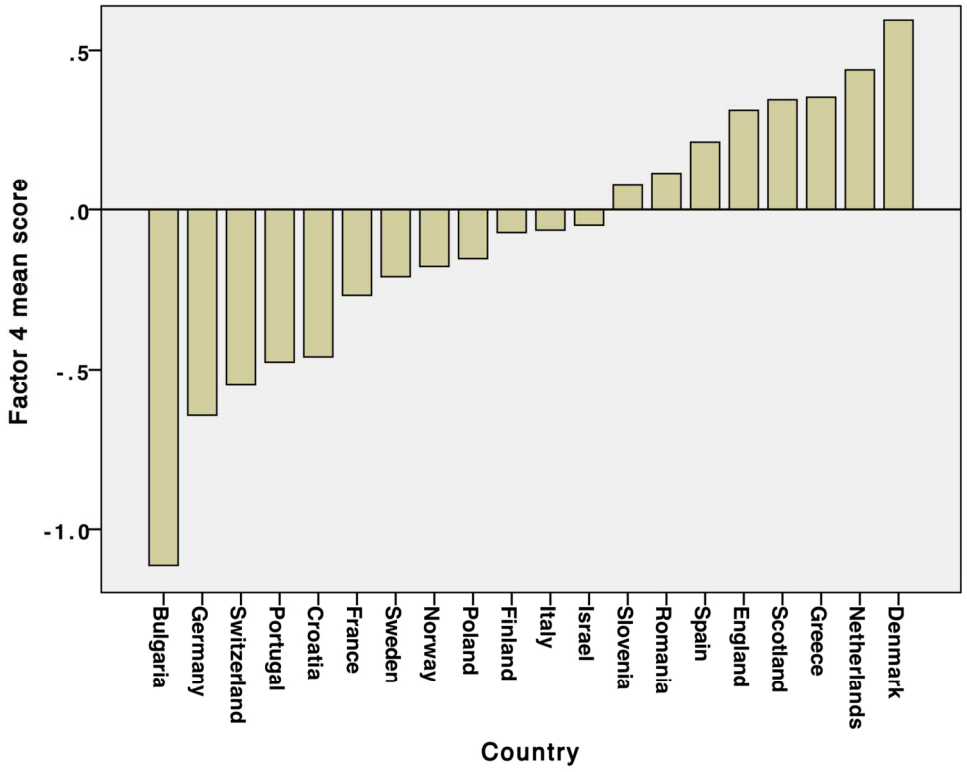


Figure 4. Comparison of national scores for Factor 4: Expectations of the PCP's role.

174x138mm (300 x 300 DPI)

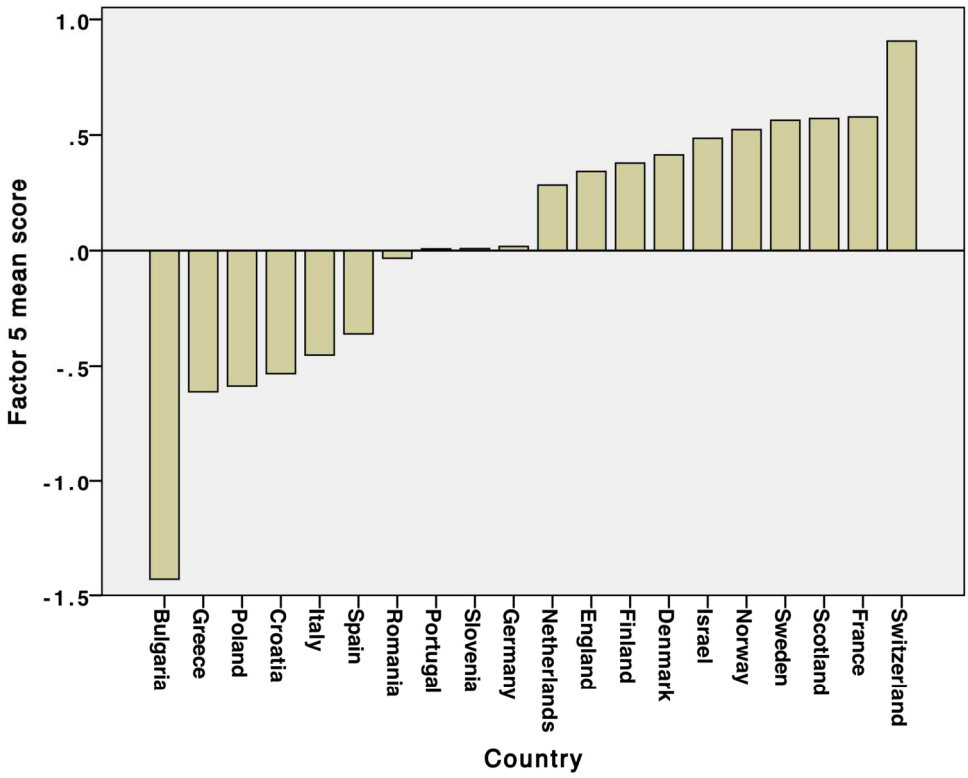


Figure 5. Comparison of national scores for Factor 5: Quality before cost.

182x145mm (300 x 300 DPI)

Appendix. 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
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	EP 14/15 66

Identifying important health system factors that influence primary care practitioners' referrals for cancer suspicion: a European cross-sectional survey

STROBE Statement – checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract **[Within the title page 1 and Design section of the abstract page 4]**
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found **[See results section of abstract page 4]**
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported **[Pages 7-8]**
Objectives	3	State specific objectives, including any prespecified hypotheses [**Page 9]**
Methods		
Study design	4	Present key elements of study design early in the paper **[Methods and Design pages 9-10]**
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection **[Pages 9-10]**
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants **[Pages 10-11]**
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable **[Page 10]**
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group **[Page 10-11]**
Bias	9	Describe any efforts to address potential sources of bias **[Pages 9-10]**
Study size	10	Explain how the study size was arrived at **[Page 10]**
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why **[Pages 11-12]**
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding **[Pages 11-12]**
		(*b*) Describe any methods used to examine subgroups and interactions **[N/A]**
		(*c*) Explain how missing data were addressed **[N/A]**
		(*d*) If applicable, describe analytical methods taking account of sampling strategy **[N/A]**
		(*e*) Describe any sensitivity analyses **[Page 12]**
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed **[Page 12]**
		(b) Give reasons for non-participation at each stage **[N/A]**
		(c) Consider use of a flow diagram **[N/A]**
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders **[Table 3]**
		(b) Indicate number of participants with missing data for each variable of interest **[N/A]**

Outcome data	15*	Report numbers of outcome events or summary measures **[N/A]**
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included **[Table 6]**
		(*b*) Report category boundaries when continuous variables were categorized **[N/A]**
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period **[N/A]**
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses **[Pages 14-15]**
Discussion		
Key results	18	Summarise key results with reference to study objectives **[Page 15]**
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias **[Pages 16-18]**
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence **[Pages 15-16]**
Generalisability	21	Discuss the generalisability (external validity) of the study results **[Pages 18-19]**
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based **[Page 20]**

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.