

**Patient perspectives on delays in diagnosis and treatment of cancer: A qualitative analysis of free-text data**

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British Journal of General Practice

DOI:

[10.3399/bjgp16X688357](https://doi.org/10.3399/bjgp16X688357)

Published: 31/01/2017

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)*Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):*Parsonage, R. K., Hiscock, J., Law, R.-J., & Neal, R. D. (2017). Patient perspectives on delays in diagnosis and treatment of cancer: A qualitative analysis of free-text data. *British Journal of General Practice*, 67(654), e49-e56. <https://doi.org/10.3399/bjgp16X688357>**Hawliau Cyffredinol / General rights**

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Title: PATIENT PERSPECTIVES ON DELAYS IN DIAGNOSIS AND TREATMENT OF CANCER

Running title: Barriers and facilitators to diagnosing cancer

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Abstract

Background

Earlier cancer diagnosis is crucial in improving cancer survival. The International Cancer Benchmarking Partnership Module 4 (ICBP4) is a quantitative survey study which explores the reasons for delays in diagnosis and treatment of breast, colorectal, lung and ovarian cancer. To further understand the associated diagnostic processes, the patient perspectives expressed in the free-text comments are also important to explore.

Aim

To use the free-text data provided by patients completing the ICBP4 survey to augment our understanding of patients' perspectives of their diagnostic journey.

Design and setting

Qualitative analysis of the free-text data collected in Wales as part of the ICBP4 survey.

Methods

A thematic framework was used to analyse the free-text comments provided at the end of the ICBP4 survey. Comments were included from 530/905 patients who returned a questionnaire.

Results

The free-text data provided a rich source of data regarding patients' perspectives of the diagnostic journey. The analysis identified factors which acted as either barriers or facilitators at different stages of the diagnostic process. Some factors such as screening, patient-doctor familiarity and private treatment, acted as both barriers and facilitators dependent upon the context.

Conclusion

The factors identified help explain how existing models of cancer diagnosis (e.g. Pathways to Treatment Model) work in practice. It is important that clinicians are aware of how these factors may interact with individual clinical cases and either facilitate, or act as a barrier to, subsequent cancer diagnosis. Understanding and implementing this knowledge into clinical practice may result in quicker cancer diagnoses.

Keywords:

1. Qualitative Research
2. Early Detection of Cancer
3. Surveys and Questionnaires
4. Patients
5. Wales

How this fits in:

There are known factors affecting the cancer diagnostic pathway. This study highlights that some factors, such as doctor-patient familiarity, can act as both a barrier and a facilitator to timely diagnosis. The findings also highlight the importance of patients' 'gut feelings' about their symptoms and the cyclical nature of some cancer diagnostic pathways. It is important for clinicians to be aware of these further potential influences on the diagnostic journey for patients.

Introduction

In the UK, cancer survival rates are poorer than in many similar countries (1). Later stage at diagnosis is a contributor to this (2). Despite an expanding evidence base surrounding the role of primary care in cancer diagnosis (3,4), there is still much to understand, and to improve, regarding the diagnosis of cancer through primary care. One widely accepted model of the diagnostic process is the 'Model of Pathways to Treatment' (5). This proposes a series of interconnected phases that patients move through in the process from first recognising symptoms to diagnosis and treatment.

The International Cancer Benchmarking Partnership (ICBP) aims to compare cancer survival rates and to examine why there may be variations in cancer survival between similar health systems in different countries (6). More specifically, module 4 of the ICBP aims to explore and compare the reasons for delays in diagnosis and treatment of four cancers (breast, colorectal, lung and ovarian) in ten participating jurisdictions (Denmark, England, Manitoba, Northern Ireland, Norway, Ontario, Scotland, Sweden, Victoria and Wales) (6). This survey study of around 800 patients in each jurisdiction included patients recently diagnosed with one of the four cancers and contained factual questions about symptoms, consultations, investigations and referrals. At the end of the survey, a free-text question asked patients to 'Please add anything else that you would like to tell us about your cancer diagnosis or treatment' with space for one side of A5 for a response.

Free-text comments at the end of questionnaires differ in two ways from open questions. Not only do they have potential to expand to fit the space supplied, but they can also cover wide a range of topics that are important to and determined by the respondent. Such responses may or may not be of relevance to the research questions being addressed. Free-text comments may be used in thematic analysis as a tool to understand replies to closed questions, for identifying new issues, to obtain feedback on research process and development of new survey questions (7). If systematically analysed, free-text comments from surveys can provide valuable data and can often be a 'neglected data source' (8). Written sources are often seen as an underutilised source of data, (9) and may give additional insight into quantitative responses (10). Previous studies have found that analysis of qualitative free-text comments in questionnaire studies can provide valuable information about individual expectations, knowledge and understanding of health services (11).

The aim of this work was to use the qualitative free-text data from the recently conducted ICBP survey to investigate the patient's journey through cancer diagnosis from their own perspective.

Methods

Study design and participants

The main methods for the ICBP Module 4 survey are reported elsewhere (6). Data were collected between October 2013 and December 2014. Patients were newly diagnosed, having received their diagnosis 3-6 months prior to identification through the cancer registry. Completed surveys were received and the free-text comments transcribed verbatim. 905 patients in Wales returned surveys that were included in the analysis presented in this paper. Of the 905 returned questionnaires, 530 (58.6%) contained free-text comments. 166/277 (59.9%) were made by patients with breast cancer, 181/306 (59.1%) with colorectal cancer, 121/224 (54.0%) with lung cancer and 62/98 (63.2%) with ovarian cancer. 352/587 (60.0%) females made comments, and 178/318 (56.0%) males made comments. The mean age of commenters was 66.1 years with a range of 23.6 – 90.8 years, and the mean age of non-commenters was 68.0 years with a range of 22.1 – 93.9 years. The socioeconomic status (Welsh Index of Multiple Deprivation) was also similar (23.8% commenters compared with 24.8% non-commenters scored 1, 23.6% vs 23.5% scored 2, 22.5% vs 19.7% scored 3, 18.3% vs 18.7% scored 4 and 11.9% vs 13.3% scored 5, where a score of 1 indicates the least deprived and 5 indicates the most deprived). 53.6% of commenters and 45.9% of non-commenters with breast cancer were screen-detected and 30.9% of commenters and 28.0% of non-commenters with colorectal cancer were screen-detected (self-reported). The free-text data for Wales was analysed separately from data from other UK countries because of the devolved nature of the health services.

Analysis

A thematic framework was used to analyse the free-text data. This is consistent with analysis approaches used in other studies of free-text survey data (10). However, in contrast to other studies (12), it was decided to treat the data as wholly qualitative as the free-text contributions were unstructured and unguided. The Framework approach was chosen as the method of organising and analysing the data. Framework analysis is a systematic, matrix-based system that encourages analysis both by theme and by case (13-15). The five stages of Framework were conducted: data familiarisation (RKP, RL), inductive development of a framework (RKP, JH, RDN), index of themes and subthemes (RKP) synthesising the data (RKP) and data interpretation (RKP, RDN, JH, RL). Two of the researchers brought clinical perspectives as GPs (RKP and RDN). Due to the brevity of free-text data, the layout of the Framework 'charts' (the matrix displaying the data) were condensed to ensure it was easy to identify patterns and associations in the data and also to ensure we maintained links to each individual respondent to visibly and easily trace comments by individual respondents and identify their characteristics (cancer type, age, gender) to facilitate the interpretative process.

All authors were involved in the interpretation stage through individual interpretative work and data interrogation interspersed with an iterative process of team data interpretation workshops. During these workshops the data and interpretations were discussed, emerging explanations formulated, reformulated and alternative explanations debated with reference to the data (charts). It was during this process that authors identified a pattern within the data that related to barriers and facilitators to diagnosis and treatment. The decision was made to focus on barriers and facilitators, in terms of what they were, and how, and why, they worked. Only data pertaining to the diagnosis, as opposed to treatment, was considered.

Results

The free-text comments covered a range of views pertaining to time points across the diagnostic journeys of the patients. The following section describes the emerging themes relating to 'barriers and facilitators' to cancer diagnosis and how they interact. The qualitative findings are arranged in a sequential order with issues pertaining to screening, followed by those pertaining to appraisal and help-seeking, interactions with primary care, and interactions with secondary care. All quotes are presented verbatim. Those in the third person were completed by carers.

Screening

From the patient's perspective, screening was usually considered to be a facilitator to cancer diagnosis, with many patients describing screening as a positive aspect of their journey which usually indicated abnormalities that were previously unknown. However, in some instances, screening was regarded by patients as a barrier to detection of cancer. Reasons for this included recent screening not picking up their cancer; and in one case, a participant did not present their suspicious symptoms because they were due to attend a screening session. Had this participant not been involved in the screening programme, they may have presented earlier to their GP with suspicious symptoms. Others had difficulty scheduling a screening appointment.

"My treatment started with the bowel screening in [name of hospital], for this reason I did not visit my GP with symptoms". (age 67, colorectal, female)

"I missed my 1st mammogram due to a poorly child and had problems rearranging a new appointment". (age 52, breast)

Appraisal and help-seeking

Patients described various barriers and facilitators to help-seeking which occurred before their cancer diagnosis. For some patients, life events impeded diagnostic tests. Some patients described the phenomenon of not having any specific symptoms, just a 'gut feeling'. For some, this 'gut feeling' was the only initial indicator that initiated help-seeking. For others, help-seeking was delayed until more obvious symptoms were found. Whether the 'gut feeling' acted as a barrier or a facilitator appeared

"Had mammogram and then vacuum assisted biopsy May 2013. Consulted doctor Nov 2012, had no symptoms just a gut feeling". (age 54, breast)

"Three days later I was told I had cancer. I knew that a year before". (age 69, male, lung)

to depend largely on the decision of the patient's GP to initiate further investigations.

Patients themselves often requested further investigations even when previous results were clear of abnormalities. Such requests often acted as facilitators, aided by their GP taking further action.

"Asked for another xray December. Cough was bad. Found cancer. A mass." (age 77, female, lung)

Those patients who had had previous malignancies described a sense of feeling entitled to further investigations or treatment due to feeling that they were high risk. Having a previous malignancy was regarded as a facilitator here;

"I was diagnosed with thyroid cancer in Dec 2013 - and because of this I was able to push for further investigation of my bowel problems." (age 43, female)

Other patients described not noticing or acting upon their symptoms until they were influenced by other people. While this was sometimes due to cognitive impairment, this input from others was seen as facilitator to diagnosis.

"I have Alzheimer's disease and my wife noticed the change in bowel habits. I had no other signs or symptoms". (age 79, male, colorectal)

"P.S. I must thank my granddaughter as she said 'Nanna you have been coughing more than a month - go to the Doctor's'. As the TV ad had shown. So I did. Thanks to her I am getting better". (age 75, lung, female)

A number of patients stated that they put the initial symptoms that they were experiencing down to other conditions. These acted as barriers to early diagnosis. Such conditions included pre-existing conditions such as bowel problems and psychological issues such as stress.

"In 2012 I experienced extreme levels of stress in work. The difficulties began in January when I started to sleep badly and experienced high levels of anxiety about my job. By July 2012 I started to feel very 'run down', stressed and unable to recover from colds etc. I had myalgia in Sept/Oct and then took 2 weeks off to rest. This coincided with a very stressful period of bullying in work. After my hysterectomy I felt very well" (age 58, ovarian)

However, whilst most patients indicated that vague symptoms were usually a barrier, in some cases these symptoms facilitated the speed of diagnosis. There was also some confusion about seemingly obvious symptoms, with some patients not realising the significance of 'alarm' symptoms, and others recognising them and seeking help. This appears to be dependent on individual patient knowledge and awareness of potential cancer symptoms.

"The only symptom was an annoying cough which I had for a few months before" (age 69, male, lung)

Going private

Some patients described how they had paid privately for accessing health services. This was usually due to the fact that patients saw NHS waiting times as being unreasonably long. Paying privately was usually viewed by patients as a facilitator to a quicker diagnosis or treatment.

"Due to waiting list (NHS) 36 weeks paid to see a private consultant." (age 54, colorectal, female).

However, paying privately for further investigations also acted as a barrier. One reason was due to the fact that the tests ordered failed to detect their cancer.

“Since July 09 I have had 4 colonoscopies, 2 endoscopies and 2 scans 1 sigmoid endoscopy (in Jan 13). As a result of poor bowel habits - diagnosed as a coeliac July 09 and had polyps removed. All on private sector. The sigmoid endoscopy in Jan 13 was clear.” (age 62, colorectal, male).

Again, while private patients may expect that further investigations or treatment to result in a quicker route to cancer diagnosis or treatment, this may not always be the case.

Interaction with Primary Care

On contact with primary care, the most common barriers to cancer diagnosis included being treated for other conditions, mis-diagnosis with another condition or not appearing to be taken seriously by health professionals. For example, if a patient has a chronic condition, there may be no indication to initiate further investigations.

“I first visited my Dr about my symptoms around Aug 2012, I was not examined, I was told the pain was coming from my back (I had a back problem for years)” (age 72, ovarian).

“They even referred me to a psychiatrist with cancer anxiety as they just didn't seem to believe how ill I felt and what was happening when I went to the toilet” (age 43, female, colorectal)

Being investigated for another condition acted in some situations as a facilitator to diagnosis and treatment. Sometimes this was based on incidental findings from investigations regarding pre-existing conditions, and other times as a result of regular checks.

“The cancer was only found on annual chest check for COPD” (age 69, male, lung cancer)

“The lump that I felt initially that led me to go to GP, on ultrasound turned out to be a cyst. This was localised below nipple L breast. However, incidental finding of a mass found on mammogram L lateral aspect of breast” (age 47, breast)

Another mediating factor was the reaction of health professionals to patient symptoms. Most patients found their health professional's reaction to their symptoms to be a facilitator. However, others found this to be a barrier. The quote below demonstrates how different health professionals acted as either barriers or facilitators to making a cancer diagnosis.

“At yearly check up with the nurse, despite high weight loss, this was considered a positive effect (June). However a different nurse noticed him in the surgery waiting for his wife and was concerned at his obvious weight loss and made an emergency appointment with the GP (late August).” (age 82, male, lung)

Some younger patients reported a sense that their GP had not taken their symptoms seriously potentially due to their age and the rare likelihood of malignancy.

"..had a number of visits to the Doctors to which I was told nothing was wrong and wouldn't listen to me" (age 24, ovarian)

Others felt that their GP did take their symptoms seriously and they were referred appropriately.

"2013 Jan - Blood test at surgery. Anaemia result. Doctor referred me to have tests at hospital. Dr wanted to know why, not treat". (age 85, female, colorectal)

Some patients described 'familiarity' with their GP as a barrier to treatment. This appears to be an important concept where it is possible for intervention.

"I feel I have been very lucky with my diagnosis as when I attend my surgery my Dr was away on holiday and saw a locum Dr. Had I seen my normal Dr she may have thought my symptoms were due to my COPD. However the locum, not knowing me, he immediately sent me for an x-ray and re-referred me to the chest clinic and my diagnosis was very swift". (age 62, female, lung)

While patients described how some health professionals inadvertently gave false reassurance, others investigated patients further despite inconclusive or negative tests.

"My GP was concerned and initiated further tests which indicated that I did in fact have bowel cancer!" (age 67, male, colorectal).

"Back to GP as had hip pain that was concerning me as well as the fatigue. By October I found a lump on my left breast as well as some pain on the side of both breasts. The GP found the lump and referred me to [name of hospital] even though he believed I just had lumpy breast". (age 39, breast).

Lastly, there were views regarding the need for all patients to be referred urgently, and general views about potentially bypassing general practice altogether when it comes to cancer diagnosis.

"I think all cases should be referred, as England, within 2 weeks, irrespective of whether GP thinks it is cancer or not - they are not the experts. I knew it was a lump - whether it was cancer or not is up to specialist". (age 46, breast)

Interaction with Secondary Care

While some patients described waiting a long time and being delayed, others felt that their cancer diagnosis had been swift, sometimes due to the quick thinking actions of their GP or their own persistence.

"NHS see urgent as within 2 weeks this is a very long time in those early days. I made my appointments by persistently waiting for cancellations so managed to bring my treatment forwards". (age 59, ovarian)

Others described the sense of disappointment that they felt due to waiting in the system for what they perceived to be a long time.

“Although the treatment I am getting now is second to none, I feel I could have investigated a lot sooner if the gastroenterologist in [name of hospital] had agreed to see me in February as my GP requested. The secondaries in my liver might not have been so serious” (age 72, female, colorectal)

“Test results for type of cancer and treatment needed: Really needs to be faster. Most people think they are going to die - I waited around 4 weeks to hear that 'actually' I would need chemo. Chemotherapy” (age 51, breast)

As in primary care, in secondary care-initiated investigations, some patients reported that specific diagnostic tests missed their cancer.

“As a result of the bowel screening on 03/12. I was diagnosed with ischemic colitis and under a gastroenterologist 30/1/13. I had a CT angiography scan. Scan showed a thickening of bowel wall 25/2/2013 I had a sigmoidoscopy as cancer was suspected, where it was ruled out. I was then referred to a surgeon to remove part of the colon.” (age 64, female, colorectal)

For others, their cancer was an incidental finding in secondary care while undergoing investigations for other health problems, or indeed from other screening or primary care testing (see section above).

“I went into hospital for a double heart by-pass and a chest X-ray identified a lump in my left lung, which was confirmed by a PET scan as cancer. The top lobe of my left lung was removed and no further treatment was needed, so far” (age 66, lung, male)

“My cancer was detected by a wonderful accident. I was undergoing tests and scans because my yearly check-up showed I was anaemic. It was only the scan on my abdomen caught my right lung.” (age 77, lung, female)

Some patients explained how that they had never accessed their GP initially. While some patients were diagnosed via accident and emergency attendance, others found novel methods of accessing secondary care services.

“Didn't go to GP - I work in the hospital and was seen in breast clinic.” (age 51, breast)

Others reported cases that appeared to indicate negligence on the part of the healthcare system. Again, while one would expect having a scan for a specific symptom to be a facilitator to diagnosis, this appeared to act as a barrier.

“09/2012 I did have a scan, and was told I had two small cysts on my ovaries, but nothing to worry about, apparently no one did report filed and forgotten” (age 73, ovarian)

Discussion

Summary of main findings

This study provides an insight into the journey of the cancer patient through their cancer diagnosis, by demonstrating the range of factors that can act as barriers and facilitators to diagnosis, and how some factors can act as both. The value of this knowledge is that it begins to explain the fine detail of how models of diagnosis actually work, and alerts clinicians to some the factors that may enable them to progress their patients through to diagnosis more quickly. There is also the potential for patient education regarding issues such as the accuracy of screening and diagnostic testing, the implications of vague recurring symptoms and navigating through the diagnostic pathway.

Strengths and limitations

The free-text comments analysed in this study add to the quantitative knowledge about the patients' diagnostic journey. However, it is also important to consider that free-text comments may not represent the survey population as over two fifths of the sample did not write anything in the free text box and for those that did we only had limited demographic data. Furthermore, just because an issue is raised by one participant, this does not mean that this is not important to others who did not raise the issue. Lastly, when analysing qualitative comments we have no way of understanding the mood or circumstances of the patients at the time of completion and its impact upon the free text comments.

Comparison with existing literature

The existing literature supports many of the findings from this study. We found evidence of delays in presenting symptoms after a previous 'all-clear' message which confirms similar results reported after symptomatic presentation (16, 17). Furthermore, our finding that some patients may wait for their next round of screening instead of seeking more immediate help from their GP regarding symptoms resonates with similar results presented by Solbjor et al., 2012 (18). Patient knowledge of cancer symptoms was shown in our study to be an important mediating factor in initiating help-seeking behaviour. This appeared true irrespective of whether the symptoms were common or uncommon. Issues relating to the variation in the public awareness of cancer symptoms and the effectiveness of awareness campaigns have also recently been reported (19,20). This builds on, and has implications for, knowledge about the effectiveness and importance of public awareness campaigns.

Our findings extend the literature by adding to the understanding of the complexities of the path to cancer diagnosis. Recent research has highlighted the range of biopsychosocial, contextual and cultural influences on the way in which people recognise, interpret and act on symptoms (21). Our findings add to this by suggesting further influences such as comorbidity can complicate the diagnosis as patients may not recognise symptoms as indicative of cancer and GPs may not act on them due to the known comorbidity. We also found that some patients experienced a 'gut feeling' which further influenced their diagnosis pathway. Our finding reinforces Whitaker et al's recent report of 'just instinct' by patients regarding cancer alarm symptoms (22).

Importantly, we report how certain factors can act as either barriers or facilitators to diagnosis in different contexts. A similar observation was reported by McLachlan et al., 2015 (23) in their study of help-seeking behaviour prior to lung and colorectal cancer diagnosis. They observed how health professionals may act as both a barrier or a facilitator to diagnosis. However, this current study highlights that some factors (e.g. doctor-patient familiarity), are commonly presumed to be a facilitators but are reported to be barriers and factors which are commonly presumed to be barriers (e.g. presence of comorbidity) are also reported as facilitators.

Lastly, this study also begins to explain some of the detail underpinning current models of cancer diagnosis. Our findings (except the data relating to screening) map very closely onto the Model of Pathways to Treatment (5). We add some complexity to this model, demonstrating how and why some patients go 'backwards' as well as 'forwards' in the model. We also show how patients may be able to enter the model at different points in time, for example by bypassing primary care and entering their diagnostic journey via secondary care.

Implications for research and practice

There are a number of implications from this analysis of patient descriptions of their diagnostic journey. These findings suggest that models encompassing cancer diagnosis and treatment need to incorporate the possibilities that patients may not travel down a pre-defined pathway of initially accessing primary care and therefore should account for the potential for less common diagnostic pathways. Screening programmes need to promote awareness of the issues of symptomatic cancers presenting soon after a negative screen and of patients ignoring symptoms if they have an upcoming screen. There also remains the need for effective awareness campaigns regarding common, and potentially less common symptoms. The study provides reminders for GPs of the potential negative consequences of multi-morbidity, the reality that some tests will come back as false-negative, and how easy it is for actions to be perceived as not taking patients' symptoms seriously. Also for GPs is the difficulty in interpreting the knowledge that some factors may act as barriers or facilitators, depending on the context. In addition, whilst doctor-patient familiarity and continuity of care is considered an important and positive aspect of high quality primary care (24), a 'fresh pair of eyes' may also be a worthwhile consideration that may expedite the diagnostic pathway. For secondary care, there are reminders again of the possibility of false-negative tests, the risk of excessive waiting times and not acting on GP requests to expedite. It is important for patients to realise that cancer may not always present in a classical manner. To assist with this, physicians need to explore the patient's understanding of their symptoms. This finding is echoed by McLachlan et al (23), who found that prompting patients for further information within a consultation may give important details about the context of their symptoms, later aiding physician decision making. We further suggest that a more 'inclusive approach' should be taken by physicians to encompassing vague symptoms (for example not just those presented in media campaigns such as coughs and rectal bleeding) when considering the investigation of patients for potential malignancy. The main implication for future research is the continued need to develop and evaluate interventions to expedite the diagnosis and avoid unnecessary delays in the diagnosis.

Conclusion

This study highlights how some factors affecting the timeliness of a cancer diagnosis can act as both barriers or facilitators, depending on the context. It highlights implications for physicians and patients to be mindful of factors that may affect the diagnostic journey such as involvement in a screening programme, continuity of care and the efficiency of diagnostic tests. These findings help to further explain how existing models of cancer diagnosis work in practice and offer further information to aid in the development and evaluation of interventions to expedite and avoid unnecessary delays in diagnosis.

Additional information

Funding: The overall study was organised by the ICBP with funding from Cancer Research UK. The study is funded in Wales by Cancer Research Wales.

Ethical approval: This study was approved by the NRES Committee East Midlands - Derby 2 Research Ethics Committee, REC No: 11/EM/0420.

Competing interests: The authors declare no competing interests

Acknowledgements: We would like to thank all the patients for taking the time to contribute to this international study. We are also grateful to the ICBP 4 central team led by Professor Peter Vedsted, Aarhus University Denmark, Professor David Weller, Edinburgh University and Professor Usha Menon, University College London. We also acknowledge all members of the ICBP Programme Board: Ole Andersen (Danish Health and Medicines Authority, Copenhagen, Denmark), Søren Brostrøm (Danish Health and Medicines Authority, Copenhagen, Denmark), Heather Bryant (Canadian Partnership Against Cancer, Toronto, Canada), David Currow (Cancer Institute New South Wales, Sydney, Australia), Dhali Dhaliwal (Cancer Care Manitoba, Winnipeg, Canada), Anna Gavin (Northern Ireland Cancer Registry, Queens University, Belfast, UK), Gunilla Gunnarsson (Swedish Association of Local Authorities and Regions, Stockholm, Sweden), Jane Hanson (Welsh Cancer National Specialist Advisory Group, Cardiff, UK), Nicola Quin (Cancer Council Victoria, Carlton, Australia), Stein Kaasa (University Hospital of Trondheim, Trondheim, Norway), Linda Rabeneck (Cancer Care Ontario, Toronto, Canada), Michael A Richards (Care Quality Commission, London, UK), Michael Sherar (Cancer Care Ontario, Toronto, Canada), Robert Thomas (Department of Health and Human Services, Victoria, Melbourne, Australia).

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