PRIMARY CAUSE?

An audit of the experience in primary care of rarer cancer patients

February 2011

RARER cancers FOUNDATION

incorporating Rarer Cancers Forum

About the Rarer Cancers Foundation

The Rarer Cancers Foundation (RCF) which incorporates the Rarer Cancers Forum was founded in 2001. Our mission is 'to ensure that people with rarer cancers have access to the best services and outcomes'. We raise awareness for people affected by rare or less common cancers, the charity is truly focused and inspired by the needs of patients and their families.

The Rarer Cancers Foundation:

- Provides a bespoke helpline to both patients, GPs and health professionals
- Enables supportive networking for patients, carers and clinicians
- Raises awareness
- Campaigns for change
- Gives a voice to 'forgotten' cancers
- Undertakes research based projects for improvement of patient care and diagnosis
- Organises conferences for patients and health professionals
- Produces both generic and tumour specific patient information literature

Through our policy programme we aim to encourage policymakers to focus on improving outcomes for patients with rarer cancers, including encouraging earlier diagnosis, enabling access to appropriate treatment and improving the experience reported by patients of their treatment and care.

The purpose of this report is to understand how rarer cancer patients were first diagnosed with cancer and to assess whether the process for identifying the signs and symptoms of rarer forms of cancer could be improved.

This report forms part of the RCF's public policy programme. This programme receives financial support from members of the RCF's healthcare industry reference group, grants from other organisations and through donations from individuals. The project detailed in this report was made possible by a Section 64 grant from the Department of Health. Editorial control rests with the RCF alone.

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Summary of key findings

- Late diagnosis of cancer is a major explanation for poor outcomes. If a person is diagnosed with cancer at an early stage, then they will have a greater range of treatment options which are often less invasive and offer a better chance of a positive long term outcome.

- If the Department of Health is to meet its goal of saving an additional 5,000 lives by 2014/15[1], then it is reasonable to assume that 2,500 of these lives would be for rarer cancers.

- Over one in four patients with a rarer cancer were first diagnosed following an emergency, indicating that their cancer had already spread significantly. This supports the findings of our survey that over one quarter of patients were first diagnosed with Stage three or four cancer.

- Over one quarter of patients were diagnosed with Stage 3 or 4 cancer – i.e. that where significant spread had occurred.

- Over four in ten respondents waited for more than three months between noticing symptoms and seeking medical help.

- Less than three in ten patients were asked by their GP about whether they had a family history of cancer, despite this being an important risk factor.

- Once patients had sought help, nearly one third of patients were reassured and not asked to return to see their GP at the end of an appointment.

- Over half of respondents reported that they had to visit their GP on more than two occasions before receiving a correct diagnosis.

- Nearly two thirds of patients responding to the survey experienced a delay of at least three months between first visiting their GP and receiving a correct diagnosis.

- Over one third of respondents rated their experience of primary care as *"poor"* or *"very poor."*

- Two thirds of patients were seen within two weeks of referral, indicating that efforts to shorten cancer waiting times have been successful.

Summary of recommendations

1. The Department of Health should ensure that progress reports on improving cancer outcomes should provide information disaggregated by type of cancer, thereby enabling scrutiny of progress in improving outcomes for all forms of cancer, irrespective of whether they are common or rare.
2. Information on the proportion of patients with cancer who are first diagnosed following an emergency presentation should be collected and published by the NHS as a matter of routine.
3. As part of the new accountability structures for public health services and the NHS, commissioners should be required to deliver year-on-year reductions in the proportion of patients who are first diagnosed with cancer following an emergency presentation.
4. The Department of Health should consider the case for extending the current cancer awareness campaign to cover all cancer signs and symptoms, including those for rarer cancers.
5. Tools should be developed to support health and wellbeing boards in commissioning effective cancer awareness interventions.
6. The Department of Health should do more to encourage public, private and voluntary employers to raise awareness of cancer signs and symptoms.
7. The Department of Health should work with the Royal College of General Practitioners to remind GPs of the significance of family history as a risk factor for many cancers.
8. All GP consortia should appoint a cancer lead tasked with improving awareness and understanding of potential cancer signs and symptoms, including a focus on less common cancers. These cancer leads should also be responsible for leading local audits to investigate missed opportunities to identify the signs and symptoms of cancer as and when these occur.
9. Tools to help GPs identify the potential signs and symptoms of cancer should be developed. These could include risk calculators to help practitioners assess a patient's potential risk and make referral decisions accordingly.
10. GP consortia should be encouraged to forge partnerships with other primary healthcare clinicians who may be in a position to identify the signs and symptoms of cancer, including community pharmacists, dentist and opticians. Referral mechanisms should be established to support this.
11. Given that assessing the potential signs and symptoms of cancer is a core part of a GP's role, their record in successfully diagnosing cancer at an early stage should be included as part of their revalidation process.
12. GPs should be incentivised for diagnosing cancer at an early stage, both in their role as the commissioner of services and as a provider. NICE should therefore prioritise the inclusion of measures to support the early diagnosis of cancer in both the Quality and Outcomes Framework of the GP contract and the Commissioning Outcomes Framework.

Chapter 1: introduction

How a patient is diagnosed with cancer will shape their entire experience of treatment and care and the stage of their cancer when it is diagnosed will have a major impact on their survival chances.

The evidence to support the link between late diagnosis and poorer outcomes is now compelling. Patients with more advanced cancer have fewer treatment options and those treatments which are available tend to be more invasive and less effective. Late diagnosis is a major reason for why cancer survival is poorer in England than in many other countries[2]. As well as compromising survival chances, delays in diagnosis can also damage a patient's experience of treatment and care. Missed opportunities to diagnose cancer can leave a patient feeling let down by the NHS, undermining their confidence in the healthcare professionals involved and restricting their ability to make an informed decision about their treatment and care.

Ensuring that patients are diagnosed at the earliest possible stage will therefore be critical in improving cancer outcomes, both in terms of mortality, survival and patient experience. It should be noted that the outcomes experienced by patients with rarer cancers tend to be poorer than those with common cancers:

- Survival is lower in most age groups[3]
- The experience of treatment and care reported by patients is poorer[4]

Given this, it is clear that there is significant scope for improving outcomes for patients with rarer cancers. Much of the evidence base on issues relating to late diagnosis has been stimulated by the National Awareness and Early Diagnosis Initiative, which is jointly led by the Department of Health and Cancer Research UK[5]. However, to date this has mainly focused on common cancers. Comparatively little work has been undertaken in exploring the impact of late diagnosis in rarer cancers or the reasons for it.

The Government's new cancer strategy, *Improving Outcomes: a Strategy for Cancer* has set an objective of saving an additional 5,000 lives by 2014/15[6]. Taking into account the incidence and mortality associated with rarer cancers, it would be reasonable to assume that 2,500 of these lives would be for rarer cancers[7].

However, if this goal is to be achieved, it is important that more is understood about the extent of late diagnosis for rarer cancers and the ways in which it can be tackled. This will involve learning the lessons on early diagnosis from common cancers and applying them to rarer cancers. It will also involve understanding the specific barriers to early diagnosis which exist for rarer cancers.

It is therefore extremely welcome that the Government has committed to beginning a new rarer cancers workstream of the National Awareness and Early Diagnosis Initiative[8]. This report is intended to help inform and support the National Awareness and Early Diagnosis Initiative's activity.

In order to explore the specific challenges presented by the diagnosis of rarer forms of cancer and in recognition of the imperative for ensuring that the views and experiences of patients are reflected in attempts to encourage earlier diagnosis, the RCF decided to conduct a detailed survey of patients' experience of the process leading to their cancer diagnosis.

This report details the findings of this survey and provides the most comprehensive picture to date of the issues which are faced in achieving an early identification of signs and symptoms, as well as a prompt and accurate diagnosis.

It is clear that there are many patients for whom the primary care pathway works very well. They seek help at an early stage; primary care professionals are able to identify the signs and symptoms of cancer and refer them for appropriate tests and investigations; and they receive an early diagnosis, resulting in a positive experience of the process. However, for others the process has been less than satisfactory, with delays in seeking help being compounded by false reassurance from GPs and a poor overall experience of primary care.

Tackling these issues will not be easy and will involve improving public awareness of the potential signs of rarer forms of cancer, providing greater support to GPs in recognising symptoms and ensuring that they have access to the necessary diagnostic tools and referral pathways to enable a prompt diagnosis. Building on the research outlined in this report, we hope to work with the Department of Health, NHS and public health services to improve the pathway to diagnosis for patients with rarer cancers. This combined with ensuring that patients get prompt access to the most effective forms of treatment and the best possible care and support, will help deliver outcomes which are comparable with the best in Europe.

Recommendation:

1. **The Department of Health should ensure that progress reports on improving cancer outcomes should provide information disaggregated by type of cancer, thereby enabling scrutiny of progress in improving outcomes for all forms of cancer, irrespective of whether they are common or rare.**

Chapter 2: background and methodology

Why early diagnosis matters

Diagnosing cancer before it has spread provides the best possible chance of achieving a positive long term outcome. In general, treatments for advanced cancers are more invasive, have more significant side effects and a lower chance of long term effectiveness. Treatments for advanced cancer also tend to have a higher unit cost, making it in the interests of both patients and the NHS to achieve diagnosis as early as possible.

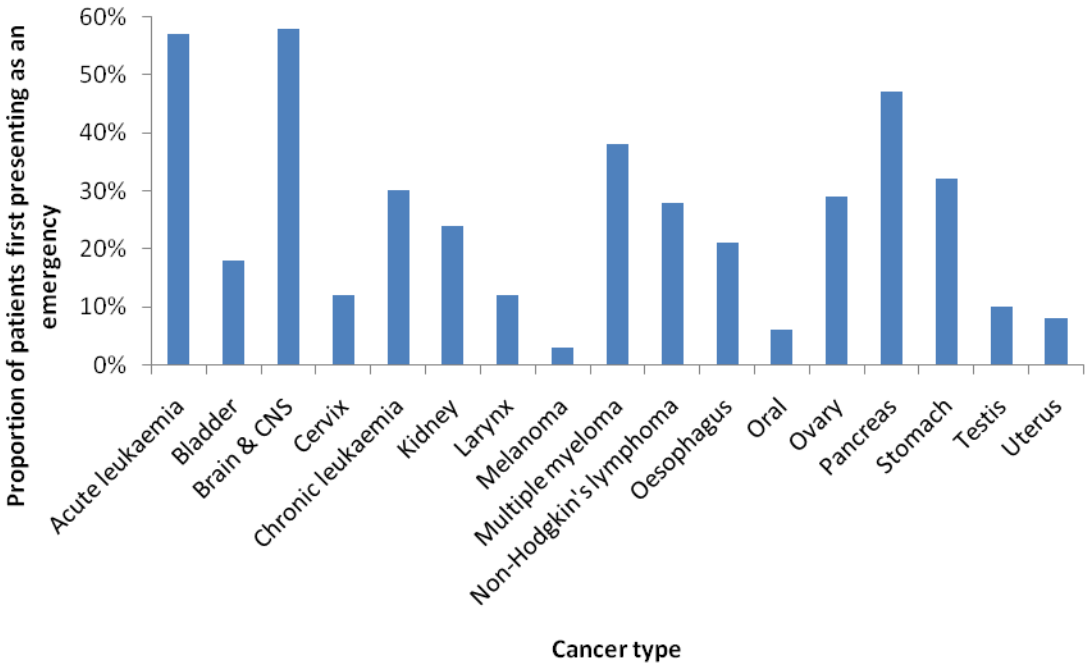
Despite this, a recent analysis by the National Cancer Intelligence Network found that, overall, 23% of newly cancer patients are first diagnosed following an emergency presentation[9]. First presenting as an emergency is a significant marker for late diagnosis, as it implies that a patient's symptoms were not diagnosed until they were acute.

Although the proportion of emergency presentations varies widely between cancer types, patients diagnosed as an emergency are almost universally less likely to be alive one year after diagnosis, supporting the importance of early diagnosis in improving outcomes. Patients under the age of 25, patients over 75 and those from less affluent groups are also more likely to present as emergencies.

Figure 1 shows the proportion of patients first diagnosed as an emergency presentation in England in 2007 is considerably higher for many rarer forms of cancer. For example, 58% of patients with cancer of the brain or central nervous system and 47% of patients with pancreatic cancer were diagnosed following an emergency presentation. 36% of patients in the 'other' category (used for particularly rare cancers) were first diagnosed following an emergency presentation[10].

In total, the NCIN's analysis suggests that over 29,500 patients with rarer forms of cancer (those outside the four most common types) were first diagnosed following an emergency presentation[11].

Figure 1 - proportion of cancer patients first diagnosed following an emergency presentation



Recommendations:

2. **Information on the proportion of patients with cancer who are first diagnosed following an emergency presentation should be collected and published by the NHS as a matter of routine.**

3. **As part of the new accountability structures for public health services and the NHS, commissioners should be required to deliver year on year reductions in the proportion of patients who are first diagnosed with cancer following an emergency presentation.**

Causes of delays in diagnosis

Delays in diagnosis can be driven by a range of factors, including:

(i) Low levels of awareness of signs and symptoms in the population, meaning that people do not seek help at an early enough stage

(ii) Embarrassment or a negative attitude towards cancer treatment, meaning that people delay seeking help even when they are aware of symptoms

(iii) A failure by primary healthcare professionals to identify signs and symptoms as potentially relating to cancer, resulting in false reassurance being given

(iv) Poor access to diagnostics or specialist help, resulting in patients waiting for a prolonged period of time once signs and symptoms have been identified

There has been significant progress in addressing factor (iv), with the introduction of the two week referral pathway and expansions in diagnostic capacity. However, the NCIN study demonstrates that late diagnosis remains a significant issue, implying that factors (i), (ii) and (iii) need further attention.

Public recognition of the signs and symptoms of cancer remains relatively poor. Although over two thirds of respondents to a survey recalled that a lump or swelling was a symptom of cancer, recognition of other symptoms was lower than 30%[12].

A significant minority of the public also report a range of factors which would prevent or delay them from seeking help. These include emotional barriers (such as feeling scared or embarrassed), practical barriers (such as difficulties in making an appointment) and problems engaging with healthcare professionals (such as fear of wasting a doctor's time or finding the doctor difficult to talk to)[13].

For rarer forms of cancer in particular, it can be challenging for primary healthcare professionals to identify cancer at an early stage. With the exception of cervical cancer, there are no screening programmes for rarer forms of cancer. In addition, the symptoms are often non-specific, making it difficult for people to know when to seek help[14]. GPs are less likely to see many cases of rare cancers when compared to other conditions which are more commonly dealt with in primary care. As a result, they may not recognise signs and symptoms as potential cancer.

Study objectives

In recognition of the particular challenges to encouraging early diagnosis for rarer cancers, the RCF applied for, and was granted, Section 64 funding from the Department of Health to carry out an audit of a patients' experience of primary care and general practice in particular.

This audit is intended to inform further work by the Department of Health, NHS and public health services in promoting earlier diagnosis of patients with rarer cancers through:

- Developing new evidence on the process through which patients are first diagnosed with a rarer form of cancer

- Providing a patient perspective on the process leading to their diagnosis, including whether there were opportunities to achieve an earlier diagnosis

- Assessing the impact of different factors during the process leading to diagnosis,

- Identifying ways in which public health services could productively raise awareness of the signs and symptoms of rarer cancers and how primary care providers could be supported in ensuring a prompt diagnosis once a patient has presented

- Making constructive recommendations for change as *Improving Outcomes: a Strategy for Cancer* is implemented

Study methodology

An initial proof of concept phase involved encouraging a number of patients to engage directly with their GPs in completing a paper-based survey. However this approach proved problematical in recruiting sufficient numbers of patients so it was decided that the most feasible approach was to undertake a series of online surveys of patients' perspectives in respect of the process leading to their cancer diagnosis.

Potential participants were identified by the RCF, with assistance from a range of other charities also encouraging participation. We are extremely grateful to charities involved in Cancer 52 for their support in this respect.

In order to ensure the study was focused on achieving the objectives set out above, the following groups of respondents were screened out:

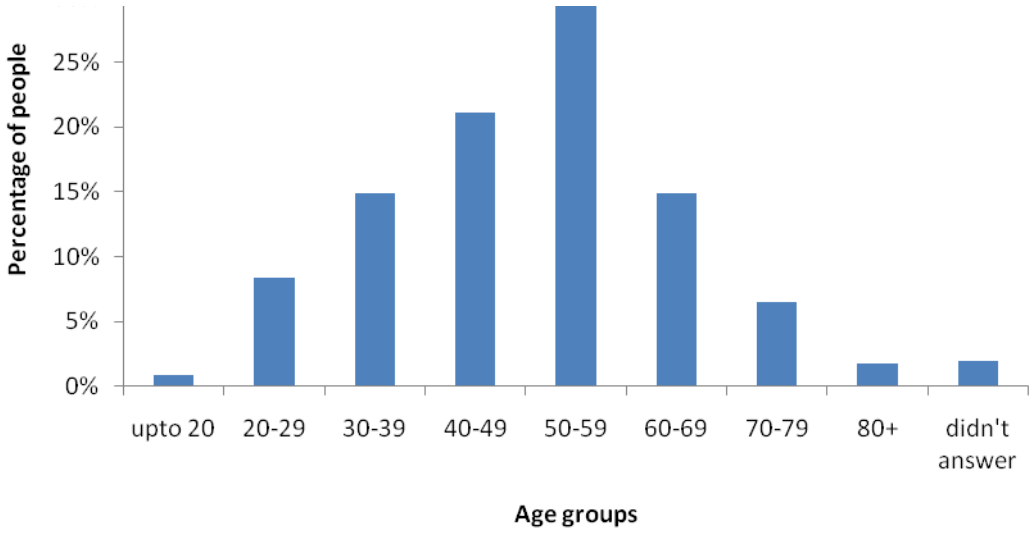
- Patients who had been diagnosed with a common cancer (lung, bowel, breast or prostate)

- Patients who had yet to receive a definitive cancer diagnosis but where cancer had been suspected

In total 322 patient responses were deemed eligible for inclusion in the study, all of whom lived in England. We are grateful to all those patients who took the time to participate.

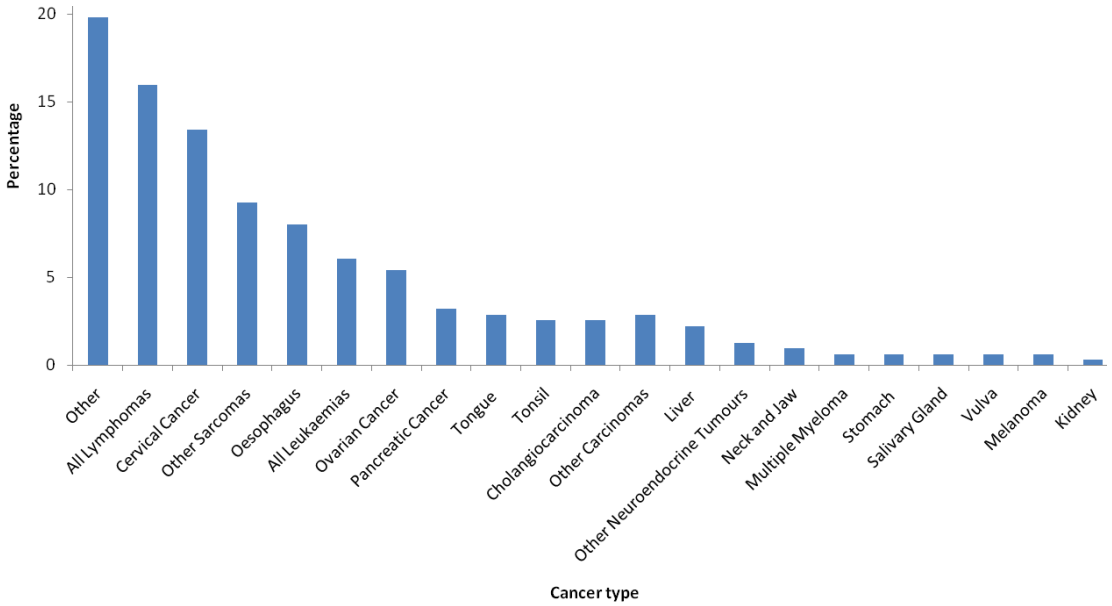
It is important to note that this sample is not entirely reflective of the demography of rarer cancer patients. 70% of respondents were female and only 30% were male. Respondents ranged from under 20 years old to more than 80 years old, with the most common age group being 50-59 years old – somewhat younger than the median age for people diagnosed with cancer (three quarters of cancer cases occur in people aged 60 and over[15]). The age distribution of respondents is set out in Figure 2.

Figure 2 - age distribution of respondents



Respondents were classified as having more than 20 different types of less common or rare cancers. Given that many of the groupings include a variety of different rare forms of cancer (for example, there are many different types of lymphoma and leukaemia), the total number of cancers represented in the study is much larger. Figure 3 summarises the different forms of cancer included in the study.

Figure 3 - different forms of cancer included in the study



It is important to note that the study is based on patient's own perceptions of patients of the process that led to them receiving a cancer diagnosis. In some cases, these perceptions may differ from the recollection of the healthcare professionals that helped them,

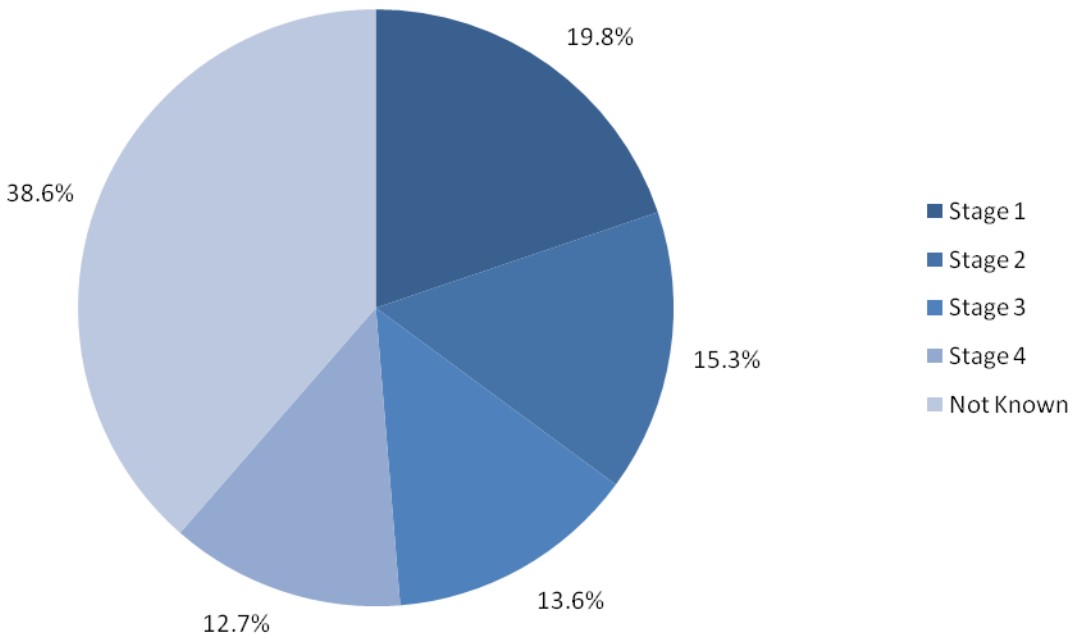
although this does not make the findings any less relevant in informing future policy and practice.

Chapter 3: the extent and causes of late diagnosis

The survey provides new insights into both the extent of late diagnosis amongst rarer cancer patients, as well as its causes.

Many patients who received a rarer cancer diagnosis did so at a point where their cancer had already spread from its initial location. Figure 4 shows that over one quarter of patients were diagnosed with stage 3 or 4 cancer – i.e. that where significant spread had occurred. Just over a third of patients were diagnosed with stage 1 or 2 cancer – the point at which the chances of achieving a long term 'cure' are at their highest. Over one third of patients either did not know the stage of their cancer at the point of initial diagnosis or were not told.

Figure 4- stage of cancer at the point of diagnosis

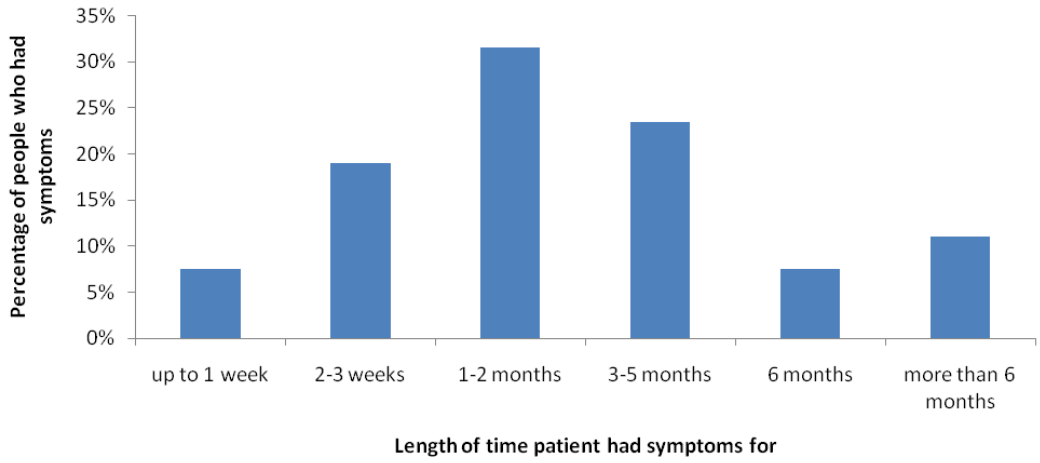


Interval between noticing symptoms and seeking help

In order to achieve an early diagnosis, it is important that people recognise the symptoms of cancer as being an indication that something is wrong and act upon their concern to seek help. Lack of awareness or knowledge of symptoms, as well as embarrassment or a negative attitude towards cancer treatment, can result in delays in patients presenting in primary care.

Figure 5 shows that over four in ten respondents waited for more than three months between first noticing symptoms and seeking help. Just over one quarter of patients sought help within a month of first noticing symptoms.

Figure 5 - length of time patients had symptoms before they sought help



It is therefore clear that more needs to be done to improve public awareness and understanding of the full range of cancer signs and symptoms, as well as encouraging people to seek early help when they notice them. Given the non-specific nature of many symptoms, there may be a case for public health action to encourage people to seek help and advice for any changes they notice in their health: although these changes may not be symptoms of cancer, they may nonetheless be indications of ill health.

Recommendations:

4. **The Department of Health should consider the case for extending the current cancer awareness campaign to cover all cancer signs and symptoms, including those for rarer cancers.**

5. **Tools should be developed to support Health and Wellbeing Boards in commissioning effective cancer awareness interventions.**

6. **The Department of Health should do more to encourage public, private and voluntary employers to raise awareness of cancer signs and symptoms.**

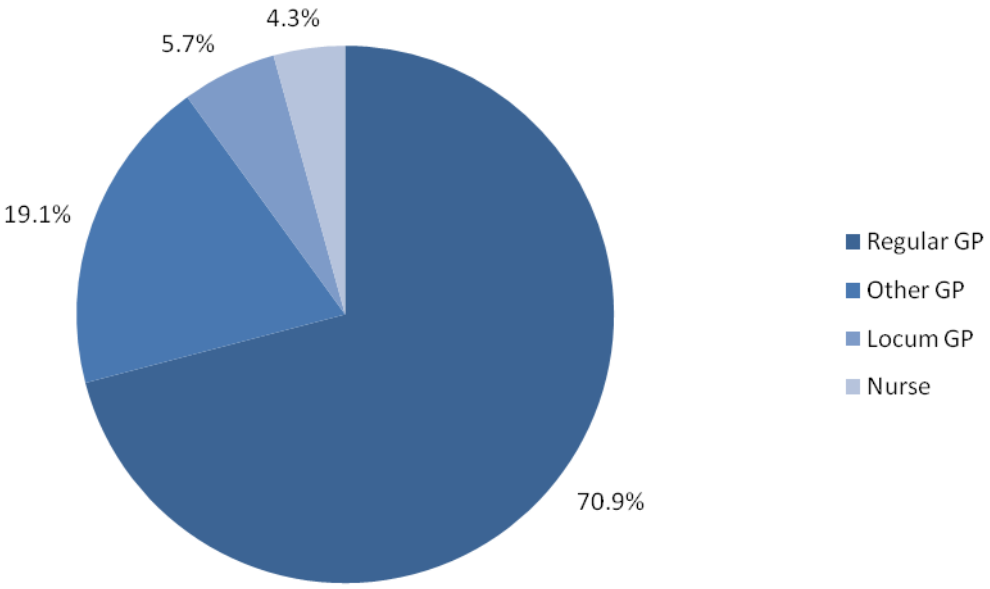
Experience of general practice

A major argument for the system of general practice used in England is the continuity of care that is established, with healthcare professionals developing a relationship with

patients over a long period of time, thereby establishing trust and enabling professionals to spot when changes occur in patients.

Figure 6 shows that over seven in ten patients first saw someone who they identified as their regular GP, indicating that continuity of care does exist for many patients.

Figure 6 - type of primary healthcare professional that patient first saw



However, this continuity of care does not always translate into GPs promptly and effectively identifying the potential signs and symptoms of cancer. Less than three in ten patients were asked about whether they had a family history of cancer, as set out in Figure 7. This is particularly concerning as many cancers have a genetic element and therefore a family history can indicate elevated risk factors.

Figure 7 - proportion of patients who were asked whether they had a family history of cancer

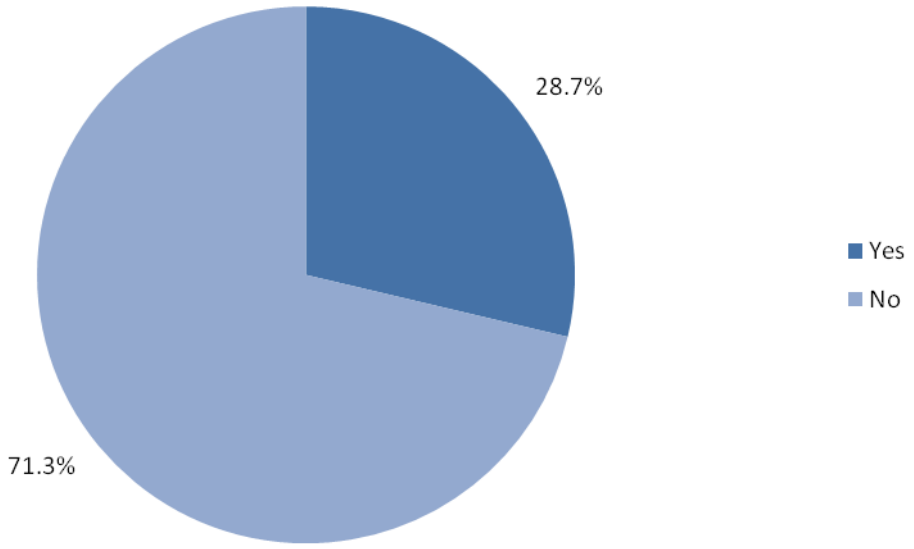
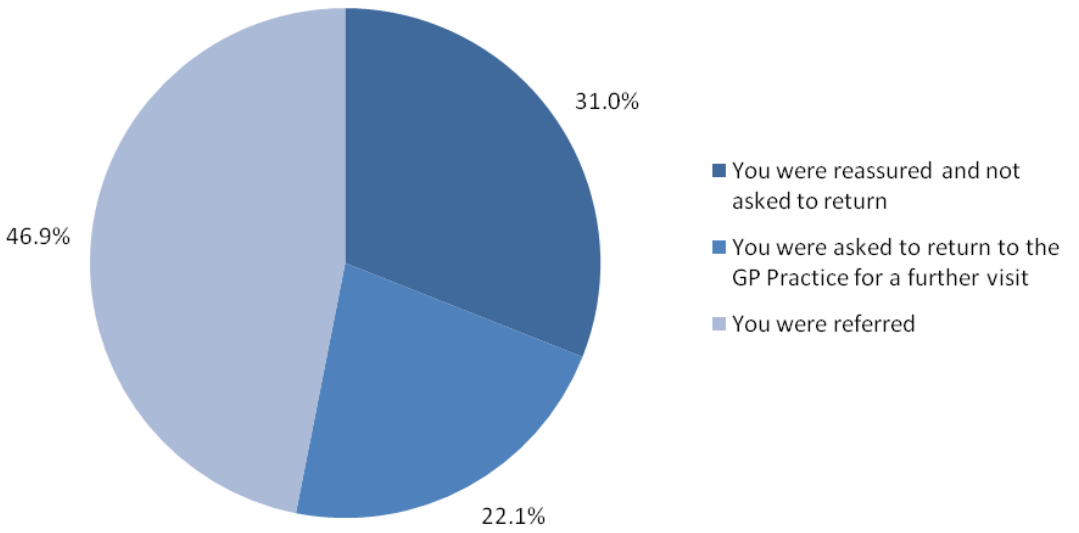


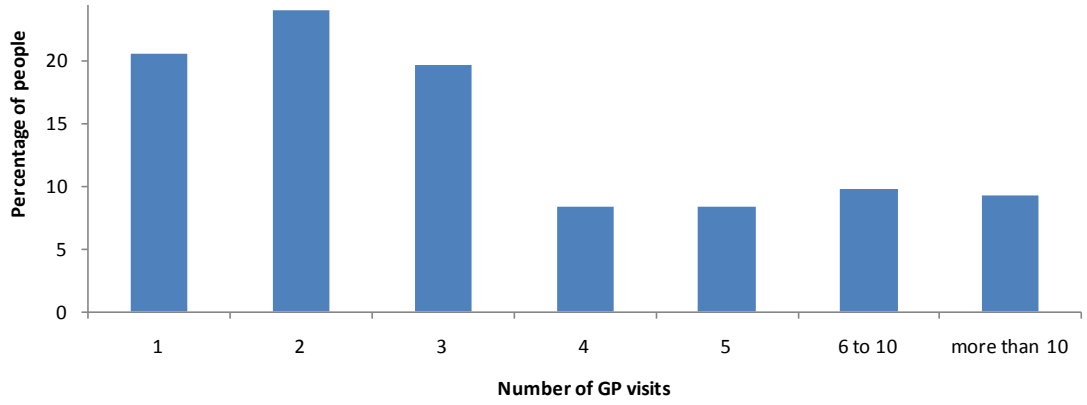
Figure 8 shows that, although just under half of respondents received a referral at the end of the initial appointment with their GP, nearly one third of patients were reassured and not asked to return. Given their subsequent diagnosis of cancer, it appears as though this reassurance was false.

Figure 8 - outcome at the end of first GP consultation



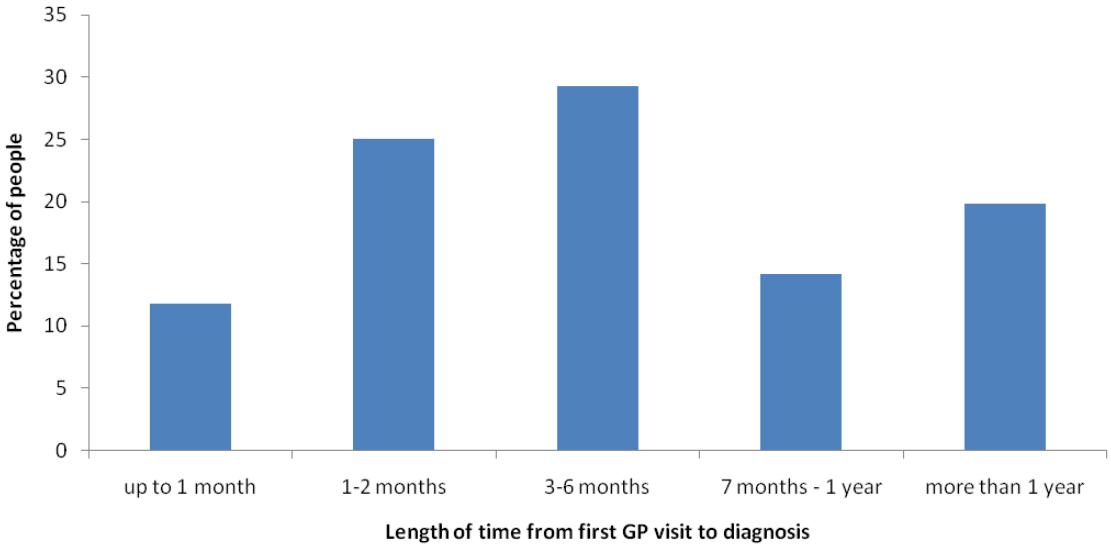
Over half of respondents reported that they had to visit their GP on more than two occasions before receiving a correct diagnosis, as set out in Figure 9. This broadly mirrors the findings of the 2010 National Cancer Patient Experience Survey[16].

Figure 9 - number of visits to GP before receiving a correct diagnosis



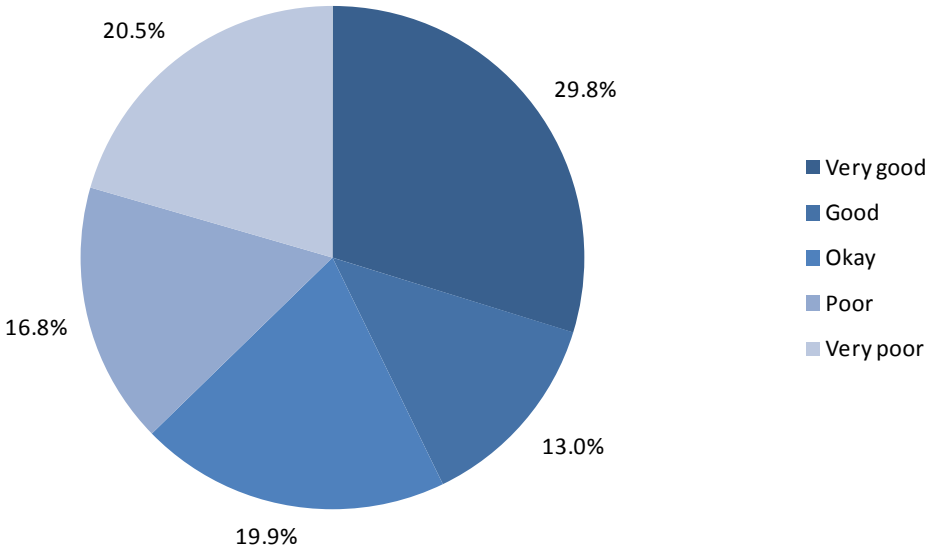
The impact of this was that nearly two thirds of respondents experienced a delay of at least three months between first visiting their GP and receiving a correct diagnosis, as set out in Figure 10.

Figure 10 - length of time between first visit to GP and correct diagnosis



Given the delays that some respondents experienced, it is perhaps unsurprising that over one third rated their experience of care as being either *"poor"* or *"very poor,"* as set out in Figure 11.

Figure 11 - rating of experience of primary care



Recommendations:

7. **The Department of Health should work with the Royal College of General Practitioners to remind GPs of the significance of family history as a risk factor for many cancers.**

8. **All GP consortia should appoint a cancer lead tasked with improving awareness and understanding of potential cancer signs and symptoms, including a focus on less common cancers. These cancer leads should also be responsible for leading local audits to investigate missed opportunities to identify the signs and symptoms of cancer as and when these occur.**

9. **Tools to help GPs identify the potential signs and symptoms of cancer should be developed. These could include risk calculators to help practitioners assess a patient's potential risk and make referral decisions accordingly.**

10. **GP consortia should be encouraged to forge partnerships with other primary healthcare clinicians who may be in a position to identify the signs and symptoms of cancer, including community pharmacists, dentist and opticians. Referral mechanisms should be established to support this.**

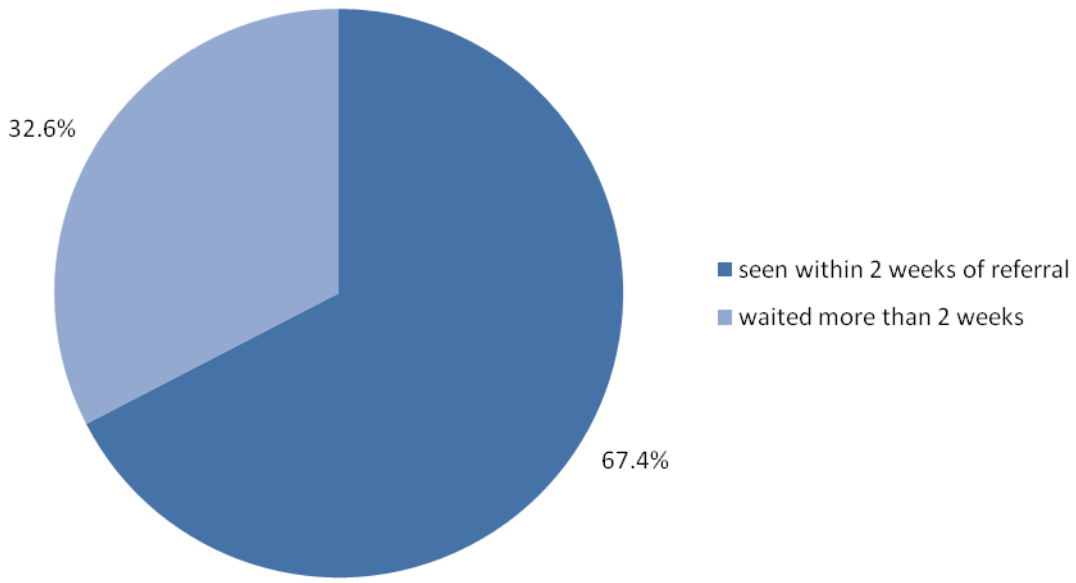
11. **Given that assessing the potential signs and symptoms of cancer is a core part of a GP's role, their record in successfully diagnosing cancer at an early stage should be included as part of their revalidation process.**

12. **GPs should be incentivised for diagnosing cancer at an early stage for both in their role as the commissioner of services and as a provider. NICE should therefore prioritise the inclusion of measures to support the early diagnosis of cancer in both the Quality and Outcomes Framework of the GP contract and the Commissioning Outcomes Framework.**

Speed of referral from primary care

Encouragingly, as shown in Figure 12, over two thirds of patients were referred within two weeks of referral, indicating that the majority of patients were ultimately diagnosed following a referral under the urgent referral pathway for suspected cancer.

Figure 12 - waiting time following referral



This finding suggests that efforts to streamline referral pathways and shorten waiting times for specialist appointments, once a referral has been made, have been broadly successful.

Chapter 4: conclusion

Given the non-specific nature of many signs and symptoms of rarer cancers, it can be difficult for both members of the public and healthcare professionals to identify them and take appropriate action. Yet, our study reveals that too many patients are experiencing unacceptable delays in diagnosis. This must be addressed if the Department of Health is to meet its ambitious goal of saving an additional 5,000 lives a year from cancer by the end of this Parliament, half of which should be delivered in patients with rarer forms of cancer.

Ensuring earlier diagnosis will not be easy, and will require a shift in culture, both in public awareness of, and attitudes to, cancer and the way in which primary healthcare professionals approach the issue. Yet feedback from the patients we support suggest it can be done. Many patients with a rarer cancer received an excellent service in primary care.

As the Department of Health takes forward implementation of *Improving Outcomes: a Strategy for Cancer*, it will be critical that examples of good practice in relation to early diagnosis are identified and emulated. The 2010 National Cancer Patient Experience Survey revealed a significant degree of variation in the speed with which GPs were able to identify the signs and symptoms of potential cancer and refer accordingly. In the best performing areas 90% of patients reported seeing their GP only once or twice before being referred, whereas in the poorest performing areas only 52% did so[17].

If improvements in cancer outcomes are to be maximised then it will be critical that patients with every form of cancer are diagnosed at the earliest possible stage. This study is intended to help inform action on early diagnosis and the RCF stands ready to work in partnership with the Department of Health and others to deliver this.

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incorporating Rarer Cancers Forum

Caring about people with rarer cancers

Rarer Cancers Foundation offers advice and information to individuals with rare and less common cancers or to their families and friends. The charity facilitates supportive networking, raises awareness of rare and less common cancers and works to ensure that people with rarer cancers have access to the best possible services.

Registered Charity No. 1109213
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