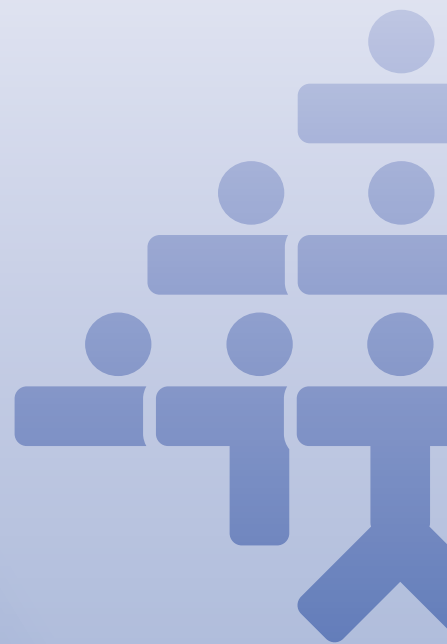


Access to Diagnostics Used to Detect Cancer

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Foreword

The Irish Cancer Society's vision is a future without cancer but we want to make sure that no one is left behind.

Since the publication of the Irish Cancer Society/Irish College of General Practitioners' (ICGP) "Needs Assessment of General Practitioners" and the second National Cancer Strategy in 2006, significant progress has been made in structuring the organisation and delivery of our cancer services, thanks in no small part to the establishment of the National Cancer Control Programme, the organisation of clinical cancer centres of excellence and the introduction of rapid access clinics. Now, we must redouble our efforts to ensure earlier diagnosis.

We know from the many cancer patients and survivors who have shared their story with us, that our anomalous system of health care leads to disparities in outcomes based on whether you can afford to pay for private health insurance or not.

The grim reality of our health care system is that the difference between life and death can come down to your ability to pay for healthcare. This situation is striking in its unjustness, but has been the modus operandi which has defined our health services for decades.

Currently, 46% of our population have private health insurance¹, around 39%² hold a medical card with the vital entitlements it brings, while the remainder of the population have access to public healthcare, but have little to no support for the costs that entails.

We commissioned the ICGP to carry out this research with a view to establishing GP experience and perception with regard to access to tests used to diagnose cancer, with a particular focus on social inequities at the primary care level.

This research makes abundantly clear that doctors working across all socioeconomic areas, not just those who identify as working in areas of deprivation, face a struggle in securing timely tests to provide diagnoses for public patients.

Early diagnosis often means a cancer is more likely to be treated successfully, intervention will be less complicated, and chances of survival may be higher. However, the ability to pay, cited by 88.5% of GPs surveyed as either 'always' or 'usually' affecting access to referral services, means that for the majority of the population without access to the private system, they may have to face lengthy waits that deprive them of early access to either a diagnosis or peace of mind. Meanwhile, those with health insurance are more likely to delay visiting their GP than medical card holders, adding weight to the argument that affordability impacts a person's diagnosis.

This report makes a number of recommendations on the basis of GPs' experience of delivery of quality service that point to the role of cancer awareness campaigns to encourage patients to present earlier, greater access to community-based cancer tests that would result in the treatment and diagnosis of a wider number of patients, and improved information sharing that would go some way to removing a reliance on personal relationships with consultants to get tests done, among others.

1 <http://health.gov.ie/future-health/financial-reform/private-health-insurance-2/>

2 <https://www.hse.ie/eng/services/publications/serviceplans/serviceplan2016/dgpres.pdf>

This comprehensive range of recommendations, if implemented, will make a big difference, across a diverse range of areas, to ensuring early diagnosis of cancer. However, without a wider discourse on, and commitment to, ensuring equal access to a universal, publicly-funded healthcare system, the inherent inequalities of our peculiar provision of healthcare will remain and those who cannot afford to pay will be left behind.

The Irish Cancer Society is committed to campaigning for universal health care. We are under no illusions as to the difficulty of seeing this implemented. It will not happen overnight. It will take years of campaigning. It will be a long, hard slog of building consensus in civil society, with policymakers, politicians, and most importantly the public, who deserve equal access to care when they need it most.

We can't and won't leave anyone behind.



Donal Buggy

Head of Services and Advocacy

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Executive Summary

Cancer is a major cause of morbidity and premature mortality. After diseases of the circulatory system, cancer is the second most common cause of death in Ireland. Between 1994 and 2012, cancer mortality rates slowly decreased. While the link between stage of diagnosis and cancer survival is multifaceted, it is apparent that treatment at an early stage offers the greatest potential for five year survival. The incidence and prevalence rates of cancer are expected to increase worldwide. In an Irish context, the ageing of our population is expected to result in a doubling in the number of people who will develop cancer over the next 15 years. In the majority of cases, the GP is the initial point of contact for patients presenting with symptoms of cancer. The detection of symptoms of cancer versus symptoms related to other illness can be an enormous challenge for GPs, with many patients presenting initially with low positive predictive values. Socio-economic and psychosocial factors can seriously impact on the early detection of cancer. Factors related to system delays can impact the time between investigation and diagnosis, and could potentially influence stage of cancer at time of diagnosis. There is a solid base of international literature on the subject of access to diagnostics, from which it is evident that barriers are encountered by GPs on a daily basis in the area of cancer detection. We conducted a survey of general practitioners (GPs) to contribute to the knowledge base of general practice in Ireland by increasing awareness of the challenges and barriers GPs continue to encounter in this area.

A postal survey with one reminder was undertaken. A total of 214 completed surveys were returned for practices comprising 592 GPs, representing a response rate of 14% of practices and 22% of the ICGP membership. This response rate is consistent with those from GPs nationally and internationally and selection bias is limited as all demographics of the responding group are consistent with national data on GPs. The key findings and discussion points from the survey are:

- In the year previous to the survey (2014), 71.5% of practices referred at least one patient for investigation for suspected cancer. The mean number of patients referred across all practices by whole time equivalent (WTE) GP was 30. The mean number of new cases of cancer per WTE GP was seven and the mean number of patient deaths recorded was three per WTE GP.
- The majority of respondents considered men and private patients to be likely to delay in presenting to their practice. This perception is consistent with other national and international findings.
- There was a striking difference in access for patients in the public system versus those in the private system for the majority of diagnostic tests. Similar to previous findings, the public system waiting times showed a wider distribution with a higher mean delay in all cases when compared to the private system.
- The majority, 88.5% of respondents reported that a patient's ability to pay privately 'always' or 'usually' affects access to referral services. Delays in accessing diagnostics forces many patients to pay for scans and tests privately to secure diagnosis. As a result, a patient's ability to pay is linked to their ability to access diagnostics used to detect cancer in a timely manner.
- One fifth of respondents considered that other GPs had direct access to tests for investigation for suspected cancer that they did not have. Of the respondents who indicated they had issues with direct access to tests in comparison to other GPs, the most commonly specified tests were Ultrasound CT Scan and MRI.

- Just over half of practices reported access to a fast track system in their local hospital for 'urgent' referrals (excluding breast, prostate, lung and melanoma). However, just under 40% of respondents had no access for any patient with suspected cancer; a marginal increase on 2006 figures. Less than 20% of respondents had access for patients with suspected cancer with non-specific symptoms only. Access has remained similar to the 2006 level for patients referred with symptoms of a specific cancer. Nearly 59% of respondents had no access for patients with symptoms of specific cancers.
- Recent data from the National Cancer Registry of Ireland shows that the five-year survival rate is much poorer among patients in deprived areas. In this survey, approximately one third of GPs perceived their practices to be located in an area of deprivation. Further analysis did not highlight any significant relationship between area of deprivation and direct access to diagnostics for public and private patients which suggests that currently all GPs find it difficult to access diagnostics for suspected cancer outside of the four rapid access clinics for breast, prostate, lung and melanoma, if their patients are unable to pay through the private system. This suggests inequity of access between those who can and can't pay.
- Respondents were asked to indicate, in cases where cancer is suspected, the types of cancers where there are unacceptable delays in accessing diagnostic equipment (or diagnosis) at their local hospital. The most common unacceptable delays were for gynaecological, neurological, urological (excluding prostate) and head and neck cancers. Breast, lung, prostate and melanoma cancers, which have dedicated rapid access clinics, were the least problematic for respondents to access.
- Overall, nearly 80% of respondents considered a waiting time of more than two or more weeks for cases they perceived to be urgent to be unacceptable. Seven out of ten respondents regarded a delay of six weeks and over as unacceptable for non-urgent cases.
- In some cases, there was a marked difference in the level of information GPs received versus the importance they placed on the information. Just over 29% of respondents always/usually receive information on a patient's prognosis following a new diagnosis, yet 86% perceived this to be necessary information; 27% always/usually receive detail on the level of information the patient received on their diagnosis, yet 82% indicated a need for this, and 18% of respondents frequently receive information on major side effects of treatment, however 77% regarded this information as necessary.
- Difficult or delayed communication between hospitals and GPs have been widely reported in the international literature, and often limits GPs in fulfilling their role in managing patients and responding to family queries after a newly diagnosed cancer.
- Respondents were presented with a list of ten possible factors which would most assist in the early detection of cancer in their practice. The most frequently selected factor was 'guaranteed direct access to diagnostic tests for cancer', followed by 'establishment of additional rapid access clinics for all suspected cancers' and 'earlier presentation to GP'.

These findings highlight that greater universality in primary health care system is vital to ensure that all categories of patients obtain the timely health services they require, without facing a dilemma of unaffordability. The necessity for appropriate access for GPs to cancer diagnostics is evident in both Irish and international literature. Appropriate access can positively impact on earlier stage diagnosis and is likely to benefit patient outcomes, including improved survival rates and improved

quality of life dependent on cancer type. By 2040, the total number of new invasive cancer cases are projected to increase linked to both changes in risk factor prevalence and the expansion of cancer screening services. It is evident that the healthcare system as it is currently structured for cancer detection, diagnosis, treatment and survivorship care must be prepared for the anticipated demand for cancer services.

Although professional collaboration is highly estimable, there is cause for concern that access to diagnostics may be influenced by established relationships, particularly considering that newer GPs may not have had the opportunity to develop such associations. In addition, due to increasing time constraints, stressors caused by poor referral processes and decreased interaction at shared forums, the relationship between GPs and specialists should not be depended on to access diagnostics on a case by case basis. Instead, a clearly defined and streamlined referral process offering timely access to relevant tests is essential for GPs to effectively manage patients with symptoms associated with cancer.

The findings suggest that although there has been some evident improvement in this area since the Irish Cancer Society/Irish College of General Practitioners Needs Assessment of GPs in 2006, GPs are still experiencing poor access to these services. Of note, GPs reported extremely limited access to fast track systems for pancreatic, neurological, head and neck and haematological cancers at their local hospital, suggesting the need for greater improvement in this area.

Taking into consideration GPs' evident positive views of the restructuring of cancer services into designated cancer centres and their encouraging experiences, particularly with improved waiting times in accessing diagnostic equipment when referring patients to rapid access clinics for breast, lung, prostate and melanoma, clear evidence led protocols similar to the 2015 NICE guidelines for all main cancer types are a necessity. Symptom based guidelines in particular would be of clear benefit to GPs as it would allow more flexibility to refer patients resulting in earlier diagnosis of cancer.

The economic impact of cancer on the health care system in Ireland is gradually increasing. Linked with delays in diagnosis, the financial benefit of early diagnosis is apparent. Lack of access in the primary care setting can increase the need for unnecessary ongoing testing of patients.

Difficulties in communication with hospitals following a new diagnosis of cancer remain evident, with a high proportion of GPs not usually informed by hospital staff of the hospital contact person for the patient, major side effects of treatment or what the patient has been told about their illness or prognosis. Consequently, GPs often encounter difficulties in providing tailored advice and support to the patient and their families. The development of a national Medical Oncology Clinical Information System (MOCIS), which is currently being piloted and due for expansion across twenty five hospitals in Autumn 2016, is expected to improve communication and information sharing between secondary and primary care regarding patients with newly diagnosed cancers.

These findings indicate the need for solutions to improve GP access to diagnostics for suspected cancers. The current structural problems resulting in unequal delayed access create barriers to healthcare provision for all socioeconomic groups in Ireland, especially patients who utilise the public healthcare system. This report makes concrete recommendations related to cancer awareness campaigns, greater access to diagnostics, cancer guidelines, improved information sharing and workforce planning. Actions in these areas would impact substantially on the landscape of cancer services in Ireland.

Introduction

Cancer is a major cause of morbidity and premature mortality. In Ireland, one in three men and one in four women will develop cancer during their lifetime. Recent figures from the National Cancer Registry of Ireland (NCRI, 2015) identify that approximately 37,000 newly diagnosed cases of cancers and non-invasive tumours were registered per annum between 2011 and 2013. Of these, approximately 30,000 per annum were invasive cancers (excluding non-melanoma) skin cancers; representing an overall age-standardised rate of 546 female and 724 male cases per 100,000 per year. The most common invasive cancers are breast cancer in women (2,917 cases p.a.) and prostate cancer in men (3,400 p.a.). Colorectal/bowel (2,460 p.a.) and lung (2,318 p.a.) are currently the most common cancers affecting both sexes (NCRI, 2015). Melanoma skin cancer was identified as the fifth most common cancer. Figures from the NCRI indicate that incidence rates of cancer are on average 26% higher in men than in women. In 2012, age-standardised incidence rates of cancer in Ireland were 10% higher than the European Union average for men and 16% higher for women; with higher rates recorded for colorectal, prostate, breast and female lung cancer in particular.

After diseases of the circulatory system, cancer is the second most common cause of death in Ireland. Between 1994 and 2012, cancer mortality rates slowly decreased. A total of 8,827 deaths from cancer were recorded between 2011 and 2012 inclusive, with a resulting age-standardised mortality rate of 153 deaths per 100,000 females and 211 deaths per 100,000 males per annum (NCRI, 2015). Mortality rates for all-cancers were approximately 37% higher in men than in women during this period. The lifetime risk of death from cancer is one in eight for men and one in ten for women. For both men and women, lung cancer is the leading cause of cancer death with 1,826 deaths annually. Colorectal (1000 p.a.), breast (698 p.a.), prostate (541 p.a.) and pancreatic (477 p.a.) are the next most common cause of cancer deaths. When compared to the European average, cancer mortality in Ireland is 14% higher for women and 9% lower for men.

Cancer survival

Research indicates that, when adjusted for demographics, there is an annual fall of 0.9% in the overall risk of dying of cancer. Yet progress in cancer survival has been uneven, with 5-year survival now greater for some cancers than others. Overall five year survival has improved for three of the most common cancers: colorectal, breast and prostate cancer. There has been an increase in survival for the four most common cancers in women - breast, lung, colorectal cancer and lymphoma. For men, survival improved for almost all cancers, notably prostate and stomach cancer, lymphoma and leukaemia. However, approximately 42% of patients with cancer do not survive five years and the proportion is very low for certain sites, specifically lung and pancreatic cancer. While the link between stage of diagnosis and cancer survival is multifaceted and further research is necessary in this area, it is apparent that treatment at an early stage offers the greatest potential for five year survival (Redaniel et al, 2015).

Across Europe, there are variances in overall five year cancer survival, however five year relative survival generally increased between 1999 and 2007 (De Angelis et al, 2014). Probable explanations of variances in survival rates are differences in the age and general health of patients, compliance with treatment, socioeconomic status, the stage of disease at diagnosis, access to diagnostic equipment and treatment, patient delay and/or other health care system factors, and differences in

human resources, organisation and funding (Coleman et al, 2001; Sant et al, 2003a; De Angelis et al, 2014). Economically robust countries with enhanced access to diagnostics, treatment and screening programmes were found to have increased overall cancer survival (Baili, 2015).

The CONCORD-2 study suggests that Ireland is mid-way in survival estimate rankings across eleven major cancer types when compared with other European countries (Allemani et al, 2014). For colorectal cancer, prostate cancer and lung cancer, relative survival was close to the European average but was below average for stomach cancer. Comparing the periods 1994-1999 and 2006-2011, survival rates increased from 72% to 81% for women diagnosed with breast cancer in Ireland. Yet survival rates for Irish women with cervix, ovarian and breast cancer continue to be lower than the European average. Tumour stage at diagnosis explains much of the survival differences in certain cancers, notably cancers of the gastrointestinal tract, female reproductive system, breast, thyroid and skin melanoma (Sant et al, 2003b).

Detection and early diagnosis in general practice

Over the next 20 years, incidence and prevalence rates of cancer are expected to increase worldwide by approximately 65%. It is predicted that cancer will result in 12 million deaths by 2030 (WHO, 2011). In an Irish context, the ageing of our population is expected to result in a doubling in the number of people who will develop cancer over the next 15 years. This projected increase in cancer rates is linked to ongoing improvements in detection and diagnosis at an earlier stage.

There are an estimated 2,954 general practitioners (GPs) in Ireland (Teljeur et al, 2014). An individual GP can expect to see approximately eight new cases and three deaths from cancer per annum (Daly and Collins, 2007). In the majority of cases, the GP will be the initial point of contact for patients presenting with symptoms of cancer (Allgar and Neal, 2005; Banks et al, 2014). More than 200 types of cancer have been identified, many with complex and/or vague signs and symptoms. The detection of symptoms of cancer versus symptoms related to other illness can be an enormous challenge for GPs, with many patients presenting initially with low positive predictive values (Hamilton, 2010; Rubin et al, 2015). On average, patients attend their GP at least three times before a cancer diagnosis is made (Thomson and Forman, 2009), with younger patients and those from ethnic minorities more likely to require repeat visits before referral (Lyrtzopoulos et al, 2012). For patients living in deprived areas, there are evident delays in the early detection of cancer and lower survival rates (Walsh et al, 2014). Deprivation has been defined by Townsend (1987) as a state of “observable and demonstrable disadvantage relative to the local community to which an individual belongs”. Socio-economic and psycho-social factors can seriously impact on the early detection of cancer; these include a lack of awareness of signs and symptoms of cancer, delays in accessing medical GP appointments due to fewer GPs working in deprived areas, and longer waiting time for referrals through the public system (Crowley, 2005; Osbourne, 2015).

Population-based studies provide further indication that what happens to patients in the early symptomatic stages of the cancer journey affects their eventual outcome. The EURO CARE programme highlighted a potential for improved cancer recognition as assessed by the stage at patient presentation for definitive treatment (Berrino et al, 1999; Richards, 2009; Banks et al, 2014). Others have concluded that in order to improve cancer survival, the focus ought to be on cancer identification at the earliest possible stage (Summerton, 2002). While emerging evidence between cancer diagnosis intervals and cancer survival is complex and consistent scientific

evidence is limited, it is clear that unacceptable delays in accessing appropriate diagnostics tests limit the role of the GP and can cause extreme anxiety for the patient (Lyrtzopoulos et al, 2012; Redaniel et al, 2015).

A mixed-methods study carried out in 2006 of the Irish College of General Practitioners (ICGP) established the needs of GPs in terms of issues affecting the early detection of cancer including information availability, communication and referral (Daly and Collins, 2007). The most striking findings of the qualitative component of this research were that barriers identified were not only confined to early diagnosis but apply to the diagnosis of cancer at any stage. The principle barriers identified by GPs were the same within and across all groups and included: delay in patient presentation, lack of direct GP access to radiological and endoscopic investigations, difficulty with referral of patients to hospital services for investigations and/or assessment, lack of clear recommendations for cancer screening, poor communication with hospital staff and inequitable access with long waiting lists for investigation and referral for patients who could not afford to pay privately. In general, the findings of the quantitative aspect mirrored those of the qualitative research, and pointed to an additional need for further education and clinical practice guidelines. In order of importance, the factors identified which would assist GPs most in the early detection of cancer were agreed criteria for screening 'high risk individuals' (54%), agreed referral criteria for suspected cancer (53%), a 'ring fenced' budget for community diagnostic services (47%), increased public awareness of early cancer symptoms (44%) and earlier patient presentation to a GP (43%) (Daly and Collins, 2007). Among the key recommendations proposed were that direct GP access to radiological investigations and endoscopy services should be improved through increased direct access to hospital services or provision of designated community diagnostic facilities; that rapid access facilities for patients with suspected cancer should be expanded to reduce waiting times for assessment; that communication between secondary and primary care should be improved to include agreed referral criteria for patients with suspected cancer, referral arrangements for urgent and non-urgent patients and provision of complete and clear information to GPs regarding their patient's diagnosis and cancer treatment plan; and that inequity of access to public hospital services between public and private patients must be eliminated (Daly and Collins, 2007).

Access to cancer diagnostics

Although evidence suggests a shorter waiting time can impact positively on earlier stage diagnosis and improve patient outcomes (Richards et al, 1999; Tørring et al, 2011, Neal et al, 2014), there are evident issues with regard to the speed of accessing cancer diagnostics and/or limited access to relevant diagnostic tests at the primary care level in Ireland.

As far back as 2006, GPs identified that a main barrier to early diagnosis of cancer was the lack of direct access to diagnostics (Daly and Collins, 2007) and this is particularly the case for public patients in comparison to access for private patients (O'Riordan, Collins and Doran, 2013; Darker et al, 2015). Access to vital tests such as gastroscopy, colonoscopy, abdominal and pelvic ultrasound have been found to be problematic for GPs in public hospitals.

Factors related to system delays can impact the time between investigation and diagnosis, and could potentially influence stage of cancer at time of diagnosis (Olesen, Hansen and Vedsted, 2009; Hansen et al, 2011; Provost et al, 2015). System delays play a prominent role in the wait between referral and specific diagnosis/

treatment; specifically waiting times for access to diagnostics and tests in secondary care, most commonly for non-urgent referrals, specialist care and health system administration.

GPs can rarely be certain that patient symptoms indicate serious disease. Limited access to diagnostics can result in GPs requesting tests and/or referrals which are most accessible rather than suitable, and in patients attending already overcrowded accident and emergency departments in order to access diagnostic tests (O’Riordan, Collins and Doran, 2013; Emery, 2015). Direct GP access to diagnostics can result in good diagnostic yield, a significant reduction in referrals, decreased need for unnecessary investigation, potential lower treatment costs, and can enable a significant amount of patient care to be directly managed in the primary care setting (Speets et al, 2006; Roland et al, 2006; Birchill, 2010).

Fears that GPs would overwork the system if direct access to diagnostics and tests was approved were unfounded in one UK based study which established that only 12% of referrals for additional tests could be defined as inappropriate (Frances et al, 1995). Another London-based study found that 71% of the patients referred for diagnostic imaging had their illnesses managed in the primary care setting (Wilson et al, 2010). Additional data from this study found that 32% of patients referred for echocardiography received an abnormal result, however 71% of those were managed directly in primary care; 79% of patients referred for an MRI had an abnormal result, with 63% referred onwards for additional investigation, and 54% of patients referred for ultrasound had abnormal results, with slightly more than one quarter of these patients referred onwards.

In 2013, the ICGP published the ‘Access to Diagnostics: A key enabler for a primary care led health service’ report (O’Riordan, Collins and Doran, 2013). It found that more than 20% of GPs did not have direct access to abdominal or pelvic ultrasound in the public system; approximately 80% of GPs had no direct access to CT scans and only 10% had direct access to MRI scans in the public system. Only 64% of GPs surveyed had direct access to gastroscopy and 57% direct access to colonoscopy testing services. Waiting periods for tests were consistently lengthy with geographical location of GP practice having an impact on access to tests. On average, there was a 14 week waiting period for abdominal or pelvic ultrasound, a 16 week wait for CT scan and a 22 week wait for MRI scan in the public system.

An overwhelming number of respondents stated that increased access to diagnostics would result in a reduction in referrals to accident and emergency departments (86%) and to out-patient departments (90%). Nearly 87% of those surveyed believed that increased access would reduce unnecessary hospital admissions. Correspondingly, a recent National Cancer Control Programme (NCCP) survey found that over four fifths of GPs sent patients to accident and emergency to bypass difficulties in accessing services (O’Shea and Collins, 2016). Issues in accessing diagnostics are also evident in international literature. One Danish based study found that waiting times for tests was a chief reason for delays in diagnosing lung cancer in the primary care setting (Bjerager et al, 2006). Another UK based study focusing on colorectal cancer, again highlighted delays in secondary care particularly for non-urgent referrals, and suggest that dedicated referral forms (either fax or electronic), referral guidelines and education reduced overall system delays and waiting times (Davies et al, 2007).

Dedicated referral guidelines and pathways can have a positive impact on early detection and diagnosis (Emery, 2015). The NICE ‘Suspected cancer: recognition and referral’ guideline (2015) estimates that 5,000 lives could be saved in the

UK annually if cancers are detected and diagnosed sooner and recommends timeframes of between 48 hours to two weeks for diagnostic tests. In Ireland, national GP referral guidelines for suspected breast, prostate, lung and melanoma were introduced by the NCCP between 2009 and 2011; referral forms accompany each and dedicated rapid access clinics are in place in eight cancer centres nationwide for breast, prostate and lung cancers, and in fourteen cancer centres nationwide for melanoma. When surveyed, the vast majority of GPs considered the organisation of these cancer services into designated cancer centres a positive step (O'Shea and Collins, 2016).

Primary care research can provide important insight into the study of cancer diagnostic pathways and delays in accessing relevant clinical diagnostics. There is a solid base of international literature on the subject of access to diagnostics, from which it is evident that barriers are encountered by GPs on a daily basis in the area of cancer detection. This survey was conducted to contribute to the knowledge base of general practice in Ireland by increasing awareness of the challenges and barriers GPs continue to encounter in this area.

Methods

Aim and objectives

The purpose was to undertake a quantitative survey among GPs, with some comparisons to the previous Irish Cancer Society (ICS)/Irish College of General Practitioners (ICGP) Early Detection of Cancer study and the ICGP Diagnostics survey, to establish current GP experience and perception in relation to accessing diagnostic services for suspected cancer cases with a focus on social inequities at the primary care level.

Within this, the specific objectives were:

1. To establish GP current experience with regard to access to relevant cancer related diagnostic tests and waiting times for public and private patients;
2. To document GP perception on how access to cancer related diagnostics and waiting times impact on the delivery of a quality GP service;
3. To gather information on possible reasons for delays and solutions from the GP perspective.

Study design

A questionnaire was developed in view of the literature and with the input of the Irish Cancer Society.

Postal questionnaires were sent during November 2015 to 1,565 GP practices in the Republic of Ireland. Alongside the questionnaire an information sheet was provided which informed interested participants of the purpose of the study and outlined the contact details of the ICGP research team. Freepost return envelopes were included in study packs. A postal reminder was sent two weeks following the initial posting. Return of the completed questionnaires was taken as consent.

The final questionnaire consisted of 27 questions in five sections. Section I queried patient presentation; Section II sought GP experience in accessing cancer related investigation from general practice; Section III focused on both investigation from general practice and referral to public hospital for investigation; Section IV asked GPs about the impact delays cause on the delivery of a quality GP service and the final section, Section V, collected GP and practice demographics.

Data analysis

A total of 214 completed surveys were returned for practices comprising 592 GPs, representing a response rate of 14% of practices and 22% of the ICGP membership. Quantitative data were entered into the Statistical Package for the Social Sciences version 22 (SPSS) for analysis. Frequency distributions, descriptive statistics and cross-tabulations were generated to establish the extent to which key objectives of the study had been achieved. Data has been presented in the form of tables and graphs as appropriate.

Ethical considerations

The return of completed questionnaires was regarded as evidence of consent. The questionnaires were completely anonymous, with no identifying information recorded. In this report no references are made to individual GP practices to ensure privacy. Data were stored in accordance with the Data Protection (Amendment) Act 2003.

Findings

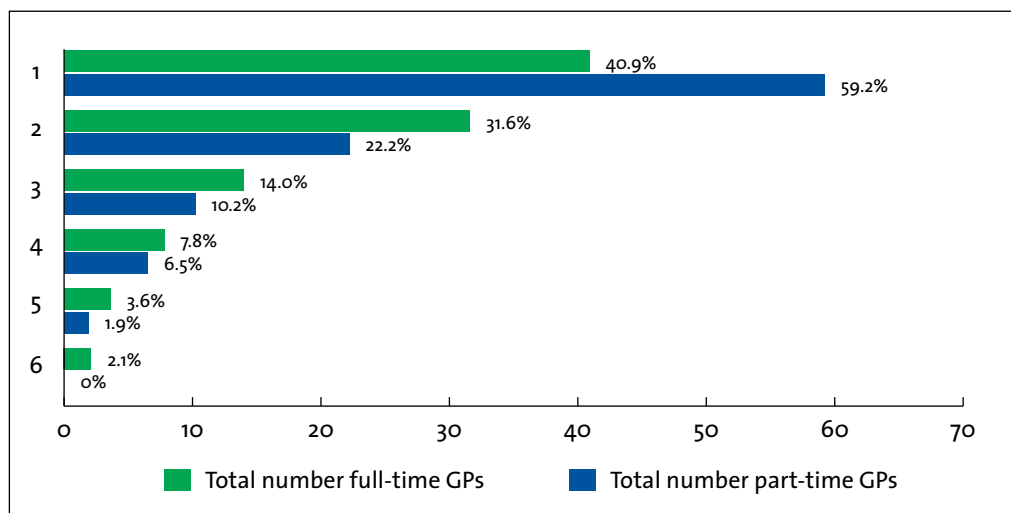
Demographics and practice profile

This section briefly sets out the demographics of the GPs who completed the survey on behalf of their practice in addition to providing some further information about their practices.

Overall, 63% (n=134) of respondents were male. The majority (8%, n=180) were over ten years in general practice. This was a practice based survey and it is likely that the principal/more senior GP completed the survey. While the statistics above are both slightly higher than those from our membership statistics of all individual GPs, they are consistent with the findings from other practice based surveys.

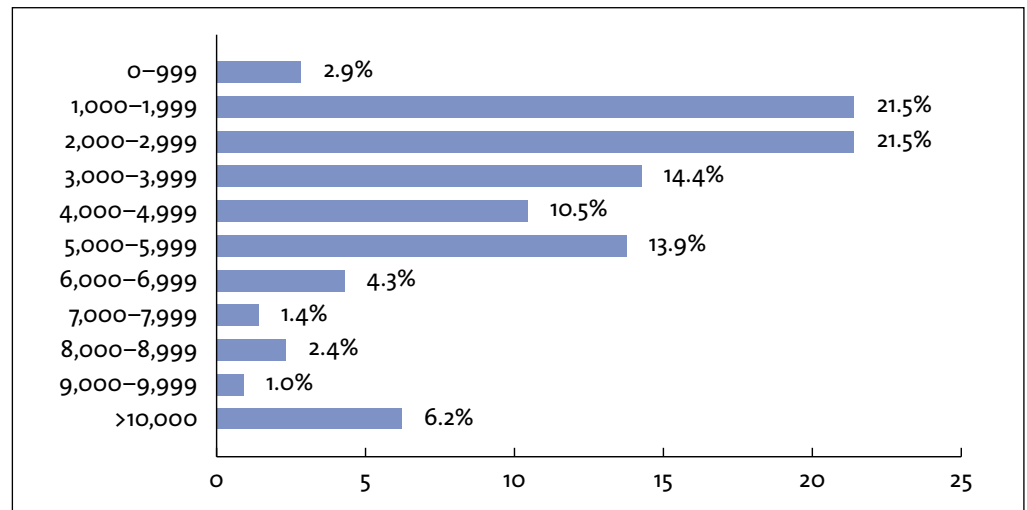
Overall 21% of practices were single-handed, which is consistent with recent national data quoting 18% (O’Kelly et al, 2016). Nearly 41% of practises had one full-time GP in practice; 45% of respondents reported that their practice had 2–3 full-time doctors; 14% had 4–6 full-time doctors. The mean number of full time GPs in each practice was 2.08. Nearly 60% of respondents had one part-time doctor in their practice; 32% had 2–3 and the remaining 8% had 4–5 in practice (Figure 1). The mean number of part-time GPs was 1.58. The mean number of whole time equivalents (WTE) in each practice was 2.4 GPs.

Figure 1. Total number of doctors in the practice



The vast majority of practices had a practice nurse (87%, n=184). These figures are comparable with the recent Structure of General Practice in Ireland report (O’Kelly et al, 2016) which identified that 82% of practices nationally have a practice nurse.

Overall, the mean practice population size was 3,916 patients. Approximately 43% of respondent’s practices had a patient population of between 1,000 and 2,999 (43%). Nearly 40% of respondents had between 3,000 and 4,999 patients and 14% had between 5,000 and 5,999 patients. The mean number of patients per WTE GP was 1,871.

Figure 2. Approximate practice size (n=209)

Slightly more than one third (n=73) of respondents indicated they were practicing in an area of deprivation. This is marginally less than previous figures from an Irish general practice survey where 40% of GPs considered they were working in a deprived area (Crowley, 2005). Respondents were asked to identify the approximate percentage of general medical card (GMS) patients in their practice population. Figure 3 shows that for just under half of practices, GMS patients constituted more than 50% of the practice population. Overall, 70% of GPs who considered that they were working in an area of deprivation indicated that GMS patients constituted more than half of their practice population (Table 1). The average practice population size was not significantly different between GPs who were working in perceived areas of deprivation and those who were not. However, the proportion of GMS population was significantly higher for those working in perceived areas of deprivation (68%) in comparison to those who were not (50%).

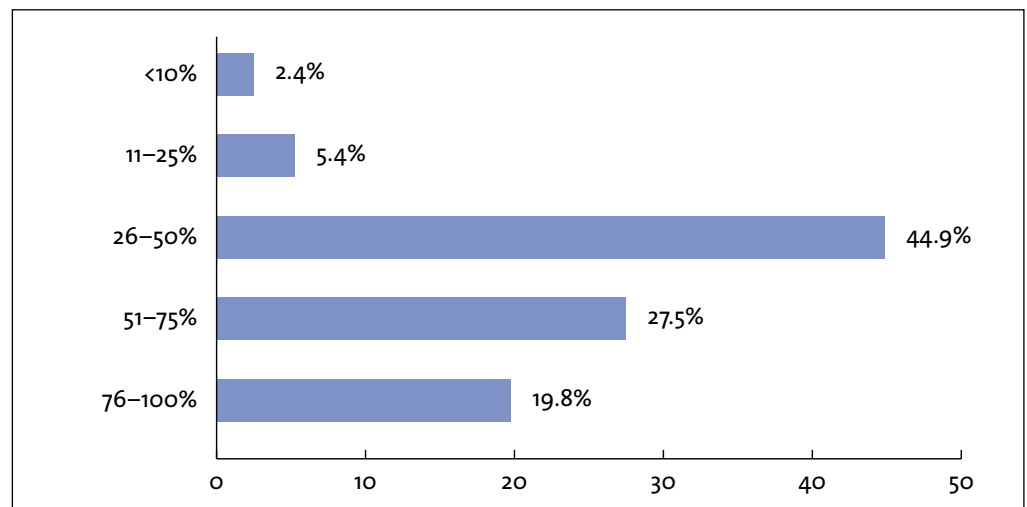
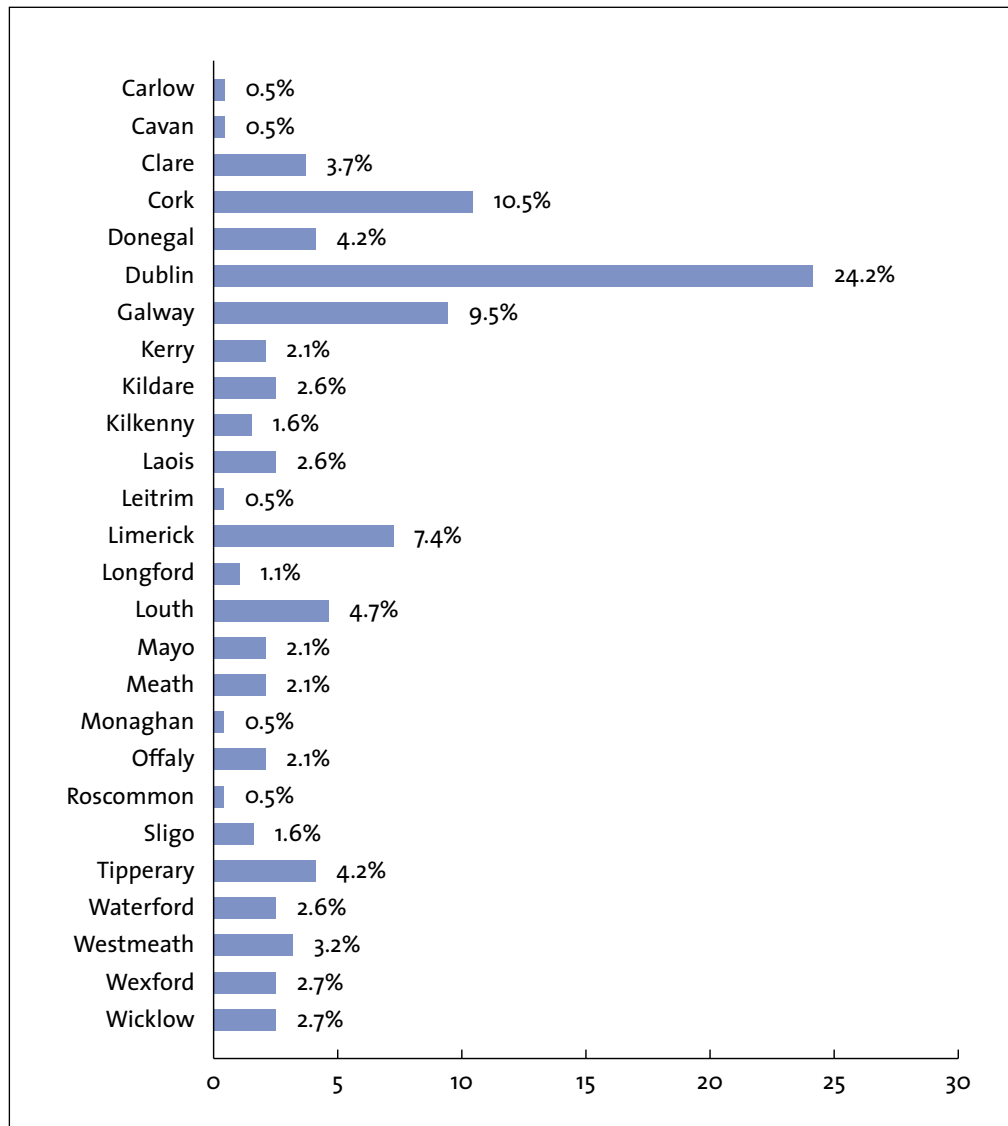
Figure 3. Percentage of practice population who are GMS patients (n=207)

Table 1. GMS practice population in area of perceived deprivation

(N=71)	GMS PRACTICE POPULATION IN AREA OF PERCEIVED DEPRIVATION
<10%	0 (0%)
11–25%	1 (1.4%)
26–50%	20 (28.2%)
51–75%	22 (31%)
76–100%	28 (39.4%)

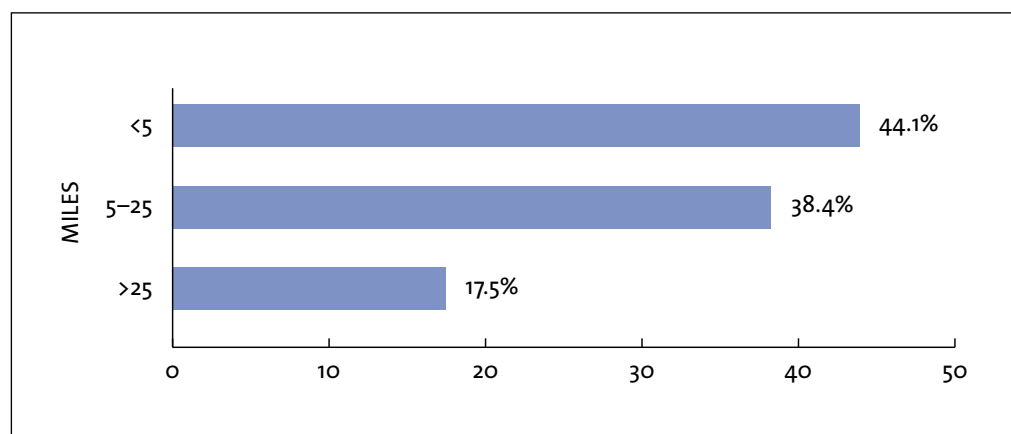
All counties in the Republic of Ireland were represented. The highest number of GPs who responded were located in Dublin (24%), Cork (10.5%) and Galway (9.5%) (Fig. 4).

Figure 4: County of practice (n=190)



Overall, 44% (n=93) of practices were less than five miles from the nearest hospital to which a GP could refer a patient for assessment of suspected cancer. Just over 38% (n=81) were between 5–25 miles and 17.5% (n=37) were between 26–50 miles from the nearest suitable hospital. These figures closely correspond to previous ICGP findings (O’Riordan, Collins and Doran, 2013).

Fig. 5: Distance to nearest hospital for referral or assessment of suspected cancer (n=211)



When comparing county and distance to nearest hospital, 68% of practices less than five miles from the nearest hospital for referral were based in Leinster, 20% based in Munster and 11% based in Connaught (Table 2). Nearly 46% of practices situated more than 25 miles from their nearest hospital for referral were based in Munster.

Table 2. Practice location and distance to nearest hospital (n=190)

PROVINCE	<5 MILES	5-25 MILES	>25 MILES
Leinster	56 (68.3%)	31 (41.4%)	8 (24.2%)
Connaught	9 (11.0%)	13 (17.3%)	5 (15.2%)
Munster	16 (19.5%)	27 (36.0%)	15 (45.5%)
Ulster	1 (1.2%)	4 (5.3%)	5 (15.1%)
Total	82	75	33

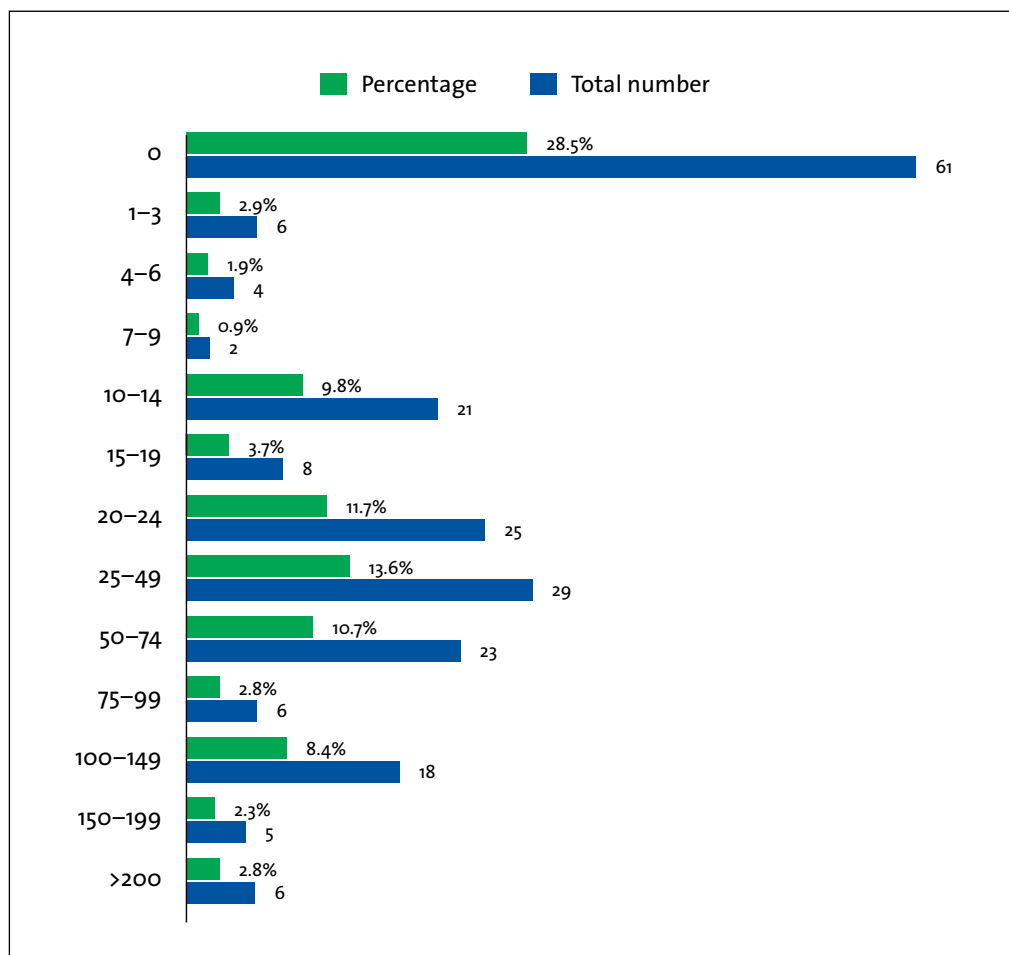
Of the 71 GPs who indicated that they were working in an area of deprivation and who provided data on the location of their practice, 35% (n=24) were based in Dublin, 10% were located in Donegal, 10% in Cork, 6% in Limerick and 4% in Wicklow with the remainder spread across all other counties.

Patient presentation

In the previous year (2014), 71.5% of GPs surveyed referred at least one patient for investigation for suspected cancer. Of those GPs who did refer, nearly 7% referred between 1–9 patients for investigation; 25% referred between 10–24 patients; 14% referred between 25–49 patients; 11% referred between 50–74 and 8% referred between 100–149 patients. Just over five percent of respondents referred more than 150 patients during this period of time. The number of patients referred was related

to practice size. The mean number of patients referred by referring practices was 54 patients (median=30); while the mean number of patients referred by all practices was 39 patients (median=20). The mean number of patients referred by WTE GP was 30.

Figure 6. Number of patients referred for investigation for suspected cancer in 2014



As would be expected, practices with larger populations referred more patients for investigation for suspected cancer.

The mean number of new cases of cancer per practice was 13 but varied from 0 to 210. The mean number of new cases of cancer per WTE GP was seven but varied from 0 to 44. Nearly 42% of respondents recorded less than ten new cases of cancer amongst their practice population in 2014, with one respondent recording no new cases (Table 3). However, half of the respondent practices recorded between 10–29 new cases of cancer and approximately 6% recorded between 30–49 new cases. One practice indicated over 200 new cancer cases were diagnosed in their practice patient population during this period of time.

Table 3. Number of 'new cases' of cancer among practice population – 2014

NUMBER OF NEW CASES OF CANCER IN 2014 (N=160)	N	%
0	1	0.6
1–4	31	19.4
5–9	35	21.9
10–14	43	26.9
15–19	14	8.8
20–29	23	14.4
30–39	6	3.8
40–49	4	2.4
>50	3	1.8

In 2014, 40% (n=61) of practices recorded between one and four patient deaths from cancer amongst their practice population. Nearly 31% of respondents noted between five to nine patient deaths; 20% noted 10–19, and 3% noted 20–29 patient deaths. One respondent indicated 32 patient deaths from cancer during this period of time, while eight respondents indicated zero patient deaths. The mean number of patient deaths recorded in 2014 was 5.85 per practice; while the mean recorded per WTE GP was three deaths.

Table 4. Number of patient deaths from cancer recorded among practice population -2014

NUMBER OF CANCER DEATHS IN 2014 (N=150)	N	%
0	8	5.3
1–4	61	40.7
5–9	46	30.7
10–14	26	17.3
15–19	4	2.6
20–29	4	2.6
>30	1	0.8

Respondents were asked to identify which of the four categories of patients with symptomatic cancer are more likely to delay in presenting to their practice. Similar to the 2006 ICGP/ICS survey, the majority of respondents considered men, most likely to present late (Table 5); as were private patients (54%).

Fewer GPs were of the opinion that those aged less than 25 years delayed presentation compared to other age groups (Table 5).

Table 5. Patients most likely to delay

SEX	% (N)	GMS/PRIVATE	% (N)	AGE	% (N)
Men	92.1 (n=164)	GMS	45.7 (n=63)	18–24 yrs	17.3 (n=31)
Women	7.9 (n=14)	Private	54.3 (n=75)	25–54 yrs	26.3 (n=47)
				55–64 yrs	30.2 (n=54)
				65+ yrs	26.2 (n=47)

Investigation from general practice

GPs were asked to identify the average length of waiting time for a range of tests (which are not exclusively related to cancer diagnosis). Respondents were not asked to distinguish between access for urgent and routine investigation due to completion complexity. There was a striking difference in access for patients in the public system versus those in the private system for the majority of diagnostic tests (Table 6). Overall, the percentage of respondents with direct access in the public system were comparable to previous data (O’Riordan, Collins and Doran, 2013); and once again public system waiting times showed a wider distribution with a higher mean delay in all cases when compared to the private system (Table 7). The narrowest mean waiting time between public and private was recorded for chest x-ray.

Essentially all GPs had direct access to chest x-ray however the waiting time varied from 0.5–30 working days with a mean of 2.24 working days. Access to private chest x-rays had a narrower waiting time distribution of 0.5–14 working days and a lower mean of 1.12 days. Over 79% of respondents reported that access to chest x-ray in the private system was within one working day. Just over 72% had access in the public system within one working day, a marked increase on the 2013 figure of 37.5%.

The waiting time for access to abdominal or pelvic ultrasound in the public system was on average 16.1 weeks in the public system, with a variation of 0.5–480 days (96 weeks) for abdominal ultrasound and 5–280 days (56 weeks) for pelvic ultrasound depending on location. In the private system, the average wait was approximately five working days for both, with 74% and 70% of respondents reporting access to abdominal and pelvic ultrasound respectively within five working days. Equivalent figures reported for the public system were 20% and 22% respectively. This represents a decrease in private access and an increase in public access since 2013.

In the public system there was an average wait of 46 working days for brain CT scan, 49 working days for chest CT scan and 55 working days for abdomen CT scan. However, waiting times ranged from 3–280 working days (56 weeks). Overall, respondents reported that direct access was problematic for all CT scans. In the private system, the average waiting times were within 5–6 working days for CT scans, a marked difference to the public system. In the private system approximately 91% of respondents reported access within 10 working days compared to 32% for brain CT scan, 24% for chest CT scan and 21% for abdomen CT scan in the public system.

In the public system, the average wait for brain MRI was 125 working days (25 weeks), 119 working days for spine MRI (24 weeks) and 120 working days (24 weeks) for musculoskeletal MRI but waiting times varied between 15–280 working days (56 weeks). Again numbers reporting direct access were very low; of note, approximately only 10% of respondents had direct access to MRI diagnostics. In the private system, the average waiting time for MRI diagnostics was five days, with waiting times of 1–21 working days. On average, 92% of respondents had direct access to MRI diagnostics within ten working days in the private system, while only 19% had direct access in the public system.

Comparable with 2013 data, the longest waiting times in the private system were for upper GI endoscopy and lower GI endoscopy – the average wait being 10 working days. However, the average wait in the public system was 12 weeks. In the private system, slightly more than two thirds of respondents had direct access within ten working days; in the public system 24.5% and 26% reported access within ten working days.

There were no significant findings when comparing average delay in the public system to distance from GP practice to nearest hospital for referral.

Table 6. Direct access for patients free of charge through the public system

	DIRECT ACCESS	IF YES, AVERAGE WAITING TIME IN WORKING DAYS			
	%	N	RANGE	MEAN	MEDIAN
Chest x-ray	99.1	210	0.5–30	2.24	1
Abdominal Ultrasound	77.0	157	0.5–480	80.53	60
Pelvic Ultrasound	75.0	153	5.0–280	72.16	60
CT Scan Brain	24.4	50	3.0–240	46.86	30
CT Scan Chest	18.8	38	7.5–200	49.40	30
CT Scan Abdomen	16.7	33	10–200	55.30	40
MRI Brain	10.9	22	20–280	125.90	110
MRI Spine	10.5	21	15–280	119.28	120
MRI Musculoskeletal	9.9	20	20–280	120.50	115
Upper GI Endoscopy / Gastroscopy	67.1	139	10–360	59.60	45
Lower GI Endoscopy / Gastroscopy / Sigmoidoscopy / Colonoscopy	66.0	136	10–360	57.81	47.5

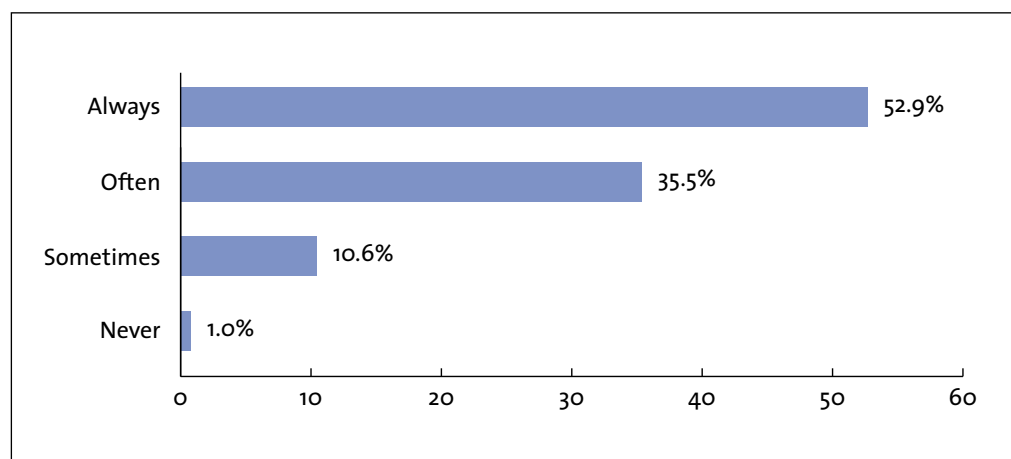
Table 7. Direct access for patients through the private system

	DIRECT ACCESS	IF YES, AVERAGE WAITING TIME IN WORKING DAYS			
	%	N	RANGE	MEAN	MEDIAN
Chest x-ray	99.0	206	0.5–14	1.12	1
Abdominal Ultrasound	98.5	202	1–60	5.44	5
Pelvic Ultrasound	98.0	200	1–60	5.90	5
CT Scan Brain	91.1	188	1–80	5.87	5
CT Scan Chest	89.1	172	1–80	6.31	5
CT Scan Abdomen	89.3	175	1–80	6.16	5
MRI Brain	96.5	194	1–20	5.69	5
MRI Spine	97.5	196	1.5–20	5.80	5
MRI Musculoskeletal	96.5	194	1.5–21	5.61	5
Upper GI Endoscopy / Gastroscopy	92.9	182	2.5–60	9.92	10
Lower GI Endoscopy / Gastroscopy / Sigmoidoscopy / Colonoscopy	92.3	179	2.5–60	10.17	10

There were a number of observed statistically significant linear relationships between distance to nearest hospital for referral and direct access to tests in the private system. The further the distance from nearest hospital the longer the waiting time for abdominal ultrasound, pelvic ultrasound, chest CT scan and upper GI Endoscopy. All reported significance of <0.05.

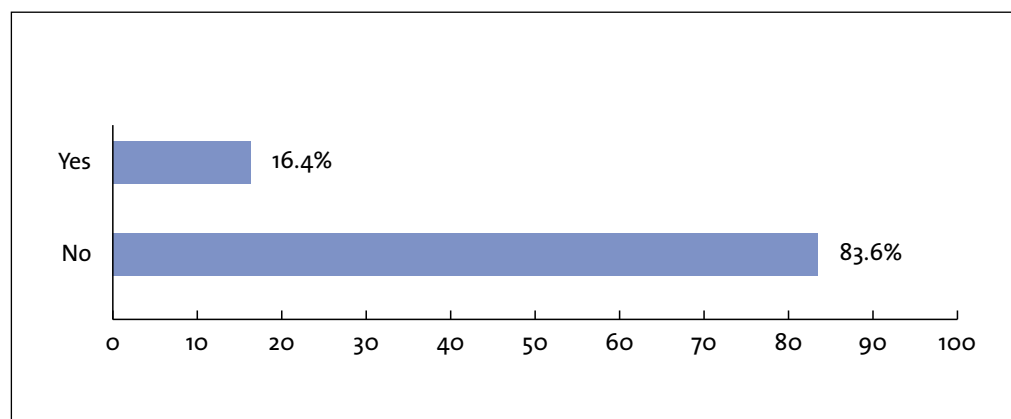
Figure 7 shows that 88.5% (n=184) of respondents reported that a patient’s ability to pay privately ‘always’ or ‘usually’ affects access to referral services; while 11% (n=22) of respondents stated that it ‘sometimes’ affects access. Only two respondents considered that a patient’s ability to pay ‘never’ affects access to referral services. These figures are closely comparable to the 2006 findings where 84% of respondents believed that the ability to pay privately affects access to referral services.

Figure 7. GP perception of whether a patient’s ability to pay privately affects access to referral services (n=208)



One fifth of respondents considered that other GPs had direct access to tests for investigation for suspected cancer that they did not have.

Figure 8. Unequal direct access to tests for investigation for suspected cancer (n=201)



Of the respondents who indicated they had issues with direct access to tests in comparison to other GPs, the most commonly specified tests were Ultrasound (n=14), CT Scan (n=8) and MRI (n=7).

Table 8. Specific tests identified as problematic to access in comparison to other GPs

TEST TYPE	N
Ultrasound	14
CT	8
MRI	7
Endoscopy	6
MRI	7
Colonoscopy	2
Dermatology	1
Blood tests	1
Biopsy	1

In 2015, just over 51% (n=100) of respondents reported access to a fast track system in their local hospital for ‘urgent’ referrals (excluding breast, prostate, lung and melanoma). These figures are similar to the 2015 ICGP/NCCP survey where 47% of respondents reported having access to a fast track system for urgent referrals. However, just under 40% of respondents had no access for any patient with suspected cancer; a marginal increase on 2006 figures. Less than 20% of respondents had access for patients with suspected cancer with non-specific symptoms only. Access has remained similar to the 2006 level for patients referred with symptoms of a specific cancer.

Nearly 59% of respondents had no access for patients with symptoms of specific cancers. Figure 10 shows that access to a fast track system in their local hospital for patients with symptoms or signs of a specific cancer was most commonly available for colorectal (37%), upper GI (23%), urological (excluding prostate) (22%), gynaecological (22%) and head and neck (19%). Access was limited for pancreatic (14.5%) and neurological (11%) cancers. These findings closely resemble those from the ICGP/NCCP survey (O’Shea and Collins, 2016) which identified that access was most commonly available for colorectal and upper GI, and access was limited for neurological cancers.

Figure 9. Direct access to tests for investigation for suspected cancer

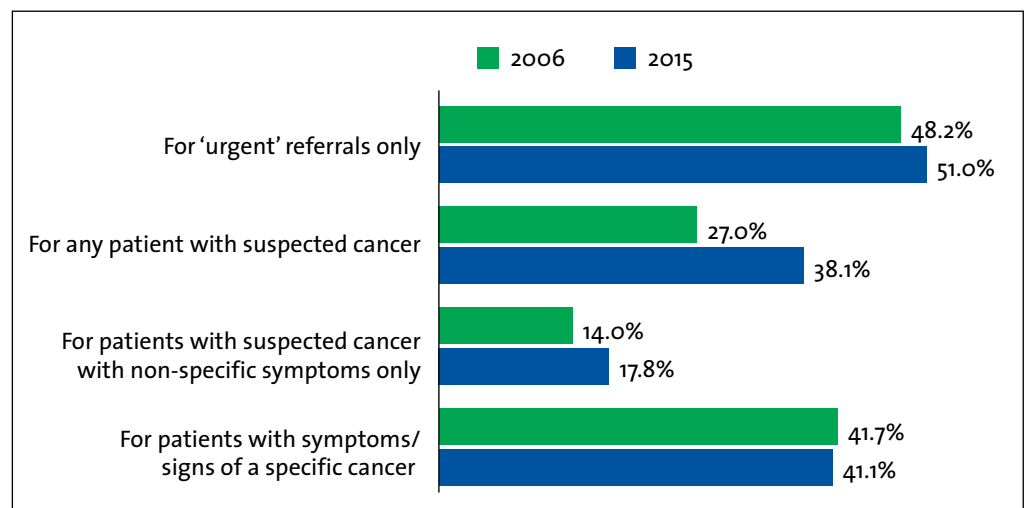
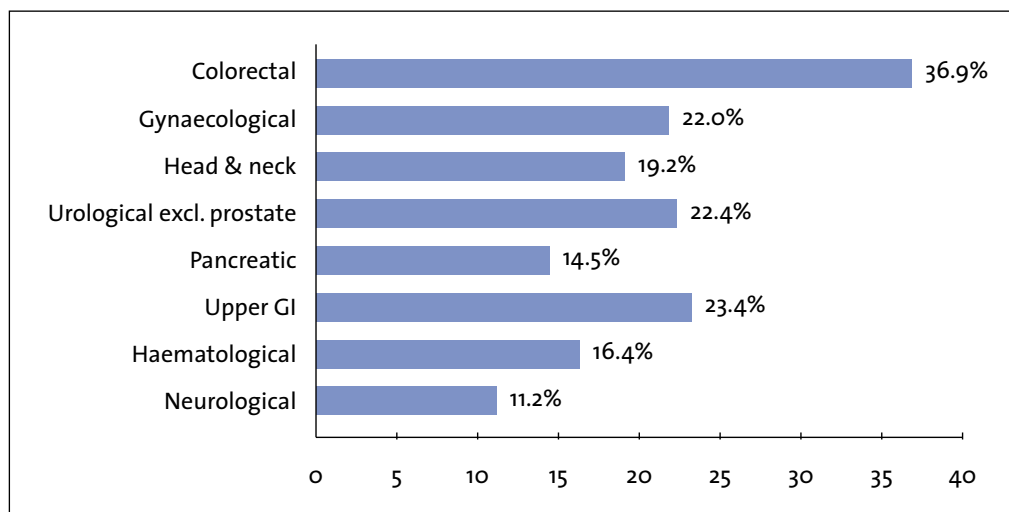


Figure 10. Cancers for which a ‘fast track system’ is available



Of the 12 respondents who specified ‘other’ in relation to access to a fast-track system, the most common responses were; ‘ring consultant/specialist if worried’ (n=4), ‘send patient via Medical Assessment Unit’ (n=3) and ‘send patient via Accident and Emergency’ (n=1). Some respondents elaborated further:

- “Can refer public patient to local hospital casualty or centres in Dublin.”
- “Generally (access system) with 2–3 follow up letters and much pressure we get patients seen.”
- “(Access system) always involves me following up and making the case. Some are more helpful than others.”
- “I can phone the relevant specialist and he/she will nearly always see patient at the next clinic – no value can be put on this co-operative corrigibility.”

Ninety-four percent of respondents reported that rapid access clinics for breast, lung, prostate and melanoma cancers were working well.

Investigation from general practice and referral to public hospital for investigation

Respondents were asked to indicate, in cases where cancer is suspected, the types of cancers where there are unacceptable delays in accessing diagnostic equipment (or diagnosis) at their local hospital. The most common unacceptable delays were for gynaecological (56.5%), neurological (55%), urological (excluding prostate) (49%) and head and neck (42%) cancers. Breast, lung, prostate and melanoma cancers, which have dedicated rapid access clinics, were the least problematic for respondents to access.

Six respondents specified ‘other’ in relation to cancer types for which there are unacceptable delays in accessing diagnostics. Of those, three respondents identified unacceptable delays for all cancer types and two respondents’ highlighted issues in accessing diagnosis for forms of skin cancer other than melanomas. One respondent concisely stated that “if the patient is public, you always wait”.

Overall, nearly 80% of respondents considered a waiting time of more than two or more weeks for cases perceived as urgent to be unacceptable. Seven out of ten respondents regarded a delay of six weeks and over as unacceptable for non-urgent cases.

Figure 11. Unacceptable delays in accessing diagnostic equipment (or diagnosis) at local hospital by suspected cancer type

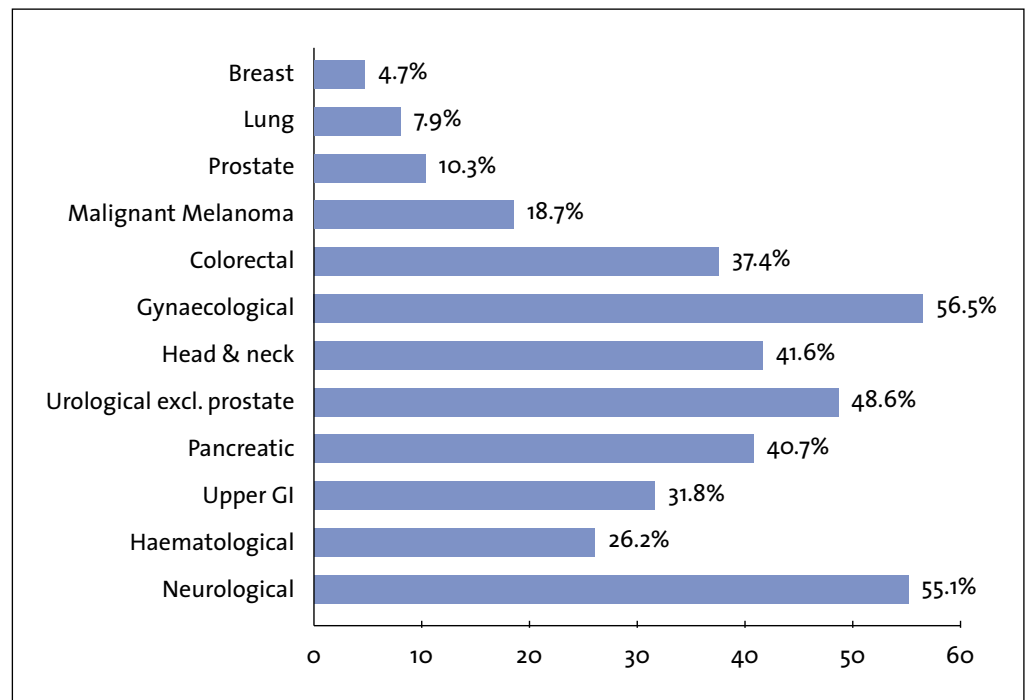


Figure 12. GP definition of unacceptable delays for ‘urgent cases’ (n=179)

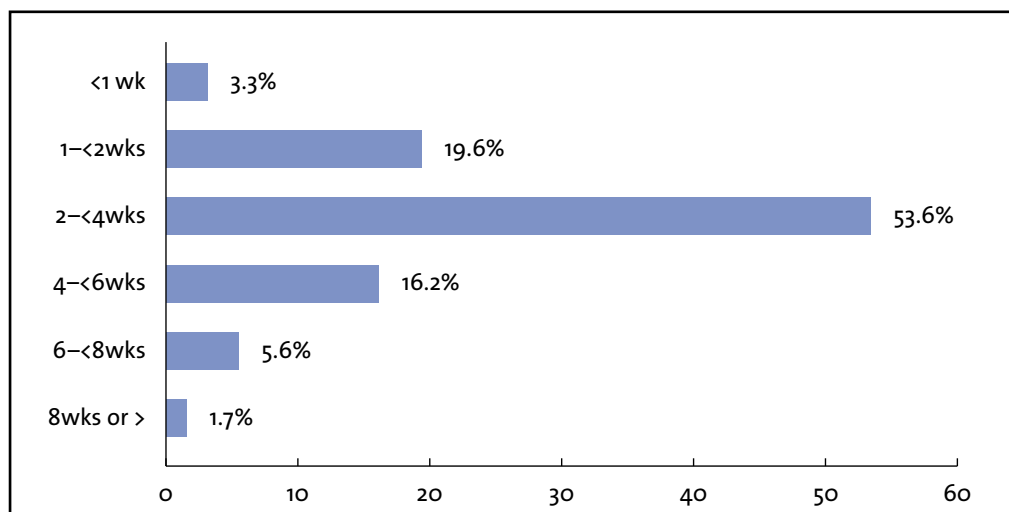
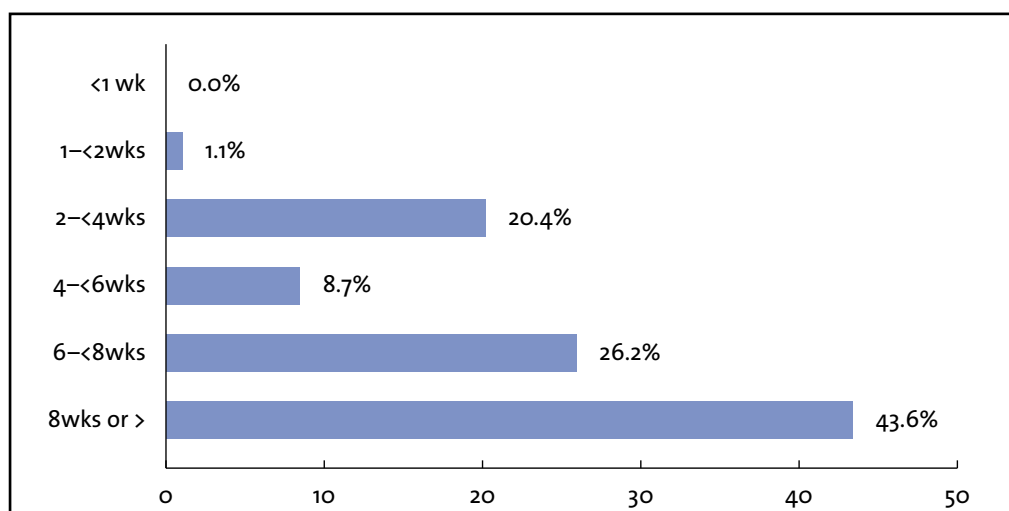


Figure 13. GP definition of unacceptable delays for ‘non-urgent cases’ (n=172)



Respondents were asked to define the information most necessary to support and advise their patients and their family members following a new diagnosis of cancer. In some cases, there was a marked difference in the level of information GPs received versus the importance they placed on the information. Just over 29% of respondents always/usually receive information on a patient’s prognosis following a new diagnosis, yet 86% perceived this to be necessary information; 27% always/usually receive detail on the level of information the patient received on their diagnosis, yet 82% indicated a need for this, and 18% of respondents frequently receive information on major side effects of treatment, however 77% regarded this information as necessary (Table 9).

Marked differences were evident when the findings here are compared to the 2006 study. Respondents’ indicated improved rates of information sharing specifically on the subjects of treatment plans, name of drugs and progress to date. As is evident in the table below, GP perception of the information they need changed somewhat between 2006 and 2015, with respondents stating that they were less inclined to need formation on the hospital contact person, 55% in 2015 compared with 82% in 2006.

Table 9. Information required following a new diagnosis of cancer in order to support/advise patient/family

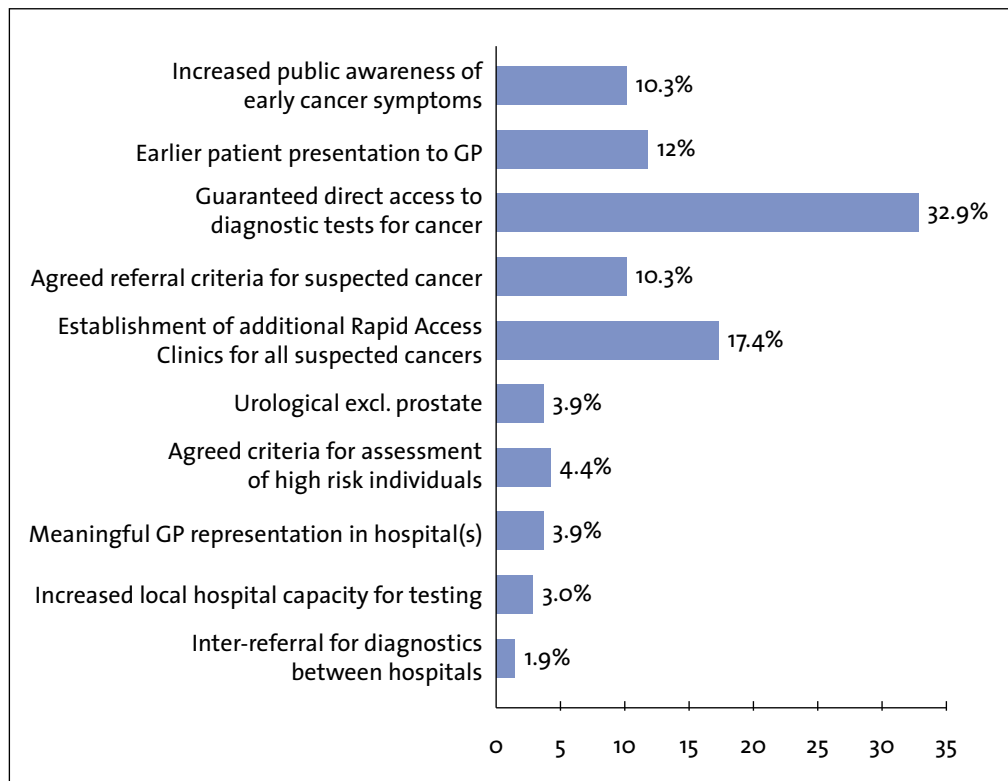
INFORMATION CATEGORY	NEED		ALWAYS/USUALLY RECEIVE	
	2016 (N=214)	2006 (N=929)	2016 (N=214)	2006 (N=929)
The diagnosis	90.7%	89.3%	87.4%	87.5%
Treatment plan/cancer care pathway	79.0%	86.4%	74.5%	49.9%
What the patient has been told about their illness/prognosis	81.8%	89.3%	27.4%	18.9%
Prognosis	86.0%	86.8%	29.4%	21.8%
The hospital contact person for the patient	55.1%	82.0%	17.6%	16.3%
Names of drugs (chemotherapy, hormones, other)	76.6%	70.4%	80.3%	49.3%
Progress to date	74.8%	80.3%	70.8%	43.5%
Major side effects of treatment	77.1%	78.5%	18.1%	11.9%
Date of discharge	76.2%	73.7%	84.1%	63.5%
Guidance regarded necessary lifestyle changes	72.0%	n/a	41.4%	n/a

Overall, 54% of respondents considered that they do not usually receive information from the hospital team on their patient's newly diagnosed cancer in a timely manner; demonstrating a slight increase since 2006 where over half of respondents considered that they received information in a timely manner.

Impact delays cause on the delivery of quality GP service

Respondents were presented with a list of ten possible factors which would most assist in the early detection of cancer in their practice and asked to identify what in their opinion was the most important factor (Figure 14). The most frequently selected factor was 'guaranteed direct access to diagnostic tests for cancer' (33%), followed by 'establishment of additional rapid access clinics for all suspected cancers' (17%) and 'earlier presentation to GP' (12%).

Figure 14. The main factor which GPs considered would assist in the early detection of cancer in general practice



Discussion

In Ireland, it is thought that up to 30% of GP practices are based in a deprived area (Crowley, 2005). Research shows that in deprived areas patient's baseline health status is lower and the use of health care is higher than in more socioeconomically prosperous areas (Reijneveld, 1998; Reijneveld, Verheij and Bakker, 2000). Patients from the most disadvantaged areas who are diagnosed with cancer have been found to have lower rates of cancer survival than those in more prosperous areas. Recent data from the National Cancer Registry of Ireland shows that the five-year survival rate is much poorer among patients in deprived areas. For colorectal cancer, significant differences in the five-year survival rates were recorded, with 64% for least deprived against 56% for the most deprived; for lung cancer, 22% for the least deprived against 16% for the most deprived (NCRI, 2015). Areas of deprivation are noted to have fewer GPs resulting in increased difficulty for patients accessing appropriate healthcare. With one GP per 1,600 population in Ireland, increasing to 2,500 in North Dublin, GPs are under extreme pressure on a daily basis (Osbourne, 2015). Deprivation was not defined for GPs in the questionnaire used for the survey reported on here due to the multifaceted and complex relationship of the term with health inequalities; instead respondents were asked whether they perceived their practice to be based in an area of deprivation based on their own understanding of the term. Results indicate that approximately one third of GPs perceived their practices to be located in an area of deprivation. Of the GPs who indicated that they were working in an area of deprivation and who provided data on the location of their practice (n=68), just over one third were based in Dublin with Donegal and Cork also among the top three areas. Further analysis did not highlight any significant relationship between area of deprivation and direct access to diagnostics for public and private patients. This suggests that currently all GPs, including those with practice populations of higher socioeconomic status, find it difficult to access diagnostics for suspected cancer outside of the four rapid access clinics for breast, prostate, lung and melanoma, if their patients are unable to pay through the private system.

This survey found that that on average there were seven new cases of cancer per year and three patient deaths from cancer per WTE GP which is consistent with previous ICGP figures (Daly and Collins, 2007). The average patient number per WTE in practices who responded is also consistent with those reported elsewhere (Osbourne, 2015).

The results of this survey once again confirm the issues raised by an inequitable two-tier health care system in accessing appropriate diagnostics. This two-tier system is best defined as the delivery of both public and private health care simultaneously, resulting in differing quality levels for opposite socioeconomic groups (Cantillon et al, 2001). Excluding emergency cases, private patients undoubtedly receive prioritised access to diagnostics for cancer. This unequal access to diagnostics and the potential subsequent delayed diagnosis and treatment is of great concern to GPs (Hamilton, 2010).

The vast majority of GPs (88.5%) indicated that a patient's ability to pay privately affects access to referral services, a slight increase on the 2006 ICGP/ICS figure of 84%. Delays in accessing diagnostics forces many patients to pay for scans and tests privately to secure diagnosis (Darker et al, 2015). As a result, a patient's ability to pay is linked to their ability to access diagnostics used to detect cancer in a timely manner. Patients without private health insurance or with limited health insurance policies who opt to pay for tests privately are likely to face financial repercussions, including depleting savings or borrowing money to fund necessary tests (Sharp and Timmons,

2010). This can cause great stress, concern and worry for both the patients and families involved (Berkman and Sampson, 1993; Quinn, 2002; Gordon et al, 2007).

GPs indicated that men were more likely than women to delay in presentation with possible signs and symptoms of cancer. Both national and international literature indicates that men are more likely to be reluctant to consult with healthcare professionals (Bendelow, 1993; Galdas, Cheater and Marshall, 2005). Men are also less likely to notice signs and symptoms of possible cancers and have a lack of awareness as to when they should attend for screening (Stakelum and Boland, 2001). This survey also found that slightly more than half (54%) of respondents considered that private patients were more likely to delay in presenting with symptomatic cancer compared to GMS patients. One recent Irish study on patient's perspectives reported that 63% of private patients surveyed were more likely to delay due to financial constraints, compared with 10% of public patients (Darker et al, 2015). These findings highlight that greater universality in primary health care system is vital to ensure that all categories of patients obtain the time sensitive and economically viable health services they require. The necessity for appropriate access for GPs to cancer diagnostics is evident in both Irish and international literature (Olesen, Hansen and Vedsted, 2009; O'Riordan, Collins and Doran, 2013). Appropriate access can positively impact on earlier stage diagnosis and is likely to benefit patient outcomes, including improved survival rates and improved quality of life dependent on cancer type (Tørring et al, 2011, Neal et al, 2014; De Angelis et al, 2014). By 2040, the total number of new invasive cancer cases are projected to increase by 84% for females and 107% for males, with cancer incidence expected to increase by 48–112% for females and 114%–128% for males (NCRI, 2014). These rates can be linked to both changes in risk factor prevalence and the expansion of cancer screening services. It is evident that the healthcare system as it is currently structured for cancer detection, diagnosis, treatment and survivorship care must be prepared for the anticipated demand for cancer services.

Extreme delays in the Irish public health care system are placing in jeopardy equal health services for all patients (O'Riordan, Collins and Doran, 2013). The findings identify that health inequalities in accessing diagnostics are prevalent. A notable divide is evident between public and private patients in accessing diagnostics, with public patients experiencing far greater waiting times than private patients for most tests and scans. The data analysis reinforces that for public patients there is a wider waiting time range and higher average waiting time, for example for MRI Brain scans waiting times in the public system ranged from 20 to 280 working days, with an average waiting time of 126 days or 25 weeks in comparison to one to twenty working days, with an average waiting time of six days for private patients. It must be noted that the range of tests presented to GPs in the survey instrument are not tests exclusively related to cancer diagnosis, however the possible impact of the delays on early diagnosis cannot be overlooked. Excluding chest x-ray, this survey reveals continued unacceptable long delays for public patients for all tests, and in particular MRI scans, abdominal and pelvic ultrasounds when compared to private patients, since previously recorded in 2013 (O'Riordan, Collins and Doran, 2013). The tests and scans referenced in this report are not only imperative for cancer diagnosis; they are also essential for diagnosis of other potential serious conditions. As such the reported waiting times are related to all patients in the system.

Difficulties in accessing diagnostics within a reasonable period of time resulted in some GPs sending patients to hospital emergency departments or medical assessment units in the hope that they would access relevant tests there. In addition, GPs indicated that if they had concerns in relation to a patient they

would personally contact the relevant consultant or specialist. The relationship between GPs and specialists or as one GP described it as the “co-operative corrigibility” evidently plays an important role ensuring access to diagnostics for patients. Although professional collaboration is highly estimable, there is cause for concern that access to diagnostics may be influenced by established relationships, particularly considering that newer GPs may not have had the opportunity to develop such associations. In addition, due to increasing time constraints, stressors caused by poor referral processes and decreased interaction at shared forums, the relationship between GPs and specialists should not be depended on to access diagnostics on a case by case basis. Instead, a clearly defined and streamlined referral process offering timely access to relevant tests is essential for GPs to effectively manage patients with symptoms associated with cancer.

Similar to the 2006 ICGP/ICS survey and the 2015 ICGP/NCCP survey, just over half (51%) of GPs reported access to a fast track system for referrals perceived to be ‘urgent’. While only 38% of GPs reported having access to a fast track system for patients with suspected cancer excluding breast, lung, prostate and melanoma cancers, this is an approximate 10% improvement on 2006 figures. Only 18% of GPs had access to a fast track system for patients with suspected cancer with non-specific symptoms only, again a marginal increase on 2006 when 14% of GPs had similar access. For patients with symptoms or signs of a specific cancer, access has remained the same since 2006 at 41%. The findings suggest that although there has been some evident improvement in this area since 2006, GPs are still experiencing poor access to these services. Of note, GPs reported extremely limited access to fast track systems for pancreatic, neurological, head and neck and haematological cancers at their local hospital, suggesting the need for greater improvement in this area. However, these findings must be interpreted in light of the differential natural history of different cancers.

GPs considered waiting times of two or more weeks for cases perceived as urgent to be unacceptable, while waiting times greater than six weeks were considered as unacceptable for cases believed to be non-urgent. The 2015 NICE guidelines for suspected cancer recommend a waiting time target of two weeks or under for patients with suspected cancer (NICE, 2015); while the UK Independent Cancer Taskforce’s 2015–2020 strategy recommends that “patients referred for testing by a GP, because of symptoms or clinical judgement, should either be definitively diagnosed with cancer or cancer excluded and this result should be communicated to the patient within four weeks” (2015, p. 35). The findings of this survey identify that the most common unacceptable delays in accessing cancer diagnostics currently are for suspected gynaecological, neurological, urological (excluding prostate) and head and neck cancers, which is consistent with delays known for these cancer types. Taking into consideration GPs’ evident positive views of the restructuring of cancer services into designated cancer centres and their encouraging experiences, particularly with improved waiting times in accessing diagnostic equipment when referring patients to rapid access clinics for breast, lung, prostate and melanoma (O’Shea and Collins, 2016), clear evidence led protocols similar to the 2015 NICE guidelines for all main cancer types are a necessity. Symptom based guidelines in particular would be of clear benefit to GPs as it would allow more flexibility to refer patients resulting in earlier diagnosis of cancer. Research indicates that lowering the risk threshold for referral to a positive predictive value (PPV) of 3% would improve the early diagnosis of cancer (NICE, 2015). In the Irish context, risk thresholds must be clearly determined for suspected cancer pathway referrals and urgent direct access investigations in order to improve the diagnosis of cancer.

The economic impact of cancer on the health care system in Ireland is gradually increasing. Linked with delays in diagnosis, the financial benefit of early diagnosis is apparent (Hiom, 2015). The treatment of early stage cancer is often shorter, less intrusive and intensive than treatment of later stage cancers. One UK based economic analysis found that treatment of later stage colorectal, ovary and lung cancers was more than twice the cost of treatment of stage one and two disease (Cancer Research UK, 2014). When other cancers were included in cost analysis metrics, the expected annual savings totalled over £200 million. In addition, the financial burden of unnecessary investigation linked to the lack of GP access to cancer diagnostics must be considered. Lack of access in the primary care setting can increase the need for unnecessary ongoing testing of patients.

Just over 54% of respondents did not consider that they promptly received information from secondary care teams on a patient's newly diagnosed cancer. This represents a marginal increase on 2006 figures indicating continued dissatisfaction in communication with hospitals. Difficult or delayed communication between hospitals and GPs have been widely reported in the international literature, and often limits GPs in fulfilling their role in managing patients and responding to family queries after a newly diagnosed cancer (Farquhar et al, 2005; Harris and Harris, 2006; Rowlands, Callen and Westbrook, 2012). However, since 2006 there have been marked improvements with more GPs now reporting always or usually receiving sufficient information with regard to:

- treatment plan/cancer care pathway, 75% compared to 50% in 2006;
- name of drugs, 80% compared to 50% in 2006;
- and progress to date, 71% compared 43.5%.

Nevertheless, difficulties in communication with hospitals following a new diagnosis of cancer are still marked since 2006, with a high proportion of GPs not usually informed by hospital staff of the hospital contact person for the patient, major side effects of treatment or what the patient has been told about their illness or prognosis. Consequently, GPs often encounter difficulties in providing tailored advice and support to the patient and their families. The development of a national Medical Oncology Clinical Information System (MOCIS) which is currently being piloted and due for expansion across twenty five hospitals in Autumn 2016, is expected to improve communication and information sharing between secondary and primary care regarding patients with newly diagnosed cancers. The overall purpose of the MOCIS is to deliver an Electronic Patient Record (EPR) for systemic cancer services in medical oncology and haemato-oncology. One primary aspect of the implementation of this system is to enable the development of a standardised Systemic Anti-Cancer Therapy (SACT) Treatment Summary for both GPs and patients, which will foster a greater understanding for patients about their cancer treatment, and effectively facilitate hospital to GP and GP to patient communication regarding the patients' cancer treatment.

More than half of GPs considered guaranteed direct access to diagnostic tests for cancer and increased public awareness of early cancer symptoms would assist them in the early detection of cancer. When compared to findings from the 2006 study, increased public awareness and earlier patient presentation still rank highly as the key supports required for the early detection of cancer in general practice. For that reason, it is right that public health campaigns educate the public to contact their GP if marked symptoms persists (Green, Atkin and Macleod, 2015).

These findings indicate the need for solutions to improve GP access to diagnostics for suspected cancers. The current structural problems resulting in unequal delayed access create barriers to healthcare provision for all socioeconomic groups in Ireland, in particular patients who utilise the public healthcare system.

Limitations

The overall response rate here is a limiting factor. Surveys of GPs frequently result in lower response rates when compared with surveys of the general population and of other medical professions. It is thought that GPs who are time poor were more likely not to reply (O'Brien et al, 2013). However, the response rate is consistent with other international and Irish GP surveys and the profile of those respondents who did reply are representative of the GP population in the Republic of Ireland (VanGeest, Johnson and Welch, 2007; Byrne et al, 2010; O'Shea and Collins, 2016).

In addition, recall bias was a minor issue with a small number of GPs experiencing difficulty with regard to estimating the numbers of patients sent for referral. This is evident from comments received in returned surveys. While the level of detail requested was kept to an absolute minimum to encourage response, some GPs clearly had difficulty recalling or accessing the information.

Recommendations

Cancer awareness campaigns

- Awareness helps to save lives. The public capacity for awareness of possible cancer signs and symptoms must be strengthened via national health promotion and cancer campaigns in order to reduce the health inequalities associated with cancer.
- Cancer awareness and healthy lifestyle campaigns should be developed for healthcare professionals and community based partners by the Department of Health in association with the ICGP and the NCCP. These should include campaigns targeted specifically at men, who are more likely to delay presentation, and at those living in areas of deprivation, who tend to present later, generally have poorer survival outcomes and are more likely to present with comorbid conditions.
- Targeted and tailored cancer awareness and healthy lifestyle campaigns should be developed for the general public by the Department of Health. These campaigns should provide basic, accurate information through clear, unambiguous messages. Strong examples of this are the UK based 'Be Clear on Cancer' campaigns such as "Blood in Pee" message, which simply advises "if you notice blood in your pee, even if it's just the once, tell your doctor", and the lung cancer awareness message focusing on coughing which states "if you've been coughing for three weeks or more, tell your doctor".
- The monitoring and evaluation of campaigns and associated materials should be built into the objectives of campaigns, to ensure that success can be measured and lessons applied to the development of other campaigns in the future.
- The NCCP currently run education sessions for practice nurses, public health nurses and nurses in acute hospital settings in the Republic of Ireland which focus on a range of cancers, cancer prevention, early diagnosis, treatment and survivorship. The NCCP should continue to run these education sessions, and ensure to consider and adopt any positive and practical recommendations made by attendees on how best to improve on these sessions.

Greater access to diagnostics

- At present, access to imaging and other tests in the public system is relatively restricted. In order to ensure smoother patient care pathways and speedier diagnoses, GPs need increased access to diagnostics. General practice must be better resourced with GPs given direct access to diagnostic tools. By 2017, GPs should be able to access diagnostics for suspected cancers within 28 days in each Hospital Group.
- Direct access to radiology and endoscopy should be supported by evidence based guidelines for referral.
- As a result of severe delays in acute hospital settings, it is recommended that diagnostic tests and scans take place within centres and clinics in the community where possible. This will control the flow of patients to the acute hospital setting and will result in greater numbers of patients having to attend hospital at the point of cancer treatment only. Bearing in mind the success of the 2015 Ultrasound Access Project pilot in primary care sites on the Irish Western Seaboard, a national rollout of improved ultrasound access would be greatly welcomed.

- Access to diagnostic tests and scans in the community setting should be led by the Health Service Executive (HSE). They must devise a separate budget for community diagnostics so as to extend the availability of diagnostics to support the management of patients in general practice.

Cancer guidelines

- The NCCP, with support from the ICGP and relevant clinical specialists, should adapt and adopt symptom based guidelines similar to the 2015 NICE guidelines for suspected cancer.
- The risk threshold must be lowered to a positive predictive value of 3% based on international best practice to improve the early diagnosis of cancer.
- The ICGP should continue to undertake any GP education and training required for all new guidelines devised.
- The NCCP should continue to monitor the delivery of cancer services in Ireland and to develop and roll out the guidelines they currently intend on launching for ovarian, colorectal and non-melanoma cancers. They should also continue to work towards the implementation of the soon to be launched National Cancer Strategy 2016–2025.

Improved information sharing

- Electronic referral must be the standard mode of GP referral for suspected cancers. At least 50% of all suspected cancer referrals should be electronic by the end of 2016. Each Hospital Group should facilitate standardised electronic GP referral by the end of 2017.
- A generic electronic referral form for all symptoms should be devised for use by GPs for all Hospital Groups in the Republic of Ireland.
- Continued promotion of electronic referral forms must be undertaken to encourage GPs to access and utilise available electronic systems.
- Hospital Groups must ensure to promote to GPs the use of electronic referral forms for suspected cancers.
- Electronic discharge for medical oncology should be universally in place throughout all hospital systems in the Republic of Ireland by the end of 2017. This will ensure that GPs will receive timely electronic discharge information on their patient following a cancer diagnosis. Healthlink must be comprehensively utilised to facilitate this process.
- The expansion of the Patient Treatment Summary Care Plan should be a target by 2017 with both the patient and GP receiving an e-version of care plans.

Workforce planning

- Planning for better access to diagnostics and appropriate cancer care is essential in the current health care environment given severe delays in the public system and the aging population, amongst other factors. The impact of the moratorium needs to be reversed at the most basic level. It is essential that health and education authorities in Ireland collaborate to increase the numbers of suitably trained health care professionals including radiographers and sonographers.
- It is essential that there is an introduction of an extended working day/week for clinicians and diagnostic technicians to enable the delivery of services outside of the traditional 9–5 pattern with consideration given to an extension of service to between 8am–8pm and at weekends.

- To increase staffing shortfalls, an appropriate number of trainee placements should be made available to sustain a quality diagnostics service.
- Ireland is currently dealing with a GP manpower crisis. ICGP data reveals a fifth of GPs are aged 60 years or above, with almost 33% older than 55 years. Taking into consideration the high number of GPs due to retire within the next five to ten years, and the large percentage of young doctors who already have or plan to emigrate, appropriate workforce planning in this area is essential. Health policy must address funding, innovation and reform, emigration, training capacity and efficiency, and workforce distribution.

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